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.

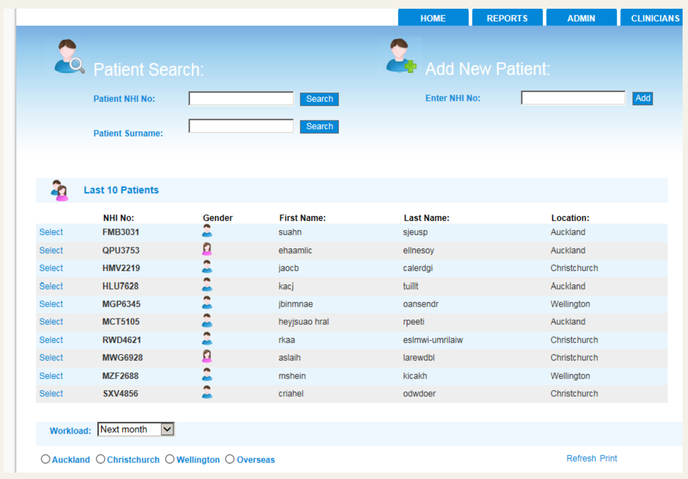
Objectives

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

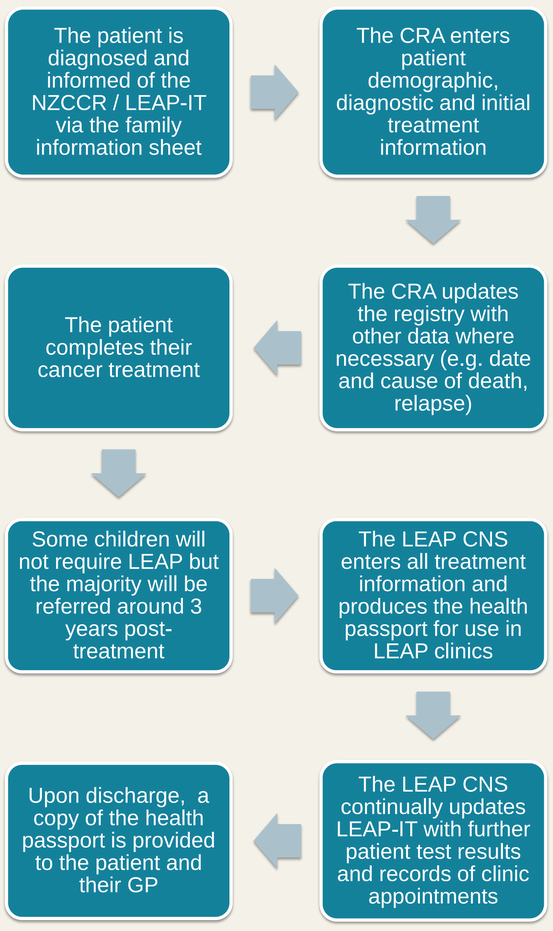
Access and Roles

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



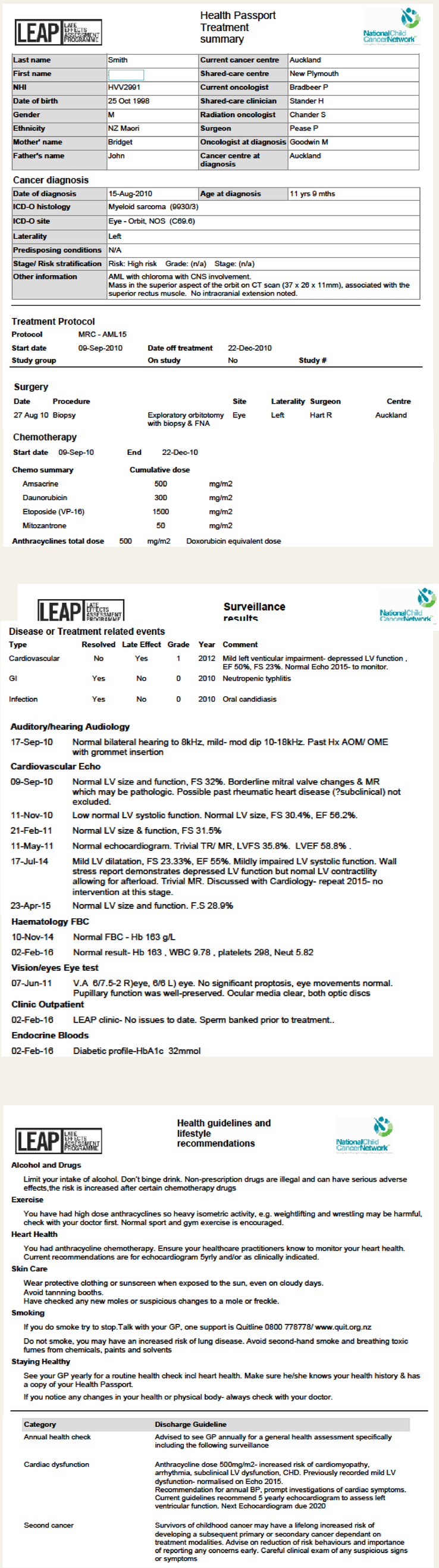
Clinical research associates (CRAs) input the initial data for new patients at their centre which is then updated by the **LEAP clinical nurse specialist (CNS)** upon entering LEAP. Clinical psychologists and oncologists also have controlled access to their patients' records.

