



# Cancer Hub Evaluation: Summary Report

CANTEEN

21 February 2024



**Nous Group** acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

---

***Disclaimer:***

Nous Group (**Nous**) has prepared this report for the benefit of Canteen (the **Client**).

*The report should not be used or relied upon for any purpose other than as an expression of the conclusions and recommendations of Nous to the Client as to the matters within the scope of the report. Nous and its officers and employees expressly disclaim any liability to any person other than the Client who relies or purports to rely on the report for any other purpose.*

*Nous has prepared the report with care and diligence. The conclusions and recommendations given by Nous in the report are given in good faith and in the reasonable belief that they are correct and not misleading. The report has been prepared by Nous based on information provided by the Client and by other persons. Nous has relied on that information and has not independently verified or audited that information.*

# Contents

## 1 SUMMARY OF RESULTS

About Cancer Hub

About this Evaluation

What data was used in the research

Key early outcomes

## 2 WHAT DID WE FIND?

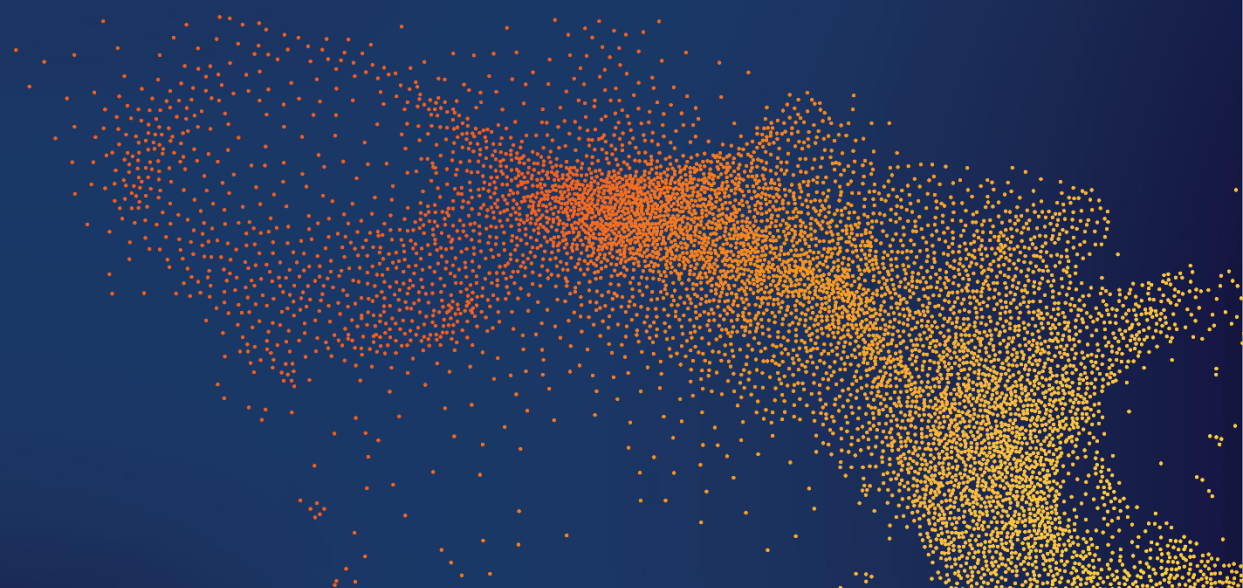
Early implementation

Reach of Cancer Hub

Short – Medium term outcomes

Opportunities for ongoing implementation and improvement

Continuous learning opportunities



# 1 SUMMARY OF RESULTS

Thank you to the individuals and organisations who shared their experiences of Cancer Hub with us. A special thank you to the parents and carers of children and young people impacted by cancer who shared their stories. Your contribution is very much appreciated. This document is a summary of what we found. We are delighted to be able to share this summary with you.



