

Community Experience Survey Findings

Background

In September 2024, ninety people responded to our Community Experience Survey. They suggested ways that could strengthen community input into Emerge Australia's work which has led to the development of a pilot of a Community Advisory Panel. Nominations will open soon.

We are very grateful for the time and energy respondents gave to this survey. We want to honour what was said and give the proposed solution its best chance of succeeding.

Please note that the survey also uncovered information about Emerge Australia's communications and engagement with our community. This is being dealt with separately. We will work with the Community Advisory Panel to address these findings.

About Survey Respondents

Most people said that community experience and advice to Emerge Australia is needed.

Do you think that community experience and advice is needed?

Yes	84
Maybe	6
No	0
<u>TOTAL</u>	<u>90</u>

Respondent Key Characteristics

Respondents came from diverse backgrounds.

25% Severe ME/CFS

20% LGBTIQ+

25% Moderate ME/CFS

24% lived in metropolitan areas

Other Characteristics

Other	11
Caring for an adult	6
Mild ME/CFS	5
Moderate long COVID	2
Severe long COVID	2
Severe LC & Severe ME/CFS	2
Mild long COVID	1

Of the 10 respondents that listed “other” characteristics, 2 identified as neurodivergent, and one listed “disability”.

Best ways to advise Emerge Australia

People selected a range of ways that they could contribute.

Bests ways of providing advice	No. of People (Total - 90)
Advisory Group	64
Written submissions	57
Online chats	56
Online meetings	49
Surveys	15
Other	44

Other Suggestions	No. of People
Paid Lived Experience roles	2
Social media	2
Online communities/forums	2
Anonymously	1
Case studies	1
Asynchronous	2
Community consultations	2
Focus groups	1
Email	1
Submissions - varying formats	2
Voice messages	1
Web page	1

Most important aspects of community experience advice

Respondents were asked to select at least three of the most important suggested aspects and to consider offering additional aspects.

Overwhelmingly, respondents indicated that “a way for the community to have input into EA’s work” was the most important aspect to them (76/90). Fifty-five participants (out of 90) selected “facilitates diverse community representation”, followed closely by “honesty and transparency (47/90), “hearing about why advice is not responded to” and “what community experience advice achieves”. 32/90 also selected “provides carers with opportunity to input” as being important.

Most important aspects of community advice	No. of People <i>Total 90</i>
A way for the community to have input into Emerge Australia's work	76
Facilitates diverse community representation	55
Honesty and transparency	47
Hearing about why advice is not responded to	38
Hearing about what community experience advice achieves	36
Provides carers with opportunity to input,	32
Other	8

How much does our advocacy work focus on issues you are concerned about?

The major (35) of respondents ranked how much our advocacy focuses on issues they are concerned about as 4/5, followed closely by 30 participants 3/5, 14 at 5/5, 7 at 2/5 and 4 as 1/5.

Ranking	No. of Respondents
*****	14
****	35
***	30
**	7
*	4
Total	90

What outcomes would you want from community experience advice?

The majority of respondents (74/90) want input into program and service delivery, input into advocacy strategies (57/90) and input into organisational policies and strategies (51/90).

Community Experience Advice - Outcomes

Input into program and service delivery	74
Input into advocacy strategies	57
Input into organisational policies and strategies	51

What is the best way for us to communicate with you about this project?

Best ways of communicating (select as many as apply)

Best ways of communicating

Emerge Australia newsletter	68
Emerge Australia website	56
Social media	35
Other	12

Of those who selected "other", 5 people suggested via email, one of whom requested that the email not include colour or pictures.

If you provided advice, would you need any of the following supports to do so?

The majority of respondents (59/90) prefer to provide advice in writing rather than a meeting.

Supports when providing advice

Writing rather than meeting	59
Hard copy	19
Support Person at Meetings	8
Audio Visual Aids	3
Other	17

Is there anything else you would like to tell us?

31 respondents provided other information.

Common themes include:

- the need for user-friendly communication
- the importance of including diverse voices from the ME/CFS community
- the necessity of compensating lived experience contributions
- the critical role of community experience in informing organisational actions
- suggestions for more accessible feedback mechanisms
- Address concerns about inclusivity for individuals with varying severity of ME/CFS
- implications of advocacy language, especially in context of long COVID.

Summary

Respondents wanted to provide advice in different formats, with most suggesting an advisory group, written submissions and online chats and meetings. Financial recognition for lived experience contributions was raised by two respondents.

Draft Recommendations

Based on the survey findings, we propose a panel of community members, who contribute as and when they can, in a variety of ways. This will allow for community experience input from a diverse range of people with individual needs. The idea of a “Community Advisory Panel” also has merit because it is realistic. Emerge Australia has limited staff to support the process. We are funded predominantly by short-term philanthropic grants and donations. With only 6 full-time equivalent staff, we need to start small, with a narrow focus, informed by a diverse group of people. We hope that this modest start will pave the way for greater community input into Emerge Australia’s work.

Recommendation 1: Pilot a “community advisory panel”

Emerge Australia to invite nominations to participate on a community advisory panel. It is proposed to pilot a panel of twelve members from diverse backgrounds and with different experiences and knowledge. Initial focus of the panel will be Emerge Australia’s “advocacy priorities”.

The survey offered suggestions for how Emerge Australia could enhance the ways it engages with our community and how communications could be improved. This is a secondary focus for the survey findings and is dealt with in Recommendation 2..

Recommendation 2: Enhancing community engagement and communications

Work with the community advisory panel to explore and enhance Emerge Australia’s community engagement and communications.

Process for establishing a way for our community to input into our work.