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.



LEAP Late Effects Assessment Programme

Health Passport Treatment summary

National Child Cancer Network

Last name	Smith	**Current cancer centre**	Auckland
First name		**Shared-care centre**	New Plymouth
NHI	HVV2991	**Current oncologist**	Bradbeer P
Date of birth	25 Oct 1998	**Shared-care clinician**	Stander H
Gender	M	**Radiation oncologist**	Chander S
Ethnicity	NZ Maori	**Surgeon**	Pease P
Mother' name	Bridget	**Oncologist at diagnosis**	Goodwin M
Father's name	John	**Cancer centre at diagnosis**	Auckland

Cancer diagnosis

Date of diagnosis	15-Aug-2010	**Age at diagnosis**	11 yrs 9 mths
ICD-O histology	Myeloid sarcoma (9930/3)		
ICD-O site	Eye - Orbit, NOS (C69.6)		
Laterality	Left		
Predisposing conditions	N/A		
Stage/ Risk stratification	Risk: High risk Grade: (n/a) Stage: (n/a)		
Other information	AML with chloroma with CNS involvement. Mass in the superior aspect of the orbit on CT scan (37 x 26 x 11mm), associated with the superior rectus muscle. No intracranial extension noted.		

Treatment Protocol

Protocol MRC - AML15
Start date 09-Sep-2010 **Date off treatment** 22-Dec-2010
Study group **On study** No **Study #**

Surgery

Date	Procedure	Site	Laterality	Surgeon	Centre
27 Aug 10	Biopsy Exploratory orbitotomy with biopsy & FNA	Eye	Left	Hart R	Auckland

Chemotherapy

Start date 09-Sep-10 **End** 22-Dec-10

Chemo summary	**Cumulative dose**	
Amsacrine	500	mg/m2
Daunorubicin	300	mg/m2
Etoposide (VP-16)	1500	mg/m2
Mitozantrone	50	mg/m2

Anthracyclines total dose 500 mg/m2 Doxorubicin equivalent dose

LEAP Late Effects Assessment Programme

Surveillance results

National Child Cancer Network

Disease or Treatment related events

Type	Resolved	Late Effect	Grade	Year	Comment
Cardiovascular	No	Yes	1	2012	Mild left venticular impairment- depressed LV function , EF 50%, FS 23%. Normal Echo 2015- to monitor.
GI	Yes	No	0	2010	Neutropenic typhlitis
Infection	Yes	No	0	2010	Oral candidiasis

Auditory/hearing Audiology

17-Sep-10 Normal bilateral hearing to 8kHz, mild- mod dip 10-18kHz. Past Hx AOM/ OME with grommet insertion

Cardiovascular Echo

09-Sep-10 Normal LV size and function, FS 32%. Borderline mitral valve changes & MR which may be pathologic. Possible past rheumatic heart disease (?subclinical) not excluded.

11-Nov-10 Low normal LV systolic function. Normal LV size, FS 30.4%, EF 56.2%.

