



Foundations for Change

2ND Edition

PART 1 **Experiences of CONSUMERS**
CONSUMERS **with the Diagnosis of Borderline**
Personality Disorder (BPD): 2017
Update



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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This is an Independent Report of the Data from a National Survey Undertaken by the Private Mental Health Consumer Carer Network (Australia) Limited

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NB: Due to the large sample size for this 2017 survey, qualitative raw data results are not provided as an appendix to this report. Please contact the authors for further information.

Acronyms

ACT	Australian Capital Territory
BPD	Borderline Personality Disorder
CBT	Cognitive Behaviour Therapy
DBT	Dialectical Behaviour Therapy
ED	Emergency Department
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
NZ	New Zealand
PTSD	Post-Traumatic Stress Disorder
QOL	Quality of Life
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

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Consumers with Borderline Personal Disorder

Executive Summary

This report provides analysis of the results of survey that was originally conducted in 2011 and repeated in 2017. This work was undertaken in order to compare and determine any changes in the healthcare experiences of consumers with BPD over time, given greater awareness of BPD within mental health and primary care service systems since the first survey was undertaken, and the release of the National Health and Medical Research (NHMRC) Guidelines for the Treatment of BPD in December 2012. A companion survey was also conducted with family members/ informal, unpaid carers of people with BPD, and results of this repeat survey are provided in a separate report.

Four-hundred and twenty-four (424) consumers with BPD entered the survey site. Of these, 424 consumers (100%) proceeded to answer survey questions, with 69 consumers (16.27%) completing all questions, and 355 (83.73%) being selective in which questions they responded to. This represents a substantial increase (almost threefold) in overall respondents compared with the original survey in 2011, although a decrease in the proportion of people who answered all questions. In 2011, 153 consumers (95.0%) proceeded to answer survey questions, with 92 consumers (60.1%) completing all questions, and 61 (39.9%) being selective in which questions they responded to.

As per the 2011 survey, participation in the current survey was open to any consumer who identified themselves as having a diagnosis of BPD. They responded to an invitation to participate distributed in the first instance to mental health service organisations and consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The survey was widely publicised and delivered online via 'Survey Monkey' across Australia, and was conducted between 1st June, 2017 and 21st July 2017 (51 days). The 2011 survey was open for 35 days. Like, the original survey, it should be noted therefore that survey respondents were not a random sample from a population-based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey. The extent to which the conclusions drawn from the survey are representative of the wider BPD population therefore depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

The questions posed to respondents in the 2011 and 2017 surveys were essentially the same. A small number of revisions and additions were made to the 2017 survey to reflect the current Australian context and to address oversights from the original survey. For example, a third option of 'other' was added to 'gender' to capture any LGBTI individuals. Questions about children were added to more accurately distinguish BPD consumers' current parental caregiver status. Any typographical errors were also corrected.

Summary of Results:

Four hundred and twenty respondents participated in the survey, representing consumers from each state and territory of Australia except the Northern Territory. Almost two thirds (64.18%, n=267) of respondents lived in capital cities, reflecting the national population pattern. Most respondents were female (92.09%, n=384). These results do not reflect the national average, with more even representation of women and men with BPD. This was similar for the 2011 survey. Of note, 7 respondents (1.68%) identified as 'other'.

The 2017 attracted a greater proportion of younger respondents with 59.43% (n=258) between 18-39 years compared with 41.14% (n=62) being in this age group in the 2011 survey. This may be due to people receiving a BPD diagnosis earlier in their contact with health services, or due to the reach of the 2017 survey to different types of mental health services. For example, Headspace centres have tripled in number since the 2011 survey.

In 2017, respondents were similarly likely to be married (42.96%, n=180) or single (42%, n=176); a slight change from 2011 (45.9%, n=68 and 39.2%, n=58 respectively). More than half of respondents (58.61%, n=245) did not have children compared with (42.7%, n=62) in the 2011 survey, and more had fewer children, though this may be due to the overall higher proportion of younger respondents in the 2017 survey.

Sixteen respondents (3.84%) identified as Aboriginal or Torres Strait Islander descent. Seventy-five respondents were born outside of Australia, 49 (79.03% of 62 who provided information) had lived in Australia for more than 20 years, and only 8 (of 35 who provided further information) spoke a language other than English at home.

Of the 382 respondents that provided information, 291 (76.18%) reported BPD as their primary diagnosis. This was similar to 2011 (75.47%, n=80); however, a greater diversity of primary diagnoses and other diagnoses was evident in the 2017 survey. Many respondents reported having 2 or more diagnoses. Of note, in 2017, complex PTSD was mentioned by seven respondents; whereas, in 2011, it had not been identified by any respondents. It is difficult to determine whether these differences are due to more accurate diagnosis by health professionals, or some other reason.

In 2017, 345 respondents provided information about their medication use. Many said they were taking anti-depressants (66.09%, n=228), which was similar to 2011 survey results (68.9%, n=84). Fewer respondents were taking an anti-psychotic medication (35.94%, n=124) compared with 2011 respondents (41.8%, n=51). Similar rates of anti-anxiety medication were used (25.80%, n=89 for 2017; and 28.7%, n=35 for 2011). A greater number of 2017 respondents reported taking no medication (24.06%, n=83) compared with 2011 respondents (17.2%, n=21).

The largest group across both survey time periods was people who had been diagnosed with BPD within the past 1-5 years. Of the 2017 survey respondents, 20.62% (n=67) had been diagnosed with BPD within the past year compared with the 2011 survey (5.7%, n=6). This could reflect a change in practice with more people receiving a diagnosis earlier in their contact with mental health professionals, or it could reflect the overall younger cohort that responded in 2017.

Comparing time in treatment with time since BPD diagnosis, many respondents across both survey periods have been in treatment for longer than their diagnosis, though 2017 results suggest a great proportion of people are being told their BPD diagnosis earlier. Across both survey periods, psychiatrists were the main health professional to make the BPD diagnosis (72.68%, n=258 of 355 responses in 2017; 76.9%, n=90 in 2011), though an increasing number received the BPD diagnosis from a psychologist in 2017 (17.46%, n=62 compared with 10.3%, n=12 in 2011).

Rates for whether a health professional explained the BPD diagnosis to them have not improved (34.63%, n=125 in 2017 compared with 37.8%, n=45 in 2011). In 2017, 14.48% (n=53) reporting that an explanation had been given but that they had not understood it, compared with 19.3% (n=23) in 2011. That is, for both survey periods, more than did not receive an explanation and most did not understand their diagnosis from the explanation given to them.

Across both survey periods, the two most highly rated concerns that caused high levels of anxiety were discrimination because of their BPD diagnosis (57.1%, n=64 in 2011; 60.69%, n= 193 in 2017) and not being taken seriously (70.5%, n=79 in 2011; 64.89%, n=207 in 2017). Not being respected was the third most important concern that caused high anxiety in 2011 (53.6%, n=60) and again in 2017 (58.44%, n=187). In the 2017 survey, being unable to access support when they needed it (56.15%, n=178) replaced fears around consistency of support (52.2% - n=59) as the fourth highest concern. Anxiety due to the long waiting lists/times to see mental health professionals appeared to have increased (44.69%, n=143 in 2017; 36%, n=41 in 2011).

Regarding helpfulness of support services, psychotherapy was rated the most helpful in 2011 (mean= 4.28 on a 0-5 scale) and continued to be so in 2017 (mean=4.15). Unlike 2011, where community support such as art therapy and friendship groups (mean=4.10) was rated as the second most helpful, in 2017, this was replaced by education and information about BPD (mean=4.05), and Dialectic Behaviour Therapy (DBT) was rated third most helpful in 2017, suggesting a small increase towards seeking more clinical understanding of BPD since 2011. Similar to 2011 (52.4%, n=55), 50.54% of 2017 survey respondents (n=159) said that they had not been able to access the services they required, due mainly to problems with waiting lists, financial barriers, and services being too far away. Of note, 2017 survey respondents also noted being told that they were ineligible; most of these respondents noting desire to access DBT groups.

Those aspects of services reported to be the most unhelpful to respondents (n=273) were similar to those reported in 2011, (access, availability, affordability and discrimination/exclusion) except that respondents now also increasingly included long waiting lists, issues with private health cover, and hospital admission as most unhelpful.

Of the 293 respondents who answered questions about their hospital admissions, 45.39% (n=133) compared with 51% (n=52) in 2011 reported having had hospital admissions for their BPD within the last 18 months, and 18.43% (n=54) compared with 20.6% (n=21) of respondents in 2011 reported an admission in the past 3 months. Many reported negative experiences of receiving hospital care, though many also made more positive comments about support from therapy, from managed hospital stays, and from learning ways to manage their symptoms and distress levels. This was somewhat different to 2011 when the pervasive flavor of comments related to perceived lack of understanding, knowledge and skills demonstrated by the health professionals from whom they sought help.

Of the 316 2017 survey respondents, 51.27% (n=162) said that their GP had supported them (similar to 2011: 50.5%, n=54); whereas 36.08% (n=114) of 2017 survey respondents, compared with 29% (n=31) in 2011, rated GP contact as neutral or not supportive. Of note, fewer 2017 survey respondents (12.66, n=40), compared with 20.6% (n=22) in 2011 had not received any support from a GP. It appears that more people with BPD are in contact with a GP but the proportion of people that perceive GPs to be supportive has not changed, nor has the proportion of people receiving longer appointments with their GP (22.08%, n=70 in 2017, compared with 22.9%, n=25 in 2011).

Patterns of GP referral to other mental health professionals appears to have changed when comparing 2017 survey results with 2011 responses. In 2011, referrals were predominantly to a psychiatrist (64.2% - n=68), a psychologist (60.4% - n=64) or a mental health team (37.7% - n=40); whereas, in 2017, respondents reported that their GP was most likely to refer them to a psychologist (72.93% (n=229), followed by a psychiatrist (57.64%, n=181) or mental health team (35.67%, n=112). Further comments by 2017 survey respondents about

their GP support included as many positive comments as negative comments. Conversely, many of the 2011 respondents' comments emphasized negative experiences with GPs who either avoided noting BPD in documentation didn't believe in it or didn't feel confident in treating it. This suggests that some GPs are now more positively engaged with people with BPD, though the overall experience continues to be mixed and inconsistent.

Of the 315 2017 survey respondents who reported their usage of hospital services, rates were similar to 2011 results for public hospital only use; however, there appeared to be slightly fewer using only private hospitals, and a greater proportion using mostly public and some private hospitals. In 2017, more people appeared to be admitted to a public hospital for their BPD (74%, n=157 in 2017 compared to 57.4%, n=31 in 2011). Of the 156 who responded to the question about the frequency of public hospital admissions, 44.23% (n=69) reported that they had been admitted five or more times for issues related to their BPD diagnosis. This was much less than the 2011 survey results but did not show significance (57.4%, n=31, p=0.06). Length of hospital stay continued to be variable and inconsistent across the survey periods.

Of the 156 respondents who answered further questions about their public hospital admission experiences, 57.69% (n=90) had been admitted to hospital involuntarily; (66%, n=35 in 2011) Approximately half of respondents (49.03% (n=76) reported that they had asked to be admitted to a public hospital because of mental health issues but been refused, compared with 57.4% (n=31) in 2011, but with no significant difference. In 2017, an increased proportion of respondents (37.88%, n=25 compared with 32% in 2011) did not know who refused their admission to a public hospital, and 15.15% (n=10), compared with 24% in 2011, said that a psychiatrist refused their admission. Commonly perceived reasons why they were refused hospital admission were shortage of beds, hospital would be unhelpful, and their condition was not severe enough. This was similar to 2011 survey responses, suggesting that people with BPD continue to experience inconsistency and discrimination in the process of seeking admission to hospital. Reasons for seeking hospital admission were similar across the two survey periods, and significantly related to feeling in crisis (feeling suicidal, feelings of self-harm, feeling unsafe). Of note, the importance of feelings of self-harm and drug/alcohol problems appeared to be less in the 2017 survey compared with 2011 results.

Of the 178 2017 survey respondents, less than half (48.88%, n=87) had being admitted to private hospitals for issues related to BPD (compared with 63.9%, n=46 of 72 in 2011). Of note, only 18.40% (n=30, compared with 45.5%, n=20 in 2011) had been admitted five or more times to a private hospital for issues related to their BPD. Responses across both survey periods about the number of admission to private hospital in the past three years indicated that there were fewer admissions to private hospitals in 2017. Overall ratio of admissions to public hospitals by number of respondents appears to have gone down (approximately 1:7 in 2011 compared with 1:3 in 2017); whereas, for private hospital, the change in this ratio was noticeably less (approximately 1:4 in 2011 compared with 1:3 in 2017).

Of the 57 respondents in the 2017 survey who reported that they had been refused admission to a private hospital, psychiatrists were those most likely to have refused this request (28.07%, n=16) compared with 40.7% being psychiatrists (n=11), in the 2011 survey. Of concern, 43.86% (n=25) did not know who refused their admission to a private hospital, compared with 18.5% (n=5) in 2011. These results showed much greater change from 2011 to 2017 than results related to public hospital use. Sixty-nine of the 2017 survey respondents gave reasons for why they were refused admission into private hospitals. None mentioned shortage of beds as a reason; several said that they were told their condition wasn't serious enough, that they were not thought to be 'at risk', or that they wouldn't benefit from an admission. These results are similar to

the 2011 survey results.

The decision to refuse admission to a private hospital had a substantial negative impact upon many respondents in the areas of anxiety, anger, frustration, depression, suicidality and isolation, similar to impacts reported from 2011 survey results. However, across all potential impacts where a majority of respondents had previously rated them as a significant impact, almost half of respondents now rated them as 'not applicable'. This was in complete contrast to results reported by respondents refused admission to public hospitals. Given the apparent shift in the amount of overall care offered to people with BPD in private hospitals described above, this result may be because more people are deferring to public hospitals and are therefore less concerned when refused private hospital admission.

Most of the 291 respondents of the 2017 survey reporting psychologists (84.19%, n=245) and most of the 105 respondents of the 2011 survey reported psychiatrists (76.2% - n=80) as the main health professionals from whom they sought support for their BPD. This suggests a clear shift towards psychologists' care between survey periods. In 2011, a small number (7.6%) reported seeing no mental health professionals; with even fewer who reported seeing no health professionals in 2017 (2.06%, n=6).

Of the 270 respondents in 2017 that reported having accessed mental health professional support, 45.56% (n=123) stated that they had done so for more than 10 years, compared with 56.3% (n=54) in 2011. Across the survey periods, similar proportions of respondents reported that they did not feel treated with respect by mental health professionals (68.94%, n=182 in 2017 compared with 65.4%, n=78 in 2011). Health professional discrimination towards them seemed to apply particularly to inpatient experiences and comments from 93 respondents in the 2017 survey indicate that discriminatory attitudes by staff are still apparent, but that there is more variability, with an increasing number of comments indicating that respect is shown some or most of the time.

Comparing the two survey periods, psychologists continued to be reported as significantly helpful in helping them to understand their feelings of depression, anger and frustration by approximately half of respondents. Helpfulness of psychiatrists and mental health workers appears to have declined, and helpfulness of GPs appears to have increased moderately. Forty respondents made further comments, identifying other support providers as helpful (eg. Peer workers, dietitians, DBT groups, support groups, Spectrum, Headspace) or made more concerning comments about the lack of support. This pattern was similar when respondents were asked to rate how much each mental health professional had helped them to manage their mental health (eg. Identifying early warning signs, and providing strategies); though psychiatrists were reported to be only somewhat helpful. The rating for GPs had improved slightly, and for mental health workers substantially, over time. Of concern, only about one quarter of psychiatrists were rated as significantly helpful in helping respondents manage their mental health, with a further one third being somewhat helpful. When asked which health professionals were least helpful, GPs continued to be identified by almost half of respondents (49.4%, n=39 in 2011 and 45.6%, n=112 in 2017), and psychiatrists came second (34.2%, n=27 in 2011 and 35.8%, n=88 in 2017).

In 2011, 48.9% (n=45) of 92 respondents reporting on help-seeking when in crisis stated that a response from services occurred within the same day and 21.7% (n=20) within two days; in 2017, these figures were 42.97% (n=110) and 24.61% (n=63), respectively. GPs and psychologists showed the most capacity to respond followed by psychiatrists; whereas, in the 2011 survey, GPs and psychiatrists had been rated as the most responsive during a crisis, followed by psychologists. The highest rate of non-applicable responses continued to pertain to mental health workers (34.2%, n=27 in 2011) increasing to 49.6%, n=124 in 2017. Satisfaction with mental health care was slightly lower for mental health workers than for the other professions in 2011 and this dissatisfaction increased by the 2017 survey period. There was also a higher rate of dissatisfaction with psychiatrists than other

professions across the two survey time periods and also a large proportion of respondents reporting that they had not accessed mental health workers.