# About Cancer Hub

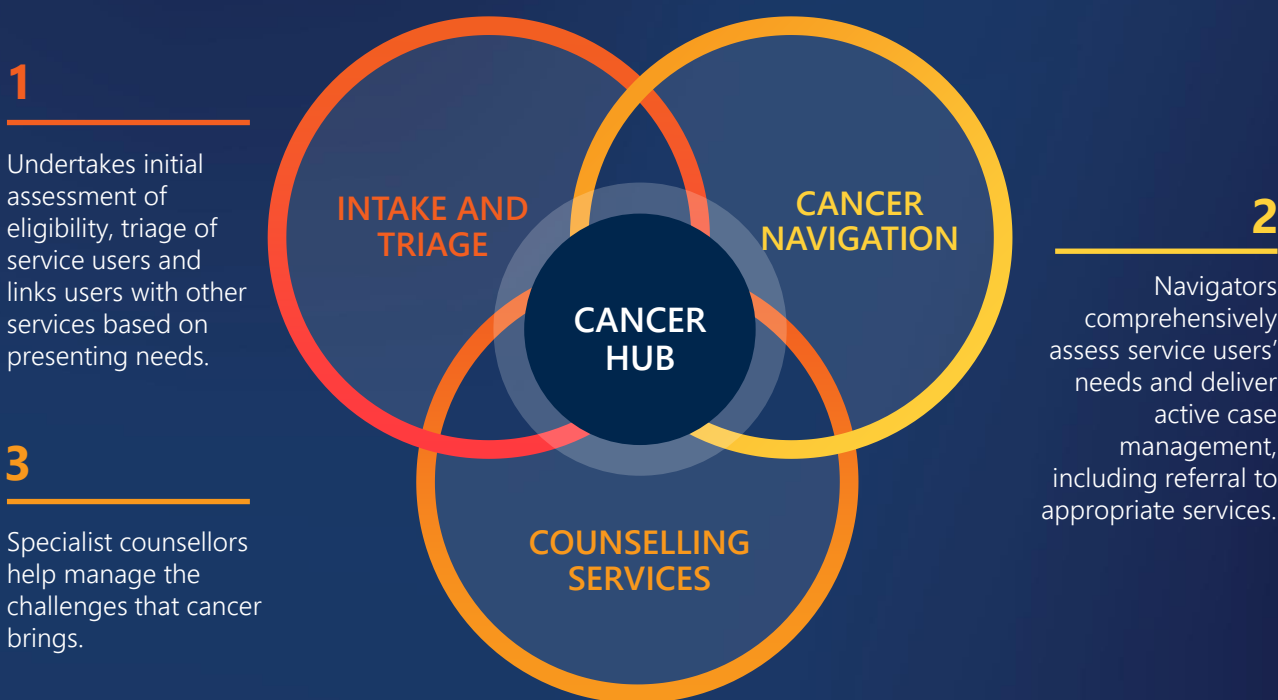
Each year 1,900 children and adolescents and young adults (AYA) aged 0-25 are diagnosed with cancer<sup>1</sup> (approximately 1,000 of these are AYA)<sup>2</sup>.

Cancer Hub is a national digital support hub designed to improve the coordination of community and health service support for parents and families of young people (aged 0-25) who have or have had a cancer diagnosis. Cancer Hub acts as a 'gateway' for families to connect with practical, psychosocial and emotional support services to meet their needs (see Figure 1 for details).

Cancer Hub was established in July 2022 and is delivered by the Child and Youth Cancer Alliance ('the Alliance') which is formed by Canteen, Redkite and Camp Quality. The initiative is funded by the Australian Government.

For further information about Cancer Hub, please visit [www.cancerhub.org.au](http://www.cancerhub.org.au)

Figure 1 | What services Cancer Hub provides\*



1. Australian Institute of Health & Welfare. Cancer Data in Australia 2022 [Available from: <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data>].

2. Canteen (2022). AYAVision2032 Scoping Review: Updating the Australian Youth Cancer Framework. Canteen: Australia; SAG minutes

## About the evaluation

Canteen engaged Nous group (Nous) to evaluate Cancer Hub to understand the early performance of the hub in the first year of delivering services. The evaluation explored what is working well and opportunities to improve the experience and outcomes for parents, children, adolescents and young adults and families.

## What data was used in the evaluation

The research team analysed service data on the performance of Cancer Hub, service user experience, satisfaction, and short-medium term clinical outcomes<sup>3</sup>. We also spoke to 26 people about Cancer Hub as part of this evaluation. These included:

5

Interviews with  
**SERVICE USERS**

1

Focus group with 5  
**CANCER HUB NAVIGATORS**

6

Interviews with  
**CANCER HUB REFERRERS**

3

Interviews with  
**ALLIANCE PARTNERS**  
From Camp Quality, Redkite and Canteen

1

Focus group with  
**INTAKE (2) AND COUNSELLING STAFF (3)**

## Key Early Outcomes

Some of the key early outcomes following 12-months (June 2022 – June 2023) of the Cancer Hub are highlighted below.