21-Feb-11 Normal LV size & function, FS 31.5%

11-May-11 Normal echocardiogram. Trivial TR/ MR, LVFS 35.8%. LVEF 58.8% .

17-Jul-14 Mild LV dilatation, FS 23.33%, EF 55%. Mildly impaired LV systolic function. Wall stress report demonstrates depressed LV function but nomal LV contractility allowing for afterload. Trivial MR. Discussed with Cardiology- repeat 2015- no intervention at this stage.

23-Apr-15 Normal LV size and function. F.S 28.9%

Haematology FBC

10-Nov-14 Normal FBC - Hb 163 g/L

02-Feb-16 Normal result- Hb 163 , WBC 9.78 , platelets 298, Neut 5.82

Vision/eyes Eye test

07-Jun-11 V.A 6/7.5-2 R)eye, 6/6 L) eye. No significant proptosis, eye movements normal. Pupillary function was well-preserved. Ocular media clear, both optic discs

Clinic Outpatient

02-Feb-16 LEAP clinic- No issues to date. Sperm banked prior to treatment..

Endocrine Bloods

02-Feb-16 Diabetic profile-HbA1c 32mmol

LEAP Late Effects Assessment Programme

Health guidelines and lifestyle recommendations

National Child Cancer Network

Alcohol and Drugs

Limit your intake of alcohol. Don't binge drink. Non-prescription drugs are illegal and can have serious adverse effects,the risk is increased after certain chemotherapy drugs

Exercise

You have had high dose anthracyclines so heavy isometric activity, e.g. weightlifting and wrestling may be harmful, check with your doctor first. Normal sport and gym exercise is encouraged.

Heart Health

You had anthracycline chemotherapy. Ensure your healthcare practitioners know to monitor your heart health. Current recommendations are for echocardiogram 5yrly and/or as clinically indicated.

Skin Care

Wear protective clothing or sunscreen when exposed to the sun, even on cloudy days.
Avoid tannning booths.
Have checked any new moles or suspicious changes to a mole or freckle.

Smoking

If you do smoke try to stop.Talk with your GP, one support is Quitline 0800 778778/ www.quit.org.nz

Do not smoke, you may have an increased risk of lung disease. Avoid second-hand smoke and breathing toxic fumes from chemicals, paints and solvents

Staying Healthy

See your GP yearly for a routine health check incl heart health. Make sure he/she knows your health history & has a copy of your Health Passport.

If you notice any changes in your health or physical body- always check with your doctor.

Category	Discharge Guideline
Annual health check	Advised to see GP annually for a general health assessment specifically including the following surveillance
Cardiac dysfunction	Anthracycline dose 500mg/m2- increased risk of cardiomyopathy, arrhythmia, subclinical LV dysfunction, CHD. Previously recorded mild LV dysfunction- normalised on Echo 2015. Recommendation for annual BP, prompt investigations of cardiac symptoms. Current guidelines recommend 5 yearly echocardiogram to assess left ventricular function. Next Echocardiogram due 2020
Second cancer	Survivors of childhood cancer may have a lifelong increased risk of developing a subsequent primary or secondary cancer dependant on treatment modalities. Advise on reduction of risk behaviours and importance of reporting any concerns early. Careful clinical exam of any suspicious signs or symptoms

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 focussed 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, 2000-2009[1,2]

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 report[3], distributed to the wider 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 the 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

[1] Sullivan, M., & Ballantine, K. (2014). *The incidence of childhood cancer in New Zealand 2000-2009: The first outcome analysis of the New Zealand Children's Cancer Registry.* Auckland: National Child Cancer Network NZ.

[2] Sullivan, M., & Ballantine, K. (2014). *Childhood cancer survival in New Zealand 2000-2009: The first outcome analysis of the New Zealand Children's Cancer Registry.* Auckland: National Child Cancer Network NZ

[3] New Zealand Children's Cancer Registry Working Group (2016). NZCCR Annual Report and Snapshot 2015. available from: www.childcancernetwork.org.nz

Acknowledgements

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We wish to thank those past and present clinicians who had the vision to develop the national children's cancer registry and late effects assessment programme and also the CRAs and LEAP CNSs who have had the primary responsibility of entering patient data since NZCCR/LEAP-IT's inception.