SANE Forums – Online Peer-to-Peer Service

COVER SHEET

Application for the TheMHS
'Achievement Award for entries with a different focus'

April 20, 2016

Application contact:

Faruk Avdi
Director – Digital, Service Design and Technology
SANE Australia
faruk.avdi@sane.org
61 + 409 434 988

Table of contents:

Additional Information About Entry

SANE Forums (Carers) released in Beta version in May 2014 as an active, live community. SANE Forums (Lived Experience) was released later that year and launched officially by the Minister for the Australian Department of Health in August 2014.

The forums have been made possible with funding from the Australian Government Department of Health, Philanthropic funding from the Colonial Foundation and Gandel Philanthropic Foundation, and through the partnerships with organisations throughout the mental health sector, as well as with commercial/technology sector partnerships with Lithium Technologies, Isobar Sydney, and Snaffle.

The primary URLs for the service are:

Landing page (SANE version)
http://saneforums.org/

Lived Experience Forum
http://saneforums.org/t5/Lived-Experience-Forum/ct-p/lived-experience-forum

Carers Forum
http://saneforums.org/t5/Carers-Forum/ct-p/carers-forum

SANE forum partners – click through to see individual partner versions of the syndicated service
http://saneforums-access.org/

1. Evidence of a significant contribution to the field of mental health on a local, state or national level.

In its 2014 Review of Mental Health Programs and Services, the National Mental Health Commission identified 690,000 Australians over 18 years who are living with a severe mental illness. If we conservatively assume that for each of these individuals there will be five family members, friends or colleagues directly impacted then we are looking at more than four million Australians who are directly affected by severe mental illness in a given year.

We also know that social isolation in people with severe mental illness is common and has a significant impact on their wellbeing, recovery and community participation. Social isolation can be a result of the symptoms of many severe mental illnesses as well as a consequence of the associated stigma, disadvantage and social exclusion that people with severe mental illness can face1. Social isolation is further increased for those who are geographically isolated.

While a proportion of people with severe mental illness withdraw from others as a way of managing symptoms such as poor energy and low self-worth, many more desire connections with others. According to the 2007 Australian National Survey of Mental Health and Wellbeing, more than half the respondents with severe mental illness noted that they needed 'good friends'.

By providing emotional support, companionship and opportunities for meaningful social engagement, social networks have an influence on self-esteem, coping effectiveness, distress and sense of wellbeing for people with severe mental illness2. Information, advocacy, supports and services for people affected by severe mental illness have been identified by the National Mental Health Commission as patchy.

Only a limited number of organisations, such as SANE Australia, offer the level of support, advice and information needed to effectively support the large number of Australians affected by severe mental illness. Furthermore, while there have been major investments in recent years to reduce stigma and discrimination for the mild to moderate mental illnesses, there has been no concerted national effort to reduce stigma and discrimination for people living with a severe mental illness along with their carers.

Social isolation increases in regional, rural and remote areas of Australia, where issues in mental health are compounded by reduced availability of services and supports and increased stigma – barriers that mean people are not accessing, or are unable to access, face-to-face support.

…

In May 2014 SANE Australia launched the beta version of SANE Forums http://saneforums.org an online Consumer and Carer Community Forum for all Australians affected by mental health issues.[1]. The service acts as a point of connection with others, enabling peer-to-peer support, access to information, advice and referrals. It embraces an approach that is based on the wisdom of the lived experiences of consumers and carers as well as clinical-based input. In the forums, community members are recognized as the experts of their lives. Through contributing the Forums they can share and draw upon each other experiences to form the shared creation of community knowledge. In this sense, the SANE Forums are *created by the community for the community*. The Forums are anonymous, moderated by health professionals, and has an established set of Community Guidelines to ensure that the service is a safe and respectful environment to users who visit and contribute to the community. To the best of our knowledge, no other service exists, which is a peer-to-peer and non-diagnosis specific forum for adults within Australia. Therefore, the establishment of SANE Forums sought to address this gap and increase access to peer support for people affected by mental health issues in metropolitan, regional and remote Australia.

