

# SUPER Survivor Profiling Exercise

by CCF research team



In May to September 2024, we reached out to over 1000 survivors with the intent to better understand their survivorship experiences. 254 survivors participated in our study, sharing with us how they are doing in their survivorship journey...

## Overview of our respondents:



**Average age at diagnosis: 8 years old**  
Ranging from 0 to 18 years old

### Diagnosis breakdown



41% were diagnosed with **Leukaemia**



16% were diagnosed with **Brain Tumor/CNS**



11% were diagnosed with **Lymphoma**

Included survivors from various age group:



**0 to 6 years old**  
N=55 (21.6%)



**7 to 12 years old**  
N=32 (12.6%)



**13 to 20 years old**  
N=94 (37.8%)



**21 years old & older**  
N=73 (28.7%)

\*Percentage indicated is the percentage of survivors' population who responded

## Quality of Life



Survivors in all age groups were generally doing comparably well to their healthy counterparts, with **the exception of psychological wellbeing**

Survivors faced different **challenges** across their survivorship journey



Survivors who recently completed treatment struggle more with:



Physical wellbeing



Cognitive wellbeing

Long term survivors struggle more with:



Social wellbeing



Psychological wellbeing

Scales used for QoL Measurements:

### PedsQL

(0 to 6 years old)

### KIDSCREEN

(7 to 17 years old)

### WHOQOL-BREF

(18 years old and older)

Domains where childhood cancer survivors were doing poorer than the healthy population<sup>1,2</sup>

No comparative study for PedsQL



Physical wellbeing



Social acceptance



Psychological wellbeing



Mood and emotions



Psychological wellbeing

## Follow up care

**91%** of the survivors were receiving some form of follow-up care

Discipline of care sought by most survivors:



Oncology



Cardiology



Endocrine

These findings are encouraging as regular medical follow-up care can support our survivors in managing their health and effects of cancer and treatment



## Late effects

Common late effects reported by survivors



Low energy/fatigue

Hearing/vision problems



Emotional problems

Growth problems



Learning/memory problems

**22%** of the survivors have experienced late effects

**24%** of the survivors were **unsure** if they have experienced late effects



Compared with St Jude's Childhood Cancer Survivor study<sup>3</sup>, where more than 90% of the survivors experience late effects, we are concerned whether there could be a **lack of awareness of late effects** among survivors

We also looked further to understand their survivorship experiences...

## Education

**22%** of the survivors experienced a **delay for at least a year** in their education pathways



**42%** of the survivors experienced troubles in **social integration**



**23%** of the survivors experienced troubles in **academic performance**



## Physical Activity

**45%** of the survivors **have sufficient exercise** as per HPB's guidelines<sup>4</sup>

On average, Survivors exercised for **2.72 days** per week & **45 minutes** per session



## Employment

Most employed survivors indicated that they are in jobs that are **appropriate** to their **education** and **physical conditions**



**23%** of the employed survivors faced **difficulties at work** due to **health conditions**.

Common challenges include:

- Physical discomfort
- Memory and attention issues
- Weaker immunity



## How does this study support CCF?



Further our understanding of survivors' well-being



Guide our program development & program evaluation



Support our future research on survivors' experiences

Updated as per 12 Nov 2025

### References

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