



## Kia ora koutou

Welcome to this update from the National Child Cancer Network (NCCN). We hope you are able to take a few minutes to read about the exciting work underway.

- Launch of the Child Cancer Counselling Network
- National Clinical Leader Retiring
- Welcome to NCCN – Monica Briggs
- SLA Portal Update
- Research Updates

## Launch of the Child Cancer Counselling Network

We were thrilled to launch the Child Cancer Counselling Network (CCCN) on 22 May. The CCCN is a joint initiative with the Child Cancer Foundation and Massey University (led by Dr. Kirsty Ross). The Network aims to increase the ability of whānau impacted by childhood cancer to access specialised counselling support in or close to their hometown. To support the achievement of the initiative's aim, a network of counsellors has been recruited and trained across Aotearoa. Members of the network receive training in the effects of childhood cancer on children, siblings, parents and wider whānau. All counselling sessions are covered by the Child Cancer Foundation. You can tune into a recent interview by Dr Ross [here](#).



Keep your eye out for the Counselling Network booklets which include the Wellness Check-in



Please complete the following Wellness Check-in

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Please circle the number (0-10) that best describes how much distress (anxiety) you have been experiencing in the past week, including today.

0 1 2 3 4 5 6 7 8 9 10  
No distress Very distressed

Please circle the number (0-10) that best describes how well you have coped over the past week.

0 1 2 3 4 5 6 7 8 9 10  
Not coped Coped well

Please indicate if any of the following has been a concern for you in the past week including today:

<b>Spiritual/Whānau Wellbeing</b>	<b>Physical/Tinana Wellbeing</b>
<input type="checkbox"/> Challenges to your faith and beliefs	<input type="checkbox"/> Sleep
<input type="checkbox"/> Feelings unsure about the meaning of life or the purpose of life	<input type="checkbox"/> Appetite
<input type="checkbox"/> Asking "Why Me?"	<input type="checkbox"/> Changes in weight
<b>Practical Concerns</b>	<input type="checkbox"/> Feeling of physical wellbeing
<input type="checkbox"/> Housekeeping	<input type="checkbox"/> Fatigue/feeling tired
<input type="checkbox"/> Housing	<input type="checkbox"/> Pain
<input type="checkbox"/> Money	<input type="checkbox"/> Concentration
<input type="checkbox"/> Transport	<input type="checkbox"/> Memory
<input type="checkbox"/> Work/Study	<b>Emotional/Hinengaro Wellbeing</b>
<input type="checkbox"/> Hospital processes	<input type="checkbox"/> Depression
<input type="checkbox"/> Child care	<input type="checkbox"/> Anxiety
<input type="checkbox"/> Cultural obligations	<input type="checkbox"/> Fears
<b>Family/Whānau Relationships</b>	<input type="checkbox"/> Worry
<input type="checkbox"/> With children	<input type="checkbox"/> Loneliness
<input type="checkbox"/> With partner	<input type="checkbox"/> Loss of interest in usual activities
<input type="checkbox"/> With ex-partner	<input type="checkbox"/> Keeping emotions under control
<input type="checkbox"/> With other family/whānau	<input type="checkbox"/> Feeling tense or nervous
<input type="checkbox"/> With friends	<input type="checkbox"/> Can't stop thinking about a specific event that has happened

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## National Clinical Leader Retiring

### Scott Macfarlane

After more than a decade as National Clinical Leader: Child Cancer, Paediatric Oncologist Scott Macfarlane will retire in November 2021. Scott has had a long and distinguished medical career, both as a Paediatrician, and then as a Paediatric Oncologist. His retirement will leave a large hole in the fabric of the child cancer and broader health community in Aotearoa New Zealand.



There will be more information about how you can get involved in Scott's farewell in the next few months. In the meantime if you would like to listen to a recent presentation he gave at Starship's Paediatric Update titled "Do we need another health system change?" you can listen [here](#).

