

Focus group research for *beyondblue* with consumers and carers

Final Report

Report prepared for:
beyondblue

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FINAL REPORT

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April 2011

A report prepared for *beyondblue*

“I had a classic comment from a family member who was talking about my daughter’s illness and said ‘it’s all in her head’... Yes, it’s all in her head!”
[Carer_17]

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Note: All materials presented in this report are confidential and not to be distributed. This report represents the views of the authors alone, and not of SPRC, UNSW or *beyondblue*.

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Abbreviations

ANX	Anxiety
BIPOL	Bipolar Disorder
Carer	‘Carer-Only’ Participant
Cons	‘Consumer-Only’ Participant
ConsCar	‘Consumer and Carer’ Participant
DEP	Depression
GLBTI	Gay, Lesbian, Bisexual, Transgender, Intersex
NESB	Non English Speaking Background
NGO	Non Government Organisation
NSW	New South Wales
OCD	Obsessive Compulsive Disorder
PND	Postnatal Depression
PTSD	Post Traumatic Stress Disorder
SA	South Australia
SPRC	Social Policy Research Centre
SUBST	Substance Abuse
TAS	Tasmania
UNSW	University of New South Wales
VIC	Victoria

1 Executive summary

Introduction

beyondblue is a national not for profit organisation that was originally established by the Commonwealth and Victorian governments in 2000. Its overarching aims are to ‘increase awareness and improve treatment of depression, anxiety and related substance use disorders¹ and reduce the associated stigma’². More specifically, it has identified in its Strategic Framework For Action (2005 – 2010) that one of its five areas of priority³ is to ‘promote the needs and experiences of consumers and carers with policy makers and health care service providers’.

To better achieve these aims, *beyondblue* commissioned the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) in September 2010 to conduct focus group research with consumers and carers. Consumers are defined as people with personal experience of depression, anxiety and related substance use disorders, and carers are defined as family members and friends who care for consumers.

This study aims to: (i) comprehensively describe the range of needs and experiences of consumers and carers, and (ii) use these as the basis for developing practice and policy recommendations to *beyondblue* about how best to increase awareness, decrease stigma, promote its impact, and improve treatment. To do this, four key themes were explored in each of the focus groups. These were consumers’ and carers’ perceptions and experiences of:

- Community awareness of mental health issues;
- Stigma associated with mental health issues;
- The social and economic impact of mental health issues; and
- Treatment for mental health issues.

Method

This six-month study was conducted in three stages: (1) *Sept-Nov 2010*: setting up the focus groups; (2) *Nov-Dec 2010*: conducting the focus groups; and (3) *Jan-Feb 2011*: analysing and writing up the findings from the focus groups.

Stage 1 was comprised of several parts including: (a) *obtaining ethics approval* for conducting the study; (b) *conducting a literature and document review* to help inform

¹ In this study, the mental illnesses of focus were limited to depression, anxiety, and related substance use disorders. Thus, psychotic disorders such as schizophrenia have not been explored here.

² *beyondblue* (2010), Request for quotation for engagement of researcher / research team to undertake consumer and carer focus group research, unpublished.

³ The five strategic priorities of *beyondblue* are: (1) community awareness and destigmatisation, (2) consumer and carer support and participation, (3) prevention and early intervention, (4) primary care, and (5) targeted research.

the theoretical framework of the study and the design of the focus group schedules; (c) *designing three semi-structured focus group schedules* that were similar in themes and structure, but tailored for three pre-determined types of focus groups: ‘Consumers only’; ‘Carers only’; and ‘Mixed groups of consumers and/or carers’; and (d) *recruiting participants* from a diverse range of demographic backgrounds, including consumer/carer status, type of mental health issue, age, sex, region of residence (urban or regional), and cultural background.

Stage 2 involved *conducting the focus groups* in eight urban and regional sites across four Australian states: Melbourne (urban Vic⁴), Bendigo (regional Vic), Hobart (urban Tas), Burnie (regional Tas), Sydney (urban NSW), Tamworth (regional NSW), Adelaide (urban SA), and Mount Gambier (regional SA). These sites were selected to ensure that a diverse range of Australian voices were captured in this study.

Finally, Stage 3 involved: (a) *transcription* of the recorded focus groups⁵; (b) *thematic analysis* to explore if and how the four key themes (i.e. awareness, stigma, impact, and treatment) may be related to the aforementioned demographic variables; and (c) *writing up* the findings from the focus groups (the subject of this report).

Sample description

In total, 61 participants took part in this study. Of these, 32 (52.5%) were categorised as ‘consumers only’, 24 (39.3%) as ‘carers only’, and five (8.2%) as ‘consumers and carers’. Of the total sample (n = 61), 31 (50.8%) were from urban sites and 30 (49.2%) from regional sites. The age range was 17 – 78 years, with an average of 43.1 years⁶. There were 23 (37.8%) males in this study and 38 females. In regards to cultural representation, only three participants (5.1%) identified as Aboriginal and/or Torres Strait Islander, 10 (16.9%) identified as non-English speaking background (NESB), and the remaining 46 (78.0%) identified as Anglo⁷.

Type of mental health issue

Depression and anxiety were the two most common mental illnesses reported by the ‘consumers only’ as affecting them; 29 of 32 (90.6%) were diagnosed with depression, and 26 of 32 (81.3%) were diagnosed with anxiety. The ‘carers only’ were most commonly caring for a person affected by depression (16 of 24; 66.7%), anxiety (10 of 24; 41.7%), and/or bipolar disorder (11 of 24; 45.8%). Finally, the ‘consumers and carers’ reported that they were most affected by depression and anxiety (4 of 5 reported that they themselves have depression and/or anxiety, and 4 of 5 reported that they were caring for a person with depression).

⁴ Vic: Victoria; Tas: Tasmania; NSW: New South Wales; SA: South Australia.

⁵ Permission to record the focus groups was sought prior to conducting each group.

⁶ This data is based on the 60 of 61 participants who completed information on their age on the Demographics Survey (see Appendix B).

⁷ This data is based on the 59 of 61 participants that completed the question on ethnicity on the Demographics Survey. However, the two participants that did not complete this question appeared to be of Anglo background. Thus, some statistics in this study are based on a sample of 48 (and not 46) Anglo participants.

Although depression, anxiety, and bipolar disorder were the most common mental health issues affecting the research participants, a range of other mental health problems were also reported. These included: substance abuse, obsessive compulsive disorder (OCD), post traumatic stress disorder (PTSD) and post natal depression (PND).

Accessing of mental health services or programs and information

The extent to which participants reported accessing mental health services or programs, and information about mental health was captured in a short Demographics Survey. Interestingly, results showed that both consumers and carers have an overall preference for accessing information about mental health rather than engaging in mental health services or programs. This finding substantiates the importance of informal help. The results also showed that: (i) compared to the ‘consumers only’ and ‘consumers and carers’, ‘carers only’ accessed more information than services, and (ii) that males accessed less information than females.

Results of thematic analysis

Community awareness of mental health issues

Many participants believed that awareness of depression has increased in the last five to 20 years. This increase was primarily attributed to media coverage. Encouragingly, awareness of mental health issues was believed to be highest among young people. Unfortunately, awareness was seen to be low among general health professionals, such as GPs. Whether this perception reflects the extent of knowledge among health professionals or not, it is problematic because health professionals like GPs are often the first point of call for consumers and carers seeking formal help. Together, these findings support the continued use of the media and efforts to target young people, but that an intervention specific to general health professionals may be required to increase their awareness of mental health issues.

Stigma associated with mental health issues

Although participants believed that awareness of mental health issues had significantly increased, stigma was not seen to have decreased to the same extent (especially among families, at work, and among males and the older generation). This suggests that other factors mediate the relationship between awareness and stigma. Arguably, increased awareness helps the process of breaking down stigma, but that ultimately individuals need to take responsibility for any ignorance and/or fear they may have about mental health issues. When this occurs, mental health issues will be responded to in the same way as physical illness: as a treatable health issue over which people present with having no control. Indeed, being seen as weak or not able to cope is most probably related to misperceptions and/or expectations about how much control consumers have, and should have, over their mental health.

When families overestimate their (sense of) control – combined with the competing need for attention among family members, issues to do with family shame, and an expectation that consumers should take control over their mental health issue – a ‘hothouse’ of stress emerges. This can create the perception among some consumers that of all groups in the community, family members hold the most stigmatic attitudes.

Expectations of self-control also contribute to stigma and discrimination in the workplace. Negative attitudes such as being seen as lazy or incompetent, and difficulty getting or maintaining employment, respectively exemplify stigma and discrimination at work. Efforts to increase employers' understanding of mental health problems may help remove consumers' reservations to disclose, hide, or feel ashamed of their mental health issues.

The social and economic impact of mental health issues

The social and economic impacts of mental health issues are significant. Focus group participants described experiences of divorce, separation and loss of friendships. There were also significant psychological, financial and/or social costs as a result of consumers and carers not being able to work.

Moreover, results seem to indicate that carers of a family member who is not a partner (such as a child or parent) and who can share caring with, and receive emotional support from, their partners, are at an advantage compared to carers who are caring for their partner. Having said that, the stress for carers (regardless of who the consumer in the family is) cannot be underestimated, and awareness of the impact mental health issues can have on the lives of family members requires significant acknowledgment.

Treatment for mental health issues

Consumers expect family carers to provide on-going informal support. Without adequate additional support, this may eventually 'take its toll' on carers. Moreover, carers are not experts. Thus, it is important that formal treatment for mental health problems is sound. When provided well, the formal system has the capacity to act as a moderator; meeting the need for empathy in both consumers and carers. As this need is met, the insight consumers and carers have into the experience of the other may increase, and in turn help bridge the gap between them.

Unfortunately, the potency of stigma is still such that some people continue to resist seeking help early. Indeed, self-stigma – where consumers themselves feel weak, lazy, burdensome, or shameful – can drive consumers to go to great lengths to hide their mental health issues. This is problematic not only because of the extra burden of managing other people's response to their illness, but also because it becomes difficult to recognise symptoms and may prevent early intervention and hinder recovery. Thus, being open about the mental health issue is crucial for getting formal help.

Professional mental health treatment that is empathic, holistic, does not have a bias to medicate, credits the steps consumers make on their road to recovery, involves and values the knowledge of carers, encourages the use of support groups with fellow consumers, is resourced to respond to the episodic nature of mental health problems, is resourced to address co-morbid substance abuse, is readily accessible (especially during crisis situations, and in regional areas) and is affordable, are all crucial elements of a sound response to mental health issues.

Practice and policy recommendations to *beyondblue*

Based on suggestions made in the focus groups, this study has formulated possible objectives – in the form of practice and policy recommendations – that *beyondblue* can consider in their future planning for national consultation forums, programs and activities. Participants suggested that the best way to increase community awareness (especially among young people) is through the use of *media*, with both high profile and everyday people, and with an increased emphasis on positive recovery stories. Decreasing stigma may be assisted by changing the *language* used to describe mental health issues, with a particular avoidance of ‘mental illness’. The continuation of *qualitative research* and dissemination of research was recommended as an effective way to promote the social and economic impact of mental health issues because it is inclusive and thus bipartisan approach. Finally, *lobbying* for treatment that is holistic, empathic, affordable, evidence based, well resourced, standardised and centralised will help ensure it becomes robust.

Discussion and conclusion

Implementing change to reform the way in which Australia responds to mental health issues needs to occur at two levels. The first is a structural ‘top-down’ approach that ensures *all* people benefit from sound mental health infrastructure. The second is a ‘bottom-up’ approach that ensures a tailored and responsive service is provided to meet an individual’s needs. At both levels attitudes and behaviours also require redressing.

However, all the important elements that would fall within these two tiers were identified in the results from a focus group study conducted by *beyondblue* in 2001 – 2002 (and written up as their ‘Consumer and carer agenda’). Yet, little has changed in the last 10 years. The results of this study show that the same needs and barriers that consumers and carers were facing then, are still being reported now.

Dishearteningly, *all* the results from the 2001 – 2002 consultations were also found in the current study. This indicates that 10 years on, little has changed; the same needs and barriers are being perceived and experienced by consumers and carers. Some nuanced differences have occurred, however. It seems that community awareness has increased over time, but the depth of understanding about the nature, symptoms and the day-to-day experience of living with mental health problems has not. This indicates that a more aggressive implementation of the ‘consumer and carer agenda’ may be required to shift from awareness raising to improving the depth of society’s understanding.

Above all else, this finding seems to point to the stubbornness of stigma. Stigma seems to inhibit: (i) the full potential of awareness-raising campaigns, (ii) help-seeking behaviour in both consumers and carers, and (iii) a prioritised response to mental health problems by health care service providers and government. Thus, the stigma in both individuals and society are feeding each other; in turn, perpetuating and entrenching its potency.

Nevertheless, the results of this study strongly affirm the role and importance of organisations like *beyondblue*, that primarily aim to raise national awareness of depression and anxiety. Having a focal point that can draw attention to mental health problems is an essential element of a sound ‘mental health response’. In addition,

more funding to the organisations that deliver mental health services and programs is an equally essential part of the response. Equitably resourcing the two necessary tiers in the response to mental health issues – structural and grassroots – improves the chances of nourishing a positive feedback loop between individuals and society, and thus finally address what seems to be the fundamental issue: stigma.

2 Introduction

2.1 Project background

beyondblue is a national and independent not for profit organisation that was established in 2000 by the Commonwealth and Victorian governments, but is now also supported by the other state and territory governments, as well as private companies, research agencies, and community based organisations⁸. The need for the inception of *beyondblue* was long overdue, and its role in drawing attention and awareness to depression, anxiety and related disorders cannot be overstated. To name but a few reasons that support the importance of an organisation like *beyondblue*:

- On average, one in five people in Australia will experience depression at some point in their lifetime;
- Around one million adults in Australia and 100 000 young people live with depression each year;
- Depression is currently the leading cause of non-fatal disability in Australia, with less than 50% receiving medical care;
- Depression-associated disability costs the Australian economy \$14.9 billion annually, with more than 6 million working days lost each year;
- Depression costs the Australian community over \$600 million each year in treatment costs;
- Postnatal depression affects 14% of new mothers in Australia;
- Depression will be second only to heart disease as the leading medical cause of death and disability within 20 years;
- Depression-related suicide in Australia continues to rise with more than 200 deaths every month; and
- There is a shortage of appropriate service and care options for those with depression.⁹

The overarching aims of *beyondblue* are to ‘increase awareness and improve treatment of depression, anxiety and related substance use disorders and reduce the associated stigma’¹⁰. More recently however, *beyondblue* has identified five areas of priority in its Strategic Framework For Action (2005 – 2010). These areas of priority are: (1) community awareness and destigmatisation, (2) consumer and carer support and participation, (3) prevention and early intervention, (4) primary care, and (5)

⁸ *beyondblue* (2005), Strategic Framework for Action (2005 – 2010) .

⁹ *beyondblue* (2005). The Way Forward (2005 – 2010).

¹⁰ *beyondblue* (2010), Request for quotation for engagement of researcher / research team to undertake consumer and carer focus group research, unpublished.

targeted research. Further, within its second area of priority – to support and involve consumers and carers – *beyondblue* specifically aims to ‘promote the needs and experiences of consumers and carers with policy makers and health care service providers’⁹.

To better achieve the overarching and specific aims of increasing community awareness, decreasing stigma, promoting the needs and experiences of consumers and carers, and improving treatment, *beyondblue* commissioned the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) in September 2010 to conduct focus group research with consumers and carers. In this study, consumers are defined as people with personal experience of depression, anxiety and related substance use disorders, and carers are defined as family members and friends who care for consumers. Importantly, the five areas of priority are not mutually exclusive and thus although the current research falls under the business of priority area two, findings from this study may also help inform the other four priority areas.

2.2 Literature and document review

Based on the aims of this study, four key themes were explored. These were consumers’ and carers’ perceptions and experiences of:

- Community awareness of mental health issues;
- Stigma associated with mental health issues;
- The social and economic impact of mental health issues; and
- Treatment for mental health issues.

To ensure that the four key themes for exploration in this study were informed by previous research, and that the questions and prompts in the focus group schedules were relevant and appropriate, a literature review of scholarly research and relevant documents was conducted. Recent national and international research and literature on depression, anxiety, and related disorders was scoped from journal articles obtained from psychology and social science databases including PsycINFO and Sociological Abstracts. Internet searches using Google Scholar were also used. The relevant practice and policy documents reviewed in this study were those provided by *beyondblue*, and included internal and publically available documentation, such as strategic or other planning documents, annual and other key reports, and findings from the 2001 – 2002 consultations¹¹. Together, the academic literature and policy documents were also used to establish the theoretical framework of this study (see Section 2.3).

Community awareness of mental health issues

The literature seems to indicate that community awareness about mental health issues has increased in recent years. For example, the number of visits to the *beyondblue*

¹¹ See Section 2.4.

website (a proxy measure of community awareness) rose from approximately 8,000 in 2001 to about 35,000 in 2004¹².

However, the degree to which this apparent increase in awareness has directly improved the everyday lives of people affected by mental health issues is not known. Thus, one objective of this study is to explore if and how campaigns and programs to promote community awareness about mental health are perceived to have had a positive effect on the lives and experiences of consumers and carers.

Stigma associated with mental health issues

Stigma refers to negative connotations, and usually produces feelings of shame in members of the stigmatised group. In this case, it can manifest either as negative attitudes to people with mental health issues (i.e. prejudice), or negative behaviours toward people with mental health issues (i.e. discrimination) (Angermeyer and Matschinger, 2003). *beyondblue* recognises that stigma, and the associated prejudice and discrimination, are difficult to overturn. Indeed, in their Strategic Framework (2005 – 2010, p. 8), it states:

It cannot be claimed that in its first term *beyondblue* completed the task of providing national focus and leadership in depression awareness to a sustainable level, nor increased the capacity of Australians to prevent depression. It cannot be asserted that Australian society now understands and responds to the personal and social impact of depression, without stigma and discrimination. It is clear and certain that there is important work to be continued.

While it may be slow or difficult to overturn such pervasive barriers, it is still crucial to monitor the extent to which stigma is perceived to affect the lives of consumers and carers. In doing so, any decreases in stigma can be acknowledged, and any increases in stigma can be more quickly addressed. Importantly, the nature of stigma may manifest differently for different groups in the community, and this needs to be identified to ensure that mental health services and programs are locally and flexibly responsive to smaller group-based needs.

Social and economic impact of mental health issues

Extensive research shows that mental health issues have an impact on several areas of people's lives including their relationships with family and friends (Huxley and Thornicroft, 2003; Lewinsohn, 1974), their involvement in social and community activities (Muir et al. 2010; Minato and Zemke, 2004), and their ability to work and study (e.g. McNair, Highet, Hickie, & Davenport et al., 2002). Thus, there is a large social and economic cost to the inclusion and participation of consumers and carers in society. Importantly, the social and economic impact of mental health issues is entwined with community awareness of, and the stigma associated with, mental health issues.

¹² *beyondblue* (2005). The Way Forward (2005 – 2010).

In regards to the impact that mental health issues have on relationships with family and friends, consumers tend to feel isolated (Byrne, 2000; Link, 1997), and carers themselves tend to report depression or anxiety (Arksey, 2002; Arksey, 2003). For both groups, these experiences can compromise the protection offered by social support networks. Thus, it is crucial to understand the nature and extent of how social relationships are affected by mental illness and in turn, the extent to which these can and should be addressed in primary care (such as family counselling).

Economic issues such as loss of productive work time (Whiteford & Buckingham, 2005) may result from barriers to full employment and educational access. Similarly, it is important to explore the extent to which consumers and carers perceive economic constraints as a result of mental health issues, as this information can then help inform targeted and informed strategies for overcoming financial loss.

Treatment for mental health issues

There is an extensive literature base on what constitutes effective treatment for mental health issues. Importantly, treatment can be either formal or informal. Informal help refers to the social protection that family and friends can offer, but also includes self-help techniques (e.g. books). Formal help can include psychological interventions (including 'cognitive behavioural'-type interventions such as dialectical behavioural therapy, problem solving therapy and third wave cognitive therapies such as mindfulness based cognitive therapy and acceptance & commitment therapy, interpersonal therapy, supportive therapy, psychoanalysis and psychodynamic therapies, family therapy, play therapy, art therapy, bibliotherapy and psychoeducation) and biological interventions (including medications, electroconvulsive therapy, transcranial magnetic stimulation, deep brain stimulation, psychosurgery and nutraceuticals) (headspace, 2011).

Yet, barriers to seeking informal and formal help still occur. For example, research has shown that help seeking behaviour is affected by attitudes about the effectiveness of non/pharmacological treatments (e.g. Hickie, Pirkis, Blashki, Groom & Davenport, 2004; McNair et al, 2002); accessibility of services, especially for people in regional areas (Rajkumar & Hoolahan, 2004); stigma, pride, attitudes and fear (Jorm, et al., 2007).

Indeed, treatment that is appropriate, relevant, and sustainable may be improved by awareness of the barriers to seeking formal and informal help, the factors that facilitated overcoming these barriers, perceptions and experiences of 'what worked' with treatment, and suggestions for how to engage with consumers and carers early to help prevent the escalation of issues. Thus, four topics related to treatment were explored in this study:

- Barriers to seeking help;
- Facilitators of seeking help;
- Examples of effective and ineffective treatment; and
- Suggestions for improving prevention and early intervention.

2.3 Theoretical framework

Based on the review of the literature and documents, this study proposes that there are two important and necessary tiers for effective service delivery. The first stresses the importance of structural or systemic efforts to increase community awareness, decrease stigma, promote awareness of its impact, and improve treatment; these efforts help ensure that *all* individuals benefit from a system that is sensitive to and aware of mental health issues. The second tier draws attention to the fact that the impact of depression, anxiety, and related disorders is unique to the individual consumer and/or carer, and thus it is also important that within a system that is sensitive and aware, treatment places the individual at its centre so that it can be tailored to meet individual needs.

Thus, the theoretical framework of this project is that there are two important and necessary tiers for promoting and understanding the needs and experiences of consumers and carers, and which should be used in conjunction with one another. The first is a ‘top-down’ approach that emphasises structural or systemic factors for improving the lives of all people affected by mental health issues. The second is a ‘bottom-up’ approach in which the lives of individual people affected by mental health issues are improved by taking a flexible, local and responsive stance to treatment.

2.4 Aims and objectives

There are two main aims of this study. The first is to holistically explore the needs and experiences of consumers and carers. However, consumers and carers are a highly diverse group; they have unique experiences and come from a range of backgrounds. To ensure that a diverse range of Australian voices were captured, this study targeted people of different:

- Consumer and/or carer status;
- Type of mental health issue (with a focus on depression and anxiety because of the *beyondblue* target group);
- Region of residence (urban or regional);
- Age;
- Sex; and
- Cultural background.

These groups were also selected to build and expand on a previous qualitative consultation conducted by *beyondblue* in 2001 – 2002. In the previous study, the sample was limited to adults residing in urban areas only. In the current study, young people (16 – 24 years old), those residing in regional areas, and people from a

NESB¹³ have been specifically targeted to address the limitations in representation from the previous study.

Additional attempts to include the voices of Indigenous¹⁴ Australians were made at each of the eight focus group sites, however a single focus group comprised only of Indigenous Australians was not targeted. Efforts were also made to ensure the representation of GLBTI (Gay, Lesbian, Bisexual, Transgender, and Intersex) Australians, however again they were not targeted as an individual focus group in the study. This represents a limitation in the current study and future targeted research on the needs of Indigenous and GLBTI Australians is required.

The second aim of this study is to use the diverse needs and experiences of consumers and carers as the basis for making recommendations to *beyondblue* about how best to improve community awareness, reduce the associated stigma, promote awareness of its impact, and improve treatment. These practice and policy recommendations can then be fed back to the consumer and carer community through relevant forums and publications.

In short, the two main aims of this study are to:

1. *Explore the range of needs and experiences* of various consumer and carer groups in Australia; and
2. *Develop practice and policy recommendations* to increase community awareness, decrease stigma, promote the social and economic impact of mental health issues to policy makers and health carer service providers, and improve treatment.

2.5 Significance of the project

There are a number of strengths of this project. The first is that it is exploring the needs of both consumers and carers. While a significant amount of research has been conducted on the needs and experiences of consumers, relatively less research has been conducted on the needs and experiences of carers. Indeed, one significant contribution of *beyondblue* has been to put the needs of carers on the mental health agenda. Thus, one main strength of this study is that it is able to demonstrate equal value for both consumers and carers, and in turn use a whole-of-community approach to improving the welfare and wellbeing of all individuals whose lives are affected by mental health issues. Having said that, it is still crucial that ongoing research be conducted on the needs and experiences of consumers. In this way, the challenges they face in relation to their psychological wellbeing, sense of inclusion, and ability to participate fully in society are continuously monitored over time.

¹³ People of NESB are those who originate from countries in which English is not the main spoken language, and is synonymous with the term 'Culturally and Linguistically Diverse' (CALD) in the Australian policy literature. However, 'CALD' has not been used in this study because the term is less clear about whom it refers to than 'NESB' (Sawrikar & Katz, 2008).

¹⁴ In this report, 'Indigenous' has been used synonymously with Aboriginal and/or Torres Strait Islander ('ATSI').

A second strength of this study is its use of the qualitative methodology of focus groups. Qualitative research is an important empirical tool because unlike quantitative research, in which the *extent* to which people's lives are affected by mental health issues is explored (i.e. 'how much'), qualitative research explores the *nature* of how people's lives are affected by mental health issues (i.e. 'what, how, and why'). Thus, qualitative focus groups take a holistic approach to people and give a direct voice to the group of interest (in this case, consumers and carers), to identify what group members themselves consider relevant and important to their wellbeing.

A third strength of this study is that the results can be compared to the findings from a series of previous qualitative consultations conducted by *beyondblue* in 2001 – 2002. That is, there is a unique opportunity to conduct a 'quasi-longitudinal' comparison and examine which issues or themes have since remained, which have been addressed since then, and which have emerged in the last 10 years. Indeed, it is important to be able to explore and compare such changes across time so that the extent to which community awareness has increased, stigma has decreased, promotion of its impact has increased, and treatment has improved, can be empirically examined.

An additional strength of this study is that it is exploring a wide range of consumer and carer groups, and thus the diversity associated with mental health issues. Indeed, the demographic groups targeted in this study were specifically selected to build and expand on the previous consultations conducted by *beyondblue* in 2001 – 2002. In the previous study, the sample was limited to adults residing in urban areas only. In the current study, young people (16 – 24 years old), those residing in regional areas, and people from a NESB have been included to address the limitations in representation from the previous study. This is consistent with *beyondblue*'s strategic plan (with the exception of Indigenous Australians) which states, "with the new five year term, *beyondblue* will address the needs of rural and regional Australia, Indigenous Australians, and culturally and linguistically diverse communities" (The Way Forward 2005 – 2010).

Finally, the results of this study can be used by a wide audience. Although this research was conducted for *beyondblue* who identified a target audience of policy makers and health care service providers, the findings could also be used by other relevant key stakeholders and peak bodies, to develop their evidence-based practice and policy guidelines and thus improve the lives of consumers and carers affected by mental health issues. Moreover, the findings from this study can be directly used by consumers and carers themselves.

3 Method

3.1 Research timeline and outputs

There were three stages involved in this six-month project:

1. *Sept-Nov 2010*: Setting up the focus groups;
2. *Nov-Dec 2010*: Conducting the focus groups; and
3. *Jan-Feb 2011*: Analysing and writing up findings in the report to *beyondblue*.

3.2 Stage 1: Setting up the focus groups

Within Stage 1, *beyondblue* provided the UNSW research team with relevant documents for review; a Project Plan constituting the project initiation document and outlining the planned approach and timeline for the project was designed by UNSW and approved by *beyondblue*; a literature and document review was conducted; three focus group schedules were developed; and *beyondblue* recruited participants and organised dates, times and venues for the focus groups in each of the eight sites. Stage 1 also included seeking and receiving ethics approval to undertake this research. Ethics approval was obtained in October 2010 from the UNSW Human Research and Ethics Committee (HREC). This project meets the principles outlined in *The National Statement on Ethical Conduct in Research Involving Humans*, and the UNSW's *Code of Conduct for the Responsible Practice of Research*, which sets out the obligations that all University researchers must abide, including confidentiality, freedom to withdraw, privacy and voluntary participation. As part of the ethics process, Information and Consent Forms were distributed to and collected from every focus group participant (see Appendix E). An easy read version of this Form was given to the youth and NESB participants (see Appendix F).

Development of focus group schedules

Based on the literature and document review, three focus group schedules were developed so that consultations could be conducted with groups of:

1. Consumers only;
2. Carers only; and
3. Mixed groups of consumers and/or carers.

Despite slightly different instruments being used for each of these three groups, the instruments followed the same four key themes to ensure systematic analysis and comparison. Each key theme also included sub-themes or 'prompts', identified from the literature and document review. Not all prompts were followed up during the focus groups, but were included on all focus group schedules so that they were readily available if required. Only the relevant prompts were used, as was appropriate and responsive to the groups' discussion in each focus group.

The questions in the focus group schedules were designed to be broad enough to ensure that consumers and carers could identify with the topics of discussion, and discuss their experiences, perceptions and areas of significance to their lives. The

instruments were semi-structured to ensure the focus groups were effective (i.e. relevant and efficient). See Appendix A for detailed information on how each question in the focus group schedules (and the prompts derived from literature and document review) matches to the four key themes of this study.

Site selection and sample recruitment

To ensure that a diverse range of consumer and carer voices were captured in this study, eight focus groups were conducted across urban and regional sites in four Australian states. The eight sites were selected by *beyondblue*. Of the eight focus groups, three were targeting ‘consumers only’, three were targeting ‘carers only’ and two were targeting a mix of ‘consumers and/or carers’. Also, one group targeted ‘youth-only’ (16 – 24 year olds) and one targeted ‘NESB-only’ (See Table 1).

Table 1: Focus group sites and types

	Site of focus group		Type of focus group			Targeted group	
	City	Urban/ Regional	Consumer only	Carer only	Consumer and/or carer	NESB	Youth
1	Melbourne	Urban VIC	✓				✓
2	Bendigo	Regional VIC		✓			
3	Hobart	Urban TAS	✓				
4	Burnie	Regional TAS			✓		
5	Sydney	Urban NSW			✓	✓	
6	Tamworth	Regional NSW		✓			
7	Adelaide	Urban SA		✓			
8	Mt Gambier	Regional SA	✓				

Consumers and carers were primarily recruited from *beyondblue*’s national consumer and carer reference group, blueVoices¹⁵, living in the local area of these eight sites. To supplement recruitment, especially for people from the Indigenous and GLBTI communities, local mental health services and organisations were asked to recruit

¹⁵ blueVoices is *beyondblue*’s national consumer and carer reference group. Anyone in Australia with personal experiences of depression, anxiety, perinatal depression/anxiety or bipolar disorder can join blueVoices. The reference group also includes carers – family members and friends who care for and support people with these illnesses. blueVoices members share their perspectives across the work of *beyondblue*, including advising on national mental health policies and programs, provide consultation on the development of *beyondblue* community awareness campaigns and information resources, sharing their experience in the media and at public events and participating in depression and anxiety-related research projects. blueVoices was established in 2002 and has evolved into an email-based group (e-group). The e-group structure allows for a large, representative and diverse membership, and increased accessibility for people across Australia to provide input into *beyondblue*’s work (2009/10 *beyondblue* Annual Report).

potential participants¹⁶. Administrative staff from *beyondblue* that were not involved in the project were responsible for recruitment, and a Recruitment Flyer was used to help recruit participants (see Appendix C).

3.3 Stage 2: Conducting the focus groups

Stage 2 involved conducting the focus groups. The duration of all the focus groups was between 2 – 2.5 hours. Each participant was provided with an Information Statement and Consent Form. A plain-English version of this Form was provided to the two targeted ‘youth’ and ‘NESB’ groups. Each group was digitally recorded for accuracy and permission to record the discussion was sought prior to the focus group. At the completion of the focus group discussion, participants were asked to complete a short Demographics Survey (see Appendix B). Finally, all participants were reimbursed travel costs and were offered \$100 cash as a sign of appreciation for their time and for sharing their perceptions and experiences (see Appendix D).

3.4 Stage 3: Analysing and writing up findings from the focus group

Within Stage 3, all the voice files were transcribed; key themes and recommendations from the focus groups were identified, along with the findings from the literature and document review, in a draft report submitted to *beyondblue*; and a final report was approved by *beyondblue* (the subject of this report). The research team will also plan, conceptualise and consider journal articles, however these articles fall outside of this project.

Thematic analysis

Thematic analysis was used to analyse the data. This involved the development of a coding framework, which was based on key themes identified from the existing literature and the focus group instruments. A small sample of the consultation data was then cross-referenced against the coding framework to validate its relevance, and appropriate changes were made (such as the addition or deleting of themes). All focus group data was transcribed, coded based on the validated coding framework and then analysed to determine the research results.

The data from the focus groups was analysed not only across key themes but also to understand the similarities and differences across a range of relevant demographic factors including:

- Consumer and/or carer status;
- Type of diagnosis;
- Urban or regional residence;
- Age;
- Sex; and

¹⁶ This is an arms-length approach consistent with ethics protocol to minimise perceived coercion to participate.

- Cultural background.

3.5 Methodological benefits and limitations

Benefits

As stated in their Strategic Framework (2005 – 2010), *beyondblue* emphasises the importance of using a ‘bipartisan’ approach; consultations that are inclusive and participatory. The methodological design of this project is consistent with this approach, as consumers and carers themselves have been invited to take part in this study and provide suggestions for how to improve mental health service delivery. Thus, one main benefit of this study is that recommendations for how best to improve community awareness, reduce stigma, promote the impact of mental health issues to policy makers and health carer service providers, and improve treatment have come from the direct voices of those whose lives are impacted by these issues.

As stated previously (see Section 2.5) one main benefit of this study is the use of qualitative research methods. Focus groups are a unique opportunity to explore the nature of mental health issues in the everyday lives of people. Moreover, by including 6 – 8 people in each group, the diversity associated with mental health issues can also be explored. Thus, the nuanced and individualised experience of mental health issues can be captured in a way that quantitative research is not able to. Further, the holistic methodology of qualitative research – exploring the whole person rather than just segmented or discrete aspects of them – means that the results of qualitative research reap the same rewards.

Participants were given an opportunity via the Demographics Survey to record any other thoughts or feelings that they did not get the chance, or feel comfortable, to raise during the focus group. Some participants used this as opportunity to record some benefits of the study. For example, some participants said: “a rewarding and informative session” [Carer_17]; “I found the session very helpful and would thank those involved” [ConsCar_3]; “thank you” [Cons_14]; and “I felt it was a great opportunity to share my experiences with others and build my understanding of other people’s experiences. I hope to do this again soon, as I find it very beneficial” [Cons_3].

