

# NZCCR REPORT 2019

The New Zealand Children's Cancer Registry (NZCCR) holds verified diagnostic, demographic and treatment information for children diagnosed with cancer since the year 2000.

The NZCCR Working Group, under the governance of the National Child Cancer Network, is responsible for monitoring the ongoing collection of registry data to support New Zealand childhood cancer research.

## THE IMPACT OF COVID-19

As I am putting together our 2019 annual report and snapshot, we have moved to COVID-19 Alert Level 1 and are beginning to grasp the far reaching effects of this global pandemic. In the future there will be a great deal of research and reflection on the impact of COVID-19 across the entire health system. We know that COVID-19 added additional stress to what is already an enormously difficult time, particularly for our newly diagnosed child cancer families. While the NZCCR will be able to help answer some of our questions about the impact of COVID-19, it will be the perspectives of our patients and their whānau which will be most valuable as we evaluate how our child cancer services responded to this unprecedented event.

From our registry's perspective, COVID-19 has highlighted the importance of having rapid access to data for decision making and monitoring at both a local and national level. Analysis by the Cancer Control Agency has shown maintenance of cancer treatment during Alert Levels 3 and 4 but a significant disruption to diagnostic services resulting in fewer new cancers diagnosed than expected. We do not believe that this applies to children with cancer, but we will continue to closely monitor our new registrations over the coming months.

One small silver lining of COVID-19 has been that one of the research projects utilising NZCCR data which had been paused due to time constraints was able to be restarted. Our surgical colleagues may have had reduced surgery lists, but they definitely put this freed up time to good use!

## ACUTE MYELOID LEUKAEMIA RESEARCH

One of our key pieces of work in 2019 was undertaking research into the incidence, survival and cytogenetics of acute myeloid leukaemia (AML). AML is a blood cancer affecting around ten children each year. An analysis of NZCCR data suggested that there may be ethnic differences in the incidence and survival of AML. The NZCCR Working Group decided to undertake a comprehensive medical record review for all children diagnosed with AML between 2005 and 2019 in order to explore both biological and non-biological factors that could contribute to any potential ethnic differences. The study was completed as a University of Otago Summer Studentship Project, led by Dr Siobhan Cross.

Notably, our analysis found that Māori and Pacific children were significantly more likely to have AML with complex cytogenetics at diagnosis than those of other ethnicities and that these children had particularly poor survival outcomes. According to the current protocol used nationally for childhood AML, the presence of complex cytogenetics does not place patients in the high-risk category for treatment. However, results from this study indicate that the presence of complex cytogenetics could be an important prognostic factor, particularly for our Māori and Pacific patients.

While our specialist child cancer centres contribute to a number of international studies, our study highlights the importance of us also continuing to conduct our own research to add to our understanding and treatment of cancer in our unique population. We would like to thank LBC for generously funding this piece of research.

If you would like to read more about this study, our registry publications are available on the NCCN website [www.childcancernetwork.org.nz](http://www.childcancernetwork.org.nz)

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# NZCCR SNAPSHOT 2019

Note: this snapshot relates to New Zealand children aged 0-14 years newly *diagnosed with cancer* in 2019. It does not include patients referred to our paediatric oncology centres from overseas, those who are aged 15 years and over, or children who are diagnosed with a non-malignant/other haematological condition. As many childhood cancers require several years of treatment, the number of patients *undergoing treatment* each year is substantially higher.

## NEW REGISTRATIONS

150 children were diagnosed with cancer in 2019. An additional 25 registrations were received for patients who commenced treatment in a paediatric oncology centre but were either over 15 years old at diagnosis or had a condition not classified as a primary malignancy.

