Online Forums 2016

A Research Report for beyondblue
11th May 2016

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EXECUTIVE SUMMARY

Wave 2 of this research project continues to demonstrate 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.

As always, it is important to start by acknowledging 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.

However, the changes that have been made since 2015 (described in detail in the following section), were designed to overcome some of these issues – for example, the addition of a specific section on the topic of suicidal thoughts and self harm, giving an outlet and voice to those who want to participate in these discussions (which were previously not permitted on the forum), whilst allowing users triggered by such material to avoid reading it (due to this forum’s clearly labelled and standalone nature).

Building on the positive impact of the forums on people’s lives noted in 2015, we saw a significant increase in those who reported feeling better, and a significant decrease in those who reported feeling worse after using the forums.

Some other notable differences from 2015 are:

- A significant increase in the proportion of male (33%) and LGBTI (11%) participants;
- An increased skew towards regional and rural respondents, and a further drop in the proportion of NSW participants compared to the distribution of the overall Australian population;
- A maturing population on the forums, with a significant increase in people who first accessed the forums more than a year ago, and a significant decrease in those who accessed in the past 3 months;
- A significant increase in active participation on the forum (that is, people who like to respond to as well as read threads);
- A general decrease in the gaps between what users hoped to gain, and what they actually gained on the forums;
- A significant increase in those who had accessed other forms of support (e.g. help from a medical professional) as a direct result of forum usage; and a significant increase in the proportion of people who say they have made one or more positive lifestyle changes (e.g.
exercise, diet) as a direct result of forum usage, with over two-thirds (69%) of people saying they had made some change;

- Some positive shifts in the Sense of Community index;

- A significant increase in the proportion of people who feel the forums have had a positive impact on their lives; that the speed of response to posts is good or extremely good; and that the forums are comprehensive;

- A significant increase in disagreement with negative statements around forum experiences such as: experiencing a sense of anxiety when responding to posts; feeling distressed by reading negative posts or posts about topics such as suicide; posts being too long; forums creating a fear of being judged.

The addition of new forums on Welcome and Orientation; Suicidal Thoughts and Self Harm; Relationship Issues and Coping with Christmas has also been successful.

There are no significant negative shifts revealed in the 2016 survey, although there does remain a small proportion of users who felt worse after using the forums, and/or reported that the forums had had a poor impact on their lives.
BACKGROUND

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

Around 68,000 people a month (up from 40,000 last year) visit the forums, making up 23% of all unique visitors to the beyondblue website. An average of 5,300 posts are made per month (up from 2,500 last year), with around 6 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. Also working in the forums on a volunteer basis are 18 “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, staying well, and treatments. Subject areas are also incorporated, including relationship issues, grief and loss, sexuality and gender identity, 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.

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.
- 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.).

This is the second wave of quantitative tracking, and as such it also allows us to monitor differences arising from changes to the way that the forums operate, and understand trends in the evolution of the forum.

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1 [www.communityscience.com](http://www.communityscience.com)
Research methodology

N=1191 participants completed a 20 minute online survey, which ran from 5th to 15th April 2016. The survey invitation was sent out to people who had 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.

As mentioned above, this is the second wave of quantitative fieldwork, with the first wave conducted in March 2015. Another phase of tracking is planned for March 2017.

This year, a new group of contacts (those who had triggered a critical or serious risk) was added. New codes were also added to some questions this year, based on the analysis of open-ended responses from 2015.

Strengths and limitations of the methodology

Strengths of the methodology

An online methodology was chosen for several reasons:

- It was seen to be a methodology that a 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 survey in their own time, in their own home or at any other location of their choosing. Allowing the survey to run for ten days 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.
- Online methodologies also allow for participant anonymity.
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.

Limitations of the methodology

Participation in research is self-selecting – though this is not an issue specific to online methodologies.

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.

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). There is also 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.

Changes on the forums since 2015

Some changes were made to the forums during 2015, as a result of findings from Wave 1 of the research. These changes included:

- Establishment of a welcome and orientation section at the top of the forums, where new users are encouraged to post an introduction after signing up – this section also includes sticky threads with tips on how to best use the forums, feedback for improvements, and answers to frequently asked questions
- Expansion of community champions volunteer programme to include volunteers with specialised peer expertise, including carers, young people, and LGBTI people
- Establishment of a dedicated section for discussing suicidal thoughts and self-harm, providing an avenue for the publication of some posts previously deemed too distressing for the general community – this section is closely monitored to ensure supportive replies are received
promptly, and its standalone nature allows users triggered by such material to avoid reading it

- Establishment of a dedicated section for discussing relationships and family issues, in recognition of the large number of users posting with these themes
- Ability for users to mark content as helpful via a button at the bottom of each post
- Expansion of threads in the off-topic Community Board section where users can take a break from mental health topics – social threads such as ‘BB Café’ have proven highly popular and have increased the average number of posts per user since the previous survey
- Introduction of a badging system for users so that community champions, staff, and veteran posters can be easily identified – the badging system also provides levels of membership, incentivising continued participation

It is important to note these changes upfront, as they may account for different user experiences in 2016, and therefore shifts in survey response.
FINDINGS

1. Forum usership

1.1 Demographics of the survey respondents

In order that beyondblue can draw meaningful comparisons between this and other data at its disposal, the demographic questions used in our survey are taken directly from the Depression and Anxiety Monitor.

Since demographic information such as gender and location is not collected through forum registration, we are unable to be certain that the demographics of our survey respondents are perfectly reflective of the wider forum population. However, we have drawn some broad conclusions based on comparison with other research (where available) and ABS data.

Demographics

Firstly, we would note that there are very few major variations from last year’s survey respondent demographics.
Two-thirds of survey respondents (66%) are female... Although this is a slight drop (6%) from last year, females still make up the large proportion of our survey respondents (and, we can assume, the broader beyondblue forum population²).

However, there has been a significant increase in the proportion of male versus female participants... 33% male, up from 28% last year.

As last year, almost half of survey respondents (48%) are 35-54 year olds¹... which is rather higher than the Australian population, but overall there is a good spread of usage across the age categories and the breakdown is very similar to last year. Almost a quarter (23%) of participants are over 55.

The survey population is roughly in line with population by state. However, as in 2015, it is a little over-represented by Victorians (24% of overall population vs 29% of survey population) and South Australians (7% of overall population vs 10% of survey population), and a little under-represented in NSW (32% of overall population vs 25% of survey population)⁴.

The metro vs. regional/rural split is 56%/44%... As in 2015, this indicates a significant regional skew, given that the actual population split in Australia is 65% metro/35% regional, according to the 2011 Census⁵; in fact this skew is even higher than last year.

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³ Noting that for ethical reasons, it was decided to screen out respondents under 18 years of age. We do know that some under 18s are using the forums, as we had 84 survey screen outs this year and 34 last year based on age.

⁴ ABS: 3235.0 Population by Age and Sex, Regions of Australia (2014)

⁵ 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 indicates that forum usage does skew towards regional users.
• 22% were born overseas... This is identical to last year, and is just slightly below the Australian population figure as a whole (24.6% of Australians were born overseas)⁶. The breakdown of those who speak a language other than English at home is also almost exactly the same as 2015, indicating no changes to this part of the forum demographics.

• However, there is a significantly higher proportion of LGBTI respondents this year... from 7% up to 11% (with the proportion of those unsure/undecided and preferring not to say remaining constant).

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The vast majority of participants (85%) indicated that they have been diagnosed with depression, anxiety or another mental condition. Over half (55%) of those who have been diagnosed have been living with their condition for more than 10 years. 

