PREVALENCE

A BPD COMMUNITY PAPER

Abstract

This paper explores the relevant research in relation to prevalence of borderline personality disorder and personality disorders in general in Victoria, Australia. The effects of the use of the DSM criteria compared with the ICD domains are considered along with the consideration of co-occurring mental illnesses, prevalence in more vulnerable groups and the effects of stigma and discrimination. The paper concludes with the position of BPD Community in relation to prevalence.

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1 Introduction

As with other personality disorders (PDs), having accurate data on the prevalence of borderline personality disorder (BPD) is vital in helping with the distribution of health care resources, the understanding of health outcomes, and efforts to improve the mental health system (Grenyer et al., 2017; Quirk et al., 2017). Accordingly, this paper explored the Australian and international research on BPD prevalence and associated issues.

This paper first explores the major diagnostic criteria, being the *DSM* and the *ICD*. The current *DSM-IV* and *DSM*-5 and *ICD-10* all use categorical criteria, even though BPD is widely regarded as a dimensional disorder. This causes various issues, including not allowing the severity of BPD to be coded. Additionally, research has found that people can have clinically significant symptoms yet not be given any diagnosis as they fall slightly under the threshold for BPD diagnosis. This paper finds that the *ICD-11* goes some way to addressing these issues, as it involves a dimensional classification system that allows for the severity to be qualified and also enables a sub-threshold diagnosis. However, the *ICD-11* is unlikely to be implemented widely in Australia for at least a few years at this stage, meaning that research is, for now, dependent on the *DSM-IV*, *DSM* 5, and *ICD-10*.

This piece then examines Australian and international prevalence data. The prevalence of BPD in Australia proves to be difficult to determine. The most recent population data in Australia of 0.95% for BPD was published 20 years ago and derives its data from a 1997 survey (Jackson & Burgess, 2000). Its estimate may be outdated and is likely conservative (Carrotte & Blanchard, 2018). Moreover, since this survey only assessed adults, for adolescents and other subgroups there is no existing population-level prevalence data.

Internationally, BPD prevalence research is also understudied, particularly in low-income countries. There have been various global reviews published in recent years, which find significant variation in prevalence estimates across studies. For PDs in general, estimates are high, with global reviews finding prevalence rates of 6.1% (across certain countries from various continents) (Y. Huang et al., 2009), 4.4% to 21.5% (across certain countries from Europe, Australia, and the US) (Quirk et al., 2016), 7.8% (across certain Western and non-Western countries) (Winsper et al., 2019a), and, from one study, either 7.74% (using expert-rated diagnostic measures only) or 12.16% (using both self-rated and expert-rated measures) across certain Western countries (Volkert et al., 2018). Not all of these global reviews provided pooled prevalence rates for individual PDs. For those that did, BPD

was found to have a prevalence of 1.8% (again, across certain Western and non-Western countries) (Winsper et al., 2019b), and, from one review, 0.92% (using expert-rated measures only) or 1.90% (using both self-rated and expert-rated measures) (Volkert et al., 2018). The authors of these studies have all urged caution in interpreting the results of these studies, for various reasons, including significant variation in the methodologies used by the studies included in the reviews.

Most epidemiological BPD studies have been conducted in the U.S., with rates between 0.5% and 1.4%, but with two studies finding higher rates of 2.7% and 5.9% (SA Health, 2017). These latter studies involved analysis of the same national US survey, but with different methodologies. The study that obtained the prevalence rate of 5.9% by Grant et al. (2008) was criticised by some researchers for over-inflating prevalence rates by requiring only one PD symptom to be tied to significant distress, impairment, or dysfunction (Tomko et al., 2014; Trull et al., 2010). These researchers argued that, for people with only one symptom tied in this way, it is questionable whether they could be validly considered to have a PD. Trull et al. (2010) conducted a re-analysis of the same data with stricter diagnostic criteria and found a prevalence rate of 2.7%. Subsequently, researchers have often chosen to cite the result of 2.7%. However, Harford et al. (2013) have argued that approaches to PD diagnosis with less stringent criteria allow the identification of subclinical patients with PDs of clinical significance, including people at risk of developing a PD. As such, these issues need to be taken into account when assessing these competing approaches and results.

This paper then concludes that BPD has a prevalence in the general population between 1% and 6%, but that there are some reasons to have confidence in a figure of 6%. These include the advantages of broader criteria in identifying those with clinically significant personality disturbances who would otherwise not receive a diagnosis and potentially be undetected, as well as the fact that the prevalence rate of 5.9% was identified by the Substance Abuse and Mental Health Services Administration (SAMHSA) in its report to the USA Congress, and was accepted by them (SAMHSA, 2011). Subsequently, the paper extrapolates these figures to the Victorian context and concludes that if 6% is accepted, this means around 401,000 people in Victoria with BPD, while if two family members are allowed for every person with BPD, this means around 1,203,000 Victorians—almost 1 in 6—directly affected by BPD.

