NSW Early Clinical Trials Alliance (NECTA)

Consumer and Patient Advisory Panel (CPAP)
Terms of Reference

1. Purpose
The Consumer and Patient Advisory Panel (CPAP) is established to ensure that the voices, experiences, and insights of patients, carers, and community members are embedded throughout the design, implementation, and evaluation of the NECTA-led program to strengthen early phase clinical trial (EPCT) access across NSW.
The CPAP will provide advice and recommendations to ensure that the program is responsive to the needs of diverse patient populations, especially those from Indigenous, culturally and linguistically diverse (CALD), and rural and remote (RAR) communities.

2. Objectives
The CPAP will:
- Provide lived experience perspectives on access to, understanding of, and participation in EPCTs.
- Ensure cultural, linguistic, and geographical considerations are integrated in program elements.
- Advise on co-design of patient-facing materials, communications, and outreach strategies.
- Recommend approaches to reduce barriers and improve equity for priority populations.
- Review and inform the development of training, recruitment, and support strategies for consumers involved in trials.

3. Scope
The CPAP will offer input across areas of the NECTA program, including:
- Culturally appropriate education and navigation tools for CALD and Indigenous communities.
- Patient journey mapping and identification of barriers, enablers, and unmet needs.
- Feedback on bilingual navigation support and interpreter tools.
- Perspectives on trial participation impacts including time, cost, travel, and emotional burden.
- Guidance on communication materials, trial consent processes, and clinical engagement.
- Input on the development and implementation of semi-structured interviews and PROs.

The CPAP is advisory in nature and will not be responsible for operational or financial decisions.

4. Membership
Composition:
The Panel will include:
- Up to 12 members, ensuring diverse lived experiences, including:

    - At least 2 members identifying as Aboriginal and/or Torres Strait Islander.
    - At least 2 members from culturally and linguistically diverse backgrounds.
    - At least 2 members from rural and remote communities in NSW.
    - Individuals with experience as patients or carers in early phase or other cancer trials.
    - A mix of ages, genders, cancer types, and experiences across the care pathway.
- Chairperson: A consumer representative elected by the panel.
- Facilitator/Coordinator: Appointed NECTA staff to support panel operations.

Terms:

- Members will be appointed for a term of 2 years, with an option for renewal.

5. Meetings and Administration

- The Panel will meet quarterly, with additional meetings or workshops as required.
- Meetings may be held in-person or virtually, with flexibility to ensure inclusive participation.
- NECTA will provide secretariat support, including agendas, minutes, and documentation.
- Pre-reading materials and briefings will be provided in plain language and accessible formats.

6. Reporting and Communication

- The CPAP will provide recommendations directly to the NECTA Steering Committee and Program Team.
- The Panel's feedback will be used to improve program design, resource development, and trial delivery processes.

7. Conflict of Interest and Confidentiality

- Members will declare any real or perceived conflicts of interest at appointment.
- Members will respect confidentiality and patient privacy.

9. Review of Terms

These Terms of Reference will be reviewed annually in consultation with the Panel to ensure they remain fit-for-purpose and responsive to consumer needs.

Approved by:
NECTA Steering Committee
Date:
Next Review: