Online Forums 2015

A Research Report for beyondblue
24th July 2015
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EXECUTIVE SUMMARY

This mixed method qualitative and quantitative research project demonstrates that beyondblue’s online forums are playing an important role in the lives of a number of people with depression, anxiety and other mental health conditions.

It is important to acknowledge that forums are not an avenue of support that everyone will embrace, and moreover that it is not possible to please everyone with the same set of policies and practices – some may want the freedom to discuss certain topics on the forum that would prove highly distressing for others, for example. But on the whole, our findings show that over half of those who’ve been diagnosed with depression and nearly seven in ten of those diagnosed with anxiety feel better following participation in the beyondblue forums, in particular by gaining practical information on conditions, tips and coping strategies, as well as anonymous emotional support.

“The online forum is ideal for someone like myself as I often feel isolated. I know that I can get online and read other people’s stories and feel more connected. It’s reassuring knowing that I can use the forum during times when the support of my psychiatrist, counsellor & MH case manager are not available.” (qualitative research participant)

With regard to policies and practices, beyondblue’s online forums are described by some community champions and forum participants² as frontrunners in their field. The tone of the forums is considered to be uniquely positive and hopeful, and the after-hours moderator and community champion roles were seen to bring a significant benefit to the beyondblue forums compared to the competition.

Through moderation, at risk users are identified quickly, content which may be particularly distressing to other users is removed (or not uploaded in the first place), and other posts are uploaded to the forum in a timely manner. Community champions contribute substantially to the overall positive and encouraging atmosphere: they use their own stories to connect with people, make effort to connect with new people and those who might not otherwise get a response, and particularly encourage people to access professional help.

A key question around online forum usage, for which an answer was sought in this research, was whether or not participation helped people to move forwards on their recovery journey. This research had three indications of the positive role beyondblue’s forums are playing in people’s lives, in the areas of:

- How depressed or anxious they felt before and after logging on… with 51% of people feeling better after access.
- Access to other avenues of help and support… 41% claim that they have contacted a health professional as a direct result of using the forums.

² In qualitative research discussions
Lifestyle changes… with 57% indicating that they have made some sort of positive lifestyle change such as diet, meditation or exercise, again as a direct result of using the forums.

“Forums are a great place for people to start. I found that I had no idea where to turn to for help - I only knew that the feelings that I had weren’t "normal". I found it extremely difficult to actually "talk" to somebody – either face to face or over the phone. I wondered if my feelings were actually "severe" enough to warrant help, or was I overreacting to something; would I be fobbed off? The forum enabled me to air my feelings; to reach out to others whilst maintaining my anonymity - I had not yet built up the courage to share my feelings with my loved ones or friends, and wanted it to stay that way until I could come to grips with myself. After I tentatively submitted my first forum post, I was surprised at how many people were supportive, encouraging and willing to offer advice and suggestions. It was through this that I was able to take the next step and find a GP who would be able to help me through the journey. The beyondblue website was invaluable in this area with their list of GPs who specialise in depression and mental illness. If it wasn’t for the forum, I doubt if I would have taken that step, and I shudder to think where I would be at now, had I not had the benefit of it.” (qualitative research participant)

“Lots of people do encourage each other to seek professional help, or to try again if they’ve had a bad experience. It can get people to that point of being willing to give it a go.” (after-hours moderator)

However, for a small but significant proportion of users (15%) the forums have had a ‘poor’ impact on their lives, and for 9%, their last interaction with beyondblue forums left them feeling worse. It is important to acknowledge that these numbers are small, and that other research has shown that some people with experience of mental illness feel worse after consulting health professionals².

Research also identifies a number of gaps between what people were looking for when accessing the forums, as compared to what they perceived that they had actually gained. Suggested improvements to the forums aimed at reducing these gaps, as well as current policies which will be important to continue with, have been detailed in the Discussion section of this report. Particular areas for consideration are: how to ensure that all posts are responded to in a timely manner, and; how to deal with potentially distressing content; particular areas for innovation are around the inclusion of clinical volunteers and moderator responses, and the development of an app to allow for easier and more personalised participation.

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² e.g. Lambert, M. (2007). What we have learned from a decade of research aimed at improving psychotherapy outcome in routine care. Psychotherapy Research, 17, page 1
Background

beyondblue’s online forums, hosted on the beyondblue website, have grown over the past 18 months into a significant platform for discussion of depression, anxiety and other related life issues.

Around 40,000 people a month visit the forums, making up 20% of all unique visitors to the beyondblue website (up from 10% a year ago). An average of 2,500 posts are made per month, with around 4 posts per day touching on themes of self-harm or suicide.

The forums are moderated by a team of people including a community manager and clinically-trained moderators for content where the user is assessed to be at risk. Users at risk receive an email from the clinically-trained moderator with counselling advice and referrals tailored to their specific situation. Also working in the forums on a volunteer basis are nine "community champions", who work closely with the community manager to provide peer support online and ensure that members of the forums receive replies to their posts.

While some contact information is held by beyondblue, the forums themselves are an anonymous space and users post using pseudonyms. Personal contact is not allowed, nor is sharing of details around specific medications, and details of suicide and self-harming methods.

Discussions take place in a range of categories. Besides general posting categories for depression and anxiety, there are also categories for supporting friends and family, recovery and staying well, and treatments. Subject areas are also used, including grief and loss, separation, and employment.

Requirement for research

A literature review undertaken by beyondblue in September 2014 concluded that there is currently little information or research on the mental health benefits of online depression and anxiety forums. Information that was available was not of sufficient depth or breadth to guide practice or policy decisions.

Members of the forums had mentioned a number of different reasons for joining, but beyondblue lacked any formal concrete information about:

- What users hope to obtain from the forums.
- Whether the forums are achieving the stated aim of creating a place where members can find encouragement, hope and a sense of belonging.
- Whether the forums are helping people to move forward in their recovery journey.
Given this dearth of available information, beyondblue commissioned independent social and market research agency Hall & Partners | Open Mind to conduct specific research into the forums as a recovery tool.

Research objectives

The research program was primarily designed to **gather detailed user feedback to help beyondblue optimise the content, structure and functionality** of the forums.

The program **covered a number of key research questions** using a mixed methods design, and will continue with two additional quantitative tracking phases that will allow us to monitor differences arising from several planned and mooted changes to the way that forums will operate over the course of 2015, and understand trends in the evolution of the forum.

Among the specific questions the research sought to answer were:

- Who uses the forums: basic demographic information such as gender, age, location
- Reasons people start (and continue) to use the forums
- What they are hoping to achieve from using the forums
- What role the forums play in their lives (e.g. ongoing or at specific points)
- How much support they obtain from the forums and how this works in conjunction with other support mechanisms e.g. psychologist, medication, face-to-face peer support, other websites, etc.
- Usefulness of the personalised emails sent by the clinical moderators
- Overall advantages and disadvantages of using the beyondblue forums
- Suggestions for improvement and enhancement of forum experiences

In addition, the Sense of Community Index developed by Macmillan and Chavis (1986) was adapted into an index relevant specifically for these online forums. The Sense of Community Index (SCI) is the most frequently used quantitative measure of sense of community in the social sciences. It has been used in numerous studies covering different cultures in North and South America, Asia, Middle East, as well as many contexts (e.g. urban, suburban, rural, tribal, workplaces, schools, universities, recreational clubs, internet communities, etc.).

Research methodology

This is the first phase of a broader research program, and included both a qualitative section – content analysis, a series of interviews with ‘community champions’ and moderators, and a 3-day online

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3 www.communityscience.com
bulletin board with up to 30 forum participants – and a quantitative section – an online survey with forum participants.

**Phase 1 Research Process**

**Qualitative Methodologies**

The qualitative methodologies in phase 1 were used for a number of different purposes: understanding usage behaviours, needs and motivations, exploring suggestions for improvement in the offering, and development of the dimensions to measure and test in the quantitative phase.

1. **7 x 30 minute telephone depth interviews with community managers, champions and moderators** (*1 x community manager; 4 x community champions; 2 x after-hours moderators)*

   Community champions and clinically-trained after-hours moderators provided a broad range of insights that helped us highlight areas for further exploration with end-users. Their experience both with users of the system and the system itself also offered direct suggestions for improvements in the way the forums work.

2. **Extended, 3-day moderated online discussion board with up to 30 forum participants**

   30 participants from the *beyondblue* online forums were invited to join our discussion boards via an invitation on the website and personal emails obtained from *beyondblue*. This covered their experience with the *beyondblue* forums, drivers and barriers to using the forums, nature of support gained, usefulness of clinical moderators’ advice and emails, deep dives into content, structure and functionality, spontaneous suggestions and response to suggestions for improvement made by moderators and community champions.