The paper then examines prevalence data on various subgroups, including vulnerable groups, before proceeding to look at research methods and other issues. The challenges in understanding the Australian and international research are considerable: whether the diagnosis is based on the *DSM*

or the *ICD*; whether it is self-reported or based on an expert interview; whether it is done in conjunction with prevalence research into other PDs or on its own. These and other factors have led to significant variation in the prevalence estimates between studies. That a mental illness with a prevalence ranging from 1% to 6% has not been included in the national figures only serves to highlight the discrimination faced by people with lived experience of BPD.

Finally, BPD Community sets out its position statement on this topic, which is as follows:

1. BPD Community accepts a prevalence of 6% for BPD based on the research analysed in this paper.
2. Sub-threshold BPD should also be considered in research and policy.
3. There is a need for up-to-date prevalence data in Australia. This should involve new population-level estimates, and up-to-date data for various subgroups, including vulnerable groups. The upcoming Intergenerational Health and Mental Health Study is noted as a valuable opportunity to provide up-to-date data that can also be updated frequently in future years. National mental health-related reports, such as those by the AIHW, also should collect and report BPD data. Finally, the National Suicide Register should link suicides with mental health diagnoses, including BPD, to provide more data on suicide rates for people with BPD.
4. The desirable key criteria for prevalence research involves:
    a. Using the *ICD-11* as soon as this is widely implemented in Australia, and the *DSM-5* until then.
    b. Until the *ICD-11* can be widely used, aiming to measure the proportion of people with various numbers of BPD symptoms to provide a measure of the degree of BPD severity and to enable the detection of sub-threshold BPD.
    c. Using larger sample sizes and, where possible, expert-rated measures of BPD rather than relying on self-report measures.
    d. Analysing BPD prevalence in the general population rather than solely using clinical populations.
    e. Researching prevalence in various subgroups, including at-risk and marginalised groups.
5. Stigma and discrimination are proposed as being factors contributing to the paucity of research into BPD and its prevalence and this must be addressed.

2 BPD Prevalence research

2.1 Diagnostic criteria: categorical and dimensional approaches

When considering prevalence research, it is important to consider the current status of the classification systems used in the diagnosis of BPD and other PDs. The two major classification systems are the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) and the *International Classification of Diseases* (*ICD*). The most recent edition of the *DSM* – the *DSM-5* – was published in 2013, while the *ICD-10* will soon be replaced by the *ICD-11*.

Recent years have brought with them an increased understanding that mental disorders can be thought of as both a categorical construct and a dimensional construct (ten Have et al., 2016). A categorical construct is binary: one either has a certain disorder or does not (ten Have et al., 2016). Therefore, a categorical construct involves a criteria cut-off point, where people who score under the threshold for a disorder are not considered as having the disorder and are consequently not given a diagnosis (Karukivi et al., 2017). In contrast, a dimensional construct can be thought of as a continuum or "severity dimension", ranging from normality, where one has almost no symptoms, right through to a disorder (ten Have et al., 2016, p. 2).

There is a broad acceptance among specialists in the field that "personality abnormality is best viewed as a set of dimensional constructs" (Tyrer et al., 2015, p. 719). However, existing diagnostic systems under the *DSM* and *ICD* rely on categorical models of PDs. They have been widely utilised in the research literature, most recently under the *DSM-IV*, *DSM-5*, and *ICD-10*. The use of categorical constructs causes significant issues in the context of PDs. The strict cut-off point leads to subclinical patients—individuals who, while meeting some of the symptom criteria for a condition, are slightly below the cut-off point for diagnosis and are therefore not diagnosed with the condition (Harford et al., 2013). As Karukivi et al. (2017,) explain, using these cut-off points means that "personality disturbances of clinical significance" that are only slightly below the diagnostic threshold will be missed (p. 2). Indeed, numerous researchers have linked personality disturbances slightly below the threshold to "mental disorder symptoms and social dysfunction" (Karukivi et al., 2017, p. 7).

For example, ten Have et al. (2016) noted at the time of conducting their study that they knew of no research looking at "prevalence rates of various numbers of BPD symptoms (an indication of severity) in the general population, and the associated consequences of such symptoms" (p. 2). Accordingly, they conducted the first known study using a variety of BPD symptoms to capture a

range of severity. They addressed this gap through data analysis of the Netherlands Mental Health Survey and Incidence Study2 (NEMESIS-2), described as "a nationally representative survey of the general adult population", to examine the "prevalence of various numbers of BPD symptoms in the general population and (. . .) their associated sociodemographic correlates" (p. 2). Rather than simply focusing on whether or not a BPD diagnosis was present, their analysis was based on whether individuals had 0, 1–2, 3–4, or ≥5 symptoms, to reflect the level of severity, where people with ≥5 BPD symptoms would meet the criteria for BPD diagnosis. The authors found that even low numbers of BPD symptoms were linked with "psychiatric comorbidity and functional disability", although the disability and comorbidity increased with more BPD symptoms (p. 6). They also found that 69.9% reported no BPD symptoms, 25.2% reported 1–2 symptoms, 3.8% reported 3–4 symptoms, and 1.1% reported ≥5 BPD symptoms. These findings led them to recommend, similar to Tyrer et al. (2015), that sub-threshold levels of BPD symptoms should receive more identification in the health system and research.

