



**Australian
Living Evidence
Collaboration**

Lived experience advisory group - Terms of Reference

Version 2, October 2025

Overview

The Australian Living Evidence Collaboration (ALEC) is led by Cochrane Australia within the School of Public Health and Preventive Medicine at Monash University.

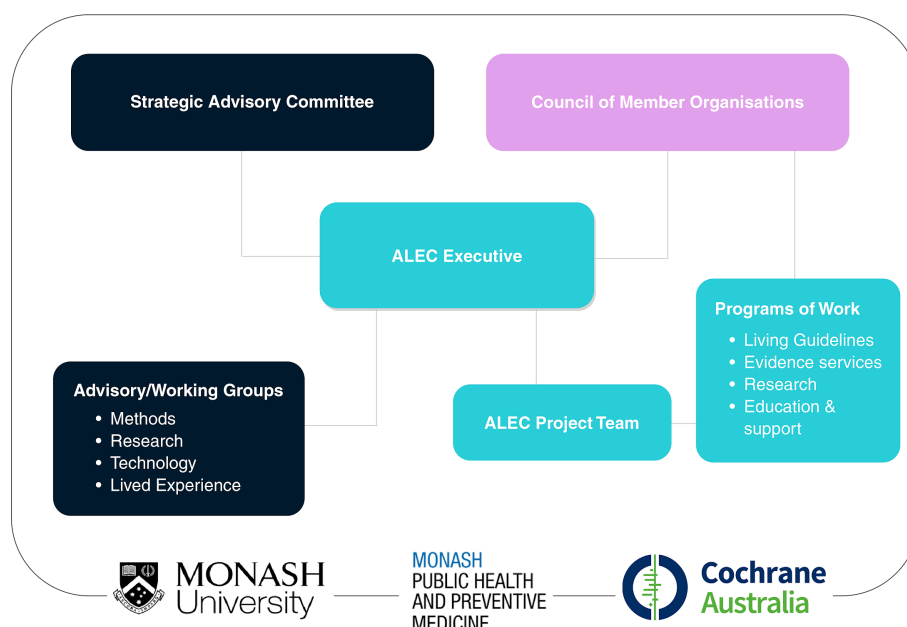
ALEC's vision is a national system that delivers up-to-date, trustworthy 'living' syntheses of health research for decision-makers, driving better health care and outcomes. We seek to achieve this by supporting evidence-based clinical decision-making in priority areas for Australian health care settings. To do this we:

- convene the sector (clinicians, people with lived experience, policymakers, organisations, researchers) to promote and build multidisciplinary collaboration
- provide living evidence syntheses
- develop living guidelines
- conduct research to improve our impact.

The purpose of lived experience engagement in ALEC is to ensure ALEC's work is co-designed to achieve better health outcomes for patients and carers. The ALEC Lived experience advisory group is one of four Advisory/Working Groups that provide advice to other advisory and operational bodies within ALEC (see governance structure, below).



Governance structure



The Terms of Reference below sets out the scope of the ALEC Lived experience advisory group and outlines how we will work together. It is expected that the Terms of Reference will be regularly revised, as ALEC, and the Group, develop over time.

Responsibilities of the ALEC Lived experience advisory group

The responsibilities of the Group are:

- To provide advice and/or flag opportunities to the Strategic Advisory Committee and ALEC Executive
- To provide strategic advice and/or flag opportunities to the ALEC project team, related to:
 - o Priority areas for new ALEC guidelines and work programs
 - o The direction of research programs and individual research projects
 - o Grant applications
 - o Lived experience engagement approaches for new ALEC living guidelines
 - o Communication, presentation and dissemination of living guidelines for people with lived experience

There will also be opportunities for interested members to join other groups and activities as they are developed, such as project-specific research advisory committees, and co-presenting at conferences and workshops, and co-authoring publications.

Membership

Currently, membership is open to up to 12 people with experience providing a lived experience perspective in one or more of the living guidelines produced by the ALEC member groups.

As the Group grows over time, the intention is to seek new members who reflect the diversity of the Australian population, with a focus on First Nations people, people from culturally and linguistically diverse backgrounds, people with disability, and those who identify as LGBTQI+, live on a low income, and/or live in regional and remote areas.

Operating procedures

Meetings are online (via Zoom) and run for up to 1.5 hours. They are held about every three months (meaning four meetings per year). Members are sent an agenda and sometimes additional material to read, before the meeting. We send out meeting minutes and the slides from any presentation after the meeting.

Meetings will be chaired by the ALEC team. Over time, the Group may decide to appoint lived experience co-chairs into this role.

The ALEC team strives to be inclusive, and can work with individual members to reduce any barriers to participation (e.g. meeting ahead of time to go through Zoom tips, ensuring members can join by phone, if preferred, or sending comments via email).

Lived experience members of the Strategic Advisory Committee

The Strategic Advisory Committee, whose substantive role is to review and advise on the strategic direction and performance of ALEC, has two positions for lived experience members.

The lived experience members of the Strategic Advisory Committee are drawn from the ALEC Lived experience advisory group, to ensure good flow of information and advice between the Group and the Committee. These members are appointed in an Expression of Interest process (open only to members of the Group), in line with the process for appointing all Strategic Advisory Committee members.

See Appendix 1 for the ALEC Strategic Advisory Committee Terms of Reference. Please note that the remuneration arrangements for people with lived experience outlined in the ALEC Lived experience advisory group Terms of Reference also apply to lived experience members of the Strategic Advisory Committee.

Conflicts of Interest

In accordance with [ALEC's Conflict of Interest Procedure](#), Group members must declare all potential, perceived and actual conflicts of interest within the previous five years at appointment and at the start of each Group meeting. A conflict of interest primarily means a situation where a person or commercial entity might benefit financially from the decisions made by ALEC or the content of its guideline programs. This could mean their advice is not objective.

The Chair of the Group will advise if the member is to refrain from participating in any discussion or decision-making process. Any conflict of interest, and the approach to managing the impact, will be recorded in the Minutes.

Declarations of interest will be reviewed annually; however, we encourage members to proactively inform an ALEC team member if a new conflict arises before the time of review.

Maintaining confidentiality

We ask that ALEC Lived experience advisory group members treat all meeting documents as confidential, unless otherwise specified. Similarly, to ensure that all members feel comfortable participating, we ask that Panel members keep the discussions held during meetings (including personal stories shared by panel members) as confidential.

Administrative and other support

Group members are provided with ongoing information and support needed for their roles, via the ALEC team, including the Lived experience engagement lead and the Research Support Officer. The ALEC team can be contacted via email or phone with any queries, or

to provide suggestions for improvement. The ALEC team will ask new members about the ways in which we can support them to participate and we regularly seek feedback about how we can improve our processes.

Payment

As a gesture of appreciation, members are offered an 'honorary' (payment) of \$210 per meeting that they attend (inclusive of preparation time). Members will be able to choose how they would prefer to receive their honorarium (direct to bank account or voucher). Honorarium amounts will increase by 2.5% every year. This same arrangement applies for Members who hold a dual role as members of the Strategic Advisory Committee.

The honorarium payments are not subject to withholding tax or superannuation as there is no employer/employee relationship between members of the Lived experience advisory group and Monash University. However, the ATO has indicated that payments may be subject to income tax in the recipient's hands where there is a connection to the recipient's income-producing activities (such as working in the health profession). We suggest that Group members obtain their own taxation advice with regard to these payments.

Contact

For any questions or more information, contact:

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