



Children's Cancer Centre Carers Network

Terms of Reference

1. Vision

The Royal Children's Hospital Children's Cancer Centre Carers Network (CCC Carers Network) works together with patients, families and carers so children and young people achieve the best care outcomes and experiences.

2. Purpose

The RCH CCC Carers Network brings the parents, families, carers, cancer and haematological disease survivors and RCH staff together to work on the shared goal of achieving the best outcomes and experiences for children and young people receiving care.

Children and young people receiving care face many challenges in having their voice heard during their care experience. The network of parents, families and carers who surround them are uniquely placed to support, articulate and amplify children and young people's needs whilst they receive expert care from the RCH's world leading paediatric team.

The RCH CCC Carers Network is led by a diverse representation of parents, families, carers and cancer and haematological disease survivors. The group also includes RCH staff representatives who provide information, support and momentum for the group's goals.

3. Objectives

The RCH CCC Carers Network ensures the voices of children and young people are heard by:

- Cultivating a culture of support amongst parents, families and carers
- Providing parents, families and carers with the knowledge and confidence they need to advocate for their child or young person as they navigate through the health system
- Building trust and a strong, mutually beneficial and ongoing partnership between those delivering and those receiving care
- Providing the RCH with feedback on, and advocate for, the needs of children, young people, parents, families and carers to inform the design and delivery of care.

The RCH CCC Carers Network supports children and young people's voices to be heard by acting as a bridge between their parents, families and carers and their health care workforce.

4. Culture & behaviours

To support the vision statement of ***working together so that children and young people achieve the best care outcomes and experiences*** each member agrees to build a culture upon the following behaviours.

Trust

We build trust together in every meeting.

We work together to create a culture of trust, inclusion, and transparency where the importance of confidentiality is respected.

Partnership

We work together to make things better for the children and young people receiving care.

We empower each other by treating each member as an equal. We collaborate to find the best pathway to our shared goal.

Open-minded

We challenge ourselves to be open to changing our views.

We actively listen to the diverse views of patients, families, carers and staff. We are considerate and understanding in even the most complex discussions.

Action

We do the things we agree to do.

We understand that change comes about because of our actions. Fulfilling our commitments builds trust and confidence in the importance of our work.

5. Roles & Responsibilities

To support the delivery of objectives, The RCH CCC Carers Network members will:

- Cultivate two-way communication between RCH staff, patients and carers through the delivery and maintenance of:
 - A 12-month work plan articulating the network's key focus areas
 - Strategies that empower patients and carers to be active participants in care
 - Systems for patients and carers to provide constructive feedback and compliments about services or care.
- Nurture a supportive and respectful environment that enables proactive and productive outputs and outcomes, including:
 - Preparing for, attending and actively contributing to scheduled meetings
 - Taking accountability for follow-up actions
 - Participating in related working groups, time and commitments permitting
 - Supporting the onboarding and mentoring of newly appointed members.

6. Membership

Consumer representation

The RCH CCC Carers Network will consist of up to 12 consumer representatives.

Network membership should reflect a breadth of views and life experiences and as much as practicable mirror the ethnic, cultural and linguistic diversity of patients and their carers. Whenever possible, at least one consumer who has experienced regional shared paediatric oncology care will be a member of the network.

The role of Chair and Deputy Chair will rest with a consumer representative, unless otherwise instructed by the Chair or Deputy Chair (in the Chair's absence).

Term of membership

Consumer representatives will be appointed to the Network for an initial term of two years from the date of appointment. A further term of two years may be offered to a consumer representative at the discretion of the Chair and Network Coordinator.

No consumer representative can be appointed for a total period that exceeds six years from date of appointment.

RCH staff

RCH staff representation will comprise of:

- Director Children's Cancer Centre
- Nurse Unit Manager, Day Cancer Centre
- Nurse Unit Manager, Kookaburra ward
- Social Work, Oncology
- Director Quality Systems
- Director Partnerships & Consumer Engagement (Network Coordinator)

RCH Staff are asked to nominate a delegate in instances where they are unable to attend a network meeting.

The RCH will provide Secretariat support.

Honorary appointments to the network will be considered as an RCH staff member.

7. Meetings

Meeting Frequency

The RCH CCC Carers Network will meet up to six times per year. The Chair will confirm meeting dates and times, if possible, at the first meeting of the network in each calendar year.

Special meetings of the network may be convened by the Chair or Network Coordinator as business requires, with notice to be given in the ordinary way.

Meetings will be ordinarily offered via a hybrid platform, Teams (virtual platform) and in-person at the Royal Children's Hospital (50 Flemington Road, Parkville) from 5.30pm to 7.00pm on the first Monday of every month (except during school or public holidays). In special circumstances, the time and venue of meetings can be altered at the discretion of the Chair and Network Coordinator.

Agenda and meeting papers

Meeting agenda and papers will be circulated to network members, wherever possible, at least 3 days prior to each meeting. Network members are expected to prepare for meetings by thoroughly reading and considering relevant papers in order to be able to provide appropriate and constructive input on matters for discussion and decision.

Quorum

The quorum necessary for a meeting of the network is three consumer representatives and at least one health service representative.

Voting

Should voting be required, consumer representatives are the only members to hold voting rights. RCH staff members hold non-voting rights. RCH staff members can actively participate in discussions relevant to the item/s being voted on however will be required to abstain from voting.

Minutes and action register

A written record of network meetings will be completed by The RCH Secretariat, including a record of action items. A copy of the Minutes and Action Register will be circulated to all members within 2 weeks of a network meeting. A copy of the minutes and action register will also be provided with the meeting papers.

8. Reporting

The RCH CCC Carers Network will report to The RCH Community Advisory Committee, via:

- Meeting minutes and actions, for noting
- A short Annual Review as at 31 December of each year (detailing activities in the past calendar year and proposed activities in the following calendar year).

The RCH CCC Carers Network Annual Review will also be made available to the Director of the Children's Cancer Centre and the Royal Children's Hospital Community Advisory Committee.