Juurlink et al. (2018) subsequently found that people with a lower number of BPD symptoms represented a large proportion of individuals in a general population sample and that these symptoms were linked to impaired work performance. However, most studies use categorical diagnostic methods that do not capture a range in severity, at a cost to accurate data in this area. The term "diagnostic orphans" has also been used as a label for subclinical patients to highlight that while these patients have symptoms for a condition, they are not covered by any diagnosis (Harford et al., 2013; Hasin & Paykin, 1998). As there is strong evidence that many people below the threshold for PD diagnosis have personality disturbances of clinical significance, this term provides a helpful way to consider the fact that these patients are not always visible in the clinical picture.

It is also worth noting that as some people with BPD relapse after initially experiencing remission (Biskin, 2015), patients can slip in and out of a categorical diagnosis of BPD (Videler et al., 2019).

The issue of subclinical patients is concerning for current diagnostic systems and prevalence research. As the next subsection discusses, this issue is addressed in the *ICD-11*, but that diagnostic system will take some time to come into effect.

2.2 The *DSM-5* and *ICD-11*

Unfortunately, the categorical approach to PD diagnosis persists in the *DSM-5*. The *DSM-5* initially developed a model with a dimensional aspect; however, this was relegated to an '*Emerging Measures and Models*' section of the *DSM-5*. In this way, the criteria for the *DSM-IV* has remained the same in the *DSM-5*, with only minor changes to the text (Tyrer et al., 2015). As such, the *DSM* is yet to adopt a dimensional approach to PDs.

In contrast, the diagnosis of PDs has been substantially revised under the *ICD-11*. The *ICD-11* uses dimensional criteria, allowing the level of severity to be specified, ranging through sub-threshold personality difficulty to mild, moderate, or severe personality disorder (Bach & First, 2018). Furthermore, this model shifts away from basing PD diagnosis on how many criteria are met. Rather, a person's overall personality functioning is assessed. Since there are different types of impairment of personality functioning, the *ICD-11* also allows the coding of traits that describe the form of PD, which can involve negative affectivity, detachment, dissociality, disinhibition, and anankastia (or obsessionality) (Irwin & Malhi, 2019) (refer to Appendix 1). There is also a borderline pattern qualifier to enable a clinician to specify if the form of PD involves BPD. The *ICD-11* has a number of advantages over the existing diagnostic systems. The ability to code for the degree of severity, while still coding for borderline, provides much more information and means that treatment can be more effectively targeted according to the degree of severity. For example, the needs of someone with severe PD may be very different from someone with mild PD, and this can be better reflected in diagnoses under this system (Bach & First, 2018). This dimensional approach also addresses the problem of subclinical patients with personality difficulties, as one can now code "subthreshold personality difficulty" where this is present (Bach & First, 2018). Personality difficulty is not viewed as a clinical disorder under the *ICD-11*, but this diagnosis can provide valuable information (Bach & First, 2018). People with personality difficulties of clinical significance below the diagnosis threshold can be detected under this system, therefore allowing these patients to be recognised in research and clinical practice. Furthermore, as subclinical patients may be at risk for developing a PD (Harford et al., 2013), patients who are at risk could likely be monitored more effectively under the *ICD-11*.

The issue here is that the *ICD-11* will not be widely implemented for some years to come. It is intended to be implemented internationally from 1 January 2022 (World Health Organization, 2019). However, implementing the *ICD-11* in Australia will be a complex process for various reasons, including the need to implement electronic medical record systems associated with the *ICD-11*

(AIHW, 2020). The Australian Institute of Health and Welfare's (2020) report on consultations with stakeholders found that many stakeholders "considered that, for their work, the time frames to readiness would be 'at least five years'" (p. 3). Consequently, it is difficult to envision Australian population data on BPD and other PDs being based on the *ICD-11* criteria anytime soon. This means that prevalence research is, for the time being, reliant on the *DSM-IV*, *DSM-5*, and *ICD-10*, which is unfortunate for the aforementioned reasons.

2.3 BPD population-level prevalence data gaps

2.3.1 No up-to-date data for Australia

There is a concerning lack of up-to-date data on PD and BPD prevalence in Australia within the general population. The most recent study providing population-level data on prevalence for BPD and other PDs was published 20 years ago (Jackson & Burgess, 2000), relying on data from the 1997 National Survey of Mental Health and Wellbeing of Adults (SMHWB). Moreover, its prevalence estimates for PDs are likely conservative (Carrotte & Blanchard, 2018), and its methodology has significant limitations (Jackson & Burgess, 2000).