Limitations

Although there are significant methodological benefits of this study, there are also some methodological limitations. For example, focus groups that involve 6 – 8 people do not allow for an as in-depth exploration of issues as is permitted with a one-on-one interview. Consistent with this, one participant recorded on the Demographics Survey that they “would have enjoyed it more if the participants input was directed more. I think some people would have contributed more – but didn’t get a chance” [Cons_8].

Indeed, moderating a focus group to ensure that some participants do not dominant discussion is a difficult but inherent problem associated with the methodology of focus groups. Thus, although we acknowledged that this was an issue we were likely to face, we were also keen to ensure that as many diverse and different voices were represented in this study and that these voices and views were able to bounce off each

other. As a result, the methodology of focus groups over one-on-one interviews was selected.

The other limitation with this study is in relation to the sample. While the results have been written to reflect the views and experiences of consumers and/or carers with mental health issues, the majority of individuals had depression and/or anxiety and several of them were already aware of and somewhat involved with (on an email list) *beyondblue*. Having said that, a diverse range of mental health issues were brought up by the participants and so this report talks generally about mental health issues, rather than just depression and anxiety.

A further limitation of this study in regard to the sample is the representativeness of some groups. Attempts to include the voices of Indigenous and Gay, Lesbian, Bisexual, Transgender, and Intersex (GLBTI) Australians were made, however a single focus group comprised only of Indigenous or only of GLBTI Australians was not targeted. This represents a limitation in the current study and future targeted research on the needs of Indigenous and GLBTI Australians is required. Moreover, this study found that recruitment of these groups was relatively more difficult. This may be because research is not be a process they are accustomed to, familiar with, and/or trust. Indeed, culturally appropriate methodology with Aboriginal and Torres Strait Islander communities emphasises the importance of face to face and verbal dialogue to enhance trust, participatory action, and relationship building (Cochran, et al, 2008; Ivanitz, 1999).

4 Sample description

Eight focus groups were conducted across urban and regional sites in four Australian states, and there were between 6 – 8 consumers and/or carers per group. In total, there were 61 participants that took part in this study.

4.1 Consumer/carer status

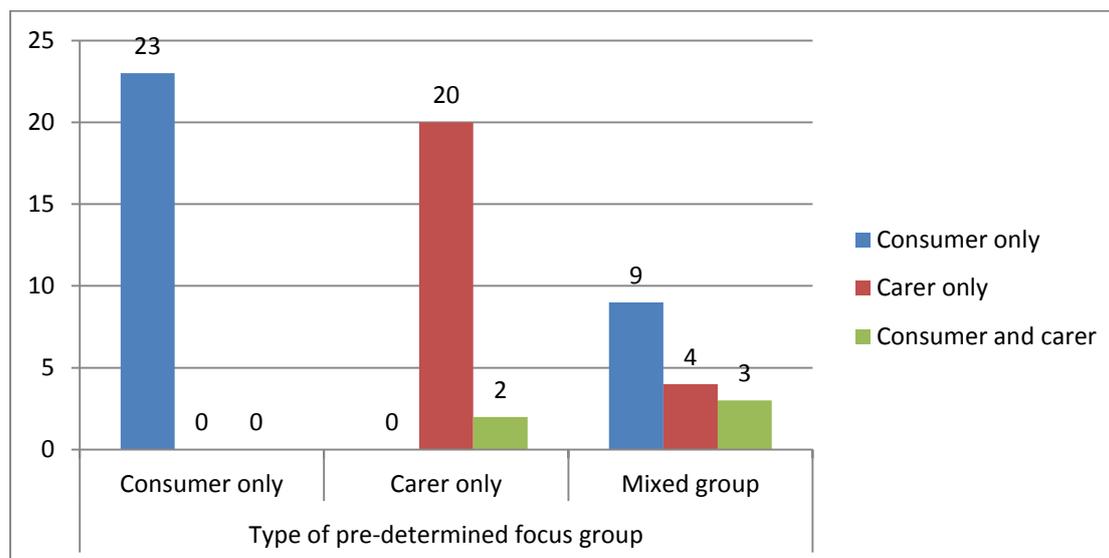
Based on information obtained during the recruitment phase, participants were invited to attend one of three pre-determined types of focus groups: (1) consumer only, (2) carer only, and (3) a mixed group of consumers and/or carers. In the analysis of the data, participants were re-categorised as either a ‘consumer only’, ‘carer only’, or ‘both consumer and carer’ using the information they provided on the Demographics Survey and during the focus group.

In this study, a ‘consumer only’ was defined as a person with personal experience of depression, anxiety or related issues and who was not significantly¹⁷ caring for another consumer. On the other hand, a ‘carer only’ was defined as a person significantly caring for a consumer and that any of their own personal experiences of depression, anxiety or related issues occurred as a direct result of their caring role. Finally, a ‘consumer and carer’ was defined as a person with personal experience of depression, anxiety or related issues, who was significantly caring for another consumer, and whose own mental health issues may or may not be directly related to their caring role.

As can be seen from Figure 1 (and Data Table 4), all of the participants in the pre-determined ‘consumer only’ focus groups were categorised as ‘consumers only’ in this study (n = 23 of 23). Most of the participants in the pre-determined ‘carer only’ focus groups were categorised as ‘carers only’ (n = 20 of 22). Finally, most participants in the pre-determined mixed groups of consumers and/or carers were categorised as ‘consumers only’ (n = 9 of 16), and the remaining participants were categorised as ‘carers only’ (n = 4 of 16) or ‘consumers and carers’ (n = 3 of 16).

¹⁷ The researchers acknowledge that it is difficult to operationalise or quantify the extent to which a caring role can be considered ‘significant’. A decision regarding the level of ‘significance’ was based on information provided by the participant in the focus group; comparing the impact they described of the personal experience of depression, anxiety, or related issues on their lives to the impact of their caring role on their life.

Figure 1: Re-categorised consumer/carer status by type of pre-determined focus group



Thus, of the total sample (n = 61), there were 32 ‘consumers only’ (52.5%), 24 ‘carers only’ (39.3%), and five ‘consumers and carers’ (8.2%). The over-representation of consumers compared to carers in this study may be reflective of a general difficulty in recruiting carers, as it replicates a similar finding reported by Langlands, Jorm, Kelly & Kitchener (2008). As stated in their study: “one of the difficulties we encountered in conducting this study was recruiting carers. A possible explanation for our comparatively low number of carer panel members is that many people who care for partners, family members or friends with depression may not identify themselves as caregivers. This may be due to the relatively high level of functioning maintained by many people with depression in comparison to others with chronic mental illnesses” (p. 164).

4.2 Residence, age, sex, and cultural background

Residence

There was equal representation of participants from urban and regional areas in this study. Of the total sample (n = 61), 31 (50.8%) were from an urban area and the remaining 30 (49.2%) were from regional areas.

Age

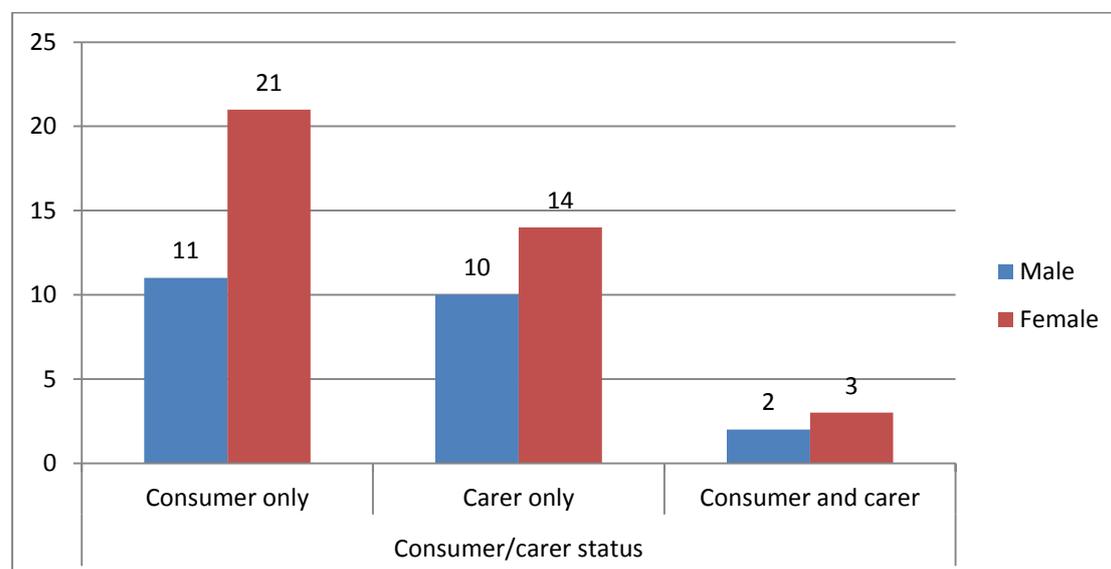
The participants ranged in age widely from 17 – 78 years, and the average age was 43.1 years. Thus, although people aged 16 years and up were invited to take part in this study, the youngest person who did take part was 17 years old.

Sex

Of the total sample (n = 61), 23 participants (37.7%) were male. When the sample was split by consumer/carer status (see Figure 2 and Data Table 5), the gender difference was greatest among ‘consumers only’; there were more ‘consumer only’ females (n = 21) than ‘consumer only’ males (n = 11). Although the representation of

males in this study is lower than females, this distribution is consistent with previous research on mental health (e.g. Eerola, et al, 2005; Littman, et al., 2010).

Figure 2: Number of participants by sex and consumer/carer status



Cultural background

Of those who completed the relevant question on the Demographics Survey (n = 59), 46 participants identified as Anglo (78.0%). Of these, 22 were ‘consumers only’, 20 were ‘carers only’, and four were ‘consumers and carers’¹⁸ (see Table 2).

Three of the 59 participants (5.1%) identified as Aboriginal or Torres Strait Islander, and all of these were ‘carers only’. Ten of the 59 participants (16.9%) identified as NESB, and of these eight were ‘consumers only’, one was a ‘carer only’, and one was a ‘consumer and carer’. The NESB participants came from a range of cultural backgrounds including China, France, Hong Kong, Italy, Iran, Laos, Lebanon, and Taiwan. Several NESB participants were born in Australia, and of those born overseas the minimum length of residence in Australia was 20 years. Thus, the NESB sample in this study are either second generation Australians or long term immigrants; caution should be exercised when making inferences about recently arrived people of NESB in Australia. Also, several of the NESB participants (n = 6 of 10) spoke a language other than English at home.

While there is representation of different cultural groups in this study, the representation is not equal. Thus, caution should be exercised when making generalisations about the study results to each of these broader communities, most especially those of Indigenous Australians.

¹⁸ Note: Two participants did not record their ethnicity on the Demographics Survey, however they appeared to be of Anglo background. Thus, the total sample of Anglo participants that has been used in this study is 48. Also, these two participants were ‘consumers only’.

Table 2: Number of participants by cultural background and consumer/carer status

Cultural background	Consumer/carer status			Total
	Consumer only	Carer only	Consumer and carer	
Anglo	22	20	4	46
Aboriginal and Torres Strait Islander	0	3	0	3
NESB	8	1	1	10
Total	30	24	5	59*

* Two participants did not record their ethnicity on the Demographics Survey

4.3 Type of mental health issues

Participants were asked on the Demographics Survey to identify the mental health issues they have or were experiencing. As mental health problems are not mutually exclusive, and participants could report several diagnoses, the frequencies reported here do not tally up to the number of participants in each of the three types of consumer and/or carer groups.

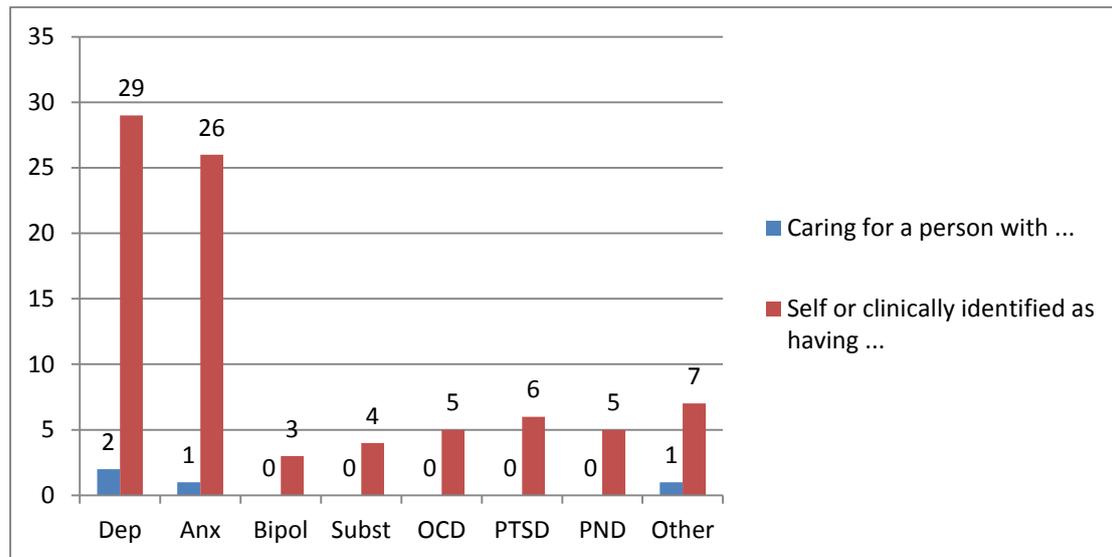
Consumers only

As can be seen from Figure 3 (and Data Table 6), most of the ‘consumer only’ participants reported experiencing depression (n = 29 of 32; 90.1%) and/or anxiety (n = 26 of 32; 81.3%). Although less commonly reported, other mental illnesses that these participants reported included bipolar disorder, substance abuse, OCD, PTSD, PND and other mental health problems (e.g. schizoaffective disorder). Given that *beyondblue* is primarily about depression awareness, it is not surprising that depression is the most frequently occurring mental health issue that significantly affects the lives of the ‘consumers only’ in this study.

Interestingly, all of these participants were also clinically diagnosed as having these mental health issues by a professional (this was indicated on the Demographics Survey). That is, the ‘consumer only’ participants who took part in this study are those that have sought formal help. As a result, caution should be exercised when making inferences about ‘consumers only’ who have not sought formal help.

Two of these ‘consumer only’ participants reported on the Demographics Survey that they were caring for another consumer. However, this caring role was not deemed as significant based on information provided during the focus group.

Figure 3: Number of ‘consumers only’ by type of mental health issues

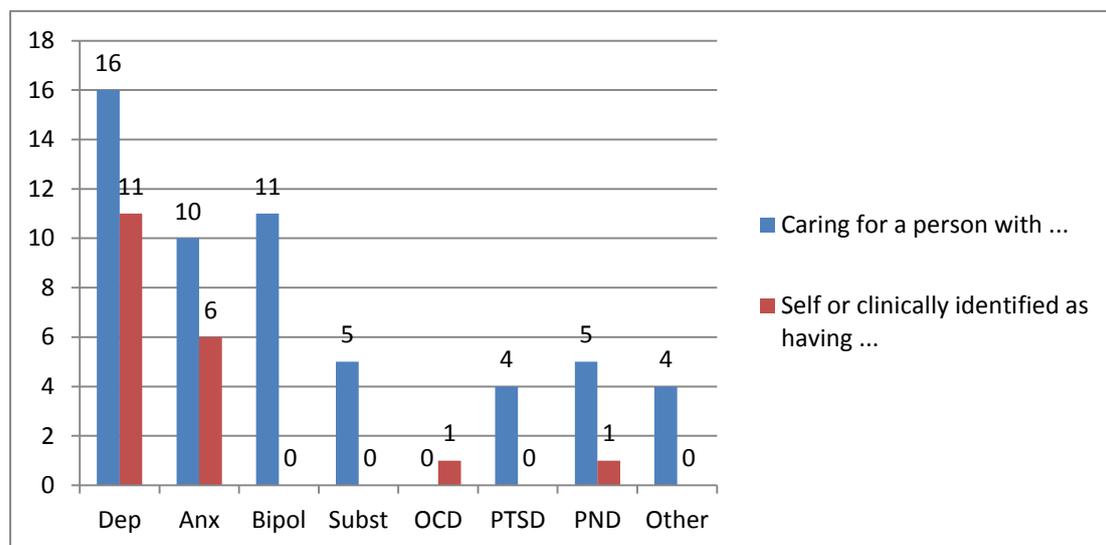


Carers only

As can be seen in Figure 4 (and Data Table 7), the majority of the ‘carers only’, indicated that they were caring for a person with depression (n = 16 of 24; 66.7%), bipolar disorder (n = 11 of 24; 45.8%), and/or anxiety (n = 10 of 24; 41.7%). Although less common, these ‘carers only’ also indicated that they were caring for a person with substance abuse, PTSD, PND or other (e.g. schizophrenia).

A significant number of ‘carers only’ either self-identified or were clinically diagnosed as having mental health issues themselves. These issues were reported as being directly related to the caring role. As can be seen from Figure 4 (and Data Table 7), 11 of the 24 ‘carers only’ in this study reported experiencing depression (45.8%) and six reported experiencing anxiety (25%).

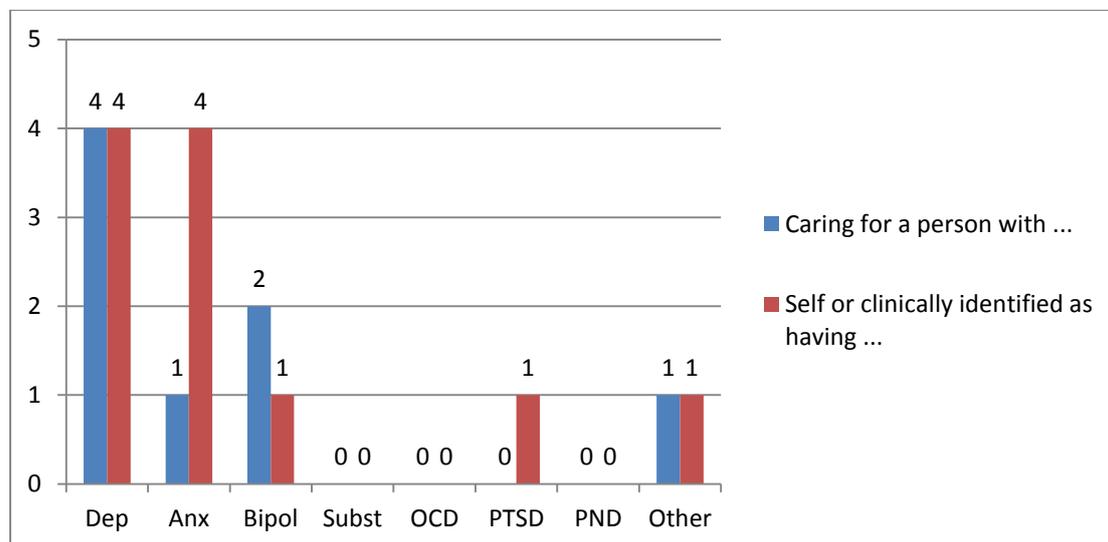
Figure 4: Number of ‘carers only’ by type of mental health issues



Consumers and Carers

Of the participants categorised as ‘consumers and carers’ (n = 5), depression and/or anxiety were noticeably the most common mental health issues affecting their lives, either as a consumer or carer (see Figure 5 and Data Table 8).

Figure 5: Number of ‘consumers and carers’ by type of mental health issues



4.4 Accessing of mental health services or programs and information

As can be seen from Table 3, there appears to be a general tendency for participants to prefer accessing information about mental health rather than mental health services or programs. For the most part, this trend occurred regardless of participants’ consumer/carer status, area of residence, sex, cultural background and age (with the exception that participants aged between 30 – 39 years and 40 – 49 years seem to access services as much as information). This finding substantiates the importance of informal help such as websites.

When comparing participants by their consumer/carer status, it is interesting to note that fewer ‘carers only’ (45.8%) accessed mental health services or programs compared to ‘consumers only’ (65.6%) and ‘consumers and carers’ (80.0%). Thus, and consistent with the trend already noted above, it appears that ‘carers only’ are more likely to access information than actively engage in services or programs. Also, these results indicate that males (60.9%) are access less information about mental health than females (78.9%).

Participants reported on the Demographics Survey a large variety of mental health services or programs that they accessed. These included:

- *Professionals:* GP, psychologist, psychiatrist, caseworker, counsellor, doctors qualified in commonwealth mental health care plan, hospitals, mental health rehab support groups, uni counselling;
- *Specific organisations:* St Lukes, Oldaker St Clinic, John Bomford Centre; some Centacare short courses, Centacare mental health service, Aspire, Grow, SBS radio, MMMH Australia, NEAMI, Marrickville cottage, MIFSA,

Anglicare, Anxiety online (from *beyondblue*), *beyondblue* materials, Mood gym (online);

- *General supports for consumers:* Mental health support group, community mental health, mental health services;
- *Specific and general supports for carers:* Carers SA, Carers Vic, carer supports, carer's support program/group;
- *Support for regional residents:* Rural mental health support;
- *Self-directed support:* Library, community services, community mental health, therapy; and
- *Psychosocial supports not mental health specific:* Choir.

Similarly, a diverse list of information on mental health services was cited as being accessed by the participants. These included:

- *Professionals:* GP, counsellor, doctors, hospital;
- *Specific organisations:* *beyondblue* websites/emails, Black dog institute, SANE Australia, Anglicare, MMHA, State government sites, ARAFEMI, Billabong Clubhouse Tamworth, Grow, MIFSA, TWLOHA, MHCA, MHCC, PRA, headspace, Mental health Association of NSW, mental health council of Australia;
- *General support:* Colleagues, carer support;
- *Self-directed support:* Internet/websites (e.g. mindgym.edu.au), books, magazines, pamphlets, TV, promotional material, research; and
- *Psychosocial supports not mental health specific:* Community involvement.

It is important to acknowledge that many of the people who participated in the focus groups were those who have previously sought formal and informal information, services and supports.

Table 3: Number and proportion of participants accessing mental health services or programs and information by various demographic factors

	N (%) accessing mental health services/programs	N (%) accessing information about mental health
Consumer/carer status		
Consumer only (n = 32)	21 (65.6%)	23 (71.9%)
Carer only (n = 24)	11 (45.8%)	17 (70.8%)
Consumer and carer (n = 5)	4 (80.0%)	4 (80.0%)
Residence		
Urban (n = 31)	17 (54.8%)	22 (71.0%)
Regional (n = 30)	19 (63.3%)	22 (73.3%)
Sex		
Male (n = 23)	13 (56.5%)	14 (60.9%)
Female (n = 38)	23 (60.5%)	30 (78.9%)
Age (years)		
18 – 24 (n = 8)	4 (50.0%)	7 (87.5%)
25 – 29 (n = 2)	0 (0.0%)	2 (100.0%)
30 – 39 (n = 14)	9 (64.3%)	8 (57.1%)
40 – 49 (n = 16)	12 (75.0%)	11 (68.8%)
50 – 59 (n = 10)	6 (60.0%)	9 (90.0%)
60 – 69 (n = 7)	4 (57.1%)	6 (85.7%)
70 – 79 (n = 2)	1 (50.0%)	1 (50.0%)
Culture		
Aboriginal and Torres Strait Islander (n = 3)	2 (66.7%)	1 (33.3%)
Anglo (n = 48)	28 (58.3%)	34 (70.8%)
NESB (n = 10)	6 (60.0%)	9 (90%)

4.5 Methodological note on results and data analysis

Key findings that emerged from the focus groups, and relating to the four themes, have been described below. The names of all participants have been replaced with codes to protect their confidentiality and anonymity. The 32 ‘consumers only’ have been coded as [Cons], the 24 ‘carers only’ have been coded as [Carer], and the five ‘consumers and carers’ have been coded as [ConsCar].

However, key demographic information for each participant has been recorded in Appendix G. This information may be helpful for understanding how a consumer and/or carers’ perceptions and experiences are related to their urban or regional residence, age, sex, cultural background, and the type of mental health issues most affecting their lives.

5 Community awareness of mental health issues

5.1 Current level of awareness

While some participants described the current level of community awareness of mental health issues as “awful” [Cons_21], “terrible” [Cons_25] or “a shambles” [Carer_16], most participants thought that community awareness had increased compared to the recent past. For example, some participants said:

- I think it has improved over the years [Carer_8];
- Community awareness is getting much better [Cons_23];
- I feel mental health issues are enjoying a slightly higher profile [ConsCar_5];
- Compared to 10 years ago when I first had to deal with it, I can guarantee you it’s a lot different [Carer_10]; and
- Community awareness has greatly improved since the early ‘90s. **My family has actually stopped saying, ‘oh, he’ll pull himself together one of these days’.** So there’s an absolute breakthrough! [Carer_24].

Some participants attributed the increased awareness to the media. These participants said, “because of the media, [mental health issues] has become more acceptable in the last five years” [Cons_28], and “the mainstream media has, in the last couple of years, picked up a lot of coverage on mental illness, so I think the awareness is getting there” [Cons_20].

Interestingly, only one participant perceived a positive relationship between awareness and acceptance of mental health issues. She said, “because our situation goes that far, I’ve gradually noticed awareness of mental health being acceptable” [Carer_5]. However, most participants did not report a positive association between awareness and acceptance, making comments such as:

- Awareness is a bit higher than it used to be, but it’s still no way near acceptable [ConsCar_5];
- Awareness is better than it was, but mental illness is still something people are reluctant to talk about [Carer_15];
- Awareness has gotten a lot better since I was in high school eight years ago. There’s still a long way to go, but definitely you can see it on the rise [Cons_4];
- In the last probably five years, mental illness – it’s not acceptable – but it has become a lot less of a taboo subject to talk about, and to actually admit to as well [Cons_26];
- In the last maybe five years, awareness has been amazing. Mostly because of *beyondblue*. But there is still a big undertone of the community who just don’t understand [Cons_9];

- It is more acceptable to have a mental illness now. Awareness is better. Not perfect, not by any means. But **this discussion group would not have been held 20 odd years ago** [Carer_5]; and
- The term [mental illness] is not so much of a faux pas to mention. Now people are prepared to mention it – not necessarily that comfortably, it is still an issue that’s quite close to the bone – but people do talk about it more [Cons_7].

Thus, it appears that although community awareness has recently increased, this has not translated into an acceptance of mental health issues. This is most likely because of the stigma associated with mental health issues. Thus, the goals of *beyondblue* to increase awareness and decrease stigma may be considered achieved when consumers and carers *unanimously* perceive an acceptance of mental health issues.

5.2 Awareness among youth

Regardless of their own age, several participants pointed out that awareness of mental health issues was especially high among young people. For example, participants said:

- 16, 17 year olds are all tuned into it now [Cons_4];
- There’s more programs right now for teenagers [Cons_2];
- There’s more of a focus now on younger people [Cons_6];
- Awareness of mental illness within that age group of youngish 20s is a lot higher [Carer_13]; and
- I would say about 50 per cent of my son’s friends are very accepting and supportive, and the other 50 per cent would be blasé about it [depression], so it must be filtering through to the younger generation – better awareness and a better empathetic attitude [ConsCar_1].

On the contrary, one young consumer said, “during high school they spoke about drugs and alcohol, but we never got anybody from mental health. I believe that had someone visited, I would have been diagnosed much sooner. That set me back at least four years” [Cons_21]. This finding may suggest that although mental health programs are being developed for young people, they are not being universally implemented across all high schools in Australia.

Despite the variations in experiences, the overall findings suggest that there has been a general increase in awareness across the community, and it is heightened among young people. Indeed, several participants noted, by corollary, that awareness was lower among the older generation: “**a lot of older people don’t know how to talk about it** [mental illness], because they were fashioned in these ages where it wasn’t appropriate, and you weren’t allowed to do it” [Cons_15]. See Section 6.8 for more information on age.

Interestingly, one participant suggested that awareness of mental health issues among the younger generation had popularised mental health problems. This participant said, “just last week, my daughter said that obsessive compulsive disorder is like the ‘in’

thing at the moment” [Cons_31]. This contrasts with a comment made by a young person who said, “depression is not just a word that gets thrown around” [Cons_2]. Despite these differences of opinion, it is important to note the potential risk of popularising mental health issues; namely that it may become difficult to identify genuine consumers and distinguish from those who are not. For example, even one consumer said, “nowadays a lot of people use depression as an excuse. It’s just an easy way out” [Cons_9].

5.3 Awareness among general health professionals

This study found that awareness of mental health issues among general health professionals was generally perceived as insufficient. This is significantly problematic, as consumers and carers understandably have a higher expectation of this particular sector of the community in regards to their awareness levels. Participants said, for example, “doctors don’t seem to have a lot of knowledge” [Cons_31], and “I find a lot of doctors don’t understand” [Cons_27].

Interestingly, this lack of awareness was corroborated by a consumer who currently works in a hospital: “There should be more awareness when people are presenting into emergency departments. Us health professionals are taught how to wash people, give medications, look for specific illnesses, but when it comes to a patient who’s having a panic attack it’s ‘oh, they’re just weird’. **I feel frustrated in my profession**” [Cons_18].

It is important to point out that these negative experiences are in relation to *general* health professionals, and not those that specialise in mental health (see Section 8 for a more detailed discussion on perceived effectiveness of formal mental health treatment). This finding points to the importance of promoting awareness among and providing education to general health practitioners.

Interestingly, one participant in a regional site noted that “part of the issue, is that we’ve got a lot of overseas trained doctors and they don’t tend to come from the same background or same understanding” [Cons_30]. Although lack of awareness or understanding can occur in general health professionals from any cultural background, Anglo-Australians may nevertheless attribute the lack of awareness to cultural difference; creating additional cultural barriers when there are ethnic differences between the client and professional.

5.4 Factors contributing to lack of awareness

Given that awareness of mental health issues was not unanimously seen to be sufficient by the participants in this study, it is important to identify where the lack of awareness may be coming from and how the barriers may be overcome. In turn, the desired and necessary level of awareness and acceptance of mental health issues can then be more readily reached.

Participants in this study attributed lack of awareness to several factors. One was a *lack of understanding of what depression actually is*. For example, two participants with a caring role said “depression is not understood enough” [Carer_5], and “**depression is a big question mark to a lot of people**” [ConsCar_5]. Contrary to this, one consumer said, “people have a bit more awareness of what depression actually is. It’s not just having a crap day. It’s an illness. It’s more prolonged and

serious” [Cons_2]. Thus, there seems to be inconsistencies in whether participants perceive that people in the general community understand what depression is. It is possible that these differences in perception are related to one’s consumer/carer status; and that some consumers may perceive that people in the general community understand that depression is an illness, because they (now) understand that it is an illness. Having said that, many consumers did not display this cognitive bias, and instead said:

- You can’t expect a person who’s never been depressed to know what it feels like [Cons_8];
- If you don’t have it [depression], you don’t understand. You don’t realise how debilitating it is [Cons_9]; and
- If you’re not affected by [depression], people have difficulty understanding it. It just goes in one ear and out the other [Cons_6]

The difficulty of relating to the experience of mental health issues was acknowledged by one consumer, who said:

When someone talks about disorders I haven’t experienced, for example schizophrenia, I feel like ‘what can I say?’ I have this mind blank. It’s scary. I don’t want to say the wrong thing. I don’t want to seem like I know what’s going on. But I also don’t want to seem like I don’t care. It’s confusing ... So I get a glimpse of what it must be like to have had no mental health problems. Not know what to say, not know how to approach it. I definitely sympathise with people when they’re struggling what to say. I don’t judge it whatsoever [Cons_3].

The difficulty of relating to the experience of mental health issues was corroborated by several carers in this study. They said:

- I had no concept, as another human being, of what bipolar or manic depression was [Carer_11];
- Sometimes I think, **‘how can I expect the rest of the world to understand what I don’t?’** Every day you’re flying by the seat of your pants. What chance has the community got? [Carer_17]; and
- We’ve been married 39 years and I’m just getting my head around what [husband] goes through. So as far as community awareness goes, it takes a long time, even for the people who live with them. If you don’t suffer, you don’t understand [Carer_21].

Thus, it may be that it is not just lack of understanding that is contributing to the lack of awareness, but the lack of *first-hand* experience as a consumer or not having information about what a *first-hand* experience means on a day-to-day basis. As one participant said, “people that have had it themselves obviously have a greater understanding. Even me, before I had depression, I probably thought it was a bit of rubbish to be honest” [Cons_9].

Another factor related to lack of awareness was *ignorance*. One participant said, “I think a lot of people, when they find out what the problem is, they tend to shun away. Only because probably ignorance” [Carer_11]. Finally, *fear* of mental health issues was also seen to contribute to lack of awareness. Participants said “people are scared of [mental illness]” [Cons_25]; and “I know that people really do care, but I think it’s the fear of mental illness” [Cons_18].

5.5 Lack of awareness for the carer experience

Interestingly, lack of awareness about mental health issues also manifests as a lack of awareness or understanding about the carer experience. This is demonstrated in one of the ‘carer only’ focus group discussions (see Case Study 1).

Case Study 1: Lack of awareness for the carer experience

[Carer_1]	I had a lady at work tell me, ‘just kick him [son] up the arse and get him off the couch’. I haven't spoken to her since.
[Carer_4]	The biggest problem is they’re not living with the problem.
[Carer_1]	That’s right. They don't understand.
[Carer_4]	They don’t know that – yes, you can do that, but the next time it’s not going to work. It’s not only that, it’s every time after that. It just creates a problem you don’t want, so you don’t do it.
[Carer_1]	It makes them worse if you do that. If you push them, it makes them worse.
[Carer_5]	Because they’re not capable of doing something.
[Carer_6]	Or they play on it and make it worse.
[Carer_5]	They’re simply and mentally not capable of doing something if you request them. People don’t understand that.

5.6 Summary

Based on the results of this study, it seems there has been a pervasive increase in community awareness of mental health issues over the last five to 20 years. This is demonstrated by the fact that the increase in awareness was perceived by participants from a range of diverse backgrounds including consumer/carers status, urban or regional residence, age, sex and cultural background. The media, and organisations such as *beyondblue*, are seen to have contributed to this increase in awareness.

However despite the increase in awareness, stigma seems to be hindering an *acceptance* of mental health issues. These findings substantiate: (i) the importance of continuing campaigns to promote awareness, (ii) the potency of the media and of focal organisations, and (iii) the need to simultaneously tackle stigma when promoting awareness.

Community awareness is noticeably higher among youth. This may be because of the development and implementation of mental health programs in schools. However it is

important to ensure that these programs reach all young people. It may also be important to emphasise in these programs the severity of depression, as a way of minimising its popularisation.

Perceived lack of awareness among general practitioners is a particularly significant issue, as they are often the first point of call for consumers and carers seeking formal help. Thus, informed, empathic and positive experiences here are crucial, and may signal to consumers and carers the likely effectiveness of longer-term treatment. This is consistent with the remark made by one consumer who said, “I think mental illness needs to be recognised by the health professions, who have the capacity to help the acceptance of the treatment and prevention of mental health in the community” [Cons_18]. Additionally, cultural barriers between general health professionals and the help-seeking consumer and/or carer need to be acknowledged or addressed. Arguably, this barrier is heightened in regional areas.

Three main reasons were seen to contribute to lack of awareness of mental health issues. These were lack of (first-hand) in-depth understanding, ignorance and fear. Of these, ignorance and fear are the barriers to increased awareness that need to be directly targeted. However, introducing the day-to-day implications of the impact of illnesses, such as depression and anxiety, into campaigns may also assist to increase the depth of understanding among people who have not had first-hand experience with mental health issues.

Finally, lack of awareness of mental health issues also impacts the level of awareness about the carer experience. In turn, this is reflective of a failure to take a whole-of-community approach to improving the lives of people affected by mental health issues.

6 Stigma associated with mental health issues

6.1 Current level of stigma

The stigmatisation of mental health issues continues to be pervasive, according to more focus group participants. In the main, participants reported that “**there’s still a fair amount of stigma**” [ConsCar_1], and that people’s attitudes to those with mental health issues are “harsh” [Cons_17]. For example, participants reported that people think of those with mental health issues as “stupid” [Cons_20] or “disgusting” [ConsCar_3]. As a result of this stigma, “a lot of people who have a mental illness are sometimes victimised by society” [Carer_15].

Moreover, the stigma associated with mental health issues also manifests in, and impacts, the lives of carers. This was indicated by one carer participant who said, “I’m a carer advocate for people with a mental illness. When I tell people what I do, you get two responses. It’s either, ‘oh, that must be wonderful, what a great job you’re doing’, or it’s an absolute conversation stopper!” [Carer_14].

A small number of participants noted that stigma has somewhat decreased recently, and they attributed this reduction to increased community awareness. For example, one consumer said, “compared to 10 years ago, they may have really labelled you in a negative way. There’s still a long way to go, but it’s improved a little bit. Probably to do with the increased awareness” [Cons_2]. Similarly, another consumer said, “when I was first diagnosed [with depression] about seven years ago, I was so ashamed and scared to tell my parents. But now there’s so much education. It’s made me more confident [to tell them]” [Cons_1]. Most favourably, one participant reported no experience of stigma; “people’s attitudes towards me would be neutral. I didn’t find any negative attitudes, and I wasn’t stigmatised or rejected in anyway” [ConsCar_2]. While this is encouraging, these reports were the exception, rather than the common experience amongst the focus group participants.

Notably, participants were more positive about the increase in community awareness compared to the limited shifting in regard to stigma (see Section 5.1). Thus, it appears that the relationship between awareness and stigma is not direct, and that other factors mediate their relationship. Arguably, one such mediator is an individual’s decision to actively engage with the issue of mental health issues. That is, mere exposure to advertisements and the idea that mental health issues are a common experience, are not sufficient, for decreasing stigma because the breakdown of stigma occurs at the individual level. Indeed, not all individuals engage with the issue of mental health problems; as one consumer put it, “I think **people don’t want to understand**” [Cons_1]. The relationship between awareness and stigma was explored in one focus group discussion (see Case Study 2).

Case Study 2: The relationships between awareness and stigma

[Carer_2]	I don't think awareness is the issue, it's the stigma associated with it, and you can't – that's up to the individual – they have to do the research and find out themselves.
[Carer_1]	Because everybody's got their own opinion about something, about everything. And you're not going to change everybody's opinion about everything.
[Carer_2]	No. Not everyone's going to accept something for what it is.
[Carer_3]	But the more information that is out there, the more people are accepting it.
[Carer_2]	Yes, that's all you can do. All you do, is put the information out there and then it's up to the people to do something about it.
[Carer_6]	Just an example from my past: I've grown up with hearing impaired friends and that's always been a stigma. 'Deaf and dumb'. Now, today, that 'deaf and dumb' stigma is gone. It's gone. They use the signage in schools, it's all friendly. I think it's the same with mental illness. People are afraid of what they don't know. If we can get these people out there and be a big part of the community, and not hidden away, shied away, then ...

While overcoming stigma requires a shift at the individual level, it is also fundamentally about moving to the next step of community awareness – increasing the depth of understanding. This begs the question: can community awareness campaigns move beyond an overall 'awareness' of mental health to increasing the depth of understanding of these illnesses?

6.2 Stigma for mental compared to physical illness

Several participants demonstrated the stigma associated with mental health issues by comparing it to the lack of stigma for physical illness. For example, these participants said:

- Depression is not seen as an illness in the way we view physical illness [Cons_2];
- Depression is no different to diabetes or heart disease. It's a medical condition. That's how I see it" [Carer_20];
- I always say, **if he had cancer or a broken leg, everyone would be around with casseroles and flowers** [Carer_1];
- It's hard to explain to people that aren't living it [mental illness] because you can't see it. It's not as accepted as a broken leg [Carer_6];
- It was easier to get signed off on the Disability Pension to say that is was because of the stroke than 'the man's depressed' [Carer_13];

- If you come down with the flu, people know you're sick. 'Ok, you need to go the doctor, and you'll be away from work for a period of time'. We all accept that you're unwell, but ... [Cons_2]; and
- If you think you're not coping, it's almost like going to the doctor, 'I'm not well today, I need a flu shot or I need Panadol'. Breaking that barrier is like breaking the Berlin Wall. It's not there [now], but eventually it will come" [Carer_10].

Such remarks highlight that mental health issues are not seen as a *health* issue in the way physical illnesses are. This disjunction between mental and physical health has a long standing medical history (Szasz, 1960).

6.3 Stigma for PND

A small number of participants noted that (awareness and) stigma was related to the type of mental disorder, in particular PND. One carer participant perceived that stigma for PND has improved, saying "there was media coverage, so yes, it's [PND] a lot more accepted now than what it used to be. There's not that stigma that you have it. Now it's, 'oh well, you've got it, treat it or find out how to get better from it' [Carer_2].

On the other hand, an actual consumer did not believe the stigma associated with PND had decreased. She said, "**for post natal depression there's a stigma around, 'I can't cope with my baby'**, 'I'm a bad mother and therefore the welfare are going to come and take my child', and that's not what happens at all. I think as a community we really need to be addressing some of these issues a lot better and supporting people who are really just trying to get it together" [Cons_10]. Thus, these results indicate that since participants are not unanimously reporting positive experiences, further efforts to increase awareness and decrease stigma for PND are required.

6.4 Stigma related to perceived control over mental health issues

Interestingly, one participant compared the stigma for depression to the stigma for schizophrenia. She said, "a diagnosis like schizophrenia still has a lot of stigma attached, whereas depression is almost fashionable. People will go, 'I'm so depressed'. It's become much less stigmatised" [Cons_11]. Contrarily, a consumer with co-morbid schizophrenia said "maybe I've just been lucky, but I've never discovered a troublesome individual. I don't tell everybody [about the schizophrenia], but when I do, it's usually fine" [Cons_15].

While schizophrenia was not a focus of this study, the aforementioned findings are still informative for understanding the stigma associated with depression and anxiety. It is possible that the general stigma attached to schizophrenia is comparatively higher than with depression (at least), but that when people interact with individuals that have schizophrenia, they are less judgmental than with those who have depression.

Arguably, this is because schizophrenia is seen to be less within one's control. Indeed, common psychological treatments for depression and anxiety (e.g. cognitive behavioural therapy; CBT) significantly centre on consumer's regaining (a sense of) control over their thoughts and lives (even if there is acknowledgement of their (sense of) lack of control). In comparison, therapies that emphasise cognitive control such as

CBT are less routinely used for people with schizophrenia (and there is greater emphasis on interventions such as medication and electroconvulsive therapy; ECT).

Thus, it may be inferred that part of the stigma associated with depression and anxiety results from the misperception of just how ‘out-of-control’ consumers feel, with the combined expectation that consumers are responsible for regaining it. And that until they do, they (and not the mental health issues) are the cause of dysfunction or disruption to people’s (family and work) lives. Indeed, this proposition is substantiated by the fact that stigma from the family and at work were the two largest areas of people’s lives affected by mental health issues.

6.5 Stigma from family

When probed for specific areas of people’s lives that stigma emerges, one participant said, “**often the ignorance is from those closest to you** rather than the actual community. Some of my family members are very patronising” [Cons_11]. Similarly, another said, “I think the public perception of mental illness is better than a family perception, because families are so utterly cruel about it. My son told me I was stupid and my husband told me I was nuts” [ConsCar_3].

Indeed, even some carers acknowledged their negative attitudes. One carer said, “I think family can be the worst. There was a time where I was probably over-judgmental” [Carer_24]. In keeping with this, another carer said “something that you can take away as a benefit or a positive, is that your attitudes towards others with mental illness is a little bit more informed, a little less judgmental” [Carer_22].

Stigma in the family can manifest in a range of ways, including:

- *Discomfort to talk about mental health issues:* e.g. “my parents played the mute game. They didn’t talk about it. I think they were uncomfortable” [Cons_3]; and “my mum didn’t find out about my mental illness till this year! No one talks. It’s very secretive in my family” [Cons_4];
- *Denial of mental health issues:* e.g. “we spent a lot of years pretending there was something else wrong with [husband]. He knew what was wrong [depression] but he didn’t want anybody to know” [Carer_5]; and
- *Dismissal of the diagnosis of mental health issues:* e.g. “I didn’t tell my mother I’d been medicated for depression for quite some years. [When I did], my mother’s response was, ‘oh what rubbish, you’re not depressed’” [Cons_8].

Causes and/or contributors of stigma within families

Not only is it important to recognise the range of ways in which stigma may take shape within a family, but it is also important to attempt to identify where the stigma is coming from; that is, the causes of stigma. In addition to a limited understanding of mental health problems, diagnoses or symptoms, the findings of this study point to an additional two possible factors: (i) shame and the desire to protect the family name, and (ii) a competing need for attention among family members. Importantly, these factors may not necessarily be causes of stigma within families, but are instead

contributing to the perpetuation of a general stigma already associated with mental health issues before they impact on a family.

Shame and the family name

One factor that may cause or contribute to stigma within families is the desire to protect the family name and thus minimise any shame. For example, participants said:

- I just couldn't let the family name down [Cons_9];
- She [mother] thought I was airing our dirty laundry in public [Cons_11]; and
- I cried for a long time at school. I begged them not to call my parents. I always wanted to please, give them pride, and I felt like it was going to be a burden, a disappointment to them [Cons_3].

Issues to do with shame, protecting the family name, and fear of disappointing parents emerged as significant issues in the targeted 'NESB' focus group. These have been described in more detail in Section 6.7.

Competing need for attention

Another factor that may cause or contribute to negative attitudes about mental health issues within families is the competing need for attention among family members. A number of consumer participants noted that they have been labelled as 'attention seekers' and that this is a stigmatic attitude. For example, one consumer said, "when I attempted suicide for the first time, my mum and few of my siblings automatically called me an attention-seeker, and from that moment on that label stuck" [Cons_4].

Similarly, another consumer said, "**the phrase 'attention seeker'** – because you don't want to do something – **is still the most common put-down**" [Cons_7]. Interestingly, this comment may again relate to the issue that stigma is related to perceptions of control over depression and anxiety (see Section 6.4). Thus, a consumer may feel disempowered by family members when they are stigmatised for not meeting their expectations 'to do something', when instead they are exercising (their right to) self-determination (or 'consumer autonomy' as Langlands et al (2008) describe it).

However, the capacity to exercise self-determination is seen by carers as indicative of a level of personal control. Thus, consumers who claim control over the right to behave in self-selected ways and at self-selected times (i.e. self-determination) – but who also claim feeling 'out of control' – confuse carers about the level of *actual* control they have over their mental health issues. This confusion or 'mixed message' creates the situation where carer's overestimate the level of (a sense of) control that consumers have. In turn, this creates an expectation within carers that consumers should take responsibility for their mental health issues and thus reduce the impact it is having on all of their lives. When consumers are seen to hold on to their right to self-determination more than the extent to which they are seen to be considering the impact that their mental health issues are having on all members of the family, this may then cause carers to become (more) judgmental about mental health issues.

At the day-to-day level, this stigma manifests in negative labels such as ‘attention seeker’, because attention is a core human need (Fiske, 2004) and a limited resource that needs to be shared among all family members. Thus, when the consumer’s mental health issues skew its equitable distribution within a household, the consumer (rather than their mental health issues) is held responsible.

6.6 Stigma at work

In this study, there were many examples cited about stigma and/or discrimination experienced at work. Some of these examples are described below.

Stigma

Stigma at work presented most commonly as a sign of laziness or feelings of incompetence. Such negative attitudes belie a (real or perceived) expectation of self-control, and when consumers feel that they will not be able to meet this expectation, it produces feelings of shame.

Attitude that mental health issues are a sign of laziness or incompetence

- You just get made to feel lazy, like I just couldn’t be bothered turning up to work. I ended up having to resign [Cons_9];
- My boss is like, ‘why you being lazy? In the old days, you had to work on the farm with a kid on each boob, and keep going!’ They definitely see it as you being lazy, but I don’t care, I need my ‘me-time’ [Cons_1]; and
- My passion is to de-stigmatise anxiety and depression in the workplace, because I found that when I was suffering, I was ashamed. I didn’t let people know what I was going through. In the workplace, everybody thinks ‘oh, everybody’s competent, should be in charge’. You think, ‘how can I tell somebody I’m anxious?’ I think as part of the introduction to the workplace, there should be a session that says that ‘if you are feeling depressed or anxious, you should talk to somebody’ [Cons_22].

Feelings of shame

Shame at work can be manifest in a number of ways, including lying about or having a reservation to disclose mental health issues. For example, consumers covered up and avoided disclosing their mental health issues in the workplace:

Consumers covering up mental health issues

- **Six weeks off for glandular fever is a lot different than six weeks off for depression** [Cons_9]; and
- When I got sick I actually lied about what was wrong with me. I said I get really bad migraines, and that I had chronic fatigue [Cons_10].

Consumers reserved about disclosing mental health issues

- When he [husband] was looking at applying for jobs, his psychiatrist said, ‘I wouldn’t mention he’s got a mental illness. They don’t need to know’ [Carer_21]; and
- I’m part of a bipolar support group. We’ve gone to different places and tried to promote awareness ... And I find, I would not disclose in a work situation that I have bipolar [ConsCar_1].

Even focus group participants disagreed among themselves as to whether their mental health issues should be disclosed in the workplace (see Case Study 3).

Case Study 3: Should mental health issues be disclosed in the workplace?

[Cons_15]	Do you think it might have been a mistake to tell them [employer] in the first place?
[Cons_11]	No, I’m always very open about it. I can’t lie.
[Cons_10]	Why should you have to lie? People don’t lie when they’re a diabetic.
[Cons_11]	Part of overcoming the stigma is people coming out of the closet.
[Cons_8]	Why do you have to even tell them? You don’t have to tell them.
[Cons_11]	Well, not necessarily have to, but if you want to, you should be able to, is the point.
[Cons_8]	If it’s a part of your life that you’ve accepted and you’re dealing with and you can do your work, there’s no reason why you need even mention it.
[Cons_15]	Yeah.

Discrimination

Many examples of discrimination in the workplace were also reported. Importantly however, one participant pointed out that “discrimination sometimes comes in subtle forms, other times pretty obvious” [Carer_15]. This range of discrimination is captured in the following examples.

Difficulty getting employment

- I work for a disability employment service. I found that there still is a lot of stigma when speaking with the employers [Cons_28]; and
- I think employers are reluctant. It’s very hard if you have any sort of disability, let alone a mental illness that you’re open about, to then be able to get employment [Cons_11].

Difficulty returning to work

- If someone has a broken your leg, they [employers] check on them all the time. They're encouraging them to come back slowly into work. If you have a mental illness, they don't say that [Cons_17]; and
- We went through the Comcare system, which is the federal equivalent of Workcover. You've all seen the Workcover 'return to work' ads. That's great if you've broken a leg or hurt your back. We had a workplace that was not interested in re-employing him [husband], that was not looking to find him another job. Our problem was we were going through a system that didn't recognise mental illness [Carer_20].

Difficulty getting promoted

- Employers use that [mental illness] against you in your promotion [Cons_22]; and
- I've suffered from discrimination. Just interactions in study or work, not being the whole package that people want you to be [Cons_19].

Employers denying or dismissing mental health issues

- I suffer from depression since I had my work accident, and I was called a liar [ConsCar_3].

Causes of stigma and discrimination at work

The most common cause cited as underpinning stigma at work was *lack of understanding* of mental health issues. Participants said:

- I think for part-time work it's still a bit difficult. I'd call up work, 'I'm not feeling up to it', and they were like 'well, without a medical certificate ...' Which I was able to get, but not really show all the physical signs of not being able to work. **She didn't understand the extent to what I was feeling**, just because I wasn't technically sick. In casual work, I was judged upon a lot more [Cons_3]; and
- I think employment is a big issue. Employers need more awareness and understanding. They can't see the physical side of things, yet you've got to go to an appointment at mental health services. They've asked you to come. Instead of being just 20 minutes, you're there for two and a half hours. You get back in, and you can see the clock's being watched, not having an understanding of why it was important to go [Carer_13].

Expectations of employers

One consumer said, "it's an old-world attitude – 'leave your problems at home' ... **'Need a cry? Do it on the train, do it at home, don't do it here'**. No matter how much effort you put in, there will always be elements of that stuff in corporate environments. Anywhere where there's money involved, and your being paid [Cons_7].

Given the pervasive presence of the ‘old world’ attitude that the workplace is not appropriate for personal issues, consumers themselves may not express an expectation for employers to develop their awareness and understanding of mental health issues and to contribute to improving the lives of those affected by it. For example, one participant said, “it’s not up for them [work] to understand. Why should they? They employ you. **Why should they go to the extra effort of caring?** It’s not like you have a personal bond with them. They don’t have that duty of care for you. **They’re not there to mother and father you; they’re there to be your boss.** I mean you get caring people obviously, but ...” [Cons_6].

Thus, perceptions of stigma and discrimination at work seem to be related to expectations of employers. Moreover, expectations of work also depend on needs; if a consumer is not psychologically, financially, and/or socially dependent on their work to help them recover from their mental health issues, then they may be less likely to perceive stigma and discrimination at work.

Positive examples

On the positive side, a small number of examples indicating no stigma or discrimination at work were provided. These participants said:

- I had to take my boss aside and have a chat with him about why my mother carried on the way she did. I had to explain to him about bipolar, and he was okay [Carer_6]; and
- Last year, when my husband was really bad, I had lots of time off work and my manager was so understanding. I would go into her office and sit for an hour in tears. She was great [Carer_1].

Structural change in the workplace

That some individuals do not experience stigma at work, suggests that perceptions and experiences of discrimination not only depend on consumers’ expectations of an employer’s duty of care, but also on the understanding and compassion of individual employers (at both an individual and organisational level). One participant did say, “it depends on the employer” [Cons_12]. However, a small number of lucky individuals should not be the only people benefitting from aware and/or empathic individuals.

All employers should be informed and aware about the fact that mental health issues are a health problem over which consumers do not have a sense of control, and that efforts to encourage them to seek help and to return to work, all assist in the recovery process. This is especially crucial because work provides psychological, financial, and social rewards that may help consumers regain a sense of self-worth, control and empowerment. Thus, structural efforts to improve awareness and decrease stigma of mental health issues in the workplace, are crucial. As one participant put it:

[Support] needs to be incorporated into a workplace. I’m quite lucky, because where I work I manage to work two days a week from home, because my wife suffers from PND. But it needs to be carried across not just by one employer. It needs to be available, acceptable, in all workplaces ... It comes down to management’s acceptance and policy. ... That will explain the absentees, and we

increase our productivity. The last thing a consumer wants to do is be at home. [Carer_10].

6.7 Stigma and culture

As one participant described, “all cultures have that stigmatism” [Carer_10]. Nevertheless, stigma manifests in its own unique way within cultural groups, in the same way that it manifests in its own unique way within families and individuals. That is, “**the stigma is there. The only difference between ethnic groups is the way it’s represented**” [Cons_19]. For example, “people in some cultures don’t acknowledge mental illness at all” [Carer_23]. In other cultures “there’s a spiritual element to it – that that person’s soul has been deformed, twisted” [Cons_21].

Although the manifestation of stigma within cultural groups is unique, at a very broad level, stigma may be related to the cultural paradigms of individualism and collectivism. Although it is a simplistic dichotomy, individualistic cultures see the individual to be the ‘unit’ of society, and collectivist cultures see the ‘family’ to be the unit of society (Hofstede, 1980). Because collectivist cultures value the family over the individual, issues to do with shame and protecting the family name are common for people from these groups. In comparison, mental health issues among people from individualistic cultures may be more seen to be a sign of weakness or lack of self-sufficiency; because the stigma centres on the individual.

While Aboriginal and Torres Strait Islander and NESB Australians tend to come from collectivist cultures, they are also still individuals, and while Anglo Australians come from an individualistic culture, they are also still family members. Thus, the relationship between cultural paradigm and stigma is only heuristic, and not mutually exclusive along ethnic lines. This is especially so because the process of ‘acculturation’ (Berry, 1980) – balancing the need for cultural preservation and cultural adaptation – means that both cultural paradigms (individualism and collectivism) significantly influence the lives of Aboriginal and Torres Strait Islander and NESB Australians. Thus, the following examples of how culturally influenced stigma manifests as ‘weakness’ or ‘shame’ can come from Anglo, Aboriginal and Torres Strait Islander, or NESB participants. Nevertheless, it is the *proportion* of participants from these three groups expressing ‘weakness’ or ‘shame’ that are indicative of the influence of cultural paradigm.

Stigma related to weakness

Several participants, of whom all but one was of Anglo background, reported that mental health issues are seen as a sign of an individual’s weakness. For example, both consumer and carer participants said:

- I looked at it as a weakness [Carer_24];
- Depression can be mistaken for laziness or some sort of weakness [Cons_2];
- My parents, they’re Australian. For a long time, they were just like ‘snap out of it’ [Cons_1];
- My father and my sister don’t believe in mental illness. If you can’t cope with something it’s a weakness of character, not an actual illness [Cons_27]; and

- Some people think mental illness is something you just push through. It's just a lack of backbone, a lack of discipline, that's stopping him getting out the door every morning [Carer_17].

Stigma related to shame

The issue of stigma manifesting as shame was a significant discussion point in the 'NESB' focus group. To demonstrate this, an excerpt from one of the participants in this group [Cons_21] has been described in Case Study 4.

Case Study 4: Stigma and shame in collectivist cultures

In the Iranian culture, it's stressed that the child becomes somebody important, in the sense they become a doctor or an engineer; someone who has a high social status. There is a massive expectation on that young person ...

So my father would have seen me as somebody who was a defect and a burden on the family, someone he could not achieve his own self-fulfilment through. He didn't want to accept that his son's got a mental illness ...

He did not understand what it is [depression]. Also his pride stopped him from trying to understand ... When I attempted suicide the first time, my father was like, 'keep it together, I don't want you to go into the mental asylum, I don't want you to be one of them [mentally ill]' ...

My father didn't know that it's treatable. He didn't know that I could come back to be the person he wanted me to, but that I just needed some help, some guidance. I needed to be in the care of professionals ...

Not only is there a huge understanding problem within my specific sub-cultural set – the Iranian people and a lot of Middle Easterners – not only is there an education problem, but there is that stigma on mental people that they're (a) not normal, (b) they won't ever be normal – which comes from the ignorance, and (c) that they're a blemish on the family ...

For his pride and for my family's pride, he was prepared to sweep my problems under the carpet. It was only until my suicide attempt that he thought 'I've got to change my thinking'.

Culture and generation

Interestingly, a number of NESB and Anglo participants pointed out that the stigma associated with mental health issues had less to do with culture than it did with generation. For example, these participants said:

- I think it's not only in culture, it's also age. [Husband]'s parents ... One wonders if it's easy to say, 'oh, he's very artistic' rather than acknowledging his depression [Carer_21];
- When it comes to stigma, I wouldn't say it's because of certain cultures. I would say it's more because there's just no exposure for the older generation. So I wouldn't blame so much on different cultures. It's more generational [Cons_20];

- I was born in Australia. My mum, who is 72, has some stigma around me having a mental illness. Mum doesn't really want to talk about it. But I talk to some people, mostly younger than my mum. They don't react in the way of 'oh, you have a mental illness' [Cons_24];
- My grandparents are Italian. Maybe it's different, European? But they just didn't get it [depression]. For a long time they were like, 'what's wrong with you? You hungry? Here, eat some food'. They didn't get it. They still have trouble. I don't know if you can change that [Cons_1]; and
- I don't blame this [older] generation because they were never educated about it [depression]. Last week, one of our cousins hanged herself. Her parents are pulling their hair out, but it's too late. When she was asking for help, they didn't pick up the signs. No-one's taught them how to pick up signs of a mental problem [ConsCar_4].

Stigma and racism

One Aboriginal and Torres Strait Islander participant reported that the stigma with mental health issues is difficult to disentangle from racism for Indigenous Australians. For example, they said: "I believe there still is a stigma with it [mental health issues], but I struggle with my mother because she's also black. **I find it hard to weigh up whether certain friends have shied away because she's black and angry, or mentally ill and angry** ... My mum's been refused a taxi because they thought she was another black lady that hadn't paid her bill. And of course, mum having a mental illness, went off her head. He looked at her as if to say, 'well, you're just a typical black woman'" [Carer_6].

6.8 Stigma by gender, age, and urban/regional residence

The relationship between stigma and other demographic variables was also explored. The results of this study suggest that gender, age and region of residence may be related to stigma.

Stigma and gender

Some participants provided examples of how stigma may be related to gender. They said:

- My father used to say, 'suck it up' [Cons_25];
- My dad used to say, 'just snap out of it' [Cons_19];
- I spoke to all of dad's mates and they're like, 'oh, he's just got to pull his head in' [Carer_13]; and
- Before I had depression, my brother and I would get along pretty good. The past few years, when he found out I had depression, he said 'get over it'. My brother never wanted to talk about it [Cons_14].

Although there are several efforts to decrease stigma among men, it appears that a continued effort is still required.

Stigma and age

As noted in Section 5.2, awareness of mental health issues among youth was noted to be high. However, according to one participant, this increased awareness was also related to a decrease in stigma among young people. They said, “I think definitely the younger generation, they are much more aware of mental health as a real problem. I feel that there is no stigma within the younger generation” [Cons_20]. By corollary, another participant said “I think it’s generational. **Once my daughter was diagnosed, my grandmother and my mum started to talk about her in past tense** ... ‘I just wish the real girl would come back’ ... Because it just wasn’t something they could handle” [Carer_17]. Thus, it appears that not only awareness among youth is higher but also that stigma is lower in this age group.

Stigma and urban or regional residence

It is possible that stigma is heightened in regional areas. One participant from a regional site said, “I think there’s much more awareness about depression and anxiety, but despite the fact that people talk about it, there’s still a lot of stigma attached to it, certainly in our local community” [Cons_30]. Importantly, this indicates that any efforts to reduce stigma need to be locally responsive and tailored to community needs.

6.9 Stigma in other specific areas of life

Some participants provided examples of stigma in specific areas of life. One carer described discrimination in *schools*. She said, “even for young kids, the first thing they write on their school reports is behavioural problems. That school report stays with them for the rest of their life. They take it to job interviews. ... they’re classed as being ‘problem people’, just because they’ve got depression ...” [Carer_12].

Another area in which stigma may occur is with interactions with *police*. One participant said, “there’s some very hairy situations in rental property, a policeman knocking the door in. It’s not an easy scene. Then he’s on the ground, and the policeman’s got his knee in his back. It’s a mental health problem, so instead of it being solved in a mental health situation, it’s solved in a [police] situation. It doesn’t give a good message to the person who’s handcuffed” [Carer_15]. Similarly, another participant said, “a policeman, when he sees a mental illness person, he just locks them up, and that makes the situation a lot worse” [Cons_25].

Finally, one carer participant provided an example of stigma and discrimination when finding a *rental property*. She said, “we’re trying to find Dad [consumer] a place at the moment. We didn’t tell them [the real estate] what our limit was, but when they met dad you could just see, she said, ‘oh, I don’t think that list is going to work, I’ll just get a few others’ ... Dad knew exactly what happened. He’s not a stupid man” [Carer_13].

6.10 Self-stigma among consumers

The stigma associated with mental health issues is so strong that some consumers themselves internalise it. This self-shame or self-stigma only adds to the suffering and burden of having a mental health issue. As examples, participants said:

- You do feel, not embarrassed, but you just don't really want anyone to find out [Carer_8];
- When you're low, it's like a cycle. You get a little low so you beat yourself up [Cons_9];
- Have to deal with their [other people's] uncomfortability [sic] on top of your own stuff [Cons_15];
- **The effort that it takes to cover up is almost worse than being depressed** [Cons_10];
- There is a stigma amongst the mentally ill themselves; that they are guilty, that they are weak [Carer_24];
- I used to have a huge amount of self-stigma about my various diagnoses. I gave myself such a hard time [Cons_11]; and
- They never saw the inside of my house, with the filthy dishes and the week and a half of laundry. You keep it to yourself because you're ashamed of it [Cons_15].

On a positive note, one participant said, "I've come to the point where I'm quite happy for anybody to know that I have mental health issues. I'm comfortable with that now. It's taken me quite a long time to get there ... I think because of where I've come from, and where I am at this point, **I have a lot of faith in people with mental illnesses. They can achieve whatever anybody else in the community can**" [Cons_28]. It seems then that ideally, when there is not just acceptance within one self but also across the whole community, then mental health issues can be said to be free of stigma.

6.11 Summary

In short, stigma is a significant issue that seems to negatively affect the lives of consumers more than carers, and most especially their family and work life. Within these two contexts, this stigma can manifest either as a sign of weakness or as bringing shame on the family name. These stigmatic views seem to be particularly heightened among men and the older generation.

Importantly, the expression of negative attitudes about mental health issues seem to differ between the family and work contexts. Within families, stigma has the appearance of being overt or "cruel" [ConsCar_3], whereas at work it seems to manifest more as a pervasive or underlying shame. Perhaps, stigma is most strongly felt from family because in this context, there are competing interests. Several members belong to this group, each with their own needs, and the self-focus that is inherent to depression is not given sufficient 'space'. The resulting disturbance in equilibrium in the way attention is distributed, and the fact that it is an entrenched and long-standing stressor within the family, may then cause overtly stigmatic attitudes to be expressed within families (see Section 7.3 for more detail on the impact that mental health issues have on relationships within the family).

In comparison, the work context seems to strongly bring about the stigmatic aspect of shame. Shame denotes a person's failure to meet another person's expectation (compared to guilt which denotes a person's failure to meet one's own expectations). In this instance, the shame may derive from consumers' feeling unable to meet the employer's expectation of competence and control. However, the results of this study show that the family context may be a 'hothouse' of stress and that work may be a hostile environment. However, it has also shown that there are some examples of supportive families and that work has the capacity to aid recovery. Work can provide psychological, financial, and social rewards that empower consumers and it can play a crucial role in overcoming stigma.

While the recent increase in awareness has contributed to a decrease in stigma, it seems that negative attitudes and behaviours ultimately occur between individuals, and therefore that individuals are ultimately responsible for tackling stigma. Nevertheless, structural efforts to tackle stigma are still necessary, as they can help start the process of individuals taking responsibility for their stigmatic attitudes. To help address stigma at the national level, especially within families and at work, it is important that awareness-raising campaigns emphasise that: (i) mental health issues are a 'health' problem in the same way as physical illnesses are, and (ii) that mental health problems are less within the consumers' control than carers or employers acknowledge or realise, and that (iii) (self-) shame is an additional burden that further detracts from consumers getting the help they need.

7 The social and economic impact of mental health issues

A key part of establishing the experiences and needs of carers and consumers involved exploring the social and economic impact of mental health issues on consumers' and carers' lives. Four areas in particular were explored: (i) relationships with family, (ii) relationships with friends, (iii) social and community involvement, and (iv) work. In particular, 'family relationships' and 'work' are intimately entwined with stigma within the family (see Section 6.5) and stigma at work (see Section 6.6), respectively.

However, to better understand and appreciate the social and economic impact of mental health issues, it is important to identify what it is like to be a consumer or carer. By describing 'the consumer experience' and 'the carer experience', this can help contextualise the impact mental health issues have on relationships with family and friends, social and community involvement, and ability to work. Thus, this report first explores the consumer and carer experience, and then looks at the social and economic impact of mental health problems from the consumers' and carers' perspectives.

7.1 The consumer experience

Given that "people don't understand the significance of depression, of how serious it is and how dangerous it is" [Carer_24], this report has pulled out some characteristics reported by consumers to help increase awareness of the symptoms and nature of depression and the lived experience of people affected by depression.

There was general acceptance among the focus group participants that anyone can experience depression and anxiety. As one carer pointed out, depression "takes no prisoners. There's no discrimination, regardless of sex or race" [Carer_10]. It was also generally agreed that "depression is such a torturous journey you don't want to see anybody else go through [it]" [ConsCar_3].

One of the most significant characteristics of depression and anxiety is that there is not always an identifiable reason for its occurrence. Despite this, some consumers felt guilt or a sense of personal weakness as a result of their depression and/or anxiety:

I think depression is still viewed as a weakness. Especially if people have had more intense life experiences than you have, and they look at it like 'Well, you're life is so much better than mine, why are you suffering? Why are you sad?' That can be really hard, because it can put you in a mode of guilt. And **you do feel like 'well, I have been given all these things, and I do have a good life, so why do I feel sad?'** [Cons_3].

This guilt or perception of personal weakness, coupled with the stigma of mental health issues (as discussed earlier), produced a common characteristic of consumers presenting as 'normal' and maintaining the perception that all is well:

- You go along living normally and nobody would know [Cons_9];
- I think there are still a lot of people that think because they can't see it all the time, that it's not that severe [Carer_22];

- A psychiatrist said [to me], it's [depression] really a malignancy of the mind. They were very ill but presented as very well [Carer_21]; and
- We've got the problem where my partner looks normal on the outside. It's the mood swings that our friends and family don't understand. He just doesn't want to go anywhere today. But they're all going, 'oh, he'll be right, just get him outside the door'. They acknowledge there is a problem, but it's the next step of acknowledging that, if he has a problem, let him be for a bit. He doesn't need to go out if he doesn't want to [Carer_20].

The issue of 'presenting as normal' is heightened by the lack of physical symptoms compared to a physical injury or illness. Several participants (as already noted in Section 6.2) made this comment, most typically comparing mental health problems to a broken bone:

- Because there isn't a broken leg to look at, or something physical that you can identify with, it's very hard to get an understanding [Carer_17];
- Mental illness hasn't got an outward sign. Like if you've got a broken arm or something, that's pretty obvious and people can see it [Carer_9]; and
- If you've got a broken leg then you get all the sympathy in the world because people can see it. You can't see depression. It's all on the inside [Cons_9].

