Cancer Epidemiology 55 (2018) 104–109

CHILDHOOD CANCER REGISTRATION IN NEW ZEALAND: A REGISTRY COLLABORATION TO ASSESS AND IMPROVE DATA QUALITY

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Keywords: data quality; cancer registry; children; completeness; accuracy; incidence

ABSTRACT

AIM: To evaluate the completeness and accuracy of child cancer registration in New Zealand. METHODS: Registrations for children aged 0-14 diagnosed between 1/1/2010 and 31/12/2014 were obtained from the New Zealand Cancer Registry (NZCR) and the New Zealand Children's Cancer Registry (NZCCR). Six key data fields were matched using National Health Index numbers in order to identify and resolve registration discrepancies. Capture-recapture methods were used to assess the completeness of cancer registration. RESULTS: 794 unique cases were reported; 718 from the NZCR, 721 from the NZCCR and 643 from both registries. 27 invalid cancer registrations were identified, including 19 residents of the Pacific Islands who had travelled to New Zealand for treatment. The NZCCR provided 55 non-malignant central nervous system tumour and 16 Langerhans cell histiocytosis cases which were not registered by the NZCR. The NZCR alerted the NZCCR to 18 cases missed due to human error and 23 cases that had not been referred to the specialist paediatric oncology centres. 762 cases were verified as true incident cases, an incidence rate of 166.8 per million. Registration accuracy for six key data fields was 98.6%. According to their respective inclusion criteria case completeness was 99.3% for the NZCR and 94.4% for the NZCCR. For childhood malignancies covered by both registries, capture-recapture methods estimated case ascertainment at greater than 99.9%. CONCLUSION: With two national registries covering childhood cancers, New Zealand is uniquely positioned to undertake regular cooperative activities to ensure high quality data is available for research and patient care.

INTRODUCTION

Cancer registries are an essential component of a cancer surveillance and control programme, providing a solid baseline for research, clinical practice and public health policy and evaluation.[1] The usefulness of cancer registries is dependent on the quality of the data; specifically the *timeliness* of reporting, *comparability* between registries and over time, the *accuracy* of data recording, and the *completeness* of case ascertainment.[2,3]

The registration of childhood cancers presents additional challenges for cancer registries as, due to the rarity of cancer in childhood, even a small number of systematic errors and omissions can have a major impact on the incidence and survival rates reported.[4] In addition, the spectrum of cancers that affect children are quite distinct from those which are diagnosed in adulthood.[5] This has led to a growing number of specialist paediatric cancer registries established worldwide.[4] These specialist registries typically classify cancers according to the International Classification of Childhood Cancers (ICCC),[5] and are often in the position to collect substantially more treatment and outcome data than general cancer registries.[4] International collaborations such as the EUROCARE project[6] and International Incidence of Childhood Cancer,[7] have led to the development of rigorous data validation procedures to ensure greater comparability between registries and to drive improvements in data quality. In addition, a few countries with access to two independent sources of paediatric cancer notifications have been able to utilise these to identify registration errors and/or estimate case ascertainment.[8-12]

Since January 1 2000, New Zealand childhood cancers have been registered by two independent registries; the New Zealand Cancer Registry (NZCR) and the New Zealand

Children's Cancer Registry (NZCCR). The NZCR is a population-based registry which includes key demographic information and detailed pathological information for all primary malignant tumours first diagnosed in New Zealand. The NZCCR was established at the request of the Ministry of Health for use in individual patient care, service delivery planning, statistical reporting, and child cancer research. With ethical approval to operate as an opt-out registry, the NZCCR collects demographic, diagnostic and treatment information for all children with cancer who are referred to New Zealand's two specialist paediatric oncology centres. It is integrated with the Late Effects Assessment Programme National Database which is used primarily by Clinical Nurse Specialists for planning and documenting the long-term follow up of patients who have completed their cancer treatment. The seamless integration of the NZCCR and the LEAP National Database removes unnecessary duplication of data input and provides additional data elements, including comprehensive chemotherapy, radiotherapy and surgical information and graded treatment-related events for approved research purposes.