Since the 1997 survey, national surveys and reports have consistently failed to measure the prevalence of BPD and other PDs. While the 1997 National Health and Wellbeing Survey included screening questions for PDs, the 2007 iteration of the survey did not (Carrotte & Blanchard, 2018). Additionally, while it was expected that this survey would be repeated in 2017, it received no funding from the Federal Government and did not proceed (Chang, 2018). The 2013-2014 Young Minds Matter Survey, which surveyed Australian children and adolescents through the Australian Government Department of Health, also failed to measure PD prevalence (Carrotte & Blanchard, 2018). Reports published by the Australian Institute of Health and Welfare (AIHW) have a similar problem, as personality disorders, including BPD, are regularly relegated to the 'other' category (Carrotte & Blanchard). Accordingly, it is unclear what proportion of people with BPD and other PDs occupy these 'other' categories, and this impedes efforts to assess prevalence rates.

Following the decision not to fund a 2017 iteration of the National Health and Wellbeing Survey, $90 million in funding was announced in 2019 for the Intergenerational Health and Mental Health Study (Australian Government Department of Health, 2019). However, at the time of writing, it is not yet clear whether this study will cover PDs.

The state of research on prevalence in various subgroups of people with PDs and BPD is also concerningly poor. However, given the gaps in data even at a population level, this is perhaps not surprising.

2.3.2 Gaps in research on BPD and other PDs

Just as in Australia, a review of the international literature indicates that that the epidemiology, including prevalence, of PDs is understudied in comparison to other mental disorders.

Internationally, PDs are frequently omitted from major epidemiological studies, and the gaps in data are particularly pronounced in low-income countries (Quirk et al., 2016). They are not included in Global Burden of Disease studies (Volkert et al., 2018), and Grenyer et al. (2017) noted that PDs have been not been factored into reporting of mental health morbidity. Furthermore, as Tyrer et al. noted in their 2015 article, at that time, only one review had looked into PD prevalence internationally, again highlighting the poor status of research on PDs internationally.

2.4 Prevalence data

2.4.1 Australian population data

As noted previously, there has only been one study providing population-level data on PD prevalence within Australia. This study estimated that 6.5% of the adult population had any PD, while 0.95% of the adult population had BPD (Jackson & Burgess, 2000). The authors also estimated from their sample data that there were no differences between men and women in the likelihood of having a particular PD. Being over 20 years old, this data needs updating, and as noted earlier, researchers have argued that its estimates are likely conservative (Carrotte & Blanchard, 2018). There are a number of significant methodological issues with the study, too. For example, the study used a self-report measure and a screening tool rather than a diagnostic assessment instrument, which impacts its validity (Carrotte & Blanchard, 2018), and there were limited questions to assess PD (Jackson & Burgess, 2000).

2.4.2 International population data

2.4.2.1 Global reviews

Tyrer et al. noted in their 2015 article that, up to that time, only one study had looked into PD prevalence internationally. This study was apparently conducted in seven countries across five continents and obtained a PD point prevalence of 6.1% (Tyrer et al., 2015). Unfortunately, it was not possible to identify this study, as the study cited by Tyrer et al. was not a multi-country study, but

rather a US-specific study by B. Huang et al. (2006). It is possible that the study referred to was one published by the World Health Organization in 2009, which did obtain a pooled prevalence rate of 6.1% for PDs (Y. Huang et al., 2009). It is unclear whether that is the case though, as that study examined PD rates across 13 countries, rather than seven countries across five continents. In the World Health Organization's study, prevalence estimates were provided for eight individual countries, as well as one for Western Europe as a whole, which involved five countries. Of the 13 countries, six were less developed countries, while seven were developed countries. Unfortunately, this study does not appear to have provided pooled prevalence rates for individual PDs, including BPD, as only data for PD clusters and PDs as a whole were reported.

Subsequently, there have been more global reviews. Quirk et al. (2016) found fairly high prevalence rates of PDs in community populations in Western countries, but with significant variation, ranging from 4.4% to 21.5%. As with the World Health Organization study, data for individual PDs does not appear to have been provided by these authors.

In 2018, Volkert et al. noted that there had been no meta-analysis on PD prevalence internationally and conducted a meta-analysis to fill this research gap. They looked at the prevalence rates for PDs in the general adult populations in Western countries, while also seeking to identify factors leading to variances in estimates across studies. These factors included self-rated (self-assessed) versus expert-rated diagnostic assessment methods, where the latter involves diagnostic interviews. In their analysis, Volkert et al. found relatively high prevalence rates of PDs in these samples. They also found that there is a "high risk of bias" due to various studies using self-rated, rather than expert-rated, diagnostic assessment (p. 6). The high prevalence rates were lowered when the analysis was modified to only include studies with expert-rated measures but remained relatively high even when allowing for this. One of the categories the study looked at was overall prevalence rates for PDs, labelled the "any personality disorder" category, with people in this category having at least one type of personality disorder. Prevalence estimates were 12.16%—with a 95% confidence interval (CI) of 8.02–17.02%—for any PD when using estimates from both self-report and expert-rated measures, and this was lowered to 7.74% (95% CI: 6.00–9.67%) when only using expert-rated measures. Either of these estimates is higher than the rate of 6.1% obtained in the World Health Organization's 2009 study. Volkert et al. also found a prevalence of 1.90% (95% CI: 0.85-3.34%) for BPD when including both self-report and expert-rated measures, and a prevalence of 0.92% (95% CI: 0.19-2.15%) when using solely expert-rated measures.

