The Power of Collaboration: The New Zealand Children’s Cancer Registry and the Late Effects Assessment Programme

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Introduction & Background

The New Zealand Late Effects Assessment Programme (LEAP) was established in 2006 in order to provide long-term surveillance of the medical, psychological and educational needs of young people who have completed cancer treatment. The national service is delivered from three centres by specialist teams which include oncologists, clinical psychologists, and clinical nurse specialists (CNSs).

When LEAP was established, a national online database (LEAP-IT) was developed to support ongoing care and provide a single health record of cancer treatment and late effects. LEAP-IT was designed to seamlessly integrate with the New Zealand Children’s Cancer Registry (NZCCR) in order to remove duplication and provide comprehensive data for a wide range of research and reporting purposes.

Objectives

Here we set out to;
1) describe the unique structure of NZCCR/LEAP-IT
2) provide illustrative examples of how NZCCR/LEAP-IT functions from both an individual patient care and a national perspective

Access and Roles

Access to the NZCCR/LEAP-IT is by secure login and users have different levels of access according to their region and respective role.

Clinical research associates (CRAs) input the initial data for new patients at their centre which is then updated by the LEAP clinical nurse specialist (CNS) upon entering LEAP. Clinical psychologists and oncologists also have controlled access to their patients’ records.

The NZCCR analyst is able to download national records in order to verify data and produce ad hoc datasets for research and clinical purposes. The analyst is also able to make modifications to all data fields as required, such as adding new diagnostic codes and protocols.

Sample Health Passport & Guidelines

Identifying, abstracting and tracking multiple treatment-related events and cancer late effects is complex, especially as the child cancer survivor transitions to adult health services. The health passport provides patients with an electronic treatment summary and care plan which they can take with them when they change healthcare providers or travel overseas.

Recent Activities

The National Child Cancer Network (NCCN) has established two working groups, the LEAP Working Group and the NZCCR Working Group, who have overall responsibility for NZCCR/LEAP-IT.

Primarily, the LEAP Working Group is focused on the optimal functioning of LEAP-IT from an individual patient care perspective, while the NZCCR Working Group is focussed on ensuring the registry gathers timely, accurate and useful data.

Some recent examples of ways that NZCCR/LEAP-IT data has been utilised:

Conference presentations and publications: e.g. late effects analyses and in-depth analyses for specific disease groups

Technical reports: A comprehensive analysis of New Zealand child cancer incidence and survival, 2000-20091

Collaboration with other registries: e.g. NZCCR’s registrations were recently matched with our national cancer registry (NZCR) to improve each registry’s registration processes and completeness

Study recruitment: e.g. the registry was used to identify a cohort for a national dental late effects study and, following ethical approval, a contact list was provided to the researchers

Data for other NCCN working groups: e.g. tracking clinical trial enrolment rates for the Protocols Working Group

Data for service planning: e.g. an analysis of survival improvements for high risk neuroblastoma patients treated with chimeric antibody therapy and an estimate of future treatment costs based on annual patient numbers

Updates to stakeholders: the NZCCR annual report1, distributed to the wider NZ Child Cancer Network, provides key demographic and diagnostic information for children diagnosed in the previous year

Conclusion

The decision to combine the NZCCR and the LEAP online clinical care tool from the very start of its development has;

- removed unnecessary duplication of data input
- improved data accuracy through repeated use
- ensured there is a clear patient benefit for ongoing data collection
- made a wealth of data that is not typically collected by cancer registries available for approved research purposes
- provided clinicians and service managers with immediate access to anonymised patient data to inform their decision making

Currently holding over 3,400 registrations, the NZCCR/LEAP-IT is unique in providing both a comprehensive patient treatment record and a rich resource for statistical reporting, service delivery planning, and research to improve child cancer outcomes in New Zealand.

References


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