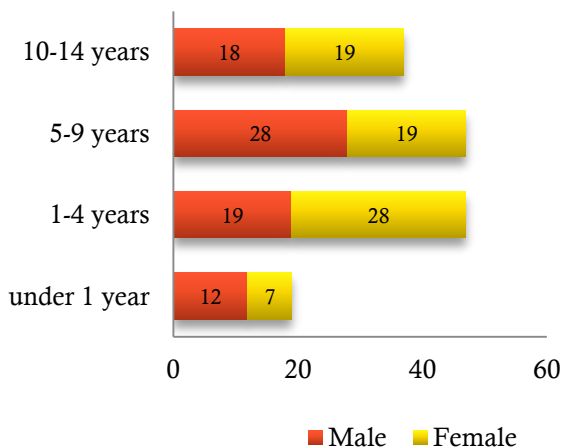
21 patients who underwent cancer treatment at Starship Blood & Cancer Centre or the Children's Haematology Oncology Centre relapsed in 2019. The duration between date of diagnosis and relapse ranged between 8 months and 11 years.

The registry also recorded the deaths of 21 child cancer patients in 2019, twelve of whom died within the year following their cancer diagnosis.

## AGE AND GENDER

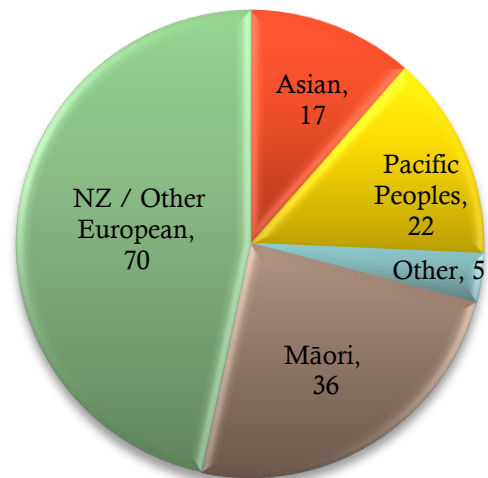
As expected, overall there were a similar number of boys (77) diagnosed with cancer as girls (73). What was a little more unusual, however, was among newly diagnosed 1-4 year olds there were around 50% more girls than boys, with the exact reverse occurring for those 5-9 years.

Compared to our ten year averages, there were fewer 1-4 year olds diagnosed with cancer and a higher number of 5-9 year olds.



## ETHNICITY

Reflecting the increasing ethnic diversity in New Zealand's child population, less than half (47%) of the children diagnosed in 2019 identified solely as NZ / Other European. Nearly one in four children diagnosed with cancer were prioritised Māori ethnicity (24%), which is identical to our child population as a whole.



## CLINICAL TRIAL PARTICIPATION

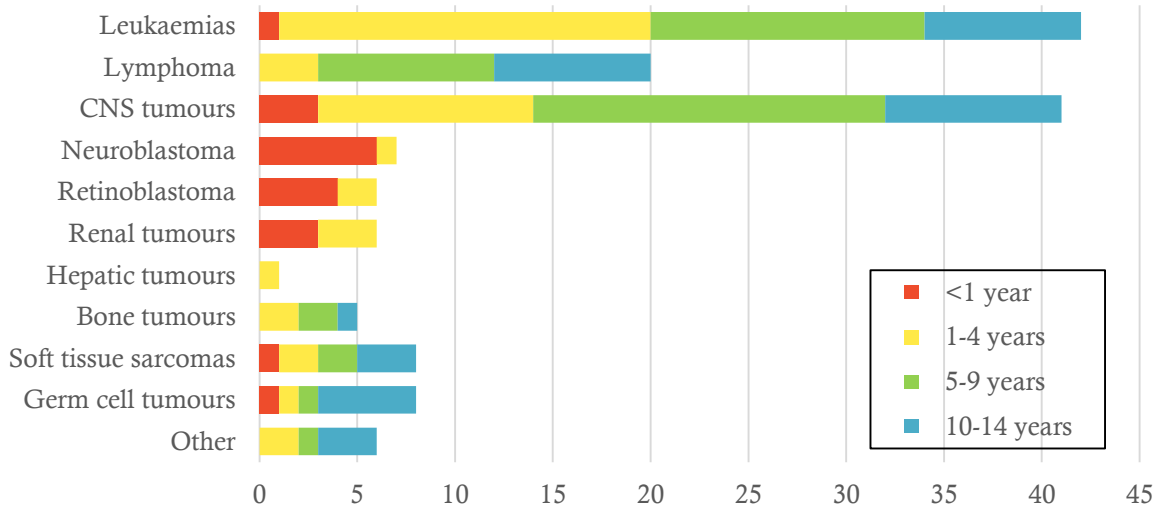
The NZCCR recorded a total of 30 enrolments in 11 open international clinical trials and a further 75 registrations in 8 different non-therapeutic studies, such as tumour biology studies, international registries, and fertility preservation research.