Responses from 269 consumers about community support services revealed that people with BPD continue to access a diverse range of services, in particular crisis lines, support groups, financial services, housing support. As with results from 2011, the most frequently accessed service was crisis lines and support groups, though both of these were accessed less in 2017 than in 2011. Of concern, an increased number of people with BPD reported not accessing any community support in 2017 (27.43%, n=65) compared with 14% (n=13) in 2011.

Of the 2017 survey respondents, 99.61% (n=255) stated that they had had thoughts of ending their life, compared with 100% of the 96 respondents to this question in 2011. Of 254 respondents to the question of whether they had ever made a serious attempt to end their life, 68.90% (n=175) of 2017 survey respondents compared with 85.6%, n=83 in 2011. When asked if they had ever had thoughts of harming themselves (eg. cutting, burning, ingesting fluids/medications) 97.65% (n=249) of 2017 respondents said 'yes'. Fewer sought help from their GP (38.86%, n=89) compared with 2011 survey respondents (48.3%, n=42). A greater proportion of 2017 survey respondents reported seeking support from a psychologist (41.05%, n=94) compared with the 2011 survey (33.7%, n=28). Fewer 2017 survey respondents sought help from a psychiatrist (31%, n=71 compared with 37.3%, n=31 in 2011). Of concern, the proportion of people not seeking any support from health professionals appears to have increased (39.30%, n=90 in 2017 compared with 32.5%, n=27 in 2011). Sixty-seven of the 2017 survey respondents further reported their longest time waiting in emergency departments for their self-harm to be addressed. When compared with results from the 2011 survey, with little improvement evident across the survey periods.

Of the 150 respondents to the 2017 survey about whether they were referred to a mental health professional as a result of their self-harm, 74.67% (n=112) said 'yes', compared with 63.3% (n=43) from the 2011 survey. This suggests that referral experiences have improved somewhat following self-harm.

A further question about child sexual abuse was added to the 2017. This had been an oversight in the 2011 survey. Eighty-five people provided responses and 35.29% (n=30) reported that they had experienced child sexual abuse, 52.94% (n=45) said 'no', and 11.76% (n=10) were unsure.

Context for the 2017 Survey

This report provides an update on the experiences and needs of Australian consumers with a diagnosis of Borderline Personality Disorder (BPD), derived from a survey conducted in 2017. It also provides a comparison of results from a similar survey conducted in 2011. The consumer survey has an accompanying family/carer survey (Part 2), also conducted in 2011 and again in 2017.

The purpose of the original 2011 surveys was to better understand the needs of consumers with BPD diagnoses and of their family members and carers, what supports were most helpful and what barriers there were to accessing help in the current mental health system. The purpose of repeating these surveys in 2017 was to determine whether any improvements in these experiences has occurred, given greater awareness of BPD within Australia's mental health and primary care service systems, and the release of the National Health and Medical Research (NHMRC) Guidelines for the Treatment of BPD in late 2012. The NHMRC BPD Guidelines include evidence-based recommendations (EBR), consensus-based recommendations (CBR) and practice points (PP). Key recommendations are summarised in the following Table 1:

Table 1: Key Recommendations from the NHMRC Guidelines for the Treatment of BPD

Key Recommendation	Type
Health professionals at all levels of the healthcare system and within each type of service setting should: acknowledge that BPD treatment is a legitimate use of healthcare services be able to recognise BPD presentations be aware of general principles of care for people with BPD and specific effective BPD treatments provide appropriate care (including non-specific mental health management, specific treatments for BPD and treatment for co-occurring mental illness) according to their level of training and skill refer the person to a specialised BPD service or other services as indicated undertake continuing professional development to maintain and enhance their skills	CBR
People with BPD should be provided with structured psychological therapies that are specifically designed for BPD, and conducted by one or more adequately trained and supervised health professionals.	EBR (B) #
Medicines should not be used as primary therapy for BPD, because they have only modest and inconsistent effects, and do not change the nature and course of the disorder.	EBR (B)
The majority of a person's treatment for BPD should be provided by community-based mental health services (public and private).	CBR
Adolescents with BPD should be referred to structured psychological therapies that are specifically designed for this age group. Where unavailable they should be referred to youth mental health services.	PP
Health professionals should inform people with BPD about the range of BPD-specific structured psychological therapies that are available and, if more than one suitable option is available, offer the person a choice.	CBR
Health professionals should refer families, partners and carers of people with BPD to support services and/or psychoeducation programs on BPD, where available.	CBR
Health professionals should consider assessment for BPD (or referral for psychiatric assessment) for people (including those aged 12–18 years) with any of the following: frequent suicidal or self-harming behaviour marked emotional instability multiple co-occurring psychiatric conditions non-response to established treatments for current psychiatric symptoms a high level of functional impairment.	PP (adults) CBR (adolescents)

B - Body of evidence can be trusted to guide practice in most situations

More specifically, the guidelines include the following further detail related to the care of people with BPD and in their communication with the person's family/carers:

“After making the diagnosis, health professionals should tell people with BPD that they have this illness, explain the symptoms, talk about how the person’s own experience would fit this diagnosis, emphasise that it is not their fault, and carefully explain that effective treatments are available. Some health professionals believe it is better not to tell a person they have BPD (particularly if the person is younger than 18 years old), mainly because some parts of the health system and society have discriminated against people with BPD and increased their suffering. However, telling the person the diagnosis can help them understand what they have been experiencing and might help ensure they receive effective treatment” (p.1).

“Admissions to hospitals or other inpatient facilities should not be used as a standard treatment for BPD and should generally only be used as short-term stays to deal with a crisis when someone with BPD is at risk of suicide or serious self-harm. Hospital stays should be short, and aim to achieve specific goals that the person and their doctors have agreed on. Health professionals should generally not arrange long-term hospital stays for people with BPD. If a person with BPD needs to visit an emergency department because they have harmed themselves or cannot cope with their feelings, staff should arrange mental health treatment to begin while the person’s medical needs are being dealt with. Emergency department staff should attend to self-inflicted injuries professionally and compassionately” (p.2).

“Having BPD should never be used as a reason to refuse health care to a person” (p.3).

“For all people with BPD, a tailored management plan should be developed in collaboration with them. The person’s family, partner or carer should be involved in developing the management plan, if this is in the person’s interests and they have given consent for others to be involved....

Health professionals should acknowledge and respect their [family/carers’] contribution. Health professionals should, with the person’s consent, involve families, partners and carers of people with BPD when developing a crisis plan. However, some people with BPD prefer not to involve others....Health professionals should help families, partners and carers of people with BPD by giving them clear, reliable information about BPD, arranging contact with any support services that are available (such as carer-led programs that educate families/carers on BPD and respite services) giving them information about how to deal with suicide attempts or self-harm behaviour, advising them about the most helpful ways to interact with the person with BPD, and offering referral to family counseling” (p.3).

The 2011 surveys reported that many of these above recommended practices and care options were not provided to people with BPD or their family/carers. Given that the national BPD guidelines were released almost 5 years ago, it is time to see how the situation has changed. In particular, we were interested in comparing survey results to answer the following broad questions:

- Has the level of discrimination towards people with BPD changed?
- Has transparency of the BPD diagnosis and education about what it means improved?
- Has medication use changed?
- Has GP support changed?
- Are there any changes across public and private hospital systems?
- Have there been any changes to urban and rural experiences?
- Has service responsiveness changed? (ED, mental health services, disciplines)
- Has the service response to self-harm changed?
- Has family/carers support changed?
- Has health professional responsiveness to family/carers changed?
- Has response to family/carers involvement changed?

Survey Method

The surveys were developed as online tools open to any Australian mental health consumer with a diagnosis of BPD, or any carer or family member of consumers with a diagnosis of BPD.

The survey instrument and questions were devised in the first instance by the Network Independent Chair, and then reviewed by consumer, carer and academic researcher stakeholders. Piloting the Australian BPD surveys was not undertaken.

Participation in the BPD consumer survey was open to any consumer who identified themselves as having a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to mental health service organisations and consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'SurveyMonkey' across Australia. The surveys were conducted between 1st June and 21st July 2017. Survey respondents were not a random sample from a population-based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey. Therefore, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

Statistical analysis

The data are presented predominantly as descriptive statistics. Univariate analysis was performed using either the "Survey Monkey" cross-tabulation function within the online survey or SPSS. Comparisons of survey proportions with known population percentages were compared using a one-sample test of proportions. Chi-square tests of association were performed in order to identify relationships between categorical variables. Fisher's exact tests were used for categorical variables with low or zero cell counts. Cramer's V effect size was also used to assess effect size. This statistic ranges from 0 to an upper limit of 1 where conventional criteria are 0.10 = small, 0.30 = medium, and 0.50 = strong. The statistic helps facilitate a meaningful interpretation of the strength of any relationship. Two sample test of proportions was used to compare findings from the 2011 and 2017 surveys to identify any significant changes to reported variables. The level of statistical significance was chosen as $p < 0.05$. Although a large number of hypotheses were tested, we did not adjust for the number of comparisons performed. Rather, we have left the p-values as they stand and interpreted the findings cautiously. The reader should be aware of this when reading the report. Confidence intervals for proportions are not presented since the results were not designed to estimate the views of the total Australian BPD population, but instead represent the views of those individuals with BPD and carers of individuals with BPD that responded to the surveys.

Results

Survey response rate

Four-hundred and twenty-four (424) consumers with BPD entered the survey site. Of these, 424 consumers (100%) proceeded to answer survey questions, with 69 consumers (16.27%) completing all questions, and 355 (83.73%) being selective in which questions they responded to. This represents a substantial increase (almost threefold) in overall respondents compared with the original survey in 2011, although a decrease in the proportion of people who answered all questions. In 2011, 153 consumers (95.0%) proceeded to answer survey questions, with 92 consumers (60.1%) completing all questions, and 61 (39.9%) being selective in which questions they responded to.

It is impossible to ascertain just how many consumers the survey was on-forwarded to. This precludes an estimate of the response rate, from a national sample, as well as obtaining details of who did not respond, ie age, geographic location etc.

Demographic Details

State and Territory Location

Of the 420 survey respondents, 420 indicated the state or territory in which they live. The distribution of the responses received from consumers in each state was similar to the distribution of the national population (Table 2). The slightly higher percentage of respondents from WA may reflect more effective network dissemination of the survey in this state or may simply reflect the large sampling variation due to the relatively small number of participants in this and other States.

Table 2: Response Rate by State or Territory (n=420)

Australian State / Territory	Total Population	Percentage of total population	Survey response count	Percentage of survey population	P-value for difference in proportions ^a
New South Wales	7 797 800	31.98%	101	24.05%	0.08
Victoria	6 244 200	25.61%	125	29.76%	0.28
Queensland	4 883 700	20.03%	59	14.05%	0.25
Western Australia	2 567 800	10.54%	33	7.86%	0.61
South Australia	1 717 000	7.04%	79	18.81%	<0.001
Tasmania	519 100	2.13%	9	2.14%	0.99
Australian Capital Territory	406 400	1.67%	14	3.33%	0.62
Northern Territory	245 000	1.00%	0	0.00%	NA ¹
Total	24 385 600	100	420	100	

Source of national population data: ABS (2017) 3101.0 - Australian Demographic Statistics, Dec 2016.

<http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0> ^aBased on a one-sample test of proportions. ¹Insufficient observations

Location Density

Of the respondents, 416 provided information on their area of residence. Almost two thirds of the respondents lived in Capital cities (64.18%, n=267), one-third (32.69%, n=136) living in regional towns and 3.13% (n=13) in remote towns in Australia. According to the ABS (2017), more than two thirds of Australians live in a Capital city and, between Censuses, the number of people living in capital cities grew nearly twice as fast as the number of people living outside of capital cities (10.5% and 5.7% respectively). Our survey results reflect the national population pattern.

Of the respondents who answered questions relating to characteristics of health service support, no significant association was observed between consumers' location and mental health support services (see Table 3):

Table 3: Association between consumer geographical location and characteristics of health service support*

Mental health service support	2011					2017				
	Location		χ^2	p	effect size	Location		χ^2	p	effect size
	Metropolitan (n=69) N (%)	Regional (n=39) N (%)				Metropolitan (n=267) N (%)	Regional (n=149) N (%)			
Main mental health hospital use			6.02	0.014	0.25			2.29	0.131	0.087
Public	33 (56.9)	25 (43.1)				119 (60.4)	78 (39.6)			
Private	33 (80.5)	8 (19.5)				72 (69.2)	32 (30.8)			
GP support for BPD			5.82	0.055	0.24			0.853	0.653	0.052
Supported	37 (69.81)	16 (30.19)				104 (64.2)	58 (35.8)			
Neutral	8 (42.11)	11 (57.89)				49 (64.5)	27 (35.5)			
No support	24 (72.73)	9 (27.27)				45 (58.4)	32 (41.6)			
Frequency of longer GP consults			0.99	0.608	0.1			0.398	0.82	0.036
Always	16 (64)	9 (36)				44 (63.8)	25 (36.2)			
Sometimes	29 (69.05)	13 (30.95)				86 (61)	55 (39)			
Never	24 (58.54)	17 (41.46)				68 (64.8)	37 (35.2)			
Frequency of GP counselling			3.06	0.217	0.17			2.77	0.251	0.094
More than monthly	13 (61.90)	8 (38.10)				20 (66.7)	10 (33.3)			
Monthly or less	5 (100)	0 (0)				34 (54)	29 (46)			
Never	49 (61.25)	31 (38.75)				145 (65)	78 (35)			

While looked into the statistical association between participants' geographical location and duration of their BPD diagnosis, no significant difference was observed in the 2017 results. See Table 4 below:

Table 4: Location and Length of Diagnosis

Location	Duration of BPD			χ^2	P	Effect size
	< 1 year	1 - 5 years	> 5 years			
2011 (n=105)						
				6.3	0.043	0.24
Metropolitan	11 (16.42)	26 (38.81)	30 (44.78)			
Regional	11 (28.95)	19 (50)	8 (21.05)			
2017 (n=321)						
				0.84	0.651	0.05
Metropolitan	21 (10)	98 (46.4)	92 (43.6)			
Regional	10 (9.1)	57 (51.8)	43 (39.1)			

Gender

Of the respondents who recorded their gender (n=417) most were female (92.09%, n=384), and only 6.24% were males (n=26). Of note, with the addition of a third option in the 2017 survey, 7 respondents (1.68%) identified as ‘other’. These results do not reflect the national gender mix of 51% females and 49% males in the overall Australian population (p<0.001). Also, there is a lack of inclusion of sexual orientation, gender identity and intersex status in population research, generally. The Australian Human Rights Commission suggests that LGBTI individuals may account for up to 11% of the Australian population, suggesting that the voices of these populations are significantly underrepresented in the current survey.

The response rate may reflect the higher rates of BPD diagnosis given to females despite the prevalence being similar in the population, or that they were more willing to participate in the survey process. A US National Epidemiologic Survey to present nationally representative findings on prevalence, socio-demographic correlates, disability, and comorbidity of borderline personality disorder (BPD) among men and women found no difference in the rates of BPD between males and females (Grant, et al., 2008). This suggests that future surveys need to be conducted using random selection processes and also weighted to the BPD male/female population. These results are similar to the 2011 survey.

Age

Almost one half of respondents who provided their age (n=420) were in the 25-39 years age group (43.33%, n=182) compared with the 2011 survey (32.7% - n=49). Another one fifth (18.81%, n=79) were in the 40-49 years age group and one fifth were in the 50-64 years age group (18.10%, n=76) compared with the 2011 survey (31.3% - n=47 and 25.3% - n=38, respectively). Smaller figures were reported in the younger age groups with those in the 18-24 years age group at 16.90% (n=71), under 18 years at 0.24% (n=1), and over 65 years at 2.62% (n=11) compared with the 2011 survey (8.7%, n=13; 1.3%, n=2 and 0.7%, n=1, respectively). This suggests that BPD continues to be prevalent across the prime working decades from 25-65 years. Also, a greater proportion of young adults appear to have participated in the 2017 survey compared to the 2011 survey. This may be due to greater awareness or provision of a BPD diagnosis more recently, or merely because of nuances in those age groups reached by the promotion of the survey and their participation rate.