   A broad mix of participants were recruited for the study:
• Activity with the beyondblue online forums
  o 15 active participants: had posted at least once in the 30 days prior
  o 8 ‘lurkers’: had read a post/logged in over the 30 days prior but had never posted
  o 7 inactive participants: had logged in at least once in the 6 months prior and posted at least once in their lifetime but not in the past 3 months

• Gender: even split
• Ages: broad spread from 18-60
• States: broad mix

In addition, we conducted one telephone interview with a person who was keen to participate on the discussion board, but was not eligible due to the fact that they worked with disadvantaged children (it was considered that people who work in certain spheres should not be included in the online group discussion, as such work might mean they have a higher tolerance for certain topics, which could risk skewing our results).

Content Analysis
N=7,926 posts from January 2014, July 2014 and January 2015 were analysed and coded by sentiment, nature of post and content of post.

Quantitative Methodology
Online survey

N=597 participants completed a 20 minute online survey – the survey invitation was sent out to people who have registered to join the beyondblue forums. The only specifications to be eligible to complete the survey were that all participants had to be over 18, resident in Australia, and had used at least one of the forums to read or post (since otherwise the majority of the survey questions would not be relevant to them).

Participation in the survey was completely voluntary. The survey was carried out in compliance with the Australian Privacy Principles, and participants were assured that their individual responses were treated in the strictest confidence.

Two further tracking phases will be conducted in September 2015 and March 2016.

Strengths and limitations of the methodology

Strengths of the methodology

An online methodology was chosen for qualitative and quantitative research (rather than face-to-face or phone) for several reasons. Firstly, it was seen to be a methodology that the large majority of
participants would feel comfortable with, given that the beyondblue forums themselves are online. It was intended to maximise participation and participant comfort levels by allowing people to complete the qualitative or quantitative survey in their own time, in their own home or at any other location of their choosing. Both qualitative and quantitative online methodologies allowed for participant anonymity; although the qualitative forum was conversational (whereas the quantitative one was completely individual), participants were encouraged to use a different pseudonym from the one they used on the beyondblue forums, and not to reveal personal information that they would not feel comfortable sharing with a stranger.

In addition, the qualitative forum required participants to sign up to a code of conduct, similar to beyondblue’s own code of conduct, before starting. In order to ensure a positive experience for all participants in the qualitative and quantitative research, only those who had not had a post of theirs flagged as ‘at risk’ in the past were contacted about the research. The qualitative forum posts were monitored on an ongoing basis (though not overnight) and beyondblue team were available to be consulted about whether editing or private response was required to any post.

The requirement for people to share their views and opinions with others each day was clearly outlined in the qualitative recruitment process; it was also made clear that people could drop out at any time during the process if they so desired, and this was also the case with the quantitative survey.

Limitations of the methodology

Participation in both qualitative and quantitative research is self-selecting – though this is not an issue specific to online methodologies. However, allowing the survey to run for several weeks increases the chances of representative participation; this is especially important when surveying those who may have depression or anxiety conditions, which may mean that they do not feel up to completing a survey at one point in time, but may be keen at another point in time.

As beyondblue does not have demographic detail on the forum users, it is not possible to map the demographics of the quantitative survey participants back against this to compare or weight; we can only map the demographics of the survey participants back to those of the population as a whole, or to other studies on forum participants.

While screenouts were limited as far as possible in the questionnaire, it was considered advisable from an ethical perspective to survey only those who were over 18, which meant that the views of younger participants were missed (approximately 5% of those who logged onto the quantitative survey).

The fact that the quantitative survey is a self-completion exercise means there is no scope for clarification on any point; the qualitative component was included in part to address this limitation. In addition, online survey methodologies give the researcher no control over participant understanding of questions – however, running the qualitative forum first helped to ensure that the correct language
was used in the quantitative questionnaire. Online survey methodologies may also offer less scope than face-to-face for exploring spontaneous recall and awareness, but this was not the objective of this study.

The inclusion in the qualitative and quantitative research of only those who had never had a post flagged as ‘at risk’ in the past can be considered a limitation, in that the views a section of forum users were not canvassed in the research; as explained above, this decision was taken to ensure all participants had a safe and comfortable experience. Content analysis included all posts accepted for publication to the forum.

Our contact database for the research only included those who have actually signed up to the forums. We would note that it is not necessary for someone to sign up in order to use the forums, if they are only reading rather than posting or commenting; therefore it is not possible to draw conclusions about how the forums are used as a whole, but only on how they are used by those who have signed up. A pop-up survey link on the forums could have captured some of these other users, but this would have created other issues (e.g. the risk of some people completing the survey more than once).

As beyondblue forum members can choose to opt in for marketing contact, and only those who opted in were contacted for this survey, there was limited risk of disturbing people who did not wish to hear from beyondblue. However, there is a section of the beyondblue community who had not opted in for contact because the option did not exist at the time they signed up, and therefore were not able to be contacted for this research.

Finally we would note that allocating sentiment in coding proved difficult. Posts can contain both positive and negative sentiments even within one sentence – for example, they may tell a very sad personal story but with the intention from the poster of showing that they have been through what the person is going through, i.e. offering encouragement and hope for the future.
FINDINGS

1. Champions, Moderators, and their view and vision for the forums

The initial phase of research involved speaking to the community manager, community champions and after-hours moderators. These are some of the people charged with ultimate responsibility for forum tone and content, and spend a substantial amount of time on the forums (champions) or dealing with forum posts.

1.1 Community Champions

Who are they?
Community champions work in the forums on a volunteer basis, working closely with the community manager to provide peer support online and ensure that members of the forums receive replies to their posts. This role was developed in the past year by the Community manager, by identifying certain regular participants with positive and helpful behaviours, and contacting them directly to seek their assistance in running the forums. At the time of research there were five community champions; this number has since grown to nine.

As such, community champions are not very different from regular forum users – they are likely to have past or ongoing experience with depression and anxiety themselves and can talk very much from a user’s perspective. The key differences between them and the regular users are:

- **Forum contribution**... The champions spend many hours on the forums reading and responding to posts; this is part of the behaviour that earmarked them for championship status in the first place, and is likely to have been reinforced and encouraged due to that status.

- **Behind the scenes knowledge**... They have some insight into the community manager’s goal for the forums, and are consulted on certain issues. They are able to interact with each other, for example to let the rest of the team know if they need to be offline for a few days.

- **Emotional connection**... The very fact that they have been acknowledged for their contributions and awarded with community champion status has enhanced their connection with the forums to some degree.

At the time research was conducted, community champions were not identified as such within the forums (i.e. they did not have a ‘badge’); other users were not aware that the role of community champion existed, although they may have noticed the champions as particularly helpful or regular posters.

*Their perspective on the forums*
Community champions are passionate about the forums – they strongly believe that the forums offer a platform to help people, and want to do whatever is in their power to assist with this. Champions contribute to an overall positive and encouraging atmosphere: they use their own stories to connect
with people, make the effort to connect with new people and those who might not otherwise get a response, and encourage people to access professional help (including when a certain thread may be more negative about mental health professionals). In addition, dealing with issues via peer-to-peer interaction where possible is seen as ideal, versus a moderator having to step in.

“The addition of community champions helps keep that [hopeful, positive] tone and energy. We help to give the answers, we help to try to balance the energy and provide hope and positivity. That is why I am such a regular contributor to beyondblue and stayed long after I needed any real help.” (community champion)

“The champions are a huge improvement… it avoids the moderators appearing overbearing” (after-hours moderator)

1.2 After-hours moderators

Who are they?
Clinically-trained after-hours moderators, both of whom were occupational therapists by profession, review content of ‘flagged’ posts, where the system has indicated that the poster may be at risk (due to mention of specific words) or in breach of the forum rules (e.g. by mentioning specific medications). High risk posts are held, and dealt with separately by Medibank Private; medium risk posts and low risk posts from first-time users are held and reviewed by the moderators, and low risk posts from other users are allowed through but flagged and can be taken down by the moderators. Moderators review the flagged posts and may either: allow them through; edit the post and allow it through; or not allow the post and potentially escalate it. Posters may receive an email from the moderator with counselling advice and referrals tailored to their specific situation, or with information on why their post has been edited, or suggestions for how to change it themselves. While a template exists, moderators prefer to adapt it to seem more personal, and put careful thought into how to deal with each post.