Figure 3: Conditions experienced

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7 We 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.
1.2 How users find out about the forums

How people hear about *beyondblue* forums

![Bar chart showing how people heard about the forums](chart)

- **68% heard about the forums through a *beyondblue* channel.**
- **46% heard about the forums through online sources (website, Google, Facebook).**
- **46% heard about the forums through beyondblue advertising (TV, billboard etc.).**
- **30% heard about the forums through beyondblue channels (website, TV or billboard advertising, newsletters and the support service).**

**Online sources** (website, Google, Facebook) and **beyondblue channels** (website, TV or billboard advertising, newsletters and the support service) remain the most common ways for people to find out about the forums.

Close to half (46%) of people come into contact with the forums via the *beyondblue* website, and although this represents a significant decrease on last year it is still the most cited awareness channel.

*beyondblue* advertising (e.g. TV or billboard) was the second most common channel (30%). However, we note that there has not been any specific advertising about the forums, or which references the forums, so this figure is more likely to indicate those who first became aware of *beyondblue* via campaigns, visited the website and found the forums. This was a new code based on open-ended responses last year, and may be responsible for part of the significant decrease in the website as primary awareness channel.
The addition of the new codes (based on open-ended responses from last year) now appears to have covered off most of the ways in which people come into contact with the beyondblue forums with a significant decrease in those answering ‘somewhere else’.

**In-person** remains the next largest channel for referrals: 14% had heard about the forums via a health professional (demonstrating that some health professionals see value in forum participation for mental health), 7% through family or a friend and 3% through an employer, manager or co-worker.

**Other organisations** have helped to drive awareness in a smaller way, including 5% from an educational institution, 4% from a community organisation and 2% from a Government organisation.

There was a significant decrease in print resources as a referral channel. 4% had heard about the forums through the beyondblue newsletter, and 1% through another newsletter or publication.

### 1.3 Accessing the forums for the first time

#### When the online forums were first accessed

![Graph showing first access of forums](graph.png)

<table>
<thead>
<tr>
<th>First Access</th>
<th>Wave 1</th>
<th>Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within the last 3 months</td>
<td>27%</td>
<td>12%</td>
</tr>
<tr>
<td>Between 3 and 12 months ago</td>
<td>36%</td>
<td>30%</td>
</tr>
<tr>
<td>More than a year ago</td>
<td>32%</td>
<td>53%</td>
</tr>
<tr>
<td>Don’t recall</td>
<td>5%</td>
<td>6%</td>
</tr>
</tbody>
</table>

A.5. When was the very first time that you accessed the beyondblue forums?  
Base: All respondents; Wave 2 n = 1138, Wave 1 n=602

**Figure 5: First access of forums**

These figures show a maturing population on the forums, with a significant decrease in those who first accessed within the last three months (down to 12% from 27%), and a significant increase in those who had first accessed more than a year ago (53%, up from 32%).

In fact, over half of our sample had first accessed the forums more than a year ago. Those accessing more recently tended to be younger (18-24).
Reasons for first access

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. The proportions of those accessing for themselves, as compared to those accessing on behalf of someone close to them, has not changed.

More than half of users (55%) stated that they first accessed the forums because they felt depressed or anxious and wanted support; this remains the most common reason for first access. A quarter (26%) specifically stated that they felt suicidal and wanted support; this is a new code for 2016.

A third (33%) wanted to connect in an anonymous way, while 1 in 5 (20%) did not want friends and family to know. This continues to illustrate an important feature of the online forums in providing information and support for those who would otherwise be less likely to engage, out of fear of judgement.

The proportions of those who wanted to complement support they were getting through a health professional (18%), to provide support to others with the benefit of their own experience (18%), or because it was a low cost option (12%) is roughly unchanged.
However there was a significant decrease in those who had first joined because they thought they might be experiencing depression and anxiety and were seeking information (17%, down from 26%), and those who had recently received a diagnosis (17%, down from 24%). This may be attributable to the maturing profile of the forums.

1.4 How the forums are used

Time of day forums are accessed

![Figure 7: Time of day](image)

Key
- ▼ indicates a significant difference at a 95%
- ▲ confidence level when compared to Benchmark

It is still most common for people to access the forums at night, between 8pm and 5am (almost half, 48% access at this time). However there has been a significant drop here, from 55% last year, and a slight increase in usage at other times. This appears to be due to female participants who are moving away from evening towards morning and afternoon.

Frequency of forum access

![Figure 8: Frequency of forum access](image)

Key
- ▲ indicates a significant difference at a 95%
- ▼ confidence level when compared to Benchmark
We note that there is still a substantial group (about a third, 31%, of participants) who access the forums at least monthly. However, there have been some significant decreases in frequency of access (weekly, fortnightly or monthly), and a significant increase in those who used to access more in the past (almost a third, 30%, up from 19% in 2015). This is not necessarily a negative: taken together with the fact that there is a maturing profile on the forums (i.e. an increase in people who first accessed more than a year ago) it may suggest that people are dipping in and out as their mental health improves.

Recent access of online forums

![Recency of access](image)

**Figure 9: Recency of access**

Although 31% say they access at least monthly, only 22% had actually accessed in the last month. Those who had not accessed for 7 months or more were less likely to say that they felt better after their last access (though not more likely to say they felt worse).
What people like to do on the forums

Figure 10: What people like to do on the forums

There has been an increase in active participation on the forums. While almost three-quarters of people's preferred pastime on the forums is to read posts (rather than respond or start their own threads), this has significantly decreased since last year (72% down from 80%); meanwhile there has been a corresponding significant increase in the proportion of people who like to respond and participate to threads (up from 12% to 19%).

Starting one's own thread remains the least favourite activity, with less than 1 in 10 (9%) listing this as their favourite activity. The figures here have remained roughly stable. People who access the forums at least 3-5 times a week are more likely to participate, and to start their own threads, than less frequent users.

The greater visible activity on the forum may also attribute to the significant improvement in speed of response to posts (Figure 32 below).

1.5 The role of forums versus other avenues of support
Other avenues of support accessed by users

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. It is very rare that forums are the only avenue of support that users are accessing; only 3% had accessed no other avenue of support, a significant decrease from last year.

Across the board, we see a general increase in other help-seeking behaviours. Almost four-fifths (79%) have sought help from a health professional – Figure 12 below shows that this was typically a GP (81% of the 79%) and/or a psychologist (72%). Around half (53%) had talked to a family or friend, and/or used the beyondblue website.
Type of health professional consulted

The younger age group were more likely to consult a counsellor; possibly this is a counsellor provided by schools or universities.

Noting the significant increase in those who said they had done ‘something else’ compared to last year (9% up from 5%), we reviewed the open-ended answers here. Some of these do seem to fall into the category of ‘health professional support’, but are more specific, while others are very different from the above.

- Hospital emergency, inpatient and outpatient programmes, and triage services
- Rehabilitation programmes
- Therapies such as CBT
- Specific support groups including: men’s groups/sheds; ARAFMI; EAP; VVCS
- Use of apps such as Pacifica and Headspace
- Blue Hope (Facebook support group on the topic of police suicide)
- Undertaken studies in psychology or wellness
- Become a counsellor, or set up an online support group of their own: “Helping others makes me feel better”
- Blogging
- Books
2. Forum achievements and impacts

2.1 What are the forums achieving?

What users hope to gain

Figure 13: What users hoped to gain

Coming into the forums, people are looking for a mix of practical and emotional support.

What users hoped to gain is roughly in line with last year, but with a significant increase in those hoping to gain 24 hour availability of communication, which may be attributable to an ever-increasing pace of life in Australia.