In addition, to enhance service provision within the mental health sector, SANE has developed a unique and innovative partnership model where mental health organisations work collaboratively to deliver the Forums. To do this, SANE shares the Forums with partner organisations, embedding the service within their websites. In return, partners have the option to provide resources for moderation and information for members. Subsequently, the Forums are not only accessible via SANE's website, but through multiple websites belonging to our partner organisations. At the time of writing, the SANE Forums had total of 35 partner organisations (http://saneforums-access.org/t5/custom/page/page-id/Forum-Access) located in different states and territories throughout the nation. The sharing of resources creates an extensive service reach throughout the nation, while also giving community members access to quality information and peer-support.

The Forums are accessible and moderated on a 24 hours basis.
They have two primary purposes:

1.) To increase access to peer-support for all Australian affected by mental health issues.
2.) To enhance service provision within the Australian Mental Health sector

Mental Health outcomes and Online Peer Support

There is a growing body of evidence that indicates that peer-to-peer, and online mental health support (e-mental health) may generate beneficial mental health outcomes. Peer-to-peer models suggest that being part of a community of individuals going through a similar experience can help participants to understand their own experience and to feel less alone. Participants may also gain hope through the experiences of others and find useful role models among other members. In the case

---

[1] This beta release was to be followed by an official launch in August 2014

of mental health support groups, interaction with other members may improve social functioning, while actively helping one another and exchanging resources can empower participants and improve self-efficacy (Davidson et al., 1999). Hope, social support, empowerment and self-management are all important elements of recovery models for mental health (Australian Health Ministers' Advisory Council, 2013).

Peer support remains a largely untapped resource across the community.
Peer support "is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships."[2]

Peer support offers many benefits, for example: shared identity and acceptance, increased self confidence, the value of helping others, developing and sharing skills, improved mental health, emotional resilience and wellbeing, information and signposting, challenging stigma and discrimination.

Peer support plays a role in building capacity within local communities and is an important adjunct to other supports and services for people with complex mental illness. While there are numerous successful peer support programs being run in organisations across Australia which offer face-to-face support, there are very few equivalent online services.

The online environment provides an opportunity to expand the reach of peer-to-peer support. Online forums can be cost-effective to the provider and offer an alternative for consumers and carers who are unable or unwilling to access face-to-face peer support groups. Participants can access social support and practical advice in between professional visits or while awaiting treatment for the first time. Those who are not involved in mainstream mental health services have access to an additional alternative.

Recent research has evaluated the effectiveness of online communities in achieving the outcomes reported in face-to-face peer-to-peer support groups. While this research is in it's early stages, a systematic review by Griffiths and others (2009) identified a number of studies in which membership in internet support groups was associated with reduced depressive symptoms. A randomised control trial by the same researchers provided further evidence for the effectiveness of internet support groups in reducing depression (K. M. M. Griffiths, Andrew J.; Crisp, Dimity A.; Christensen, Helen; Bennet, Kylie; Farrer, Louise, 2012).

---

[2] Mead, S., Hilton, D., Curtis, L. Peer support: A theoretical perspective. PsychiatrRehabilJ. 2001 Fall;25(2):134-41.

SANE's online community development is guided by a unique participatory and partnership model, which seeks to gain extensive reach across Australia to substantially increase access to peer support for people affected by mental illness. It uses sophisticated technologies that disseminate the Forums via multiple websites that belong to a growing number of mental health organisations working collaboratively with SANE. Within the Forums, anonymity is secured, and moderation is provided, creating safe spaces for peer-to-peer (P2P) support for carers and people with lived experiences. At its core, the Forums are guided by users for users, where all developments are informed by their experiences and feedback, including the website architecture, content generation, and evaluation processes. This ideally positions SANE to further examine the potential role of P2P online communities for users and mental health services.