“I don’t want to sound like a robot, especially if someone has received a few emails from us” (after-hours moderator)

“With smaller edits, I tell them it’s how the system works, not them personally … with larger edits, I don’t want to change it so it’s not their story, so sometimes I reject it and suggest to them how they could change it so it’s OK” (after-hours moderator)

Moderators typically spend three hours per day on weekends and public holidays, reviewing between 20 and 40 flagged posts per day.

Their perspective on the forums
Because of their limited interaction with forum content through the dashboard system, the after-hours moderators did not feel that they were able to provide insight into the forums more broadly e.g. in terms
of how or why people might use them, or what they might gain from them; however, they did feel that forums provide a platform for people who are struggling or have received a new diagnosis to ask questions or access support, and for those with recurring conditions to be able to feel a sense of connection and not feel alone, perhaps especially those with anxiety conditions.

By contrast, the after-hours moderators are well-placed to comment on the safety processes in place to identify at-risk users and prevent distressing or inappropriate content from reaching the forums and affecting others. These processes are considered to be highly effective – the dashboard system is seen to be identifying the right posts, and the after-hours process means that (a) at risk people can be contacted quickly, (b) users are protected from particularly distressing or inappropriate content, and (c) posts can be uploaded to the forum with minimal delays. This type of moderation is considered to be best practice on mental health forums.

“The moderation is a significant difference compared to other forums of this sort” (after-hours moderator)

“The risk of negative impact comes where forums haven’t been moderated well. Our team is working well and the dashboard is so refined.” (after-hours moderator)

Moderators agreed that the platform has a role in encouraging people to seek professional help, and that the champions in particular are good at doing so. They did note that there was occasionally a thread which was more negative about professionals – which is potentially discouraging – but it is felt that the champions do their best to address such comments with their own personal narratives.

In addition, the platform can be used to improve mental health literacy and understanding; for example if someone writes something unhelpful or incorrect, champions and moderators can address this.

The issue of distressing posts is a tricky one, as it is seen to be important that people are able to tell their story and seek help, even though some other users may feel upset by reading them (27% of users stated that they feel this way, as seen and discussed in Figure 26). While moderators can edit posts, there is a reluctance to do this unless really necessary, as it is seen as removing or sanitising a part of the user’s reality.

However, there is general agreement from moderators, champions and users that repeat posts on the same subject, without a demonstration of progress or at least an acknowledgement of support, are unhelpful, and in extreme cases some people may need to be blocked from the forums in order to benefit the broader community and to provide the impetus for them to seek further help. Overly explicit details of current or past abuse or similar are also seen to be, on balance, unhelpful to the community.
“We can tell who’s high risk, but forum users aren’t experts, and a post can scare the whole community… it’s not fair to them… they might be thinking that something bad has happened to someone if they then don’t come back online for a few days” (after-hours moderator)

Moderators shared a common vision for the future which they felt the forums were largely already meeting. The continuation of the champion program, the addition of further champions and even different levels of champions working together to mentor people and take a guiding role was considered a main part of meeting this vision. The question was posed as to how to answer the challenge of giving people a reason to remain on the forums after they have ‘got what they need’, in order to provide this mentorship and positive lived experience stories – although it was not one that the moderators could answer.

“I can’t suggest any major improvements… just keeping an eye on the overall tone, and what tone you want to create. It should be a safe place for people to express experiences and seek support.” (after-hours moderator)

“It should be a dynamic place where people can share stories and how to live their lives, but not inundated with negativity… Some people use it as a place to dump or blurt without asking for advice or listening, and that’s not helpful for the community.” (after-hours moderator)

“We don’t always need to have positive stories, but we need to create conversation and avoid drag,” (after-hours moderator)
2. Coding of forum content

2.1 Sentiment of Posts

Nearly 8,000 forum posts from January 2014 (2,679 posts), June 2014 (3,200 posts) and January 2015 (2,047 posts) were coded by sentiment.

Of the 7,926 posts coded, 5,821 were by users and 2,103 were by community champions, and analysis has been provided separately by these groups.

*Sentiment of forum postings*

![Circular chart showing sentiment analysis]

- **Positive/Hopeful/Supportive** 61%
- **Neutral** 10%
- **Negative/Hopeless/Desperate** 29%

*Figure 1: Post Sentiment*

Sentiment analysis shows that six in ten (62%) of postings are positive, hopeful and supportive, while less than a third (29%) are negative, hopeless or desperate. However, there is evidence (Figure 2) that user posts were more negative in January 2015 compared with a year previous.
Sentiment of forum postings

Figure 2: Change in user post sentiment over time

2.2 Nature or Purpose of Posts

The forum posts were also coded into a number of discrete categories by nature and content. Posts could be assigned to a number of different ‘purpose and content’ categories if they fit appropriately. Figure 3 details the results of this ‘nature of post’ (purpose) coding.
Over a quarter (28%) of user posts (and nearly half (48%) of champion posts) can be classified as offering general encouragement or support – around a third (34%) of posts on the beyondblue forums have this as their central purpose. In forum socialising (30% Users, 39% Champions) was the next most common purpose for posting, Offering practical or specific advice (17% Users, 37% Champions accounted for a little over a fifth (22%) of total forum posts.

Overall, users had on average 1.5 purposes for posting, but encouragingly only one in six (17%) posts were classified as venting, and in general, most of the forum posts can be seen to be encouraging, social or supportive. In January 2015, users were less likely to be offering encouragement or support (30% in Jan 2014 => 26% in Jan 2015) and more likely to be sharing their experiences (13% => 17%) or introducing themselves (3% => 8%) compared to a year prior.

2.3 Content of Posts

Users were most likely to be talking about mental health professionals; but depression, relationship issues, anxiety and improvement in mental health were also common themes.
In January 2015, users were more likely to be posting about professional help (25% Jan 2014 => 30% Jan 2015), depression (19%=>30%), relationships (15%=>23%) and Anxiety/OCD/Panic attacks (15%=>23%), workplace (9%=>12%), other mental illnesses (5%=>8%), non-medical remedies (3%=>8%), and addiction (3%=>8%) issues compared with January 2014. On average, users are posting about 2.44 topics on forums suggesting that they have more than one thing they want to talk about.

2.4 Demographic patterns

SEIFA (SocioEconomic Index For Areas) decile values were appended to the analysis using user postcode. These values indicate relative socio-economic advantage and disadvantage, with users living in areas in the highest decile having access to the highest levels of advantage and those in the lowest decile living in areas of economic and social disadvantage.

As Figure 5 shows, around four in ten (41%) posts come from the highest 3 deciles and a similar proportion (37%) come from the lowest 3 deciles. This leaves a fifth (22%) coming from the middle 4 deciles. This finding suggests that those with the highest incomes and lowest incomes are more likely to be contributing to the beyondblue forums with those in the middle band either not contributing or not using the forums with the same frequency.
Those in higher SEIFA deciles were significantly more likely to be posting about professional help, depression, anxiety, medications, workplace issues, stress and other mental health issues; those in the lowest three deciles were significantly more likely to be posting about relationship and family issues.

### 2.5 Classifying posts

Examining the coded data for underlying patterns reveals a ‘post typology’ (Figure 6) that shows how posts can be classified into 5 broad categories that may help moderators and champions quickly classify the type of post and identify appropriate responses, as well as helping understand the broad nature of what goes on in the forums.

[Segment 1] Around one in eleven (9%) of posts fit into the checking in or updating category, where users are checking up and socialising – the main purpose of these kinds of post is to keep in touch and check progress.

[Segment 2] About a fifth (22%) of posts could be classified as negative venting, and are significantly more likely to be posting about most of the negative content areas. Perhaps implicit in venting is a cry for help, but here the users are not explicitly stating their need, and so users who are venting may just be asking for help in a different way.

[Segment 3] One in six (16%) of posts are focused on positive practical advice, tending to emphasise solutions, such as professional help, non-medical remedies.
[Segment 4] About one in seven are about sharing to seek support and tend negative in sentiment, with a similar pattern of content to the negative venting. It may be that this style of post is a better example and better for the community than the venting type noted above, and perhaps users could be encouraged to set their thoughts out in this way rather than merely venting.

[Segment 5] Over a third (37%) of posts are positive in sentiment and with the purpose of general encouragement or in-forum socialising. These posts are most likely to be about an improvement in mental health, but have a diverse array of different content mentions.
3. Forum users

3.1 Demographics of the survey respondents

We note here that demographic information such as gender and location is not collected through forum registration. This means we are unable to be certain that the demographics of our survey respondents are perfectly reflective of the wider forum population. However, we can make some broad assumptions based on comparison with other research (where available) and ABS data.