If you think you could be the next Clinical Lead for NCCN please:

- Read the [Expression of Interest](#) form
- Send a copy of your CV and covering letter to [elizaryan@adhb.govt.nz](mailto:elizaryan@adhb.govt.nz) by 13 August 2021

## Welcome to NCCN!

### Monica Briggs

We would like to extend a warm welcome to recently appointed Child Cancer Foundation Chief Executive Monica Briggs. Monica brings a wealth of governance and management expertise to the Foundation and we look forward to continuing the close working relationship that NCCN has enjoyed over many years, across many mutually important child cancer initiatives.



## What is shared care?

NCCN's Paediatric Oncology Shared Care Agreements are negotiated between each of the 14 shared care centres and either Starship Blood and Cancer Centre (SBCC) or Children's Haematology Oncology Centre (CHOC), on a three-yearly cycle. More commonly referred to as Service Level Agreements (SLA) the online "template" combines international best practice with nationally agreed guidelines to outline "who does what, where and when".

The National Clinical Leader and Programme Manager visit each of the 14 shared care centres involved in the delivery of child cancer services once every three years. This is then followed by a process of renegotiating and finalising the SLA for the next period.

## SLA Portal Update

We have recently refreshed the online SLA template to streamline and update questions where practice has changed. The look and feel remains the same and we have received positive feedback from the two shared care centres that have used it so far this year.

## If you are based in a shared care centre what do you need to know?

The URL to access the Service Level Agreement has changed to <https://sharedcareportal.azurewebsites.net/>

Please note the URL is best accessed through Google Chrome.

You can also access SLAs (if you're a user) via the NCCN website [childcancernetwork.org.nz/](http://childcancernetwork.org.nz/)

## Reference Group

You can see what has been happening at NCCN Reference Group meetings including the most recent 7 May meeting [here](#).

## Kids Health

The child cancer pages on the [KidsHealth](#) website have recently been updated. If you have any feedback on content please contact Elizabeth Ryan ([elizaryan@adhb.govt.nz](mailto:elizaryan@adhb.govt.nz)).

We hope you have enjoyed this update!

Kind Regards,  
NCCN Exec Team

## NZCCR Updates

The 2020 NZCCR Annual Report containing the latest child cancer information (and research updates) has just been published on our website [here](#). Other news relating to the registry can be found [here](#).

# 131

children were diagnosed with cancer in 2020

## Research

### Publications

**Return to Social Activities:** The results of this research, which was led by Dr Claire Gooder, and co-funded by Child Cancer Foundation and NCCN, was recently published.

**Read the full article here in Cancer Reports:**

[Ballantine, K, Gooder, C, Ryan, E, Macfarlane, S. Listening to the experts: Parents' perspectives around infection risk and returning to education and social activities following their child's diagnosis of acute lymphoblastic leukemia. Cancer Reports. 2021:e1424. <https://doi.org/10.1002/cnr2.1424>](#)

### Neuropsychological Assessment Audit

Dr Rebecca Slykerman has recently published her work on the number of brain tumour survivors receiving neuropsychological assessments.

**Read the full article here in J Paediatr Child Health:**

[Slykerman, R.F., Jenner, E., Tsui, K. and Laughton, S. \(2021\), Neuropsychological assessment of paediatric brain tumour survivors: Factors associated with assessment. J Paediatr Child Health. <https://doi.org/10.1111/jpc.15568>](#)

### Exercise Interventions to Manage Fatigue

A systematic review and narrative synthesis of exercise interventions to manage fatigue among children, adolescents and young adults with cancer led by NCCN Research Lead, Dr Gemma Pugh has been published.

**Read the full article here in JAYAO:**

[Ito N, Petrella A, Sabiston C, Fisher A, Pugh G. \(2021\) A Systematic Review and Narrative Synthesis of Exercise Interventions to Manage Fatigue Among Children, Adolescents, and Young Adults with Cancer. J Adolesc Young Adult Oncol. Online ahead of print.](#)