Compounding the issue that people with depression and anxiety can present as 'normal', its symptoms and occurrence are also irregular and recurring. The episodic nature of mental health problems compounds the stress for consumers: "I have to live with that [anxiety] every day and never know how I'm going to wake up feeling. Basically it's just a bitch" [Cons_12]. Similarly, another consumer said,

It's on and off for me essentially, so some years better, others not. I just refer to myself now as having a melancholy streak, because it comes when it comes. You recognise that it's there. Not sure if it ever leaves to be honest. I don't think you're ever out of the woods. You might be out of the bit with the big trees, but there's still the bit with the grass and snakes. Yeah, you deal with it [Cons_7].

While community awareness of mental health problems has improved over recent years, there is still limited understanding about the lived experience of mental health issues, including its episodic nature.

Carer insight into the consumer experience

The lack of understanding about the lived experience of depression was evident even among some carers. Several consumers pointed out that carers do not have insight into their lack of control over their mental health issues. For example, participants said, "if we could 'get over it' we would. Like you choose to be here?!" [Cons_11]; "**if you could snap out of it, you would**. Who would want to be in it? It's crazy" [ConsCar_2]; and "it's like they're assuming you're enjoying being unhappy" [Cons_2].

Given that even carers – who perhaps have the most contact with consumers – report difficulty in relating to the experience of what it is like to have mental health issues (see Section 5.4), it is important to promote education, awareness and knowledge about the symptoms of depression and anxiety and the implication of these symptoms on consumers' lives.

7.2 The carer experience

There are several characteristics that mark 'the carer experience'; what it is like to be a carer. These are described more fully below.

Identifying as a carer

Part of the experience of being a carer is that many do not even identify as carers. For example, one participant said:

I have an issue saying that I'm a carer because I don't have to do those physical things – wipe their bottom, pick them up off a bed to put them in a wheelchair – but that's my own problem. I hated saying that I'm a carer to him [husband] because then it feels like I'm supposed to be wiping his backside every day, when in fact all I'm doing is making sure that he gets out of bed, he eats, and that if there's any stress in our life, I'm trying to sort it out. We're not seen as true carers in that respect [Carer_20].

The nature of caring

Caring for a person with mental health issues is *time-consuming*. For example, one participant said, "I look after my wife. She's got bipolar. The plan is that I'm part time looking after her, but often it becomes extended like the whole week or something. Going to fill up the car, or even dropping a video off, is a major event" [ConsCar_5]. Also, caring is *unpredictable*. In the words of one participant, "as a carer, we all know it's a roller coaster, isn't it? It's good, good, good and then the bad comes" [Carer_14]. These features may contribute to a third characteristic which is that it is also *tiring*. For example, carers said:

- **When my reserves are low, I'm impatient. I get angry, fed up.** Because I'm involved virtually in a one-sided discussion and I can't win it. It's very wearying [Carer_15];
- Probably the most challenging thing I found is the physical burnout. My health has gone down. You're not just running your life, you're holding up another person as well [Carer_17]; and
- She [mother] lives on her own but she doesn't feed herself. Her house is just a mess. I've got to go and clean her house. She eats at my house every night [Carer_6].

Indeed, some consumers reported that they had also experienced exhaustion as a result of playing a carer's role. This is described in the following dialogue between three consumers (see Case Study 5).

Case Study 5: Consumers tired from caring

[Cons_25]	I've been a very lonely person all my life, so I've become desperate for friendship. When you get involved in a group like this [focus group] you think you're in a safe place, but I've been burnt ... She offloaded all her problems onto me. So it can smother you.
[Cons_31]	It's about boundaries and being safe. In the particular group I had to keep, I didn't need someone talking about mental health issues all the time and offloading it onto me. I found it drained me. You need to have different types of people to socialise with.
[Cons_30]	I went to see a lady on the weekend. Whilst she's a lovely lady, it was like four hours of offloading. I just felt so exhausted that I ended up hiding in the room from her. It's just about recognising that this isn't healthy for me.

Finally, the nature of caring is such that it is *all-encompassing*. As one carer said, “**I don't want my son's illness to be what defines me**. I have this whole other life. I had to work very, very hard to not let this consume me” [Carer_19]. Thus, carers desire, but struggle, with separating themselves from their role. Indeed, the all-encompassing and stressful nature of caring is so great that one carer said, “it's so ironic. You only get 10 years for murder” [Carer_5]. The nature of these comments demonstrates the substantial gap in support for carers.

Perceptions of difficult behaviour

Compounding the exhaustion associated with caring is the perceived and/or real behaviour of consumers. Sometimes carers may feel that consumers have an extreme need for attention, that they are being taken for granted and/or that their behaviour is objectionable or violent. All these behaviours or perceived behaviours may in part explain why stigma within the family is so high.

Need for attention

Although consumers perceive the label ‘attention-seeker’ as stigmatic, and have no control over their illness, this is difficult for carers to understand or have empathy for, because they still perceive that attention is being taken away from others in the family. As one carer said, “it's always about her [mother]. As soon as I cuddle my three year old, my mother turns her back, because it's always about her. I feel bad when I cuddle my three year old. It's horrible. The feelings I have to feel, to please my mother, are horrible” [Carer_6].

Feeling taken for granted

Carers may feel that consumers have become so dependent on them that they are being taken for granted. This is demonstrated in the dialogue from one focus group (see Case Study 6).

Case Study 6: Carers feeling taken for granted by consumers

[Carer_4]	I got to the stage where I basically had to go away because [wife] wasn't getting any better. She was getting worse because she was relying on me so much. Half the time, it was just like I was her father, and she just was playing on it.
[Carer_6]	Yes, they get comfortable.
[Carer_4]	Going away meant that she had to get out of bed. She had to look after herself.
[ConsCar_1]	It is very difficult when you've got someone who's got no insight into their condition.
[Carer_5]	Yes, it's hard when the person doesn't realise how bad they are.
[Carer_6]	I feel, the more you do for them, it's never enough anyway.
[Carer_4]	No, it actually makes it worse.
[Carer_6]	Yes, it makes them more lazy.
[ConsCar_1]	I think that's for a lot of mental illnesses across the board; that if you don't encourage people to just lift themselves a bit and do a few little things every now and again, that they will just take you for granted; they will let you do everything.
[Carer_6]	My mum's over for tea every night and she knows how to do a dish but she won't do it. She'll leave the dishes for me, as if she's the daughter. You think, 'oh, can you wash even just that one cup?' But she won't offer.
[Carer_4]	I said to [wife], 'if anything happens to me, what are you going to do?' She said, 'well, when you die, then I'll do something about it'.
[Carer_6]	Did you say, 'I'm already dead. I'm already dead'?

Difficult, angry and/or violent behaviour

Several participants noted that their family member's behaviour was difficult, angry and/or emotionally abusive. For example, carers said:

- It's an ongoing thing. At the moment, he [son] feels I'm not a good carer [ConsCar_5];
- Mine [daughter] will never forgive people that she perceives have crossed her or treated her badly [Carer_14];
- If he [son] feels somebody is taking a rise out of him, or not treating him with respect, boy it's on for young and old! [Carer_15];

- Oh it stirs you up so much. You say to yourself, ‘bite your tongue, shut up, say nothing’. Gradually, bit by bit, it’ll come back to normal behaviour [Carer_16];
- She’s got a lot of baggage. Sometimes it’s very difficult to talk to her. You know you’re in the right, but I always think maybe I shouldn’t make too big a point out of it [ConsCar_5];
- People who are suffering some form of mental illness can be extremely objectionable and angry, to the extent that you just feel totally helpless. ‘There’s nothing I can do for this person, I’d just better back out’ [Carer_7]; and
- The family carers are really hammered more than people in the community. **I can watch my son going around, and he’s as nice as pie to a whole lot of people he sees on his way, yet I get taken apart.** You’ve got to be really patient [Carer_15].

The dialogue from one focus group also demonstrates the difficulties faced coping with objectionable behaviour (see Case Study 7).

Case Study 7: Verbal abuse from consumers to carers

[ConsCar_1]	... That’s the other side of depression too, anger. I don’t think people talk about that enough. Depressive people can get very, very, very angry at you.
[Carer_1]	The verbal abuse is just as bad as what physical abuse is.
[Carer_4]	It can be worse.
[Carer_6]	It’s hard for us to learn how to cope with that and not bite back. I don’t disrespect my mother, but in her eyes it is, and she still makes me feel like I disrespect her, even though all I do is help her.

Indeed, difficult behaviours from consumers reap difficult behaviours from carers. As an example, one carer said “I had to put a court order on my mother for six months. It’s the hardest thing I ever did. She resented that but she hasn’t abused me again. **Sometimes we’ve got to be cruel to be kind**” [Carer_6].

Interestingly, some consumer participants indicated that they were aware of their difficult behaviour. For example, one participant said “with the whole depression and anxiety, I just got to be a mean person. I was arguing about everything. Whatever people did, it was just not right” [Cons_13]. Similarly, another consumer said “yeah, I was touchy and reactive” [Cons_11].

Fear

A significant emotion that affects the lives of carers is fear. For example, several participants said:

- We have the phone on all the time [Carer_24];
- With my husband, who had had three fairly significant suicide attempts, I got to the point where I was scared to go home because I never knew what I'd find. I got frightened because he was saying things like 'we can't be together because you might cop a bullet that's meant for me'. I feared for my safety [Carer_11]; and
- My daughter hasn't suicided for some time. But she's threatened to. I can't get over the fear that runs my life. I can't not answer the phone. I'm scared 'if I don't, this'll be the time'. But that's no way to live your life. I don't get to do the things that I need to do. I don't get to spend time with my husband. We try and have a dinner or go out and he says, 'just this once, let it go'. I sit there and I feel physically ill at the thought of doing that. I know that I need to be able to do that because physically I can't sustain this any longer [Carer_17].

Importantly, fear in carers is not just of the unknown, but also of the consequences for taking action to protect oneself or seek help. This is demonstrated in the discussion in Case Study 8.

Case Study 8: Fear in carers

[ConsCar_1]	When she [daughter] came back to my place, she was very violent, full of rage. Said she was going to kill me if she stayed with me. Ended up going and staying with my mum. It was just a crisis period and she just needed somewhere to direct her anger. She was very angry and violent toward herself and other people.
[Carer_6]	You're scared of the ramifications. Like if someone got locked up because you rang the police on them, and then they get out, you feel like they're going to come for you. That's like battered women syndrome, where the women feel safer to go back to the man that's beaten on them. I've grown with this, with my mother, for 30 years. I've had it drilled in my head. But, as I was growing into a woman, different things have changed in my head. Now I won't put up with it. So I'm not scared to ring the police. I'm not scared to not take action. But some people are, and they do live in fear.
[Carer_1]	Yes, I found that sometimes when he [husband] was having a bad episode, I'd say 'I'll ring the [mental health NGO] team'. 'No, you don't. Don't you ring them. Or I'll walk out and I won't come back'. I had a lot of times like that.
[Carer_6]	That's a husband to a wife. This is a mum to a daughter. It's different. She's battered me growing up and I've been scared of her.

Worry

Carers also reported feeling worried about who would continue to care for their child with a mental health issue after their own passing:

- What happen when the folks pass away? It's very frightening and we're not getting any younger [Carer_16];
- We've finally managed to sort out our will so that when we're not around – which is a big worry for all of us – that he [son] has some protection from being taken apart [ConsCar_5]; and
- My daughter's an only child, so I've tried to work very hard on her being independent, being able to leave her at home. She doesn't have that extended family network, and we're not going to live forever. So it's about them knowing how to access the support stuff that she needs, the community, that she can keep her house running and do those sorts of things [Carer_17].

Grief and loss

The stress associated with caring can lead some carers to feel a sense of grief and loss over 'what could have been' for both their family member and themselves. For example, carers said:

- I just want to break free from all of this. I'm 38. I've got a life to live and I haven't got it yet [Carer_6];
- For those that have developed an issue later in life, you have to grieve for the person that you lost. I was told that he would never, ever be the person that he was when he first met me ... Some things have changed for the better. But some things are for the worst as well [Carer_20]; and
- That's one of the curses of being a carer. If you had the choice, you would be somewhere else, doing something else. I actually have a life too ... And your family member would have the life that you thought that they were going to have when you brought them into this world. That's one of the hardest things, I've found. I've got a friend whose husband and two sons were bipolar. She said to me, '**you just need to let go of the story of how you thought your child's life was going to be**' [Carer_17].

Coping with caring

Helplessness

In response to coping with mental health issues, and the associated stress of caring, some carers report feeling helpless. Even if formal treatment is received, this feeling of helplessness may persist: "as soon as he [son] was diagnosed [depression], we did everything. I used to say to a psychiatrist, 'What more can we do?' He said, 'You're doing it'. But it's that horrible feeling that you can't make it better." [Carer_21].

Interestingly, even some consumers reported feeling helpless when their carers came to them for assistance with their depression. For example, one consumer said, "she's [mother] not been diagnosed, but recently she'd had real anxiety and depression issues. She's like, 'now I really know what you've been through. I've only had this or a week, and this is horrible' ... And when she came to me and said, 'what should I do?' I was like, 'oh, I don't know, it's not that bad, just keep going to work'. I was like, 'I don't know what to do'. And I've been through it! 'Go to a GP, mental health

plan, you'll be right'. I didn't know what to do" [Cons_1]. This comment further reinforces the need to educate the public (including carers and consumer) on how to react to/ talk with and support consumers.

Similarly to consumers needing to recognise the role between self and illness, some carers required assistance to differentiate their role as family members and carers. Importantly, carers need support to recognise that it is not their role to be the clinician. For one carer this message had made a significant difference:

The psychiatrist said, 'Just remember, you need to be his parent not his therapist'. That was really liberating for me. Because no, I am not the expert here. It's my job to be a parent and to love this child. I can't fix this. I don't have that expertise. I can contribute to his recovery in many ways. But I am not the therapist. I thought it was really sound advice [Carer_22].

Escapism

Feelings of helplessness may cause carers to look for escape in other areas of life. For example, one young carer said "**I used school as my safe haven**. Just somewhere I could go and forget about it [mother's bipolar]" [Carer_8], and another participant said "going to work was wonderful. You could get away for a while" [Carer_5].

Accepting suicide

Long standing feelings of helplessness and witnessing long term suffering of a family member can also cause carers to accept or prepare for the death of the consumer. For example, one participant said: "this might sound hard, but we came to the conclusion that if it [suicide] did happen, we understood. We thought, 'if this is the life he is leading, it would be understandable that he might do something'" [Carer_15].

At times, carers may even feel relief (and then guilt for having the relief) at the consumer's passing. As one carer said, "When [son] died, it was so desperately sad. But there was almost a relief. He was a beautiful human being, but his personality was just starting to disintegrate. There's a hell of a lot of guilt over stuff you can't control" [Carer_21].

Carer depression and anxiety

Again, at the more extreme end, carers may develop their own depression and anxiety. Several participants reported this:

- I'm on some medication now for depression [ConsCar_5];
- I'm probably depressed actually. I went through a phase where it was just beating me up and I resented it [Carer_15];
- I was determined that I was not suffering from depression. I said, 'I might get depressed about certain things, but I'm not suffering from depression' [Carer_19];

- I suppose it does take its toll. You've got needs as well. You think it's quite selfish if your needs are not getting met. That puts a strain on the marriage [Carer_19];
- Have I been depressed since? Yeah I probably have. But not to the stage that depression becomes a real problem if you cannot exist in your daily routine. I think depression is something that follows us all like a shadow. I mean, grief is a form of depression [Carer_15]; and
- I've started to feel depressed lately because I've never felt like I've had a life. **Mental illness has made me depressed and my life a misery.** I feel every year I want to burst out, live a real quality life, grab it with both hands. I haven't been able to have a job, a relationship, or anything without my mum being the centre of attention all the time [Carer_6].

Effective ways of coping

Having strategies for coping with the responsibility of caring can be important for carers. Carers in the focus groups used a range of different methods to assist them and their families to cope.

Prioritising the self

Importantly, this study identifies that a key necessity for effectively coping with the caring role is to prioritise the self. As some carers put it:

- That's one thing we learned. If we crash, everything's going to crash. That took us about four or five years to learn. We realised that we had to look after ourselves. That's a must [Carer_24];
- I find it is sometimes time consuming, but it is also draining. I seek help whenever I need it because I've got to look after myself. If you don't look after yourself, you can't look after anyone else. Yourself is the first priority [Cons_23]; and
- I'm priority number one. **If I don't look after myself, I can't care for the person I'm caring for.** I've learned that. That's how I'm able to survive where I am today. I've tapped into the mental health plan. I've used the bulk billing psychologists attached to the medical centre [Carer_10].

Sharing caring

Some carers reported that they were able to share the caring. For example, one participant said "we ran into a series of 'bad cop, good cop'. When [husband] would fall out of favour [with daughter], I was the good cop" [Carer_15]. Similarly, another participant said "our daughter had this amazing ex-boyfriend. We actually worked like a tag team. I still think she would be dead of he didn't find her, and bring her home. I used to handle it most of the time. Then when I couldn't do it anymore, my husband would take the baton" [Carer_14].

Humour

Interestingly, humour was identified as an effective way of coping with caring. As one participant said: “We talk about it openly to people. [Husband] will say funny things like, ‘I’ve got to take my crazy pills, just a minute!’ We’ve been very lucky that we’ve been able to turn it somehow into a humorous story. The humour is what’s enabled us to cope, even though it’s not funny at the time” [Carer_11].

Faith

Some participants noted that their faith allowed them to cope with caring. As one carer put it, “I think, not necessarily being Christian, but having faith or hope in something, can help you take that higher perspective. I think that can help” [ConsCar_1].

Respite

Services that offer respite may not be widely known to carers. One carer pointed out that she used the “Commonwealth Respite Centre. I’ve had someone come out and clean my house for two hours a week, for up to eight weeks at a time” [Carer_20]. However, very few carers in the focus groups seemed aware of or tapped into respite services.

The carer experience for males

Because of gender socialisation, the carer experience for males emerged as a key theme.

Not assuming a responsibility to care for a family consumer

In some families, males had chosen not to be the primary carer for the family member with mental health issues. As one carer described:

Whether it be your view or not, I think the male ego has always been that you don’t show your emotions. And that’s always been the Aussie way. My brother’s three years younger than me, he’s 35, but he’s never been accepting of my mother’s illness. He would lock her up, ‘fix that and don’t let her out until she’s better’. He left when he was 21 and he hasn’t looked back. He’s saying now, he will never go to her funeral. So I’m left here to pick the pieces up. It’s horrible. I’ve tried to explain, I’ve been in tears to him on the phone, ‘I need your help, I need your support’. He said, ‘you get on with your life’, and I thought, ‘well, I can’t do that’ [Carer_6].

This could have been related to the daughter being the eldest child, rather than gender based. There were, however, other gender related findings in the focus groups.

Not discussing mental health issues

While some male carers accept the responsibility of caring, they are not necessarily comfortable to (continuously) share or discuss the experience. For example, participants said:

- My husband would hate me talking [openly about mental health issues] [Carer_17]; and
- It was a rollercoaster ride that went on. I used to find it hard to keep talking about it. Women handle it differently from men [Carer_15].

The difficulty male carers experience in sharing their emotions is highlighted in one of the focus group discussions. This is described in Case Study 9.

Case Study 9: Male carers and expressing emotion

[Carer_1]	Some of the girls at work have been good. It's good to be able to talk to some of them during work to voice it out.
[Carer_4]	It's very hard for a guy to talk. With myself, for many years, I wouldn't talk about it much. I'm 59. You just didn't talk about it.
[Carer_3]	I don't think guys go to work, or to our mate's place, and talk about emotions or anything like that.
[Carer_1]	That's how women get things out, where men keep it bottled up.
[Carer_2]	If you're talking to someone that doesn't know anything about it, it's going to be a one-sided conversation. You might get it off your chest, but it hasn't helped in any way really.
[Carer_4]	The only time it helps is when you're talking to somebody else in a similar position and they can give you feedback. That's why I've come [today], not because I needed to get rid of anything, but in case there was anybody that needed information.

Having to be in control and problem-solvers

Another issue compounding the experience for male carers is that they are socialised to be in control and problem-solvers, and that when they are unsuccessful in the gendered attempts, it can be wearying. As these participants said:

- I went into the bathroom, away from my wife, and had a quiet sob, until I sorted it out. I came out, under control again. Because men are supposed to be in control" [Carer_15];
- Well when there's a real tough event, when my partner was trying to fix it as well. Through trying to fix it, it's actually resulted in him becoming chronically depressed and suffering from anxiety. So it's the gift that keeps on giving! [Carer_17]; and
- There's a problem with men. **Men are the 'Mr Fix-its'**. We go through a stage of some years of trying to rectify the problem. 'If you do this, if you do that, if you get out of bed, if you study, if you get a job, it'll all be okay' But it

does one of two things. It either drives the son or daughter away, or breaks the marriage up. Most men just say, 'it's too hard. I'll bail out' [Carer_24].

Lack of acknowledgement

Unfortunately, because of the lack of awareness and/or stigma associated with mental health issues, there is a lack of acknowledgment for the informal work carers do in supporting consumers. For example, participants said:

- **As far as a carer goes**, the understanding on a public perception is that **it can be quite thankless** [Carer_17]; and
- I think even government departments have a bias or stigma ... 'Do you wipe their backsides? Do you feed them with a spoon?' All that sort of stuff when you're filling out the carers' payment form, for instance. They don't give reports to such things as cleaning their house. Honestly, if my sons didn't have their houses cleaned, didn't get a lot of cooking done for them, didn't get their gardening done, they would have been evicted from their houses long ago. Yet those things are not counted [Carer_24].

Consumer insight into the carer experience

Given that mental health issues have, by far, the greatest impact on the quality of family life for carers, it is important to explore the extent to which consumers have insight into the carer experience. Indeed, bridging the gap between the consumer and carer experience requires empathy and insight from both parties. One consumer indicated some insight, saying "people are often far more supportive than we give them credit for" [Cons_8].

Comments by other consumers suggested that similar to carers not fully understanding the consumer experience, consumers did not fully understand the caring experience. As one consumer said: "Initially, it was tough on both of us because each didn't know how to help the other. I didn't know how I could get my dad to come to my side of the table and understand what I was going through, and he couldn't get himself to come to my side of the table. So there was that impasse, that breach, that none of us could cross" [Cons_21]. Neither party were able to understand and acknowledge the other's experience.

7.3 Relationships with family

Some participants spoke of positive family relationships as a result of mental health issues. In the main, however, consumers and carers perceive that mental health issues cause significant strain on the family.

Consumers

Depending on who the consumer is in the family, the relationship within the family that is affected can be with parents, partners, or other family members. The impact on particular relationships may also differ within and between families.

Relationships with parents

Several consumers spoke of positive relationship with their parents:

- When I was growing up, my mother was very empathetic, so I probably had the softest experience [Cons_7];
- Once Dad reached out to me, we've grown together to the point where my dad's, far and away, my best friend [Cons_21];
- Once my parents realised how sick I was they bent over backwards. They did everything they could to try and help me [Cons_11]; and
- Having a mental illness actually brought my family altogether. Our relationships, communication, got so much stronger. I could say anything and they'd sit there and give me their undivided attention [Cons_5].

However, some negative experiences were also reported. For example, participants said:

- I don't really talk about my problems with my parents [Cons_20];
- **I think my parents feel that they're a failure.** They haven't said it to me directly, but I feel that that's why I've been wiped [Cons_25]; and
- My parents are completely toxic and dysfunctional. The only way to deal with it is to leave. I feel like my parents have contributed to my mental illness through their abusive and toxic aggressive behaviour. They've taught me how to feel subservient and less than equal, quite low self-esteem [Cons_19].

In some cases, both positive and negative experiences with family were reported by consumers. For example, one participant said "my parents were the most supportive people. But when I got diagnosed [with depression], my mum thought it was her fault. She'd go to bed crying every night saying 'I did something wrong', like how I was born or brought up" [Cons_5]. Indeed, to help avoid feelings of guilt in the consumer, one 'consumer and carer' said: "I don't let him [son] see. If I'm going to get upset, I just leave, I go walking. Because he's too young, and I don't want to make him feel guilty or responsible. He might see me and think he's setting me off and I don't want that happening, so I remove myself. It works" [ConsCar_1]. Arguably, it was the personal experience of having mental health issues that allowed this participant to provide empathic care.

Another example of having both a positive and negative relationship with family was provided by a participant who said "my mother was always supportive of me. The flipside is, of course, when she perceives that I'm about to go over, she's a bit too attentive sometimes" [Cons_7]. This experience was corroborated by a carer in the study who said, "when you're caring for an adult, there is this perception that you're being overprotective, that you're trying to be too involved in their life" [Carer_17].

In summary, some consumers may report positive experiences with their family as a result of their mental health issues, but when negative experiences are reported they most often manifest as withdrawal, to a greater or larger extent, from parents. In addition, negative experiences such as managing guilt and a sense of over-protectiveness, can still be reported by consumers who also report having supportive families.

Relationships with (marital) partners

Several consumers spoke of the negative impact their mental health issues had on their marriages or significant relationships. These participants said:

- I just don't see how a marriage could survive if you don't get information and support for yourself [ConsCar_2];
- My mental illness cost two marriages, but I've got two lovely children, and they've supported me [Cons_23];
- My depression and anxiety cost me my marriage because my partner wasn't aware or very giving. It was just too hard [Cons_22];
- **My husband actually said to me that if he'd known I had depression earlier in my life he would never have had anything to do with me** [Cons_17];
- I lost a partner once. I don't know if he didn't understand, or he didn't sympathise, but we ended up breaking up. I guess I can't entirely blame him because I probably wasn't the nicest person to deal with, to be honest [Cons_9];
- We were going to separate at one stage, and I said to him [husband] I can understand that. 'It's just been so hard and I appreciate that you stayed with me as long as you did'. I know the attrition rate's really high. I was just really fortunate. But he found it very, very difficult to accept that this was as good as it was going to get, it wasn't something that was going to go away, and that basically our relationship had to accommodate that [Cons_8]; and
- My husband used to say, 'I think you're just doing this. I think you're just putting this on. I think you just like the attention. I don't think you're realistic. There's nothing really wrong with you'. It went on and on because he couldn't see why I shouldn't be better. It had got to the point where he couldn't take it anymore, he was going under, so I had to get myself right [Cons_16].

These results indicate that there is a risk of divorce or separation relating to mental health issues. Further, the results indicate that only some consumers are self-aware; acknowledging the impact of mental health problems on their relationships.

Relationships with other family members

Finally, some consumers spoke of their relationship with other family members. One report was positive, saying "my sister bent over backwards, but she's different, she understands" [Cons_14]. However, one participant pointed out that relationships with other family members can *become* negative over time. This consumer (with PND) said:

The difficulty is that because your family and your friends are the people closest to you, for them it doesn't end quickly. It goes on and on, and they need to support you for an extended period of time.

That takes a huge toll. In my situation, I was admitted to hospital six times after suicide attempts and there was no one to talk to. You just laid there and felt more and more guilt. It got to the point where I had my only sister. I felt supported initially, but then it got to the stage where her reserves were running low and she turned the other way. She said, ‘look snap out of it, get up now, look at your family, look at your children, they need you, why are you still doing this?’ I know it was frustration for her but that just made things worse [Cons_16].

Carers

The perceived impact of mental health problems on carers’ family relationships largely depended on who the consumer in the family was. Three types of relationships are explored below: (i) carers with consumer partners, (ii) carers with consumer children, and (iii) carers with consumer parents.

Carers with consumer partners

Given the high risk of divorce, it is important to point out examples of carers who stay with their mentally ill partner. One participant said, “It’s individual carers making the choice to either stay or go. The first thing I chose was to stay. **I’m traditional – ‘in sickness and in health’**. A majority of people don’t stay. By me staying, it actually built my defences, and I learned to accept all walks of life. I must admit, the early stages of our relationship were hard – postnatal, having kids. I changed and fed the kids from day one” [Carer_10].

Importantly, some carers may choose to stay, whereas others stay because they feel they have no choice. As one participant caring for his wife said, “you just get stuck with it [depression]” [Carer_4].

Carers with consumer children

Generally, carers with a consumer child felt supported by their family. As one carer said, “my family have been incredibly supportive” [Carer_7]. Interestingly, carers with consumer children talked less about the effect mental health issues had on their relationship with that child, and more about how their caring role affected the quality of their relationship with their partner. For example, one participant said:

It made it very difficult with my husband. All I could do was bring up all this garbage about our daughter. Then one day he said, ‘you’ve said it all before and we been through all this before and nothing’s changed’. That’s when I started to think, ‘oh my God, I can’t talk to you about it’ ... We then made a decision that she would go, rather than one of us. I know a lot of people would say my child will always come first, but in our case she had to be removed from our house for us to exist. It’s a whole lot better for everybody. She’s happier, we’re happier. At the end of the day, she’s an adult. So yeah, that’s probably what saved us [Carer_14].

This quote indicates just how important relationships with partners are in terms of providing social and emotional support. It may be inferred then, that carers whose

partner is not the consumer are at an advantage. When it is the partner who experiences mental health issues, it may no longer possible to share carer based experiences and feelings. Indeed, one carer with a consumer child said, “I feel shockingly for people who don’t have someone supporting them. I think that would be so hard. Because no matter how much shit happens, you’ve got someone else there” [Carer_21].

Different family member attitudes towards mental health issues can also increase friction and stress within families. As one carer described: “We separated [husband] because all his Dad wanted to do was belt it [depression] out of him. My eldest daughter, she’s in denial – ‘he’s fine’. My mum said he just had to grow up. [Brother’s] jealous because he was getting the attention. And they think he’s a loser. Now I’m just that tired, I can’t cope anymore” [Carer_12]. Thus, the impact of mental health issues on family relationships and dynamics can be significant.

Carers with consumer parents

In the same way that carers with consumer children expressed concern to protect their marital relationship, carers with consumer parents also talked about the impact of caring on their own marital relationship. For example, one participant said, “we’ve had to spend a lot of time on setting guidelines ... But it doesn’t make it any easier on our relationship. Instead of being able to sit down at our table and talk about what’s going on, how I’m feeling, we’re going to bed at 11 o’clock at night and that’s where we’re talking. Because we can’t be talking in front of Dad [consumer]” [Carer_13].

7.4 Relationships with friends

Consumers

Loss of friendship appeared to be a more significant issue for the consumers in this study than the carers. Some participants lost friendships because of fear or lack of knowledge about mental health issues, whereas others lost friendships because consumers pushed them away or self-selected their isolation (and this is characteristic of depression and anxiety). For example, participants said:

- I’ve lost family and friends. I don’t have that at all [Cons_25];
- The people I’ve told feel a bit intimidated by it. Maybe they’re not sure what to do? [Cons_2];
- I know my friends want to help, but because they don’t know how to, it makes it worse [Cons_5];
- I’ve isolated myself from most of my friends. I just enclose myself, and not out and about all the time [Cons_32];
- They’d [friends] like to help, but for a lot of people, mental illness is a mystery they’re not very comfortable with [Carer_9];
- I lost quite a few friends because they were scared of me or didn’t know how to treat me. They tried to support, but weren’t quite sure how to or what to do for me [Cons_28];

- I got to a point one day **when my best friend came to visit me and I actually asked her to leave**. Then that was the end of that. I never ever saw her again. She got scared and she didn't understand. She didn't know how to handle it and that's all it was [Cons_31];
- When I had agoraphobia I didn't tell anyone. Occasionally someone might come to the house and I wasn't even comfortable with them being there. Then people just stopped coming around. I couldn't explain to them what was wrong and they didn't ask. They just stopped [Cons_27]; and
- Yes, friends, 'she's mental, ra ra ra' ... There's definitely a stigma to it. Hanging with the outcasts, that was fun. But yeah, I couldn't go back to my normal friends, which is a shame ... But they're teenagers, they're gonna bitch about something anyway! I just gave them a good reason [Cons_1].

On the positive side, one consumer said, "I lost a few friends once the word got around. On the other hand, **it flushed out all the fickle friends** that I had and the people who weren't worth caring about. If I ever need support I know who I can rely on" [Cons_21].

Given the relationship between loneliness and depression, it is not surprising that consumers commonly reported difficulty maintaining friendships. As one consumer put it, "you can be in a crowded room and still feel like you're by yourself" [Cons_9]. Moreover, loneliness can either be caused, or exacerbated, by social isolation or withdrawal. For example, participants said:

- [Depression] makes you more introverted. I'd rather just be by myself [Cons_2];
- It's easier [to withdraw]. Don't have to worry about having a panic attack. I closed a lot of opportunities I could have done. I want go to that party, but I'll stay home [Cons_1]; and
- I was at my worst when I was by myself and just had time to think, so I try to be as social as possible. I'm my calmest, when I'm talking or interacting. The more I think, the worse it [OCD] gets. I know I'm avoiding it, but it's where I'm happiest [Cons_3].

Importantly, consumers reported that loneliness and isolation are minimised when they seek out the company of other consumers. For example, one participant said, "mental illness makes you reflect on your identity and where you belong. Being diagnosed with mental illness isolates you from the general public. But that isolation brings you with other people who also suffer. So you're not actually isolated" [Cons_5]. Similarly, another participant said, "I've met a couple of ladies that are participants with [NGO]. We were always comfortable in each other's company. Didn't have to put up a front. We were able to discuss anything about our mental illnesses freely. There was an acceptance there" [Cons_31]. (See Section 8.3 for more examples of the benefit of consumer support groups).

Carers

Carers also reported that mental health issues in the family could impact on their ability to maintain previous friendships but they also helped carers determine quality friendships (or friends who understood mental health issues). As an example, one participant said “friends that we thought were very good friends fell off like flies. Yet, to restore your faith, a couple of people came out of the woodwork that we knew vaguely but then offered help” [Carer_11]. Similarly, another carer said “I’d say with our friends, they have been absolutely fantastic and very aware and supportive. But then we’ve been really open too” [Carer_21].

7.5 Ability to work

Examples of discrimination experienced at work were reported in Section 6.6. In this section, there is a focus instead on psychological, financial, and/or social loss in the work context as a result of mental health issues.

Consumers

Consumers reported that mental health issues affected their ability to work, and that this was associated with psychological, financial, and/or social costs. For example, participants said:

- I was out of work for a good two years, so that was bad financially [Cons_4];
- Having an anxiety disorder really hampers my career, as well as social life [Cons_20];
- Last time I got employed, within a week of doing that, I said ‘why didn’t I do this before?’ Really got my confidence up. And my bank balance! [Cons_32];
- **You can’t say, ‘I’ll be better in six months or I’ll be better in a year’ because you don’t know. We were in dire problems financially.** We had no or very little income [Cons_17];
- These disability employment service providers, their success rate is something like 20 per cent, which is pathetic. One of the biggest parts of recovery is getting work again. That’s how you can pay for stuff, that’s going to help you have social inclusion. You can pay to have quality of lifestyle. But unless you can get a job, that’s a real barrier for people with mental illness [Cons_11]; and
- I would love to go out and work in my profession that I’ve been trained for. But I still feel I lack the confidence because of the panic feelings that I sometimes get. I feel as though I’m missing out. I’ll do volunteer work because I feel safe. I’m not tracked there. I can make a mistake or I can leave. I find it really hard to go that next step and actually commit to working in a regular job where I get paid [Cons_31].