Marital status

Of the 419 respondents that provided information on marital status, almost half were single (42%, n=176 and almost half were in a spouse/partner relationship. This was similar to the 2011 survey (45.9%, n=68 and 39.2%, n=58 respectively). A smaller number were separated or divorced (14.08%, n=59) and this was also

similar to the 2011 survey (13.5%, n=20), with 0.95% (n=4) widowed (1.4%, n=2, 2011). Given the age of respondents and the national figures for marital status within the same age groups (Hayes et al., 2011), this suggests that people with BPD may be more likely to be single compared to their age-matched counterparts in the general population. However, it also shows that almost half are in relationships where their spouse/partner may be impacted by their BPD.

Children

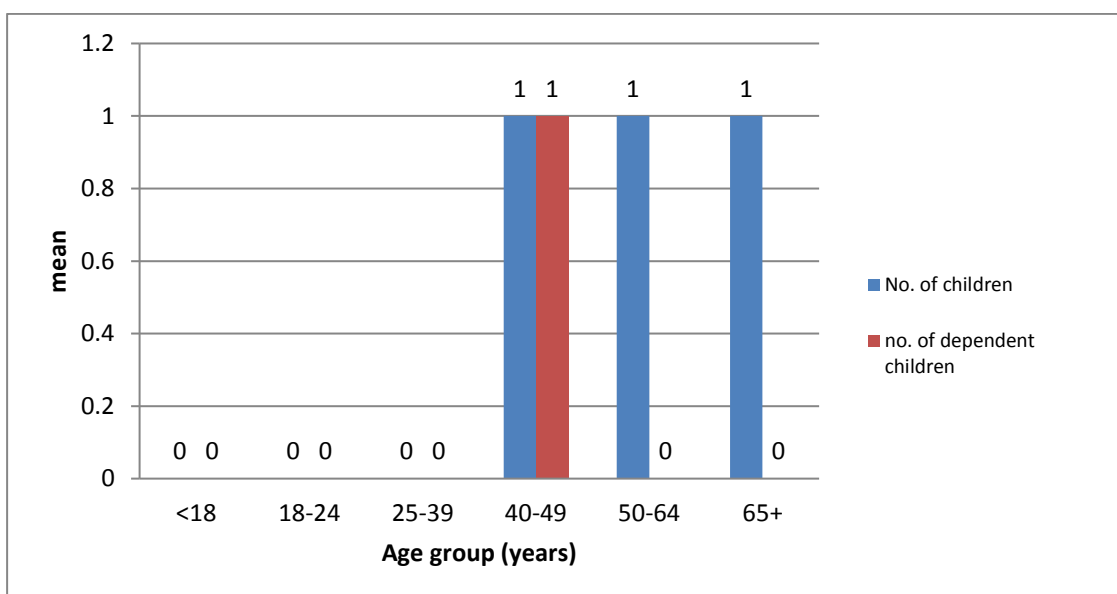
More than half of the 418 respondents who provided information did not have children (58.61%, n=245) compared with the 2011 survey (48.6%, n=71). Of those respondents with children, 35.41% (n=148) had one, two or three children, compared with 42.7% (n=62) for the 2011 survey, and 5.98% (n=25) had 4 children or more children (8.9%, n=13, 2011). Further statistical analysis showed that there was a significant association between the reported number of children for consumers with BPD and their relationship status according to whether they were married/partnered or single ($p=0.003$). This was similar to the 2011 survey. Consumers with none or one child were more likely to be single, and those with 2 children or more were more likely to be partnered. There was also significant association between relationship status and whether the consumer had dependent children or not. Single consumers were more likely to have no dependent children ($p=0.01$) (Table 5 and Figure 1).

Table 5: Association between relationship status of consumers with BPD, number of children, and dependent children*

	Relationship status 2011 (n=146)		χ^2	P	Effect size	Relationship status 2017 (n=416)		χ^2	P	Effect size
	Single	Spouse/ partner				Single	Spouse/ partner			
No. of children			22.02	<0.001	0.39			16.07	0.003	0.19
0	53(75.71)	17(24.29)				155 (63.5)	89 (36.5)			
1	14(73.68)	5(26.32)				30 (69.8)	13 (30.2)			
2	9(37.50)	15(62.50)				20 (35.7)	36 (64.3)			
3	9(50)	9(50)				20 (40.8)	29 (59.2)			
4 or more	3(23.08)	10(76.92)				13 (52)	12 (48)			
Dependent children			2.43	0.119	0.13			6.49	0.011	0.13
No	70(63.64)	40(36.36)				181 (61.1)	115 (38.9)			
Yes	16(48.48)	17(51.52)				57 (47.5)	63 (52.5)			

*Data are presented as number (percentage)

Figure 1: Mean number of children by age group for consumers having a diagnosis of borderline personality disorder (n=417)



Aboriginal or Torres Strait Islander Descent

Of the 417 respondents that provided information on this question, 3.84% (n=16) were of Aboriginal or Torres Strait Islander descent, compared with 5% (n=7) for the 2011 survey. This ratio continued to reflect the approximate proportion of this population within the overall Australian population (2.8 per cent of the population counted in the 2016 Census). The number of responses obtained from Aboriginal consumers was again too few to undertake specific analysis for this population.

Country of Birth, Years in Australia, and Language Spoken at Home

Of the 49 respondents born outside of Australia that provided information on this section, they came from a range of countries including: 16 from the UK, 12 from New Zealand, 4 from the Pacific Islands, 3 from Germany, 2 from Singapore, and one from each of the following countries: Brunei, Chile, Canada, Germany, Hong Kong, India, Japan, Malaysia, Malta, Poland, South Africa, and USA.

Most of the respondents had been in Australia for 20 years or more, with 6 in Australia for less than 10 years. Only 7 respondents spoke a language other than English at home (n=4 in the 2011 survey).

This diversity is similar to the 2011 survey with most non-Australian-born respondents being from the UK and NZ and fewer from PNG, China, Cyprus, Vietnam, the Netherlands, South Africa, Tanzania and Sri Lanka. Although the number of respondents to this question was small, the variety of the responses obtained suggests that the survey did capture the views of people from diverse cultural backgrounds but that experiences of individual non-English speaking sub-populations was not possible due to small samples.

Mental Health Diagnoses

Of the 382 respondents that provided information on primary mental health diagnosis, 291 (76.18%) reported BPD was their primary diagnosis. The following table (Table 6) displays the respondents' primary diagnoses and other diagnoses. 'Other' was included as an option, and 161 respondents provided further answers, many indicating two or more other diagnoses. Of note, 5 respondents noted 'complex PTSD' as their primary diagnosis.

In the 2011 survey, 30 respondents skipped the question about primary diagnosis which may have indicated that they did not wish to respond, did not know their primary diagnosis or could not determine it due to having multiple comorbid conditions. Fewer respondents skipped this question in the 2017 survey (n=42). A similar proportion of 2017 survey respondents reported BPD as their primary diagnosis (n=291, 76.18%) compared with the 2011 survey (n=80, 75.47%) and thus didn't show any significant difference. However, a greater diversity of primary diagnoses was reported in 2017.

Several other diagnoses were reported once, and these included: schizophrenia, chronic fatigue, psychosis, dissociation, conversion disorder, dermatilomania, complicated grief, adjustment disorder, premenstrual dysphoria, cyclothymic disorder, acute adjustment disorder, Aspergers, and sensory processing disorder. Since respondents could tick more than one diagnosis when reporting 'other' diagnoses, this made further statistical analysis difficult. Of note, the results suggest that many people had multi-morbid mental health diagnoses. Also, a greater diversity of other diagnoses was also reported in the 2017 survey. It is difficult to determine whether this is due to more accurate diagnostic practices by health professionals, some reluctance to make a BPD diagnosis, greater uncertainty in identifying a clear diagnosis, or some other reason.

Table 6: Patterns of Primary diagnosis and Other Mental Health Diagnoses

Primary Diagnosis (n=382)	Count (%)	Other Diagnoses (n=318)	Count
Borderline Personality Disorder	291 (76.18%)	Anxiety Disorder	222
Bipolar Disorder	30 (7.85%)	Post-Traumatic Stress Disorder	144
Post-Traumatic Stress Disorder	28 (7.33%)	Depression	108
Anxiety Disorder	27 (7.07%)	Eating Disorder	74
Depression	22 (5.76%)	Obsessive Compulsive Disorder	54
Schizo-Affective Disorder	6 (1.57%)	Bipolar Disorder	48
Dissociative Identity Disorder	6 (1.57%)	Dysthymia	5
Obsessive Compulsive Disorder	4 (1.05%)	Alcoholism/substance Dependence	4
	2 (0.52%)	Schizo-Affective Disorder	3
Autism	2 (0.52%)	Panic Disorder	2
Postnatal Depression	1 (0.26%)	ADHD	2
	420 (100%)	Other	15
		Total	681

Medication

Of the respondents, 345 selected from which medication option applied to them and 65 respondents provided information in 'other', giving a total of 410 responses to them question. The majority of the respondents who reported on their medication use from the options provided said they were taking anti-depressants for their mental health issues (66.09%, n=228) which was similar to 2011 survey results (68.9%, n=84). Fewer respondents were taking an anti-psychotic medication (35.94%, n=124) compared with 2011 respondents (41.8%, n=51). Similar rates of anti-anxiety medication were used (25.80%, n=89 for 2017; and 28.7%, n=35 for 2011). A greater number of 2017 respondents reported taking no medication (24.06%, n=83) compared with 2011 respondents (17.2%, n=21), and slightly fewer 2017 respondents did not know what medication type they were taking (0.86%, n=3) compared with 2011 respondents (1.6%, n=2). Overall, concerns for reliability of the responses is an issue given that some respondents may describe and understand their medication to a mood stabilizer, for example, when it is actually an anti-psychotic medication.

Of the 65 respondents who selected 'other', 36 stated 'mood stabilizer' with a small number of these naming a brand, 5 named an anti-depressant brand, 4 named an anti-psychotic brand, 3 named a benzodiazepine, and 17 named other types of medications (melatonin, dexamphetamine, 'beta blockers', 'Prazosin for nightmares', St John's Wort, 'sleeping aides such as Clonidine', 'opiate antagonist', 'sleeping tablets', 'non-stimulant ADD strattera', 'frankensence resin, lavender oil, etc', 'estrogen/progesterone medication', and 'medications to treat nightmares, flashbacks, and disassociation').

A further question asked respondents to name their medication if they were unsure what they were for, with 36 responses given. Similar to the 2011 survey, most of these 2017 respondents were taking a combination of anti-psychotic medications, mood stabilizers and anti-depressants.

Time since BPD Diagnosis

The largest group across both survey time periods were people who had been diagnosed with BPD within the past 1-5 years (see Table 7). Of note, a significantly greater proportion of the overall respondents within the 2017 survey had been diagnosed with BPD within the past year (n=67, 20.62%) compared with the 2011 survey (n=6, 5.7%) (p=0.001). This could reflect a change in practice with more people receiving a diagnosis earlier in their contact with mental health professionals.

Table 7: Comparing Length of Time since Diagnosis of BPD 2011-2017

Years since first diagnosed with BPD	Respondent Count (%) 2011 (n=105)	Respondent Count (%) 2017 (n=325)
0 – 1 year	6 (5.7%)	67 (20.62%)
1 – 5 years	44 (41.9%)	113 (34.77%)
6 – 10 years	28 (26.7%)	66 (20.31%)
11 – 15 years	12 (11.4%)	37 (11.38%)
16 – 20 years	11 (10.5%)	23 (7.08%)

21 – 25 years	2 (1.9%)	9 (2.77%)
26+	2 (1.9%)	6 (1.84%)
Don't know		4 (1.23%)
	105 (100%)	325 (100%)

Of the 351 respondents who indicated length of time in treatment, 29.63% (n=104) had been in treatment for less than a year, compared with the 2011 survey results (20.2%, n=22) with no significant difference (See Table 7). Similarly, there was also no significant difference between those who are in treatment for more than 9 years. The time since diagnosis is unlikely to be an accurate reflection of actual length of time that the person has experienced BPD. Changes in systems of care and greater recognition and acknowledgement of BPD as a serious mental illness within the responsibility of mental health services to treat, may mean that many of these respondents have only been told their diagnosis more recently; hence, further analysis was undertaken.

Table 8: Time in Treatment for BPD

Time in Treatment for BPD	Respondent Count (%) 2011 (n=105)	Respondent Count (%) 2017 (n=351)
Less than 1 year	22 (20.2%)	104 (29.63%)
1 – 3 years	29 (26.6%)	79 (22.51%)
3+ – 5 years	30 (27.6%)	44 (12.54%)
5+ – 7 years		43 (12.25%)
7+ – 9 years		22 (6.27%)
More than 9 years	29 (26.6%)	61 (17.38%)
	105 (100%)	351 (100%)

Comparing time in treatment with time since first BPD diagnosis, these figures suggest that many people in the 2017 have similar experience to those who completed the 2011 survey; that is, may have been in treatment for longer than the reported time since their diagnosis. This would confirm the hypothesis that people have not always been told their diagnosis of BPD at the time they started receiving treatment for their condition. It may also reflect that their diagnosis was unclear initially. The 2017 survey results across these variables suggest that a greater proportion of people receiving treatment are being told their BPD diagnosis earlier.

In univariate analysis, a significant association between duration of BPD and whether or not the participant had received an adequate explanation of the disorder from a medical professional, was observed (p=0.003). Similar to 2011 survey, a greater number of participants reporting to have not received adequate explanation of their illness, had duration of BPD greater than 5 years (56.6%) compared to those with a

diagnosis, either 1 to 5 years (35.8%) ago, and less than one year (7.5%) ago (Table 9).

Table 9: Explanation of BPD by Medical Professional

Adequate explanation of BPD by medical professional	Time since BPD diagnosis			χ^2	P	Effect size
	< 1 year	1 - 5 years	> 5 years			
2011 (n=106)						
				9.54	0.049	0.21
No	11 (27.5)	11 (27.5)	18 (45)			
Yes	7 (14.89)	28 (59.57)	12 (25.53)			
Yes, but didn't understand	4 (21.05)	7 (36.84)	8 (42.11)			
2017 (n=321)						
				15.7	0.003	0.16
No	8 (7.5)	38 (35.8)	60 (56.6)			
Yes	16 (9.7)	95 (57.6)	54 (32.7)			
Yes, but didn't understand	5 (10)	22 (44)	23 (46)			

*Data are presented as number (percentage)

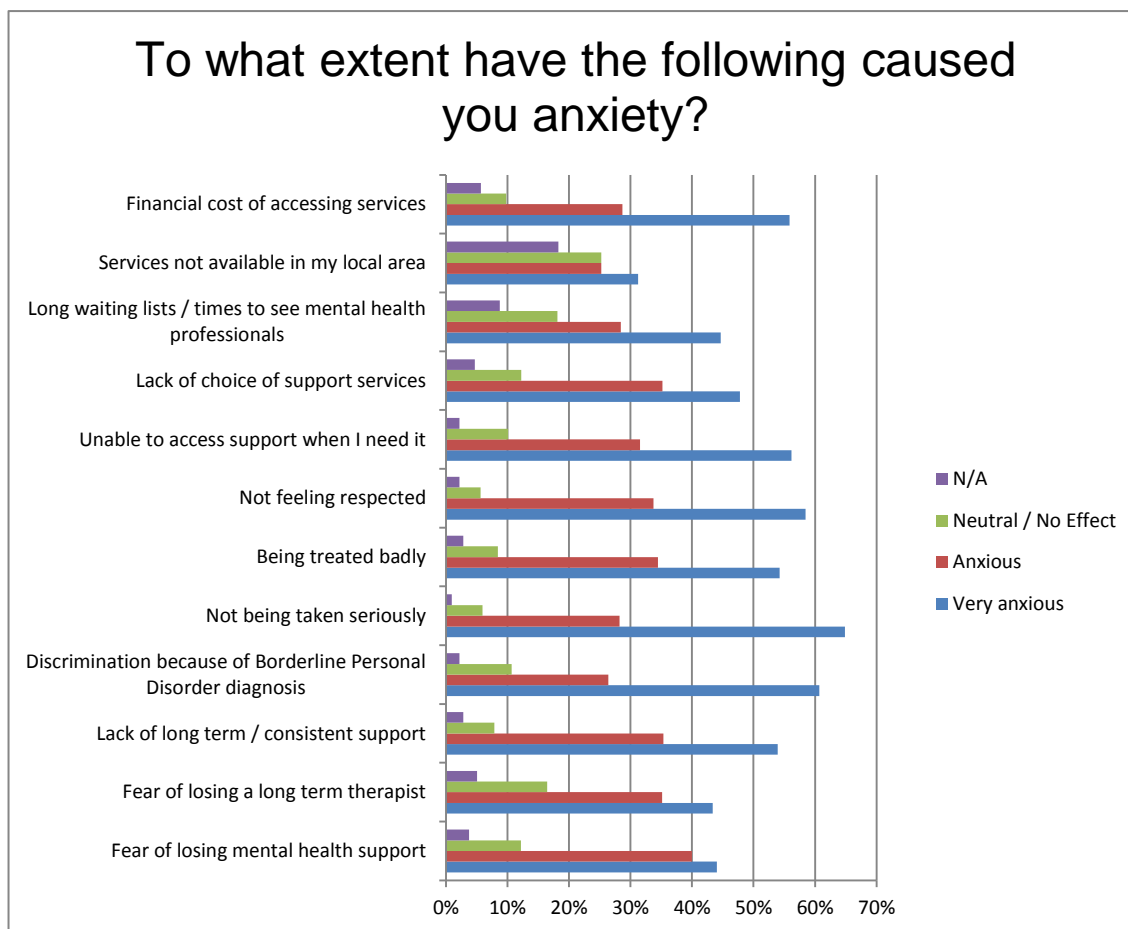
For the majority of respondents (n=355) who responded to the question about who diagnosed their BPD, 72.68% (n=258) said this was a psychiatrist. This is similar to the 2011 survey (76.9%, n=90). A greater proportion of people received their BPD diagnosis from a psychologist (17.46%, n=62) suggesting that more people are using these service providers as their primary treatment provider compared with 2011 survey respondents (10.3%, n=12) but didn't show any significant difference. Very few 2017 survey respondents reported a GP making this diagnosis (5.35%, n=19), and this was similar in 2011 (5.1% - n=6). Twelve of the 2017 survey respondents (3.38%) did not know who made the diagnosis. Fourteen respondents named 'other' health professionals in this role; these included ED doctor, mental health service provider visiting them in hospital, case manager, DBT counsellor, Spectrum clinician. In the 2011 survey, most respondents reported the diagnosis was made by a crisis mental health team.