**Cancer Hub is providing valued support for users to navigate a complex system of community services.**

Almost 1 in 9 service users report they find navigating existing support services difficult, prior to engaging with Cancer Hub navigation services.



**Cancer Hub users present with significant concurrent needs, with almost 1 in 10 identifying needs across >50% of assessed 'domains of need'.**

Cancer Hub users often present with complex needs. The Cancer Hub model is flexible to ensure users' needs are met.



**Cancer Hub has exceeded four of its five first-year targets at twelve months of operation.**

The service has met year 1 targets for triage sessions, new Cancer Hub users, navigation sessions and navigator referrals to external services (July 2022-2023).

3. Data sources for this evaluation included: Salesforce analytics on intake and assessment, utilisation of the service, inbound referral data, navigation sessions, outgoing referrals and triage sessions, Documentation on Cancer Hub service model pathways and processes, marketing and media analytics, Clinical outcomes data, including family functioning, level of distress, health literacy, and limited longitudinal data, Client satisfaction and Canteen satisfaction survey data

## 2 WHAT DID WE FIND?

### Overall, the experience with Cancer Hub is highly positive

Cancer Hub is a highly regarded service. Data showed high satisfaction rates, with over 90% of users rating the quality of the service as excellent (n=28). Alliance partners, staff and service users consulted all reported high satisfaction with the service.



*I hope Cancer Hub continues because it's an amazing service and I know other parents get a lot out of it.*

*Cancer Hub Service User*

## Early implementation

### Cancer Hub has been implemented in a changing environment

Cancer Hub was setup within 6-months of the funding announcement from the Department of Health and Aged Care. Due to its rapid setup, Cancer Hub has had to respond to changing demands.

The Cancer Hub service model has been adaptive to meet the challenges with recruitment and retention of staff during COVID and the higher than anticipated volume of users with complex needs.

## Reach of Cancer Hub

### A mix of young people, parents and siblings impacted by cancer are accessing Cancer Hub

Cancer Hub received a total of 2,873 inbound referrals with 2,678 reaching the intake service from July 2022 to July 2023.

### Hospitals and social workers are the largest single source of Cancer Hub awareness

Over a third of people contacting Cancer Hub were made aware of the service by their hospital staff or social worker. Alliance partners and Cancer Hub staff noted that early work to strengthen relationships with healthcare services has been an important aspect of enabling referrals from hospitals and health services.

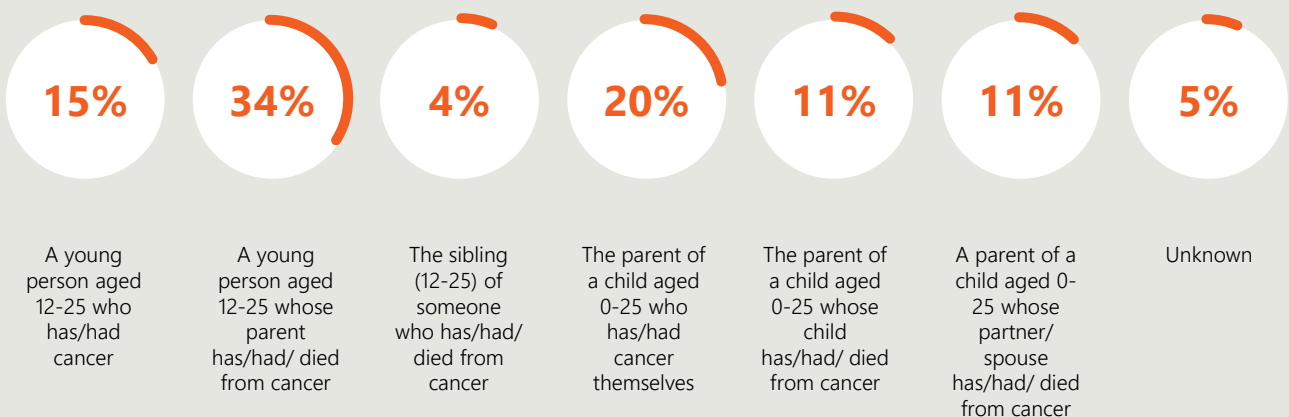
### Cancer Hub has seen significant and increasing demand and activity during its first year

Data from July 2022 to July 2023 shows that Cancer Hub experienced significant growth and demand across four key areas – (1) the number of new Cancer Hub users, (2) triage sessions, (3) navigation sessions and (4) navigator referrals to external services.