Carers

The carers in this study also expressed that mental health issues affected them psychologically, financially, and/or socially. For example, participants said:

- I took some time off work because I realised that I needed some time out [Carer_19];
- The financial impact is huge. We used to live the high life. Thank God we did, because we've got those memories [Carer_21]; and
- The sort of work that I do requires a lot of concentration. I found my capacity to do my jobs diminished. Then I get upset. I became quite resentful the impact my family situation was having on my levels of professionalism, and what I wanted to achieve out of my job. I was always worried too that, if I was unable to do my job, what happened if I lost my job? [Carer_17].

The impact of mental health issues on ability to work was highlighted in one case [Carer_20]. This has been described in Case Study 10.

Case Study 10: Impact of mental health issues on ability to work

My partner ended up having a long stint off work because we realised he wasn't coping. He had nearly two years off ...

[Husband] was like 'I want to get a job because I hate that we got no money because of me' We've gone from a joint income over 80 grand to now, lucky to earn 35 for the year. He's a man. He's a provider. He's supposed to look after his family. He hates it. He hates relying on me and my income ...

I'm the only person I know that uses up their carers' leave, annual leave, sick leave, their full entitlements for the year.

7.6 Summary

The impact mental health issues have on the family, and relationships within the family, is perhaps the most significant area affecting the lives of both consumers and carers. However, the family context seems to most strongly highlight or bring about the issue of competing needs and interests; both groups require significant empathy and insight into the others' experience to be able to bridge their disjunction.

The results show that carers with consumer partners, consumer children, and consumer parents all most commonly reflected on the impact mental health issues had on their (marital) relationship. This is consistent with the finding that divorce was a significant risk in families with a family member experiencing mental health issues, and suggests that the social and emotional support that partners can offer, to help cope with the stress associated with caring, can be crucial. By analogy then, it may be inferred that carers with consumer partners, and carers without partners, are at a disadvantage compared to other carers; they may not have the same type of significant source of support.

The results also show that loss of friendship and community involvement affects the lives of consumers and carers, but most especially consumers. Also, ability to work significantly affects both consumers and carers. There are psychological and social costs to not being able to work, but it is the financial cost that seems most detrimental to families affected by mental health issues.

The experience of carers is as unique as the experiences of consumers. The on-going nature of caring can make it exhausting. Where they occur, carers' frustrations and stigmatic attitudes and behaviours may cause consumers to (further) withdraw from what they perceive to be unsupportive families. This then only exacerbates the loneliness and social isolation that is characteristic of depression, and entrenches their need for empathy. Arguably, the greater the consumer's need for empathy, the less insight they have into the impact their mental health issues are causing to the family who also want their experiences to be understood. Thus, a vicious cycle begins to reinforce the disjunction between consumers and carers.

8 Treatment for mental health issues

It's not so long ago, just pre-1950s, that people were locked up. They've only started to look at different ways of treating people now. The treatments have improved out of sight since I've was diagnosed fifteen years ago [ConsCar_1].

Providing early and effective treatment for people with mental health issues is an important part of the recovery process and improving the quality of consumers' lives. Arguably, treatment is also essential for family carers, to help address the impact that mental health issues have on their own well-being and quality of family life.

Knowing what constitutes effective treatment for consumers and carers is only one part of the solution. Getting people to even access treatment is a barrier that first needs to be overcome. To be able to target such barriers, it is important to identify what they are, and any factors that have been experientially identified by consumers and carers as effective for overcoming them.

Thus, there are four topics explored in this section:

- Barriers to seeking help;
- Facilitators for seeking help;
- Examples of perceived effective and ineffective practice; and
- Suggestions for early intervention.

Importantly, help can occur formally or informally. Formal help refers to professional help from counsellors, psychologists, and psychiatrists, etc; and informal help refers to self-help strategies and help from family and friends. Both are important and necessary complements to one another.

8.1 Barriers to seeking help

For consumers

Not recognising the symptoms of depression

To assist the help seeking process to start, it is obviously important that there is some recognition of the symptoms of mental health issues. This study found that lack of recognition can occur either from the consumer themselves or from the people around them, but that either the consumer or carer can help start the recognition process:

- Mum called the crisis line, but prior to that I had absolutely – I didn't even really know what depression was [Cons_9];
- My husband had depression quite badly. Not that I understood it at the time. The first thing you've got to do is identify that there's a problem [Carer_11];

- When I first became unwell 13 years ago, I didn't know what was wrong with me. It wasn't something that had happened to anybody I knew, so I knew very little about it [Cons_28]; and
- There's a really high awareness of mental illness now because of the work of *beyondblue*. Everybody accepts and understands that mental illness is an issue. But I don't think people are well informed. I was in contact with a lot of people from all walks of life, but **nobody picked up the signs** and symptoms in me, **and said 'mate you're struggling**, I think you need to see a doctor' [ConsCar_2].

Consumers pushing help from friends away

Part of the difficulty associated with not recognising the symptoms of depression, is that consumers may push away the help offered. This is partly a result of the loneliness and social isolation characteristic to the symptoms of depression. For example, participants said:

- I didn't feel comfortable talking to friends or anything like that [Cons_27];
- Nobody was following me up because I isolated myself. I wouldn't leave the house, I wouldn't leave my bedroom. So I wasn't going to the clinic for someone to pick up the signs. And **most people, when they're severely depressed, won't seek out help**. When we're really ill, we don't [Cons_16]; and
- Depression is all experiential. Unless you experience it, you don't know what it's like. I know what the warning signs are because I've lived with this. But for someone like a friend, he doesn't know what it's like. And the nature of depression is that you drive away the people who are close to you [Cons_21].

Moreover, consumers may push friends away because of feelings of worthlessness and being undeserving of the help; again, characteristic of depression. As one consumer put it, "one thing that stopped me getting formal help was strongly linked to my depressive symptoms at the time; which was **I didn't feel that I deserved help**. I felt I was too far gone, that I couldn't be helped, that it was a waste of government resources, that they should allocate it to people who actually deserved it, who were worth it, who were more valuable than I was" [Cons_21].

That consumers tend to isolate themselves and/or push friends away, only substantiates the importance of ensuring that close family and friends are not unresponsive or dismissive of consumers who indicate their intent to seek help. That is, encouragement is crucial. For example, one consumer said, "I remember telling my dad I was getting help, and his first reaction was 'do you really need it?' So rather than it being a platform to start talking about it, it just made me shut down ... So I think family members or friends, even if they're not sure what to say, if they're at least open to hearing a bit more about it ... If they're closed, you feel disempowered" [Cons_2].

In addition to not just being open to a conversation, it is important that family and friends listen more than providing advice. As one consumer said, "I think that **the**

person they're talking to needs to just listen and let them explain it all without offering advice too soon. Sometimes it can be complicated by friends who think they know, and so then they start off down a different direction to where the person's actually needing to go" [Carer_9].

Stigma

While stigma has been addressed in detail earlier in the report, it is important to acknowledge the role stigma plays in preventing help seeking:

- The guilt and shame of being officially classified as a basket case stopped me getting formal help [Cons_21]; and
- I was afraid of getting help because it would confirm my worst fears – that I had a mental illness. Because of the stigma of it all, I just couldn't face the whole idea that I needed to see a psychologist, and that I was cracked and on antidepressants [ConsCar_2].

Importantly, stigma can manifest in a number of ways within consumers including denial, pride, fear, avoidance, and/or resistance to treatment; and stigma may cause carers to downplay, deny, or neglect the severity of the consumer's mental health issues. Examples of these are provided below.

Denial

- In my case, the denial was holding me back from getting help [Cons_27].

Pride

- Pride is always an issue [Carer_4];
- It was in Year 6. I swallowed my pride and was like, I need to do something about this. So I went to the closest adult that I trusted [teacher] [Cons_3]; and
- I didn't open up to anybody, **I just struggled on like a warrior. 'Warrior' may be a glorious word, but there's nothing glorious about depression.** You should find humility and reach out to somebody. There's nothing praiseworthy about trying to struggle on alone and being too proud to tell anybody [Cons_15].

Avoidance

- I'd left the family, nobody knew where I was. I'd gone away to try and commit suicide because I thought, 'I'm never going to get better and I'm a burden to my family'. Then I thought, 'if I'm considering suicide, maybe there's something wrong with me'. I waited until it got so bad that I was almost incapacitated and couldn't function, before I got the help I needed [ConsCar_2].

Resistance

- I find that people want to help, but the husband doesn't want it [Carer_1];

- I have the support there, but I can't get him to respond to it. He refuses to go a doctor or a counsellor [ConsCar_1];
- We were trying to get a family counselling thing going with my son because his perception was that the other kids in the family were turning from him. (At times they were) [Carer_15];
- It's very hard to get – it doesn't matter whether it's a child or whether it's an adult – **if they're just not wanting to be part of any sort of life, it's very hard to get them going** [Carer_4]; and
- I'm talking to him [father] about getting help. 'Yes, yes, yes' Made appointments for him, got his GP to map out a mental health care plan for him. But it never – it wasn't until I've gone, 'enough's enough' and knew what he was going to do [attempt suicide] till we got help [Carer_13].

Downplaying

- My wife was depressed. You could see that she was depressed. But **I didn't realise exactly how depressed until she tried to OD on some Valium** one night. **That was a wakeup call.** It's just been downhill from then really [ConsCar_5].

Cultural issues

As collectivist cultures significantly value the family, people from these cultures may have a preference to seek help from within the family rather than seeking formal, external treatment. For example, one participant said, "with the Lebanese people, it's extra hard than the Australians, because we have this stigma about suicide or sexual assault, to hide it all under the carpet. It makes it extra hard for that person to cope and get out of that hole. So you end up seeking help from strangers, rather than your family, which should be supporting you" [ConsCar_4].

Thus, the stigma associated with culture can prevent family from being a necessary and important source of support. This suggests that perhaps part of what constitutes 'culturally appropriate service delivery' for Aboriginal and Torres Strait Islander and NESB families, is an acknowledgement of their preference for family support, but combined with an emphasis on the need for formal treatment to help overcome the issues of shame and stigma.¹⁹

Not knowing where to get help and cost of services

Other barriers to seeking help are less to do with the attitudes of consumers and carers, and more to do with structural and practical issues. Specifically, a lack of awareness on how to get help and navigate the mental health system is an additional barrier. For example, one participant said, "I think I'm lucky because I'm a registered nurse, and I know the ins and outs of the public hospital system. I know how doctors

¹⁹ Importantly, the shame associated with seeking help for sexual abuse is not exclusive to Lebanese culture, but occurs cross-culturally including in families of Anglo background.

and GPs and everyone work. But I worry about the person next to me who doesn't have any idea how to contact anyone, or what to do, or what to ask" [Cons_18].

The cost of professionals was cited as another practical barrier to seeking formal help. These participants said:

- Finding help that didn't cost anything was so hard to do [Cons_4];
- People don't have the income of doctors. They don't have the money. That's something that needs to be recognised [Cons_7];
- If you're medicated as well, people just go [to psychiatrists] to get their prescriptions renewed. They can barely afford the prescription let alone the sessions [Cons_7];
- I still need to pay money to fill the gap from Medicare to see him, which is hard because I live on my own, I work and I study. It's hard to make the ends meet in that sense [Cons_21].

Cost may be prohibitive to ongoing help-seeking, especially after the immediate crises has been overcome: 'People are stopping treatment perhaps before they're ready because of the cost' [Cons_2]. Another participant reflected a similar sentiment:

To maintain ideal optimum mental health you need regular visits to a psychologist. You do need to be case managed. Not just in a critical stage, but in a stage where you're quite well. But cost is a factor [ConsCar_1].

For carers

Given the magnitude of the affect mental health issues have on the well-being and lives of carers, it is also important that carers seek help. Indeed, some carers said, "**it seems to be almost an accepted fact that the carer will eventually need some help**" [Carer_5], and "I get really upset and frustrated. But I've got people I can talk to and I really draw on those support networks. Because if you're caring for somebody, you're going to suffer at some point. You can't do it by yourself" [ConsCar_1].

However, the results of this study show that there is a tendency among carers to resist seeking help. For example, one carer said, "I'm seeking help myself now. But I put up with it for 30 years" [Carer_5]. Similarly, another carer explained,

I got help. But I had to hit rock bottom ... I still kick myself and look back and go, 'why in the world did I let it get to that stage?' Because I was the one that needed to be handling things. I was the one that needed to be constantly going, 'if Dad knew what was going on and how I was feeling, this would push him to the edge'. I need to be the one that handles all this stuff, but yet didn't ... [I feel like] I'm a hypocrite! [Carer_13].

While not all carers will need help, carers' resistance to seeking help may occur for a number of reasons. Some carers will not identify as carers; others will not identify

that they need help; carers experiences of and exposure to the mental health problems of their family member may prevent them from acknowledging and prioritising their own mental health; and stigmatic attitudes may also hinder some carers from seeking help.

8.2 Facilitators for seeking help

Two of the most significant factors that encouraged focus group participants to seek help was being open about their problems and knowing people who were informed about mental health issues. Not only did “being open” with family and friends assist one consumer to be “more confident” and to “feel empowered”, it is also the first step for families and friends being able to initiate and/or encourage support.

As one participant said, “I’ve been lucky because [my wife] has been fairly open about it [PND]. **As soon as she knew, she told her family.** Whereas I know a lot of people that suffer it but wouldn’t admit it to their closest friend. That’s something they have to deal with themselves. It’s probably why they’re still not getting better. I’ve always been open about it and told my family. Whether they accepted it or not, didn’t worry me. If they wanted to accept it and be helpful, they could. If they didn’t want to, and just ignore it, it didn’t bother me” [Carer_3]. Importantly, receptive and responsive families also help. Particularly helpful were family members/ friends who were informed about mental health issues and/or know how to seek help. For example, participants said:

- My current husband has bipolar. I think, though my experience with my ex-husband, I was the one that directed him to say, ‘you probably need some help with this, whatever it is’ [Carer_11]; and
- My sister’s a doctor, so she told me about this scheme they currently have, where you go to a GP, they diagnose you, run a series of tests, and if they consider you depressed or have a mental illness, then they’ll send you to a psychologist for 12 sessions. So that’s how I got onto it [formal help] [Cons_6].

Indeed, one consumer pointed out the potency of first-hand experience, saying “my episodes [of suicide] educated all my friends about depression. What it’s like, but also how to help somebody who’s got that” [Cons_21].

Age

A number of participants suggested that as they got older help seeking was easier: “the older I get, the easier it is” [Cons_4]. Another consumer explained the difference in help seeking approaches as she got older “when I was older, I certainly sought help myself. When I had the bulimia [when I was younger], I wasn’t in denial. I knew what I was doing. And they put me in hospital. But when I had the agoraphobia and the panic attacks, I didn’t know what was wrong, but I knew there was something wrong. So I booked myself into a psychologist” [Cons_27]. While older consumers may be more ready and accepting of the need for help, this may be in relation to past experiences of help seeking, rather than chronology.

8.3 Examples of effective and ineffective treatment

As one consumer put it, “**if you can just latch onto that one person who gets it, it’s lifesaving**” [Cons_11]. Thus, it is important to describe examples of perceived effective and ineffective practice. In this way, positive experiences can be replicated in the future, and experiences seen to be ineffective can be used as ‘lessons learnt’ and inform how best to improve treatment. Moreover, the intense stress that mental health issues can cause both consumers and carers means that the role formal treatment plays in recovery cannot be under-estimated, and is essential for ‘brokering’ assistance to both consumers and carers. Indeed, consumers are in the end responsible for taking action to protect their well-being. As one carer said, “**I got to the point where you say, ‘I can’t do any more than I’ve done. It’s his [husband] responsibility**” [Carer_11].

Thus, because formal treatment can help both consumers and carers (and perhaps in turn bridge the gap between them) – and because carers are not mental health experts responsible for consumers’ well-being – it is essential that the system that provides formal assistance to people whose lives are affected by mental health issues and that this assistance is aware, informed and empathic to consumers’ and carers’ respective needs. When such systemic infrastructure is in place, suicide prevention and strategies for intervening early are likely to be more effective.

Effective practice

Several examples of good practice were cited by the participants in this study. These examples were important for consumers’ experiences of help seeking and treatment and could be used to help inform service delivery.

Caring and/or passionate mental health professionals

- Because I couldn’t actually get to the doctor, because I’m OCD, we actually had a GP that came to my front door and just talked to me through the window. That was the beginning of my [recovery] [Cons_30];
- You get a lot of nurses and doctors in a mental health hospital. It’s not that they’ve been chosen to be a nurse in mental health – it’s a passion. They want to be there. Not like a general hospital. **The nurses in a mental hospital give you the encouragement, that positive reinforcement, that will help you to recover** [Carer_10]; and
- I’ll talk of the first suicide attempt. When I had to take him to hospital, it took four hours to get him to walk from his room to the car. He honestly thought he was going to be grabbed and put in a straight-jacket. That was why he didn’t want to go [to the hospital]. We finally got there and immediately they took us into a room. The doctor was brilliant. We were just blown away. We’ve obviously been lucky, because we have heard bad things happening too. But we can’t fault it [formal treatment] [Carer_19].
- I’ve found that my best experiences have been through counsellors. Basically, the more casual their title, the better. I find they’re able to relate better. They’re able to talk about their experiences as well, and actually form a proper relationship [Cons_3].

Effective case managers

- The difference between a case worker and your family is that the case worker is not emotionally involved with you [Carer_9]; and
- You need **a good case manager** that you can talk to, and that you trust, and has time for you. Because there has to be someone who **can see the whole picture for you**. Your husband is running around, your friends are trying to do the little bit they can, but someone who's got the whole picture is really important ... The case manager can see how other family members feel as well, and make the person who's suffering, aware that they're not all out to get you, they're trying to help you, and this is the way they're doing it [Cons_16].

Encouraging psychosocial rehabilitation

- The clinical system had given up on me. They said that my health care was palliative. At that time, I joined a local choir. That was like a stepping stone, a solution 'outside the square'. I believe strongly in psychosocial rehabilitation. That might take a whole variety of different forms. Volunteering helped me as develop confidence and skills, connections in the community. They wasted so much money on medications and hospitalisations, and **who would have thought it would be as cheap as a dog and a community choir?!** [Cons_11].

Helping carers overcome biases to specific treatments for mental health issues

- The one thing that pulled him out of his major depression, which he was in for 12 months probably, at the end of that, his psychiatrist said to me, 'have you thought about ECT?' I've seen *One Flew Over the Cuckoo's Nest* and I said, 'no way'. He said, 'seriously, his medication, nothing's working' ... Well, long story short, ECT. One treatment. It [the outcome] was lovely [Carer_11].

Cognitive behavioural therapy

- I did a bit of cognitive therapy and I've used that years later down the track. I know when I have certain thoughts, I think to myself, 'no, that's your depression. You don't really feel that way when you're fine, you're only thinking that way because you're having a bad time at the moment' Just sort of acknowledging that to yourself. I mean you still feel like crap, but you just keep going [Cons_27].

Encouraging consumers to separate themselves from their mental health issues

In the same way that some carers pointed out the importance of separating themselves from their caring role, it is also important for consumers to separate from their mental health issues. Examples from the study include:

- You don't want to be Kathy with depression, you just want to be Kathy [Cons_9];

- I work quite hard, but I'm not depression. **I am not my depression. I am me. And depression is something I suffer.** I don't confuse that, and feel that I am depression, it's not beneficial to me [Cons_8]; and
- We have a mental illness, but it's only a part of you. So that we're not overwhelmed, and you lose yourself. You can learn to believe in yourself again. I think that was really important for me. You can separate the two [Cons_28].

Acknowledging the effort consumers are making

- We've been married 39 years. He's [husband] been really well for the last two and a half years. It's just dawning on me about how much hard work he's putting in to maintain his good health [Carer_21]; and
- I notice each time, she's [daughter] picking it [mental illness] up a little bit earlier and going to hospital a bit earlier. Sometimes you think, 'my God, is she ever going to learn?' But then when you look back on it, I think, 'well she is actually taking steps forward earlier than she had been'" [Carer_14].

Sharing experiences with others to gain perspective on personal issues

- I got a tremendous amount out of [mental health first aid course] ... You sat around the table and there were another 23 people there. You suddenly realise that you're problems are very small compared to what they'd been [Carer_16].

Consumers sharing with other consumers

- I was at work the other day and said something about depression, and there's a new girl, and she said 'yeah, I had depression a couple of years ago'. Then the other girl who I've known for two years said 'yeah, I did too a couple of years ago'. Then we had this big conversation about it and we all felt great after it. Nobody had an agenda, nobody was trying to analyse each other. All we were doing was sharing experiences and it feels so good. **It feels really good to just know that somebody else has gone through it** [Cons_9]; and
- You can't really laugh with people who've never experienced it, like how your brain slows down, you can't make decisions. I remember I spilled something on the floor and I wasn't sure what to use to wipe it up. I had too many options. I could have got toilet paper, tissue, a cloth, paper towelling. I just thought, 'what do I use, which am I going to go for?' I just stood there for ages! With a support group, we can just have a laugh about things like that [ConsCar_2].

Perhaps part of why sharing with other consumers is beneficial, compared to sharing with professionals, is that it removes power differences. This was demonstrated in a dialogue from one of the focus groups (see Case Study 11). Thus, although professionals have an important role to play, treatment may be enhanced with the use of such complementary coping strategies.

Case Study 11: Power differences between professionals and consumers

[Cons_11]	Sometimes there are people going through issues that won't actually hear it from a psychologist. But if they hear it from somebody who's actually been there, they take it on board more, because you're an 'expert by experience'.
[Cons_9]	You're not such a victim when you're talking to someone who's had the same experience. When you're talking to a doctor, it's more of a professional. You're the victim and they're the doctor.
[Cons_11]	The big powerful doctor.

Ineffective practice

Although several examples of good practice were provided by consumers and carers in this study, unfortunately many more examples of ineffective practice were provided. These are described more fully below.

Dissatisfaction with psychologists

Several participants in this study indicated that they found it difficult to find a 'good' psychologist. For example, one participant said: "I guess I'm a bit biased against psychologists. I've known three in my life. One of them wasn't any good and the others were useless. That's my experience with psychologists – not really great" [ConsCar_5].

It is possible that dissatisfaction with psychologists is related to consumers' expectations of what they wish to attain from formal treatment. Some consumers may require more empathy, and others may desire more practical strategies. For example, as the discussion in Case Study 12 demonstrates, consumers who more need empathic care seem less likely to report 'a human connection' with professionals.

Case Study 12: Satisfaction with, and expectations of, professionals

[Cons_8]	I was very fortunate they sent me to a fabulous psychologist.
[Cons_15]	My first three psychiatrists, their mouths were moving but they weren't talking to you. They weren't listening to you. He went to five years or six years of uni for this? He's not connecting as a human being. They're doing everything but being human in some cases.
[Cons_11]	No, they do about 12 actually.
[Cons_8]	But psychologists, they're taught 'don't listen to the story' because the story is just an example of what it is that's going on. It's the illness behind it.
[Cons_9]	That's why it's good to talk to someone.

However, regardless of whether satisfaction with professionals is related to expectations of them, lack of empathic care is a real barrier to effective treatment. For example, participants said:

- **One day I had a suicidal attempt and the doctor treated me like I was dumb** [Cons_27];
- I've gone through a lot of mental health professionals. I've had a lot of psychiatrists being cold and intimidating and very clinical [Cons_4];
- I think education is the key to a lot of things, in terms of understanding. I mean, I went through medical school and my psychology was the ego and the super ego, right? That's very, very handy [*sarcastic*]. It's useless. [Carer_15];
- I think there needs to be more focus with psychiatrists on developing empathy, and not just looking at identifying a symptom and treating that. The psychologists I've seen, it's about treating you as a condition, there's no building of empathy. Because I was treated like that, I didn't want to talk about it, I didn't feel comfortable. You're just touching the surface. You come out, 'well, I enjoyed the seat – \$200 later! [Cons_2];
- I hate when people compare. You're having a bad day, and they say 'you shouldn't be unhappy, little children are dying off in Africa'. To me, I don't really care, and I'm not obliged to care. As cruel as that makes me sound, honestly, I think it's not a constructive way of dealing with problems; 'oh the grass is a lot drier on the other side, so you should be happy' It's very stupid, respect to people with good intentions, but it's stupid [Cons_7]; and
- I feel like I've had these flings with psychologists! I've had a really bad run with about five terrible psychologists. Two were quite demeaning. I didn't feel like they genuinely cared. I think OCD's one of those things, it's even frustrating for people who understand the illness, because I understand how irrational it is. They're like, 'why don't you just like, not do it?' I have a fear of going to a psychologist because I've had just such bad experiences [Cons_3].

Indeed, consumers on the cusp of seeking formal help enter with fears of lack of empathic care, and any evidence that supports these fears are only going set back their recovery time. As one consumer said, "I felt a bit of fear. I actually have to have the responsibility of getting better if I started going for formal help ... What's it going to be like? How do I know that these people will care?" [Cons_21].

Also, consumers need not only empathy but practical advice on how to overcome their mental health issues. That is, empathy is necessary but not always sufficient for (full) recovery. For example, some participants said:

- We talked about it and talked about it, but I needed practical things, like I was stuck in the house, I couldn't get out. I need something I can do, 'I'm sick of talking about it' [Cons_1]; and

- I saw an adolescent psychologist. Sometimes it got a bit nerve-racking because all they get you to do is just talk and talk, whereas you expect answers, you want solutions to your problems, and you don't get any of that [Cons_6].

Given the importance of professional intervention, and the difficulty of finding a 'good' professional, the results indicate that it is important that *all* professionals are effective; that is, they acknowledge the importance of establishing an empathic relationship and know when to introduce practical strategies. This need for universally effective services is especially crucial since, "now and for the next five years, *beyondblue* is emphasising that depression is a treatable illness and effective treatments are available"²⁰.

Having said that, in the same way that each consumer is an individual, each professional is also an individual; and 'doctor shopping' may be necessary to ensure that 'the shoe fits'. As one participant said, "I could not get along with the first therapist I saw. I had to keep switching. It was incredibly difficult. There were times where I thought, 'oh dear, I don't think I'll ever get better if I can't get along with any of my therapists'. It took so much effort to keep trying again and again, to finally find the therapist that I have now. Now, I see him every week. He's really good. I'm really lucky in that regard" [Cons_21].

Thus, an element of trial and error may be an unavoidable characteristic of formal treatment. In terms of being empowered with their own care, it is especially important that consumers are mindful that "yes, **you're mentally ill, but you still have rights to your own care**. [It's important to] realise that not all people that treat you are good" [Cons_27].

Bias to medicate

A significant issue that emerged from the focus groups was the fact that medical professionals were seen to have a bias to medicate people with mental health issues over encouraging counselling and psychosocial rehabilitation (although the bias to medicate was also noted among some mental health professionals). This is surprising given the overwhelming amount of evidence and literature in the field of psychology that indicates that the most effective treatment for depression is a combination of medication and counselling. It is disturbing that this 'common knowledge' among non-medical professionals is not being implemented by medical professionals with whom an integrated service to the consumer is required.

The many examples of resistance to a 'medical model' of mental health issues included:

- Medication is handed out too easily sometimes [Cons_11];
- I had post-natal depression after all my children. Every doctor instantly would try to put me on anti-depressants [Cons_31];

²⁰ The Way Forward 2005 – 2010.

- The first lady I went to basically said ‘right, you’ve got depression, here’s the medication’ **They’re so quick to give you medication** [Cons_26];
- I think just medication wouldn’t have done it for me. I think you need find a good counsellor, that knows your triggers well before it happens [Cons_28];
- My GP was the first person I went to, but he didn’t know where to send me, who to refer me to, what to do, other than to give me medication [Cons_16];
- I had one psychiatrist. She didn’t want to know any of my experiences, she didn’t want to talk to me. She just wanted to give me medication [Cons_27];
- When I was first diagnosed, the GP was very good, but she gave me an anti-depressant that really disagreed with me. I went back to her and she said, ‘no, it’s not the medication, stay on it’. I did for six weeks. I was ill for six weeks. So I had that to deal with on top of having depression [Cons_28];
- I remember sitting there at the doctors telling them my whole story. The next minute I got a script for Valium [for the panic attacks] and I was sent home. That was my first experience of formal treatment. There was no explanation, I didn’t understand anything. I come out none the wiser and it wasn’t therapeutic at all [Cons_31];
- The first response for me when I went and saw the psychologist was, ‘let’s get you on some medication’. I was like, ‘no, I know there’s strategies and things I can do. Let’s work on those things first’. She was very thrown back by that. A lot of people don’t have that education or understanding. The pill may solve the symptom but it doesn’t solve the issue [Carer_13];
- I tried three GPs of them and none of them had any idea what they were doing. They were giving me medication that made me feel bad and insisted for me to stay on them. I think what’s actually more important in formal help is a psychologist. It helped me a lot. I had a good counsellor. The only person during that process who actually tried to deal with the things [Cons_13]; and
- I found that if you have good counselling set up, more people will be inclined to want to do that, than be stuffed full of medication, which is the medical model. The medical model is ‘fill them up with medication. Depression is a biochemical disorder. Give them their tablets and she’s right’ But the thing is, people have feelings, and their feelings dictate these things [Carer_15].

Consumers’ attitudes to medication

Obviously, consumers’ perceptions of professionals’ bias to medicate is in part related to their own attitudes toward medication. Some consumers had positive attitudes to medication, for example:

- Certainly for myself, medication is essential [Cons_30];
- **I’d be dead if my GP hadn’t said ‘take these’** [Cons_8];

- Medication helped amazingly. It just did the trick [Cons_1];
- I still use a small amount of drugs just to help me keep cognisant, because I can still get a bit overwhelmed in general [Cons_7];
- I haven't had a [counselling] session for about two years now. For me, it's [medication] better than any hour-long academic discussion with the psychologist which is what mine were becoming; talking with no end [Cons_7]; and
- One of my sisters is in denial that these things [mental health issues] exist, so she told me to go off my medication. She said, 'you don't need it, you'll be fine, it stuffs you around'. I tried to cut down and 'bam'. I was just – I just said, 'no, I don't care if I've got to take medication for the rest of my life. There's something in my brain that's not working properly chemically. I need this just to function'. It doesn't make me happy, but it stops me feeling like crap [Cons_27].

However, other consumers had negative attitudes to medication. Sometimes these attitudes were related to their side effects, and at other times they were based on past experiences and/or attitudes. These participants said:

- I won't go on medication [Carer_6];
- I am completely and perpetually over-sedated by medications [Cons_19];
- I don't think people are actually aware how potent these things are [Cons_13];
- I have bipolar ... he's [son] watched me up and down, change medication, which has made him very anti-medication as well [ConsCar_1];
- My wife suffers from bipolar. She was on that wonderful drug called lithium. It crucified her kidneys and she's now a renal patient [Carer_16];
- I just can't get off it. I've tried to wean myself off it and I just get that sick that I can't function. If I'd gone to counselling before I got on the antidepressants, maybe I wouldn't be in the position I'm in now, 10 years later, still trying to get myself off them [Cons_9];
- I tried Zoloft once or twice, but I didn't want it. I didn't want to be numbed. I felt the emphasis on medication was a bit scary. I have a friend who actually can't cry. **He's been on medication for so long that he doesn't have the ability to cry.** He hasn't cried for about five years. I understand people definitely benefit from it, but it's just something I'm very – not sceptical – but wary of whether that's right for me [Cons_3]; and
- I was put on medication for a long time. I found out afterwards it's not meant for long-time use because you have to take more to get the same effect. When I started coming off it, I had episodes of psychosis, where I'd become extremely violent. I'd punch my mother and I'd wake up with bloody, bruised

knuckles from destroying things, and I wouldn't remember properly. That took me a long time to come off [Cons_27].

Consumers who had a more 'middle ground' position in their attitude to medication said:

- I had medication and therapy, and it helped me in the sense that the medication helped when I wasn't with the psychologist [Cons_5];
- Medication and counselling go hand in hand. They can fix the symptoms in the short term, but you also need to work on the stuff that's in your head [Cons_4];
- If you can put off taking medication – try other methods, vitamins, minerals anything – but leave medication as a last resort. Because if it's the wrong medication, it can make things worse. Try and seek that help before you go to medication [Cons_27]; and
- Everyone's different. I look at my sisters that have been on medication for years, but still have the disorder. They haven't changed their behaviour, they haven't gone and sought therapeutic help, counselling. Facing what's caused it in the first place and talking through it, going through the healing process [Cons_31].

Dissatisfaction with hospitals

Some consumers reported negative experiences in (general) hospitals, as described below. As one consumer put it, "a hospital is probably the worst place you can send a person with either mental health or depression issues. It's a place to rot and die" [Cons_15]. Similarly, another said, "people living with mental illness or disorders should be treated at the least restrictive environment. We should put a lot into community treatment and service, instead of always beds, beds, beds. Depression can be treated in the community" [Cons_23].

Lack of awareness in general hospitals

- The medical ward at the hospital is where you're admitted. The staff on that ward are not trained in mental health in any way, shape or form. Therefore, when we're admitted to hospital we can be treated without respect or dignity, and often totally ignored. They have no understanding of mental health. And sometimes, the nurses are so frightened they don't want to come near you. It's just a horrible, degrading experience [Cons_28].

Failure to acknowledge or address mental health issues during crises

- I think *beyondblue* does a lot to raise awareness of depression. But from my experience, I didn't get any help at all with post natal depression. No one pointed me in that direction at the critical time. Later, when I was starting to recover a bit, yes, they said 'how about this and how about that', but at the critical time when I was in bed, overdosing, no one pointed me in that direction. I think it's a lack of awareness from health professionals in

particular. Nobody spoke to me about it when I was admitted to hospital each time. Nobody mentioned it when I was in the public hospital in the high dependency unit. Nothing [Cons_16].

Lack of compassion

- **What you are hungry for in hospital is not your meds. It's a decent conversation with anybody.** You don't necessarily need a degree on this stuff. If you're willing to offer something of yourself, in a warm manner, and build a little bit of a bridge, show a genuine interest, whether you're talking about astrophysics or the colour of my boots, it doesn't matter. It's a terrific medication. It may even be better than many of the antipsychotics I've been on [Cons_15].

Long term misdiagnosis

Some participants noted that long-term diagnosis meant that recovery was also stifled. These participants said:

- I had post-natal depression. I had it with my first daughter when I was 21 and it was never diagnosed [Cons_31]; and
- My son has a diagnosis of schizophrenia, but that's been up and down like a yoyo for about 20 years. Now they say that he's bipolar. I don't know, because I'm dealing with experts [Carer_15].

