



# First outcome analysis of the New Zealand children's cancer registry

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## Objective

To describe the development of the New Zealand Children's Cancer Registry, and report the first national analysis of childhood cancer in New Zealand.

## Background

Like most national cancer registries, mandatory reporting of cancer to the New Zealand Cancer Registry (NZCR) records only a minimum dataset, classified by ICD-O site and histology. The absence of registration according to the International Childhood Cancer Classification system (ICCC-3) has made it difficult to compare the pattern and incidence of childhood cancer in New Zealand to other comparable national registries. Furthermore, NZCR does not link cancer registrations to patient survival and long-term outcome. The only previously reported national data on the nature and outcome of childhood cancer in New Zealand was from a cohort study done between 1990-1993<sup>1</sup>.

## New Zealand Children's Cancer Registry (NZCCR)

In 2000 the New Zealand Paediatric Oncology Steering sought to develop a New Zealand Children's Cancer Registry to provide contemporary and relevant clinical and outcome data on childhood cancer in New Zealand. The national online Children's Cancer Registry (NZCCR) is a fully relational database (MS SQL) integrated with our national late effects assessment programme (LEAP-IT). NZCCR has registered all cancers in children (0-14 years) since 1/1/2000 and is governed and supported by the New Zealand Paediatric Oncology Steering Group.

All patients are registered against a single national health index (NHI). The database captures demographic data including geographic location, country of origin, cancer diagnosis, disease stage and risk stratification, familial cancer history, disease treatment, patient outcome, treatment related toxicity and status at long term follow up. Ethnicity is recorded in accordance with the standard New Zealand Health ethnicity classification. All malignant cancers and benign tumours presenting to the cancer centres are registered and classified by ICD-0 site and histology, as well as by the International Childhood Cancer Classification v 3.0 (ICCC 3.0).

## Methods and Analysis

This research was reviewed and approved by the New Zealand Ministry of Health Multi-Regional Ethics Committee. All cases registered in the 10-year period from 1/1/2000 to 31/12/2009 were checked for accuracy and completeness, including ethnicity and gender. Excluded were all cases over 15 years of age and non-resident children. Cancers were classified by both ICD-O and ICCV v3.0 including benign intracranial and intraspinal tumours as classified by ICCV. The verified dataset was analysed against the New Zealand Cancer Registry to identify any cases of cancer not referred to a childhood cancer centre and cross-checked against national deaths registry.

## Results

Over the 10-year period 2000-2009, 1275 cases of cancer were diagnosed in children 0-14 years. Maori and Pacific Island children accounted for 29.6% of diagnoses (Maori 19.6% and Pacific 10.1%) and Asian 6.6%, these incidences reflect child the population distribution by ethnicity. Figure 1 shows the distribution of cancers by ICCV class in New Zealand, and Table 1 shows that the frequency of each cancer group in New Zealand is similar to Australia and the United Kingdom. There was a slight male predominance (male 52.45%, female 47.55%) and Figure 2 shows the ratio of gender by ICCV diagnostic class. The median age at diagnosis was 4 years, and the distribution of diagnoses by age is shown in Figure 3.

Overall 5-year survival for children with cancer in New Zealand between 2000-2005 is shown in Figure 4 compared to data from the previous New Zealand cohort study from 1990-1993, the Australian Children's Cancer Registry and the USA SEER database<sup>1-3</sup>. A 5-year overall survival of for New Zealand Children of 79.2% shows a significant improvement compared to the early 1990s and is comparable to outcomes reported from Australia (79.5%) and USA (80.4%).

## Discussion

Here we report the development of a national children's cancer registry and first national analysis of childhood cancer in New Zealand. Although indigenous Maori and Pacific Island children account for nearly 30% of cancer diagnoses in New Zealand, the distribution of cancers by ICCV classification is comparable to that seen in other Western countries. The 5-year overall survival for children in New Zealand has improved significantly over the last decade and is comparable to that seen in Australia and the USA.

## References

1. Douglas, N.M., and, Dockerty, J., (2005) Population-based survival of children in New Zealand diagnosed with cancer during 1990-1993, European Journal of Cancer, 41: 1604-1609.
2. Youlden, D., Baade, P., Ward, L., Valery, P., Hassall, T., Green, A.C., Aitken, J.F. (2010). Childhood cancer survival in Australia, 1995-2004. Viertel Center for Research in Cancer Control, Cancer Council Queensland and the Australian Paediatric Cancer Registry. Brisbane, Queensland.
3. Surveillance Epidemiology and End Results (SEER) USA <http://seer.cancer.gov/>

Figure 1: Average number of childhood cancers (0-14 years) diagnosed in New Zealand between 2000 - 2009 by ICCV-3 diagnostic classification.

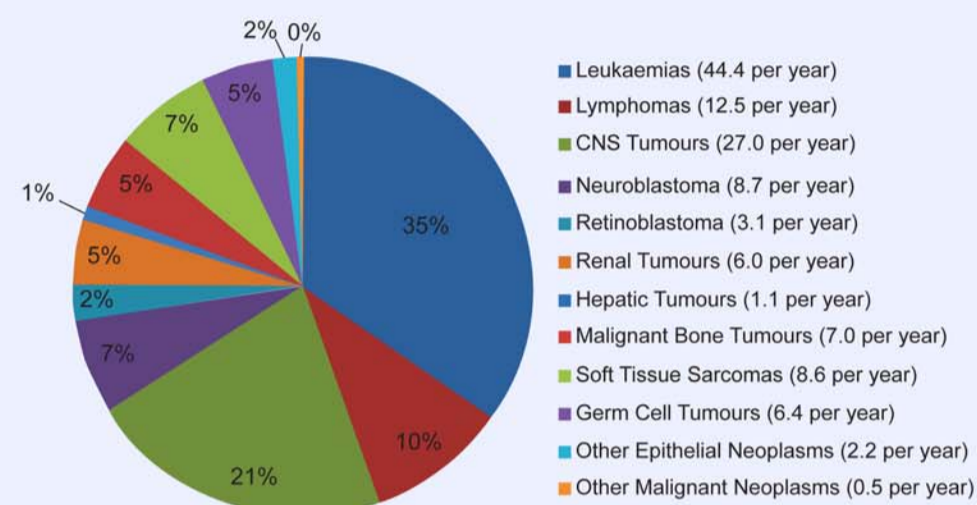


Table 1: Frequency of cancer diagnoses (%) for each ICCV diagnostic class for children diagnosed with cancer in New Zealand 2000 - 2009 compared with Australia and the United Kingdom.

ICCC V3.0 DIAGNOSIS by %	NZCCR 2000-2009	Australia 1997-2004	UK 2001-2005
Leukaemias	34.8	33.5	31
Lymphomas	9.8	10	10
CNS Tumours	21.2	22.7	25
Neuroblastoma	6.8	5.9	6
Retinoblastoma	2.4	2.4	3
Renal Tumours	4.7	5.3	6
Hepatic Tumours	0.9	1.6	1
Malignant Bone Tumours	5.5	4.3	4
Soft Tissue Sarcomas	6.7	5.4	7
Germ Cell Tumours	5	4.1	3
Other Epithelial Neoplasms	1.7	4.7	3
Other Malignant Neoplasms	0.4	0.2	1

Figure 2: Gender distribution of childhood cancers diagnosed in NZ as classified by ICCV diagnosis between 2000 - 2009.

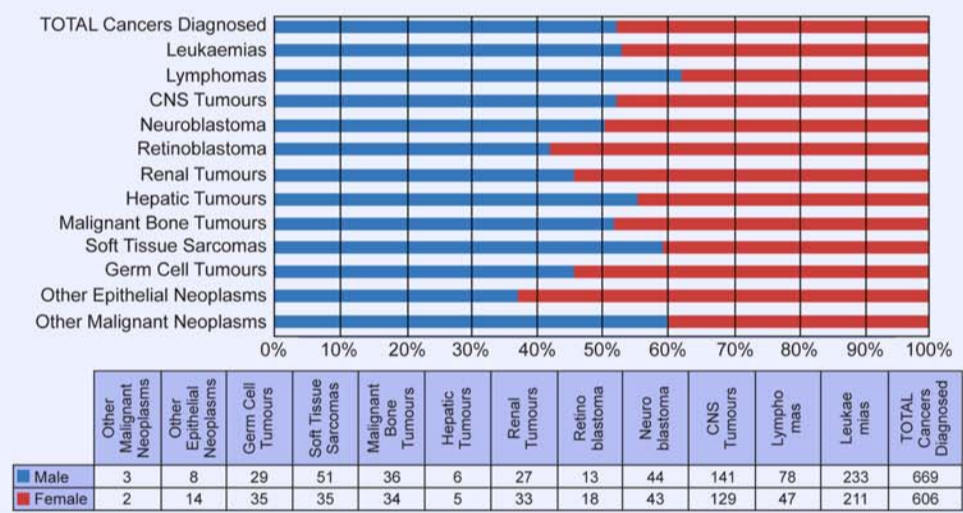


Figure 3: Age distribution of childhood cancer in New Zealand by ICCV classification between 2000 - 2009.

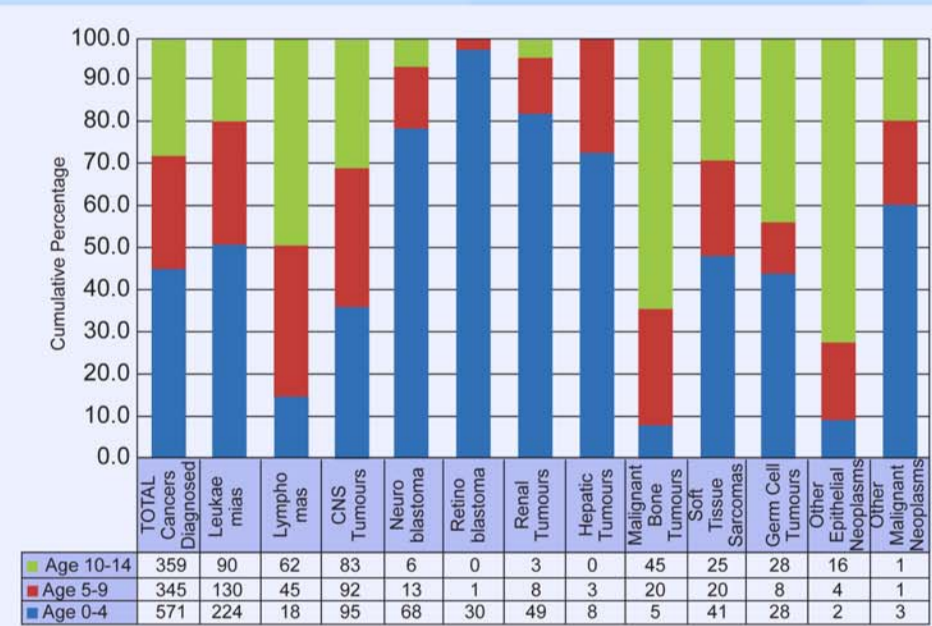


Figure 4: 5-Year Overall Survival for children diagnosed in New Zealand 2000 - 2005 compared to the New Zealand 1990 - 1993 cohort and comparable published data from Australia and the USA (SEER).