Due to the high demand for services, this evaluation of Cancer Hub recommends expanding its eligibility criteria to allow access for additional users to receive navigation and/or counselling. For example;

- parents that have/had cancer with a child 0-25 are ineligible for cancer navigation support, and
- children 0-12 years with a parent who has/had/died of cancer are not eligible for counselling services.

Figure 2 | Breakdown of Cancer Hub intake service users (n=2678)





## User experience and short – medium term clinical outcomes

### Cancer Hub services respond to high levels of distress in services users

Cancer Hub service users, staff, referrers and Alliance partners told us that Cancer Hub is playing a significant role in supporting the psychosocial wellbeing of service users (including distress) through access to counselling, care navigation and referrals to support programs of Alliance partners.

### Cancer Hub referrals are effectively matching users with appropriate services

There were consistent views across service users, referrers, Alliance partners and Cancer Hub staff that the bringing together of the three cancer support services to a single point of navigation and assessment allows for a more comprehensive view of the whole family's needs. Users and their families now experience more timely referrals to appropriate services which meet their needs.



*If a person is so overwhelmed with the level of distress that's happening in their life, there's a lot of needs being raised ... I offer a direct referral [to Cancer Hub].*

**Cancer Hub Referrer**



*Mainstream counselling was near impossible to get because of the impact of COVID and more people had mental health issues and that just jammed everything up. So to get cancer specific counselling was an absolute godsend.*

**Cancer Hub Service User**



*I actually kind of had a bit of a breakdown [when my daughter was diagnosed] because I was like, what is going on and I was feeling like I was being squished from all directions.*

**Cancer Hub Service User**

## Service users are seeing benefit from Cancer Hub over the medium-term

Early data from service users suggest potential changes in key clinical outcomes over time (3-6 months). This is based on a small sample over both stages of the evaluation (n=27) and therefore caution is warranted in extrapolating these limited findings to the broader cohort of service users.

## Opportunities for ongoing implementation and improvement

### Service users highlighted the importance of Cancer Hub in assisting them to navigate existing support services and identified potential opportunities for the service:

- **Grow the awareness of Cancer Hub.** Several service users reported only becoming aware of the service at a later stage in their journey with cancer. Growing awareness through continued partnerships with hospital clinicians and social workers, between cancer support organisations and through direct advertising and promotion.
- **Expand service offerings.** Users identified opportunities to expand the service offering including assistance with education for school-aged young people and co-counselling for children and parents.
- **Provide graphic mapping and descriptions to service users of who does what and how the different support services fit together so that carers can determine who to seek out for various issues.** Service users also requested resources to help unlock the abbreviations and jargon that they encounter after receiving a cancer diagnosis.

## Longitudinal data from service users at either 3- or 6-months (n=27)

Users experienced a **30%** decrease in their overall distress levels.

User reported a **decrease** in the number of overall needs.

There was minimal change in family functioning, with **high levels of satisfaction** at entry to the service and at the 3 or 6-month reassessment.

There was a **67%** improvement in the users ability to navigate support services.

Users reported **consistent levels** of difficulty navigating healthcare services, however this was not their primary concern.

Data is from reassessment surveys at either 3 or 6 month (n = 27).

Cancer Hub referrers view the Cancer Hub as a service that streamlines access to a holistic system of supports for young people and families affected by cancer.

They also provide several suggestions:

- Increase referrer awareness of the Cancer Hub to support a greater number of referrals and promote the ways that referral to the hub can reduce burdens in the clinical setting.
- Continue to educate clinicians through face-to-face and online sessions on the services provided by the Cancer Hub and the ease of the referral process.
- Provide information to referrers so they can better understand the Cancer Hub services accessed by their clients and their progress. This was seen as an important factor to enable continuity of care and to inform future referral practices. This encompasses potential areas for improvement in the handover process to ensure the person is fully supported at transition points between services.
- Diversify the resources and educational material available to users including the potential for additional resources via social media, video resources and podcasts.