Diagnosis is an important part of recovery. As one consumer said, "I was given medication when I was diagnosed with depression. I was actually quite glad when she said 'you've got depression' because **I didn't know what was wrong with me. It was almost a relief to find out**, and the medication really helped. I didn't have highs and lows [anymore]. So I'm a big advocate for medication as well" [Cons_26].

Resource issues

A number of participants pointed out that insufficient resources were a problem with the mental health system. Participants said:

- I wanted it [formal help] from day dot, but I couldn't get it because there was no service for him [son] [Carer_12];
- The more you try to find a service that fits the need at the time, the more you get referred on to other services. It's a big roundabout, and a turmoil in itself [Carer_9]; and
- Red tape. I threatened to go to the minister. That's how far I had to go before help was – not even given to me – but forthcoming. It shouldn't have to be that far. They [carers] shouldn't have to be loaded with that much burden on top of what they have to personally support as a crew for their loved ones. It could have sent me into a secondary depression, because I was carrying so much burden. Not just financially; emotionally and mentally. There's a lot of

people out there that would not have the, I suppose, courage to ask for help or even go that far [Carer_10].

Resource issues emerged in specific and identifiable domains. These are explored in more detail below.

Availability

One area of resource shortage was the lack of availability of services at the time they are required. For example, one participant said, “you need someone round the clock. These places are nine to five. What do you do after that?” [ConsCar_4]; and “in fact, **I get most vulnerable between five and nine**” [Cons_21]. Also, support groups for carers may not be appropriately timed. For example, one carer said, “the problem for me is I don’t drive. And most support groups are run at night. Or if they’re run during the day, it’s the days I’m working” [Carer_20]. Finally, at the most extreme end, the lack of timely resources can occur in crisis situations. This is demonstrated by one carer participant [Carer_24] in Case Study 13.

Case Study 13: Lack of resources during crisis

Back in the mid ‘90s, every single time my son went into hospital, we had to go through the entire process, what was wrong, etc etc ...

My dilemma was: What do I do? I’ve been [to the hospital] twice this year. We called the crisis intervention service. They agree he needs to go to hospital. We’re in emergency for 12 to 14 hours before they finally tell him, ‘we’re seeing you with your mum and dad, so you can go home’ What do we do then? ...

We can call the police and have him detained. But that’s going to badly damage our relationship with our son ...

You might say, ‘I’m in private health funds, I can get him into private hospital’. Wrong. When our two psychiatrists have rang them [the two private hospitals in site], they said, ‘oh no, we’re full at the moment and we’ve got a waiting list’. ‘Oh, how long is the waiting list?’. ‘Oh, it could be four days. But we can’t say’ ...

So there is our dilemma. We take our son home and we sleep in the bedroom, doors open. We listen to him getting up and counting his tablets, and hiding knives, and all that sort of stuff ...

When we need help, we need it now. We need it right now. Two, three, four days’ time, it’s tapering off. This is the dangerous time.

Urban and regional areas

Although one participant said “Rural Mental Health was fantastic” [Carer_5], findings show that service shortages were a significant issue in several of the focus group sites most especially in the rural areas. Indeed, all but the Sydney and Melbourne groups reported this issue. Examples include:

- Back here, it doesn't have the same sort of resources that Sydney does;
- I think promotion and prevention is very hard in a regional area. Like **with the mental health care plans, people are waiting six weeks to get into a GP** [Carer_13];
- Regionally, I think it's harder to access things, whereas when you get on the Internet, in the metropolitan areas, it actually is a little bit easier. But, up here, we're just so spread out [Carer_6]; and
- I have a 20 year history of depression. In terms of services being available, this occurred to me 20 years ago, and there's still no services in [site]. I had to be flown to [hospital], leave everything behind, my job, my partner, everything [Cons_18].

PND

Lack of resources specific for PND also emerged in this study. Participants said:

- Unavailability of suitable support services, or people really understanding the issues [of PND] [Carer_9];
- **Child protection now are breathing on people with post natal depression** just because, often they're not seeking the help that they're really needing, that's identified, **and the services just aren't there to back up what's going on** [Cons_10]; and
- I'm at the point now where I'm ready to look at what the options are for people who are suffering with post natal depression because I found that there was very little support for me at that time. There just weren't agencies available to help at all [Cons_16].

Literacy and English level

Some participants pointed to the need for easy-read versions of information. One participant said, "you *Google* it [depression], but everything's not in plain English. So imagine someone that was from a culturally different background, or even from a literacy point of view" [Carer_10]. However, another participant pointed out that "all the brochures on the Multicultural Mental Health website are in simple language" [Cons_23]. Thus this points not just to the need to ensure that easy-read versions are available, but that they are available in forums where people know where to access them and how.

Mental health system not equipped to address co-morbid substance abuse

Substance abuse issues are an important covariate to consider when addressing mental health issues. One carer said, "someone in his [son] dropkick friends gives him some methamphetamines. Then dope cigarettes. Plus the fact that he cannot live without booze. He regards all these sorts of things as a harmless, helpful, temporary cure. But all these things are part of the problem. They're not part of the cure" [Carer_24].

There has been a recent push to increase holistic treatment that meets the needs of people with both mental health issues and substance abuse. As one participant said, “I think the most exciting thing that’s happened is Professor Patrick [McGorry], the fact that he monitors the substance abuse and mental illness” [Carer_21]. Nevertheless, there is still an on-going need for a system equipped to address this comorbidity. As one participant put it, “they’re not dealing with the two issues together. It’s, ‘oh sorry, you have drug problems. That’s not our problem. That’s somebody else’s problem’” [Carer_24]; these “**people are falling between the cracks**” [Carer_15].

Interestingly, people with a mental health issue but not with co-morbid substance abuse, were careful to point this out and differentiate themselves from people who experience both mental health and substance use problems. For example, one participant said, “we’re getting mixed up now with mental health. Drug and alcohol, that’s a separate issue altogether. What we’re talking about is mental health. It’s not fair on the patients who are genuinely mentally ill” [Carer_16].

Lack of consistency in professionals

Lack of consistency in the treatment and messages provided by different professionals was a significant issue for consumers and their families. For example, one participant said, “[husband] saw six psychiatrists in the time he was there [hospital]. **If you’ve got a sore knee, can you imagine telling the story six times?**” [Carer_21].

Despite being empathetic to the fact that people do change jobs, or experience professional burn-out, this does not take away the impact that a lack of consistency has on quality treatment. As one participant said, “I know people change positions and jobs quite regularly, but when I first met [name], I had to explain my whole situation again. And not only for carers, but for consumers of mental health, that can be very unsettling” [Carer_6]. Insightfully, one participant responded, “unfortunately, there’s not a great a deal you can do about that” [ConsCar_1].

Professionals failing to acknowledge carers

Another significant barrier to carers’ perceptions of effective treatment is the failure of professionals to acknowledge the importance of carers in the recovery process. As one carer said, “it’s important to get that professional network around you who do honour and support your role” [Carer_17]. Some carers reported positive experiences such as, “I actually have a really good relationship with his [husband] psychiatrist” [Carer_20]. However, some carers did not feel acknowledged:

- We had to shop around to find one [professional] that fits the family profile. But I’ve had some rather nasty things said to me from professionals, while I’ve been trying to be a responsible parent [Carer_17]; and
- Unbeknownst to us, he [son] was going to be discharged. They didn’t consult with us. My big thing is that **they don’t respect your knowledge**. They don’t use the resources that are there. The private psychiatrist is a resource. We are a resource. So it’s that co-operation or integration of all the various parties. I think that’s so important. That’s what happened with [son]. We were all working together as a team. Then he went to the [hospital]. Suddenly his

private psychiatrist is no longer part of the team. Then we're not part of the team [Carer_21].

It is important that where consumers agree to family involvement that treatment encompasses and/or acknowledges the role of carers.

Mental health and other systems not sensitive to the recurring nature of mental health issues

- I've said, 'it's an illness. It's recurring. It's not going away'. So **why can't we, as a society, have a structure that is elastic enough to go with the ebbs and flows**, rather than having to revisit and go back, which you know with your therapy, your healing, you need to be able to move forward. If you keep having to go back all the time, it just keeps you stuck in the pain of the past. It's counterintuitive [Cons_8]; and
- We looked at the disability support pension for our son as a safety net. But if he claims six [work] payments then he's cut off from the pension. Then when he's ill again, we would need to start the process again. I don't quite understand where the missing link is within government agencies that don't recognise that this is a reoccurring disease and needs that safety net under that. They shouldn't be made to jump through more hoops [Carer_18].

8.4 Suggestions for early intervention

Unfortunately, a sense of desperation is often what brings consumers into formal treatment. As one participant said, "I was on my own. I didn't have anyone to discuss it [depression] with. That's why I decided I will look for help. If I don't help myself, no one else will ... I was suicidal. I knew I had two options; I either have to look for help from someone who will listen to me or I have to die. There was nothing in between [Cons_13]". To help prevent escalation and crisis situations, it is important to identify the symptoms of mental health problems early.

An important part of 'getting in early' is identifying, acknowledging and addressing barriers to seeking help, especially not recognising the symptoms of depression and stigma (see Section 8.1). Education campaigns explicitly stating the nature and symptoms of depression (including the impact it may have on people's lives) is necessary. Further, strategies should go beyond raising awareness to directly tackling factors that entrench stigma.

More immediately, however, participants suggested ways for other consumers to take steps of early intervention. These include:

- Go see your GP [Carer_20];
- Recognise the early warning signs, and seek the GP. Seek professional help and get it treated [Cons_23];
- Support groups. Talking to people who have similar experiences to yours is the most critical thing, and it's what you can do early on [Cons_16]; and

- Hopefully, the steps I'm doing will progress to the next generation. ... By educating them early, hopefully it will give them a better foundation to be able to seek help. Me and my wife didn't have that family support [Carer_10].

8.5 Summary

Formal treatment for consumers is perhaps the most crucial element in the response to mental health problems. However, entrenched stigma, among other structural and practical factors, are still preventing consumers and carers from seeking formal help. Consumers with self-stigma may avoid or resist seeking formal help because of pride, denial, or downplaying the mental health issue. Indeed, results showed that those who were open to discussing their mental health issues were the most likely to seek help.

Based on the examples of consumers and carers' perceptions of effective and ineffective treatment practices, this study found that a number of key aspects were important to consumers and carers. These include:

- Early recognition and diagnosis of mental health issues;
- Empathic, compassionate and/or passionate mental health professionals who:
 - Can see 'the whole picture' for families;
 - Equally encourage medication, counselling and psychosocial rehabilitation through community involvement (e.g. support groups);
 - Offer practical strategies and advice;
 - Credit consumers for their effort and milestones on the road to recovery; and
 - Value the knowledge of carers.
- Round-the-clock services that are readily accessible:
 - During crisis situations;
 - In urban and regional areas; and
 - For specific mental health diagnoses (e.g. PND);
- Information about mental health issues that is in plain English; and
- Affordable treatment that is:
 - Sensitive to the recurring nature of mental health issues; and
 - Responsive to comorbidities such as substance abuse.

As a complement, any informal help that friends can provide should be encouraging of formal treatment, and provide the comfort of 'a listening ear' rather than advice. Moreover, friends who are informed of the isolating nature of depression will be

better able to see through consumers who push friends away or feel that they don't deserve their help.

To prevent a crisis situation consumers suggested that it was most useful to (i) see a GP early, (ii) attend a support group, and (iii) for help-seeking behaviour to be normalised.

Although carers also express a resistance to seek formal help for themselves, it may be an important element of the healing process for both consumers and carers. The long term stress associated with caring for a family consumer may eventually 'take its toll' on carers, compromising their ability to provide the empathy consumers so desperately and doggedly need. Furthermore, in some situations, the consumers' 'fight for life' may compromise the carer's 'quality of life' creating a situation where a third party is required to meet both their needs. Formal treatment may play this role. The research has shown that there is a clear need to further develop a depth of understanding and empathy in both consumers and carers to increase insight and close the gap between the two groups.

9 Practice and policy recommendations to *beyondblue*

Focus group participants were asked during the discussion, and on the Demographics Survey, to make explicit suggestions about what *beyondblue* can and should do in the future to further increase awareness of mental health issues, decrease associated stigma, promote awareness of impact, and improve treatment for all people whose lives are affected. This section documents these suggestions.

Importantly, the results of the thematic analysis highlight that there are five key groups that should be targeted if and when these suggestions or recommendations are followed-up in more detail via further consultations and implemented. These are: (i) the general community, (ii) policy makers, (iii) health care service providers, (iv) employers, and (v) family members. If each of the key relevant issues – awareness, stigma, impact, and treatment – are addressed across each of the five aforementioned groups, then this may assist *beyondblue* to inform their programs and activities and to promote consumer and carer experiences.

9.1 Positive feedback on *beyondblue*'s current work

Before exploring the suggestions that participants made to *beyondblue* regarding 'where to from here', it is first important to identify what participants perceive and experience to be effective efforts by *beyondblue*. These findings provide an evidence base for continuing these efforts into the future.

Overall feedback

Overall, several participants made positive comments about *beyondblue*, such as:

- Continue what they're doing! [Carer_5];
- Keep on doing what you're doing [Carer_24];
- My husband survives because of *beyondblue* [Carer_21]; and
- I truly believe *beyondblue* has been instrumental in decreasing the stigma associated with mental illness [Cons_26].

Specific feedback

There were identifiable areas of work in which *beyondblue* were seen to be particularly effective. These are summarised below.

Website

- I think the website does itself justice. It's really easy to navigate and get around [Cons_3];
- The website is pretty simple. Don't have to go through pages to find stuff. Pretty fool proof! [Cons_2];
- Where I am at today is because of *beyondblue*'s fact sheets. It's gone down to almost plain English, and it's for your average person to understand and recognise the symptoms early [Carer_10];

- I suffer depression. I don't know when it started, I just know that by the time I got suicidal I figured I needed help. So **I went on the *beyondblue* website and looked up that little check list. That was the start of my recovery.** That's why I am passionate about what *beyondblue* does [ConsCar_2]
- I think *beyondblue*'s done really well with the fact sheets for different mental illnesses. Because I did see my dad having a couple of these fact sheets lying around the computer table. They have to be commended by actually putting the information out there in language that is understandable to my dad, a first generation Australian, who migrated here. If my dad can read it, they're doing something pretty good [Cons_21]; and
- I think *beyondblue* have been a fabulous resource. When I was in the corporate environment, I would always access their materials and make sure it was distributed and had awareness days and everything. As far as the online environment, as far as information goes, it's accessible. So in the middle of the night, if you can't sleep, if you want to do something, there's a resource there that you can sit down and have a look at it. That can be invaluable [Carer_17].

Provision of information

- They provide a lot of information [Carer_3];
- I think that education is very important. *beyondblue* have great resources. Keep them coming! [Carer_13];
- About 12 months ago my pharmacist gave me a carer's pack from *beyondblue* with a lot of literature in it [Carer_5];
- My daughter came home from school a few weeks ago with a package from *beyondblue*. They had a mental health day at the school. She brought the pack home but she said, 'well, I know all about this' [Carer_1];
- Thankfully, I picked up a *beyondblue* pamphlet in the library, which gave me a bit of a steer. I phoned and they were very helpful. They sent me a book and a video and all that kind of stuff which was extremely helpful [Carer_7];
- I am part of blueVoices, and our bipolar group gets quite a lot of information and resources from them to distribute to people. They're very generous with all their stuff. They supply everything free of charge. We have had mountains of literature! [ConsCar_1]; and
- The fact that you can join as an individual and access information for yourself, and they'll post it all to you free of charge. That one book that they provide, *Taking Care of Yourself and Your Family*, is an excellent resource book and should be distributed as widely as possible across the community [ConsCar_1].

Provision of other resources

- **I produce lots of blue bags. People love them**, and they're not ashamed to walk down the street with *beyondblue* bags. They love it! [Carer_14]; and
- *beyondblue* resources in this region get a great work out. From the comics, the bands, the flip cards, you name it. They're used everywhere [Carer_13].

Media and advertisements

- Those ads are quite helpful [Carer_6];
- I think the ads are really good [Cons_1];
- [The TV coverage] means it's just out there now [Carer_3];
- I think their advertising's really good, especially when you go to Melbourne, there's so many on the backs of toilet doors and things like that [Cons_26];
- I think the ads are very effective. They sort of aim to the human side, people can identify themselves. It's really easy to relate to many people [Cons_13];
- I think *beyondblue* has done a lot in terms of raising community awareness. I remember the first time I saw *beyondblue* on TV, I was like 'wow, there's this thing out there that actually help people's anxiety or depression' or whatever. Since then, I've seen *beyondblue* on quite a lot of different media, so I think they've done well in that respect [Cons_20];
- The ads in the toilet are really good. The picture of the person and the quote like 'I don't want to burden my family', yeah, they're really good. **Public toilets, it's bizarre! But it's a really great place to send a message**, I mean, because everyone kinda has to go! And in the city as well, I find that, I go out to dinner or something, and I have this hit of anxiety. I go to the toilet, and a couple of times, I've seen a *beyondblue* poster, and I was reminded that there's other people out there. I've got support and I can call someone if I need to. Seeing that in the middle of the city can be good, cos the city can be quite chaotic and stressful [Cons_3].

Use of high profile people

- I find that the promotion of mental illness from high profile people – I remember Norman Gunston came here a few years ago to try and go into the community, instead of hiding. It was really interesting. Here's this man saying, 'look, I'm bipolar'. I find that has made people a lot more aware, a lot more accepting [Carer_11].

Use of everyday people

- I reckon the Ambassador Program is awesome. You go out and talk to schools and conferences with like 500 doctors. You just get up there and tell them

your story. You notice people's faces change, people start to relate. I think it's really good to get normal, everyday people out there [Cons_4].

Significance of *beyondblue*

Arguably, the most significant contribution that *beyondblue* has made is 'normalising' the word depression. As some participants put it:

- I think with initiatives like *beyondblue*, it's made it feel less embarrassing to admit to. *beyondblue* does highlight the fact that there are so many people that suffer from depression [Cons_26]; and
- They [*beyondblue*] may not know how to deal with it, but the word depression is used in the popular lexicon. 'Oh, that's depressing', or something like that. Having the term there, which is what you want in the first place, that's been successful [Cons_7].

Because of the perceived success and effectiveness of *beyondblue*, they are a reputable organisation. For example, participants said:

- They've got credibility [Carer_15];
- They have a high reputation [Cons_25];
- It's a wonderful organisation. It has a wonderful reputation. I wouldn't come here [today] if it weren't for that [Carer_24]; and
- Definitely I think they've got a very good name. I know they had a big 'farmer's day'. People flocked to that, where they wouldn't usually [Carer_14].

9.2 Suggestions for increasing community awareness about mental health issues

In the main, *beyondblue* was seen to be a highly successful, reputable, and effective organisation that has "really helped an awareness of mental illness" [Carer_5; Carer_2]. Nevertheless, participants pointed to specific areas or domains that may need to be targeted to further improve awareness about mental health issues.

Continue targeting young people

Overwhelmingly, most participants pointed to the importance of increasing awareness in schools and targeting youth. This is despite the fact that of all sub-groups within the community, awareness among young people was seen to be highest (see Section 5.2). This suggests that although awareness is high among youth, much work is still required in engaging and informing this age group.

Indeed, the strong push from consumers and carers to continue efforts focused on youth may indicate just how important education in up-coming generations is seen to be necessary for ensuring an aware, informed, sensitive, and empathic holistic approach to mental health issues in the future. These participants, including young people themselves, said:

- Couple more youth-based ads would be good [Cons_3];
- Normalise it at school. Especially with the shame and stigma against each other [Cons_1];
- You can't start telling these kids these big words, if teachers aren't going to make a deal as well [Cons_7];
- I believe a mental health course should be compulsory at school for the next generation to understand and accept this [ConsCar_4];
- I think this sort of [focus] group is a step in the right direction to educating the younger generation and say 'it is okay' [Carer_10];
- Get more people in high schools talking about mental illness to the younger children, so they feel more comfortable discussing mental illnesses [Carer_8];
- Currently, I believe focus on education of mental health within schools is essential and something I believe hasn't been given enough attention [Cons_3];
- I don't know if they do this already, but I think it would be really good to go out to schools and say, 'look, you're not the only one and don't be ashamed of it' [Cons_31];
- Awareness in high schools amongst teachers – I don't think there's enough done early on. If his [son] problem could have been apprehended before it got worse, we might not be in this same relapse stage that we're in now [ConsCar_1];
- I think *beyondblue* can definitely do something in schools. There are a lot of young people who can be caught early by just coming to schools. I would send people to every primary school or high school there is in the country, just to make sure that each person in that generation gets at least one visit from someone in mental health. I think that's a great place to start. We talk about the workplace, about studying and just general discrimination. But if you can educate young people, it's a platform by which you can start educating the rest of the people [Cons_21];
- **I think primary school is something that's often ignored.** That would be really important because I think at that age, it's not such a serious problem. It's more the adolescent stage where you'll develop more of those anxieties. But if you're aware of it before you go into high school, that's really good. If you have that basic knowledge, nothing intense obviously, even just a speaker, like Harold, the health giraffe! I still remember the whole 'be healthy'. So why isn't there an equivalent to mental health? I think Years 4, 5, 6, definitely deserve to be told what's going to happen to them basically, not like what they'll experience, but these kind of issues are in society. Not to scare them, but to normalise it ... Not knowing there's a name for it. If I was told, I could have recognised my symptoms to something. I think they leave it too late, when it's already happened and people are dealing with it [Cons_3].

Expand use of media

The power of media, most especially TV, was noted by some participants. For example, one said “you can tell people something till you’re blue in the face, but if they see it the next night on TV, it’s like ‘right, now I’ll believe it’” [Carer_14]. Thus, the need for “more publicity” [Carer_1] to “keep the message out there” [CONS_9] was highlighted by participants. Importantly, participants talked about the potency of a national/mass media campaign. They said:

- I’ve got a slogan: ‘It’s okay not to be okay’ [Carer_6];
- Maybe that’s what *beyondblue* have got to concentrate on, a commercial that is drummed into people enough that they will start understanding [Cons_25]; and
- Big mass media campaign to raise public awareness, such as the ‘splash slop ...?!’ An ad campaign on TV that’s accessible by everyone. Then people can learn how to detect early warning signs [Cons_20].

One participant said, “**how many people in a psychiatric ward get sent flowers**, a card, someone to come in and say, ‘do you want to go for a two minute walk?’ ... With other illnesses, it’s common ... That might just turn things around and empower that person a little bit more” [Cons_18]. Interestingly, another participant suggested on the Demographics Survey to, “use advertisements e.g. ‘visitors to psych ward’. Help isolated patients with some contact. Nice to promote ‘get well cards’; encouragement to psych ward patients just like other patients with other diseases receive” [Carer_9].

Increase the use of positive recovery stories

In addition to increasing general exposure to messages about mental health issues, carers were keen to see an increase in the number of positive recovery stories:

- I think the general media should be more positive awareness rather than negative awareness [Carer_10];
- If it’s positive they tend to accept it more. When you’re negative they look down on it more, just push it under [ConsCar_4]; and
- I think they need to see the good – that there is another side – that people do end up coping some times, and that there is light at the end of the tunnel [Carer_11];
- I think that within a lot of different campaigns, they focus on some fairly depressing people. It’s terrible. I think it would be good to change the focus to the opportunities or the optimism that can go with good public awareness, rather than having that focus on that very sad face or that tragedy. We need to shift the focus; ‘there is a whole beautiful world out there if there is the right support’ [Carer_19].

Continue use of high profile and everyday people

Although some participants noted their effectiveness, others indicated that more (general and positive) awareness through the use of high profile and everyday people in the media is required. In regards to the use of high profile people, participants said:

- We've got nobody high profile to keep on pushing it in front of the bureaucrats [Carer_16];
- Hopefully bring out a lot more high profile people to encourage the general public to be positive, accepting [Carer_10];
- Go more into what appeals to the public, which is celebrities or sports people. They've all got an impact, an appeal, on the young ones. Use that. Put it out there [Carer_6];
- I think stories like the Jeff Kennett story are good. I think more public figures should be encouraged. If they are courageous to disclose their mental problems, that gives the rest of us – 'oh, I can also tell people that I have a problem' [Cons_22];
- I think with the help of celebrities that come out and say, 'hey look, I've got it too', the stigma has slowly gotten less. With someone like Jeff Kennett, love or hate him, he is an amazing man. I think he's been a really good voice for it. He's very passionate, you can tell. He was instrumental in getting *beyondblue* out there [Cons_31].

However, some participants pointed out the importance of using everyday people as well. These participants said:

- The **personal story is very important, not just using high profile people** but normal people as well. I mean normal people – it could be you, it could be me, it could be anyone. So the personal story is very powerful; and
- You've got the ads, the books, the fact sheets, the website. Now we've got blueVoices, and I think there's about 10,000 people on that. So it's become a very large organisation, very top heavy. ... I think it should be more grassroots. Not so much the high profile people, but an everyday person going out, and speaking and sharing their experiences [Cons_10].

Expand Ambassador Program

Linked to the use of everyday people is the importance of the Ambassador Program. Although its success has already been noted, some participants pointed out their keenness to act as ambassadors for other people; indicating the need for further promotion of this program. For example, participants said:

- Having an ambassador is different to advertising and giving out pamphlets and magnets. It really makes a statement [Cons_25];

- I am pushing my own wheelbarrow here because I work as a speaker, but I've seen the effect it has. I think having a more expansive speaker program [Cons_11];
- I think some volunteer work, going out and speaking to people, sharing my experiences with other young people, maybe even primary school kids. I'd be interested in doing something like that [Cons_6]; and
- I work in high schools delivering the *beyondblue* high school curriculum. Just working with young people – in terms of improving their resilience, early intervention and promotion, de-stigmatisation – I think **if I can help people not go through what I went through, then it's a bit of a victory** [ConsCar_2].

Increase education about the nature and symptoms of depression

There was also some recognition of the need for further education about the nature and symptoms of depression. One participant said, "I felt their commercials weren't saying enough, they were very basic" [Cons_27]. Thus, it seems that there is a need to increase not just awareness, but education to increase the depth in understanding about the nature and symptoms of depression. For example, one participant said, "I would like the community to better understand that depression is not just the result of something going wrong, and is that an imbalance of brain chemicals" [Cons_32]. Another consumer noted that an education campaign on symptoms would have helped them to identify if they needed assistance: "I didn't know about depression, so I was unwell but didn't know what was wrong with me. So I think they need to advertise the possible symptoms; 'if you feel like this, then maybe you've got depression'" [Cons_28].

Increase awareness of where to get help

Proceeding the recognition of depression or another mental health issue, it is important to readily know where to get help. Promotion of a readily available and accessible number for people to contact can also help carers:

- I think a recognised phone number to be highly promoted is very important. People need an avenue to go when they need help/support [Cons_9]; and
- Maybe the next step is to help people in the public know what they can do to help. A lot of the time people feel helpless, or they feel 'what can I do?', or they're frightened because it's the unknown [Cons_11].

Increase awareness of mental disorders other than depression

Some participants suggested that awareness of mental disorders other than depression is important. For example, one participant said: "mental illness covers a lot more than depression. Depression is the face I guess *beyondblue* has put forward and that's really good, but I do think there's a lot of other mental illnesses that are more marginalised" [Carer_9].

Increase awareness of co-morbid substance abuse

Given that there is a reported tendency for people to think, ““oh, you’re dealing with drugs, that’s a separate issue”” [Cons_2], it is important that co-morbid substance abuse receives increased attention. For example, consumers said:

- **Substance abuse has gone off the radar**, it’s considered more of a high school thing. We’re a bit of an older group than some of the people dealing with those issues, but it’s still a very valid group [Cons_7]; and
- The other thing I don’t think they focus on at all is substance abuse. For me, drug effects have been a massive side effect of mental illness and *beyondblue* doesn’t really have much about that [Cons_4].

Increase awareness of the needs and experiences of specific groups

Aboriginal and Torres Strait Islander and NESB

- Maybe more focus on the older migrant generations [Cons_20];
- I think it should be compulsory in churches, mosques, whatever. The subject should be constantly brought up and put in their face [ConsCar_4]; and
- I think more programs and resources aimed at young Aboriginal fathers, as they are a specific group of consumers that require specific programs and help [Carer_12].

GLBTI

- I love *beyondblue*. The only thing I think they could do a lot better is the way they deal with SSATI people, same sex attracted trans- inter-sex. Focus more on homophobia and GLBTI issues. Their defence is, ‘we’ve got facts sheets on the website’, but it needs more advertising, more posters. Strategically, *beyondblue* should partner with [NGO] which is the same sex attracted network for [site]. That would really help with homophobia in schools and targeting those isolated people [Cons_4]

Homeless people

- Do some focus groups with homeless people – young and old. This group is so marginalised and don’t have access to services, internet easily [FG 1_4].

Provide resources for people short on internet access or confidence

- Internet resources of *beyondblue* for consumers that can’t afford the internet [Cons_19].

Increase awareness of the carer experience

- As far as what more they can do, I think talking about carers [Carer_21];

- Through my work, we make up show-bags and it's mostly *beyondblue* stuff. I make sure that every bag has a carers' booklet and DVD, because I don't want carers to be forgotten about. They need to know it's not just the person that they [professionals] are sitting with. It's the family" [Carer_20]; and
- *beyondblue* is a wonderful, effective organisation. If I could make one small suggestion, perhaps it would be to be more aggressive in promoting carers' health issues. Carers are the major resource in the battle, possibly the most important, because the professional sees them about half an hour or whatever. The carers are much more closely aligned. So I guess mainly that *beyondblue* could devote a bit more attention to carers" [Carer_24].

Increase dissemination of research findings

Finally, it is important that consumers and carers feel that the outcomes of research are fed back to them. For example, one participant said, "I think the research on consumers and carers is developing, but to what extent is it getting out there to help them along?" [Carer_22]. Similarly, another said, "make the findings of this research public with fanfare" [Carer_16].

9.3 Suggestions for decreasing stigma associated with mental health issues

When asked about areas of priority that *beyondblue* should tackle, "stigma" [Cons_32; Carer_24] was often cited (along with "education" [Cons_28]). Again, the difficulty of decreasing stigma was highlighted; as one consumer said, "not necessarily because of failings on *beyondblue*'s part, but **it's very difficult to change an attitude in society**" [Carer_17].

Some evidence of reduced stigma was provided. For example, one participant said, "**there are tell-tale signs that *beyondblue* have brought down that stigma**. People now wear the wristbands, or walk along with their bags with *beyondblue* written on them. It's not like they're hiding them" [Cons_26]. However, as described in Section 6.2, a lack of stigma is indicated when it is treated in the same way that a physical illness is. As one participant put it, "I would say the testing of social stigma would be the most important thing. That would sort of a lot of problems out. If anyone just regarded somebody who has depressive anxiety as if they have a broken leg, then I would say the stigma had gone" [Carer_24].

Targeting specific areas

Two specific areas for possible target to decrease stigma were suggested.

Decrease stigma among employers

Given that stigma at work was one of the largest areas that affected the lives of consumers especially, it was surprising to find that only a small number of participants identified this as a target area for *beyondblue*. However this may be reflective of a general tendency among participants to focus on how to increase awareness rather than on how to decrease stigma. These participants said:

- We have a care plan that we share in our workplace [Cons_30];

- Acceptance of employers of employees who have acquired mental illness in their line of work [ConsCar_4];
- The first thing I would do if I was the CEO of *beyondblue* is get the stigma in the private sector employment. That's where I find all the stigma is, because they're so narrow minded [Cons_19].

Decrease stigma among male carers

- There needs to be more awareness towards men from *beyondblue*. Looking from that postnatal side of things, they've [*beyondblue*] got to look at educating men to be supportive of their wives that are going through all these things and be understanding. Hopefully, that will break down a lot of the stigma [Carer_10].

Changing the terminology

In conjunction with decreasing stigma in specific domains, it may also be important to instigate a more global change in approach and attitude to mental health issues. Several participants talked about the importance of changing the language and terminology that is used. For example, one participant said, "I think we should take the 'mental' away from 'mental illness' and it might make it more acceptable ... Take away the mental. Treat it as an illness" [ConsCar_3].

On the other hand, it was not always the word 'mental' that was seen as bothersome, but rather the 'illness' part of the term. For example, one participant said "to me, just referring to it as 'mental health' rather than 'mental illness' [is better]" [Cons_2]. Similarly, another said:

The terminology we use is important. Like the word 'illness', people associate that with negative implications. The thing is, I don't consider any condition to be illness. Illness implies abnormality, difference. That's an issue. The current campaigns do deal with that – 'this is normal, it happens to everyone' – but the language that's used has to be very carefully thought out. The whole terminology of 'illness' comes back from [a time] when it wasn't understood [Cons_7].

Arguably, the terminology people prefer depends on their primary goal or need. Generally for consumers, positive terminology is important because it is empowering and therefore aids recovery. In comparison, for many carers perceiving the consumer as 'ill' can aid their ability to develop or increase their empathy for the consumer and help them understand the lack of control a consumer may have over their symptoms. Finally, for professionals, it is important that they distinguish between those who are clinically 'ill' from those that are not to ensure that treatment is appropriate and effective.

It seems then, that reconciling the needs of consumers, carers, and professionals about what constitutes appropriate and useful terminology is difficult. However, one participant insightfully pointed that 'wellness' and 'unwellness' may be useful. This participant said:

I think ‘mental wellness’ is a better term, because ‘illness’ is a medical construct. There’s a spectrum for people who are coping very well, to the ordinary Joe Blow who has their ups and downs for the day. Then down the end there is this bad – bad’s not a good term – difficult area of the spectrum. What you’re trying to do is move these people from a degree of unwellness to a better degree of wellness. You might never get right back down here, but if you move from there to there, that’s okay [Carer_15].

Indeed, the language of “recovery and wellness” [ConsCar_2] was also noted by another participant.

9.4 Suggestions for promoting awareness of the social and economic impact of mental health issues

Continuing qualitative research

In terms of promoting awareness of the impact of mental health issues, the most common suggestion from participants was to continue research like the current study and to promote the findings. As one participant said, “this focus group is a step further to awareness of an ignorant society and de-stigmatising mental illness” [ConsCar_4].

Awareness for other people’s experiences

Qualitative research had several benefits including increased awareness of other people’s experiences. For example, one participant said:

I just can’t come to grips with what you and [name] are going through. It must just be this side of hell when it gets bad. I mean, I think everything’s bad, but at least I have a wife that I can talk to and she can talk to me. When you’re in the situation where you’re the carer for a spouse, I just can’t imagine how the hell you cope [Carer_15].

