

# 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.

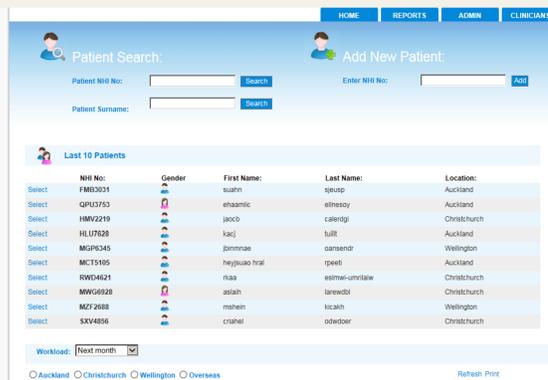
## Objectives

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

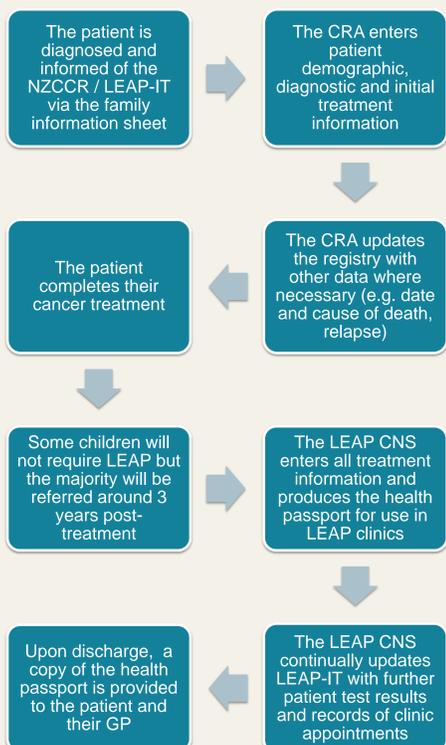
## Access and Roles

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



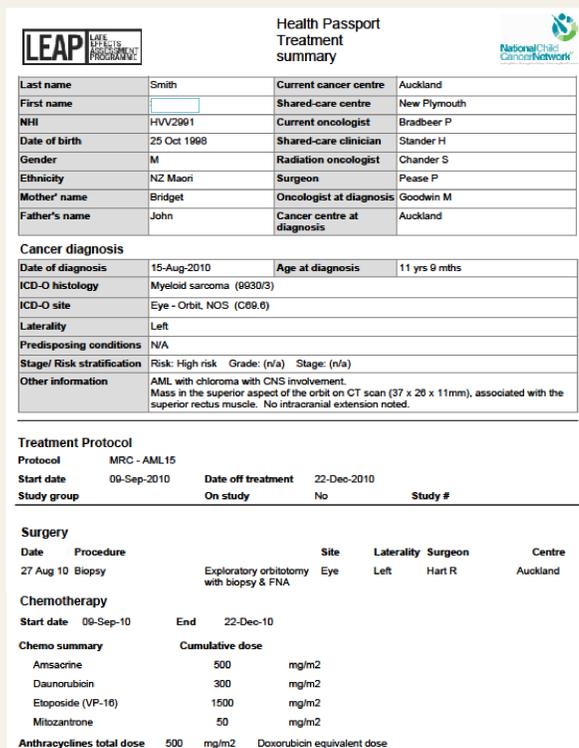
Clinical research associates (CRAs) input the initial data for new patients at their centre which is then updated by the LEAP clinical nurse specialist (CNS) upon entering LEAP. Clinical psychologists and oncologists also have controlled access to their patients' records.

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.