![Forum demographics](image)

Figure 7: Survey demographics

- Over three-quarters of survey respondents (78%) are female... we note that this is slightly higher than the 70% proportion of female users documented in a previous study of 793 members of 16 online depression communities; based on our respondent breakdown plus this previous research, we feel that it is a safe assumption that a substantial proportion of beyondblue forum users are female. Within our research, we observed that some female users are using male pseudonyms on the forum, perhaps to increase their anonymity, so we would caveat that looking at user names alone is not a reliable indicator of gender.

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Almost half of survey respondents (48%) are 35-54 year olds\(^5\)... which is rather higher than the overall population, but overall there is a good spread of usage across the age categories.

The metro/regional split is almost half and half (53%/47%)... This indicates a significant regional skew, given that the actual population split in Australia is 65% metro/35% regional. However, there were no strong differences in response between metro and regional/rural respondents to any areas of the online questionnaire, including around topics such as reasons for forum use (such as anonymity), or access to other methods of support (e.g. where we might expect that regional respondents had fewer access to other services). We note that there is some propensity for regional respondents – who are also more likely to be older, retired people – to complete online surveys more generally; however this response rate is still higher than we would expect, and therefore indications are that forum usage does skew towards regional users.

The survey population is in line with population by state; but a little over represented by Victorians (24% of pop), a little under represented in NSW (32% of pop), a little under in Queensland (20% of pop) and a little over represented by South Australians (7%).\(^6\)

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\(^5\) Noting that for ethical reasons, it was decided to screen out respondents under 18 years of age.

\(^6\) ABS: 3235.0 Population by Age and Sex, Regions of Australia
• Other figures such as occupation, sexual orientation and CALD (24.6% of Australians were born overseas) appear to be roughly in line with the broader population.  

Conditions experienced by forum users

Figure 9: Survey demographics

Figure 10: Conditions experienced

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The vast majority (83%) indicated that they have been diagnosed with depression, anxiety or another condition such as bipolar or borderline personality disorder. Of the 14% who have not been diagnosed, we know that at least some of these are researching on behalf of someone else (in a personal or professional capacity), while others may suspect that they have a condition and want to know more.

Around half (50%) have been living with their condition for more than 10 years.

3.2 How users find out about the forums

How people hear about beyondblue forums

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The beyondblue website (<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>)</td>
<td>53%</td>
</tr>
<tr>
<td>From a health professional (e.g. GP, psychologist, counsellor)</td>
<td>15%</td>
</tr>
<tr>
<td>Search engine e.g. Google</td>
<td>11%</td>
</tr>
<tr>
<td>beyondblue newsletter/publication</td>
<td>7%</td>
</tr>
<tr>
<td>School / University / TAFE</td>
<td>6%</td>
</tr>
<tr>
<td>Through family/friend</td>
<td>5%</td>
</tr>
<tr>
<td>The beyondblue Support Service live online chat</td>
<td>4%</td>
</tr>
<tr>
<td>Community organisation / not for profit organisation / charity</td>
<td>3%</td>
</tr>
<tr>
<td>The beyondblue Support Service 24 hour phoneline</td>
<td>3%</td>
</tr>
<tr>
<td>Through an employer/manager/co-worker</td>
<td>3%</td>
</tr>
<tr>
<td>Another newsletter/ publication</td>
<td>2%</td>
</tr>
<tr>
<td>Local government/government department (e.g. Centrelink)</td>
<td>2%</td>
</tr>
<tr>
<td>The beyondblue Support Service email (response within 24 hours)</td>
<td>3%</td>
</tr>
<tr>
<td>Somewhere else</td>
<td>9%</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>5%</td>
</tr>
</tbody>
</table>

Figure 11: How people hear about beyondblue forums

The majority of people find out about the forums through online sources: over half (53%) learned of them from the beyondblue website, and 11% via Google (using search terms such as ‘anxiety’, ‘depression’, ‘depression help/assistance/support’ – rarely specifying forums within the search term). Facebook was also mentioned as a source of information.

Note that the questions in the Depression and Anxiety monitor differentiate between a formal diagnosis and when the user first started experiencing the condition, which means potentially that some of the users who have been living with their condition for 10+ years were undiagnosed for some or all of that time.
In-person was the next largest channel for referrals: 15% had heard about the forums via a health professional, demonstrating that some health professionals see value in forum participation for mental health; 5% through a family or friend and 3% through the workplace.

Print resources were the third most common referral source, with 7% having heard about the forums through the beyondblue newsletter, and 2% through another newsletter or publication.

Other organisations were also a small referral channel, including 6% from an educational institution, and 3% from a community organisation.

3.3 Reasons for initially accessing the forums

When our sample first accessed the forums

Within the research sample, approximately a third (32%) had been signed up for more than a year, while a slightly smaller percentage (27%) had signed up within the last three months.
Reasons for first accessing the forums

The majority of people accessing the forums for the first time are doing so in order to seek help, support or information on their own behalf. Half of users (50%) stated that they first accessed the forums because they felt depressed or anxious and wanted support. A quarter (26%) thought they might be experiencing depression and anxiety and were seeking information, highlighting an important role for the forums in terms of guiding people through the initial stages of understanding their condition. A quarter had recently received a diagnosis (24%).

A third (31%) stated that they wanted to connect in an anonymous way, and a fifth (19%) stated that they did not want to let family and friends know how they were feeling. This illustrates an important feature of the online forums in providing a reference point or outlet for those who would otherwise be less likely to engage, out of fear of judgement. As detailed later, confidence is built up and the need for non-disclosure may be broken down via continued forum participation.

"Technically the forum is my 'support group' and sometimes face to face makes me anxious. So online you can say what you feel and not feel judged and not so anxious because you don't need to put on a front [as you would] in front of people face to face." (qualitative research participant)

A smaller number of users are participating specifically in order to help others – slightly under a fifth (17%) wanted to provide help to others with the benefit of their own experience, while 13% accessed
the forums on behalf of someone close to them that they wanted to help, and a number in the ‘other reason’ category were looking to learn in a professional capacity.

3.4 How the forums are used

**Time of day**

![Time of day chart]

**Figure 14: Time of day**

The majority of people (over half, 55%) access the forums at night, between 8pm and 5am (Figure 14) – the majority of this access is between 8 pm and midnight.

**Frequency of forum access**

![Frequency of forum access chart]

**Figure 15: Frequency of forum access**

Frequency of use is highly variable. As we can see in Figure 15, one fifth of users (21%) access forums at least weekly, and another fifth (21%) fortnightly to monthly, while a further fifth (19%) accessed the forums in the past but have not done so for several months. Here the evidence is mixed: people may come to the forums at specific low points, and leave the forums when they are feeling better; conversely some community champions, for example – and we can assume others who access the forums in order to help others – cited that they may only participate in forums when they are feeling well.
What people like to do on the forums

The majority of people are what we might call ‘lurkers’ — that is, people who read but do not post. Reading posts is far and away the preferred thing to do in the forums; responding to posts made by other people is second most preferred (Figure 16). Only 8% of people preferred to start their own threads, and 33% had never made a post (Figure 25).

“Many, many nights I have just read through all the information and just tried to reassure myself that I wasn’t alone, and that if other people could deal with depression and anxiety, well then I could too!” (qualitative research participant)

“Advice may help the poster but also the person reading. When you see someone so desperate with this illness and then see an improvement, wow what a bonus. I would not like to think the forum would ever cease to exist, it is a lifeline and more.” (qualitative research participant)

The fact that people vastly prefer reading rather than contributing to posts, combined with the fact that people are much more likely to respond to a post about a topic with which they are familiar and can identify, means that posts on less common topics or less visited forums may go unanswered for a longer period of time. Qualitative research discussions with forum participants and community champions indicated that this can be very disheartening, especially for those for whom posting is more difficult or confronting in the first place – there was a general sense from this audience that no more than 24 hours should pass before a post is responded to, particularly if it is a first post or the beginning of a new thread.
Unanswered posts are already flagged for community champions but further recommendations have been made in the discussion section.

3.5 The role of forums versus other avenues of support

Forums are only part of a broader recovery journey, whether they are the initial step on this journey or accessed along the way, possibly due to recommendations from other sources. Rarely are forums the only avenue of support that users are accessing; only 6% had accessed no other avenue of support (Figure 17).

