

# A study of the wellbeing of Adolescent Cancer Survivors in New Zealand

Eighty percent of children diagnosed with cancer now survive. Many return to good health and psychosocial wellbeing, while others have an increased risk of health, emotional or social problems due to their disease and/or treatment.

The Adolescent Cancer Survivor Impact Study (ACSIS) is the first New Zealand study to examine the psychosocial wellbeing of childhood cancer survivors (CCS). This was a case-controlled study in which 170 CCS aged 12 to 18 completed a multimedia computer-based survey, which included questions about family and school life, physical and mental health, and risk taking behaviours. The CCS survey was a modified version of the Youth 2007 (Y'07) survey completed by 9100 college students throughout New Zealand.

By comparing CCS responses to responses from the Y'07 students, the aim was to understand if the wellbeing of CCS was different to that of young people who have not had cancer.

This booklet presents key facts from the ACSIS study.

## Who took part in ACSIS?

Male 57%  
 Female 43%

## Ethnicity:

Euro 72%  
 Maori 12%  
 Pacific 8%  
 Asian 8%

## Age:

median 15.4 years

## Cancer diagnosis groups:

Leukaemia/Lymphoma 49%  
 CNS 13%  
 All other 38%

## Key Findings

- In many areas CCS are doing as well as, and in some cases better than, Y'07 participants.
- Most CCS report being happy, well adjusted young people who feel close to their family and friends.
- CCS were more protective of their health, reporting less use of cigarettes, alcohol, and illegal drugs than Y'07 students.
- CCS who had a cancer of the central nervous system (CNS) reported more difficulties with every day activities, including learning.



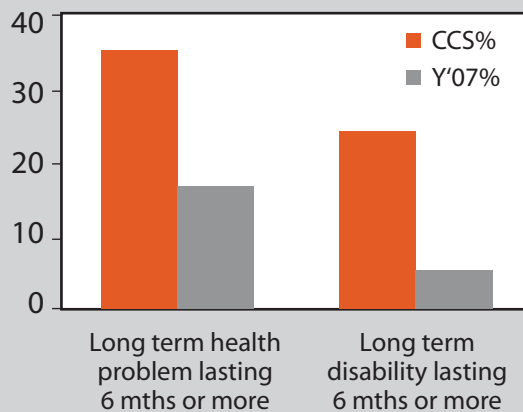
## General Health

While most CCS reported their general health as being good to excellent, it is worth noting that:

- 35% CCS reported having a long term health condition compared with 17% Y'07 participants.
- One third of CCS reported that their long term health condition is caused by their cancer.
- 24% CCS had experienced a disability lasting six months or more, compared with 5% Y'07 participants.

Those most affected were CCS who had a cancer of the CNS. They reported problems with everyday activities such as communicating, mixing with others, and socialising.

**Comparison of CCS and Y'07 reporting of chronic health problems or disability**



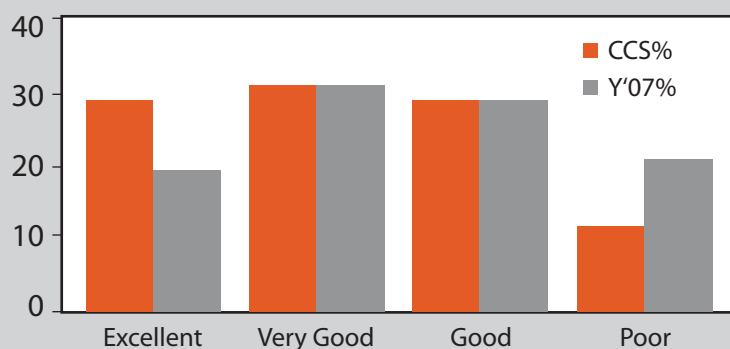
## Mental and Emotional Health

Mostly CCS regard themselves as well adjusted young people who are happy with their lives.

Overall the study found that:

- CCS reported greater emotional wellbeing ( $p=0.0003$ ; WHO-5 scale).
- No significant difference between CCS and Y'07 participants in reporting depressive symptoms.
- For CCS, older age was associated with poorer wellbeing ( $p=0.003$ ) as was older age at time of diagnosis ( $p=0.007$ ).
- CCS did not report any greater anxiety symptoms than students who answered the earlier Youth 2000 survey.

