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Title: The International Staging System for Paediatric Cancers Pilot Study: A Review of the NZCCR Staging for CHOC Patients

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#### Introduction:

Cancer staging is an essential process for determining prognosis and is crucial for comparing outcomes between groups and over time. Paediatric cancers are rare, accounting for under 1% of all new cancer registrations each year. Historically, there has been no international consensus for the staging of childhood cancers. The New Zealand Children's Cancer Registry (NZCCR) records comprehensive diagnostic and treatment information, for all children treated at New Zealand's two specialist paediatric cancer centres. As NZCCR data is transferred to the patient's Health Passport and used for planning patient follow-up care, it is vital that clinically relevant prognostic information is collected. In 2012, paediatric oncologists were consulted to determine the most appropriate staging system to adopt for each tumour group and the NZCCR standard operating procedures were updated to ensure that stage, grade and risk information was being consistently and accurately recorded.

In 2014, a panel of experts met in Toronto to develop staging guidelines for the 18 major paediatric cancers. The Toronto Paediatric Cancer Stage Guidelines were published in April 2016 and the Australasian Paediatric Cancer Registry began to develop an online-staging application to ensure consistent and easy application of these guidelines. The NZCCR was invited to participate in the piloting of the application through a retrospective review of paediatric cases treated at the Children's Haematology and Oncology Centre (CHOC).

#### Aim:

To improve the completeness and accuracy of staging information held by the NZCCR for future analyses

To pilot an online-staging application that has the potential to improve paediatric cancer registrations internationally

To provide recommendations to the NZCCR national working group regarding whether the Toronto Paediatric Cancer Stage Guidelines should be adopted nationally

#### Impact:

The completeness and accuracy of recording within the NZCCR was high and missing information was usually able to be found within CHOC clinical summaries. Application of the Toronto Paediatric Cancer Stage Guidelines appears to be feasible, and given that they are likely to be utilized in future registry collaborations such as the 'International Incidence of Childhood Cancer', it is recommended that they are adopted by the NZCCR. Through participation in an international staging application pilot study, this project has also contributed to an initiative to provide consistency and clarity in the collection of paediatric cancer staging data. The adoption of the Toronto Guidelines by population-based registries will facilitate greater international collaboration that will ultimately lead to improved outcomes for New Zealand children with cancer.

#### Method:

Medical records for all paediatric cancer patients treated at CHOC between 2009 and 2016 were reviewed to determine disease staging at time of diagnosis according to the Toronto Paediatric Cancer Stage Guidelines using the online staging application.

Gaps in NZCCR stage/grade/risk stratification data fields were filled where necessary. Feedback on the online staging application was provided to the Australian Paediatric Cancer Registry through weekly teleconferences and email correspondence.

Evaluation of feasibility included the number of cases which could be staged and the ease of locating staging information in the medical records.

#### Results:

324 paediatric cancer cases were treated at CHOC between 2009 and 2016. The audit identified 68 gaps in stage, grade and risk stratification according to NZCCR registration criteria. The majority of these gaps were able to be filled from medical records but information was unavailable for 18 cases. With regard to the Toronto staging pilot, 74 cases were excluded from the onset, as several of the rarer paediatric cancers do not have endorsed staging systems. 250 cases were eligible for staging and 207 cases were able to be staged. Of the 43 cases which were unable to be staged, 40 were due to the online clinical algorithms for 3 of the 18 cancer groups still being under development. A further 3 cases were unable to be staged due to missing information from patient records. Cases took between 5-10 minutes to stage, apart from Wilms tumours and neuroblastoma which took 20-30 minutes per case. CHOC oncologists produce comprehensive clinical summaries collating all the diagnostic information in one place, making information easy to find for many cases. However, acute lymphoblastic leukaemia cases were initially unable to be staged by the web application due to the lack of reporting of red blood cell counts on the clinical summaries. Retrieving this information required access to Canterbury Medical Laboratories electronic records. Where the Toronto Guidelines and the NZCCR used the same staging system, there were no discrepancies between the staging obtained from the staging application and that held by the registry.

#### Conclusion:

The accuracy of recording within the NZCCR was high and missing information was usually able to be found within CHOC clinical summaries. Application of the Toronto Paediatric Cancer Stage Guidelines appears to be feasible; most required information was readily accessible and 76% of all cancers will be staged once the staging application is complete. Given that the Toronto Guidelines are likely to be utilised in future registry collaborations such as the 'International Incidence of Childhood Cancer', it is recommended that they are adopted by the NZCCR. For some tumour groups this will be in addition to, rather than in replacement of, the clinical staging system that is recorded on the Patient Health Passport. Through participation in the staging application pilot study, this project has contributed to an international initiative to provide consistency and clarity in the collection of paediatric cancer staging data. The adoption of the Toronto Guidelines by population-based registries will facilitate greater international collaboration that will ultimately lead to improved outcomes for New Zealand children with cancer.