Other avenues of support accessed by users

As Figure 17 shows, most (75%) have sought help from a health professional - Figure 22 on page 34 indicates that over half of these have done so as a result of using the forums, while Figure 11 on page 24, as we have already seen, shows that a number have come the other way i.e. found out about the forums via a health professional.

Congruent with other research in this area, a majority (60%) of the younger 18-34 audience had talked to someone close to them about depression or anxiety.
4. Forum achievements and impacts

4.1 What are the forums achieving?

The stated aim of the beyondblue forums is to create a place where members can find encouragement, hope and a sense of belonging, and there is a sense that they do have a positive and hopeful tone, especially compared to other forums (on mental health topics and more broadly):

“There are a million depression and anxiety forums out there on the net and I’ve frequented a fair few briefly... Many are dens of negativity, full of endless negative posts with very little positivity. Those forums usually aren’t moderated, and you tend to get a lot of people complaining about their meds, trying to self doctor e.g. ask each other about disses (sic) and alternative drugs… I hate hate hate those forums, there’s almost no hope or positivity there, each post is answered by a sad story of someone else’s… I found beyondblue and went “thank God”… There’s a culture at beyondblue that is more hopeful, more positive. The general tone is that people come for answers and help, where as other forums they go to well, complain, honestly.” (community champion)

“I have been a part of other online forums (not for depression) and sadly personalities have clashed as everyone of course has their own opinion. Like any real life situation you can also have people with strong views or that think their way is the only way. Sometimes people can read into posts that which is not meant or take it personally and become offended starting an online argument. However I don’t feel this would happen with the beyondblue forum with good moderation as it appears to have now.” (qualitative research participant)
What users hoped to gain and actually gained

Figure 18 shows that, coming into the forums, people are looking for a mix of practical and emotional support. Almost two-thirds (61%) of people were looking to gain tips/advice on how others have coped; while approximately half are looking for factual information on conditions (49%); the ability to communicate with others who know what they are going through (48%); and the opportunity to connect in an anonymous way (47%).

“I’ve witnessed others in the forum come in feeling lost and hopeless, sharing their stories reeking of hopelessness only to have them respond after reading some of what the community has said to them with a new sense of optimism. It might not be much, but clearly it helps.” (qualitative research participant)

However, when we compare what people were looking for with what they perceived that they had actually gained, there are large gaps on all aspects, suggesting that the forums are not completely meeting users’ expectations.

Users were then asked to rank the things they felt they had actually gained from the forums, in terms of what had been most useful to them Figure 19. On the whole the order is similar to that in Figure 18, although the 24-hour availability of communication emerges as a rather stronger benefit in this ranking (with 12% ranking it as the most useful thing they had gained from the forums, and 28% of participants including it in their top three), and factual information provided was found to be more valuable than the tips and advice.
4.2 The impact of forum participation on mental health outcomes

Just as with any other support or recovery methods, the forums work better for some people than others. It is clear that participating in online forums is not for everyone – and the smaller proportion of users with more negative experiences is discussed in the following section. However, there are THREE key indicators within this research that the forums are having a beneficial effect on many users, enabling them to move forward or better manage their condition:

1. **General improvement in mood**... When describing their state of depression and anxiety before accessing the forums on the last occasion that they used them (Figure 20), 29% of people ranked themselves as ‘very depressed’ (9 or 10 out of 10) and 27% of people as ‘very anxious’. After they had used the forums, this figure fell to 13% for depression and 10% for anxiety. The figures for those ranking their depression or anxiety at a 7 or 8 out of 10 also fell after use. This is an encouraging result that indicates that the forums provide short-term relief of symptoms for a number of users.
Feelings before and after accessing the forums

<table>
<thead>
<tr>
<th>How Depressed were you feeling</th>
<th>Before accessed online forum</th>
<th>After accessed online forum</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>22%</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>18%</td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>29%</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How Anxious were you feeling</th>
<th>Before accessed online forum</th>
<th>After accessed online forum</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>22%</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>25%</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>23%</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>27%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Figure 20: Feelings before and after accessing the forums

Comparing feelings before and after forum use

![Graph showing feelings before and after forum use]

Figure 21: Comparing feelings before and after forum use

Subtracting how users felt from after using the forums from how they felt before using the forums, 51% of users said that they felt better, and 40% gave the same score for both before and after forum use (similar results across both depression and anxiety). 9% gave a lower score for how they felt after interacting with the forums; this is discussed further in the ‘Disadvantages and negative experiences’ section below.
2. **Accessing other avenues of help and support...** As we can see in Figure 22, 41% of people state they have contacted a health professional, and 33% state they have spoken to someone close to them, as a direct result of using the forums.

**Support accessed as a direct result of using forums**

![Figure 22](image)

**Figure 22: Support accessed as a direct result of using forums**

3. **Making positive lifestyle changes...** A number of other positive lifestyle changes were also attributed to being a direct result of forum usage, with over half of users (57%) saying they had made one or more lifestyle changes based on forum usage (Figure 23). This included taking more physical exercise (32%), meditation (27%), dietary changes (19%) and reduced alcohol or drug intake (16%).

**Changes users have made as a result of forum use**

![Figure 23](image)

**Figure 23: Changes users have made as a result of forum use**
In addition, 64% of people were positive about the usefulness of the forums, and 37% described the forums as having a good or very good impact on their lives (Figure 24).

**Figure 24: Rating of forum aspects**

Nearly 1 in 6 (15%) say the forums have had a poor impact on their lives – again this is discussed further in the ‘Disadvantages and negative experiences’ section below.

The usefulness of the personalised emails sent by the clinical moderators was also assessed. This email response varies depending on the nature and risk assessment of the initial post: some are simple courtesy emails when a post needs to be edited, or can’t be published; but those who are considered to be at higher risk will receive a private reply from a counsellor about their specific life situation as expressed in the post. Of those who had received an email communication of any type, more than half (56%) found it quite or very useful, and only 8% found it not at all useful (Figure 25).
Email communications as a result of forum posts

Users who have received an email as a result of a post made on a forum

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I haven’t made any posts on the forums</td>
<td>14%</td>
<td>38%</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>14%</td>
<td>33%</td>
</tr>
</tbody>
</table>

22% of users who received an email were male.

Perceived usefulness of this communication

<table>
<thead>
<tr>
<th></th>
<th>Not useful</th>
<th>A little useful</th>
<th>Okay</th>
<th>Moderately useful</th>
<th>Very useful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8%</td>
<td>33%</td>
<td>24%</td>
<td>32%</td>
<td></td>
</tr>
</tbody>
</table>

A11. Have you ever received an email communication from BeyondBlue, as a result of a post that you made on the forums?
Base: All respondents, n=602
A12. How useful did you find this email communication?
Base: Respondents who received an email as a result of the post, n=87

Figure 25: Email communications as a result of forum posts

4.3 Disadvantages and negative experiences

As mentioned above, 9% of users gave a lower score for how they felt after interacting with the forums. Demographically, these people did not differ significantly from other users. However, although what they hoped to gain from the forums was consistent with the remaining survey participants, when asked what they had gained from the forums they were significantly less likely to report that they had been able to share their experiences and offer support to others. They were also significantly more likely to report that they hadn’t used the forums for long enough to say.

In addition, as seen in Figure 24 above, 1 in 6 (15%) say the forums have had a poor impact on their lives. This group was significantly more likely to be male and to report that they hadn’t made any lifestyle changes or accessed any other forms of support as a direct result of the forums.

The qualitative research and some open-ended responses within the quantitative survey also indicated that some of these users may not be happy with the responses (or lack of) to their posts, or with a clinical moderator interjection. Some felt they were being pushed to contact mental health professionals when they simply wanted to express their emotions and receive support online. It is also clear that sometimes it is necessary to leave one person less satisfied with their experience, in order to protect others on the forum – some people want to be able to talk about the details of their past experiences or their current suicidal feelings, for example, without a filter.
Some of the negative forum experiences identified in qualitative research were then measured in the quantitative survey (Figure 26). This shows that a quarter (26%) of people agree that they have experienced a sense of anxiety when thinking about responding to posts. As one person explained:

“Unfortunately, my social anxiety/shyness tends to make me hesitate over whether or not to comment on the forum, and definitely it has stopped me from creating my own post – even when I knew deep down that reaching out to others on the forum would most likely help! That’s anxiety for you :))” (qualitative research participant)

Given the topic of the forums, and the sort of experiences that lead people to contribute to them, this may seem self-evident: for example, users experiencing social anxiety may feel unable to participate in discussions due to their condition, even if they want to, as some participants on the qualitative forum described. Further information on this benchmark will be gained from future repeat surveys.