The majority (60%) are looking to gain tips/advice on how others have coped; while approximately half are looking for the opportunity to connect in an anonymous way (50%); the ability to communicate with others who know what they are going through (49%); and factual information on conditions (47%).
What users felt they actually gained

Users were then asked what they felt they had actually gained from the forums. As in 2015, there is a gap between what people hoped for and what they felt they actually gained, suggesting that the forums are not completely meeting users’ expectations. However, encouragingly, Figure 15 below shows that the gaps are smaller than they were last year.

In addition, there has also been a significant increase in the proportion of people who felt that they had gained encouragement to seek professional help, and 24 hour availability of communication.
Gap between hope to gain and actually gained

Figure 15: Gap analysis

The gap analysis in Figure 15 clearly shows that there have been improvements in many dimensions between Wave 1 and Wave 2. It also shows us where the biggest gaps between hopes and actual experience lie. Perhaps somewhat surprisingly, these are in the areas of ‘anonymous and confidential way to communicate’ (20%), followed by ‘just someone to talk to about how I am feeling’ (19%), and ‘ability to communicate with others who know what I am going through’ (17%).

The open-ended responses show that some people who seemed to have gained less had in fact gained more, but in different ways. Those who had gained less cited various reasons including:

- Personal barriers to engagement
  - Struggles with being introverted, lacking confidence, not feeling comfortable, fear of judgement;
  - Prevented by own thoughts or situation e.g. problem still too ‘raw’, struggle with acceptance of it, feel resistant to help at this stage;
  - Expectations may have been too high: realised forums alone could not help them;
  - Simply not accessing forums enough for them to be helpful;

- Limitations of forums as a channel
Looking for immediate help and relief which the forums cannot necessarily provide (e.g. not guaranteed to have an immediate response to a post, can experience time delays on posting);

Wanting a personal, face-to-face connection;

- Negative experiences with the beyondblue forums specifically
  - Lack of responses (or not knowing when someone had responded);
  - Feeling that other posters had ‘hijacked’ threads;
  - Technical issues… slow-running and not seen as user-friendly;
  - Felt censored, not allowed to discuss the topics they wanted to;
  - Not knowing where to start (the new Welcome and Orientation forum may assist with this);

- Lack of relevance
  - Their specific condition (e.g. bipolar, derealisation) not there (or not obvious enough) – or not believe to be well understood on the forums;
  - Advice or others’ situations didn’t seem to fit with or reflect their own situation;
  - Reading about people who had been able to access services that the person themselves could not access where they lived;
  - Nothing they didn’t know already;

Some also struggled with computers or poor internet connection.

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.
Most useful aspects of the forums: 1st rank

Figure 16: Most useful aspects of the forum – 1st ranked

There has been no marked change in the aspects that people find most useful. Factual information about depression and anxiety (15%), followed by tips and advice on coping with certain situations (15%) remain the most useful aspects.

References:

All 10b. And which of these aspects have been most useful to you? Please place in order from most important to least important...

Base: All respondents; Wave 2 n = 1138; Wave 1 n = 602
Most useful aspects of the forums

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Wave 1</th>
<th>Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factual information about depression / anxiety</td>
<td>1.5%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Tips/advice about how others have coped with certain situations</td>
<td>1.0%</td>
<td>1.2%</td>
</tr>
<tr>
<td>24 hour availability of communication</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Ability to communicate with others who know what I'm going through</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Anonymous / confidential way to communicate</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Just someone to talk to about how I am feeling</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Being able to share my experiences and offer support to others</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Easy way to communicate</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Being able to think through and make sense of my feelings by the exercise of writing them down</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Encouragement to seek professional help</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Ability to vent my frustrations</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

![Figure 17: Most useful aspects of the forums – all ranks](image)

The ranking of the 1st, 2nd and 3rd most useful aspects of the forums has remained relatively consistent with last year. When we include the 2nd and 3rd place rankings, Tips about Coping has a higher overall usefulness than Factual Information, but overall the order is very similar, with the forums seen as most useful for informing, followed by connecting.

2.2 The impact of forum participation on mental health outcomes

As we acknowledged in Wave 1, just as 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, Wave 1 of this research showed 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**... by comparing feelings before and after last use
2. **Accessing other avenues of help and support**... as a direct result of using the forums
3. **Making positive lifestyle changes**... again, as a direct result of using the forums

In all cases, we have seen further improvements on these indicators in Wave 2.
2.2.1 General improvement in mood

Comparing feelings before and after forum use

Figure 18: Comparing feelings before and after forum use

When describing their state of depression and anxiety before accessing the forums on the last occasion that they used them, 34% of people ranked themselves as ‘very depressed’ (9 or 10 out of 10) and 31% of people as ‘very anxious’. After they had used the forums, this figure fell to 14% 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 continues to indicate that the forums provide short-term relief of symptoms for a number of users.

Subtracting how users felt after using the forums from how they felt before using them, about half (56%) of users said that they felt less depressed, and 60% said that they felt less anxious, while just 6% gave a lower score for how depressed or anxious they felt after interacting with the forums. This represents a significant increase in those who felt better, and a significant decrease in those who felt worse.

Overall a total of two-thirds (67%) reported feeling better and less than 1 in 10 (9%) reported feeling worse on one or both of these aspects.

Figure 19 and 20 below provide further detail on this issue. What is particularly encouraging (in terms of the positive impact of the forums) is that this increase in people who felt better (and corresponding decrease in people who felt worse) comes despite the fact that users in Wave 2 were significantly

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8 This is discussed further in the ‘Disadvantages and negative experiences’ section below.
more likely than in Wave 1 to have high levels of depression prior to access, and significantly more likely to have moderate-high anxiety.

**Depression: feelings before and after access**

**Figure 19**: Depression: feelings before and after accessing the forums

**Anxiety: feelings before and after access**

**Figure 20**: Anxiety: feelings before and after accessing the forums
2.2.2 Accessing other avenues of help and support

Support accessed as a direct result of using forums

Figure 21: Support accessed as a direct result of using forums

There has been a significant decrease in the proportion of people who said they had accessed no other avenue support a result of using the forums (just over a third, or 35%, had not done so, compared to 43% last year).

This suggests that the forums are playing an increasingly positive role in terms of encouraging people to access other forms of support such as seeking help from health professionals, talking to family or friends about how they are feeling, doing further reading about conditions, or joining a support group.

Other avenues included:

- More research or study, including accessing information on mindfulness
- Links to other online resources: Mindspot course, online depression course, 7 Cups website, link to live PTSD chat, ehealth forums
- Linking in with other organisations e.g. Butterfly Foundation, PANDA
- Accessing another beyondblue resource (online chat)
- Starting their own online support group
- Watching a documentary on OCD
- CBT
• Spiritual healing
• Exercise and work.

2.2.3 Making positive lifestyle changes

Changes made as a result of forum use

Figure 22: Changes users have made as a result of forum use

A number of other positive lifestyle changes were also attributed to being a direct result of forum usage, with over two-thirds (69%) saying they had made one or more lifestyle changes based on forum usage, a significant increase compared to last year. The most common actions included around a third of people taking more physical exercise (33%), starting or increasing meditation and mindfulness (31%), and/or connecting more with friends and family (29%). A quarter of people (26%) had taken up or rekindled a hobby, and around one-fifth (21%) had made dietary changes.