While there were more studies open at our two specialist centres than ever before, clinical trial enrolment numbers overall were lower than some previous years due to the closure of a Children's Oncology Group clinical trial for acute lymphoblastic leukaemia, our biggest patient group.

## DIAGNOSTIC GROUP

In 2019 central nervous system (CNS) tumours accounted for a higher proportion of cases (27% of all diagnoses) than the ten year average of 21%. In contrast, leukaemias, which usually account for one third of all childhood cancers, only narrowly remained the most common cancer for those under 15 years old; 42 children were diagnosed with leukaemia, representing 28% of all child cancer cases. Acute lymphoblastic leukaemia (ALL) was again our most common diagnostic subgroup with 32 children newly diagnosed with ALL in 2019.

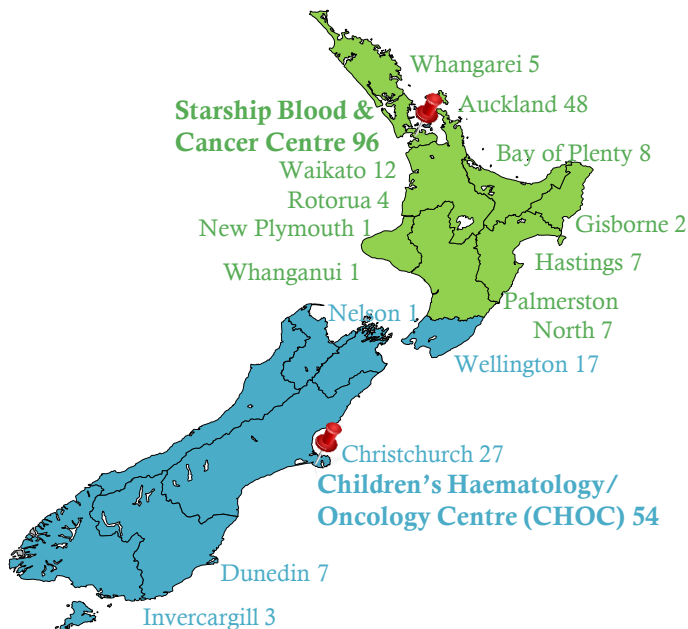
By age group, neuroblastoma, retinoblastoma, Wilms tumour and hepatoblastoma were exclusively diagnosed in children under the age of five. Leukaemia was the most common cancer for 1-4 year olds (19 cases) while 18 children aged between five and nine were diagnosed with a CNS tumour.



## RESIDENCE AT DIAGNOSIS

64% of the children diagnosed in 2019 resided in the region covered by Starship Blood and Cancer Centre and 36% in the region covered by the Children's Haematology Oncology Centre.

Exactly half of the families did not usually live in the Auckland or Christchurch region, and needed to travel to a specialist cancer centre for at least some of their child's cancer treatment.



The shared care centre with the highest number of new patients in 2019 was Wellington, with 17 children diagnosed with cancer living in the greater Wellington area compared to eight in 2018.

In contrast, three shared care centres – New Plymouth, Whanganui, and Nelson – each had only one new patient.