Further, some users cite the benefits of contribution, only realised after many sessions of passively observing. For these users who have plucked up the courage to make a first-time contribution, it is especially important to be acknowledged in a timely fashion.

“I usually read what other people say without posting… but recently I started to post which I found cathartic.” (qualitative research participant)

### Negative forum experiences

<table>
<thead>
<tr>
<th>Experience</th>
<th>Disagree (0–3)</th>
<th>Neither Agree nor Disagree (4–6)</th>
<th>Agree (7–8)</th>
<th>Completely Agree (9–10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have experienced a sense of anxiety when thinking about responding to posts</td>
<td>9%</td>
<td>41%</td>
<td>24%</td>
<td>14%</td>
</tr>
<tr>
<td>Reading negative posts or posts about topics such as suicide, sexual abuse and domestic violence distress me</td>
<td>6%</td>
<td>41%</td>
<td>25%</td>
<td>16%</td>
</tr>
<tr>
<td>Some of the posts on the forum are too long to bother reading</td>
<td>8%</td>
<td>35%</td>
<td>32%</td>
<td>17%</td>
</tr>
<tr>
<td>Forums create a fear of being judged</td>
<td>7%</td>
<td>57%</td>
<td>23%</td>
<td>10%</td>
</tr>
<tr>
<td>Forums have caused me to feel more depressed/anxious by reading about the situations of others</td>
<td>5%</td>
<td>56%</td>
<td>22%</td>
<td>10%</td>
</tr>
<tr>
<td>The layout of the forum is daunting/intimidating</td>
<td>9%</td>
<td>58%</td>
<td>24%</td>
<td>6%</td>
</tr>
</tbody>
</table>

*All respondents, n=602*

**Figure 26: Negative forum experiences**

A quarter of people (27%) agree that reading negative posts distresses them, and 16% agree that forums have caused them to feel more depressed or anxious by reading about the situations of others.
This is a difficult balance to strike, because it is also clearly important that people are able to share their feelings and experiences in order to feel heard and access support. As previously mentioned, the general consensus is that repeat posts on a topic without progress or acknowledgement of others’ responses are seen to be particularly unhelpful.

A further quarter (25%) feel that some posts on the forum are too long to bother reading. This is clearly an issue where it means that some people do not get a response to their posts, or that it becomes a monologue rather than a conversation. However, we would note that some people also feel hampered by the character limit on posts; having to revise what they have written limits their freedom of expression and may cause them to become discouraged or frustrated with the process. Again, one quarter (23% - see Figure 33 later on) felt that the limit on first posts should be cut down; however we do not feel that this constitutes a mandate for limiting word length, especially since overall only 4% of people are dissatisfied with length of posts (Figure 32). Beyond this, there are also some simple improvements to forum layout and logistics which may help to diminish the gap. These are covered in Section 6 and 7 below.
5. Building a sense of community

Importance of a sense of community

A third (37%) view a sense of community on the forums as important or very important, while only one in eight (12%) would prefer not to be part of the community.

Included in the survey was a brief and edited form of the ‘Sense of Community Index’ (Figure 28), and at a general level the beyondbue forums perform quite strongly.
### Sense of community index

<table>
<thead>
<tr>
<th>Description</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>The beyondblue forums have members that help others feel welcome</td>
<td>5%</td>
<td>32%</td>
<td>44%</td>
<td>19%</td>
</tr>
<tr>
<td>The beyondblue forums create a sense of community</td>
<td>10%</td>
<td>44%</td>
<td>33%</td>
<td>12%</td>
</tr>
<tr>
<td>Participants of the beyondblue forums care about each other</td>
<td>5%</td>
<td>43%</td>
<td>40%</td>
<td>12%</td>
</tr>
<tr>
<td>I expect to be part of the beyondblue forums for a long time</td>
<td>25%</td>
<td>43%</td>
<td>21%</td>
<td>11%</td>
</tr>
<tr>
<td>I can trust people in the beyondblue forums</td>
<td>13%</td>
<td>45%</td>
<td>30%</td>
<td>11%</td>
</tr>
<tr>
<td>The beyondblue forums are successful in meeting the needs of members</td>
<td>6%</td>
<td>41%</td>
<td>43%</td>
<td>11%</td>
</tr>
<tr>
<td>When I have a problem I can talk about it with members of the beyondblue forums</td>
<td>24%</td>
<td>38%</td>
<td>28%</td>
<td>9%</td>
</tr>
<tr>
<td>I care about what the other beyondblue forum participants think of me</td>
<td>42%</td>
<td>32%</td>
<td>18%</td>
<td>9%</td>
</tr>
<tr>
<td>People in the beyondblue forums have similar needs, priorities and goals to me</td>
<td>9%</td>
<td>45%</td>
<td>38%</td>
<td>8%</td>
</tr>
<tr>
<td>I feel supported through being part of the beyondblue online forums</td>
<td>20%</td>
<td>42%</td>
<td>30%</td>
<td>8%</td>
</tr>
<tr>
<td>Being a member of the beyondblue forums helps me to deal with my depression and/or anxiety</td>
<td>20%</td>
<td>48%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>beyondblue forum members value the same things as I do</td>
<td>10%</td>
<td>49%</td>
<td>35%</td>
<td>6%</td>
</tr>
<tr>
<td>It is very important to me to be part of the beyondblue forums</td>
<td>34%</td>
<td>44%</td>
<td>16%</td>
<td>6%</td>
</tr>
<tr>
<td>Participating in the beyondblue forum is part of my identity</td>
<td>66%</td>
<td>22%</td>
<td>9%</td>
<td>2%</td>
</tr>
<tr>
<td>I have influence over what the beyondblue forum is like</td>
<td>54%</td>
<td>35%</td>
<td>9%</td>
<td>2%</td>
</tr>
<tr>
<td>I put a lot of time and effort into being a member of the beyondblue forums</td>
<td>55%</td>
<td>33%</td>
<td>10%</td>
<td>9%</td>
</tr>
</tbody>
</table>

*All B. How well do each of the following statements represent how you feel about the beyondblue forums? Base: All respondents, n=602*

**Figure 28: Sense of community index**
Nearly two-thirds (63%) felt that the forums mostly or completely have members that make others feel welcome; over half (52%) feel that forum participants care about each other. A similar proportion (54%) feel the forums are successful in meeting the needs of members, and slightly less (45%) feel they create a sense of community.

While most believe the forums either completely or mostly have members that welcome them, the largest proportion (44%) believe the forums only ‘somewhat’ create a sense of community and a similar proportion (43%) believe that members ‘somewhat’ care for each other. This pattern is evident across many of the sense of community dimensions – the forums only go so far in meeting the definition of a strong community.

Only a third (32%) mostly or completely feel that they will be part of the forums for a long time. While this is a key dimension of the original Sense of Community Index, in the specific case of online mental health forums they may well play a time-limited role in people’s lives, and many participants may look forward to a time when they no longer need to use them.

At this point in time (we note that 2 more surveys are to follow at semi-annual intervals) there is little point in providing an initial index score; we will observe if and how this changes over time.

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9 The decision was made to make minor changes to the survey questions to make sense to survey respondents in the context of the beyondblue forums. This means that it is not technically possible to compare the scores with others, only to track them over time.
6. Forum user experience

There is general satisfaction with the number of forum categories available, with almost three-quarters (70%) of people feeling that there are just the right amount of categories (Figure 29).

**beyondblue** forum categories

![Bar chart showing forum category satisfaction](image)

**Figure 29: beyondblue forum categories**

There is some demand for fewer categories, with a fifth (19%) of people feeling there are too many; so striking the balance here is clearly complex.

**Usage of specific beyondblue forums**

![Bar chart showing forum usage](image)

**Figure 30: Usage of specific forums**

A5. Which of the following beyondblue online forums have you used - whether to read or post or both?

Base: all respondents n= 602

31% of female users viewed the women’s forum

51% of male users viewed the men’s forum

Average number of forums used: 3.62
Some forum categories, such as Depression and Anxiety, are more widely used than others (Figure 30). Those participating on the less frequented forums such as Older People, Younger People, or Trauma and Chronic Illness may have a slightly different forum experience than those on the more widely used forums (for example, they may see less activity and a smaller number of different responses to posts). But at the same time, we would note that it is important for people to feel that they are connecting with people in a similar situation to them, who understand what they are going through – and therefore that these less frequented forums are nonetheless likely to be very important to their users.

