



Terms of Reference

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Summary: These Terms of Reference clarify the role, purpose and responsibilities of the members of ConViCTioN, (Consumer Voices in Clinical Trials in NSW) and the project team supporting ConViCTioN

Applies to: ConViCTioN Members and project team supporting ConViCTioN

Author: Project Team and
ConViCTioN members

Approved by:

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1. What is this document about?

The purpose of this document is to describe the roles and responsibilities of members of ConViCTioN, Consumer Voices in Clinical Trials in NSW, and the Project Team to achieve the project deliverables (described below) to support increased awareness and participation of consumers and the public in Clinical Trials (CTs) across NSW.

2. Background

ConViCTioN is a group of NSW health consumers that were brought together in late 2021 for a project funded by the NSW Government's Office of Health and Medical Research. The Project Team comprises representatives from four partner organisations: Health Consumers NSW (HCNSW), AccessCR, Northern NSW Local Health District, and Sydney Health Partners (SHP).

The aim of the original project was to develop consumer co-designed resources to help increase awareness and participation in clinical trials in NSW. Membership of the group is diverse in health and cultural backgrounds, age, sex, location and in clinical trials and lived experiences.

There are 10 foundational ConViCTioN members who were recruited in 2021 from across NSW who are continuing as members in 2023/2024 including two consumer co-chairs. An additional 6 members will be recruited in 2023 to join ConViCTioN.

3. Purpose of ConViCTioN

The purpose of ConViCTioN is to continue to help promote consumer awareness and interest in clinical trials across NSW by developing associated consumer-led resources and activities. ConViCTioN will work with the Project Team to achieve the project deliverables (as described below) between July 2023 and June 2024.

Project Deliverables

The Project Team will work with ConViCTioN to deliver the following by June 2024:

1. Expansion of ConViCTioN's membership (to at least 16 members) that supports a rich representative breadth of consumer diversity across NSW;
2. Identifying options for consumers wanting to be involved in clinical trials (eg creating an online community, exploring strategies for sharing information about clinical trials to consumers);
3. Scope and provide guidance on a Consumer Clinical Trial Ambassadors program;
4. Provide guidance on the content, relevance and improved functionality of the [Consumer Voices in Clinical trials Website](#);
5. Promote consumer voices in clinical trials by sharing information and resources through member networks across NSW .

4. Reporting

The Project Team will report progress to the Clinical Innovation and Research Division, NSW Ministry of Health.

5. Responsibilities

ConViCTioN is responsible for:

- working with the Project Team to deliver on the project deliverables (described above).
- engaging and collaborating as an effective working group for the timely achievement of the Project Deliverables; and
- leveraging members' consumer skills, knowledge and diverse lived experiences as they relate to participation in Clinical Trials.

ConViCTioN members are expected to:

- Attend up to four meetings via Zoom for 1 hour and up to 1 hour preparation time between meetings for up to 12 months (with the possibility of an extension).
- Attend one face to face meeting for up to 3 hrs in Sydney (HCNSW will support members with travel and accommodation arrangements).
- Actively engage in constructive contribution to the discussion, be respectful of people with different capacities, knowledge, and experience.
- Attend at least 80% of meetings.

6. Frequency of meetings

ConViCTioN will have four online meetings and one 3 hour face to face meeting between June 2023 and June 2024. ConViCTioN may also convene on an ad hoc basis.

The quorum (the minimum number of members that must be present to make the proceedings of the meeting valid) for ConViCTioN shall be 80% of its members. If a quorum is not met, then the meeting will be rescheduled.

7. Membership, Roles and Meetings

ConViCTioN members will receive a payment of \$50 per hour for attendance (this includes meeting preparation time).

All ConViCTioN members have been selected through an Expression of Interest process, and chosen to reflect the diversity (culture, language, age, gender and Aboriginal and Torres Strait Islander) of people from across NSW with varying experience of clinical trials and/or health consumer knowledge (from none to considerable experience).

ConViCTioN is chaired by two group members, a Chair and Co-chair. ConViCTioN will consist of up to 16 members (including 10 Foundational members) for a period of 12 months from July 2023 to June 2024.

An HCNSW employee will act as secretary to ConViCTioN, record deliberations and share these documents with the group.

8. Confidentiality and Conflict of Interest

ConViCTioN members must respect confidentiality and disclose any conflict of interest in any matters being considered by ConViCTioN.

ConViCTioN members may receive information that is regarded as confidential or has privacy implications. Members acknowledge their responsibility to maintain confidentiality of all information that is discussed or shared with the group and not in the public domain.

9. Workplan and Deliverables

The key deliverables described in **section 3** are expected to be delivered by June 2024. ConViCTioN will be involved until June 2024. There may be a possibility of an extension for future projects depending upon the availability to apply for further funding.