

# IMPROVING THE ACCURACY AND COMPLETENESS OF NEW ZEALAND CHILD CANCER REGISTRATION: THE BENEFIT OF TWO NATIONAL REGISTRIES

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## Background / Objectives

New Zealand has two cancer registries covering childhood cancers; the New Zealand Children's Cancer Registry (NZCCR), based in the two specialist paediatric oncology centres, and the New Zealand Cancer Registry (NZCR), a population-based register of primary malignant tumours. Both registries collaborated to determine the accuracy and completeness of child cancer registration.

## Materials and Methods

2010-2014 registrations for children aged under 15 years that met International Classification of Childhood Cancers (ICCC-3) criteria were obtained from each registry and matched by National Health Index (NHI) number. Anomalies were reconciled using patient management systems, clinical summaries and laboratory reports.

## Results - Accuracy

Following review, 2 records were removed from the NZCCR and 19 from the NZCR – primarily due to the registration of children who came from the Pacific Islands for treatment. In addition, errors were corrected for sex (n=5), age at diagnosis (n=15), and ICD-O site/histology resulting in a change of ICCC-3 diagnostic group/subgroup (n=25).

Registered in error	NZCR	NZCCR	Any
<b>Total notifications</b>	<b>716</b>	<b>721</b>	<b>794</b>
Incorrect date of diagnosis (pre 2010)	-	1	1
Non-malignant tumour	6	1	7
Relapse registered as a new primary	1	-	1
Overseas at diagnosis	19	-	19
Inclusion criteria differences	4	-	4
<b>Total notifications removed</b>	<b>30</b>	<b>2</b>	<b>32</b>
<b>Total notifications confirmed</b>	<b>686</b>	<b>719</b>	<b>762</b>

## Results - Completeness

Of the 794 unique cases identified, 643 cases were informed by both registries. By ICCC-3 subgroup, NZCCR particularly under-reported 'XId: melanomas' and 'Id: myelodysplastic syndrome' while NZCR under-reported 'IId miscellaneous lymphoreticular neoplasms' and 'IIlb: astrocytomas'. Case completeness (according to their respective registration criteria) was 99% for the NZCR and 94% for the NZCCR.

Cases informed by one registry only	NZCR	NZCCR	TOTAL
Non-malignant CNS tumours <sup>1</sup>		55	55
LCH prior to 1/1/2014 <sup>2</sup>		16	16
Missed by second registry in error	18	5	23
Diagnosed <1 week prior to death	5		5
Case not referred to a specialist centre	18		18
Pending registration as at 1/1/2016	2		2
<b>TOTAL</b>	<b>43</b>	<b>76</b>	<b>119</b>

<sup>1</sup> NZCR does not register non-malignant tumours, NZCCR registers *all* CNS tumours as per ICCC-3  
<sup>2</sup> NZCR registered LCH from 2014 (the date the ICD-O-3-1 was implemented), NZCCR from 2010

Total cases by ICCC-3	NZCR	NZCCR	FINAL
I Leukaemias	265	249	254
II Lymphomas	69	79	82
III CNS tumours	109	150	158
IV Neuroblastoma	59	55	56
V Retinoblastoma	30	27	28
VI Renal tumours	35	33	33
VII Hepatic tumours	14	12	14
VIII Bone sarcomas	48	42	45
IX Soft tissue sarcomas	41	43	44
X Germ cell tumours	19	17	22
XI Carcinomas	25	14	25
XII Other	2	0	1

## Discussion

Collaboration resulted in the reporting of an average of 152 annual child cancer cases meeting ICCC-3 criteria each year compared to the 143-144 identified by either registry alone. Age-standardised child cancer incidence for 2010-2014 was 167 per million (95%CI: 155-179).

Analysis of the accuracy and completeness of child cancer registrations highlighted each registry's respective strengths;

### NZCCR

- ✓ Registers non-malignant CNS tumours
- ✓ Identifies overseas patients coming to NZ for treatment & excludes from incidence counts
- ✓ Is updated if a diagnosis changes following expert review
- ✓ Can make registry modifications readily (e.g. ICD-O revisions)
- ✓ Includes comprehensive diagnostic and treatment information for patient care, service planning, and research

### NZCR

- ✓ Mandatory pathological reporting – includes cases not referred to specialist centres
- ✓ Includes cases diagnosed at autopsy / death certificate only
- ✓ Cancers are registered by expert clinical coders
- ✓ Access to date of death directly from the NHI
- ✓ Many fields are automatically populated from the NHI, reducing data entry errors

## Conclusion

This study has identified improvements that can be made in the registration processes of each registry and some gaps in New Zealand's child cancer referral pathways which require addressing at a national level. With two registries covering childhood cancers, New Zealand is uniquely positioned to undertake regular collaborative activities, thereby ensuring that highly accurate and complete data is available for research and statistical reporting purposes.