Those who did request additional (or different) categories mentioned an introduction or ‘newbies’ section; Bipolar; a forum for parents; something on the topic of isolation; relationships/being single; and eating disorders. Some of the above may be addressed by a simple rewording of existing categories.

Figure 31: Topic areas most likely to read/contribute to

People were more likely to read most topics than contribute, with the exception of general venting. How to cope with emotions appears to be the most widely relevant topic, with the highest number of readers (56%) and contributors (42%).
The qualitative research indicated a strong desire for the forums to be more user-friendly in layout, in particular as regards long threads and navigation within a thread. This was not so clear-cut in the quantitative survey although we can see there is room for improvement, with users most dissatisfied with the speed of response to posts (10% of users (approximately 15% of those who have posted) dissatisfied with this aspect).

Comparing the experience of those who have posted, with those who have not
When it comes to the forum experience, we see a number of interesting differences between those who have posted and those who have not, as outlined in Tables 1-6 below. Particular points to note are:

- Those who had posted were more likely to be looking for emotional support, while those who had not posted were more likely to be looking for factual information, tips and advice (Table 1).
- Those who had posted were also more likely to feel that they had gained this emotional support, particularly in the areas of ‘ability to communicate with others who know what I’m going through’, ‘someone to talk to about how I am feeling’, and ‘being able to share my experiences and offer support to others’. Those who had not posted were indicatively more likely to say that they had gained factual information about depression/anxiety, tips/advice and encouragement to seek professional help (Table 2).
• Those who had posted were also more likely to have accessed other forums / support lines, etc. (Table 3).
• Those who had not posted were also significantly more likely to prefer not to be a part of the community (Table 4).
• Those who had posted were also significantly more likely to disagree that forums create a fear of being judged, that they have experienced a sense of anxiety when thinking about responding to posts, and that the layout of the forum is daunting/intimidating (Table 5).
• Those who had not posted were significantly more likely to disagree with the statement that ‘When I have a problem I can talk about it with members of the beyondblue forums’ (Table 6).

Table 1: A9. What are the main things you hope to gain from using the beyondblue forums?

<table>
<thead>
<tr>
<th></th>
<th>Have Posted</th>
<th>Haven’t Posted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy way to communicate</td>
<td>21%</td>
<td>16%</td>
</tr>
<tr>
<td>Anonymous / confidential way to communicate</td>
<td>48%</td>
<td>46%</td>
</tr>
<tr>
<td>24 hour availability of communication</td>
<td>34%</td>
<td>38%</td>
</tr>
<tr>
<td>Ability to communicate with others who know what I’m going through</td>
<td>50%</td>
<td>44%</td>
</tr>
<tr>
<td>Ability to vent my frustrations</td>
<td>20%</td>
<td>14%</td>
</tr>
<tr>
<td>Just someone to talk to about how I am feeling</td>
<td>48%</td>
<td>33%</td>
</tr>
<tr>
<td>Encouragement to seek professional help</td>
<td>12%</td>
<td>15%</td>
</tr>
<tr>
<td>Tips/advice about how others have coped with certain situations</td>
<td>58%</td>
<td>67%</td>
</tr>
<tr>
<td>Factual information about depression / anxiety</td>
<td>44%</td>
<td>60%</td>
</tr>
<tr>
<td>Being able to share my experiences and offer support to others</td>
<td>40%</td>
<td>29%</td>
</tr>
<tr>
<td>Being able to think through and make sense of my feelings by the exercise of writing them down</td>
<td>24%</td>
<td>28%</td>
</tr>
<tr>
<td>Something else</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

10 Colours denote a significant difference at the 95% confidence level. Blue text indicates a figure is significantly higher, while red indicates that it is significantly lower.
Table 2: A10. And thinking about the same list, what do you feel you have actually gained so far from beyondblue’s online forums?

<table>
<thead>
<tr>
<th></th>
<th>Have Posted</th>
<th>Haven't Posted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy way to communicate</td>
<td>22%</td>
<td>12%</td>
</tr>
<tr>
<td>Anonymous / confidential way to communicate</td>
<td>29%</td>
<td>21%</td>
</tr>
<tr>
<td>24 hour availability of communication</td>
<td>23%</td>
<td>27%</td>
</tr>
<tr>
<td>Ability to communicate with others who know what I’m going through</td>
<td>32%</td>
<td>19%</td>
</tr>
<tr>
<td>Ability to vent my frustrations</td>
<td>15%</td>
<td>9%</td>
</tr>
<tr>
<td>Just someone to talk to about how I am feeling</td>
<td>30%</td>
<td>15%</td>
</tr>
<tr>
<td>Encouragement to seek professional help</td>
<td>10%</td>
<td>15%</td>
</tr>
<tr>
<td>Tips/advice about how others have coped with certain situations</td>
<td>41%</td>
<td>47%</td>
</tr>
<tr>
<td>Factual information about depression / anxiety</td>
<td>34%</td>
<td>43%</td>
</tr>
<tr>
<td>Being able to share my experiences and offer support to others</td>
<td>26%</td>
<td>14%</td>
</tr>
<tr>
<td>Being able to think through and make sense of my feelings by the exercise of writing them down</td>
<td>21%</td>
<td>14%</td>
</tr>
<tr>
<td>Something else</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>I haven't been using the forums long enough to say</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>I have not gained anything from the forums</td>
<td>6%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Table 3: A13. What other support have you accessed to get help with depression, anxiety or other related life issues?

<table>
<thead>
<tr>
<th>Support Accessed</th>
<th>Have Posted</th>
<th>Haven't Posted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used the beyondblue website</td>
<td>45%</td>
<td>47%</td>
</tr>
<tr>
<td>Used other websites</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>Used other forums related to issues of depression and anxiety</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>Called the beyondblue Support Service (1300 22 4636)</td>
<td>13%</td>
<td>12%</td>
</tr>
<tr>
<td>Called another support line e.g., Lifeline</td>
<td>24%</td>
<td>15%</td>
</tr>
<tr>
<td>Used the beyondblue Support Service live online chat service</td>
<td>16%</td>
<td>10%</td>
</tr>
<tr>
<td>Used the beyondblue Support Service email service (response within 24 hours)</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Got involved in a face-to-face support group</td>
<td>12%</td>
<td>9%</td>
</tr>
<tr>
<td>Sought help from a health professional (e.g., doctor, psychologist, counsellor)</td>
<td>75%</td>
<td>75%</td>
</tr>
<tr>
<td>Talked to family or friend about depression or anxiety</td>
<td>48%</td>
<td>54%</td>
</tr>
<tr>
<td>Talked to a manager or co-worker about depression or anxiety</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>Something else</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>None of these</td>
<td>5%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Table 1: A17. How important is it to you to feel a sense of community with other participants on the beyondblue forums?

<table>
<thead>
<tr>
<th>Sense of Community</th>
<th>Have Posted</th>
<th>Haven't Posted</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer not to be part of the community</td>
<td>10%</td>
<td>18%</td>
</tr>
<tr>
<td>Not at all important</td>
<td>5%</td>
<td>8%</td>
</tr>
<tr>
<td>Not very important</td>
<td>15%</td>
<td>19%</td>
</tr>
<tr>
<td>Somewhat important</td>
<td>31%</td>
<td>24%</td>
</tr>
<tr>
<td>Important</td>
<td>24%</td>
<td>21%</td>
</tr>
<tr>
<td>Very important</td>
<td>16%</td>
<td>11%</td>
</tr>
</tbody>
</table>
Table 5: A16A. Some people have told us that they experience the following on the forums… how much would you agree that

<table>
<thead>
<tr>
<th></th>
<th>Completely disagree (1 + 2 + 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Have Posted</td>
</tr>
<tr>
<td>Forums create a fear of being judged</td>
<td>56%</td>
</tr>
<tr>
<td>Forums have caused me to feel more depressed/anxious by reading about the situations of others</td>
<td>57%</td>
</tr>
<tr>
<td>I have experienced a sense of anxiety when thinking about responding to posts</td>
<td>47%</td>
</tr>
<tr>
<td>Some of the posts on the forum are too long to bother reading</td>
<td>39%</td>
</tr>
<tr>
<td>The layout of the forum is daunting/intimidating</td>
<td>62%</td>
</tr>
<tr>
<td>Reading negative posts or posts about topics such as suicide, sexual abuse and domestic violence distresses me</td>
<td>42%</td>
</tr>
</tbody>
</table>