Since the launch of SANE Forums, two strong online communities have grown enjoying over 1 million page views by 116,000 unique visitors since the first community went live in May 2014. There are now approx. 3,000 members, and 45,000 comments have been posted on the two communities.

Regional and remote community support

Where most of the membership of the service lives in metropolitan areas, a significant and growing number from regional and remote areas of Australia are also using the service.

In 2015, the National Rural Health Alliance reported that people living in regional, rural and remote areas of Australia are 20 per cent less likely to access mental health services than their counterparts in the major cities. They are also less likely to have consulted a psychologist, with twice as many people accessing these services in major metropolitan areas.[3] Also in 2015, SANE conducted 'Outback Voices', an online focus group with SANE online forum members who identified themselves as living in these areas. The aim of the research was to explore the experiences and difficulties encountered living in rural and remote communities, and in doing so, understand what motivates, or deters regional, rural, and remote residents to access online peer support.

This research found that the members use the forums to address social isolation that arises as a result of geographic location. Primarily, the research found that these members use the forums to:
  • maintain their privacy and reduce a sense of stigma by connecting with others who can normalize living with mental illness
  • bridge the gap between appointments, which were hard to access due to lack of resources in their communities or their own financial resources

---

[3] Mental Health in Rural and Remote Australia, 2015, National Rural Health Alliance Inc., viewed 29 January 2016, <http://www.ruralhealth.org.au/factsheets/thumbs>

- give and receive support to and from peers who have had similar experiences, something which they infrequently encounter within their own communities
- practice their social skills for offline interactions.

The research was presented in a paper that was peer reviewed and showcased at the 7th Annual Australian Rural and Remote Mental Health Symposium.[4]

Importantly, 27% of members using the forums identify as being from regional, rural and remote areas. While this aligns closely with the overall urban/regional population split nationally it contrasts markedly with the split for accessing mental services where the regional, rural and remote share is far lower.

This result is also strikingly consistent with the view expressed by the NMHC in its 2014 Review where it concluded "access to services for people in rural and remote areas can be improved by wider use of technology." It should also be noted that contributing factors for the forums achieving such an impressive reach in regional and rural Australia are likely to be the platform having many partners which have a footprint in regional and rural areas, combined with media coverage of the Forums generated by SANE (predominantly through ABC regional radio).

2. Evidence of innovation and/or recognised best practice.

Human-centred design

SANE Forums - http://saneforums.org - has been designed utilising human-centred and participatory design to ensure inclusion of people with lived experience. This approach closely aligns with international standards on the design of interactive systems.[5]

The human-centred design approach facilitated SANE in adopting an inbuilt learning cycle in the design process. This involved an iterative cycle of research, concept development, design and testing that included specialist design and technical resources in addition to consumers and carers – via interview, feedback and participatory work-shopping, in addition to usability testing. This helped SANE to identify potential difficulties whilst helping carefully tailor features, functionality, our Duty of Care and approach to moderation and other elements, in response to the needs of users of the service.

---

[4] Baylosis, C., Isolated connections: Re-writing the self and social support within online communities, SANE Australia, 2015.
[5] (**ISO 9241-210:2010** Ergonomics of human-system interaction -- Part 210: Human-centred design for interactive systems
http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075)

The human-centred approach led the design team at SANE to understand the difficulties the community experiences associated with the fragmented and disparate nature of mental health services. This, combined with factors such as a generally underfunded sector (particularly in terms of technology and technology skills), SANE's historical role in helping build sector capability, and the opportunities provided by the technology we had chosen, led us to the partnership and syndication model.