Inclusive approach

Additionally, qualitative research is an inclusive practice that ensures consumers’ and carers’ direct voices are heard. As one participant put it, “these sorts of studies, you’ve got to keep at it all the time, bringing it to the notice of the people that count” [Carer_16]. Similarly, another said “**the inclusion of voices is really important**. That sends the message across really effectively. *beyondblue* do that, but I think to continue that, and emphasise that, is really important” [Cons_3].

Forum for sharing and release

- I always find it really helpful to hear people’s stories [Carer_21]; and
- I feel good talking about this stuff. It feels good to be able to talk to people who understand. It’s beneficial [Cons_9].

9.5 Suggestions for improving treatment for mental health issues

The suggestions reported here reflect strategies to further increase education for mental health and other health professionals. It is important that the suggestions provided here are read in conjunction with information provided in Section 8, which more fully documents barriers to effective treatment.

Encouraging a holistic approach to treatment

Participants want an increase in holistic focus from health professionals. As one participant put it,

If they could focus on total health care, instead of isolating the body into one segment. Realising that mental illness has a flow-on effect over the total body. What I would really love, in an ideal world, is that they would treat my daughter as a whole person. Like it's not just her brain chemistry that's the problem. It rolls over into the issue of medication, causing weight gain, and then loss of self-esteem and then the inability to exercise [Carer_17].

Moreover, educating GPs to take a holistic response may be especially important as they are often the first point-of-call. As one participant said, “[it is important to have] a GP who'll look at you holistically and be responsive” [Cons_30].

Increasing empathy and service delivery among mental health professionals

Given the importance of empathy for consumers – which they seem to receive little from their family carers – it is important this need is fulfilled by mental health professionals. Indeed, one participant suggested that “*beyondblue* do more with mental health professionals or university students, to develop empathy skills when dealing with patients” [Cons_2].

Additionally, the bias to medicate and the lack of a holistic response that includes psychosocial rehabilitation, are important issues in need of addressing. One participant said, “more promotion of treatment options other than just medication or psychiatrists etc” [Cons_11].

Improving self-knowledge about prevention and early intervention

One participant said, “everything I've learnt has been the hard way. If *beyondblue* could teach people like myself in preventing suicide, then I don't have to learn the hard way” [Carer_24]. This remark highlights the importance of ‘getting in early’. As stated in Section 8.4, the stigma associated with mental health issues coupled with a lack of real understanding of the symptoms and day-to-day impact of depression and anxiety seems to be the strongest factor stifling early help seeking. Indeed this was captured by one carer who said “**close the gap between those who think they're ok and are not**. Initiate groups for people who do not have their lives together” [Carer_7].

Developing better resources for carers

It is also important to support carers by having effective resources that they can use to help complement formal treatment. One carer said, “when you first start, you're so stressed. You get all this information. It's almost like you need a flowchart saying this

is where you need to go, this is the path. Because otherwise, you're just in crisis and you're trying to access the pathways to get support. Just a quick cue card. Go here. If that doesn't work, go here. If that doesn't work, try that" [Carer_17].

Importantly, one carer participant pointed out research that may be of use for other carers. He said, "[university] did a research project on the life of a carer. It was called *A Carer's Journey*. It describes the flow cycle of a carer from the 'unsure, don't know what's going on' stage, then heading to a diagnosis, then getting to treatment. This kind of goes around and round in circles – treatment, crisis, treatment, crisis – then when you get to the other side of that circle, you're in a kind of coping mode" [Carer_24].

Lobbying for reducing the cost of mental health services

- In terms of [site], I think there are too many gaps between privately insured people and uninsured people. And I think for the uninsured it's just a disastrous recipe, there are just too many holes in the system. If you don't have the money you cannot access the services. It's socially unjust" [Cons_10].

Lobbying to promote national standards in mental health service delivery

- I'd really like to see *beyondblue* lobbying, advocating, for federal government to take over mental health funding from the states, to ensure equity and national standards in mental health service delivery. The states involving their own money, that brings in a whole lot of hierarchy of administrative people in every state. So it's all top-heavy. Need to maybe look at services and reduce administrative duplication [Cons_30].

Lobbying to centralise health information

Some participants pointed to the helpfulness of a system where "you've got all your information in one spot, so you don't have to tell the story over and over again" [Cons_28]. One participant suggested the value a 'mental health plan book'. She said:

How many years are we going to wait until an e-health personal record comes out? There's all this stuff about the security. I'd like to see *beyondblue* develop a resource, a nationally recognised book between GPs and hospitals with the *beyondblue* insignia so it's less discriminating, that a person could then take to their GP. Have in there, a treatment plan, their medication protocols, so that when they go from organisation to organisation, they've got it all documented. A document that they can carry recognises that mental illness is about a whole self-approach [Cons_30].

Additionally, centralising a list of services within areas could also help improve treatment. For example, one participant said "the next thing could be some sort of centralisation of resources. If they could develop area service directories of resources. The information is there but it's just all over the place [ConsCar_1].

Ensuring policies are implemented

- I think that's the problem, isn't it? It's what appears to be a really robust infrastructure, but when it comes to policies and procedures and acknowledgement of integral issues in our society, the great divide is between the implementation of those policies and the real everyday rest of our lives [Cons_30]; and
- I think where they [*beyondblue*] could probably make the biggest difference is that policy stuff, and making sure it gets filtered through. **It's one thing to have a policy**, you can have all the papers in the world, **but if it sits on the wrong person's desk**, doesn't hit his radar, **it doesn't happen**, it doesn't get implemented ... I was at a consultation the other day for carers, and one of their biggest things was, 'why are we sitting here again? We told you this two, three, four years ago'. So people know what the needs are. It's just not filtering through. You can give all the money in the world for positions, but if they don't get filled in regional areas, what's the point in having the money for them" [Carer_13].

Lobbying for increased funding

Funding is necessary for research and the provision of services. For example, participants said:

- More government financial backing [needed] [Cons_21];
- Get the government behind you, make that a big priority, because money is a big issue obviously [Cons_25];
- *beyondblue* do a great job and are very well respected in the community. Keep hammering federal government for more money for mental health [Carer_14]; and
- With *beyondblue*, it basically comes back to money, to be able to provide the services, provide the staff, everything. I know, in a real world, it doesn't happen, because there's only so much money. It would be nice though" [Carer_22].

Indeed, one participant said, "I heard on the radio the other day that mental health services are 13 per cent of all services, yet it only gets six per cent of the budget. So they don't even get a one-on-one percentage wise" [ConsCar_5].

Given that "people put more in research on coronary artery disease than mental health" [Carer_15], it is important to "somehow make more funds to medical research" [Cons_20]. One consumer suggested, "I think lobby the government to put more funding into medical research, that would be good. Because I'm still looking for the day when there's some sort of medicine, or some sort of therapy, or whatever works, just to bring people back to their normal self" [Cons_20].

Additionally, participants wanted government lobbying to increase the number of MBS covered mental health sessions: "If someone needs intensive support then those Medicare packages aren't good enough. Twelve sessions a year aren't enough. Mental

health services are not funded enough, and they don't have enough staff. There just needs to be much better community support and more money" [Cons_11].

9.6 Other suggestions to *beyondblue*

A number of suggestions were provided by participants that related less to the four key themes – awareness, stigma, impact and treatment – and more to do with the organisation of *beyondblue* itself. These are described below.

Increasing awareness of *beyondblue*, and as a national organisation

Although one participant said, "I think you could say to almost anyone, 'what's *beyondblue* about' and they'd be able to tell you, so that's a huge tick" [Carer_21], in fact some participants had not heard of *beyondblue* (and notably, these were participants from regional sites), or they perceived that it was not a national organisation. These participants said:

- I've not come across *beyondblue* before today [Carer_6];
- To be honest I thought they were Victorian based. I didn't realise we had it here [Cons_32];
- I feel like I've been living under a rock because I've hardly seen any advertising! [Cons_28];
- I must admit *beyondblue* has stepped up to the plate in leading the awareness campaign, but it's driven by the Victorian Government from down there. So we have nothing in [our state] [Carer_10].

Thus, *beyondblue* may benefit from making explicit that it is a national organisation that is not exclusive to Victoria. Furthermore, awareness of the organisation in regional areas needs to increase.

Increase awareness of *beyondblue*'s mission statement

Some participants expressed that they were unclear about what *beyondblue* do. For example, participants said:

- What have they done? I don't know [Carer_4];
- I've seen a brochure and stuff. But I don't actually know what they offer [Cons_29];
- Dad's got a logo on his fridge with a phone number on there. But what do they actually do? [Cons_31]; and
- I've just seen ads, '*beyondblue*, anxiety, depression', but they don't really say anything about themselves [Cons_27].

Therefore, it may be beneficial to make explicit that *beyondblue*'s mission statement is to increase awareness of depression and other mental health issues.

Increase partnerships with services

One participant said, “I think *beyondblue* is doing a fantastic job in raising something that you could never, ever, mention 20 years ago. They should be credited for what they’re doing. But I think though that *beyondblue* should hand over the responsibility to other areas now because they have the evidence to say ‘this is what’s needed’” [Cons_18].

Indeed, several participants corroborated this sentiment, saying:

- *beyondblue* are a conscience organisation but you may have to get your hands dirty [Cons_7];
- I think they should support groups who are working with the cause that they’re promoting [ConsCar_3];
- Maybe just on their website, they have sections for links to organisations that they deal with [Cons_2];
- *beyondblue* is a private organisation but it’s bankrolled massively by the federal government. So it does have the potential to drown out small organisations, it distorts the people actually working on the ground. It’s a matter of working together [Cons_7];
- *beyondblue*’s doing really well, but there’s so many organisations struggling behind because they are such a strong brand. ... If they feel so strongly about the issues that they’re portraying, then they shouldn’t have any problem with assisting other organisations. In the long run, they’re only going to assist *beyondblue* with their cause of more awareness. So you’d hope that wasn’t their main aim – to be number one [Cons_3];
- Groups like [NGO] need to get some assistance. They [*beyondblue*] can say ‘one in five people have depression’ but they [*general public*] don’t understand that it could be anybody. That it’s not just people who are strange and off the planet, and not able to fit into society ... [NGO] is really struggling because of funding. We feel that we don’t get promoted enough. It is extremely difficult to get noticed as a group ... *beyondblue* is just seen as a referral centre, that’s all. They get the big grants because they’ve got Jeff Kennett. People are questioning it, ‘what do they do?’ ‘Well, come on *beyondblue*, help us, the groups that are trying to help the people’. That’s what I say [ConsCar_3]

According to *beyondblue*’s Strategic Framework (2005 – 2010), “after 2010, *beyondblue* aims to ‘put itself out of business’, leaving a sound infrastructure for the community and health professionals to carry forward the national objectives of promoting early treatment and prevention of depression, anxiety and related disorders, educating Australians about depression and reducing the stigma associated with this debilitating condition” (p. 2).

Yet, the results of this study seem to indicate that this goal is far from being realised. Arguably, the goal of ‘putting itself out of business’ is not necessarily helpful even as

infrastructure improves. This is because a focal point that draws attention and awareness to mental health issues is itself a significant part of the infrastructure that can promote its ongoing sustainability. Thus, it may be that as *beyondblue* evolves as an organisation into the future, it develops and establishes funded partnerships with grassroots services and programs rather than aiming to ‘put itself out of business’.

9.7 Summary of recommendations to *beyondblue*

The following list represents ‘action plans’ extracted from all participants’ suggestions, that *beyondblue* could enact to meet their goals of improved awareness, reduced stigma, promotion of its impact, and better treatment. This list is not seen to be exhaustive, and nor is it seen that all are necessary for an improved response to mental health issues by *beyondblue*. Thus, they are more seen to be *possible* ‘action points’ and it is within *beyondblue*’s scope and mission to determine which, if any, should be implemented.

- Strategies to address the issues of awareness, stigma, impact, and treatment should reach key target audiences including the general community, policy makers, health care service providers, employers, and family members;
- Continue resourcing the *beyondblue* website, and the provision of information and other resources;
- Expand the use of media by developing a large-scale national campaign, with both high profile and everyday people, that includes:
 - positive recovery stories,
 - detailed information about the nature and symptoms of depression and other mental health issues,
 - the lived-experience of consumers and carers; and
 - information about where to get help
- Expand awareness campaigns in schools, including primary school;
- Expand the Ambassador Program;
- Increase awareness of co-morbid substance abuse;
- Promote awareness of the needs and experiences of marginalised and/or minority groups such as Aboriginal and Torres Strait Islander, NESB, GLBTI, low socio-economic, and homeless people;
- Promote awareness of the carer experience;
- Expand the ways in which research findings are disseminated;
- Acknowledge that efforts to increase awareness do not automatically translate into a decrease in stigma, and that the factors which keep stigma entrenched are directly addressed;

- Explore changes in terminology and encourage mental health professionals to stop using the term ‘mental illness’;
- Continue conducting and disseminating qualitative research;
- Encourage a holistic approach to treatment;
- Promote the importance of empathy, and address the bias to medicate, among mental health and general professionals;
- Identify and target consumers that are downplaying their level of illness;
- Develop more resources to help carers navigate mental health services and obtain support for themselves when needed;
- Lobby to ensure more equitable access to mental health services regardless of consumers’ and carers’ socio-economic status;
- Lobby to ensure national standards in mental health service delivery;
- Develop a resource book for consumers to help centralise their history;
- Consider developing a list of area-specific services;
- Oversee and lobby to ensure policies are implemented;
- Lobby for increased government funding;
- Promote awareness of *beyondblue*, as a national organisation, including its mission statement; and
- Consider funding mental health services as a way of establishing partnerships with them.

10 Discussion and conclusion

10.1 Summary of main findings

The aim of this study was to explore consumers' and carers' perceptions and experiences, and then use these as the basis for developing recommendations about how best to increase awareness of mental health issues, reduce the associated stigma, promote the impact, and improve treatment for it. *beyondblue* can use these recommendations as the basis for planning their future agendas, broader consultation forums, programs and activities.

The results show that while awareness has significantly increased in last decade or so, the depth of understanding is limited. The findings of this study suggest that the best way to increase awareness is through the use of *media*, with both high profile and everyday people, and with an increased emphasis on positive recovery stories.

This study also found that the stigma associated with mental health issues prevails. Any efforts to decrease stigma need to explicitly address the factors that reinforce its entrenchment such as ignorance or fear, but most especially misperceptions of the consumers' (sense of) control. Arguably, the issue of terminology is important to address. For example, changing the *language* from 'mental illness' to 'mental unwellness' may be an effective way of starting to decrease stigma.

Findings show that mental health issues most significantly affect family relationships and workforce participation. Focus group participants discussed experiences of divorce and separation, extreme family stress and immense financial stress. The continued conducting and dissemination of *qualitative research* seems the best way to promote the social and economic impact of mental health problems to policy makers and health care service providers because it is an inclusive, bipartisan approach.

Finally, the results of this study indicate that consumers' and carers' experiences of formal treatment were often inadequate. *Lobbying* for a mental health system that is holistic, empathic, affordable, evidence based, well resourced and funded, standardised and centralised would help build a robust system.

A more detailed summary of the four key themes – awareness, stigma, impact, and treatment – can be found at the end of each section of the thematic analysis. See Sections 5.6 for a summary of community awareness; Section 6.11 for a summary of stigma; Section 7.6 for a summary of social and economic impact; Section 8.5 for a summary of treatment; and Section 9.7 for a summary of practice and policy recommendations.

10.2 Comparison of findings to the '2001 – 2002 consultations'

Focus group consultations were conducted by *beyondblue* in 2001 – 2002 with 69 participants across all states and territories in Australia, and most "had recovered and resumed social and occupational roles" (McNair et al, 2002, p. S70).

The main findings from this study were published in an article by McNair et al (2002, p. S70-S.73). They included:

- The major theme elicited by our consultation was the stigma experienced by people whose lives had been affected by depression;
- The personal, family, social, occupational and health consequences of the ongoing stigma associated with even common forms of mental health issues, such as depression and anxiety, were highlighted;
- The inability of family members to appreciate the experiences of people with depression was emphasised;
- Family and community members may not believe or understand that depression is an illness;
- Failure to understand that depression is an illness often prevents the establishment of an empathic or supportive home environment;
- The absence of any medical sign of illness was likely to contribute to a reluctance to accept depression as “real”;
- One participant said, “How often do you see flowers and chocolates brought into a psychiatric ward?”;
- Depression is largely perceived as personal inadequacy rather than an illness;
- The lack of responsiveness of emergency services was frequently raised;
- It was not uncommon for people to receive demeaning responses from their GP; the most frequent ‘first contact’ with healthcare services;
- The burden of care was generally underestimated in caring for people with depression;
- The inability or unwillingness to view depression as an illness has major repercussions in the workplace, resulting in overt and covert discrimination including the inability to get work or promotions;
- The widespread experience of stigma contributes significantly to delays in seeking treatment and reluctance to continue medical treatments;
- Many of the experiences portray a healthcare system that has not given sufficient consideration to issues such as access, cost, physical characteristics of treatment settings, integration of medical and psychological care, natural history of illness, disability due to illness, ongoing personal and social needs and factors that predict long term recovery; and
- To help move from tokenism to a more mature state in which the role of consumers and carers is respected and affirmed, a consumer and carer agenda was developed.

Dishearteningly, *all* the results from the 2001 – 2002 consultations were also found in the current study. This indicates that 10 years on, little has changed; the same issues

are being perceived and experienced by consumers and carers and a more aggressive implementation of the ‘consumer and carer agenda’ may be required. Some nuanced differences have occurred, however. It seems that community awareness has increased over time, but the depth of understanding about the nature, symptoms and the day-to-day experience of living with mental health problems has not.

10.3 Areas for following up in the consultation forums around Australia

Based on the findings of this research, *beyondblue* may wish to follow-up on some of the following themes in their broader consultation forums around Australia:

- Stigma associated with mental health issues: how people define it, the extent to which it continues to persist, why, and in what circumstances has stigma been overcome;
- The impact of mental health issues in relation to participation in the workforce for carers and consumers (including strategies that have been effective in addressing workplace discrimination);
- The type of information and distribution format that would support the increase in a depth of understanding about the nature, symptoms, and lived experience of consumers and carers;
- Negotiating and mediating the needs of both consumers and carers;
- Impact *beyondblue* could have on the health professions that fits within their scope;
- Differences in the key findings by people from different stakeholder minority groups:
 - people from Aboriginal and Torres Strait Islander backgrounds
 - people who identify as GLBTI
 - people from different cultural backgrounds
 - male consumers and carers.

10.4 Conclusion

Overall, the findings of this study suggest that the greatest barrier to an effective response to mental health issues is stigma. Stigma seems to inhibit: (i) the full potential of awareness-raising campaigns, (ii) help-seeking behaviour in both consumers and carers, and (iii) a prioritised response to mental health issues by health care service providers and government. Thus, the stigma in both individuals and society feed each other, perpetuating and entrenching its potency.

If stigma is the base or core issue from which all other barriers to an effective response emanate, then this means that reducing stigma should be the topmost priority. Having said that, all key elements of the ‘mental health response’ – awareness, stigma, impact and treatment – are intimately related and targeting any and all of them will have positive flow-on effects to the other parts.

Thus, the aims of *beyondblue* to help increase awareness, decrease stigma, promoting its impact, and improve treatment are all essential goals to have, but are all yet to be realised. Arguably, even if these goals come to fruition, the results of this study suggest that an organisation like *beyondblue* is a crucial part of the infrastructure to an effective mental health response; by being a focal point, it has the capacity to draw attention to depression and other related mental health issues.

However, the efforts and goals of *beyondblue* are part of the structural ‘top-down’ approach because they have a national audience. It is important that organisations that deliver mental health service and programs are also supported because they form part of the ‘bottom-up’ approach that places the individual consumer and carer at its centre; and in doing so, is able to provide a flexible response that is tailored to meet individual needs. By sufficiently resourcing these two necessary tiers, there will be a better chance of nourishing a positive feedback loop between individuals and society and thus address what seems to be the fundamental issue: stigma.

“If you walk past somebody without a smile on their face, give them one of yours” [Carer_16].

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Appendix A: Focus group schedules matched to study themes

‘Consumer only’ focus group schedule matched to study themes

Question	Theme
<p>1. Going around the group, if you could spend one minute introducing yourself, and tell us three things about you: (10-15 mins)</p> <ul style="list-style-type: none"> • your name • something about yourself that you’re happy to share with the group <ul style="list-style-type: none"> ○ e.g. something about where you live, something you like to do, your family etc • if you’re comfortable sharing it ... <ul style="list-style-type: none"> ○ what kinds of mental health issues you experience, and ○ how long you’ve been experiencing these for? 	<p>General needs and experiences</p>
<p>2. Thank you everyone. We’ll now work through the 6 topic areas or discussion points. The first one is on <u>community awareness</u> of mental health issues. (15-20 mins)</p> <ul style="list-style-type: none"> • How would you describe the current level of community awareness about mental illness? <ul style="list-style-type: none"> ○ How do you think it compares to community awareness in the last 5-10 years? ○ How would you describe the effectiveness of public campaigns? <ul style="list-style-type: none"> ▪ What was effective about them? • What has been your experience of community awareness with different groups of people? E.g. <ul style="list-style-type: none"> ○ Friends ○ Family ○ Work colleagues and employers ○ Non mental health professionals (e.g. GPs) ○ Mental health professionals ○ Local community ○ General public • How important would you say community awareness is for you, or people with depression/anxiety? 	<p>Community awareness of mental illness</p>
<p>3. The second topic area is about people’s <u>attitudes and behaviours to people with mental illness</u>. (15-20 mins)</p> <ul style="list-style-type: none"> • How would you describe <i>your</i> attitude to people with mental illness? • How would you describe <i>other</i> people’s attitudes to people with mental illness? • Have you experienced discrimination as a result of your mental health issues? <ul style="list-style-type: none"> ○ Who did you experience the discrimination from? E.g. <ul style="list-style-type: none"> ▪ Friends ▪ Family 	<p>Stigma associated with mental illness</p>

<ul style="list-style-type: none"> ▪ Work colleagues and employers ▪ Non mental health professionals (e.g. GPs) ▪ Mental health professionals ▪ Local community ▪ General public <ul style="list-style-type: none"> • How do you think people’s current attitudes and behaviours to people with mental illness compares to attitudes and behaviours 5-10 years ago? 	
<p>4. The third topic area is about your experiences of the times <u>you’ve sought and received help</u> for your mental health issues. (15-20 mins)</p> <ul style="list-style-type: none"> • First, with your use of formal help – so with people like doctors, mental health professionals and websites ... <ul style="list-style-type: none"> ○ Was there anything that encouraged or prompted you to seek formal help? <ul style="list-style-type: none"> ▪ Previous positive experiences/expectations with professionals ▪ Public information and campaigns (e.g. advertising and websites) ▪ Carer support/encouragement ○ Was there anything that discouraged or stopped you from seeking formal help? <ul style="list-style-type: none"> ▪ Attitudes/fears (yours or other people’s): <ul style="list-style-type: none"> ▪ about depression and anxiety (e.g. that depression/anxiety is not really an illness, or that the consumer has more control than they do) ▪ to receiving professional help (e.g. pride) ▪ feeling disempowered/lack of autonomy ▪ to medication (e.g. a belief that medication is addictive or vegetative?) ▪ about the effectiveness of psychological (or non-pharmacological) interventions ▪ Perceived or actual availability of services (esp. in regional areas) ▪ Perceived or actual cost of professional services ▪ Cultural appropriateness of services ▪ Language barriers ○ Would you describe the formal help you received as useful or not useful, and why? • Now thinking about your use of informal help – like with friends or family, or self–help techniques or strategies ... <ul style="list-style-type: none"> ○ Was there anything that encouraged or prompted you to seek informal help? ○ Was there anything that discouraged or stopped you from seeking informal help? ○ Would you describe the informal help you received as useful or not useful, and why? 	<p>Treatment for mental illness</p>
<p>5. The next topic I want to talk about is <u>the impact of mental illness on</u> different parts of your life. (20-30 mins)</p> <ul style="list-style-type: none"> • Firstly, how have your mental health issues impacted on your <i>family relationships</i>? <ul style="list-style-type: none"> ○ Have there been any changes in ... ? <ul style="list-style-type: none"> ▪ Dynamics, roles and responsibilities ▪ Sense of empowerment/disempowerment and independence/dependence ▪ Sense of feeling over- or under-protected/involved by family or friends? • Have your relationships with <i>friends</i> changed? 	<p>Social and economic impact of mental illness</p>

<ul style="list-style-type: none"> • Has your <i>involvement in the community</i> changed? <ul style="list-style-type: none"> ○ E.g. taking part in leisure, sport, and recreation ○ other social and community activities • Has your ability to <i>work</i> been affected? <ul style="list-style-type: none"> ○ Financial issues • Has your ability to study or obtain an <i>education</i> been affected? 	
<p>6. Only two more topics left. The first is about your thoughts on <u>prevention and early intervention</u> with mental illness. (10-15 mins)</p> <ul style="list-style-type: none"> • What do you think made the most difference to improving your wellbeing? • What do you think the best advice is to give to someone who is on the cusp of seeking formal treatment for mental health issues? 	Treatment for mental illness
<p>7. The final topic area is about your <u>suggestions for what you think <i>beyondblue</i> can or should do</u> to further improve awareness of mental health issues in the wider community. (20-30 mins)</p> <p>[BV leave].</p> <p>So the final questions for today are</p> <ul style="list-style-type: none"> • <i>beyondblue</i> aims to increase awareness, decrease stigma, improve people’s access to treatment and promote the needs and experiences of people with anxiety and depression with policy makers and health care services. In your opinion or experience, to what extent do you think <i>beyondblue</i> has achieved these aims? • In what areas do you think <i>beyondblue</i> is doing well and in what areas do you think they could improve? • If you were in charge of <i>beyondblue</i>, and wanted to change the way society views and responds to depression and anxiety, what 3 areas would you make a priority? What would you do? 	Experiences with, perceptions of, and suggestions for <i>beyondblue</i>

‘Carer only’ focus group schedule matched to study themes

Question	Theme
<p>1. Going around the group, if you could just spend one minute each introducing yourself, and tell us three things about you: (10-15 mins)</p> <ul style="list-style-type: none"> • your name • something about yourself that you’re happy to share with the group <ul style="list-style-type: none"> ○ e.g. something about where you live, something you like to do, your family, etc • if you’re comfortable sharing it <ul style="list-style-type: none"> ○ who in your life is experiencing mental health issues? ○ And how long have you been caring for them? 	<p>General needs and experiences</p>
<p>2. Thank you everyone. We’ll now work through the 6 topic areas or discussion points. The first one is on <u>community awareness</u> of mental illness. (15-20 mins)</p> <ul style="list-style-type: none"> • How would you describe the current level of community awareness about mental illness? <ul style="list-style-type: none"> ○ How do you think it compares to community awareness in the last 5-10 years? ○ How would you describe the effectiveness of public campaigns? <ul style="list-style-type: none"> ▪ What was effective about them? • What has been your experience of community awareness with different groups of people? E.g. <ul style="list-style-type: none"> ○ Friends ○ Family ○ Work colleagues and employers ○ Non mental health professionals (e.g. GPs) ○ Mental health professionals ○ Local community ○ General public • How important would you say community awareness is for you, as a carer? 	<p>Community awareness of mental illness</p>
<p>3. The second topic area is about people’s <u>attitudes and behaviours to people with mental illness</u>. (15-20 mins)</p> <ul style="list-style-type: none"> ○ How would you describe <i>your</i> attitude to people with mental illness? <ul style="list-style-type: none"> ○ How important is patience and empathy as a carer? ○ Do you feel comfortable talking about mental illness with the person you are caring for? ○ How would you describe <i>other</i> people’s attitudes to people with mental illness? <ul style="list-style-type: none"> ○ Have other family members or friends had a different reaction to you? ○ Have you or the person you are caring for experienced discrimination as a result of the mental health issues? <ul style="list-style-type: none"> ○ Who did you experience the discrimination from? E.g. <ul style="list-style-type: none"> ▪ Friends 	<p>Stigma associated with mental illness</p>

<ul style="list-style-type: none"> ▪ Family ▪ Work colleagues and employers ▪ Non mental health professionals (e.g. GPs) ▪ Mental health professionals ▪ Local community ▪ General public ○ How do you think people’s current attitudes and behaviours to people with mental illness compares to attitudes and behaviours 5-10 years ago? 	
<p>4. The third topic area is about your experiences of the times <u>you’ve sought and received</u> help for your mental health issues. (15-20 mins)</p> <ul style="list-style-type: none"> • First, with your use of formal help – so with people like doctors, mental health professionals and websites ... <ul style="list-style-type: none"> ○ Was there anything that encouraged or prompted you to seek formal help for the person you care for? <ul style="list-style-type: none"> ▪ Previous positive experiences/expectations with professionals ▪ Public information and campaigns (e.g. advertising and websites) ▪ Other carer support/encouragement ○ Was there anything that discouraged or stopped you from seeking formal help for the person you care for? <ul style="list-style-type: none"> ▪ Resistance from the consumer to professional help <ul style="list-style-type: none"> ▪ How did you tell the person that you care for that you think they need help? ▪ How did they react? <ul style="list-style-type: none"> ○ Did they feel bullied? ○ Disempowered? ▪ Attitudes/fears (yours or other people’s): <ul style="list-style-type: none"> ▪ about depression and anxiety (e.g. that depression/anxiety is not really an illness, or that the consumer has more control than they do) ▪ to receiving professional help (e.g. pride) ▪ feeling disempowered/lack of autonomy ▪ to medication (e.g. a belief that medication is addictive or vegetative?) ▪ about the effectiveness of psychological (or non-pharmacological) interventions ▪ Perceived or actual availability of services (esp. in regional areas) ▪ Perceived or actual cost of professional services ▪ Cultural appropriateness of services ▪ Language barriers ○ Would you describe the formal help you received as useful or not useful, and why? • Now thinking about you, as a carer, providing informal help ... <ul style="list-style-type: none"> ○ How useful do you think your informal help has been to the person you care for? ○ How do you feel, as a carer, about being expected to have the skills and knowledge to address mental health issues informally? • People who care for others with depression or anxiety sometimes themselves feel depressed or anxious. <ul style="list-style-type: none"> ○ Has this been the case for you? 	<p>Treatment for mental illness</p>

<ul style="list-style-type: none"> ▪ Why or why not? <ul style="list-style-type: none"> ○ Do you feel overwhelmed by your caring role? ○ Do you even see yourself as a carer? ○ If yes, have you sought any formal or informal help? <ul style="list-style-type: none"> ▪ If yes, which types were helpful/not helpful? 	
<p>5. The next topic I want to talk about is <u>the impact of mental illness on different parts of your life. (20-30 mins)</u></p> <ul style="list-style-type: none"> • Firstly, how has their mental health issues impacted on your <i>family relationships</i>? <ul style="list-style-type: none"> ○ Have there been any changes in ... ? <ul style="list-style-type: none"> ▪ Dynamics, roles and responsibilities ▪ Sense of empowerment/disempowerment and independence/dependence • Have relationships with your <i>friends</i> changed? • Has your <i>involvement in the community</i> changed? <ul style="list-style-type: none"> ○ E.g. taking part in leisure, sport, and recreation ○ other social and community activities • Has your ability to <i>work</i> been affected? <ul style="list-style-type: none"> ○ Financial issues • Has your ability to study or obtain an <i>education</i> been affected? 	<p>Social and economic impact of mental illness</p>
<p>6. Only two more topics left. The first is about your thoughts on <u>prevention and early intervention</u> with mental illness. (10-15 mins)</p> <ul style="list-style-type: none"> • What do you think made the most difference to improving the wellbeing of the person you care for? <ul style="list-style-type: none"> ○ Education for the carer <ul style="list-style-type: none"> ▪ How did you educate yourself about depression/anxiety? ▪ What would you have liked more of? • What do you think the best advice is to give to someone who is on the cusp of seeking treatment for mental health issues? 	<p>Treatment for mental illness</p>
<p>7. The final topic area for today's discussion is about your <u>suggestions for what you think <i>beyondblue</i> can or should do</u> to further improve awareness of mental health issues in the wider community. (20-30 mins)</p> <p><i>[BV leave].</i></p> <p>So the final questions for today are</p> <ul style="list-style-type: none"> • <i>beyondblue</i> aims to increase awareness, decrease stigma, improve people's access to treatment and promote the needs and experiences of people with anxiety and depression with policy makers and health care services. In your opinion or experience, to what extent do you think <i>beyondblue</i> has achieved these aims? • In what areas do you think <i>beyondblue</i> is doing well and in what areas do you think they could improve? • If you were in charge of <i>beyondblue</i>, and wanted to change the way society views and responds to depression and anxiety, what 3 areas would you make a priority? What would you do? 	<p>Experiences with, perceptions of, and suggestions for <i>beyondblue</i></p>

‘Consumer and carer’ focus group schedule matched to study themes

Question	Theme
<p>1. Going around the group, if you could just spend one minute each introducing yourself, and tell us 3 things about you: <i>(10-15 mins)</i></p> <ul style="list-style-type: none"> • your name • something about yourself that you’re happy to share with the group <ul style="list-style-type: none"> ○ e.g. something about where you live, something you like to do, your family etc • if you’re comfortable sharing it ... <ul style="list-style-type: none"> ○ whether you consider yourself are consumer or carer or both? ○ And if you consider yourself a consumer, what kinds of mental health issues you experience and how long you’ve been experiencing these for? ○ And if you consider yourself a carer, who in your life is experiencing mental health issues, how long for, and how long have you been caring for them? 	<p>General needs and experiences</p>
<p>2. Thank you everyone. We’ll now start to work through the 7 topic areas or discussion points. The first one is on <u>community awareness</u> of mental illness. <i>(15-20 mins)</i></p> <ul style="list-style-type: none"> • How would you describe the current level of community awareness about mental illness? <ul style="list-style-type: none"> ○ How do you think it compares to community awareness in the last 5-10 years? ○ How would you describe the effectiveness of public campaigns? <ul style="list-style-type: none"> ▪ What was effective about them? • What has been your experience of community awareness with different groups of people? E.g. <ul style="list-style-type: none"> ○ Friends ○ Family ○ Work colleagues and employers ○ Non mental health professionals (e.g. GPs) ○ Mental health professionals ○ Local community ○ General public • How important is community awareness about mental illness for you, either as a consumer or carer? 	<p>Community awareness of mental illness</p>
<p>3. The second topic area is about people’s <u>attitudes and behaviours to people with a mental illness</u>. <i>(15-20 mins)</i></p> <ul style="list-style-type: none"> • How would you describe <i>your</i> attitude to people with mental illness? <ul style="list-style-type: none"> ○ How important is patience and empathy as a carer? ○ Do you feel comfortable talking about mental illness with the person you are caring for? • How would you describe <i>other</i> people’s attitudes to people with mental illness? 	<p>Stigma associated with mental illness</p>