Of concern, it does not appear that rates have improved for whether or not a health professional explained their diagnosis to them. In 2011, 37.8% (n=45) said that no healthcare professional had explained to them what BPD means, and 19.3% (n=23) said it had been explained but that they had not understood the explanation. In 2017, only minor improvement in this process was apparent, with 34.63% (n=125) reporting that no explanation had been given, and 14.48% (n=53) reporting that it had been given but they didn't understand it. That is, for both survey periods, more than half did not receive an explanation, or did not understand their diagnosis from the explanation given to them.

The Journey of Receiving Support for BPD

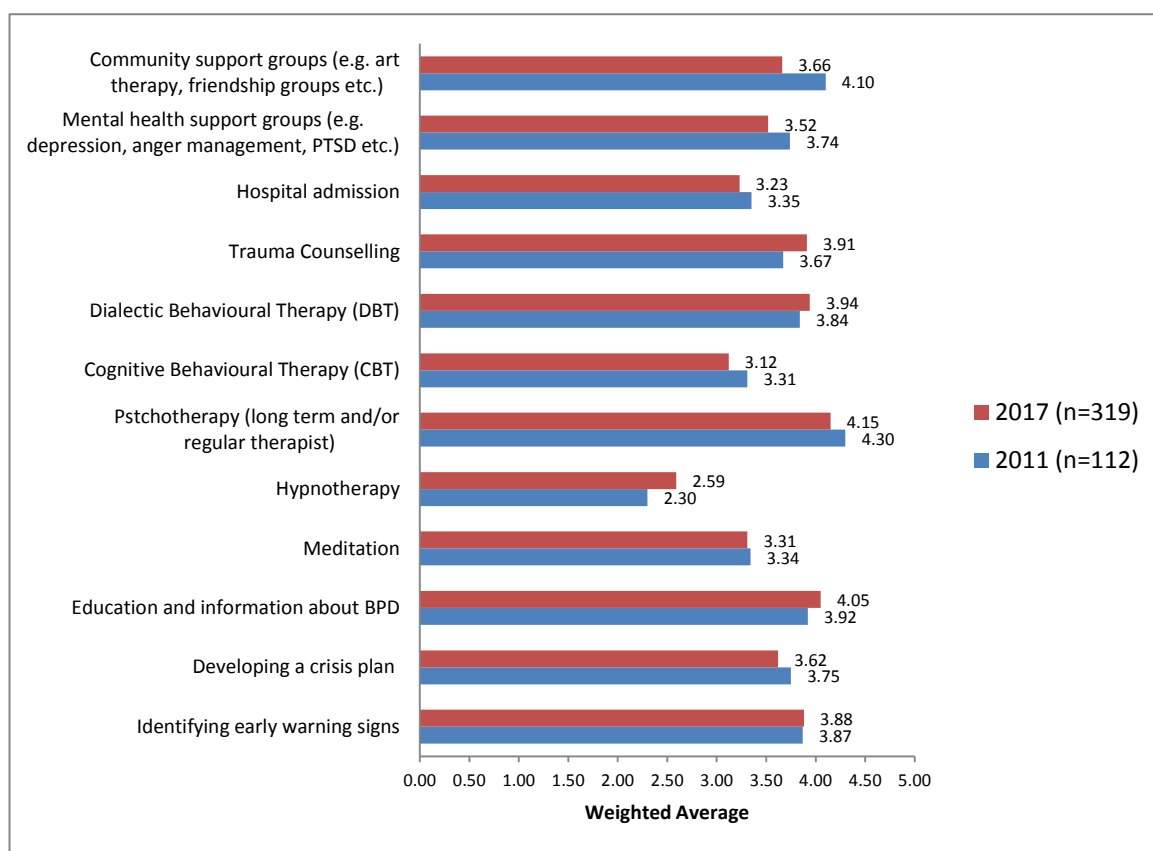
Of the 112 survey respondents who reported their experience of BPD services, it appeared that there were multiple issues that cause them distress, and these were related directly to their attempts to seek help from services. These are displayed in the following figure (Figure 2). In the 2011 survey, the two most highly rated concerns that caused high levels of anxiety were discrimination because of their BPD diagnosis (57.1%, n=64) and not being taken seriously (70.5%, n=79). Unfortunately, these 2 issues continued to rate the highest in the 2017 survey, with high levels of anxiety due to not being taken seriously (64.89%, n=207) and discrimination because of their BPD diagnosis (60.69%, n= 193). Not being respected was the third most important concern that caused high anxiety in 2011 (53.6%, n=60) and again in 2017 (58.44%, n=187). In the 2017 survey, being unable to access support when they needed it (56.15%, n=178) replaced fears around consistency of support (52.2% - n=59) as the fourth highest concern. Across both time points, respondents were less concerned about services not being available in their local area (2011: 33%, n =37; and 2017: 31.23%, n=99). Anxiety due to the long waiting lists/times to see mental health professionals appeared to have increased (2017: 44.69%, n=143; and 2011: 36%, n=41). These findings reflect the continuing high anxiety related to needs that people with BPD have for security, stability, consistency of support that have not changed since 2011. Twenty-five participants provided further information in response to 'other' issues that caused anxiety. They cited cost, waiting lists due to NDIS, changes to private health cover, lack of understand by health professionals, and fear of police involvement when acutely unwell, among other issues.

Figure 2: What Causes Anxiety for Consumers with BPD? (n=112)



Of the 319 consumers who responded to the range of services on offer (rated across a scale of very unhelpful to very helpful), psychotherapy was reported to be the most helpful in 2011 (mean= 4.28 on a 0-5 scale) and continued to be so in 2017 (mean=4.15). Unlike 2011, where community support such as art therapy and friendship groups (mean=4.10) was rated as the second most helpful, in 2017, this was replaced by education and information about BPD (mean=4.05), and Dialectic Behaviour Therapy (DBT) was rated third most helpful in 2017, suggesting a small shift towards seeking more clinical understanding of BPD since 2011. Hypnotherapy rated as the least helpful across both time points (2011: mean=2.30, and 2017: 2.59) (Figure 3). Few respondents rated the range of services as either very unhelpful or unhelpful. That is, they were neutral as to the services they received.

Figure 3: What has Helped Consumers Manage their BPD



Qualitative questions about helpfulness of services and access to these services

Of the 32 respondents who answered further questions about service helpfulness, respondents mentioned personal strategies (studying, social relationships, exercise, internet information, choir), specific types of therapy (such as Acceptance and Commitment Therapy (ACT), Mindfulness, Mentalisation), and specific services (such as headspace, Health for Life Foundation, Facebook peer support groups).

Similar to 2011(52.4%, n=55), half of 2017 survey respondents (50.54%, n=159) said that they had not been able to access the services they required. The range of reasons for this varied, and were similar to 2011, with most noting problems with waiting lists, financial barriers, and services being too far away. Most responses

indicated a high motivation to seek either group or individual therapy support. Of particular note, 73 of the 145 respondents who provided further information said that they wanted to access community support groups but were unable to due to cost, availability, waitlists or being told that they were ineligible; most of these respondents noting DBT groups.

Of the 301 respondents who answered further questions about which services they feel had contributed most to their recovery, respondents variously reported psychologists, psychiatrists, GPs, medication and mental health groups. The most important component was that the support was consistent. This was similar to the 2011 survey.

Those aspects of services reported to be the most unhelpful to respondents (n=273) were similar to those reported in 2011 (as per the below dot points), except that respondents now also increasingly included long waiting lists, issues with private health cover, hospital admissions in addition to the following:

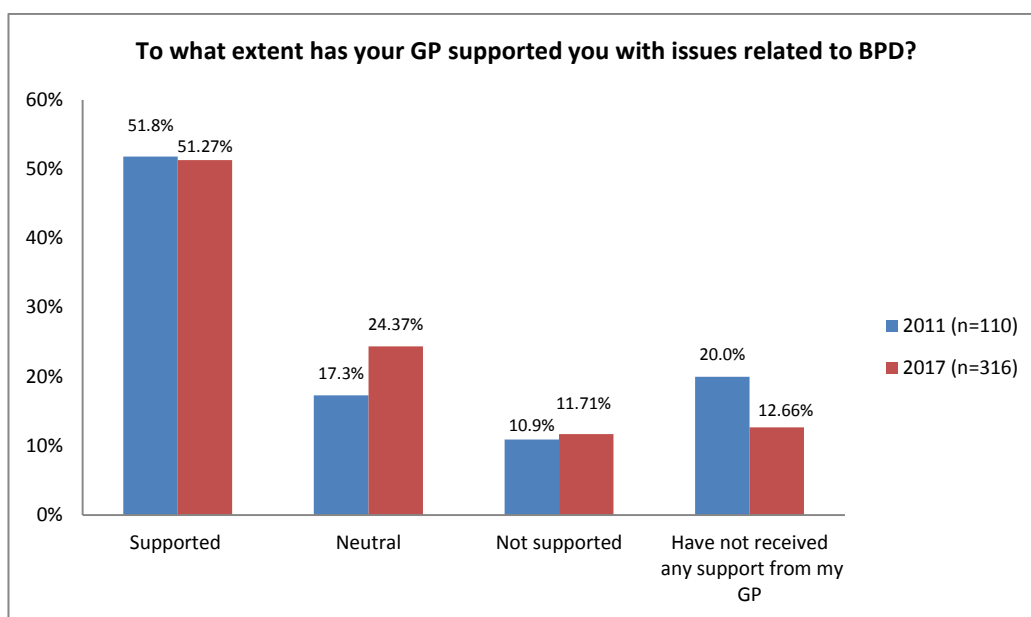
- Lack of access to services either because they were not available in their area or they were excluded from using them (medications, hospital admission, seeing health professional) when they needed them
- Non-affordability of services – cost of seeing private psychiatrist or psychologist, cost of medications
- Discrimination and not being taken seriously

Of the 293 respondents who answered questions about their hospital admissions, 45.39% (n=133) compared with 51% (n=52) in 2011 reported having had hospital admissions for their BPD within the last 18 months, and 18.43% (n=54) compared with 20.6% (n=21) of respondents in 2011 reported an admission in the past 3 months. Of the 97 respondents who made further comments about admission to hospital, many reported negative experiences of receiving care, though many also made more positive comments about support from therapy, from managed hospital stays, and from learning ways to manage their symptoms and distress levels. This was somewhat different to 2011 when the pervasive flavor of comments related to perceived lack of understanding, knowledge and skills demonstrated by the health professionals from whom they sought help.

The GP Role in Supporting People with BPD

Of the 316 people who responded to questions about GP support, 51.27% (n=162) said that their GP had supported them; this was very similar to 2011 results (50.5%, n=54); whereas 36.08% (n=114) of 2017 survey respondents, compared with 29% (n=31) in 2011, rated GP contact as neutral or not supportive. Of note, fewer 2017 survey respondents (12.66%, n=40), compared with 20.6% (n=22) of 2011 survey respondents, had not received any support from a GP (Figure 4). However, no significant difference was observed upon further statistical analysis. It appears that more people with BPD are in contact with a GP but the proportion of people that perceive GPs to be supportive has not changed.

Figure 4: GP Support



Likewise, the proportion of people who reported having longer appointments with their GP appears not to have changed; in 2017 less than a quarter of respondents (22.08%, n=70, compared with 22.9%, n=25 in 2011) reported always having longer appointments with their GP. In 2017, 44.48% (n=141) of respondents (compared with 39.4% (n=43) in 2011) reported sometimes having longer appointments, and 33.44% (n=106) of respondents (compared with 37.6% (n=41) in 2011) reported never having longer appointments with their GP. Few respondents received regular (weekly or fortnightly) personal counselling support from their GP (7.26%, n=23; compared with 13.9%, n=15 in 2011). Most respondents (70.66%, n=224) reported that their GP does not provide personal counselling; similar to 2011 results (75%, n=81). Of those who did report receiving counselling from their GP, 91 provided further details: 18.68% (n=17) had been receiving personal counselling for 5-10 years (compared with 25.9%, n=7 in 2011, no significant difference) and 27.47% (n=25) had been receiving this support for 2-5 years (compared with 22.2%, n=6 in 2011).

Many people with BPD had not received support for their mental health conditions from a GP. Instead, GPs appeared to have referred their patients with BPD to other mental health professionals. This referral pattern appears to have changed when comparing with 2011. In 2011, referrals were predominantly to a psychiatrist (64.2% - n=68), a psychologist (60.4% - n=64) or a mental health team (37.7% - n=40), with a much smaller number of referrals made to social workers, occupational therapists or other counselors; whereas, 2017 respondents reported that their GP was most likely to refer them to a psychologist (72.93% (n=229), followed by a psychiatrist (57.64%, n=181) or mental health team (35.67%, n=112). Of the 314 respondents to this question, 11.46% (n=36) reported that their GP did not refer them to any other mental health professionals; this was similar to 2011 (11.3%, n=12). Seventy-one respondents made further comments about their GP support and this covered a broad range of experiences, with as many positive comments as negative comments. Conversely, many of the 2011 respondents' comments emphasized negative experiences with GPs who either avoided noting BPD in documentation, didn't believe in it or didn't feel confident in treating it. This suggests that some GPs are now more positively engaged with people with BPD, though the overall experience continues to be mixed and inconsistent.

“Having a really understanding and caring GP has helped my recover”.

“So much worse than I expected and so difficult to find a GP willing to work with BPD”

The Role of Public Hospitals

Respondents were more variable in which questions they answered in this section of the survey, opting to answer some and not others in greater or lesser numbers.

Of the 315 2017 survey respondents who reported their usage of hospital services, rates were similar to 2011 results for public hospital only use. However, there appeared to be slightly fewer using only private hospitals, and a greater proportion using mostly public and some private hospitals but didn't show any significant difference (see Table 10).

Table 10: Use of Public and Private Hospitals

Hospital Usage by type	2011 survey	2017 survey
Only use public mental health hospital services	39.3% (n=42)	38.73% (n=122)
Only use private mental health hospital services	16.8% (n=18)	12.70% (n=40)
Use mostly public mental health hospital services and some private	15.9% (n=17)	24.13% (n=76)
Use mostly private mental health hospital services and some public	21.8% (n=23)	20.63% (n=65)
Don't know	6.5% (n=7)	3.81% (n=12)

Of the 210 people who responded to the question about ever having been admitted to a public hospital because of issues related to their BPD, 74% (n=157), compared with 80.6% (n=54) in 2011) said 'yes' and 25.24% (n=53, compared with 19.4% (n=13) in 2011) said 'no'.

Of the 156 who responded to the question about the frequency of public hospital admissions, 44.23% (n=69) reported that they had been admitted five or more times for issues related to their BPD diagnosis. This was much less than the 2011 survey results (57.4% n=31) but didn't show any significant difference (p=0.06).

