**Infancy and Early Childhood Advisory Group: Terms of Reference**

**Purpose and Aim**

The Infancy and Early Childhood Advisory Group (IECAG) has been established to provide a community perspective on the research and services being provided by Ngala and the Early Neurodevelopment and Mental Health team at Telethon Kids Institute (TKI).

Our aim is to empower community members to have a say in what we do and how we do it. We believe that is crucial to have community members involved in our work to ensure that it is appropriate, understandable, and applicable to the needs of children and families in WA.

This approach is aligned with the National Health and Medical Research Council and Consumers Health Forum’s *Statement on Consumer and Community Participation in Health and Medical Research (2016).*

**Terms of Reference**

The IECRG will provide or facilitate:

* Consumer and community perspectives on the research and services provided by Ngala and the Telethon Kids Institute
* Advice and support on methodologies and evaluation procedures
* Advice and support on communication, dissemination, and translation strategies. This may include assistance with plain language summaries and translating research results into policy and practice
* Advice and expertise on consumer and community issues and priorities for future work

**Membership**

The IECAG will include parents and caregivers with a child aged 0-6 years, and appropriate staff from TKI and Ngala. Membership is a minimum of two staff and a minimum of eight (and maximum of 18) community members. TKI or Ngala staff will facilitate the meetings and provide secretariat.

**Responsibilities**

***IECAG members:***

* Have a commitment and interest in research and services at TKI and Ngala.
* Have the ability to work cohesively in a team environment with energy and enthusiasm.
* Ability to attend most meetings as outlined in the Terms of Reference (TOR).
* Sign a Confidentiality and Non-Disclosure Declaration Form.

***TKI/Ngala:***

* Provide a staff support person to assist and support consumer representatives with their role.
* Provide remuneration/honorarium for consumer representatives for out of pocket expenses.
* Conduct recruitment and CAG selection in a respectful manner.
* Maintain confidentiality of names and contact details of IECAG members, saved on a password protected spreadsheet.
* Regularly inform IECAG of how their input and feedback has contributed to research decisions and directions.
* Acknowledge consumer contributions on all publications and outputs where appropriate.
* Call the IECAG meetings, arrange meeting room, prepare an agenda, and chair and provide secretariat for the meetings.

**Term**

Members will be appointed for 1 year initially.

**Meetings**

Meetings will be held quarterly. Meetings will last for up to an hour and a half.

**Quorum**

A quorum will consist of half of the members being present at any meeting. In the absence of a quorum, any discussion or decisions can take place outside of the meeting.

**Payment and Support**

IECAG members will be offered an honorarium, in line with Consumer and Community Health Research Network Guidelines, for each Advisory Group meeting attended and for time spent reviewing project documents.

All paperwork relating to the IECAG meetings will be emailed to members at least one week prior to the IECAG meeting.

**Terms of Reference**

The IECAG Terms of Reference will be reviewed annually.

**Accepted**

**Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Review Date - May 2022**