As a long-established population-based registry, the New Zealand Cancer Registry plays an important role in New Zealand research and healthcare decision-making yet few studies have evaluated its data quality.[13-15] To date, only one study has assessed the completeness and accuracy of childhood cancer registrations in New Zealand; a comparison of the NZCR 1990-1993 childhood cancer registrations with the Children's Cancer Registry, a predecessor of the NZCCR overseen by clinicians from the five regional paediatric oncology centres in operation at this time.[8] While the completeness of registration was high for the NZCR – ascertaining 97% of the confirmed incident cases of childhood cancer for the period – registration errors such as the erroneous coding of benign conditions as malignancies were 'more common than expected', with nearly 10% of the total NZCR notifications being

subsequently identified as invalid. In contrast to the over-reporting of the NZCR, the Children's Cancer Registry held only 85% percent of the total cancers diagnosed as some children were treated exclusively by specialists in other medical disciplines. It was therefore only through matching both registries that New Zealand child cancer incidence and survival could be accurately reported.

Ethical approval for data sharing between the NZCR and NZCCR and the use of the National Health Index (NHI) number – a unique seven digit personal identification number used in all health records – provides us with the opportunity to thoroughly assess the quality of child cancer data in New Zealand. The primary aim of this study was to determine the accuracy and completeness of child cancer registration for the 2010-2014 period. In addition, we aimed to produce updated child cancer incidence rates, to detect any gaps in national paediatric oncology referral pathways, and to identify future improvements which can be made to NZCR and NZCCR cancer registration practices.