Table 6: A18. How well do each of the following statements represent how you feel about the beyondblue forums?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Have Posted</td>
</tr>
<tr>
<td>I feel supported through being part of the beyondblue online forums</td>
<td>17%</td>
</tr>
<tr>
<td>beyondblue forum members value the same things as I do</td>
<td>9%</td>
</tr>
<tr>
<td>The beyondblue forums are successful in meeting the needs of members</td>
<td>5%</td>
</tr>
<tr>
<td>Being a member of the forums helps me to deal with my depression and/or anxiety</td>
<td>19%</td>
</tr>
<tr>
<td>When I have a problem I can talk about it with members of the beyondblue forums</td>
<td>20%</td>
</tr>
<tr>
<td>People in the beyondblue forums have similar needs, priorities and goals to me</td>
<td>7%</td>
</tr>
<tr>
<td>I can trust people in the beyondblue forums</td>
<td>12%</td>
</tr>
<tr>
<td>I put a lot of time and effort into being a member of the beyondblue forums</td>
<td>53%</td>
</tr>
<tr>
<td>Participating in the beyondblue forum is part of my identity</td>
<td>65%</td>
</tr>
<tr>
<td>I care about what the other beyondblue forum participants think of me</td>
<td>40%</td>
</tr>
<tr>
<td>I have influence over what the beyondblue forum is like</td>
<td>52%</td>
</tr>
<tr>
<td>The beyondblue forums have members that help others feel welcome</td>
<td>4%</td>
</tr>
<tr>
<td>It is very important to me to be part of the beyondblue forums</td>
<td>33%</td>
</tr>
<tr>
<td>I expect to be part of the beyondblue forums for a long time</td>
<td>25%</td>
</tr>
<tr>
<td>Participants of the beyondblue forums care about each other</td>
<td>4%</td>
</tr>
<tr>
<td>The beyondblue forums create a sense of community</td>
<td>11%</td>
</tr>
</tbody>
</table>
7. Improvements and enhancements to the forums

A number of suggestions were made in the qualitative research component by users, community champions and the community manager, and these were then measured in the quantitative survey.

**Suggestions for improvement**

Most of the suggestions were warmly received. There is particularly high interest in having volunteer mental health professionals respond to comments and questions, with three-quarters of users (77%) voting for this option. Similarly, 42% wanted to see clinical responses from moderators on the forum – provided that they would not reveal any personal details.

There was also a good deal of interest in an app to access the forums, with over half of people (55%) and three-quarters of the younger age group wanting this to be introduced, with a sense that this would make things easier to use and increase their participation.

**Expected usage of app versus web page**

A158: You mentioned that you would be interested in Beyond Blue developing an app so people can access the forums on a smartphone or tablet. Please let us know whether you agree / disagree with the following statements:

- Disagree  Agree
- I would prefer to look for information about mental health in an app rather than on a web page  53%  67%
- I would allow a Beyond Blue app to know my location in order to provide me with a better experience tailored to me (e.g. location based help services)  25%  71%
- I would be more likely to publish personal stories of my mental health history in an app than I would on a web page  10%  84%

Figure 33: Suggestions for improvement

Figure 34: Expected usage of app versus web page
The principal benefit of any app seems to lie in its accessibility at any time and place, and its ability to provide a personalised user experience. Of the specific features we tested, the most desired were location-based help services (72%), followed by notifications of beyondblue events that you might be interested in (66%). Almost half (48%) of users also saw value in being able to connect with their favourite posters in more or less real time.

**Desired features of an app**

![Figure 35: Desired features of an app](image-url)

Aside from the app, another main addition of interest was notifications when users have received replies to their posts. This saves angst and effort in checking for responses, and also facilitates dialogue.
DISCUSSION

Benefits of the forums

Participation in online mental health forums – while it is not for everyone – is beneficial for many people suffering from depression, anxiety and other conditions, providing both practical and emotional benefits. These include:

- Providing a confidence boost or encouragement to access professional help, and/or discuss issues with friends or family;
- Inspiring people to make positive lifestyle changes which are known to have a positive impact on mental health (e.g. increased exercise, meditation, improved diet, reduced alcohol or drug intake);
- Providing tips and coping strategies;
- The emotional support of knowing that you are not alone, that someone is listening to you that other people have been through the same situation as you and have come out on the other side.

It is also clear that some of the processes and practices put in place by beyondblue have positioned these online forums above alternative online forums – in particular, the vision of a hopeful and supportive community and the conscious effort to create one via the community champions, forum rules and regulations, moderation of posts and the occasional direct contact or ban on those users who are acting to the detriment of the broader community.

The Sense of Community measures tell us that, while some respondents agree that the forums should provide a sense of community (37% view a sense of community on the forums as important or very important), for others this is less of a driver for forum participation, and other factors may be more important; and in fact, one in eight (12%) would prefer not to be part of the community at all. This highlights the need to flexibly allow people to interact with the forums and other users in a way that suits them, rather than forcing them to contribute to community activity. The differences between those who have posted and those who have not (outlined in detail in Section 6 of this report) also bring up an interesting question here: in creating a sense of community, should we be concentrating on the needs/wants of people who post, or on the needs of the overall community?

Limitations of the Forums

Ensuring that people are responded to in a timely manner is clearly a part of satisfaction; since we know that both champions and the broader community feel most comfortable answering posts with which they can identify, it seems to call for defined roles or specialties and potentially training for the community champions in certain areas; and/or the ability for a champion to call on a clinical moderator or volunteer psychiatrist to give a more detailed answer on a certain topic.

In addition, in order to ensure that information needs are met, user feedback indicates that the following would be useful:
The inclusion of links to other areas of the beyondblue website (or other websites) which contain factual information, tips and advice on coping strategies;

Different ways of sorting or filtering or laying out information to make it clearer and easier to find;

Bringing in trained professionals to provide information on particular issues;

Moderators or community champions stepping in to respond in a timely manner, potentially forging connections between users with similar issues.

It must also be noted that around 1 in 11 (9%) forum users leave the forums feeling worse than before they started; and it is important that the potential for unintended adverse effects be monitored and mechanisms be considered for responding to these circumstances. It would be interesting to look into this group further and understand reasons why the forums leave them feeling worse, and whether this indicates a need to change anything – as such, we recommend that further iterations of the quantitative survey include a follow-up open-ended question.

The most frequently selected reason for having negative experiences on the forums was experiencing anxiety about posting, so ensuring that users know there are no trolls on beyondblue forums, and that other users and the community are relatively judgement-free, supportive people wanting to share similar experiences, may assist – as would a guaranteed response to posts.

There is general agreement from moderators, champions and users that repeat posts on the same subject by the same user, without any indication of change or progress or acknowledgement of support, are unhelpful.

**Features and Functionality**

Given the general sense that no more than 24 hours should pass before a post is responded to, particularly if it is a first post or the beginning of a new thread – and that qualitative research indicates that people may appreciate a response from more than one person – there is evidence to suggest that adding a formal system for notification of posts which have not yet been responded to (for champions, moderators and the broader community) to forum functionality would be useful.

The ability to use stickers or emoticons which allow people to express themselves without needing to worry or think too much about exactly how to do so was suggested as a way of facilitating interaction; additionally a ‘thank you’ or ‘I’ve read your post’ type of acknowledgement button was also felt to be worthwhile, particularly to reassure those seeking to help someone in need that the person has seen their response, even if they may not yet feel up to replying more fully. In fact, any way in which the forums could facilitate easy (and perhaps non-verbal) contribution is likely to be beneficial especially to those users who experience anxiety around posting more fully: for example, the ‘like’ button which was already planned but introduced after the research was conducted.

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11 Noting that the community manager already flags such posts for champions
70% of people feel there are just the right amount of forum categories; of the others, 19% felt there were too many and 10% too few. This indicates that if any new categories are added in, other categories should ideally be merged.

Improvements to the layout are likely to make for a more enjoyable experience for users. Our YourWord™ platform was seen by many of the qualitative participants as offering a great starting point for redevelopment of the forum layout.

Many – especially younger – users would prefer to interact with the forums through a smartphone app, which would give them a more personalised and localised experience. Use of the forums through a smartphone becomes far more personal than through a desktop, and we feel that both the amount and intimacy of contributions will be increased through development of an app.

The suggestion of volunteer mental health professionals to respond to comments and questions was extremely popular with users, with many preferring to see more active participation of those with mental health qualifications – sharing practical and even clinical advice where possible.

Beyond this, moderators and participants themselves saw it as important that users are gently encouraged both to contribute to the forums and eventually to think beyond the forums, as there is a risk that some people with anxiety may otherwise use forums to avoid doing what makes them anxious.