Responses from 143 people about the actual number of admissions to a public hospital in the past three years, and comparison with responses from 54 people in 2011, suggests that the proportion of people who had no admissions was similar across the period and that the proportion of people with multiple admission of 10 or more has reduced. In the 2017 survey, the median was 1-5 admissions, and the range was 0-40 admissions, compared with 2011 when the median was 0 admissions, and the range was 0-50 admissions. However, there was a significant difference between 2011 and 2017 admission numbers of 20 or more (11.11% vs 2.1%, p=0.001). See Table 11 for detail.

Table 11: Number of admissions to a Public Hospital in the last 3 years (2011-2017)

Frequency of Admissions	2011 Survey (n=54)	2017 Survey (n=143)
None	16 (29.63%)	40 (27.97%)
1-5	26 (48.15%)	77 (53.85%)
6-9	2 (3.70%)	15 (10.49%)
10-19	5 (9.26%)	7 (4.89%)
20 or more	6 (11.11%)	3 (2.10%)
Total actual number of admissions	391 (ratio 1:7.24)	476 (ratio 1:3.33)

In 2011, fifty-three respondents reported that their longest stay in a public hospital for issues directly related to BPD ranged from 24 hours to 7 months. This level of inconsistency was also apparent from the 2017 survey (24 hours to 9 months), though most (n=138) of the 143 respondents reported their longest stay was between 24 hours and 3 months.

Respondents' longest stay in a public hospital for mental health issues generally (as distinct from BPD) also varied between the two survey periods, suggesting that public hospital treatment for persons with BPD continues to be highly variable and that treatment for comorbid diagnoses for this population also continues to vary widely. Of note, it appears that a greater proportion of respondents now experience shorter admissions (see Table 12).

Table 12: Longest Stay in a Public Hospital for Mental Health Issues (2011-2017)

Admission time periods	2011 Survey (n=51)	2017 Survey (n=151)
1 week or less	10 (22.7%)	55 (36.42%)
2 weeks	11 (20.8%)	29 (19.21%)
3 or more weeks	30 (56.5%)	67 (44.37%)

Of the 156 respondents who answered further questions about their public hospital admission experiences, 57.69% (n=90) had been admitted to hospital involuntarily; whereas, almost two thirds (66%, n=35) had been admitted to hospital involuntarily in 2011. Approximately half of respondents (49.03% (n=76) reported that they had asked to be admitted to a public hospital because of mental health issues but been refused. This contrasted with a greater number being refused according to 2011 survey responses (57.4% n=31) but with no significant difference. Interestingly, 37.88% (n=25) of 2017 survey respondents, compared with 32% of 2011 survey respondents, did not know who refused their admission to a public hospital, and 15.15% (n=10), compared with 24% in 2011, said that a psychiatrist refused their admission.

Sixty-six respondents who were refused hospital admission provided further comments about the perceived reasons why they were refused hospital admission. The most common reasons given were that there was a shortage of beds, hospital would be unhelpful, and their condition was not severe enough. This was similar to responses provided in the 2011 survey. This suggests that people with BPD continue to experience inconsistency and discrimination in the process of seeking admission to hospital.

For respondents who answered further questions about their experience of seeking hospital admission, their reasons for this appeared to be similar across the two survey periods, and significantly related to feeling in crisis (feeling suicidal, feelings of self-harm, feeling unsafe). Table 13 provides further detail. Of note, the importance of feelings of self-harm and drug/alcohol problems appeared to be less in the 2017 survey compared with 2011 results.

Table 13: Importance of Issues when Seeking Hospital Admission – Public Hospitals (2011-2017)

Reason for seeking hospital admission	Year	Very important	Important	Not important	Not applicable	Response Count
Feeling suicidal	2011	93.1% (27)	6.9% (2)	0.0% (0)	0.0% (0)	29
	2017	93.42% (71)	5.26% (4)	1.32% (1)	0.0% (0)	76
Feelings of self-harm	2011	92.9% (26)	7.1% (2)	0.0% (0)	0.0% (0)	28
	2017	69.33% (52)	17.33% (13)	10.67% (8)	2.67% (2)	75
Feeling unsafe	2011	89.3% (25)	10.7% (3)	0.0% (0)	0.0% (0)	28
	2017	70.67% (53)	25.33% (19)	4.00% (3)	0.00% (0)	75
Life in chaos	2011	63.0% (17)	33.3% (9)	3.7% (1)	0.0% (0)	27
	2017	63.16% (48)	22.37% (17)	9.21% (7)	5.26% (4)	76
Depression	2011	69.2% (18)	19.2% (5)	11.5% (3)	0.0% (0)	26
	2017	69.74% (53)	23.68% (18)	6.58% (5)	0.0% (0)	76
Anxiety	2011	59.3% (16)	25.9% (7)	11.1% (3)	3.7% (1)	27
	2017	48.00% (36)	32.00% (24)	17.33% (13)	2.67% (2)	75
Drug / Alcohol problems	2011	38.5% (10)	15.4% (4)	15.4% (4)	30.8% (8)	26
	2017	16.67% (12)	11.11% (8)	22.22% (16)	50.00% (36)	72

Respondents across both survey periods reported high levels of distress at being refused admission to hospital, as the following Table 14 shows. Ten 2017 survey respondents provided further comments, stating that hospital refusal made them feel ‘ashamed’, ‘helpless’, ‘scared’, ‘hopeless’, ‘trapped’, ‘guilty’ and ‘disbelieving’. Combined with the Likert-rated results in the below table, these comments appear to reflect a potential shift in attitudes of people with BPD; fewer appeared to report types of distress that could be considered as ‘acting out’. Of concern, it might mean that a small but increased proportion of people with BPD were now more likely to internalize these negative feelings.

Table 14: Levels of Distress after being Refused Public Hospital Admission (2011-2017)

Type of Distress	Year	Had a significant impact	Had some impact	Did not impact	Not applicable	Response Count
Anxious	2011	81.5% (22)	14.8% (4)	3.7% (1)	0.0% (0)	27
	2017	78.38% (58)	17.57% (13)	2.70% (2)	1.35% (1)	74
Angry	2011	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
	2017	54.05% (40)	35.14% (26)	9.46% (7)	1.35% (1)	74
Frustrated	2011	89.7% (26)	3.4% (1)	6.9% (2)	0.0% (0)	29
	2017	74.32% (55)	20.27% (15)	2.70% (2)	2.70% (2)	74
Depressed	2011	82.8% (24)	13.8% (4)	3.4% (1)	0.0% (0)	29
	2017	66.22% (49)	27.03% (20)	5.41% (4)	1.35% (1)	74
Suicidal	2011	82.1% (23)	10.7% (3)	3.6% (1)	3.6% (1)	28
	2017	72.60% (53)	20.55% (15)	5.48% (4)	1.37% (1)	73
Relieved	2011	8.3% (2)	8.3% (2)	20.8% (5)	62.5% (15)	24
	2017	5.48% (4)	12.33% (9)	41.10% (30)	41.10% (30)	73
Alone / isolated	2011	89.3% (25)	10.7% (3)	0.0% (0)	0.0% (0)	28
	2017	77.03% (57)	18.92% (14)	0.00% (0)	4.05% (3)	74

The Role of Private Hospitals and their Comparison to Public Hospitals

Of the 72 2011 survey respondents to answer questions about private hospitals, 63.9% (n=46) had been for issues related to their BPD diagnosis. This is significantly in contrast to the 178 2017 survey respondents, with less than half (48.88%, n=87, p=0.03) being admitted for issues related to BPD.

Of note, only 18.40% (n=30) compared with 45.5% (n=20) in 2011 had been admitted five or more times to a private hospital for issues related to their BPD, which was significantly different (p<0.001). It appears that more people are seeing admission to public hospitals for their BPD (74%, n=157 in 2017 compared to 57.4%, n=31 in 2011), as reported previously. Again, the results of 2011 and 2017 surveys were significantly different (p=0.01).

Responses across both survey periods about the number of admission to private hospital in the past three years indicated that there were fewer admissions to private hospitals in 2017. In 2011 and in 2017, the median was 0 admissions, and the range was 0-15 admissions. The total number of admissions to private hospitals in 2011, over the three years, was 233 admissions, compared with 391 for public hospitals. In 2017, this was 332

admissions, compared with 476 for public hospitals (see Table 15).

Table 15: Number of Admissions to a Private Hospital in the last 3 years (2011-2017)

Frequency of Admissions	2011 Survey (n=56)	2017 Survey (n=113)
None	17 (30.36%)	43 (38.05%)
1-5	29 (51.78%)	48 (42.48%)
6-9	5 (8.93%)	13 (11.50%)
10-19	5 (8.93%)	9 (7.96%)
20 or more	0	0
Total actual number of admissions	233 (ratio 1:4.16)	332 (ratio 1:2.94)

In 2011, respondents reported that their longest stay in a private hospital for issues directly related to BPD ranged from 24 hours to 12 months, compared with 24 hours to 7 months for those in public hospitals. In 2017, this ranged from 24 hours to 4 months compared with 24 hours to 9 months for those admitted to public hospitals, though, for most, their longest stay was up to 3 months, as reported previously. Overall, it appears that, compared with public hospitals, fewer people with BPD are now being admitted to private hospitals and, once there, they are having shorter admissions, generally. Conversely, more people with BPD appear to be admitted to the public hospital system.

In 2011, comparison of responses about their longest stay in hospital did not show any significant differences, with 56.6% (n=30 from sample of 53) of public hospital users stating three weeks or more compared with 66.1% (n=41 from a sample of 61) of private hospital users (p=0.24). In 2017, this comparison did show significant differences, with 36.36% (n=52 from a sample of 143) of public hospital users stating that their longest hospital stay in the past three years was three weeks or more, compared with 55.56% (n=60 from a sample of 108) of private hospital users (p=0.004).

When asked about their longest stay in a private hospital for mental health issues (as distinct from BPD), responses varied between the two survey periods, suggesting that private hospital treatment for persons with BPD also continues to be highly variable and that treatment for comorbid diagnoses for this population also continues to vary widely in this setting. Of note, it appears that a greater proportion of respondents now also experience shorter admissions to private hospitals (see Table 16).

Table 16: Longest Stay in a Public Hospital for Mental Health Issues (2011-2017)

Admission time periods	Public Hospital Users		Private Hospital Users	
	2011 Survey (n=51)	2017 Survey (n=151)	2011 Survey (n=54)	2017 Survey (n= 108)
1 week or less	10 (22.7%)	55 (36.42%)	5 (9.26%)	23 (21.30%)
2 weeks	11 (20.8%)	29 (19.21%)	9 (16.67%)	14 (12.96%)
3 or more weeks	30 (56.5%)	67 (44.37%)	40 (74.07%)	71 (65.74%)

Of the 57 respondents in the 2017 survey who reported that they had been refused admission to a private hospital, psychiatrists were those most likely to have refused this request (28.07%, n=16). This compares to 40.7% being psychiatrists (n=11), as reported in the 2011 survey with a borderline significant difference (p=0.053). Of concern, 43.86% (n=25) of respondents in the 2017 survey did not know who refused their admission to a private hospital, compared with 18.5% (n=5) in 2011, which was significantly higher (p<0.001). These results showed much greater change from 2011 to 2017 than results related to public hospital use, as already reported.

While compared the data between public and private hospital admissions for 2017, there was a significant difference between those who said psychiatrists refused their admissions (15.15% vs 28.07%, p=0.02). Also, a non-significant but higher trend was observed among the private hospital users who didn't know who refused their admissions (37.88% vs 43.86%, p=0.38).

Interestingly, 37.88% (n=25) of 2017 survey respondents, compared with 32% of 2011 survey respondents, did not know who refused their admission to a public hospital, and 15.15% (n=10), compared with 24% in 2011, said that a psychiatrist refused their admission. However, neither of these results showed any significant difference. Since only 26 people responded to this question in relation to private hospital experience, there is insufficient power to determine if these observed differences were likely to be real or simply due to sampling variation.

Sixty-nine of the 2017 survey respondents gave reasons for why they were refused admission into private hospitals. None mentioned shortage of beds as a reason; several said that they were told their condition wasn't serious enough, that they were not thought to be 'at risk', or that they wouldn't benefit from an admission. One respondent said their psychiatrist thought they were 'manipulative and a liar', and another respondent said that they weren't refused, but that they were 'kicked out of the private hospital and sent to the public hospital for self-harm'. These results are similar to the 2011 survey results.

Of 163 subjects that had been admitted to private hospitals, 18.4% (n=30) had been admitted five or more times, slightly lower than 2011 (28.6%, n=20, p=0.08). This was less than half the rate of 5 or more admissions amongst the 69 subjects (44.2%) with public hospital admissions (p<0.001) (Table 17). Likewise, the number of zero hospital admissions between public and private hospitals was significantly different (0.6% vs 47.2%, p<0.001). It is possible however that a large majority of subjects that chose not to respond to questions regarding hospital admissions did so because they had not had any BPD-related admissions.

Table 17: Comparison of Public and Private Hospital Admission Rates

Admission to hospital	2011			2017		
	Public Hospital (n=56) N (%)	Private Hospital (n=70) N (%)	Pub vs Pvt admission difference (p value)	Public Hospital (n=156) N (%)	Private Hospital (n=163) N (%)	Pub vs Pvt admission difference (p value)
Never	0 (0.0)	28 (40.0)	-40% (p<0.001)	1 (0.6)	77 (47.2)	-46.6% (p<0.001)
1 time	11 (20.8)	8 (11.4)	9.4% (p=0.053)	30 (19.2)	21 (12.9)	6.3% (p=0.24)
2 times	4 (7.1)	8 (11.4)	-4.3% (p=0.32)	23 (14.7)	14 (8.6)	6.1% (p=0.19)
3 times	2 (3.7)	4 (5.7)	-2% (p=0.51)	17 (10.9)	11 (6.7)	4.2% (p=0.32)
4 times	6 (11.1)	2 (2.9)	8.2% (p=0.02)	16 (10.3)	10 (6.1)	4.2% (p=0.29)
5 or more times	31 (57.4)	20 (28.6)	28.8% (p<0.001)	69 (44.2)	30 (18.4)	25.8% (p<0.001)

As per public hospital users, private hospital users reported high importance of a full range of feelings about their mental health symptoms when seeking admission. In 2011, the responses of the two groups varied across the different domains of interest, with public patients rating ‘feeling suicidal’, ‘feelings of self-harming’ and ‘feeling unsafe’ noticeably higher than ‘life in chaos’, ‘depression’ and ‘anxiety’; whereas, private patients appeared to rate all six domains of interest with more similar importance. However, in the 2017, there was a clear change, with a much great proportion of public hospital users rating ‘feeling suicidal’ as of high important when seeking hospital admission (p<0.001) (see Table 18).

Table 18: Comparison of the Most Important Issues when Seeking Admission – Public and Private Hospital Users (2011-2017)

Most important Issues	2011 Survey			2017 survey		
	Private BPD Patients (n=53)	Public BPD Patients (n=29)	p-value for difference ¹	Private BPD Patients (n=127)	Public BPD Patients (n=76)	p-value for difference ¹
Feeling suicidal	83.0% (44)	93.1% (27)	0.20	73.23% (93)	93.42% (71)	<0.001
Feelings of self-harm	83.0% (44)	92.9% (26)	0.42	62.70% (79)	69.33% (52)	0.36
Feeling unsafe	77.4% (41)	89.3% (25)	0.33	66.67% (84)	70.76% (53)	0.59
Life in chaos	69.8% (37)	63.0% (17)	0.31	55.65% (69)	63.16% (48)	0.21
Depression	79.2% (42)	69.2% (18)	0.09	67.46% (85)	69.74% (53)	0.68
Anxiety	66.7% (34)	59.3% (16)	0.43	50.00% (63)	48.00% (36)	0.75
Drug/Alcohol problems	23.4% (11)	38.5% (10)	0.17	18.03% (22)	16.67% (12)	0.77

¹Two sample test of proportions

Also of note, when examining data across the two time periods, regardless of hospital type, ‘feelings of self-harm’ (p<0.001) and ‘feeling unsafe’ (p=0.02) were rated as highly important (see Table 19).

Table 19: Comparison of the Most Important Issues when Seeking Admission (2011-2017)

Most important issues	2011 BPD patients n=82 N (%)	2017 BPD patients n=203 N (%)	p-value for difference ¹
Feeling suicidal	71 (86.58)	164 (80.78)	0.24
Feelings of self-harm	70 (85.36)	131 (64.53)	<0.001
Feeling unsafe	66 (80.48)	137 (67.48)	0.02
Life in chaos	54 (65.85)	117 (57.63)	0.2
Depression	60 (73.17)	138 (67.98)	0.38
Anxiety	50 (60.97)	99 (48.76)	0.06
Drug/Alcohol problems	21 (25.61)	34 (16.74)	0.08

As with respondents’ attempting to be admitted to public hospitals, the decision to refuse admission to a private hospital had a substantial negative impact upon many of them in the areas of anxiety, anger, frustration, depression, suicidality and isolation (Table 20). This impact was similar to that reported from 2011 survey results. However, across all potential impacts where a majority of respondents had previously rated them as a significant impact, almost half of respondents now rated them as ‘not applicable’. This was in complete contrast to results reported by respondents refused admission to public hospitals. Given the apparent shift in the amount of overall care offered to people with BPD in private hospitals described above, this result may be because more people are deferring to public hospitals and are therefore less concerned when refused private hospital admission.