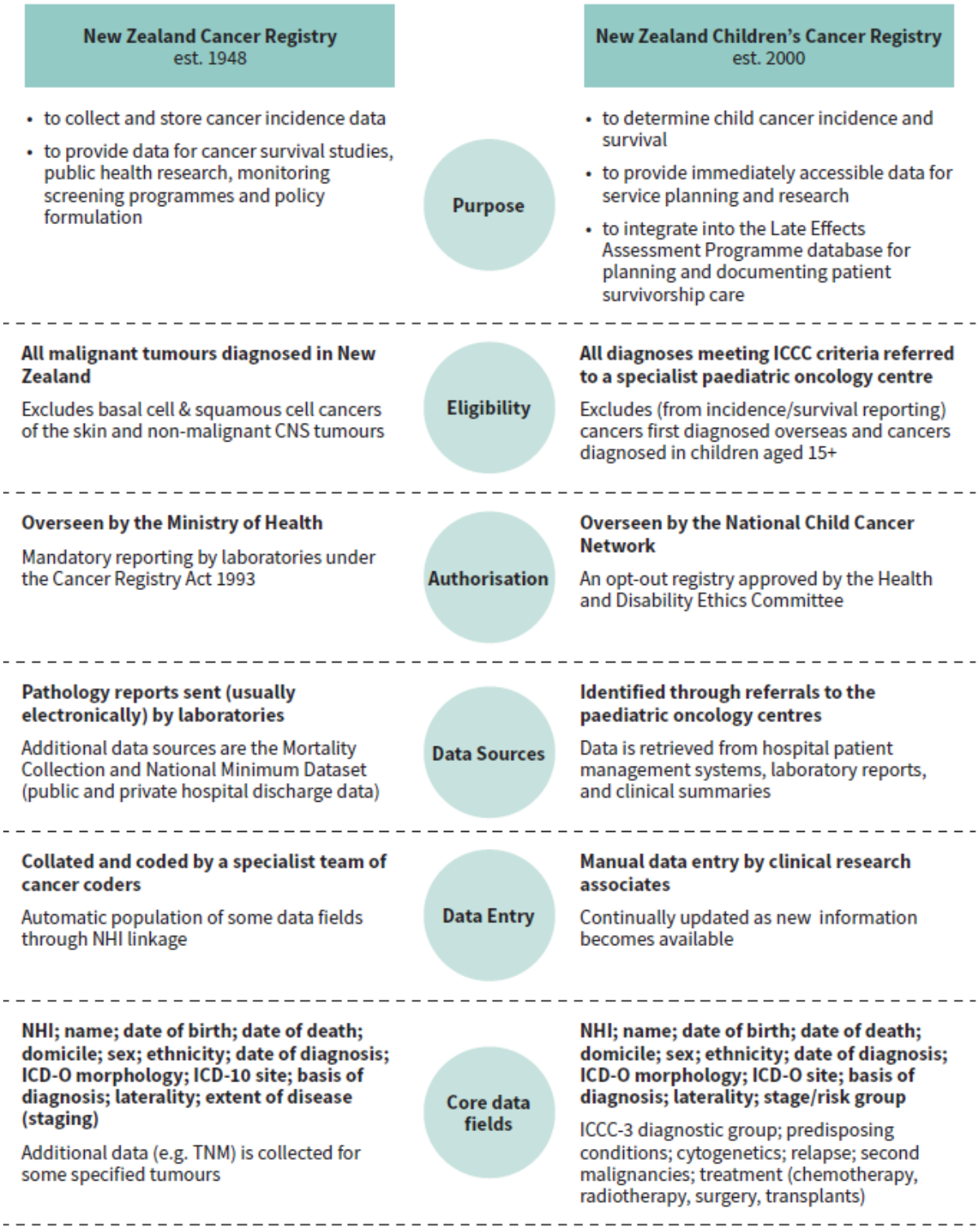
MATERIALS AND METHODS

Data Fields

All new cancer cases for children under the age of 15 years diagnosed between January 1 2010 and December 31 2014 were obtained from the NZCR and the NZCCR. Descriptions of the two data sources are provided in Figure 1. Data fields included the NHI number, date of birth, sex, date of diagnosis, topography, morphology, ICCC-3 diagnostic group and subgroup, and date of death. Topography was classified by the NZCR according to the Australian modification to the 10th edition of the International Classification of Diseases (ICD-10-AM)[16] and by the NZCCR according to the World Health Organisation (WHO)

International Classification of Diseases for Oncology Third Edition (ICD-O-3-1).[17] Morphology was coded according either to the ICD-O-3 or its first revision (the ICD-O-3-1).[17] The ICD-O-3-1 incorporates the morphology and behaviour code revisions from the 'WHO Blue Books' published between 2007 and 2010[18-20] and was adopted by the NZCCR from the 1/1/2010 and the NZCR from the 1/1/2014. As the NZCR does not classify cancers according to the ICCC, the ICCC-3[5] diagnostic group and subgroup for NZCR registrations were derived from the morphology and topography according to the ICCC recode produced by the National Cancer Institute.[21]

FIGURE 1: A comparison of the two sources of childhood cancer registrations in New Zealand



Datasheets from the NZCCR and NZCR were merged and discrepancies were resolved through co-operation between a senior NZCR Clinical Coder and the NZCCR Registry Manager. New Zealand residency at the time of diagnosis was established using patient management systems and clinical summaries. Date of birth and sex were verified using patient management systems. Death registrations were provided by the Ministry of Health. For reconciling differences in date of diagnosis and ICCC-3 diagnostic group/subgroup histopathology reports were used as the gold standard. Prior to the correction of detected errors, the registrations held by each registry were evaluated according to completeness and accuracy. Accuracy between the two registries was defined as within one month for date of diagnosis and exact for date of birth, sex, ICCC diagnostic group, ICCC diagnostic subgroup, and date of death.