The authors noted that the result of overall prevalence rates for PDs is similar to the prevalence of various physical health conditions and that this is true even when using the lower figure of 7.74% from studies using only expert-rated measures. For instance, lower back pain and chronic respiratory diseases have a prevalence rate of 12% and 7% respectively in high-income adult populations in Western countries. We can compare this to the prevalence rate for PDs ranging from 7.74% or 12.16%, being a similar rate of occurrence. This suggests that while the use of self-rated measures in studies may inflate the reported prevalence rates of PDs, their prevalence is still notably high, as it is comparative to chronic physical conditions such as back pain and respiratory disease. As another example, the physical health conditions of diabetes and cardiovascular diseases have significantly lower prevalence rates than PDs, with these physical health conditions having a prevalence of around 3% (Volkert et al., 2018). Despite these prevalence rates, the authors noted that these physical health conditions are all included in the Global Burden of Disease studies, while PDs are not. This highlights that while PDs are highly prevalent, they do not receive nearly as much attention in research as other conditions, even some with comparable or lower prevalence rates.

However, there are some notable limitations of the Volkert et al. (2018) meta-analysis. There was a low number of studies identified for inclusion in the meta-analysis, and this was exacerbated by the decision to not include studies from non-Western countries so as not to increase variability in prevalence estimates. The authors noted that this low amount of studies might reduce the generalisability of findings, and also meant that the data did not permit analysis of age, gender, or socioeconomic status (SES). A further limitation is that the authors' quality assessment found that there was a high risk of bias for the 'non-respondents' criterion. This means that there is a risk that the prevalence rates are underestimations, as people with more severe impairments are less likely to participate in studies (Volkert et al., 2018). Stigma affects participation in mental health research also (Woodall et al., 2010), and this may have therefore affected participation rates.

Another international study was recently published by Winsper et al. (2019a). These authors found that there had been no review of the global prevalence of PDs in the context of variations between high-, middle-, and low-income countries. Accordingly, these authors conducted a narrative review on this topic to fill this gap. This review again found that PDs are highly prevalent globally. However, similar to Volkert et al. (2018), they found significant variance in the prevalence rates obtained and the methodologies used, though this is likely partly due to their inclusion of different income-level countries. The overall global pooled prevalence rate for having any PD was estimated at 7.8%. This

rate is notably higher than the global period prevalence rates of mood (5.4%) and anxiety (6.7%) disorders. The global pooled rate for BPD was estimated at 1.8% (Winsper et al., 2019b), close to the Volkert et al. study's estimate of 1.9%.

Notably, there were lower PD prevalence rates for low- and middle-income countries, compared to high-income countries. The authors noted that it is unclear what factors might influence this. They noted that the lower rate could be due to differences in behavioural norms between countries (including between individual and collectivist societies), highlighting that little is known "about the impact of culture, race, and ethnicity on mental disorders in general, and PDs specifically" (Winsper et al. 2019a, p. 7). In this way, they speculated that PDs and other disorders might become more prevalent where there are shifts towards Westernisation, and noted that Paris and Lis (2013) have proposed a theory that the prevalence of BPD has increased where "there is a breakdown of social cohesion and social capital" (Winsper et al. 2019a, p. 7). However, Winsper et al. (2019a) also raised other possible contributing factors, including differences in study methodologies creating a misleading picture, or perhaps diagnostic criteria being ill-suited to low and middle-income countries. Accordingly, this exemplifies the need for large-scale, multi-country studies with standardised methods to test whether there are differences between high-income, middle-income, and low-income countries. However, the authors observed that "current diagnostic tools may not adequately capture subtle cultural nuances" (p. 7). There was also a noticeable paucity of studies in low and middle-income countries, and again, significant variation in methodologies used between studies, lowering the reliability of the results obtained. A further limitation was that their analysis indicated a potential publication bias towards higher prevalence rates, meaning that studies with higher prevalence rates were more likely to be published. The authors noted that this could have led to slightly inflated pooled prevalence rates, but that, since interpreting publication bias in prevalence studies is complex, it is unclear if this did impact these rates.

2.4.2.2 US studies

While the global reviews that have been conducted are of value, caution must be taken in interpreting their results, due to the significant variation in target populations, methodologies, and prevalence rates from studies included in these reviews. SA Health (2017) have noted that, when it comes to population-level data, most epidemiological studies on BPD have been conducted in the United States and have obtained rates between 0.5% and 1.4%, with two studies finding higher rates

of 2.7% and 5.9%. These latter two studies were conducted by Trull et al. (2010) and Grant et al. (2008) respectively.