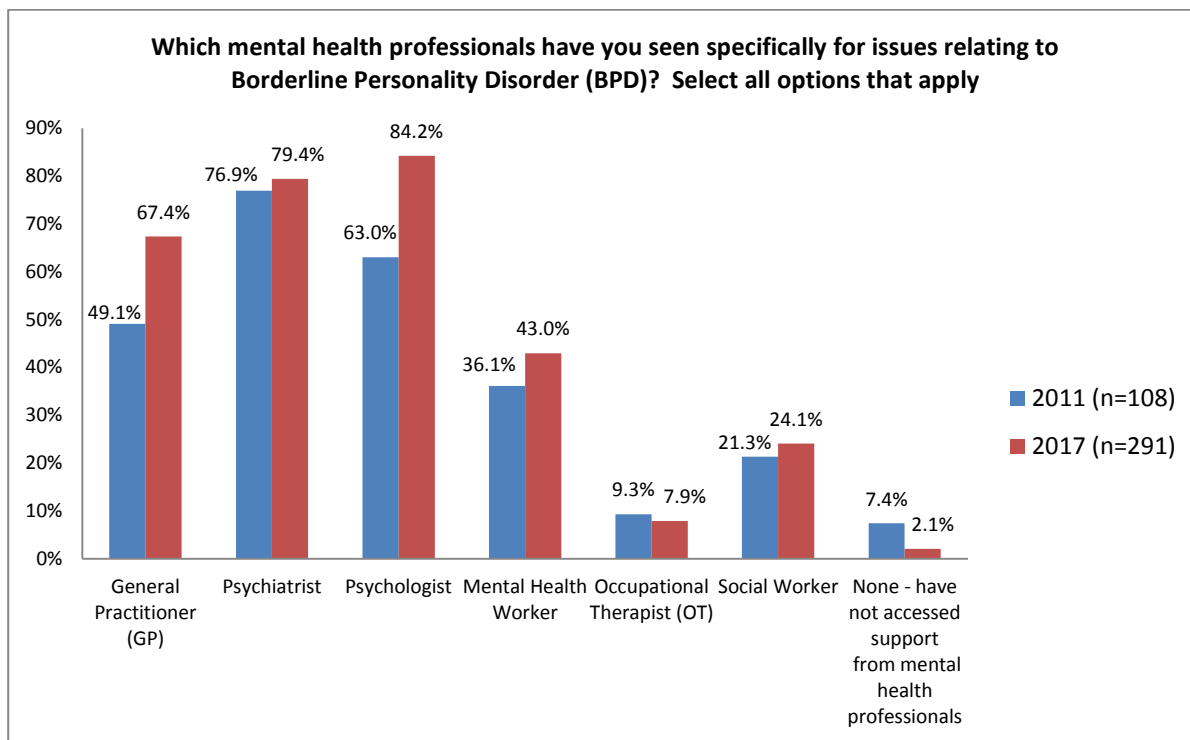
Table 20: How Respondents Felt and the Level of Impact on their Mental Health when Refused Admission to Private Hospitals (2011-2017)

Feeling and Impact	Year of Survey	Had a significant impact	Had some impact	Did not impact	Not applicable	Total (n)
Anxious	2011	55.0% (22)	15.0% (6)	2.5% (1)	27.5% (11)	40
	2017	40.40% (40)	16.16% (16)	0 (0)	43.43% (43)	99
Angry	2011	56.1% (23)	17.1% (7)	0.0% (0)	26.8% (11)	41
	2017	34.02% (33)	13.40% (13)	7.22% (7)	45.36% (44)	97
Frustrated	2011	57.5% (23)	15.0% (6)	0.0% (0)	27.5% (11)	40
	2017	38.78% (38)	14.29% (14)	3.06% (3)	43.88% (43)	98
Depressed	2011	53.7% (22)	19.5% (8)	0.0% (0)	26.8% (11)	41
	2017	42.71% (41)	11.46% (11)	2.08% (2)	43.75% (42)	96
Suicidal	2011	53.7% (22)	17.1% (7)	0.0% (0)	29.3% (12)	41
	2017	40.82% (40)	11.22% (11)	4.08% (4)	43.88% (43)	98
Relieved	2011	7.9% (3)	7.9% (3)	21.1% (8)	63.2% (24)	38
	2017	3.19% (3)	7.45% (7)	23.40% (22)	65.96% (62)	94
Alone / isolated	2011	58.5% (24)	12.2% (5)	0.0% (0)	29.3% (12)	41
	2017	40.21% (39)	14.43% (14)	2.06% (2)	43.30% (42)	97

BPD and Mental Health Professional Care

Respondents reported seeing a range of mental health professionals for issues related to their BPD, with most of the 291 respondents of the 2017 survey reporting psychologists (84.19%, n=245) and most of the 105 respondents of the 2011 survey reporting psychiatrists (76.2%, n=80) as the main profession. There was a significant increase in seeing psychologists in 2017 compared to 2011 (84.2% vs 63.0%, p<0.001). Across both time periods, occupational therapists were reported as the least seen profession (7.90%, n=23 in 2017; and 9.5%, n=10 in 2011). In 2011, a small number (7.6%) reported seeing no mental health professionals; with fewer who reported seeing no health professionals in 2017 (2.06%, n=6). See Figure 5 for detail.

Figure 5: Mental Health Professionals seen for Support of BPD



Of the 270 respondents in 2017 that reported having accessed mental health professional support, 45.56% (n=123) stated that they had done so for more than 10 years, compared with 56.3% (n=54) in 2011, which was significantly lower ($p < 0.001$). In the 2011 survey, 65.4% of respondents (n=78) reported that they did not feel that they were treated in a respectful manner by mental health professionals; whereas, in the 2017 survey, 68.94% (n=182) reported that they did feel respected. Further comments from 44 respondents in the 2011 survey recounted multiple examples of health professional discrimination towards them. This seemed to apply particularly to inpatient experiences where staff didn't know them and didn't have a long term relationship with their care. Respectful relationships were perceived where relationships and understanding of the person's individual needs were built. Further comments from 93 respondents in the 2017 survey indicate that discriminatory attitudes by staff are still apparent, but that there is more variability, with an increasing number of comments indicating that respect is shown some or most of the time.

Satisfaction with Mental Health Professional Support

When asked to rate how much each mental health professional had helped them to understand their feelings of depression, anger and frustration, the responses varied according to the professional group to whom they had sought help (Table 21). Comparing the two survey time points, Psychologists continued to be reported as the significantly helpful by approximately half of respondents. Helpfulness of psychiatrists and mental health workers appears to have declined, and helpfulness of GPs appears to have increased. Social workers and occupational therapists were not accessed by many respondents for this form of support for their BPD. Of the respondents who answered this question in the 2017 survey, many also reported that they had not access health professionals for this support. Forty respondents in the 2017 survey made further comments, identifying other support providers (eg. Peer workers, dietitians, DBT groups, support groups, Spectrum, Headspace) or made more concerning comments about the lack of support.

Table 21: Helpfulness of Mental Health Professionals in Supporting the Person to Understand Feelings (2011-2017)

Health Professional	Year of Survey	Significantly helped me	Somewhat helped me	Has not helped me	Not applicable / have not accessed	Response Count
General Practitioner (GP)	2011	25.0% (23)	33.7% (31)	39.1% (36)	2.2% (2)	92
	2017	21.11% (57)	40.37% (109)	33.70% (91)	4.81% (13)	270
Psychiatrist	2011	40.2% (37)	34.8% (32)	23.9% (22)	1.1% (1)	92
	2017	29.48% (79)	37.69% (101)	28.73% (77)	4.10% (11)	268
Psychologist	2011	49.5% (46)	24.7% (23)	16.1% (15)	9.7% (9)	93
	2017	54.44% (147)	31.85% (86)	11.48% (31)	2.22% (6)	270
Mental Health Worker	2011	27.4% (23)	32.1% (27)	16.7% (14)	23.8% (20)	84
	2017	24.03% (62)	27.13% (70)	14.34% (37)	34.50% (89)	258
Occupational Therapist (OT)	2011	10.0% (8)	8.8% (7)	11.3% (9)	70.0% (56)	80
	2017	4.10% (10)	8.61% (21)	8.20% (20)	79.10% (193)	244
Social Worker	2011	14.5% (12)	19.3% (16)	14.5% (12)	51.8% (43)	83
	2017	10.80% (27)	18.00% (45)	10.80% (27)	60.40% (151)	250
None	2011	5.6% (2)	0.0% (0)	0.0% (0)	94.4% (34)	36
	2017	1.96% (3)	1.96% (3)	4.58% (7)	91.50% (140)	153

This pattern was similar when respondents were asked to rate how much each mental health professional had helped them to manage their mental health (eg. Identifying early warning signs, providing strategies); although psychiatrists were reported to be only somewhat helpful here. The rating for GPs had improved slightly, and for mental health workers substantially, over time. Of concern, only about one quarter of psychiatrists were rated as significantly helpful in helping respondents manage their mental health, with a further one third being somewhat helpful (see Table 22).

Table 22: Helpfulness of Mental Health Professionals in Supporting the Person to Manage their Mental Health (n=92)

Type of Health Professional	Year of Survey	Significantly helped me	Somewhat helped me	Has not helped me	Not applicable / have not accessed	Response Count
General Practitioner (GP)	2011	25.3% (21)	32.5% (27)	34.9% (29)	7.2% (6)	83
	2017	21.80% (58)	38.35% (102)	34.59% (92)	5.26% (14)	266
Psychiatrist	2011	34.1% (30)	38.6% (34)	25.0% (22)	2.3% (2)	88
	2017	26.69% (71)	36.47% (97)	30.45% (81)	6.39% (17)	266
Psychologist	2011	50.0% (43)	24.4% (21)	17.4% (15)	8.1% (7)	86
	2017	52.43% (140)	33.33% (89)	11.24% (30)	3.00% (8)	267
Mental Health Worker	2011	22.8% (18)	29.1% (23)	17.7% (14)	30.4% (24)	79
	2017	52.43% (140)	33.33% (89)	11.24% (30)	3.00% (8)	267
Occupational Therapist (OT)	2011	8.2% (6)	8.2% (6)	12.3% (9)	71.2% (52)	73
	2017	4.12% (10)	8.64% (21)	7.00% (17)	80.25% (195)	243
Social Worker	2011	16.9% (12)	16.9% (12)	14.1% (10)	52.1% (37)	71
	2017	4.12% (10)	8.64% (21)	7.00% (17)	80.25% (195)	243
None	2011	2.7% (1)	0.0% (0)	2.7% (1)	94.6% (35)	37
	2017	3.27% (5)	0.65% (1)	4.58% (7)	91.50% (140)	153

When asked which mental health professionals that had been accessed had been least helpful understanding and managing their mental health, the views has not changed substantially across the two survey periods. GPs and psychiatrists continued to be rated as providing the least helpful support. This remains a potential concern given that most people with BPD rely on the support of these two professional groups the most (see Table 23).

Table 23: Professionals who have Helped People with BPD the Least (2011-2017)

Type of Health Professional	2011 Survey (n=84)	2017 Survey (n=246)
General Practitioner (GP)	49.4% (39)	45.6% 112
Psychiatrist	34.2% (27)	35.8% 88
Psychologist	16.5% (13)	14.2% 35
Mental Health Worker	16.5% (13)	14.2% 35
Occupational Therapist (OT)	8.9% (7)	5.3% 13
Social Worker	6.3% (5)	8.9% 22

Responsiveness of Services

The length of time that mental health professionals took to respond to people with BPD in crisis continued to vary considerably and little improvement was evident. In 2011, 48.9% (n=45) of 92 respondents stated that a response occurred within the same day and 21.7% (n=20) within two days; in 2017, these figures were 42.97% (n=110) and 24.61% (n=63), respectively (see Table 24 for further detail). No significant difference was observed between two time points for any of the service response time categories.

Table 24: Service Response Time to BPD Consumers in Crisis (2011-2017)

Type of Health Professional	2011 Survey (n=92)	2017 Survey (n=256)
The same day	48.9% (n=45)	42.97% (n=110)
Within 2 days	21.7% (n=20)	24.61% (n=63)
Between 2 days and 1 week	16.1% (n=14)	21.48% (n=55)
Longer than a week	8.0% (7)	7.03% (n=18)
Did not respond	6.5% (n=6)	3.91% (n=10)

In the 2017 survey, 264 respondents gave further ratings of responsiveness of different mental health professionals (Table 25). GPs and psychologists showed the most capacity to respond effectively, followed by psychiatrists; whereas, in the 2011 survey, GPs and psychiatrists had been rated as the most responsive during a crisis, followed by psychologists. In 2011, further analysis indicated that an association was apparent ($\chi^2=25.4$, 9df, $p=0.003$); this was also confirmed from the further analysis of 2017 survey responses ($\chi^2=88.01$, 9df, $p<0.001$). The highest rate of non-applicable responses continued to pertain to mental health workers (34.2%, n=27 in 2011, increasing to 49.6%, n=124 in 2017, $p=0.01$) suggesting that an increasing number of people with BPS do not have a dedicated mental health worker to assist them in a crisis.

Table 25: Responsiveness of Mental Health Professionals during a Crisis (n=92)

Type of Health Professional	Year of Survey	Very responsive	Somewhat responsive	Did not respond	Not applicable	Chi-squared test of association
General Practitioner (GP)	2011	44.8% (39)	26.4% (23)	9.2% (8)	19.5% (17)	
	2017	38.02% (100)	27.76% (73)	7.98% (21)	26.24% (69)	
Psychiatrist	2011	33.3% (29)	37.9% (33)	20.7% (18)	8.0% (7)	
	2017	24.90% (65)	32.95% (86)	14.94% (39)	27.20% (71)	
Psychologist	2011	33.3% (27)	27.2% (22)	18.5% (15)	21.0% (17)	
	2017	38.31% (100)	31.03% (81)	12.64% (33)	18.01% (47)	
Mental Health Worker	2011	26.6% (21)	25.3% (20)	13.9% (11)	34.2% (27)	$\chi^2=25.4$, 9df; p=0.003
	2017	16.00% (40)	26.40% (66)	8.00% (20)	49.60% (124)	$\chi^2=88.01$, 9df; p<0.001

Of the 268 respondents who rated their satisfaction with services provided by different mental health professionals, many were generally either very satisfied or satisfied with each of the different mental health professionals, although satisfaction was slightly lower for mental health workers than for the other professions in 2011 and this dissatisfaction increased by the 2017 survey period (see Table 26).

This contrasts with earlier results about health the professionals who respondents said had helped them least to understand and manage their mental health. There was also a higher rate of dissatisfaction with psychiatrists than other professions across the two survey time periods and also a large proportion of respondents reporting that they had not accessed mental health workers. Results of satisfaction with social workers and OTs were not included in either time point’s analysis due to low cell counts. Due to less cell counts, some of the variables were also collapsed and reanalyzed, which showed significant difference in both 2011 ($\chi^2=13.1$, 6df; p=0.04) and in 2017 ($\chi^2=25.95$, 6df; p<0.001) (Table 27 collapsed). Upon further analysis, it was evident that consumers’ satisfaction with services from psychiatrists significantly decreased in 2017 (48.86% vs 60.5%, p=0.03), which is a concern.