Statistical analysis

Statistical analyses were performed in SAS v9.3 (SAS Institute, Inc, Cary, NC). Incidence rates were calculated as the average annual number of cases per million person-years and age-standardised to the World Standard Population. The denominators were annual mean population-estimates produced by Stats NZ based on national census data. 95% confidence intervals (95% CI) were calculated assuming the cases were drawn from a Poisson distribution.

Two-source capture-recapture methods were used to determine the total number of incident cases that would have been expected if ascertainment had been complete and to thereby estimate the completeness of New Zealand child cancer registration. Independence of sources was assumed and the estimator of the number of incident cases in the population was defined as $a + b + c + (b \times c)/(a + 1)$ where a is the number of registrations notified by both registries,

b by the NZCR only, and c by the NZCCR only.[22] The analyses were conducted by sex, age group, ICCC diagnostic group/subgroup, and for all childhood cancers combined. Only cases which were covered by both registries were included in capture-recapture estimates. This resulted in the exclusion from the capture-recapture estimates of non-malignant central nervous system (CNS) tumours, which the NZCR does not register, and Langerhans cell histiocytosis (LCH), due to differences in the timing of adoption of the ICD-O-3-1 in which all variants of LCH were reclassified as malignant.

RESULTS

Accuracy

Table 1 shows that a total of 54 corrections were made for the 643 cases registered by both registries, representing an error rate of 1.4% across the 3858 data items assessed for six core data fields. The NZCCR recorded 12 single-digit typos for the date of birth which resulted in errors ranging from 2 days to 10 years and had not recorded six deaths which had occurred within the study period. Nineteen errors were identified in topography or histology which resulted in the diagnosis being assigned to a different ICCC diagnostic group (n=8, 1.2%), or subgroup (n=11, 1.7%). In many cases the discrepancies in ICCC classification and/or date of diagnosis were the result of a revision of disease morphology based on further diagnostic testing, particularly for children enrolled in international collaborative trials.

Table 1: Reconciliation of differences in six core data fields for 643 children's cancers registered by the NZCCR and NZCR, New Zealand, 2010-2014

Data Field	NZCR Errors	NZCCR errors	Total errors	Accuracy (%)
Date of diagnosis (>30 days)	5	7	12	98.1
Date of birth	-	12	12	98.1
Sex	1	3	4	99.4
Date of death (not recorded)	1	6	7	98.9

ICCC-3 diagnostic group	6	2	8	98.8
ICCC-3 diagnostic subgroup	7	4	11	98.3
	20	**34**	**54**	**98.6**

Completeness

Of the 794 children notified through one or both of the two registration sources, 718 were informed by the NZCR (IR: 157.9 per million), 721 were informed by the NZCCR (IR: 158.5 per million) and 643 were informed by both registries (See Table 2). Data matching resulted in the subsequent removal of 27 registrations both from the incident dataset and from the informing registry; 19 non-NZ residents, seven non-malignant tumours misclassified as malignant, and one registration of a relapse as a new primary. In addition, one registration was excluded from the incident dataset as their corrected date of diagnosis was outside of the study period. An additional four cases reflected differences in registration practices between the two registries. Three of these cancer cases met NZCR inclusion criteria because the children had a New Zealand address at the time of diagnosis but were excluded from NZCCR incidence reporting because they were non-New Zealand residents who had flown to New Zealand for their cancer treatment. In the fourth case the date of clinical diagnosis used by the NZCCR was prior to 2010 while the NZCR used the date of histological diagnosis obtained at autopsy which was within the study period. These four cases remained in the registries but were excluded from the incident dataset.

At the conclusion of the review, 762 cases had been verified as incident cases. Five cases were missed by the NZCR in error compared to 43 missed by the NZCCR, although in 23 cases this was due to the child not being referred to either of the paediatric oncology specialist centres. The 18 cases known to the centres but not registered by the NZCCR included 11 cases - predominantly of myelodysplastic syndrome - which were mistakenly classified as non-malignant by the registrars.