Grant et al. (2008) analysed the second wave of The National Epidemiologic Survey on Alcohol and Related Conditions (NESARC-II) data in the US. Their analysis obtained high PD prevalence rates, with 21.5% for any PD in addition to the result of 5.9% for BPD. This study was subsequently criticised as over-inflating prevalence rates and for being inconsistent with similar epidemiological studies in other countries. Trull et al. (2010) criticised their approach of only requiring one PD symptom to be tied to significant distress, impairment, or dysfunction. These authors argued that if only one symptom is linked with distress, impairment, and/or dysfunction, then it is questionable as to whether the person with these symptoms can be validly categorised as having a PD. They were concerned that inflated prevalence rates would, among other things, impact the comorbidity rates with other disorders by also artificially inflating these rates. This is because a lower threshold of diagnosis for BPD would mean more people diagnosed with BPD, and therefore, more people with other conditions being flagged as also having BPD alongside those conditions. Along the same lines, Tomko et al. (2014) argued that the approach of Grant et al. likely led to people with sub-threshold BPD being included in their prevalence estimate and that this may also affect "assessments of functioning and treatment utilisation" (p. 3).

Trull et al. (2010) reanalysed the NESARC data with a new approach that required each symptom to be tied to significant distress, impairment, or dysfunction to contribute to a PD diagnosis. This approach led to a significant reduction in prevalence rates for PDs, with the rate for having any PD decreasing from 21.5% to 9.1% and with BPD's prevalence decreasing from 5.9% to 2.7%. The authors also noted that this brought their results in line with previous epidemiological studies in the US (Lenzenweger et al., 2007) and Great Britain (Coid et al., 2006). A review of the literature indicates that the results of Trull et al. (2010) have been accepted by many researchers, with many papers choosing to cite these revised results rather than the results published by Grant et al. (2008). Two of these examples include the previously mentioned reviews by Winsper et al. (2019a) and Volkert et al. (2018). In both reviews, the authors chose to incorporate the revised NESARC PD data into their analyses, rather than the higher estimates obtained by Grant et al. (2008). However, there are some important implications of these stricter diagnostic requirements that should be considered. Approaches to PD diagnosis that result in a lower prevalence rate may increase the number of subclinical patients/'diagnostic orphans' (Harford et al., 2013). In contrast, approaches to

PD diagnosis that involve broader and less stringent criteria enable the identification of subclinical patients with personality difficulties of clinical significance, including those who are at risk of developing a PD (Harford et al., 2013). These issues—as well as the competing arguments of Trull et al. and Tomko et al.—must be taken into account when assessing the adoption of stricter diagnostic criteria.

2.4.3 Accepted BPD prevalence rates in the general population

It is clear that the heterogeneity involved in BPD prevalence studies—in terms of both methodologies and results—means that it is difficult to be confident in an individual estimate of the prevalence of BPD or PDs in general. Once more research is conducted with more consistent methodologies and the *ICD-11* can be widely used, this should resolve many of the issues entailed in relying on current diagnostic criteria and other limitations. In the meantime, the data analysed in this paper indicates that BPD has a prevalence rate of between 1% and 6% in the general population. This estimate derives from the Volkert et al. (2018) meta-analysis, which found a global pooled prevalence rate of 0.92% (95% CI: 0.19-2.15%) across Western countries from studies with expert-rated measures; US studies having generally found prevalence rates between 0.4% and 1.4% but with two studies suggesting prevalence could be as high as either 2.7 or 5.9% (SA Health, 2017); and the existing but likely conservative Australian population data of around 1% (Jackson & Burgess, 2000). However, there are also some reasons to have confidence in the figure of 5.9% found by Grant et al. (2008). These include the advantages of broader criteria in identifying those with clinically significant personality disturbances, who would not receive a diagnosis under stricter criteria. Additionally, it is worthwhile noting that the prevalence of 5.9% is identified by the Substance Abuse and Mental Health Services Administration (SAMHSA) in its report to the USA Congress, and was accepted by them (SAMHSA, 2011).

As of March 2020, Victoria has a population of 6.689 million (ABS, 2020). If we accept a BPD prevalence rate of 6%, then that equates to about 401,000 people in Victoria with BPD. If we allow for an average of two family members for every person with BPD, that is about 1,203,000 people. This equates to almost 1 in 6 Victorians directly affected by BPD.

2.4.4 Subgroup research

This section explores the prevalence research on various subgroups, including marginalised groups, for the most part within Australia. Some of the vulnerable groups are derived from the 2014 Report of the National Review of Mental Health Programmes and Services and the South Australian Action

Plan published by the SA Mental Health Commission (2016). This research did not involve a systematic review, so while this section delves into the research on these topics, it does not purport to be an exhaustive summary.

2.4.4.1 Sex differences

Most epidemiological studies find that there is no difference in BPD prevalence between men and women (Grant et al., 2008). Higher prevalence rates for women are sometimes found in clinical studies, but this is possibly due to women being more likely to utilise treatment, and/or other factors such as sampling biases and "biological or sociocultural differences" (Grant et al., 2008, p. 539).

