

NZCCR REPORT 2014

The New Zealand Children's Cancer Registry (NZCCR) was established in 2002 and holds verified diagnostic, demographic and treatment information for children diagnosed with cancer in New Zealand since the year 2000. All data is entered by clinical research associates (CRAs) at each specialist paediatric oncology unit and submitted electronically to the NZCCR National database. The NZCCR Working Group, under the governance of the National Child Cancer Network, is responsible for monitoring the on-going collection and the regular reporting of anonymised registry data.

Welcome to the 2014 annual update from the NZCCR Working Group. This brief report provides a summary of our recent activities and a snapshot of the children who were diagnosed with cancer in 2014.

The NZCCR Working Group continue to receive requests for registry data for research purposes. NZCCR data formed the basis two conference presentations in 2014. Dr Ruellyn Cockcroft presented a paper on the outcomes of hepatoblastoma in children at the South African Paediatric Association meeting in September and Dr Peter Bradbeer presented a paper with updated 2013 incidence and survival figures at the Paediatric Society 66th Annual Scientific Meeting in November.

In addition to research requests, we also regularly receive requests for anonymised data to inform service delivery planning and review. This year the NZCCR Working Group has implemented changes to the registry to ensure consistent disease staging and to collect additional data around the enrolment of our patients in clinical trials. This will allow us to provide data to other NCCN working groups for informing decisions around priorities for new clinical trial openings, identifying and addressing barriers to clinical trial participation, and reviewing referral pathways. One of the advantages of the NZCCR over other registries is that it has been developed in a way that makes it relatively easy to make modifications and enhancements when needed.

For accurate reporting, the NZCCR relies on all child cancer cases being known to the Clinical Research Associates. The vast majority of children with cancer spend time in either Starship Blood and Cancer Centre or on CHOC (Children's Haematology/Oncology Centre) in Christchurch. Information about the registry is provided to the families during their child's stay on the ward. However, a small number of children diagnosed with cancer each year spend little or no time in a specialist paediatric oncology unit. For example, some children who have a non-malignant central nervous system tumour may be treated exclusively by the paediatric neurosurgical team. Recently the NZCCR working group has strengthened processes to identify these few children and to contact their families with information about the registry. It is pleasing that a recent audit of children who had been recorded as having received cancer treatment in Christchurch over the past five years found that 98% of these children were registered on the NZCCR and that case ascertainment for 2013 and 2014 was 100%.

If you would like further information about childhood cancer, two comprehensive reports describing New Zealand child cancer incidence and survival for the 2000-2009 period can now be downloaded the National Child Cancer Network website; www.childcancernetwork.org.nz. A complementary report, describing cancer incidence and survival in New Zealand's adolescent and young adult population is also available at the same address.

Please feel free to share this report with your colleagues who have an interest in children's cancer research. If you have any questions about the registry or wish to request registry data for use in research that will benefit New Zealand children with cancer, feel free to contact either of us on the email address below.

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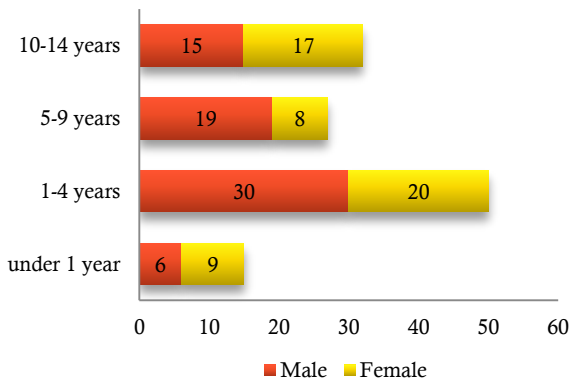
NZCCR SNAPSHOT 2014

This snapshot relates to NZ children aged 0-14 years *diagnosed with cancer* in 2014. It does not include patients receiving on-going treatment for tumours diagnosed in previous years, non-NZ residents, those aged over 14 years, or those diagnosed with other non-malignant/haematological conditions. The number of patients *receiving treatment* in our paediatric oncology specialist centres each year is significantly higher.

NEW CASES DIAGNOSED

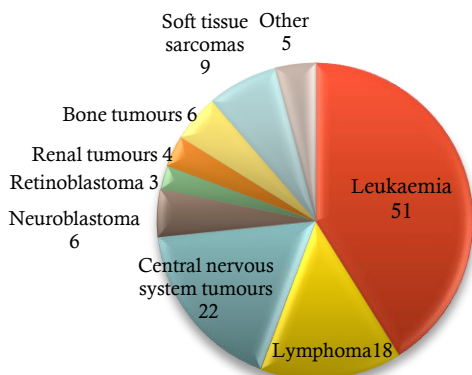
124 New Zealand children under the age of 15 were diagnosed with cancer in 2014. This was 27 fewer than in 2013. While child cancer incidence is stable in New Zealand, there are natural year-on-year fluctuations in patient numbers which can have a considerable impact on our national service.

In 2014 there were more males (70) diagnosed than females (54) and more 0-4 year olds (65) than 5-14 year olds combined (59).



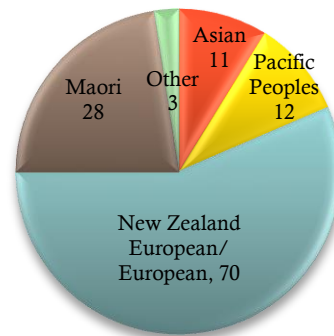
TYPES OF CANCERS DIAGNOSED

The most frequently diagnosed childhood cancer in 2014 was leukaemia (51 cases), the vast majority of which were Acute Lymphoblastic Leukaemia (40). All new cases of retinoblastoma, renal tumours (i.e. Wilms' tumour), and neuroblastoma were diagnosed in children under the age of 5. More males (44) than females (25) were diagnosed with a haematological malignancy.



NEW CASES BY ETHNICITY

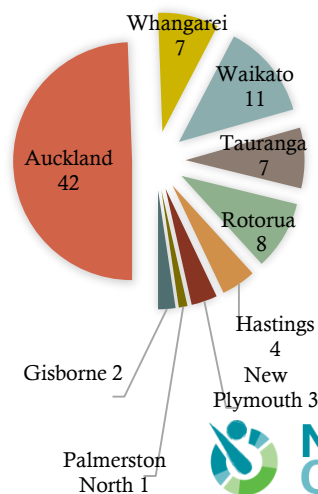
By prioritised ethnicity, 23% children diagnosed in 2014 were Maori, 10% Pacific Peoples, 9% Asian, 2% 'Other' and 56% NZ European/European.



SHARED-CARE CENTRES

86 of the children diagnosed with cancer in 2014 are under the care of Starship Blood and Cancer Centre in Auckland and 38 are under the care of the Central & Southern Child Cancer Service (based in the Children's Haematology and Oncology Centre in Christchurch). Over half of the children (54%) diagnosed in 2014 do not primarily reside in either Auckland or Christchurch and therefore have needed to travel to one of these specialist centres for at least a portion of their cancer treatment.

Starship Blood & Cancer Centre



Central & Southern Child Cancer Service