Table 2: Source and confirmation of child cancer registrations, New Zealand, 2010-2014

	Registry source					
	NZCR		NZCCR		Any source	
Original notifications		**716**		**721**		**794**
Less: Notifications not confirmed						
Non-malignant tumour not classified by ICCC	6		1		7	
Registration of a relapse as a new primary	1		-		1	
Overseas residence at diagnosis	19		-		19	
Total notifications removed from the registries		**26**		**1**		**27**
Less: Incorrect date of diagnosis (pre 2010)	-			**1**		**1**
Less: Registration criteria differences		**4**				**4**
Total notifications included in 2010-2014 incidence		**686**		**719**		**762**
Cases notified by one registry only						
Non-malignant CNS tumours			55		55	
Langerhans cell histiocytosis			16		16	
Missed by one registry in error	18		5		23	
Patient not referred to a paediatric centre	23				23	
Pending registration as at 1/1/2016	2				2	
Total cases informed by one registry only		**43**		**76**		**119**
Cases informed by both registries						**643**

Capture-recapture estimates

The NZCCR held 94.4% of all valid registrations for the time period (See Table 3). The NZCR captured 99.3% of child cancer cases when assessed against the NZCR's own registration criteria. However, relying on the NZCR alone would result in the reporting of only 90.0% of New Zealand childhood cancers meeting ICCC criteria which were diagnosed in this time period due to the non-registration of 55 non-malignant CNS tumours and 16 of the LCH cases

In total, 762 cases were classified as incident in the 2010-2014 period. Capture-recapture methods (excluding non-malignant CNS tumours and LCH) estimated completeness of case ascertainment at greater than 99.9%. Estimates of case completeness were lowest for germ cell tumours (95.7%) and 'other malignant epithelial neoplasms and melanomas' (96.5%). In the case of germ cell tumours, both the NZCR and NZCCR missed cases (three and five

respectively). The NZCCR was most likely to miss ‘other malignant epithelial neoplasms and melanomas’ (12 cases) and CNS tumours (eight cases).

Table 3: Number of child cancer cases notified from each source, with capture-recapture estimates and incidence rates, New Zealand, 2010-2014

	Number of registrations by source of notification						Capture-recapture estimates[a, b]		New Zealand cancer incidence[c]		
	NZCR		NZCCR		Both sources	Any Source	Estimated cases		Observed incidence per million person-years		
	(n)	% of total confirmed cases	(n)	% of total confirmed cases	(n)	(n)	(n)	%	Average annual cases	Incidence per million	95% CI
Sex											
Male	378	99.5%	357	93.9%	355	380	380.1	100.0	85.8	183.2	165.8 - 200.5
Female	299	99.0%	281	93.0%	278	302	302.2	99.9	66.6	149.6	133.5 - 165.7
Age at diagnosis											
0-4 years	343	99.7%	328	95.3%	327	344	344.0	100.0	76.4	243.6	219.2 - 268.0
5-9 years	156	99.4%	149	94.9%	148	157	157.1	99.9	36.6	123.5	105.6 - 141.4
10-14 years	178	98.3%	161	89.0%	158	181	181.4	99.8	39.4	131.5	113.1 - 149.8
ICCC-3 diagnostic group											
I Leukaemias, myeloproliferative & myelodysplastic diseases	253	99.6%	246	96.9%	245	254	254.0	100.0	50.8	55.5	48.7 - 62.4
II Lymphomas and reticuloendothelial neoplasms[a]	57	100.0%	56	98.2%	56	57	57.0	100.0	16.4	18.0	14.1 - 21.9
III CNS and miscellaneous intracranial and intraspinal neoplasms[b]	103	100.0%	95	92.2%	95	103	103.0	100.0	31.6	34.7	29.3 - 40.2
IV Neuroblastoma and other peripheral nervous cell tumours	56	100.0%	55	98.2%	55	56	56.0	100.0	11.2	12.2	9.0 - 15.3
V Retinoblastoma	28	100.0%	27	96.4%	27	28	28.0	100.0	5.6	6.1	3.8 - 8.3
VI Renal tumours	33	100.0%	33	100.0%	33	33	33.0	100.0	6.6	7.2	4.7 - 9.6
VII Hepatic tumours	14	100.0%	12	85.7%	12	14	14.0	100.0	2.8	3.1	1.5 - 4.7
VIII Malignant bone tumours	45	100.0%	42	93.3%	42	45	45.0	100.0	9.0	9.9	7.0 - 12.8
IX Soft tissue and other extraosseous sarcomas	44	100.0%	43	97.7%	43	44	44.0	100.0	8.8	9.7	6.8 - 12.5
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	19	86.4%	17	77.3%	14	22	23.0	95.7	4.4	4.8	2.8 - 6.8
XI Other malignant epithelial neoplasms and malignant melanomas	24	96.0%	13	52.0%	12	25	25.9	96.5	5.0	5.5	3.4 - 7.7
XII Other & unspecified malignant neoplasms	1	100.0%	0	0.0%	0	1	2.0	50.0	0.2	0.2	0 0 - 0.7
Total included in capture-recapture estimates[a,b]	677	99.3%	639	93.7%	633	682	682.3	>99.9	136.4	149.3	138.1 - 160.5
Total cases meeting ICCC inclusion criteria	686	90.0%	719	94.4%	643	762	[c]	[c]	152.4	166.8	155.0 - 178.7