Sector Partnerships – working to the sector's natural instinct to cooperate

The partnership-syndication model that emerged from our user experience research allows individuals in the community to discover and participate in SANE Forums via a trusted context of a not-for-profit mental health organisation they are already familiar with. With 35 partners and growing (see footnote for full partner list and access to their versions of the service)[6], this has extended the reach of SANE Forums to potentially hundreds of thousands more individuals predisposed to accessing services online, than otherwise.
(See: http://saneforums-access.org/t5/custom/page/page-id/Forum-Access for a full list of partners currently live with the service. You can also click through from here).

Early partners including MIFA, Mind Australia, and ARAFMI also helped with refining the service concepts with their feedback.

The partner-and-syndicate model has also had many collateral benefits. Taken together they demonstrate a highly innovative, world-first approach to the provision of online services by the mental health sector:

- Between 79% and 82% of users are obtaining the intended benefits of the service[7]
- Approx. 30% of service traffic (over 1 million page views since going live, 3,000 members, 45,000 comments, and 116,000 unique visitors) has come in through partner websites
- The service is free of charge to partners in return for a contribution of hours and/or expertise into the pool of moderators, thus increasing the specialist advice available via the forums. We now have a pool of 70 such moderators, with expertise covering all high and low prevalence mental illnesses and a wide range of support programs
- Organisations in a chronically underfunded sector are able to leverage expensive world-class technology, pooling efforts and expertise, and growing capability
- Public funding has been used in an exceptionally cost effective way. To replicate the service SANE has built, each current partner organisation would

---

[7] See the summary of the first evaluation of the service attached in the Appendix of Support Material – 'SANE Australia Research Bulletin 19' – for details

have needed to spend $1.3mil (the initial grant to SANE from the Australian Department of Health). With 35 partners, that amounts to over $45 Mil in avoided costs to the community for the same result.

A further, important partnership to note, was that made possible by the history of the CEO of our organisation and the Inspire Foundation/ReachOut. The common CEO and also similar focus but different target demographic of SANE (adults) and Reachout (youth) provided an amenable circumstance where the SANE design team were able to approach Reachout for learning and materials they had developed over the course of 10 years of running their own online community. This led to great early insights into community management in particular, which provided a significant boon to SANE forums early development.

Technical and design partnerships

SANE engaged a resource with specialist expertise in the design and delivery of user-centred online interactive services. This resource then helped SANE identify and build key relationships with several technology and technology service, as well as digital design providers.

These partnerships were more than fee for service relationships. They involved low-bono contributions from the providers. They also involved a great deal more latitude in the pursuit of service quality than regular commercial contracts typically allow.

These partnerships were a critical element in SANE's ability to innovate in the design and development of the services at the technical level. Lithium Technologies allowed SANE to syndicate the service in a way it does not typically support either technically or from a business perspective. Isobar Sydney helped us find visual expression for our templates and wireframes. And Snaffle, a Melbourne based digital development firm, threw everything they had at making this service the best it could be for the community.

Technology

SANE Forums is built on the Lithium Community Platform, a high-end cloud based technical platform supporting communities for major organisations and corporations throughout the world (See: http://www.lithium.com/)

That said, the particular implementation of the Lithium Community that SANE has delivered involved not just configuration but a complex build, to support the partnership and syndication model.

In addition, SANE developed:

- Desktop and mobile versions of the forums for SANE, and for all partners

- A function whereby tagged discussions from the forums are pulled into the SANE website in the Facts and Guides area, to enable serendipitous discovery of the existence of the communities. See https://www.sane.org/mental-health-and-illness/facts-and-guides/borderline-personality-disorder for an example
- SANE, and partner-organisation specific content is provided in the right-hand modules of the forum pages. See http://mindaustralia.saneforums.org/t5/Our-experience-stories/bd-p/le-forum-0001 for an example
- Application of a third party technology, Inbenta, to pull out highly granular views of conversation data from the service. With 45,000 comments from metropolitan, regional and remote Australia, this data will form a new evidentiary basis from which SANE intends to extract numerous reports to assist in improvements in service delivery by the mental health sector and government

Nothing like SANE Forums is know to exist anywhere else in the world, in terms of the service's syndication and partnership model. Taken together, the human-centred approach that involved consumers and carers, combined with SANE's efforts to build mental health sector and commercial (technical) partnerships, led by suitably skilled resources, opened up a necessary path of innovation – to meet the specific and particular needs of these two new online peer-to-peer support communities.