2.4.4.2 Suicide rates in people with BPD and other PDs

Internationally, rates of suicide for people with PDs have been obtained from longitudinal studies of people accessing treatment (Grenyer et al., 2017). They have been estimated at around 10% (American Psychiatric Association, 2001, cited in Grenyer et al., 2017). Most studies are based in North America, which indicates that there are significant data gaps internationally (Grenyer et al.). There is very little data on rates of suicide for people with PDs in Australia. Just a few years ago in 2017, Grenyer et al. wrote that there is no data on this available in Australia. While there is now some Australian data available (Spectrum, 2019), the overall poor coverage of research in this area is concerning. Grenyer et al. advocated for the establishment of a national suicide register, with the inclusion of mental health diagnoses linked to PDs, as this would provide more data in this area. Subsequently, a national suicide register was commissioned in 2019 and is due to be completed in 2022 (Dalzell, 2020). This represents a valuable opportunity to improve knowledge of suicide rates of people with BPD and other PDs, and associated issues.

In a currently unpublished study, Spectrum (2019) recently conducted research in a partnership with the Coroners Court of Victoria. They examined suicides in Victoria from 2009-2013 and found that PD was the "underlying cause" in around 10% of suicides (p. 1). They also found that there was an average of 50 BPD-related suicides in Victoria per year, which constitutes around one BPD suicide per week. Another highly concerning finding was that 99% of individuals with BPD who died by suicide had attended mental health services in the 12 months beforehand, while 88% had in the six weeks before their death. This finding provides evidence that Victoria's mental health system is failing the needs of those with BPD and other PDs. It is also important because, as Spectrum noted, this high access rate offers the potential for intervention at these points of access, including through

suicide prevention strategies. Indeed, Spectrum stated that they have treated 2500 patients with PD over the last two decades and that the suicide rate has been low with only eight deaths out of the 2500 patients. This demonstrates the possibility for much more effective treatment in this area; indeed, Spectrum advocated for Victorian mental health services to implement the treatment strategies used at Spectrum.

2.4.4.3 At-risk groups

2.4.4.3.1 Aboriginal and Torres Strait Islander people

According to community prevalence surveys, between 4–16% of people in Aboriginal and Torres Strait Islander (ATSI) populations fulfil PD diagnostic criteria (Parker & Milroy 2010, cited in Carrotte & Blanchard, 2018). Parker and Milroy (2014, p. 114) have also noted that community prevalence surveys have indicated PD rates of 4% in Mornington Island, 16% in Bourke, and 8.2% in a Kimberley community. However, it is difficult to obtain reliable diagnoses in cross-cultural settings, and obtaining prevalence data in remote locations is especially difficult (Carrotte & Blanchard, 2018). Furthermore, factors such as cultural security need to be considered (Parker & Milroy, 2014).

There has been little research into Aboriginal and Torres Strait Islander (ATSI) populations in relation to BPD, not just in terms of prevalence, but also treatments (Parker & Milroy, 2014). Carrotte and Blanchard (2018) noted in their literature review that there is a paucity of data for Aboriginal and Torres Strait Islander people diagnosed with BPD. The South Australian Department of Health (2019) also noted that they could not find any reliable population BPD prevalence or severity data in Aboriginal populations in SA. Similarly, no data could be identified for Victoria during research for this piece, although this does not preclude the existence of such data.

Some data indicates a BPD prevalence among Indigenous people of 3-4% (Nagel 2005 cited in Fromene et al., 2014). However, Fromene et al. (2014) have suggested that this may be an underestimate. This is because most people are not hospitalised with reference to a BPD diagnosis, but rather are hospitalised under other codes such as self-harm. Accordingly, hospitalisation records may obscure the true proportion of ATSI individuals with BPD presenting to hospitals (Fromene et al., 2014).

2.4.4.3.2 Forensic settings

BPD rates are significantly higher among forensic samples than in community samples. The SA Mental Health Commission (2016) noted that while no research had looked at SA prisoners in

relation to BPD, a survey in WA had. This survey obtained estimates that around 23% of women and 15.8% of men met the criteria for BPD in the forensic population, notably similar to a New Zealand study which found BPD prevalence rates of 20.3% for women and 25.7% for men in a forensic setting (SA Mental Health Commission, 2016). Tye and Mullen (2006) conducted a study with female prisoners in two Victorian prisons and found that 26% of participants were diagnosed with BPD, again significantly higher than in the general community. These high rates are alarming, particularly given that, as the SA Mental Health Commission (2016) observes: "prisons were never designed to be therapeutic environments and can exacerbate symptoms in people with trauma-related mental health issues", making it particularly difficult to provide effective targeted support for this subgroup (p. 8).

2.4.4.3.3 Clinical subgroups

Similar to forensic populations, data highlights that BPD and other PD rates are significantly higher in clinical populations compared to the general community. In a recent and currently unpublished study, Spectrum (2019) estimated that 10,000 presentations to the emergency department in Victoria over a one-year period were from people with BPD. Elsewhere, a literature review by Carrotte and Blanchard (2018) highlighted that studies have found BPD rates of 23% for adult outpatient populations and 25-43% for adult inpatient populations. For youth aged 15-25, around 11-22% of outpatient populations and 42-49% of inpatient populations had BPD (Carrotte and Blanchard).