Of those who mentioned a different positive change, these included: positive change in mindset; greater self-understanding; making more ‘me time’; switching off screens; new friends, relationships, pets; taking medication; yoga; acupuncture; naturopathy; distraction techniques; better sleep or time management; decluttering; quitting smoking; leaving a job or relationship; starting a journal.
Adding to the above positive findings, more than 2 in 5 (42%) of people say that the forums have had a good or extremely good impact on their lives – this total represents a significant increase on last year. However, we should not ignore the fact that 1 in 6 (17%) say the forums have had a poor impact on their lives – this is discussed further in the ‘Disadvantages and negative experiences’ section below.

2.3 Disadvantages and negative experiences

As mentioned above, 6% of users gave a lower score for how depressed or anxious they felt after interacting with the forums. In addition, as seen in Figure 23 above, 1 in 6 (17%) say the forums have had a poor impact on their lives.

Of those who gave a lower score and explained why, the comments have a degree of overlap with those above about why some people felt they had gained less than they were hoping. This included: not finding the information (or understanding / reassurance) they needed – including lack of information on medication; some perception of the forums being ‘misandric’ or strongly feminist, or otherwise lacking assistance for men specifically; contradictory information; lack of professional support; inability to upload posts / posts being rejected; the wait for people to answer increasing feelings of anxiety; posts ‘hijacked’ by other users; slowness and lack of structure.

Some of the negative forum experiences identified in qualitative research in 2015 were then measured in the quantitative survey (Figure 24). Overall, we can see a clear improvement on all these aspects compared to last year.
Negative forum experiences

The proportion of people who agree/strongly agree that they have experienced a sense of anxiety when thinking about responding to posts has remained steady at around one-quarter (24%). 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. However, the proportion of people who disagree that they feel anxiety has significantly increased (from 41% in 2015 to 47% in 2016).

The proportion of people who agree that reading negative posts distresses them has significantly decreased, which could perhaps be attributed to the separate forum dedicated to Suicidal Thoughts and Self Harm (meaning that users in 2016 are less likely to encounter such posts). The slight (but not significant) decrease in agreement (and increase in disagreement) with the statement ‘forums have caused me to feel more depressed/anxious by reading about the situations of others’ could also be related to this.

People were also significantly more likely to disagree that some posts on the forum are too long to both reading, or that forums create a fear of being judged (although those agreeing or strongly agreeing with the statements decreased slightly but not significantly – at 21% compared to 25% last year for ‘overlong posts’, and 16% compared to 18% last year for ‘fear of being judged’).
There was no real change in the proportion of those who feel the layout is daunting/intimidating (11%); we understand that there have not been any significant design improvements to the forums in the past year, other than a change in font and point size.

3. Building a sense of community

Importance of sense of community

Figure 25: Importance of a sense of community

Overall we see a slight shift in the belief in the importance of a sense of community amongst forum users, including a significant decrease in the number of those who prefer not to be a part of the community.

Almost three-quarters (72%) view a sense of community on the forums as being at least somewhat important, while 1 in 5 (19%) see it as not important, and less than one in 10 (9%) 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’, described in the Background section above. 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.

The beyondblue forums performed quite strongly in 2015, and have improved on several measures in 2016 (Figure 26 below).
### Sense of community index

<table>
<thead>
<tr>
<th>Statement</th>
<th>Wave 1</th>
<th>Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>The beyondblue forums have members that help others feel welcome</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>Participants of the beyondblue forums care about each other</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>The beyondblue forums create a sense of community</td>
<td>10%</td>
<td>4%</td>
</tr>
<tr>
<td>I can trust people in the beyondblue forums</td>
<td>11%</td>
<td>4%</td>
</tr>
<tr>
<td>I expect to be part of the beyondblue forums for a long time</td>
<td>21%</td>
<td>4%</td>
</tr>
<tr>
<td>When I have a problem I can talk about it with members of the beyondblue forums</td>
<td>26%</td>
<td>4%</td>
</tr>
<tr>
<td>The beyondblue forums are successful in meeting the needs of members</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>I care about what the other beyondblue forum participants think of me</td>
<td>38%</td>
<td>3%</td>
</tr>
<tr>
<td>People in the beyondblue forums have similar needs, priorities and goals to me</td>
<td>38%</td>
<td>3%</td>
</tr>
<tr>
<td>I feel supported through being part of the beyondblue online forums</td>
<td>30%</td>
<td>4%</td>
</tr>
<tr>
<td>Being a member of the beyondblue forums helps me deal with my depression and/or anxiety</td>
<td>25%</td>
<td>4%</td>
</tr>
<tr>
<td>beyondblue forum members value the same things as I do</td>
<td>35%</td>
<td>4%</td>
</tr>
<tr>
<td>It is very important to me to be part of the beyondblue forums</td>
<td>16%</td>
<td>4%</td>
</tr>
<tr>
<td>I have influence over what the beyondblue forum is like</td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>I put a lot of time and effort into being a member of the beyondblue forums</td>
<td>10%</td>
<td>3%</td>
</tr>
<tr>
<td>Participating in the beyondblue forum is part of my identity</td>
<td>6%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 26: Sense of community index

The most notable improvement has been in complete agreement with the statement ‘the beyondblue forums have members that make others feel welcome’, with around one-quarter (24%) stating this. The increase in the number of community champions since last year, the ‘badging’ of champions and the new Welcome and Orientation forum may be some of the factors influencing this change.
There have also been significant increases in people who feel the forums ‘mostly’ create a sense of community (40%, up from 33%); amongst those who feel ‘completely’ supported through being part of the forums (now more than one in 10, or 11%); amongst those who ‘completely’ agree that people on the forums have similar needs, priorities and goals to them (also 11%); and amongst people who ‘completely’ agree that they have influence over what the forums are like (although this is still only a very small proportion at 3%).

There have also been significant decreases in those who only ‘somewhat’ agree that the forums have members that help others feel welcome, that forum participants care about each other, and that the forums create a sense of community.

4. Forum user experience

Usage of specific beyondblue forums

Figure 27: Usage of specific forums

The usage of forums has remained quite stable overall, with some successful additions. This year includes three new forum categories (Suicidal Thoughts and Self Harm, Relationship and Family Issues, and Welcome and Orientation) plus a seasonal fourth, Coping with Christmas.

Looking specifically at usage of the new forums, we see that:

- Those who have triggered a Serious or Critical Risk and people making 20+ posts are significantly more likely to use all these new forums;
Males are significantly less likely to use the ‘Relationship and family issues’ forum than females;

Older people (60+) are significantly more likely to use Coping with Christmas than younger age groups.

We asked people’s views on the number of categories, which is perhaps particularly relevant given the increase in categories.

**Thoughts on number of forum categories**

![Bar chart showing responses to number of forum categories](image)

**Figure 28: Number of forum categories**

We can see that most people (73%, almost three-quarters) are happy with the number. Those who are not happy are more likely to think there are too many categories (17%, down from 19%) as opposed to too few. Some voiced a concern that more would be too overwhelming, or that it would result in there not being enough traffic on individual forums.

The additional ideas that were suggested fall into two categories: topic types, and groups of people. Below is a selection of the suggestions.

**Topic suggestions**

- Bipolar (also suggested last year)
- Eating disorders (also suggested last year)
- Post-natal (and antenatal) depression
- Drugs and alcohol
- Infertility
- Loss of pregnancy
- Menopause
- BPD and PTSD
- Social anxiety
- Self esteem / self worth
- Prescription drug withdrawal and side effect support
- Tips on mindfulness practice (or drug-free treatment options)
- Other tips e.g. getting through a bad day, how to talk to doctors, affordable support, journals, relevant TED talks, coffee gatherings, art groups

We note that these requests for Tips sections are connected to the second most useful benefit of the forums (as ranked in Figure 16 above), and that indicating these more clearly on the forums may be appreciated.

Some suggested topics may already be covered but could be relabelled to be clearer:
- Getting to know you (probably already covered by Welcome and Orientation)
- Some were also unclear as to what was meant by Trauma and whether abuse (domestic, sexual, child) was covered. It was also suggested that Trauma and Chronic (physical) Illness should be separated.
- Could Coping with Christmas be changed to something relevant year-round (e.g. Coping with Events)?

Suggestions for areas for specific groups of people
- Carers only
- Parents (which could be covered by the carers suggestion above)
- Multicultural
- People with disabilities
- Health professionals

We also asked about particular topic areas (not specifically related to the forum categories, but identified by beyondblue as being common areas of discussion) that people liked to read and/or contribute to.
Topic areas most likely to read

2016 shows a general decrease – and in many cases a significant one – in the topic areas people are likely to read (and, in Figure 30 below, contribute to). This can be explained by the addition of a number of new topics – PTSD, workplace issues, bipolar and workplace support – which have diluted the audience for the ‘old’ topics. However some areas (such as Explaining Depression to Family and Friends, Suicide/Self Harm, Medication Side Effects and Unemployment) have remained stable, presumably because there is less overlap with the new topics.

Overall, this ‘dilution’ does not appear to have an adverse impact on the forum experience, for example in terms of usefulness, comprehensiveness or satisfaction with speed of response (Figure 32).

It is also interesting to note that separating out OCD from intrusive thoughts (in the survey) has significantly increased the interest in OCD and intrusive thoughts overall.
Topic areas most likely to contribute to

In almost all cases, as in 2015, people are more likely to read most topics than contribute to them, with the exception of general venting.

The pattern of popularity of topics follows roughly the same lines for ‘contribute to’ as for ‘read’. Within the top 10 topics, the only slight variations are that Suicide/self harm moves above Panic attacks (into third place), and workplace issues and PTSD switch spots with the former moving into 9th place.
**Difference between those who read and contribute**

<table>
<thead>
<tr>
<th>Topic</th>
<th>2016 Wave 1</th>
<th>2016 Wave 2</th>
<th>2017 Wave 1</th>
<th>2017 Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping with difficult emotions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explaining depression/anxiety to family/friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic attacks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship/marriage/family issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication side effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suicide/self harm</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PTSD (Post traumatic stress disorder)**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bipolar disorder**</td>
<td></td>
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<td></td>
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<tr>
<td>OCD (obsessive compulsive disorder)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BPD (borderline personality disorder)</td>
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</tr>
<tr>
<td>Sexual abuse</td>
<td></td>
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</tr>
<tr>
<td>Gender identity and sexuality**</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Help for a partner, spouse, friend, family member</td>
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</tr>
<tr>
<td>Unemployment</td>
<td></td>
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<tr>
<td>Workplace issues**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting support**</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Domestic abuse</td>
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<td></td>
</tr>
<tr>
<td>Something else</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General venting</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Figure 31: Gap analysis

Figure 31 shows the difference between likelihood of reading and contributing on each topic, and is listed in order of the size of the gap in 2016. Some interesting things to note are:

- As we might expect, people are more likely to read than contribute in almost every area, with the exception of General Venting (and this year, also Domestic Abuse).

- There has been a reduction in the gap on many topics, suggesting a higher level of contribution overall, potentially due to a higher level of comfort or greater length of time on the forums (maturing population).

- There has been a particularly large decrease in the topic of Suicide and Self Harm (down to 6% from 14%) which could be attributable to the fact that this topic now has its own dedicated forum.

- There has been an increase in the gap in just one area (Explaining Depression to Family and Friends, up from 5% to 9%).
Rating of forum aspects

Views on ease of reading posts, ease of navigation, length of posts and general usefulness of the forums have remained steady, with a significant positive shift in views on comprehensiveness (total of those rating it as good or extremely good).

Of particular note is the significant increase in people who feel the speed of response to posts is good or extremely good, and people who felt that the quality of moderation is extremely good. The fact that more people are posting explains the significant decrease in those who ‘don’t know’ about speed of response to posts.

The older group (60+) were significantly more likely than other age groups to rate certain aspects as poor; this is true of Usefulness, Quality of Moderation, Speed of Response, Length of Posts and Impact on Life. Those who had triggered a serious or critical risk were also more likely to rate these aspects as poor (with the exception of Length of Posts).
5. Suggested improvements

An open-ended question at the end of the survey asked participants for their suggestions on improving the forums. These can be grouped into nine broad themes – ideas to facilitate engagement, ease of accessing relevant information, opportunities to connect further, touching base/updates, positive stories and inspiration, linking in, improvements to functionality, look and feel, content suggestions and building awareness. We note that some of the comments below may have already been addressed, but that the participant was unaware of this e.g. because they had not been back to the forums recently.

We would also note that there were a number of comments that the forums could not be improved, and even some resistance to the idea, as any significant chance of a beloved resource can be distressing.

a) Ideas to facilitate engagement

A number of people suggested an app, for flexibility of access. (If an app is planned, it might be nice to advertise it on the forums e.g. ‘Coming soon – a Forum app’.

Notifications when people have responded (with a one-click option to reply rather than log on and search through). Similarly, notification of activity on a ‘favourite’ forum:

“My Apple Mac allows me to set notifications as a desktop pop-up when an update from facebook, twitter or imessage is posted. Rather than an email notice of changes to posts etc., I would be more likely to engage further in forums if the desktop notifications facilitated me responding directly, rather than having to login, navigate the forum and then respond.”

“An email notification idea would have been good... since I found myself logging in constantly to check if I had a response to find myself being disappointed.”

And conversely, one requested being able to turn off notifications: “Sometimes I enter a thread and then I don’t want to see it again, like the BB Cafe with 100 posts a day - can we turn that off in our posts?”

Related to the two points above, some felt that an app could subtly encourage a continuous engagement: “I first accessed the forums during a brief moment where I desired help, the next day that fleeting feeling had passed and I was back to completely hopeless again. Perhaps having the
easy access, and some subtle notifications could encourage people when they are so close to getting help to continue on that path. The notifications could direct people to read previous threads about techniques different people have used, to normalise the situation and make them begin to realise they are not alone. Depression and anxiety can be exhausting so the first visit to the forums may not lead people to the threads that will ‘click’ for them or have the advice that they need to hear. Users could be surveyed on which topics were most helpful for them initially and these topics used to notify new comers and encourage them back. The notifications however would have to be subtle as this is often a very private struggle. Perhaps having an option to receive an email instead of a push notification would be helpful? Also the branding on the notification must be neutral so as not to expose people before they are ready."

Thinking about ways to increase the number of replies (and therefore variety of opinions): “I didn’t feel confident when the same name answered many messages from members. I don’t know the reason for that but maybe it felt less personal.”

Related to the above, some would like greater comfort to be built about posting; they would like to engage more but feel anxious about doing so. However, they are not sure how this could be achieved. [Perhaps a button on screen that says ‘Want to post but aren’t sure how? Click here’ (or similar)?] Some would also like more tips on how to provide support on the forums. Some suggested beyondblue should connect with new members, and guide them through the forums – we note that these people may not have been aware of the new Welcome and Orientation forum.

Some requested a chat room for more instant response and support (though some also acknowledged that there could be issues with this, especially if it was not moderated.)

A number of people felt that a topic of the week or month would help to facilitate engagement.

b) Ease of accessing relevant information

A search function, and/or Tags (which could help both to find and to avoid certain things)... “I have come across a method where users can flag messages that they don’t want to see. After a while, a pattern of the person’s preferences emerges and perhaps filters messages which would be more likely read by members.”

Ability to bookmark things you found helpful, so that you can go back to them the next time you aren’t feeling well.
c) **Opportunities to connect further**

... For example a **message inbox**, or a **buddy or penpal system**:

“I’d like to see how we could connect with each other more personally. I’m happy to keep the moderator and have limit to the amount of personal information shared, but a few members I would like to connect with without having to have a public conversation. I also see others having conversations that would be better off private. I guess I’m looking for a way to be ‘friends’ with people on the forum. And maybe there could be potential to share contact information if it was suitable. Maybe if two people both request for each other’s details? If you are looking for a major revamp to maximise the support the forum could be to people I’m wondering about how you could make support groups. People could get to know each other and their stories and you could avoid people getting lost in the thousands of posts. I notice many people come with a story, a plea for help, looking for someone to listen and then drift off. I have found myself coming back to the forum when I’m feeling lost and my normal supports feel too hard to connect with. At those times, probably getting a weird response from a random stranger isn’t so helpful, but sometimes I do get a response from someone who I think actually ‘gets it’. If you promote the forum as a support group and promote the online chat or phone call as immediate support, I could see your wonderful work as having the best reach. An idea of what it might look like:
- I sign up to join the forum
- I complete a simple survey to check what my immediate needs are. The survey also finds out a bit about me. - the results help to group me with others in a similar situation (parents, carer, depression, OCD, chronic pain etc)
- I get grouped with others that are reaching out at a similar time.
- you have a volunteer or community champion or whatever who facilitates the group.
- we connect easier as we are all at a similar spot and belong to a group, not just one of 100s floating in and out.
- I’d suggest starting a group of 15-20 and I imagine that a group of 5-10 would stick around longer term.
- I imagine the benefits of belonging, being able to connect at any time, talking freely with a sense of anonymity would all be increased above what currently exists.
- I also imagine that the people who come looking for support when they are at a really bad spot will get the most appropriate help too.
- the volunteer facilitator and the moderators would be able to better connect with people and not feel overwhelmed or see too many people slip through the cracks.”

“As wonderful as it is to have a community, someone who struggles with social anxiety may find that all they need is one person who’s going through what they are. Someone that can relate, that you can learn from and even teach. It might be a good way to for people who aren’t yet ready to deal with things in the real world to open up a little bit. It could be on the homepage as an option, answer a short survey and then randomly match two people together. This chats can be monitored with keywords and also would be a good way to get a better idea of the types of
people using beyondblue that aren’t very vocal about what they want from the site. All I ever wanted when I was growing up was to meet someone like me. I felt alone but too afraid to find help. This is an opportunity to safely and softly edge them into seeking support and feeling like they’re part of something rather than just one of a million.”

d) **Touching base/updates**

Following up e.g. a month down the track… how are you coping?

**Update/wrap-up option:** “Maybe you could have an UPDATE option so the original poster can come back and let everyone know how it all turned out and it can pop back up the top with a bold UPDATE in the front because when you read people’s posts it’s helpful for others to see how things worked out for different situations and people even years later you may read something similar to you and it will help you. Encouraging people to wrap up their post could help a lot of people.”

Some request **more email communication** (though this would need to be an opt-in) – from simple reminders the forums exist, to uplifting quotes. “Maybe sending e Alerts to keep beyondblue forums in the forefront of members minds. It’s really easy to forget you have that resource and support with you always.”

e) **Positive stories and inspiration**

A forum (or sub-section of each forum) dedicated to positive stories, especially stories of recovery, was suggested by a number of people: “I would really like to hear more about the inspirational stories from people who have their mental illness under control. They are motivating and make you realise that it’s normal to experience mental illness, especially when the illness itself makes you feel so alone. Emphasising that Beyond Blue is more of a community through the marketing would really help.”

A page for **inspirational quotes** was suggested by several… one also mentioned music. One person suggested that the quotes could be designed by beyondblue, watermarked and sharable, which would then help to increase awareness. One person suggested a **chill out room** called the Blue Room with calming videos and sounds.
Some people mentioned a **creativity and artistic expression** area which would encourage those who use the arts as a form of therapy, and may also encourage others to get involved. This could include being able to upload writing, art etc.

**f) Linking in**

There were several requests to **connect with mental health professionals** through live chat. One also suggested visits by experts to discuss particular issues which crop up e.g. workplace bullying or returning to work (something that the SANE forums do each week).

Some want to be **linked-in to other helpful resources** e.g. recommendations of books, local support groups, seminars, online courses, mindfulness and meditation techniques, exercise etc. Interactive sessions on meditation, nutrition, sleep etc. were also suggested – especially meditation and sleep for those accessing in the middle of the night. [Perhaps a ‘struggling to sleep?’ button?]

One person requested more links to counsellors and medical help by state.

**g) Improvements to functionality**

Some had experienced problems with the site being **slow**, taking a long time to refresh, freezing and dropping out which had been frustrating and distressing. There were requests for forums to be easily usable on different devices and platforms, and without using a lot of data.

Some also find the **layout difficult** and request better spacing of long posts, easier menus to scroll through topics and icons to identify threads: “A lot of posts are very long without any spaces to break them up. I find it much more easier to read when there are paragraphs. It would be nice if lengthy posts have spaces to create paragraphs… Perhaps also having some sort of icons next to threads to indicate threads I started, threads I replied to so that they can be found easier.”

Some mentioned **log-in/access issues**: “After you log into your account, it would be easier if you didn’t have to re-login once you click ‘my profile’, as it seems pointless to have to sign in again. Also, making the forums easier to access would be super beneficial, as once I sign in it is difficult to see where I access these (as that is the main reason I have a Beyond Blue account).”
There were also requests to have a shorter time lag between posting and it appearing on the forum – and to allow people to rewrite posts rather than changing it for them.

**h) Look and feel**

Some suggested that forums should give participants a real sense of ownership – that is, be clear when you land here that this is your forum. Feeling immediately welcoming (e.g. by having a welcome screen / home page that sets this tone for everyone, not just if you click into Welcome and Orientation) was also touched upon.

Having more videos (e.g. for people who can't read well) and more visible representation of diverse communities were both mentioned.

**i) Content suggestions**

A number of people requested the ability to discuss medications more openly… and potentially also good (if not “bad”) practitioners, helpful groups etc.

Some wanted to see more information on specific topics: for example gender dysphoria and a list of gender therapists; medication tolerance; CBT; resources for children and parents of those experiencing conditions were all mentioned.

Some wanted the forums to feel more active than reactive in content – especially in terms of posting the newest research and thinking. This may happen on the website more broadly, but some participants may no longer be going through the website home page.

**j) Increasing awareness**

A number of people suggested advertising to increase awareness and visibility (including of men’s forums e.g. at sporting or car events) – including advertising the forums more visibly on the website.
6. Differences by audience

We looked at specific groups of people of interest to beyondblue, to understand if and how their experience was different on the forums. We looked at significant differences in response to each answer between: those who had previously triggered a serious or critical risk on the forums, as compared to those who had not; those who had posted 20+ times, those who had posted 0 times or only once; males; LGBTI; older (60+) and younger (18-24); those living in regional and rural areas vs. those living in capital cities. The differences of particular interest and relevance for understanding the forum populations are summarised below.

Those who had previously triggered a Serious/Critical risk on the forums (as compared to those who had not triggered a risk):

Those who had triggered a critical or serious risk were more likely than those who had not triggered a risk to have:

- **Accessed the forums very recently**, and to access the forums frequently (more likely to have accessed within the last week, and to say they access daily or almost daily). However, they were also more likely to say they used to access the forums more in the past, but have not done so for several months. In some cases this might be because they felt better, but it might also be because they had not been happy with the experience (as they were more likely to rate the forum negatively on certain aspects – see detail below).

- **Scored 8-10 for feeling depressed before access, and also after access, and also more likely to have scored 8-10 for feeling anxious after access.** (Please note that this does not mean that they were more likely to feel worse after access, but rather that their depressed or anxious feelings were more likely to have remained on the higher side than those who had not triggered a risk.)

- **Have used the Suicidal Thoughts forum**, and to say they had accessed forums because they felt suicidal and wanted support; they were also more likely to report reading about, and also contributing to, suicide and self-harm topics.

There are also indications that they are **more likely to be active participants** (rather than ‘lurkers’) on the forums, as they are more likely to rank Starting Threads as their most preferred thing to do (and less likely to rank it as their least preferred), and to put reading or responding as their least preferred thing to do.

Unfortunately, those who had triggered a critical or serious risk were more likely than those who had not triggered a risk to:

- say they had not gained anything from using the forums;
• say they didn’t access any other form of support as a result of using the forums;
• say they had not made a lifestyle change;
• rank comprehensiveness, quality of moderation, usefulness, speed of response and impact on life as poor;
• say that the forums are not at all successful in meeting the needs of members, that forums do ‘not at all’ create a sense of community, or that being a member does ‘not at all’ help them to deal with their depression. They were also more likely to feel that members can ‘not at all’ be trusted, and that the forums do ‘not at all’ have members that make others feel welcome. All of this notwithstanding, however, they were more likely than those who had not triggered a risk to completely agree that it’s very important to them to be part of the forums.

Those who had triggered a critical or serious risk were more likely than those who had not triggered a risk to have accessed a health professional, to have called a non-beyondblue support line, and to have used beyondblue chat.

They were also more likely than those who had not triggered a risk to:
• say they wanted to connect in an anonymous way;
• be using the forums just to have someone to talk to about how they are feeling, and also to share their experiences and offer support to others (rather than being using the forms to access factual information about depression/anxiety – they were less likely than those who had not triggered a risk to be using the forums for these latter purpose). They were also more likely than those who had not triggered a risk to want to be able to, and to report they had been able to, think through and make sense of feelings by the exercise of writing them down.
• … and were less likely to report reading about and contributing to bipolar topics.

Analysis of the open-ended responses indicates that some of the more negative feelings and experiences of the forums of some participants who have triggered a serious or critical risk might be because some people were not happy with what took place when they triggered the risk (e.g. their post not being posted, feeling ‘censored’). The creation of the Suicidal Thoughts forum may help to address this to a degree by providing people with a platform to express feelings and thoughts that were previously blocked on the forums, so it will be important to observe if and how the negative views of some of this audience change over the course of the next year.

People making 20+ posts (as compared to 0 or 1 post):

Those who had made a comparatively large number of posts (at least 20) were more likely those who had made none, or at most just one, to have:
unsurprisingly, accessed a large number of forums, and accessed the forums quite recently, and quite frequently;

contributed to a range of topics areas (suicide / self-harm; general venting; help for a partner, spouse, friend, family member; bipolar disorder or domestic abuse).

Additionally, they were more likely to be interested in supporting others. For example they were more likely to:

- have accessed the forum because they wanted to provide help or support to other people;
- have hoped to gain an ability to communicate with others who know what they’re going through and be able to share experiences and offer support to others;
- have rated ‘ability to communicate with others who know what they’re going through’ as the most useful aspect of the online forums;
- have rated ‘being able to share experiences and offer support to others’ as an advantage of the online forum;
- have given a lower score for feeling depressed before access;
- think it is very important to feel a sense of community with other participants on the beyondblue forums.

Additionally they were more likely to say they had gained ‘being able to think through and make sense of feelings by the exercise of writing them down’; and an ‘ability to vent frustrations’ from the forums, which again fits in with the comparatively large number of posts they are making. They are more likely to have ranked ‘Starting Threads’ or ‘Responding / Participating’ as the more preferred activity on the forum, and less likely to rank ‘Reading Posts made by other people’ as the most preferred thing to do.

In terms of help-seeking, there are indications that this group are accessing help from a variety of sources, though not necessarily as a direct result of forum usage:

- more likely to have sought help from a health professional;
- more likely to have used the beyondblue website to seek support for depression, anxiety or other related life issues;
- more likely to have talked to a manager or co-worker about depression or anxiety; or to have got involved in a face-to-face support group;
- more likely to have consulted a counsellor;
- … but less likely to have sought help from health professional (e.g. GP, psychologist, counsellor, practice nurse) as a direct result of using the beyondblue online forums and less likely to have accessed none of the support as a direct result of using the beyondblue online forums.

Unsurprisingly given how often they had posted on the forum, they are more likely to feel mostly or completely that they put a lot of time and effort into being a member of the beyondblue forums, and that participating in the beyondblue forum is part of their identity, and they are less likely to not at all expect to be part of the beyondblue forums for a long time. They were more likely to have a high opinion of the sense of community on the forum, including being more likely to completely feel that
beyondblue forums have members that help others feel welcome, that participants of the beyondblue forums care about each other, and that beyondblue forums create a sense of community. They are more likely to completely feel that they can talk with members of the beyondblue forums when they have a problem; that it is very important to be part of the beyondblue forums; and that they care about what the other beyondblue forum participants think of them.

**Males (as compared to females):**

In terms of forum usership, males were of course far more likely than females to use the Male forum (and less likely to use the Female forum). They were less likely to use Anxiety, Relationship, Supporting Family, Young People and Trauma forums.

Further, compared to females, males tended to be more longstanding and frequent forum users; they were more likely to have accessed for the first time 1-3 years ago, less likely to have accessed between four and six months ago, and less likely to have only accessed the forums on one occasion.

Additionally, as compared to females, males were:

- less likely to have first accessed because they “didn't want to let family / friends know how I was feeling”;
- more likely to feel not at all anxious (0-3), and less likely to feel very anxious (8-10) before access; males were also more likely to feel not at all depressed or anxious (0-3) after access;
- more likely to put responding to posts as their first preferred activity, and less likely to put reading as their first preferred;
- more likely to read about unemployment, and less likely to read about domestic or sexual abuse, PTSD, panic attacks and coping with difficult emotions; and
- more likely to contribute to intrusive thoughts, unemployment and gender identity topics, and less likely to contribute to help for a partner or domestic abuse.

Other differences by gender suggest that males tended to have lower expectations of the forums than females. Specifically, they were less likely to have hoped to gain, or actually gained: an anonymous / confidential way to communicate; the ability to communicate with others who know what they’re going through; 24 hour availability of communication. Males were also less likely to have hoped to talk about how they are feeling. They were more likely to say they haven’t gained anything from the forums and, consistent with this, less likely to have gained factual information about depression / anxiety or an easy way to communicate.
Males overall were less likely than females to report having sought help from a range of sources outside of online forums, including a health professional, by talking to family or friend about depression or anxiety, the beyondblue website, or the beyondblue Support Service live online chat service. They were, however, more likely to have consulted a psychiatrist or a practice nurse. Consistent with this finding, compared to females, males were:

- more likely to have accessed no other support as a direct result of using the beyondblue online forums, and less likely to have accessed print resources or books about depression or anxiety (they were, however, more likely to have joined a face-to-face support group);
- less likely to have started / increased use of meditation/ mindfulness techniques or alternative therapies, or to have connected more with friends or family (they were, however, more likely to have reduced alcohol / drug intake).

Generally, males tended to express more negative views about the forums than females and were:

- less likely to rate as good (and therefore also more likely to rate as poor) comprehensiveness, quality of moderation, length of posts and impact on life, and also less likely to rate as good ease of navigation, usefulness and ease of reading posts;
- more likely to feel not at all: supported through being part of the beyondblue forums, that beyondblue forum members value the same things they do, that beyondblue forums are successful in meeting the needs of members, that being a member of the beyondblue forums helps them deal with depression and or anxiety, and that people in the beyondblue forums have similar needs, priorities and goals to me;
- more likely to somewhat feel they can trust people in the beyondblue forums, and give a rating of not at all towards beyondblue forums having members that help others feel welcome; and
- more likely to believe there are far or a few too many categories (and less likely to think there are just the right amount).

We know that females are more likely than males to use online forums as a whole (see citation in Demographics section above), and there are indications that the beyondblue forums are similarly weighted towards females (if we hypothesise that the survey response rate is somewhat representative of the forum population as a whole). Anecdotally, the open-ended responses suggest that some males are finding the environment to be too female-dominated – despite the fact that the majority of community champions are male. Overall, the more negative experiences of males as compared to females suggests that beyondblue may wish to take further consideration as to how to improve the environment for males on the forums and help them to feel more a part of the forum community.

LGBTI (as compared to not LGBTI):
Compared to those in the broader community, members of the LGBTI community were, unsurprisingly, more likely to use sexuality and gender identity forums. They were also more likely to:

- have first accessed the forums because they felt suicidal and wanted support;
- rate themselves 8-10 for depression and/or anxiety prior to access (but no more likely than the non-LGBTI group to do so afterwards afterwards);
- read about suicide and self-harm, sexual abuse, gender identity and sexuality, and more likely to contribute on these topics (as well as topics of explaining depression/anxiety to family/friends, and workplace issues); and
- give a ‘not at all’ rating towards trusting people on the forums.

In contrast, compared to those in the broader community, members of the LGBTI community were less likely to:

- read about relationship issues, help for a partner, or parenting support;
- have become aware of the forums through beyondblue advertising (however we note that no beyondblue advertising has specifically mentioned the forums in any case);
- be looking for factual information about depression/anxiety;
- disagree (0-3) that forums have caused them to feel more depressed/anxious by reading about the situations of others;
- completely feel that “when I have a problem I can talk about it with members of the beyondblue forums”.

These findings suggest that the forums are providing an environment that meets the needs of LGBTI members to a reasonable degree.

**Differences by age (60+ as compared to other age groups, and 18-24 as compared to other age groups):**

A large number of differences were observed by participant age.

Compared to other age groups, older participants, aged 60 years and over, were more likely to prefer more active pursuits on the forum i.e. rank Reading Posts as their 3rd preferred option after Starting Threads and Responding. In keeping with their age, they were more likely to have first accessed the forums more than five years ago (and it is possible that this longer-term use of the forums has contributed to their greater preference for starting threads and responding to threads, as comfort may have been built up over time).

In terms of what they like to do on the forums, they were more likely to read about coping with difficult emotions, explaining depression to family, medication side effects, PTSD and domestic abuse; they were also more likely to contribute to PTSD, and less likely to contribute to help for a partner, spouse,
friend, family member. They were less likely to be looking to vent, wanting to make sense of their feelings by writing them down, or tips or advice on how others have coped.

They were more likely to rate their feelings of depression before access, and also after access, as 0-3. But they were also more likely to respond pessimistically on a range of measures, including:

- say they haven’t gained anything (and were less likely to say they had actually gained tips or advice about how others have coped, or encouragement to seek professional help).
- feel that beyondblue forums members don’t at all help others feel welcome, feel that participants of the beyondblue forums don’t at all care about each other, not at all, expect to be part of the beyondblue forums for a long time or that beyondblue forums not at all create a sense of community
- believe the forums contain far too many categories.

Compared to other age groups, older participants, aged 60 years and over, were less likely to say they had reduced alcohol or drug intake than younger segments.

Consistent with this picture of older participants tending to be more pessimistic, younger participants tended to be more optimistic. Compared to other age groups, those aged 18-24 were:

- more likely to have talked to someone close to them about depression or anxiety as a result of using the forums;
- less likely to not at all think it is very important to me to be part of the beyondblue forums;
- more likely to mostly expect to be part of the beyondblue forums for a long time;
- more likely to think there are just the right amount of forum categories.

Regional and rural users (as opposed to those living in a capital city):

Despite their proportionately higher usership of the forums (described in the Demographic section above) there were comparatively few differences detected by whether survey participants lived in a regional centre or rural area, as compared to a capital city – and no differences which appeared to be meaningful, other than the fact that those outside of metro areas were less likely to contribute to the Unemployment forum. This is also in line with the findings from the 2015 report, and suggests that forums are doing equally well in meeting the needs of users from metro, regional and rural areas.
DISCUSSION

Participation in the beyondblue forums – while it is not for everyone – continues to be beneficial for many people suffering from depression, anxiety and other mental health conditions. 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;
- 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.

The various changes made to the forums during 2015 appear to have had a positive impact on user experiences, with overall significant shifts on a number of dimensions; these have been described in the body of the report and summarised all together in the Executive Summary above.

Particular areas which may benefit from further consideration

- There are still gaps, albeit slightly smaller than last year, between what people hoped to gain and what they actually gained. These are highest in anonymous/confidential way to communicate (20% gap), someone to talk to about how I am feeling (19%) and ability to communicate with others who know what I am going through (17%).
- About a quarter (24%) agree that they feel a sense of anxiety when responding to posts, and about 15% agree that forums create a fear of judgement.
- About 1 in 10 (11%) feel that the layout of the forum is daunting.
- While speed of response to posts has increased, about 1 in 10 (9%) feel this is poor.
- Consideration could be given to ways in which to improve the sense of community, along various dimensions including a sense of feeling supported, being able to talk about any problem, and having influence over what the forums are like.
- The large gap between the NSW population breakdown and forum participation could indicate a need for more target marketing in NSW.
- While increasing the number of forum categories is unlikely to be beneficial overall, a number do want to connect with more specific topics... A mechanism that allows them to search for a thread may help? Related to this, one person requested a way of being able to view relevant posts without having to enter each forum in turn: “There are a lot of categories that are
applicable to me, [so] it would be useful if you could do a search of the forums to include a combination. For example, I am a young woman who has difficulty with depression and anxiety, and suffers from workplace stress, [and] I have also experienced discrimination as a result of my condition. It’d be great if I were able to see relevant stories without having to go into each individual board.”

Participant suggestions for improvement have been described in Chapter 5 above. The development of an app, and notifications when receiving a response to a post (or even, when something is posted in an area you have flagged as being of interest) were seen as particularly important when it comes to driving traffic to the forums – and thereby potentially improving user experience further through more, and quicker, responses to posts. Building comfort around posting would be welcomed by the newer, less confident or more anxious forum users, and could perhaps become a clear part of the Welcome and Orientation forum, or a permanent button on the Home page. A positive stories forum, ‘guest’ health professionals, greater personalisation and ownership (which we understand is already underway) and occasional ‘touching base’ emails, particularly for those who have not been onto the forums for some time, were also suggested.

When it comes to improving the forum experience for particular groups of users, it appears that males are a key audience to consider further. While those who have triggered a serious or critical risk also report more negative feelings and experiences, there are indications that some of this dissatisfaction may have been addressed with the addition of the Suicidal Thoughts forum. However it will also still be important for beyondblue to continue to deal as sensitively as possible with those whose posts have been flagged.