[a] Case completeness and capture-recapture excludes diagnostic group II(d): miscellaneous reticuloendothelial neoplasms as due to changes in the ICD-O-3-1 only 9 of the 25 LCH cases were registered by the NZCR in the study period

[b] Case completeness and capture-recapture excludes 55 non-malignant CNS tumours which are only registered by the NZCCR

[c] Capture-recapture estimates could not be calculated for the total population as notifications for some LCH cases and all non-malignant CNS tumours came only from a single source

New Zealand Child Cancer Incidence

Consolidated data from the NZCR and NZCCR confirms that approximately 150 children under the age of 15 are diagnosed in New Zealand each year (See Table 3). Between 2010 and 2014, overall child cancer incidence was 166.8 per million person-years. Incidence was higher for boys (IR: 183.2 per million) compared to girls (IR: 149.6 per million) and higher for children aged 0-4 (IR: 243.6 per million) compared to 5-9 year olds (IR: 123.5 per million) or 10-14 year olds (IR: 131.5 per million). The most common diagnosis was leukaemia (30.5% of all cases), CNS tumours (20.7%) and lymphomas (10.8%).

DISCUSSION

Ascertainment of childhood cancer appears to be virtually complete in New Zealand with an overall capture-recapture estimate of greater than 99.9%. Data accuracy was high at 98.6% for the six core data fields assessed. New Zealand's assigning of a NHI number from birth supports effective record linkages and prevents duplication of case registrations. We can therefore be confident in our reporting of child cancer incidence for the period of 166.8 per million, in line with that reported in Australia, the United States and Western Europe.[23-26]

At 94.4% completeness, this study has illustrated that the NZCCR has good, but not yet complete case ascertainment. Changes to address the 18 cases that were referred to the specialist paediatric oncology centres but missed from the NZCCR in error included the Registry Manager providing updates to staff whenever new WHO classifications are released and strengthening communication between the two centres regarding which centre has responsibility for registering patients not following standard referral pathways. The vast majority of the 23 cases which were unknown to the two specialist paediatric oncology