**World Health Organization WHO-5 scale of wellbeing**



## Family, Friends and Community

With regard to how well they get on with their family, closeness to their parent/s, and how much time their parents are loving and warm towards them, there was no difference between CCS and the Y'07 participants.

Similarly, Y'07 participants and CCS both reported having good friendships; friends to hang-out, talk, and have fun with, as well as good friends who look out for and help each other.



When discussing bullying and how often it occurred, there was no significant difference between CCS and Y'07 participants.

There was also no significant difference when it came to the importance CCS placed on spiritual beliefs or religious faith.

## School

The majority of CCS who took part in this study (88%) were still at school. Of those who had left school, half were working and half were completing further study or training.

When it came to missing school due to their cancer and its treatment, the most common length of time was less than six months.

30% CCS received at least one specific learning intervention such as teacher aide, additional time for exams, and/or reading recovery. When looking at which CCS received these interventions, it was

- 71% CCS with CNS cancers.
- 23% CCS with leukaemia or lymphoma.
- 28% CCS with other cancers.

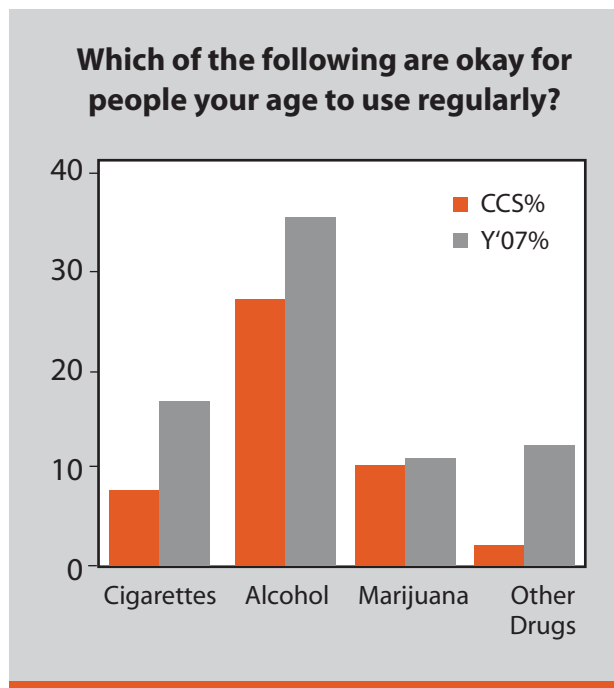
The findings suggest that for those who had a CNS cancer and/or treatment, it is likely to have impacted upon their learning ability.

School missed	Percentage
Less than six months	45
Less than one year	27
One to two years	20
More than two years	8

## Risk and Safety Behaviour

When it came to risk taking and safety CCS demonstrated more protective health behaviours than their Y'07 peers

- 85% CCS would wear a seatbelt compared with 74% Y'07 participants ( $p < 0.001$ ).
- 16% CCS had smoked a cigarette compared with 32% Y'07 participants ( $p < 0.0001$ ).
- 53% CCS had drunk alcohol compared with 72% Y'07 participants ( $p = 0.0001$ ).
- 16% CCS had smoked marijuana compared with 27% Y'07 participants ( $p < 0.002$ ).
- 23% CCS were sexually active compared with 36% Y'07 participants ( $p = 0.0005$ ).
- CCS also had different ideas compared to their Y'07 peers about what is ok for young people to use (see graph).



## Acknowledgements

Thank you to the childhood cancer survivors who completed our survey. You are amazing young people who constantly inspire us with your courage and resiliency.

To the Rotary Club of Newmarket Inc and CanTeen, a sincere thank you for funding this study.



Our thanks also to Dr Simon Denny and the research team at the University of Auckland for the use of the Youth2000 and Youth'07 survey data. [www.youth2000.ac.nz](http://www.youth2000.ac.nz).

We acknowledge and thank the national Late Effects Assessment Programme (LEAP) team for all they have contributed to the study.

If you would like more information about the ACSIS, please contact:

- Kathy Yallop, Principal Investigator, on [KYallop@adhb.govt.nz](mailto:KYallop@adhb.govt.nz)
- Heather McDowell on [HeatherM@adhb.govt.nz](mailto:HeatherM@adhb.govt.nz)
- Auckland LEAP Long Term Follow-up Programme
- Starship Blood and Cancer Centre  
Private Bag 92024, Auckland 1124, New Zealand.