Table 26: Satisfaction with Services (2011-2017)

Type of Health Professional	Year of Survey	Very satisfied	Satisfied	Neutral	Unsatisf'd	Very unsatisfied	Not applicable / have not accessed	Chi-squared test of association
General Practitioner (GP)	2011	30.3% (27)	25.8% (23)	24.7% (22)	7.9% (7)	6.7% (6)	4.5% (4)	
	2017 (n=264)	34.47% (91)	22.73% (60)	24.24% (64)	9.47% (25)	7.58% (20)	1.52% (4)	
Psychiatrist	2011	34.1% (31)	26.4% (24)	13.2% (12)	9.9% (9)	14.3% (13)	2.2% (2)	
	2017 (n=264)	25.38% (67)	23.48% (62)	20.45% (54)	14.02% (37)	11.36% (30)	5.30% (14)	
Psychologist	2011	38.4% (33)	23.3% (20)	9.3% (8)	10.5% (9)	7.0% (6)	11.6% (10)	
	2017 (n=266)	39.10% (104)	28.95% (77)	16.92% (45)	6.39% (17)	5.26% (14)	3.38% (9)	
Mental Health Worker	2011	19.8% (16)	24.7% (20)	6.2% (5)	6.2% (5)	13.6% (11)	29.6% (24)	$\chi^2=57.0$, 15 df; p<0.001
	2017 (n=254)	13.39% (34)	22.05% (56)	12.60% (32)	5.91% (15)	5.91% (15)	40.16% (102)	$\chi^2=282.0$, 15 df; p<0.001

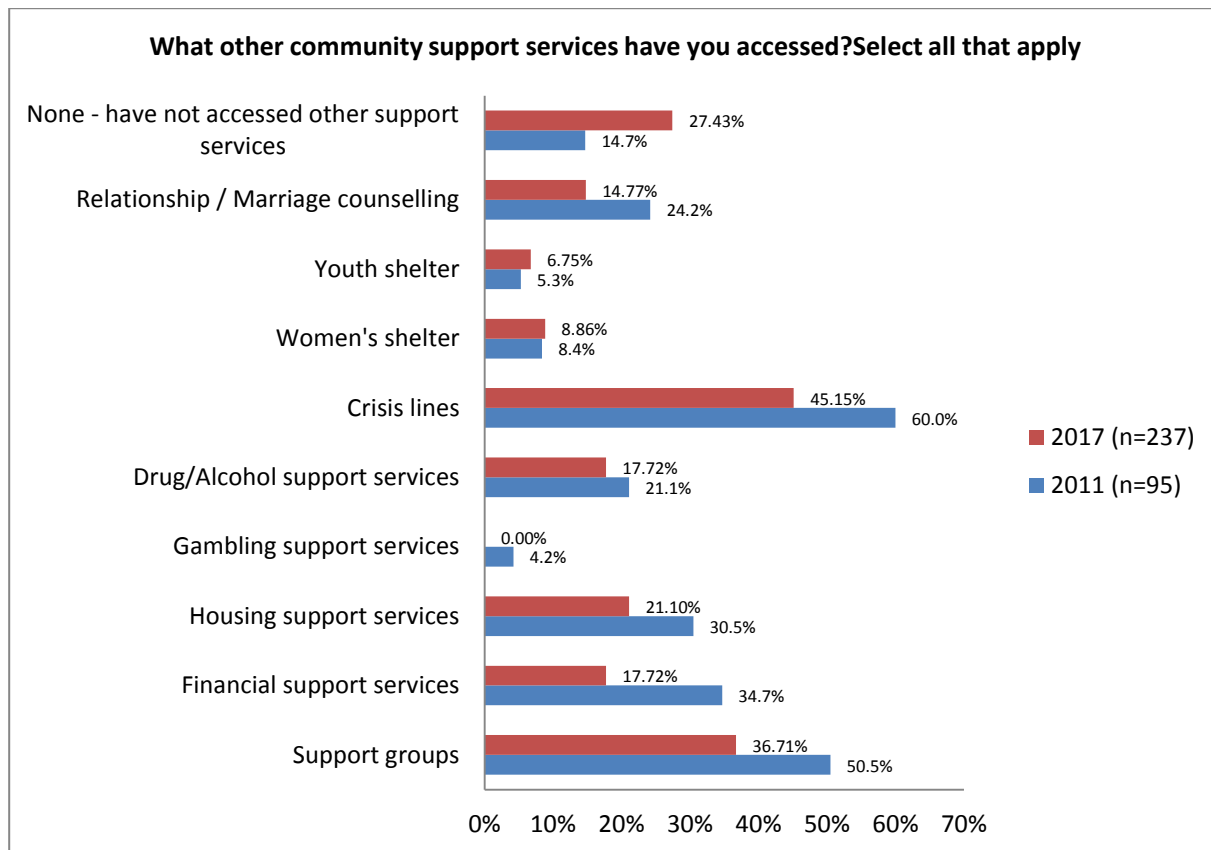
Table 27: Satisfaction with Services (2011-2017) (collapsed)

(Collapsed Table)	Year	Very satisfied / Satisfied	Neutral	Unsatisfied / Very Unsatisfied	Chi-squared test of association
General Practitioner (GP)	2011	56.1% (50)	24.7% (22)	14.6% (13)	
	2017	57.2% (151)	24.24% (64)	17.05% (45)	
Psychiatrist	2011	60.5% (55)	13.2% (12)	24.2% (22)	
	2017	48.86% (129)	20.45% (54)	25.38% (67)	
Psychologist	2011	61.7 % (53)	9.3% (8)	17.5% (15)	
	2017	68.05% (181)	16.92% (45)	11.65% (31)	
Mental Health Worker	2011	44.5% (36)	6.2% (5)	19.8% (16)	$\chi^2=13.1,6df$; p=0.04
	2017	35.44% (90)	12.6% (32)	11.82% (30)	$\chi^2=25.95,6df$; p<0.001

The Role of Community Support Services

There were 269 responses to questions about community support services from the 2017 survey. These revealed that people with BPD access a diverse range of services, in particular crisis lines, support groups, financial services, and housing support. However, many of the 269 respondents to this question appeared to have not accessed particular services for support (Figure 6).

Figure 6: Community Support Services Accessed



As with results from 2017, the most frequently accessed service was crisis lines, noted by 45.15% (n=107) of respondents (61.3%, n=57 in 2011,) and support groups (36.71%, n=87; and 54.4%, n=47 in 2011,) though it should be noted that both of these were significantly accessed less in 2017 than in 2011 ($p=0.02$ and $p=0.01$ respectively). Of concern, a significantly increased number of people with BPD reported not accessing any community support in 2017 (27.43%, n=65) compared with 14% (n=13) of the 93 respondents who answered this question in the 2011 survey ($p=0.001$).

When asked about the helpfulness of various community support services, less than 10% of respondents were 'very satisfied' with services, across all service types. A high proportion of respondents did not use these community services (Table 28).

Table 28: Perceived Helpfulness of Community Services (2011-2017)

Service type	Year of Survey	Very Satisfied	Satisfied	Neutral	Unsatis'd	Very unsatis'd	N/A not use	Rating Average	Count
Crisis lines	2011	9.1% (9)	22.2% (22)	13.1% (13)	17.2% (17)	17.2% (17)	21.2% (21)	3.14	99
	2017	7.84% (21)	21.27% 57	13.43% 36	16.42% 44	15.30% 41	25.75% 69	3.14	268
General support groups	2011	9.3% (9)	24.7% (24)	9.3% (9)	6.2% (6)	2.1% (2)	48.5% (47)	2.36	97
	2017	5.97% 16	17.16% 46	10.82% 29	7.09% 19	4.48% 12	54.48% 146	2.71	268
Financial support	2011	7.1% (7)	16.3% (16)	6.1% (6)	8.2% (8)	16.3% (16)	45.9% (45)	3.19	98
	2017	3.37% (9)	7.12% 19	8.61% 23	9.74% 26	10.86% 29	60.30% 161	3.44	267
Housing support	2011	6.0% (6)	8.0% (8)	7.0% (7)	9.0% (9)	13.0% (13)	57.0% (57)	3.35	100
	2017	2.61% (7)	6.34% 17	5.60% 15	6.72% 18	13.06% 35	65.67% 176	3.62	268
Gambling support	2011	1.0% (1)	1.0% (1)	1.0% (1)	0.0% (0)	3.1% (3)	93.9% (92)	3.50	98
	2017	0.00%(0)	0.00%(0)	1.13% (3)	0.38% (1)	1.89%(5)	96.60% (256)	4.22	265
Drug / Alcohol support	2011	6.1% (6)	9.1% (9)	6.1% (6)	0.0% (0)	4.0% (4)	74.7% (74)	2.48	99
	2017	2.27% (6)	7.58% 20	6.06% 16	4.17% 11	2.65% 7	77.27% 204	2.88	264
Relationship counselling	2011	3.0% (3)	5.1% (5)	8.1% (8)	5.1% (5)	12.1% (12)	66.7% (66)	3.55	99
	2017	1.51% (4)	7.17% 19	6.42% 17	6.79% 18	5.66% 15	72.45% 192	3.29	265
Women's shelter	2011	0.0% (0)	6.1% (6)	2.0% (2)	0.0% (0)	1.0% (1)	90.8% (89)	2.56	98
	2017	2.26% (6)	3.40% 9	1.89% 5	2.26% 6	3.77% 10	86.42% 229	3.14	265
Men's shelter	2011	0.0% (0)	3.1% (3)	0.0% (0)	0.0% (0)	1.0% (1)	95.8% (92)	2.75	96
	2017	0.00% (0)	0.00% (0)	0.00% (0)	0.38% (1)	0.77% (2)	98.85% (257)	4.67	260
Youth shelter	2011	0.0% (0)	2.1% (2)	0.0% (0)	3.2% (3)	0.0% (0)	94.7% (90)	3.20	95
	2017	0.38% (1)	2.66% (7)	0.38% (1)	3.42% (9)	1.90% (5)	91.25% (240)	3.43	263

Upon further analysis, there was a significant overall difference in the level of satisfaction across groups in 2017 ($\chi^2=45.12$, 18df; $p<0.001$), as there was in 2011 ($\chi^2=34.9$, 18df; $p=0.01$) (Table 29 collapsed). Fewer respondents were very satisfied or satisfied.

Table 29: Perceived Helpfulness of Community Services (2011-2017) (collapsed)

	Year	Satisfied / Very Satisfied	Neutral	Unsatisfied/Very unsatisfied	Chi-squared test of association
Crisis lines	2011	39.7% (31)	16.7% (13)	43.6% (34)	
	2017	29.1% (21)	13.4% (36)	31.7% (85)	
General support groups	2011	66.0% (33)	18.0% (9)	16.0% (8)	
	2017	23.1% (62)	10.8% (29)	11.6% (31)	
Financial support	2011	43.4% (23)	11.3 % (6)	45.3% (24)	
	2017	10.5% (28)	8.6% (23)	20.6% (55)	
Housing support	2011	32.6% (14)	16.3 % (7)	51.2 % (22)	
	2017	9.0% (24)	5.6% (15)	19.8% (53)	
Gambling support	2011	33.3% (2)	16.7% (1)	50.0% (3)	
	2017	0.0% (0)	1.1% (3)	2.3% (6)	
Drug / Alcohol support	2011	60.0% (15)	24.0% (6)	16.0% (4)	
	2017	9.9% (26)	5.6% (16)	19.8% (18)	
Relationship counselling	2011	24.2% (8)	24.2% (8)	51.5% (17)	
	2017	8.7% (23)	6.4% (17)	12.5% (33)	
Women's shelter	2011	66.7% (6)	22.2% (2)	11.1% (1)	
	2017	5.7% (15)	1.9% (5)	6.0% (16)	
Men's shelter	2011	75.0% (3)	0.0% (0)	0.0% (1)	
	2017	0.0% (0)	0.0% (0)	1.2% (3)	
Youth shelter	2011	40.0% (2)	0.0% (0)	60.0% (3)	$\chi^2=34.9,18df;$ $p=0.01$
	2017	3.0% (8)	0.4% (1)	5.3% (14)	$\chi^2=45.12,18df;$ $P<0.001$

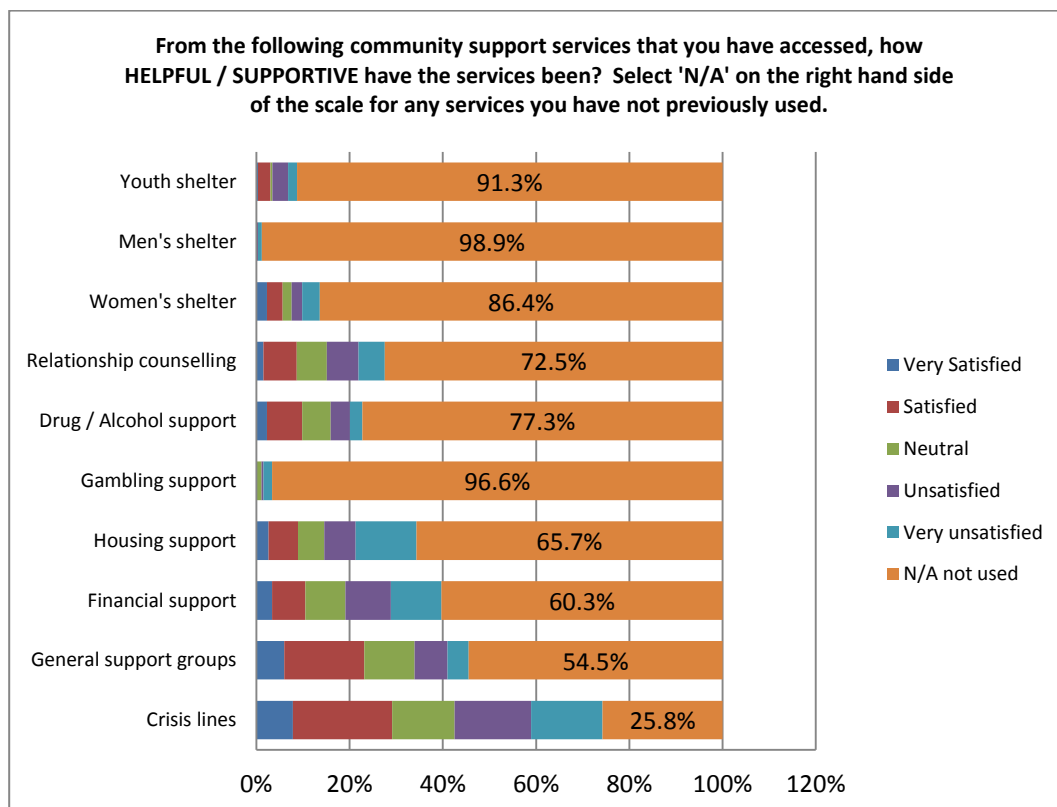
We assessed whether or not a relationship existed between levels of satisfaction with crisis lines and length of diagnosis but observed no statistically significant association ($\chi^2=2.96$, 6 df; $p=0.81$) (Table 30 and Figure 7). The results were similar to that of 2011 survey ($p=0.16$).

Table 30: Satisfaction with Support from Crisis Lines (2011-2017)

Satisfaction with crisis lines	Year	Duration of BPD			p-value
		< 1 year	1 - 5 years	> 5 years	
Satisfied	2011	4 (15.4)	15 (57.7)	7 (26.9)	
	2017	4 (7.5)	31 (58.5)	18 (34)	
Neutral	2011	4 (30.8)	6 (46.1)	3 (23.1)	
	2017	0 (0.0)	18 (52.9)	16 (47.1)	
Unsatisfied	2011	4 (12.9)	11 (35.5)	16 (51.6)	
	2017	5 (11.9)	20 (47.6)	17 (40.5)	
Not used	2011	4 (12.9)	11 (35.5)	16 (51.6)	0.16**
	2017	7 (11.3)	30 (48.4)	25 (40.3)	$\chi^2=2.96, 6 \text{ df};$ P=0.81

*Data are presented as number (percentage) ** Fisher’s exact test

Figure 7: Satisfaction with support from Community Services



The Issue of Suicide and Suicidal Ideation

Subjects were asked if they wished to continue with this section of the survey and 95.88% (n=256) said 'yes'. This was equivalent to 95.2% (n=100) of the 105 respondents to this question in the 2011 survey. Of the 2017 survey respondents, 99.61% (n=255) then stated that they had had thoughts of ending their life, compared with 100% of the 2011 96 respondents to this question. Of 254 respondents to the question of whether they had ever made a serious attempt to end their life, 68.90% (n=175) of 2017 survey respondents (compared with 85.6%, n=83 of 2011 survey respondents) stated 'yes'. Respondents were asked to rate how supportive various health professionals were when they were experiencing suicidal thoughts, whether their suicidal thoughts are taken seriously by others, and the longest time it took to get support after requesting it. However, no responses were received for health professional support and how long that support took, and only two respondents answered the question related to whether or not they were taken seriously. This was similar to the responses from the 2011 survey. This may be a reflection of an overall lack of support felt by respondents across both time periods.