3. Evidence of participation of mental health consumers, in the planning, implementation and evaluation as relevant.

As mentioned above, SANE involved consumers and carers in the design of SANE Forums. This occurred at the planning, implementation and (ongoing at the) evaluation stages via the human-centred design approach taken by the SANE design team.

Activities included:
- Interviews with consumers and carers, individually and in groups
- Contextual inquiry with consumers and carers in five Australian states, with a mix of metropolitan, regional and remote
- Interviews with remote community Aboriginal and Aboriginal support community workers
- Participatory workshops with consumers and carers, on service structure, nomenclature, information architecture, and interface elements
- Concept testing (consumers, carers and partners)
- Iterative formative design testing (consumers, carers and partners)
- Usability testing (consumers, carers)
- Community seed and early beta groups, 40 individuals for the Carers Forum and 90 individuals for the Lived Experience Forum participated in initial 2 week forum beta testing. This enabled discussion to flow whilst allowing for technical and usability kinks to be ironed out, resulting in fully functional and well-populated services being released to the open community
- Structured community responses to evaluation surveys

4. Evidence of Partnerships and Linkages (collaboration for continuity between organisations).

Please information about partnerships and the innovative collaboration model that SANE has developed, in Section 2, 'Evidence of Innovation' section of this application.

5. Verification and evaluation of the program's effectiveness

Beyond user experience research and user testing, SANE Forums have been evaluated for the period 2014-15, and is currently undergoing an evaluation for 2015-16.

Results of the first evaluation are included in the **Appendix** to this application.

A high-level summary of benefits identified by the evaluation is as follows:

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.

Referees

Removed for privacy

Appendix

Please see the document: 'ForumsEvalSummary.pdf' submitted with this information ('SANE Research Bulletin 19').

Research Bulletin 19

SANE AUSTRALIA

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 registered 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.

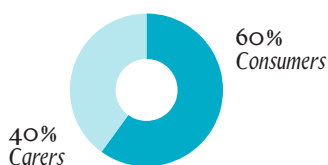## How do family and other carers use the Forums?

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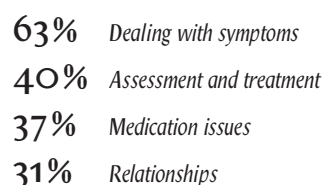
In contrast to consumers, the top-ranking purpose for starting a discussion was information and advice-seeking (50%), followed by sharing stories (40%) and seeking similar experiences (30%).

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.
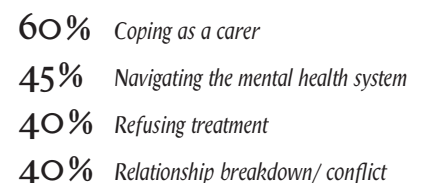
Forums users

- **60% Consumers**
- **40% Carers**

Lived Experience: Topics discussed

- **63%** *Dealing with symptoms*
- **40%** *Assessment and treatment*
- **37%** *Medication issues*
- **31%** *Relationships*

Carers: Topics discussed

- **60%** *Coping as a carer*
- **45%** *Navigating the mental health system*
- **40%** *Refusing treatment*
- **40%** *Relationship breakdown/ conflict*

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

18% *Practical support*
2% *Other*
80% *Bonding*

Carers: Responses

24% *Other*
31% *Practical support*
43% *Bonding*

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.*

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
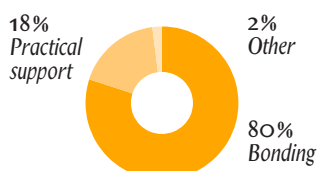- Enhance data collection and analysis.

SANE Australia

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