centres should have ideally been referred to a paediatric oncology multi-disciplinary meeting. Despite the immediate treatment needs for a thirteen year old with localised melanoma, for example, being well met by our surgical colleagues, a concurrent referral to a specialist paediatric-oncology centre provides the child with expert review and access to long-term follow-up and survivorship education through each centre's Late Effects Assessment Programme. Pleasingly, referral pathways have been strengthened throughout the 2010-2014 period, with children diagnosed with 'other malignant epithelial neoplasms and malignant neoplasms' the one remaining group of patients who are not consistently being referred to the specialist centres. Further work is being undertaken to ensure all surgeons - including those operating in the private system – are aware of the paediatric oncology multi-disciplinary meetings and the benefits of referral. With consistent referrals to the specialist centres and additional registrar training, the NZCCR has the potential to achieve almost complete case ascertainment, missing only those rare cases that are diagnosed at autopsy or very close to death.

Due to there being no legal mandate for the NZCR to register CNS tumours of benign or uncertain behaviour, only 103 of the 158 CNS tumours were recorded by the NZCR during this time period, resulting in their underreporting of this important group of childhood tumours by 34.8%. Also, 26 of the 27 non-incident cases came from the NZCR. New Zealand paediatric oncology centres, as part of the National Child Cancer Network Twinning Partnership, are often involved in the cancer treatment of children from neighbouring Pacific Island nations. These children may fly to New Zealand for part of their treatment and undergo further diagnostic testing here, the results of which are automatically reported to the NZCR. Understandably, the NZCR find it difficult to identify and remove non-resident incident cases, potentially inflating their reported child cancer incidence for New Zealand's Pacifica

population. However, overall the NZCR had excellent case completeness (99% taking into account their own registration criteria) with the NZCCR alerting them to only five additional cases that met NZCR criteria for registration from the entire five-year period. These cases were all complex, where second opinions were sought internationally in order to obtain a definitive diagnosis. This supports the notion that the NZCR is a high quality population-based registry with robust pathological reporting systems and data validation practices.

There are some limitations with the study. Although basal cell and squamous carcinomas are extremely rare in children and the proportion of non-malignant CNS tumours recorded by the NZCCR is similar to what has been reported elsewhere[7], the accuracy and potential undercounting of these groups of tumours was not able to be assessed given that such cases are not registered by the NZCR. Also, as both registries utilise hospital records and pathology reports for case ascertainment, the independence assumption of the two registries cannot be fully justified.

Although the NZCR and NZCCR were established for different purposes and operate relatively independently, this study shows how well they complement each other. The NZCR can alert the NZCCR to cases not referred to the paediatric oncology specialist centres and cases diagnosed at autopsy or by death certificate only. As many NZCR fields are automatically populated from the NHI, they are less susceptible to the manual data entry errors which require careful checking in the NZCCR. Equally importantly, the NZCCR is able to provide data pertaining to non-malignant CNS tumours and can inform the NZCR of overseas patients coming to New Zealand for treatment so that they can be excluded from incidence counts. Although the data quality measure of timeliness was not examined in this study, NZCR data is released up to 18 months following diagnosis while NZCCR has the

advantage of immediate availability of data for patient care, research, and to inform decision-making regarding child cancer services. The NZCR and NZCCR will continue to undertake regular reviews of our registrations and will also look for new ways in which the two registries can work together to support child cancer research. An example of this is the recent release of the Toronto Paediatric Cancer Staging Guidelines which specify 16 different staging systems for the most common childhood cancers.[27] Given that childhood cancers make up less than 1% of all new registrations, it would be difficult for the NZCR to justify the additional resources required to record paediatric cancer staging. The NZCCR has therefore taken responsibility for staging all new registrations according to the Toronto Guidelines and making this available to the NZCR and other interested parties.

CONCLUSION

This study demonstrates that childhood cancer registration in New Zealand is highly accurate and virtually complete. It also highlights the significant benefits of ongoing collaborations between paediatric and national registries. Regular data exchanges and cooperative activities offer the opportunity to improve data quality in both sources, indicate whether national paediatric oncology referral pathways are operating as they should, and ensure that comprehensive data is available for child cancer research, policy development and clinical care.

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