The Issue of Self-Harm

Subjects were asked if they wished to continue with this section of the survey and 95.82% (n=252) of 263 respondents said 'yes'. This was very similar to the 2011 survey response. When asked if they had ever had thoughts of harming themselves (for example cutting, burning, ingesting fluids/medications, etc where you have caused yourself harm), 97.65% (n=249) respondents said 'yes'; patterns, fewer sought help from their GP (38.86%, n=89) compared with 2011 survey respondents (48.3%, n=42, p=0.11). A greater proportion of 2017 survey respondents reporting seeking support from a psychologist, compared with the 2011 survey (41.05%, n=94 compared with 33.7%, n=28, respectively, p=0.19). Fewer 2017 survey respondents sought help from a psychiatrist (31%, n=71 compared with 37.3%, n=31 in 2011, p=0.27). Of concern, the proportion of people not seeking any support from health professionals appears to have increased (39.30%, n=90 for 2017 compared with 32.5%, n=27 for 2011, p=0.29). The range of professional from whom they sought help is shown in the figure below (Table 31).

Table 31: Support Sought After Self-Harming

Mental Health Professionals	2011 N (%)	2017 N (%)
General Practitioner (GP)	43 (48.9)	89 (38.9)
Psychiatrist	33 (37.5)	71 (31.0)
Psychologist	29 (33.0)	94 (41.1)
Mental Health Worker	28 (31.8)	47 (20.5)
Occupational Therapist (OT)	3 (3.4)	4 (1.8)
Social Worker	12 (13.6)	14 (6.1)
Did not seek support	29 (33.0)	90 (39.3)
Skip this section	0 (0.0)	1 (0.4)
Total	88	229

Respondents were also asked to name ‘other’ if they sought help from someone other than these health professionals. Of the 39 responses, many (n=18) indicated that they sought help from a hospital emergency department, 10 didn’t seek help, 6 sought help from a friend or family member, 2 sought help from a peer support worker/support group leader, 1 sought help from a school counselor and 1 sought help from a crisis line. For the 2011 survey, many of the 13 respondents who stated ‘other’ attended to their wounds themselves. Sixty-seven of the 2017 survey respondents further reported their longest time waiting in emergency departments for their self-harm to be addressed. When compared with results from the 2011 survey (Table 32), it appears that there has been significant improvement in the ‘immediate’ response (17.9% vs 2.8%, p=0.02) and little or no improvement in the other experiences of emergency department care for people with BPD.

Table 32: Longest Waiting Time in the Emergency Department for Self-Harm (2011-2017)

Waiting time in an ED	2011 N (%)	2017 N (%)
Immediately	1 (2.8%)	12 (17.9%)
1 - 4 hours	10 (27.8%)	19 (28.4%)
5 - 8 hours	6 (16.7%)	13 (19.4%)
More than 8 hours	8 (22.2%)	8 (11.9%)
Don't know	8 (22.2%)	12 (17.9%)
Prefer not to answer	2 (5.6%)	2 (3%)
Total	36	67

Of the 150 respondents to the 2017 survey about whether they were referred to a mental health professional as a result of their self-harm, 74.67% (n=112) said ‘yes’, compared with 63.3% (n=43) from the 2011 survey, which showed a non-significant improvement, p=0.08. This suggests that referral experiences have improved somewhat following self-harm (see Table 33).

Table 33: Referral to a Mental Health Professional Following Self Harm (2011-2017)

Referred to a MH professional after self-harm	2011 N (%)	2017 N (%)
No	20 (28.2%)	29 (19.3%)
Yes	45 (63.4%)	112 (74.7%)
Don't know	5 (7%)	8 (5.3%)
Total	71	150

History of Child Sexual Abuse

A further question about child sexual abuse was added to the 2017. This had been an oversight in the 2011 survey. Eighty-five people provided responses and 35.29% (n=30) reported that they had experienced child sexual abuse, 52.94% (n=45) said ‘no’, and 11.76% (n=10) were unsure.

Appendix 1: Survey: Experience of consumers with the diagnosis of Borderline Personality Disorder

DEMOGRAPHICS

1. In which State/Territory do you live?

QLD
NSW
ACT
VIC
TAS
SA
WA
NT

2. Location

Capital City Regional Town
Remote Town

3. Gender

Male Female
Other

4. Age

Under 18
18-24
25-39
40-49
50-64
Over 65

5. Marital status

Single
Spouse/Partner Separated/Divorced
Widowed

6. How many children do you have?

None 1
2
3
4 or more

7. How many are currently dependent on you for care and support?

None 1
2
3
4 or more

8. How many are under 18 years of age?

None 1
2
3
4 or more

9. Are you of Aboriginal or Torres Strait Islander descent?

Yes
No

10. What is your country of birth (if not Australia)

11. If you were not born in Australia, how many years have you lived here?

12. What language do you speak at home (if other than English)?

BACKGROUND INFORMATION

13. What is your main or primary diagnosis?

Borderline Personality disorder (BPD)
Anxiety Disorder
Post Traumatic Stress Disorder (PTSD)
Obsessive Compulsive Disorder (OCD)
Bipolar Disorder
Schizo-affective disorder
Eating disorder

14. Do you have any other mental health diagnoses? Select all options that apply

Anxiety Disorder
Post Traumatic Stress Disorder (PTSD)
Obsessive Compulsive Disorder (OC)
Bipolar Disorder
Schizo-affective Disorder
Eating disorder
Not applicable
Don't know

15. What medications do you currently take for mental health issues?

None
Don't know
Anti-Depressants Anti-
Anxiety
Anti-Psychotic

16. If you are not sure of what the medications are for, please list the names here

17. How many years ago were you diagnosed with Borderline Personality Disorder?

Less than 1 year Between 1-3
years
Between 3-5 years
Between 5-7 years
Between 7-9 years More than
9 years

18. How many years ago were you diagnosed with Borderline Personality Disorder?

Less than 1 year
Between 1-3 years
Between 3-5 years
Between 5-7 years
Between 7-9 years
More than 9 years

19. Which medical professional made the diagnosis of BPD?

General Practitioner (GP)
Psychiatrist
Psychologist
Mental Health Nurse
Don't know

20. Did that medical professional explain to you what Borderline Personality Disorder means?

No

Yes
Yes but didn't understand

IMPACT OF MENTAL HEALTH SUPPORT SERVICES

21. To what extent have the following caused you anxiety?

	Very anxious	Anxious	Neutral/No Effect	N/A
Fear of losing mental health support				
Fear of losing a long term therapist				
Lack of long term/consistent support				
Discrimination because of Borderline Personality Disorder diagnosis				
Not being taken seriously				
Being treated badly				
Not feeling respected				
Unable to access support when I need it				
Lack of choice of support services				
Long waiting lists/times to see mental Health professionals				
Services not available in my local area				
Financial cost of accessing services				

22. How helpful have the following been in the management of your condition? Self N/A on the right hand side of the scale for any services you have not previously used.

	Very unhelpful	Unhelpful	Neutral	Helpful	Very Helpful	Not used
Identifying early warning signs						
Developing a crisis plan						
Education and information about BPD						
Medication						
Hypnotherapy						
Psychotherapy (long term and/or Regular therapist)						
Cognitive Behavioural Therapy (CBT)						
Dialectic Behavioural Therapy (DBT)						
Trauma Counselling						
Hospital admission						
Mental health support groups (e.g. depression, anger management, PTSD, etc.)						
Community support groups (e.g. art therapy, Friendship groups, etc.)						

23. From the above services, are there any you wanted to access but were/have not been able to?

No
Yes

24. From the above services in the past, what has contributed most to support your recovery? For example, support from GP or Psychologist, Group Therapy, Mental Health Team, medications, etc.

25. From the above services in the past, what has been least helpful/prevented/interfered the most with your recovery? For example, unable to access support when I need it, am not taken seriously, affordability or availability of support services, etc.

26. Have you been admitted into hospital for issues related to BPD in the last:

3 months
6 months
9 months
18 months

More than 18 months or no admissions

27. Do you have any further comments about this section?

GENERAL PRACTITIONERS

28. To what extent has your GP supported you with issues related to BPD?

Supported Neutral

Not supported

Have not received any support from by GP

29. How often do you have longer appoints with your GP (i.e. double appointments)?

Always Sometimes

Never

30. How often does your GP provide you with personal counselling?

Weekly Fortnightly

Monthly

More than monthly

N/A does not provide personal counselling

31. How long have you been receiving personal counseling from your GP?

Less than 6 months 6-12

months

1-2 years

2-5 years

5-10 years

Longer than 10 years

32. Has your GP referred you to any of the following mental health professionals? (Select all than apply)

Mental health team Psychiatrist

Psychologist

Social Worker Occupational Therapist

Counsellor (other)

No referral given

33. Do you have any further comments about this section?

PUBLIC & PRIVATE MENTAL HEALTH SERVICES

34. Select from the following options which one best describes your access to public and/or private mental health/hospital services

Only use public mental health services/hospitals

Only use private mental health services/hospitals

Use mostly public mental health services/hospitals and some private

Use mostly private mental health services/hospitals and some public

Don't know

HOSPITAL ADMISSIONS PUBLIC

35. Have you ever been admitted to a public hospital because of issues relating to BPD?

Yes

No

36. How often have you been admitted to hospital for issues relating to BPD?

Never 1 time

2 times

3 times

4 times

5 or more times

37. How many hospital admissions have you had in the past 3 years for issues relating to BPD?

38. Have you ever been admitted into hospital involuntarily (i.e. without your request/consent to be admitted)?

- No
- Yes
- Don't know

39. Approximately, how many days/weeks was your longest stay in hospital for issues relating to BPD?

40. What has been your longest stay in hospital for mental health issues?

- Not applicable 1 day
- 3 days
- 1 week
- 2 weeks
- 3 or more weeks

41. Have you ever asked to be admitted into hospital because of mental health issues but been refused?

- No
- Yes

42. How important was each of the following to you when requesting a hospital admission?

	Very important	Important	Not important	Not applicable
Feeling suicidal				
Feelings of self harm				
Feeling unsafe				
Life in chaos				
Depression				
Anxiety				
Drug/Alcohol problems				

43. If you asked to go to hospital, who refused to admit you into hospital?

- General Practitioner (GP)
- Psychiatrist
- Psychologist
- Case Manager
- Mental Health Nurse
- Director of Nursing
- Clinical Director
- Don't know

44. Briefly describe the reason why you were refused hospital admission

45. Indicate below how you FELT and the level of IMPACT on your mental health state when you were refused hospital admission

	Had a significant Impact	Had some Impact	Did not Impact	Not applicable
Anxious				
Angry				
Frustrated				
Depressed				
Suicidal				
Relieved				
Alone/isolated				

HOSPITAL ADMISSION PRIVATE

46. Have you ever been admitted to a private hospital because of issues relating to BPD?

- No
- Yes

HOSPITAL ADMISSIONS – PRIVATE

47. How often have you been admitted to a PRIVATE hospital for issues relating to BPD?

- Never 1 time
- 2 times
- 3 times

4 times
5 or more times

48. How many hospital admissions have you had in the past 3 years for issues relating to BPD?

49. Approximately how many days/weeks was your longest stay in hospital for issues relating to BPD?

50. What has been your longest stay in hospital for mental health issues?

Not applicable 1 day
3 days
1 week
2 weeks
3 or more weeks

51. How important was each of the following to you when requesting a hospital admission?

Very important Important Not important Not applicable

Feeling suicidal Feeling of self
harm Feeling unsafe
Life in chaos Depression
Anxiety
Drug/Alcohol problems

52. If you asked to go to hospital, who refused to admit you into hospital?

General Practitioner (GP)
Psychiatrist
Psychologist Case
Manager
Mental Health Nurse
Mental Health Unit Manager
Director of Nursing
Clinical Director
Don't know

53. Briefly describe the reason why you were refused hospital admission

54. Indicate below how you FELT and the level of IMPACT on your mental health state when you were refused hospital admission?

Had a significant impact Had some impact Did not impact Not applicable

Anxious Angry
Frustrated
Depressed
Suicidal
Relieved
Alone/isolated

SUPPORT SERVICES – MENTAL HEALTH PROFESSIONALS

55. Which mental health professionals have you seen specifically for issues relating to Borderline Personality Disorder (BPD)? Select all options that apply

- General Practitioner (GP)
- Psychiatrist
- Psychologist
- Mental Health Worker
- Occupational Therapist (OT)
- Social Worker
- None- have not accessed support from mental health professionals

56. How long have you been accessing support from mental health professionals?

- Less than 6 months
- 6-12 months
- 1-3 years
- 3-5 years
- 5-10 years
- More than 10 years

57. From the mental health professionals you have accessed, rate how much each has helped you UNDERSTAND your FEELINGS the most? (e.g. depression, anger, frustration, etc.)

Significantly helped me somewhat helped me Has not helped me Not applicable/
Have not accessed

- General Practitioners (GP)
- Psychiatrist
- Psychologist
- Mental Health Worker
- Occupational Therapist (OT)
- Social Worker
- None

58. From the mental health professionals you have accessed, rate how much each has helped you MANAGE YOUR MENTAL HEALTH the most? (e.g. identifying early warning signs, provided strategies to help me, identifying triggers, know when I am more at risk, helped me maintain relationships, etc)

Significantly helped me somewhat helped me Has not helped me Not applicable/
Have not accessed

- General Practitioners (GP)
- Psychiatrist
- Psychologist
- Mental Health Worker
- Occupational Therapist (OT)
- Social Worker
- None

59. From the mental health professionals you have accessed, who has helped you the LEAST in understanding and managing your mental health? Select all that apply

- General Practitioners (GP)
- Psychiatrist
- Psychologist
- Mental Health Worker
- Occupational Therapist (OT)
- Social Worker

60. Do you feel treated in a respectful manner?

- Yes
- No

61. When you are in a crisis and have requested help, how long does it take for a mental health professional to respond to you?

- The same day
- Within 2 days
- Between 2 days – 1 week
- Longer than a week
- Does not respond

62. How responsive have each of the following mental health professions been in a crisis?

- General Practitioners (GP) Psychiatrist
- Psychologist
- Mental Health Worker Occupational Therapist (OT) Social Worker
- Non were responsive

63. In general, how satisfied have you been with services provided by the following mental health professional that you have accessed?

Very satisfied Satisfied Neutral Unsatisfied Very unsatisfied Not applicable?
Have not accessed

- General Practitioners (GP) Psychiatrist
- Psychologist
- Mental Health Worker Occupational Therapist (OT) Social Worker
- None were responsive

64. Do you have any further comments about this section?

65. From the following community support services that you have accessed, how HELPFUL / SUPPORTIVE have the services been? Select 'N/A/' on the right hand side of the scale for any services you have not previously used.

- Crisis lines
- General support groups
- Financial support
- Housing support
- Gambling support
- Drug/Alcohol support
- Relationship counseling
- Women's shelter
- Men's shelter
- Youth shelter

66. What other community support services have you accessed? Select all that apply

- Support groups
- Financial support
- Housing support
- Gambling support
- Drug/Alcohol support

Crisis lines
Women's shelter

Youth shelter
Relationship / marriage counseling
None – have not accessed

67. Do you have any further comments about this section?

SUICIDE

68. Would you like to continue with this section?

69. Have you ever had thoughts offending your life?

No
Yes
If you do not wish to answer

70. If you sought support after having these thoughts from any of the list below, rate how supportive they were

General practitioner (GP)
Psychiatrist
Psychologist
Mental Health Worker
Hospital

71. What is the longest time it took to get support after requesting it?

Same day 1-2 days
2-3 days
3-5 days
4 days – 2 weeks
Longer than 2 weeks
Did not get a response

72. When you have suicidal thoughts and request support, are you generally taken seriously?

No
Yes

73. Have you ever made a serious attempt to end your life?

No
Yes
Do not wish to answer

SELF HARM

74. Would you like to proceed with this section?

No – I want to skip this section
Yes – Proceed with this section

75. Have you ever had thoughts of harming yourself (for example cutting, burning, ingesting fluids/medications, etc where you have caused yourself harm)

No
Yes
Prefer not to answer this question

76. Have you ever self harmed? (for example cutting, burning, ingesting fluids/medications, etc where you have caused yourself harm)

No
Yes
Prefer not to answer

77. After self harming, did you seek support from any of the following health professionals? Select all that apply

- General Practitioners (GP) Psychiatrist
- Psychologist
- Mental Health Worker Occupational
- Therapist (OT) Social Worker
- Did not seek support

78. As a result of your self harm have you ever sought medical attention?

- No
- Yes
- Prefer not to answer

79. Who did you see for medical attention relating to your self harm?

- General Practitioner (GP)
- Hospital/Emergency Department

80. What is the longest time you had to wait in an emergency department for your self harm?

- Immediately 1-4 hours
- 5-8 hours
- More than 8 hours
- Don't know
- Prefer not to answer

81. As a result of your self harm, were you referred to a mental health professional (for example psychiatrist, psychologist, social worker, mental health team, etc)

- No
- Yes
- Don't know

82. Do you have a history of child sexual abuse?

- Yes
- No
- Not sure

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