<ul style="list-style-type: none"> ○ Have other family members or friends had a different reaction to you? • Have you or the person you are caring for experienced discrimination as a result of the mental health issues? <ul style="list-style-type: none"> ○ Is discrimination different with different groups? E.g. <ul style="list-style-type: none"> ▪ Friends ▪ Family ▪ Work colleagues and employers ▪ Non mental health professionals (e.g. GPs) ▪ Mental health professionals ▪ Local community ▪ General public • How do you think people’s current attitudes and behaviours to people with mental illness compares to attitudes and behaviours 5-10 years ago? 	
<p>4. The third topic area is about your experiences of the times <u>you’ve sought and received help</u> either for yourself or for the person you care for. (15-20 mins)</p> <ul style="list-style-type: none"> • First, with your use of formal help – so with people like doctors, mental health professionals and websites ... <ul style="list-style-type: none"> ○ Was the formal help you received useful? ○ Was there anything that encouraged or prompted you to seek formal help for yourself or the person you care for? <ul style="list-style-type: none"> ▪ Previous positive experiences/expectations with professionals ▪ Public information and campaigns (e.g. advertising and websites) ▪ Other carer support/encouragement ○ Was there anything that discouraged or stopped you from seeking formal help for yourself or for the person you care for? <ul style="list-style-type: none"> ▪ Resistance to professional help <ul style="list-style-type: none"> ▪ How did you tell the person that you care for that you think they need help? ▪ How did they react? <ul style="list-style-type: none"> ○ Did they feel bullied? ○ Disempowered? ▪ Attitudes/fears (yours or other people’s): <ul style="list-style-type: none"> ▪ about depression and anxiety (e.g. that depression/anxiety is not really an illness, or that the consumer has more control than they do) ▪ to receiving professional help (e.g. pride) ▪ feeling disempowered/lack of autonomy ▪ to medication (e.g. a belief that medication is addictive or vegetative?) ▪ about the effectiveness of psychological (or non-pharmacological) interventions ▪ Perceived or actual availability of services (esp. in regional areas) ▪ Perceived or actual cost of professional services ▪ Cultural appropriateness of services 	<p>Treatment for mental illness</p>

<ul style="list-style-type: none"> ▪ Language barriers • <i>This question is for the consumers in the group:</i> Thinking about your use of informal help – like with friends or family, or self–help techniques or strategies ... <ul style="list-style-type: none"> ○ Was there anything that encouraged or prompted you to seek informal help? ○ Was there anything that discouraged or stopped you from seeking informal help? ○ Would you describe the informal help you received as useful or not useful, and why? • <i>This question is for the carers in the group:</i> How useful do you think your informal help has been to the person you care for? <ul style="list-style-type: none"> ○ How do you feel, as a carer, about being expected to have the skills and knowledge to address mental health issues informally? • People who care for others with depression or anxiety sometimes themselves feel depressed or anxious. <ul style="list-style-type: none"> ○ Has this been the case for you? <ul style="list-style-type: none"> ▪ Why or why not? ○ Do you feel overwhelmed by your caring role? ○ Do you even see yourself as a carer? ○ If yes, have you sought any formal or informal help? <ul style="list-style-type: none"> ▪ If yes, which types were helpful/not helpful? 	
<p>5. The next topic I want to talk about is <u>the impact of mental illness on</u> different parts of your life (20-30 mins)</p> <ul style="list-style-type: none"> • Firstly, how have mental health issues impacted on your <i>family relationships</i>? <ul style="list-style-type: none"> ○ Have there been any changes in ... ? <ul style="list-style-type: none"> ▪ Dynamics, roles and responsibilities ▪ Sense of empowerment/disempowerment and independence/dependence ▪ Sense of feeling over- or under-protected/involved by family or friends? • Have relationships with your <i>friends</i> changed? • Has your <i>involvement in the community</i> changed? <ul style="list-style-type: none"> ○ E.g. taking part in leisure, sport, and recreation ○ other social and community activities • Has your ability to <i>work</i> been affected? <ul style="list-style-type: none"> ○ Financial issues • Has your ability to study or obtain an <i>education</i> been affected? 	<p>Social and economic impact of mental illness</p>
<p>6. There are only two more topics left. The first is about your thoughts on <u>prevention and early intervention</u> with mental illness. (10-15 mins)</p> <ul style="list-style-type: none"> • What do you think made the most difference to improving the wellbeing of yourself or the person you care for? <ul style="list-style-type: none"> ○ Education for the carer? • What do you think the best advice is to give to someone who is on the cusp of seeking treatment for mental health issues? 	<p>Treatment for mental illness</p>
<p>7. The final topic area for today’s discussion is about your <u>suggestions for what you think beyondblue can or should do</u> to further improve awareness</p>	<p>Experiences with, perceptions of,</p>

<p>of mental health issues in the wider community. (20-30 mins)</p> <p>[BV leave].</p> <p>The final questions for today are</p> <ul style="list-style-type: none">• <i>beyondblue</i> aims to increase awareness, decrease stigma, improve people’s access to treatment and promote the needs and experiences of people with anxiety and depression with policy makers and health care services. In your opinion or experience, to what extent do you think <i>beyondblue</i> has achieved these aims?• In what areas do you think <i>beyondblue</i> is doing well and in what areas do you think they could improve?• If you were in charge of <i>beyondblue</i> and wanted to change the way society views and responds to depression and anxiety, what 3 areas would you make a priority? What would you do?	<p>and suggestions for <i>beyondblue</i></p>
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Appendix B: Demographics Survey



Focus group research for *beyondblue* with consumers and carers

DEMOGRAPHICS SURVEY

You do not have to answer any or all of these questions.

Please ask if you are unsure.

- 1 How old are you? _____ (in years)
- 2 What is your gender? (Please circle) **FEMALE MALE**
- 3 What is your postcode? _____
- 4 What is your cultural background? (You may tick ✓ more than ONE box)
 - Aboriginal or Torres Strait Islander (ATSI)?
 - Anglo Saxon and/or Celtic?
 - Non-English speaking background (NESB)?
- 5 Do you consider yourself to be a: (Please tick ✓ ONE box only)
 - Consumer ONLY?
(i.e. a person with personal experience of depression, anxiety and/or related disorders)
 - Carer ONLY?
(i.e. a family member and/or friend of a consumer)
 - BOTH a consumer and carer?
- 6 If you consider yourself to be a 'carer' ONLY, which issues related to mental health affect the life of the person you are caring for? (You may tick ✓ more than one box)
 - Depression
 - Anxiety disorders
 - Bipolar disorder
 - Substance use disorder

Other → Please list up to three other issues (e.g. PND, OCD, PTSD)

1. _____

2. _____

3. _____

N/A – I do not consider myself to be a carer only

7 If you consider yourself to be a ‘consumer’, which issues related to mental health have you been diagnosed with by a mental health professional?

Depression

Anxiety disorders

Bipolar disorder

Substance use disorder

Other → Please list up to three other issues (e.g. PND, OCD, PTSD)

1. _____

2. _____

3. _____

N/A – I am a consumer, but I have not been diagnosed by a mental health professional

N/A – I do not consider myself to be a consumer

8 What are some of the issues related to mental health that you think significantly affect your life? (You may tick ✓ more than one box)

Depression

Anxiety disorders

Bipolar disorder

Substance use disorder

Other → Please list up to three other issues (e.g. PND, OCD, PTSD)

1. _____

2. _____

3. _____

N/A – I do not think any mental health issues affect my life

9 Do you access any services or programs related to mental health in your local community?

No

Yes → Please list up to three commonly used services or programs

1. _____

2. _____

3. _____

10 Do you access information about issues related mental health? (e.g. from *beyondblue*, websites, organisations, etc)

No

Yes → Please list up to three commonly used sources of your information

1. _____

2. _____

3. _____

11 Do you have any other comments or suggestions that you would like to make, that you did not feel comfortable or have the opportunity to share during the focus group?

For example:

- Any negative experiences with *beyondblue*?
- Any feelings or thoughts about the current state of awareness of mental health issues in Australia?
- Any suggestions that *beyondblue* can do to improve the awareness of mental health issues in Australia?
- Or any comments about the research project/focus group itself?

THIS IS THE END OF THE DEMOGRAPHICS SURVEY.

THANK YOU VERY MUCH FOR YOUR TIME.

Office use only

Site Location

- | | | | |
|--------------------------|-----------|--------------------------|--------------|
| <input type="checkbox"/> | TAS Urban | <input type="checkbox"/> | TAS Regional |
| <input type="checkbox"/> | SA Urban | <input type="checkbox"/> | SA Regional |
| <input type="checkbox"/> | NSW Urban | <input type="checkbox"/> | NSW Regional |
| <input type="checkbox"/> | VIC Urban | <input type="checkbox"/> | VIC Regional |

Date: ____ / ____ / ____

Time start: _____

Time finish: _____

Appendix C: Recruitment Flyer

Letter of Invitation

**We are looking for people with
personal experience of depression, anxiety
or related disorders and their carers to take part
in research**

This project is being funded by *beyondblue* and conducted by The University of New South Wales (UNSW).

We are interested in speaking with people whose lives have been impacted by depression or anxiety, to assist us in increasing awareness about mental health and reducing the associated stigma.

Participants will take part in a focus group with 6-8 other people, where we will discuss your needs and experiences as a consumer and/or carer. The group will be 2-2.5 hours in duration:

Type (consumer and/or carers)

City (venue will not be listed)

Date & Time

Your travel expenses will be reimbursed and you will be given \$100 in recognition of your time and contribution.

To take part in this study or find out more information:

Please contact Bridget Allan from *beyondblue*
on (03) 9810 6112 or blueVoices@beyondblue.org.au



Appendix D: Reimbursement Form



RECEIPT OF REIMBURSEMENT FOR PARTICIPATION IN THE STUDY

I am signing below to indicate that I have received a \$100 from Ms Bonnie

Vincent from *beyondblue* for my participation in the project:

Focus group research with consumers and carers for beyondblue

Name: _____

Signature: _____

Date: _____

**** Quick document check ...**

- | | |
|--|----------|
| 1. Have you returned the Demographics Survey to the researcher? | Yes / No |
| 2. Have you signed and returned the Consent Form to the researcher? | Yes / No |
| 3. Have you taken the Participant Information Sheet for you to keep? | Yes / No |
| 4. Have you taken the Revocation (withdrawal) of Consent Form for you to keep? | Yes / No |

Appendix E: Information Statement and Consent Form



Approval No 10333

THE UNIVERSITY OF NEW SOUTH WALES AND *beyondblue*

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Focus group research with consumers of beyondblue and their carers

What is this study about? This study is about the needs and experiences of consumers of *beyondblue* and their carers. A consumer is defined in this study as a person with personal experience of depression, anxiety and/or other related mental health issues. A carer is defined in this study as a person who cares for a consumer, such as a family member or friend. You may identify as one or both of these.

What is the aim of the study? The aim of the study is to use your needs and experiences to help inform the direction of *beyondblue's* national objectives, programs, and activities. Therefore, this study will use your voices to help set the national agenda on meeting and promoting awareness about the needs of carers and consumers with mental health issues.

Why have I been invited to take part in this study? The invitation to take part in this study was given to all members of blueVoices – the national reference group for *beyondblue*. You have received this invitation because you are a member of blueVoices.

If I agree to take part, what is involved? If you decide to take part in this study, you will be involved in a focus group with approximately 6-8 people and asked to complete a short Demographic Survey. The focus group will take between 2-2½ hours. As a group, we will discuss your needs and experiences as a consumer and/or carer. The focus group will be conducted primarily by a researcher from the University of New South Wales (UNSW) and will be co-facilitated by a member of *beyondblue*.

Will my responses be kept confidential and anonymous? We would like to take notes during the focus group and will ask you to agree to let us record the focus groups to make our notes better. You will not be identified in any of the papers that we write or publish. What you tell us will be completely confidential and will not be told to anyone other than the researchers involved in the study, except as required by law. We also ask that all participants in today's focus group agree to keep confidential any information that is shared by others during the focus group discussion.

How will my responses be used? In total, there will be eight focus groups across four different states in Australia (NSW, Vic, SA, and Tas). This will help ensure we have views from different people living in different areas around Australia. All eight focus groups will be conducted in November and December 2010. All the findings will be reported in a Final Report to *beyondblue* in February 2011. We will also write journal articles based on the findings. If you would like a short summary of the main findings from this study, please indicate this on the last page of this Form. We will send this to you by email or post (as per your request).

Will I receive any reimbursement for my participation in this study? We expect that the focus group will last for approximately 2 - 2½ hours. We acknowledge that this is a significant amount of your time,

and as a sign of appreciation *beyondblue* will reimburse you \$100. We will also reimburse you for any travel expenses. You will be required to sign a form at the end of the focus group simply indicating that you have received this amount.

Are there any benefits for taking part in this study? The results of this study will be used to identify key themes and make recommendations for future strategic planning and community forum development. As a participant in this study, you have the opportunity to express your needs and experiences (both positive and negative) as consumers or carers of *beyondblue*, as well as contribute to the improvement of *beyondblue*'s programs and activities. However, we cannot and do not guarantee or promise that you will receive these or any other benefits from this study.

Are there any risks for taking part in this study? It is possible that as a result of the discussion in this focus group, you may experience some level of distress. If this is the case, please inform the research team immediately.

What if feel uncomfortable with a member of *beyondblue* being present for the focus group? We acknowledge that some of you may feel uncomfortable to discuss your needs and experiences in front of a person from *beyondblue*. To address this issue, we will ask this person to leave the focus group during the part of our discussion that is about *beyondblue*. You also have the opportunity to anonymously make suggestions for improving awareness about the needs and experiences of consumers and carers at the end of the Demographic Survey if you wish.

What if I don't want to take part or what if I change my mind later and want to leave the study? Taking part in this study is voluntary. You do not have to take part if you don't want to. If you decide to take part and then change your mind, you can leave (withdraw from) the study at any time. After starting the focus group, you can choose not to answer some questions and you are free to leave the focus group at any time. Your decision whether or not you take part will not have any effect on your future relations with The University of New South Wales or *beyondblue*.

I want to take part in the study ... So what do I do now?

If you have read this Participant Information Statement and are happy to take part in the study, please now sign the Consent Form on the next page.

If you do not wish to sign the form, a verbal consent is acceptable.

Who can I talk to if I have any problems with this study? If you have any concerns or complaints at any time about your part in the study, you can contact the Ethics Secretariat, University of New South Wales, Sydney 2052, phone (02) 9385 4234, fax 02 9385 6648, email ethics.sec@unsw.edu.au, quoting this reference number: HREC 10333. Any complaint you make will be investigated promptly and you will be informed of the outcome.

Any other questions? If you have any questions, please feel free to ask us – Pooja Sawrikar (from the University of New South Wales) or Bonnie Vincent (from *beyondblue*). If you have any additional questions later, Kristy Muir from the University of New South Wales (02 9385 7818) will be happy to answer them.

This Participant Information Statement is for you to keep.

Staff from *beyondblue* will be available during and after the interview if you would like to talk to someone about any problems you are experiencing. If you want to talk to a different counsellor you can call:

Lifeline (a free 24 hour counselling service) on **13 11 14**

or

Kids Helpline (a free 24 hour counselling service for 12-18 year olds) on **1800 551 800**

Appendix F: Information Statement and Consent Form (Easy Read)



Approval No 10333

THE UNIVERSITY OF NEW SOUTH WALES AND *beyondblue*

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Focus group research with consumers of beyondblue and their carers

Easy read form

What is this study about? This study is about the needs and experiences of people with depression and anxiety (and other related issues), as well as the needs and experiences of their carers (such as family members and friends).

A consumer is a person with experience of depression, anxiety and/or other related mental health problems. A carer is a person who cares or looks after a consumer, like a family member or a friend. You might be a consumer and/or a carer.

Why is this study being done? This study will help *beyondblue* to decide on their goals, plans and programs. To do this well, it is important for *beyondblue* to hear the real needs, experiences and views of consumers and carers. This study will help *beyondblue* to shape mental health policy and raise awareness about the needs of people with mental health issues and their carers.

Why have I been asked to take part in this study? You have been asked to take part in this study because you are a member of blueVoices – the national reference group for *beyondblue*.

If I take part, what do I have to do? If you want to take part in this study, you will be part of a focus group (or group discussion) with around 7 other people. You will also be asked to complete a short survey. If you need help filling this out, you can ask the researchers. The focus group will take about 2-2½ hours. In the group, we will discuss your and other people's needs and experiences as consumers and/or carers. A researcher from the University of New South Wales (UNSW) will be in charge of the discussion. She will be helped by someone from *beyondblue*.

Will my answers be kept confidential? We would like to take notes during the focus group and will ask you to agree to let us record the focus group discussion to make our notes better. However, you will not be identified in any of the papers that we write or publish. What you tell us will be completely confidential and will not be told to anyone other than the researchers involved in the study, except as required by law. We also ask that all participants in today's focus group agree to keep confidential any information that is shared by others during the focus group discussion.

Can I see how my answers have been used? Eight focus groups will be held around Australia (in NSW, Vic, SA, and Tas). This will help us get views from different people living in different areas. All the findings will be reported in a Final Report to *beyondblue* in February 2011. We will also write journal articles based on the findings. If you would like to see some of the findings from this study, please tick the box on the last page of this Form. We can send you these by email or post.

Will I receive any reimbursement for my participation in this study? We expect that the focus group will last for approximately 2 - 2½ hours. We know this is a long time and to thank you for your time, we will give you \$100. We will also pay you back for any travel costs you paid to get to the focus group. You will need to sign a form at the end of the focus group saying you have received the money.

Are there any benefits for taking part in this study? The findings of this study will be used to by *beyondblue* for future planning and future focus groups. As a part of this study, you will be able to talk about your needs and experiences (both good and bad) as a consumer or carer. You will also be able to give ideas as to how *beyondblue* could make its programs and activities better. But, we cannot and do not guarantee or promise that you will get these or any other benefits from this study.

Are there any risks for taking part in this study? It is possible that as a result of the focus group discussion you may experience some distress. If this is this case, please tell the researchers straight away.

What if don't want the *beyondblue* person listening to what I have to say? We know that some people might not want to discuss things about *beyondblue* in front of a person who works for *beyondblue*. When we talk about *beyondblue* in the focus group, we will ask the *beyondblue* worker to leave the focus group. If you want, you can also tell the UNSW researcher any extra ideas you have at the end of the focus group.

What if I don't want to take part or what if I change my mind later and want to leave the study? Taking part in this study is voluntary. You do not have to take part if you don't want to. If you decide to take part and then change your mind, you can leave (withdraw from) the study at any time. After starting the focus group, you can choose not to answer some questions and you are free to leave the focus group at any time. Your decision whether or not you take part will not have any effect on your future relations with The University of New South Wales or *beyondblue*.

I want to take part in the study ... So what do I do now?

If you have read this Participant Information Statement and are happy to take part in the study, please now sign the Consent Form on the next page.

If you do not wish to sign the form, a verbal consent is acceptable.

What if I have complaints about the study? If you have any concerns or complaints at any time about your part in the study, you can contact the Ethics Secretariat, University of New South Wales, Sydney 2052, phone (02) 9385 4234, fax 02 9385 6648, email ethics.sec@unsw.edu.au, quoting this reference number: HREC 10333. Any complaint you make will be quickly investigated and you will be told of the outcome.

Any other questions? If you have any questions, please feel free to ask us – Pooja Sawrikar (from the University of New South Wales) or Bonnie Vincent (from *beyondblue*). If you have any additional questions later, Kristy Muir from the University of New South Wales (02 9385 7818) will be happy to answer them.

This Participant Information Statement is for you to keep.

Staff from *beyondblue* will be available during and after the interview if you would like to talk to someone about any problems you are experiencing. If you want to talk to a different counsellor you can call:

Lifeline (a free 24 hour counselling service) on **13 11 14**

or

Kids Helpline (a free 24 hour counselling service for 12-18 year olds) on **1800 551 800**

Appendix G: Participant code and demographic characteristics

The demographic characteristics of each participant have been provided in the table below. This may help readers gain an insight into how urban or regional residence, age, sex, and cultural background are related to the perceptions and experiences of the consumers and carers in this study.

Additionally, the two most significant mental illnesses affecting the lives of consumers and/or carers have also been reported. This data is based on information provided during the focus group and on the Demographics Survey. For the five ‘consumers and carers’, the diagnoses can either be their own or of the person they are caring for. For the 24 ‘carers only’, the diagnoses are of the person they are caring for (rather their own). Finally, for the 32 ‘consumers only’, the diagnoses is of the mental illness they have.

Consumer/carer status	Urban/Regional	Age group	Sex	Culture	Diagnosis 1	Diagnosis 2
ConsCar_1	Regional	40 – 49	F	Anglo	Depression	Bipolar
ConsCar_2	Regional	40 – 49	M	Anglo	Depression	Anxiety
ConsCar_3	Regional	60 – 69	F	Anglo	Depression	Anxiety
ConsCar_4	Urban	40 – 49	F	NESB	Depression	PTSD
ConsCar_5	Regional	50 – 59	M	Anglo	Depression	Bipolar
Carer_1	Regional	40 – 49	F	Anglo	Depression	Bipolar
Carer_2	Regional	30 – 39	M	Anglo	PND	
Carer_3	Regional	30 – 39	M	Anglo	PND	
Carer_4	Regional	50 – 59	M	Anglo	Depression	Anxiety
Carer_5	Regional	60 – 69	F	Anglo	Depression	Anxiety
Carer_6	Regional	30 – 39	F	ATSI	Bipolar	
Carer_7	Regional	60 – 69	M	Anglo	Depression	
Carer_8	Regional	16 – 24	M	Anglo	Bipolar	
Carer_9	Regional	40 – 49	F	Anglo	Depression	PND
Carer_10	Urban	40 - 49	M	NESB	Bipolar	PND
Carer_11	Regional	60 – 69	F	Anglo	Depression	Bipolar
Carer_12	Regional	40 – 49	F	ATSI	Depression	Anxiety
Carer_13	Regional	30 – 39	F	Anglo	Depression	Substance
Carer_14	Regional	50 – 59	F	Anglo	Depression	Bipolar

FOCUS GROUP RESEARCH FOR BEYONDBLUE WITH CONSUMERS AND CARERS

Consumer/carer status	Urban/Regional	Age group	Sex	Culture	Diagnosis 1	Diagnosis 2
Carer_15	Regional	70 – 79	M	Anglo	Bipolar	Schizophrenia
Carer_16	Regional	70 – 79	M	Anglo	Depression	Bipolar
Carer_17	Urban	60 – 69	F	Anglo	Depression	Bipolar
Carer_18	Urban	40 – 49	F	Anglo	Depression	Bipolar
Carer_19	Urban	40 – 49	F	Anglo	Depression	Anxiety
Carer_20	Urban	30 – 39	F	Anglo	Depression	Anxiety
Carer_21	Urban	60 – 69	F	Anglo	Depression	Anxiety
Carer_22	Urban	50 – 59	F	Anglo	Bipolar	Schizophrenia
Carer_23	Urban	30 – 39	M	ATSI	Depression	PND
Carer_24	Urban	60 – 69	M	Anglo	Depression	Substance
Cons_1	Urban	16 – 24	F	NESB	Depression	Anxiety
Cons_2	Urban	16 – 24	M	Anglo	Depression	
Cons_3	Urban	16 – 24	F	Anglo	Anxiety	OCD
Cons_4	Urban	16 – 24	F	Anglo	Depression	Bipolar
Cons_5	Urban	16 – 24	F		Depression	
Cons_6	Urban	16 – 24	M	NESB	Depression	Substance
Cons_7	Urban	16 – 24	M	Anglo	Depression	Anxiety
Cons_8	Urban	50 – 59	F	Anglo	Depression	Anxiety
Cons_9	Urban	25 – 29	F	Anglo	Depression	
Cons_10	Urban	40 – 49	F	Anglo	Anxiety	PND
Cons_11	Urban	30 – 39	F	Anglo	Bipolar	PTSD
Cons_12	Urban	40 – 49	M		Depression	Social phobia
Cons_13	Urban	25 – 29	F	NESB	Depression	Anxiety
Cons_14	Urban	50 – 59	M	Anglo	Depression	Anxiety
Cons_15	Urban	40 – 49	M	Anglo	Depression	Schizophrenia
Cons_16	Regional	30 – 39	F	Anglo	Depression	PND
Cons_17	Regional		F	Anglo	Depression	Anxiety
Cons_18	Regional	40 – 49	F	Anglo	Depression	PND

Consumer/carer status	Urban/Regional	Age group	Sex	Culture	Diagnosis 1	Diagnosis 2
Cons_19	Urban	30 – 39	M	Anglo	Depression	Anxiety
Cons_20	Urban	30 – 39	M	NESB	Anxiety	
Cons_21	Urban	16 – 24	M	NESB	Depression	
Cons_22	Urban	50 – 59	F	NESB	Depression	Anxiety
Cons_23	Urban	40 – 49	F	NESB	Bipolar	Schizo affective
Cons_24	Urban	40 – 49	F	NESB	Depression	Schizophrenia
Cons_25	Regional	40 – 49	M	Anglo	Depression	Social phobia
Cons_26	Regional	30 – 39	F	Anglo	Depression	Bulimia
Cons_27	Regional	30 – 39	F	Anglo	Depression	Agoraphobia
Cons_28	Regional	50 – 59	F	Anglo	Depression	Anxiety
Cons_29	Regional	30 – 39	F	Anglo	PND	OCD
Cons_30	Regional	50 – 59	F	Anglo	Depression	Anxiety
Cons_31	Regional	50 – 59	F	Anglo	Anxiety	PND
Cons_32	Regional	30 – 39	M	Anglo	Depression	OCD

Appendix H: Data Tables

Table 4: Re-categorised consumer/carer status by type of pre-determined focus group

Re-categorised consumer/carer status	Type of pre-determined focus group			Total
	Consumers only	Carers only	Mixed group	
Consumer	23	0	9	32
Carer	0	20	4	24
Consumer and carer	0	2	3	5
Total	23	22	16	61

Table 5: Number of participants by sex and consumer/carer status

Sex	Consumer/carer status			Total
	Consumers only	Carers only	Consumers and carers	
Male	11	10	2	23
Female	21	14	3	38
Total	32	24	5	61

Table 6: Number of ‘consumers only’ by type of mental illness

Mental health issue	Caring for a person with ...	Self-identified or clinically identified as having ...	Total
Depression	2	29	31
Anxiety	1	26	27
Bipolar	0	3	3
Substance abuse	0	4	4
OCD	0	5	5
PTSD	0	6	6
PND	0	5	5
Other	1	7	8
Total	4	85	89

Table 7: Number of ‘carers only’ by type of mental illness

Mental health issue	Caring for a person with ...	Self-identified or clinically identified as having ...	Total
Depression	16	11	27
Anxiety	10	6	16
Bipolar	11	0	11
Substance abuse	5	0	5
OCD	0	1	1
PTSD	4	0	4
PND	5	1	6
Other	4	0	4
Total	55	19	74

Table 8: Number of ‘consumers and carers’ by type of mental illness

Mental health issue	Caring for a person with ...	Self-identified or clinically identified as having ...	Total
Depression	4	4	8
Anxiety	1	4	5
Bipolar	2	1	3
Substance abuse	0	0	0
OCD	0	0	0
PTSD	0	1	1
PND	0	0	0
Other	1	1	2
Total	8	11	19

Appendix I: First aid recommendation for depression

The following table has been reproduced from an academic journal article by Langlands et al (2008). The items refer to recommendations that at least 80% of carers, consumers, and clinician panel members all consensually regarded as essential or important to include in 'first aid education' about depression for carers.

Theme	Items
The first aider recognising and acknowledging that someone they know may have depression	<ul style="list-style-type: none"> • The first aider should be able to recognise the symptoms of depression. • If the first aider notices changes in mood, the behaviour (e.g. drinking and/or drug abuse), energy level, habits (e.g. an increase or decrease in sleep or appetite) or the personality of someone they know, they should consider depression as a possible reason for these changes. • If the first aider knows someone who is showing signs of depression, they must not ignore the symptoms or assume that the depression will just go away. • The first aider should not lie or make excuses for the depressed person's behaviour as this may delay getting assistance. • The first aider needs to learn about depression in order to help someone with depression. • The first aider should take time to find out information about depression such as its causes, its symptoms, how it can be treated, and what services are available in their local area. • The first aider should remain aware that each individual is different and not everyone who is experiencing depression will show the typical signs or symptoms of depression.
How the first aider should approach someone who may be experiencing depression	<ul style="list-style-type: none"> • Contrary to myth, talking about depression makes things better, not worse. If the first aider thinks someone may be depressed and needs help, the first aider should say something to that person. • If the first aider is worried about someone who may be depressed, s/he should give the person appropriate opportunities to talk and let the person choose the moment to open up. • The first aider should choose a suitable time when s/he and the depressed person are both available to talk, as well as a space where they both feel comfortable. • The first aider needs to let the depressed person know s/he is concerned about them and is willing to help. • If the person says that they are feeling sad or down, the first aider should ask them how long they have been feeling that way. • The first aider should not assume that the person knows nothing about depression. • The first aider should ask the person if they would like some information about depression. • If the first aider does give the person information about depression, they must ensure that the resources are accurate and appropriate to the person's situation. • The first aider should respect how the person interprets their symptoms. • If the person doesn't feel comfortable talking to the first aider, s/he should encourage them to discuss how they are feeling with someone else.
How the first aider can be supportive	<p><i>The first aider should treat the person with respect and dignity</i></p> <ul style="list-style-type: none"> • The first aider needs to recognise that each person's situation and needs are unique. • The first aider needs to respect the person's autonomy while considering the extent to which the person is able to make decisions for themselves, and whether the person is at risk of harming themselves or others. • The first aider should respect the person's privacy and confidentiality unless they are concerned that the person is at risk of harming themselves or others.

	<p><i>The first aider should not blame the person for their illness</i></p> <ul style="list-style-type: none"> • The first aider needs to realise that depression is a medical illness and remember that the person cannot help being affected by depression. • The first aider should remind the person that this is an illness and that they are not to blame for feeling “down.” <p><i>The first aider needs to have realistic expectations for the person</i></p> <ul style="list-style-type: none"> • The first aider should accept the depressed person as they are and have realistic expectations for them. • The first aider should let the depressed person know that they are not weak or a failure because they have depression, and that s/he doesn't think less of them as a person. • Everyday activities like cleaning the house, paying bills, or feeding the dog may seem overwhelming to a depressed person. The first aider should acknowledge that a person with depression is not “faking”, “lazy”, “weak” or “selfish.” • The first aider should ask the person if they would like any practical assistance with tasks but should be careful not to take over or encourage dependency. <p><i>The first aider should offer the person consistent emotional support and understanding</i></p> <ul style="list-style-type: none"> • It is more important for the first aider to be genuinely caring than for them to say all the “right things”. • The depressed person genuinely needs additional love and understanding to help them through their illness so the first aider should be empathetic, compassionate and patient. • A depressed person is often overwhelmed by irrational fears. The first aider needs to be gently understanding of someone in this state. • The first aider needs to be patient, persistent and encouraging when supporting someone with depression. • The first aider should offer the depressed person kindness and attention, even if it is not reciprocated. • The first aider needs to let the person with depression know that they will not be abandoned. • The first aider should be consistent and predictable in their interactions with the depressed person. <p><i>The first aider should encourage the person to talk to them</i></p> <ul style="list-style-type: none"> • The first aider should not be afraid to encourage the person to talk about their feelings, symptoms and what is going on in their mind. • The first aider should let the person know that s/he is available to talk when they are ready, and should not put pressure on the person to talk right away. <p><i>The first aider should be a good listener</i></p> <ul style="list-style-type: none"> • The first aider can help someone with depression by listening to them without expressing judgement. • The first aider should be an "active listener" and reflect back what the depressed person has said before responding with their own thoughts. • The first aider needs to listen carefully to the depressed person even if what they tell her/him is obviously not true or is misguided. • Although the depressed person may not be communicating well, and is probably speaking slower and less clearly than usual, the first aider must be patient and must not interrupt. • If the depressed person is repetitive, the first aider should try not to get impatient but rather keep trying to be as supportive as possible. <p><i>The first aider should give the person hope for recovery</i></p> <ul style="list-style-type: none"> • The first aider needs to encourage the depressed person that, with time and treatment, they will feel better. • The first aider should offer emotional support and hope of a more positive future in whatever form the depressed person will accept.
<p>What isn't helpful for a person who may have</p>	<ul style="list-style-type: none"> • The first aider needs to realise that there's no point in just telling someone with depression to get better. • The first aider should keep in mind that the depressed person can't “snap out of it” or “get over it.”

depression	<ul style="list-style-type: none"> • The first aider should not be hostile or sarcastic when the depressed person attempts to be responsive; s/he should accept these responses as the best the person has to offer at that time. • The first aider should not adopt an over-involved or over-protective attitude towards someone who is depressed. • The first aider should not nag the person to try to get them to do what they normally would. • The first aider should not trivialise the depressed person's experiences by pressuring them to "put a smile on their face," to "get their act together," or to "lighten up". • The first aider should not belittle or dismiss the person's feelings by attempting to say something positive like, "You don't seem that bad to me." • The first aider should avoid speaking to the depressed person with a patronizing tone of voice and should not use overly-compassionate looks of concern. • The first aider should resist the urge to try to cure the person's depression or to come up with answers to their problems.
Whether the first aider should encourage the person to seek professional help	<ul style="list-style-type: none"> • Everybody feels down or sad at times, but the first aider should be able to recognise when depression has become more than a temporary experience for someone and when to encourage that person to seek professional help. • The first aider should ask the person if they need help to manage how they are feeling. • The first aider should discuss the options that the person has for seeking help and should encourage them to use these options. • If the person does not know where to get help, the first aider should offer to help them seek assistance. • The first aider can help someone who may be depressed by encouraging them to get an appropriate professional diagnosis and effective treatment. • The first aider should encourage the person they are helping to get professional help as early as possible. • If the first aider accompanies the person to the doctor's appointment, they must not take over completely; a person with depression needs to make their own decisions as much as possible. • Depression is often not recognized by health professionals; it may take some time to get a diagnosis and find a healthcare provider with whom the depressed person is able to establish a good relationship. The first aider should encourage the person s/he is helping not to give up.
Whether the first aider should encourage the person to use self-help strategies	<ul style="list-style-type: none"> • The first aider needs to recognise that the person's ability and desire to use self-help strategies will depend on their interests and the severity of their depression. • The first aider should not be too forceful when trying to encourage the depressed person to use self-help strategies.
What the first aider should do if the person doesn't want help	<ul style="list-style-type: none"> • The first aider should find out if there are specific reasons why the depressed person does not want to seek professional help (e.g. concerns about finances, not having a doctor they like, or being worried they will be sent to hospital) as sometimes such reasons are based on mistaken beliefs, or can be overcome with help. • The first aider should let the person know that if they change the mind in the future about seeking help, they can contact the first aider. • The first aider must respect the person's right not to seek help at all times unless the first aider believes that they are at risk of harming themselves or others.