

SANE Forums: online peer support for people living with mental illness and for carers

Evaluation of the SANE Forums demonstrates the benefits of online peer support for Australians living with mental illness, and for family and other carers

About this study

This SANE Research Bulletin summarises key findings of an evaluation report produced for the Australian Government, Department of Health, which funds this initiative, as well as anonymous demographic data on usage from the first 12 months of operation (May 2014 - May 2015). The evaluation included detailed analysis of 1,024 posts during October-November 2014 as well as a feedback survey of users. The SANE Forums are delivered in partnership with over 20 community-based non-government organisations around Australia.



How many people use the SANE Forums?

As well as consumers – people with lived experience of mental illness – the online Forums are also popular with carers.

The Forums rapidly exceeded expectations in terms of the number of people who used the service, as well as the those who go on to register as members in order to contribute posts and comments themselves.

In the first 12 months of operation, there were 47,000 unique visitors to the Forums, of whom 1,347 have resgistered as members. Overall, the 15,000 posts created so far have been viewed over 483,000 times.

The safe, anonymous, and moderated nature of the Forums is especially valued by users. Many also live in regional, rural, or remote areas where other support may be hard to access.



How do people with lived experience use the Forums?

The Lived Experience Forum, for people living with mental illness, is most likely to be used for sharing stories and opinions.

Consumers using the Lived Experience Forum report valuing it as a safe place to share stories about how their lives have been affected by mental illness, and to exchange opinions.

The top-ranking purpose for starting a discussion was exchange experiences (66%), followed by seeking opinions and advice (37%), and requesting information and referral (17%).

The top four topics discussed focused on challenges raised by symptoms, issues related to assessment, treatment and medications, and the impact of mental illness on relationships.



How do family and other carers use the Forums?

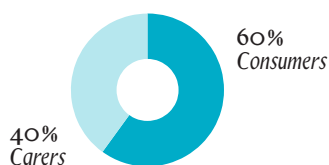
The Carers Forum is most likely to be used for seeking information and advice.

Family and other carers using the Forum appear to value it principally as a tool to locate practical support for their caring role.

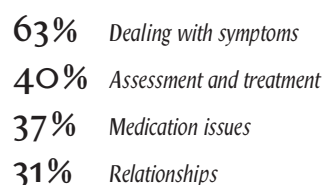
In contrast to consumers, the top-ranking purpose for starting a discussion was information and advice-seeking (50%), followed by sharing stories (40%) and seeking similar experiences (30%).

The top four topics discussed in the Carers Forum related to the practical challenges of being a carer, including the difficulty of navigating the mental health system and the challenge of someone being unwell and refusing treatment.

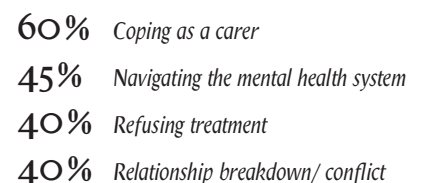
Forums users



Lived Experience: Topics discussed



Carers: Topics discussed



SANE Forums



Responses

Forums members respond positively to posts by others, providing active, helpful peer support to each other.

The great majority of posts on the Forums are generated by users (75-85%), a level indicative of a healthy online community.

Lived Experience Forum

Eighty per cent of responses in the Lived Experience Forum are bonding and supportive – discussing common experiences, and making normalising and praising comments.

Around 18% of responses provide practical support – information, direction to resources, and advice on how to deal with situations.

Carers Forum

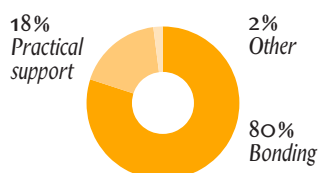
Forty-three per cent of responses in the Carers Forum are bonding, offering support and praise.

Around 31% of responses offer practical information, advice, and referral. A further 24% are conversational or otherwise provide no direct emotional or practical support.

The different pattern of usage between the two Forums is notable. Twice as many consumers respond with bonding comments, suggesting a more engaged community is flourishing in the Lived Experience Forum.

In the Carers Forum, on the other hand, twice as many responses provide practical suggestions. This variation suggests the differing current needs and priorities of people living with a mental illness and of carers.

Lived Experience: Responses



Benefits

Members of the Lived Experience and Carers Forums report many common benefits, despite different emphases in usage patterns.

While consumers primarily use the Forums as a supportive online community, and carers make greater use of the Forums as a practical resource, they both identify and value many of the same benefits.

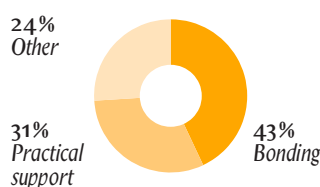
82% *Felt empowered by being an anonymous member of a safe, moderated online community dedicated to their needs.*

81% *Gained new insights into their condition and managing symptoms and daily life, through sharing experiences and tips.*

79% *Valued the sense of connection which is associated with a supportive community, whether offline or online as in the Forums.*

79% *Valued a supportive online environment free of stigma, where they felt understood by others who had shared similar experiences.*

Carers: Responses



Recommendations

The evaluation's recommendations for growth and improvement in the online Forums service are now being pursued by SANE Australia.

The evaluation made recommendations for future development in three key areas.

Improved access

through growth of the Forums, so that as many as possible may benefit from them:

- 24/7 moderation (achieved June 2015)
- Increased promotion in rural/ remote areas
- Content-sharing and user involvement.

Partnership development

with mental health and other community organisations:

- Increased engagement with and promotional support for partner-organisations
- Encourage and support moderation and other involvement from partners.

Technology innovation

to enable continuous improvement:

- Leverage technical capabilities to enhance service design and delivery
- External evaluation
- Enhance data collection and analysis.

SANE Australia

A national charity helping all Australians affected by mental illness lead a better life.

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PDF version available at www.sane.org