*There are multiple people in the family that need support the hospital doesn't provide. Cancer Hub navigators are that one point of referral.*

*Cancer Hub Alliance Partner*



*Having one place to refer [patients] to and the Cancer Hub team have made things a little bit less pressured in the clinical space. I find it has worked really well.*

*Cancer Hub Referrer*

Cancer Hub staff expressed a shared view that Cancer Hub addresses a genuine gap in the service system of supports for families affected by cancer. They identified potential opportunities to enhance the service by:

- **Increasing equity of services** to be more inclusive of cultural and specialised support needs of users.
- **Expanding service inclusion criterion to meet gaps in service offerings** including the provision of navigation service to families where the parent has a cancer diagnosis and free counselling for children <12 years old.
- **Providing more frequent data to staff** so they can better understand trends and patterns.
- **Continuing to strengthen approaches to measuring client outcomes and experience.** Some staff suggested a strengths-based approach to assessments to understand what the strengths the user brings to the service and how those expand over time. Others reported the length of surveys and/or the process for getting reassessment data should be reconsidered.

Alliance Partners expressed support for the Alliance as a way of strengthening organisational and service level coordination. Partners identified potential opportunities for the Alliance:

- **Greater partner involvement in joint service planning for Cancer Hub**, underpinned by sharing of service data, trends and insights – ‘More strategic coming together around the Alliance and the hub itself to improve and understand what is possible now and in the future’.
- **Coordinated Alliance communication to referrers on the purpose and role of Cancer Hub** (to address perceptions of duplication with hospital social worker roles in cancer navigation).
- **Explore integrated case management/CMS systems across partners** that ‘would revolutionise the way we support families as an Alliance’.
- **Consider expansion of Alliance membership and/or service partner networks** to deliver even greater value to young people and families.



*We have great flexibility in the services we provide. We can just say to a family 'what do you need?' It doesn't have to be related directly to the cancer.*

*Cancer Hub Staff*

# Continuous improvement opportunities

Since its establishment in 2022, Cancer Hub has responded to short implementation timelines and adapted its operations in a complex and dynamic environment.

During early implementation, there was significant work invested into the design of Cancer Hub service model and implementation approach, including:

- Recruiting and training staff.
- Establishing referral pathways and developing assessment tools.
- Building relationships with Alliance partners and other health and community-based services.
- Adjusting resources to accommodate higher than anticipated demand from families impacted by cancer.
- This evaluation has identified future opportunities and priorities for continuous improvement, to ensure Cancer Hub continues to deliver high-quality services which meet the needs of users. These are outlined to the right.

To find out more about Cancer Hub, please [Click here](#) or go to [www.cancerhub.org.au](http://www.cancerhub.org.au)

Additional resources can be found at:

- [Canteen Australia](#)
- [Camp Quality](#)
- [Redkite](#)

## FUTURE OPPORTUNITIES FOR CANCER HUB

1

### BUILD SERVICE & ALLIANCE PARTNERSHIPS

Continue to deepen and expand service networks through both informal & formal relationships, based on clear purpose and roles.

2

### DATA-LED PRACTICE IMPROVEMENT

Explore ways user and service data and insights can continuously inform Cancer Hub practices.

3

### EXPAND ACCESS TO CANCER HUB SERVICES

Amend Cancer Hub eligibility and address service gaps to more fully meet needs of young people, parents and families.

4

### DEEPEN UNDERSTANDING OF USER EXPERIENCE & OUTCOMES

Consider refining measures, data collection and reporting of user experience, satisfaction and outcomes to better demonstrate impact over time.

5

### ENSURE CULTURAL SAFETY & EQUITY

Explore ways to deliver equity of access and cultural safety for First Nations and culturally diverse groups.

6

### STRENGTHEN ICT SYSTEMS & PROCESSES

Opportunities for ICT/CRM platforms and Hub processes to better enable workflow for staff and Alliance partners.

7

### STRENGTHEN CANCER HUB AWARENESS

Build awareness through targeted promotion and community engagement to increase reach to those that may benefit most.

8

### STRENGTHEN ENGAGEMENT WITH CANCER HUB REFERRERS

Strengthen engagement with referrers in tertiary cancer settings and embed routine communication pathways (including feedback loops).



A bigger idea of success

---

**Nous Group** is an international management consultancy operating across Australia, New Zealand, the United Kingdom, Ireland and Canada. We are inspired and determined to improve people's lives in significant ways. When our strengths complement yours and we think big together, we can transform businesses, governments, and communities.

We realise a bigger idea of success.

A bigger idea  
of success

750

PEOPLE

75

PRINCIPALS

5

COUNTRIES

+80.7

**2020-22 NET PROMOTER SCORE**  
– global consulting average: +76.6