

Terms of Reference - About Emerge Australia's Community Advisory Panel ("the Panel")

Purpose

Emerge Australia is piloting a Community Advisory Panel from August 2025. Its purpose is for Panel members from our community to provide advice to Emerge Australia about our [advocacy priorities](#).

This will ensure that Emerge Australia represents our community's needs based on their input. The Panel's advocacy aims to influence governments to change legislation and policies that affect our community, rather than focusing on individual cases.

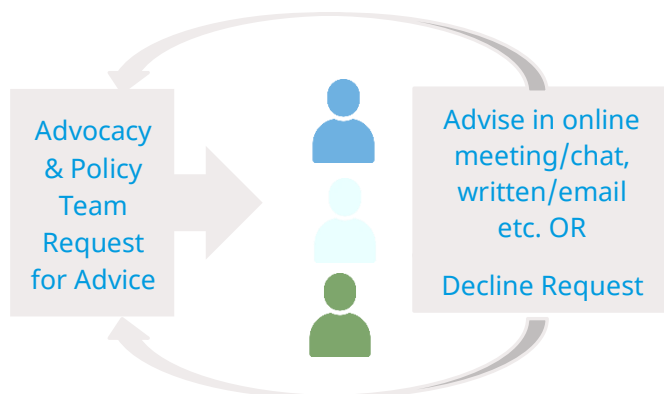
How the Panel Operates

The Advocacy and Policy Team will

- Provide Panel members with the information and support they need to participate in a meaningful way
- Contact you in your preferred format, with as much notice as possible. For example, the government may request a written submission related to an advocacy priority. We will offer all Panel members the opportunity to contribute, in their preferred method of communication. The process must be able to be managed within our limited staff resources.

How Panel Members will Contribute

Emerge Australia Community Advisory Panel



The Advocacy and Policy Team will make requests to Panel members to provide:

- Input/feedback informed by personal experiences, whilst representing the needs of our broader community
- Input according to their capacity to contribute at any given time

We will endeavour to:

- Provide as much time as possible when requesting advice (although sometimes it will unavoidably be short turnarounds)
- Provide information in simple language that is easy to read, within the constraints of the work, for example, when seeking input a government consultation process.
- Provide a range of ways of contributing e.g. on-line chats, one-to-one phone calls, emails, written submissions etc.

We recognise, and will cater to, the fluctuating and personal needs of panel members. We understand that anyone may need to withdraw or wish not to respond to requests for advice, for any reason. Panel members will be empowered to decide which advice requests they respond to, according to their capacity, knowledge or interest. Panel members can decline a request for input for any reason

Advice can be provided in the member's preferred format (for example, email, documents, recorded message (that can be dictated and turned into text), by phone or other format, as requested by a member.

Members may decline to provide advice on any occasion. We recognise that people may be unwell or have caring responsibilities or, may not have an interest or knowledge to contribute to a particular topic.

We welcome your feedback at any time if things aren't working for you.

When a request for input is called, members may participate via

- written submission (digital or hard copy)
- online chat with Advocacy and Policy Team member
- online meeting
- by telephone

There is no requirement to attend meetings.

Panel members are expected to contribute in a respectful, helpful manner that is considerate of Emerge Australia's resource-limitations and members' energy limitations¹.

Membership

The Panel is made up of more than 30 people who are broadly reflective of the diverse ME/CFS and long COVID community including:

- differing levels of symptom severity
- carers of child or adult
- younger and older people
- people from culturally and linguistically diverse backgrounds
- LGBTQIA+
- First Nations
- people living in metro, regional and rural locations

Panel members are selected through a nomination process and chosen to provide Emerge Australia with a diverse panel from which to draw on expertise and experience.

Appointment for Panel Members is for an initial term of eighteen months. The process thereafter will be dependent upon Evaluation of the Panel.

A Panel Member may resign or take leave of absence for up to one year, at any time, by advising the Manager, Advocacy and Policy.

Panel members must uphold Emerge Australia's vision and mission.

Our Vision

Australians with ME/CFS achieve the highest quality of life possible.

Our Mission

Every Australian diagnosed with ME/CFS receives effective medical and other services without stigma or discrimination contribute.

¹ The format for the panel is based on the International Association of Public Participation Spectrum <https://iap2.org.au/resources/spectrum/>

Our Promise to Members

Members will act in an advisory capacity and do not have a formal decision-making role. They will have the opportunity to present their views and opinions for consideration. Where we are unable to act on members' advice, we will explain the reason for the decision.

We will provide feedback on how the Community Advisory Panel has influenced our work.

Note

Emerge Australia is a small, not-for-profit charitable organisation, with only 6 full-time equivalent staff. Each year we apply for grants in an effort to maintain or increase the number of paid staff. Our volunteers participate on an equal basis. We are therefore, regrettably, unable to remunerate or pay an honorarium to members of the Community Advisory Panel.