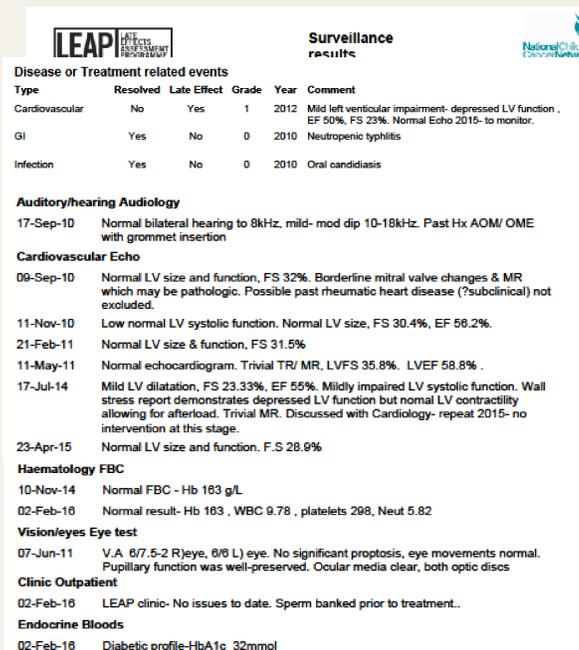


## Sample Health Passport & Guidelines

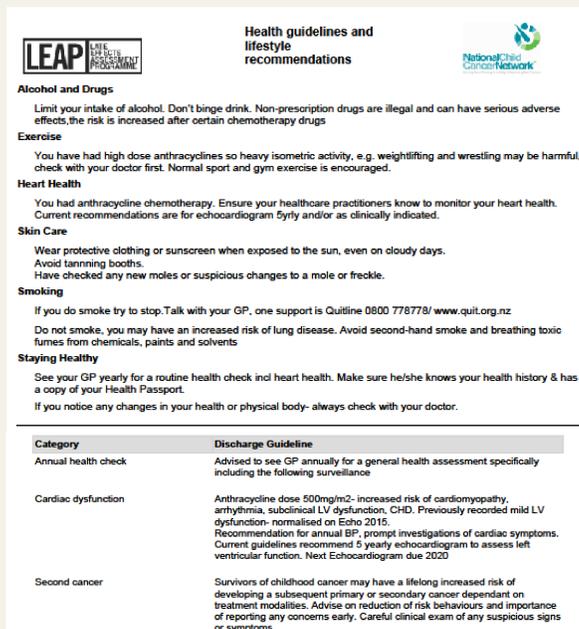
Identifying, abstracting and tracking multiple treatment-related events and cancer late effects is complex, especially as the child cancer survivor transitions to adult health services. The health passport provides patients with an electronic treatment summary and care plan which they can take with them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



LEAP		Health Passport Treatment summary	
Last name	Smith	Current cancer centre	Auckland
First name		Shared-care centre	New Plymouth
NHI	HVV2901	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's name	Bridget	Oncologist at diagnosis	Goodwin M
Father's name	John	Cancer centre at diagnosis	Auckland
<b>Cancer diagnosis</b>			
Date of diagnosis	15-Aug-2010	Age at diagnosis	11 yrs 9 mths
ICD-O histology	Myeloid sarcoma (9630/3)		
ICD-O site	Eye - Orbit, NOS (C69.0)		
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.		
<b>Treatment Protocol</b>			
Protocol	MRC - AML15		
Start date	09-Sep-2010	Date of treatment	22-Dec-2010
Study group		On study	No
		Study #	
<b>Surgery</b>			
Date	27 Aug 10	Procedure	Exploratory orbitotomy with biopsy & FNA
		Site	Eye
		Laterality	Left
		Surgeon	Hart R
		Centre	Auckland
<b>Chemotherapy</b>			
Start date	09-Sep-10	End	22-Dec-10
<b>Chemo summary</b>			
		Cumulative dose	
Amsacrine	500	mg/m2	
Daunorubicin	300	mg/m2	
Etoposide (VP-16)	1500	mg/m2	
Mitoxantrone	50	mg/m2	
Anthracyclines total dose	500	mg/m2	Doxorubicin equivalent dose



LEAP		Surveillance results			
<b>Disease or Treatment related events</b>					
Type	Resolved	Late Effect	Grade	Year	Comment
Cardiovascular	No	Yes	1	2012	Mild left ventricular impairment- depressed LV function, EF 50%, FS 23%. Normal Echo 2015- to monitor.
GI	Yes	No	0	2010	Neutropenic typhilitis
Infection	Yes	No	0	2010	Oral candidiasis
<b>Auditory/hearing Audiology</b>					
17-Sep-10	Normal bilateral hearing to 8kHz, mild- mod dip 10-18kHz. Past Hx AOM/ OME with grommet insertion				
<b>Cardiovascular Echo</b>					
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 normal 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%				
<b>Haematology FBC</b>					
10-Nov-14	Normal FBC - Hb 163 g/L				
02-Feb-16	Normal result- Hb 163 , WBC 9.78 , platelets 298, Neut 5.82				
<b>Vision/eyes Eye test</b>					
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				
<b>Clinic Outpatient</b>					
02-Feb-16	LEAP clinic- No issues to date. Sperm banked prior to treatment.				
<b>Endocrine Bloods</b>					
02-Feb-16	Diabetic profile-HbA1c 32mmol				



LEAP		Health guidelines and lifestyle recommendations	
<b>Alcohol and Drugs</b>			
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			
<b>Exercise</b>			
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.			
<b>Heart Health</b>			
You had anthracycline chemotherapy. Ensure your healthcare practitioners know to monitor your heart health. Current recommendations are for echocardiogram 5yrs and/or as clinically indicated.			
<b>Skin Care</b>			
Wear protective clothing or sunscreen when exposed to the sun, even on cloudy days. Avoid tanning booths. Have checked any new moles or suspicious changes to a mole or freckle.			
<b>Smoking</b>			
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			
<b>Staying Healthy</b>			
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.			
<b>Category</b>	<b>Discharge Guideline</b>		
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<sup>1,2</sup>

**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<sup>3</sup>, 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 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.