2.4.4.3.4 Homeless populations

It is difficult to find reliable BPD and PD data in homeless populations in Australia. A meta-analysis conducted by Fazel et al. (2008), which covered seven Western countries including Australia, found the prevalence rate of PDs to be high on average, with a pooled prevalence of 23.1%. However, there was significant heterogeneity in estimates, resulting from variation in methods and group characteristics. A recent study conducted in Victoria by Holmes et al. (2017) examined people with an extensive history of homelessness and housing instability who were clients of housing associations in Melbourne. This study found that 31% had a current or past mental health disorder recorded and that PDs constituted 45% of diagnoses. It also found that clients with a mental health disorder who had been evicted in the past were significantly more likely to have a PD than those who had not been evicted.

2.4.4.3.5 Parents living with BPD who have children, particularly infants

The SA Mental Health Commission (2016) highlighted this subgroup as being an important group for policy considerations. This body's review of the literature (2016, p. 7) found that there is a high rate of BPD prevalence from adolescence through to adults in their mid-30s, "corresponding with the peak child-bearing ages for women". 90% of people who are admitted to hospital with a principal diagnosis of BPD are female, and in SA, half are less than 30 years old, and two-thirds are under 35 (p. 7). Additionally, this review highlighted research showing that 89% of people in contact with community mental health care services with a principal diagnosis of BPD were for women, with women up to the age of 39 comprising two-thirds of these contacts (p. 7). Furthermore, women aged up to 34 comprised half of the contacts, while women aged between 20 and 24 had the most contacts (p. 7). Among the research drawn upon to explain the selection of this group as a target group, this review highlighted international research showing that children of mothers with BPD have an elevated risk of poor psychosocial outcomes, including BPD symptoms and other types of symptoms.

2.4.4.3.6 Young people

There is a general scarcity of data on the prevalence of PDs, including BPD, in young people in Australia (Carrotte & Blanchard, 2018; National Health and Medical Research Council, 2013). One study has placed BPD prevalence for Australians aged 24-25 years at around 3.5% (National Health and Medical Research Council, 2013). However, there is an absence of data for Australian adolescents (Carrotte & Blanchard, 2018).

Chanen et al. (2017) have noted that BPD is prevalent among young people, with an estimated prevalence of 1-3% in the community and with elevated rates in clinical adolescent populations, with an estimated 11-22% in outpatients and 33-49% in inpatients. Carrotte and Blanchard (2018) have also noted that community-based studies have obtained much higher prevalence estimates for PDs in young people than the estimates by Jackson and Burgess, and argued factors contributing to this could be any of the following: PDs being over-represented in these samples (though they observed this is unlikely), decreasing stigma resulting in increased awareness and reporting of PD symptoms, increased prevalence, or differences in methodologies. These factors make it difficult to assess the representativeness of these data (Carrotte & Blanchard).

2.4.4.4 Older adults

There is evidence that the prevalence of BPD may be lower in older age groups above 60 years of age (Khasho et al., 2019). However, there is also evidence that BPD in this age group "differs in presentation from that seen in younger adults", posing challenges to diagnosing BPD in older adults, with an associated possibility that using the *DSM* description of BPD traits may underestimate BPD prevalence in this age group (Khasho et al., 2019, p. 1). Cruitt and Oltmanns (2018) have also noted the possibility of age bias in diagnostic criteria resulting in prevalence underestimates in this group for PDs in general. Whether or not BPD and other PD prevalence are underestimated in older adults, sub-threshold personality difficulties may be another significant issue in this group that categorically based PD research might not detect (Cruitt & Oltmanns).

Internationally, prevalence estimates for one or more PDs in older adults in community samples range from 3% to 13%; however, the prevalence is most likely around 10% in older adults who are 50 years of age or older (Cruitt and Oltmanns, 2018). Within Australia, Jackson and Burgess (2000) reported on BPD and PD prevalence for adults in community samples but did not separately assess people aged 65 or over. Consequently, the prevalence data they obtained applied to adults generally, without allowing any differentiation of older adults.

In their review, Beatson et al. (2016) noted that they had not been able to find any reliable data on the prevalence of BPD in the aged psychiatric population in Australia. However, they highlighted that studies in Australia have obtained high prevalence rates of "any PD" in elderly psychiatric patient samples, with a previous review of six studies finding estimates between 10% and 63% (Widiger & Seidlitz, 2002), and a more recent study obtaining a prevalence of 60% in a sample (Stevenson et al., 2011).

2.4.4.5 Prevalence in rural and remote areas

Research has consistently found that the prevalence of mental illness across geographic categories in Australia is around 20% (Bishop et al., 2018, p. 26). However, these data may be unreliable. It is based on "a person with a mental health condition" accessing the health system, "when the visit is recorded as specifically related to mental health" (NRHA 2014, p. 3). Consequently, this data does not account for people with a mental illness who do not access the health system, which may be affected by many different factors, including barriers to access, e.g. those posed by stigma, distance, and shortages of services and health professionals (NRHA 2014, p. 3). While the data does not show a higher prevalence of mental illness for regional, rural, and remote areas, the impact of mental

illness is far more acute in these areas (CRRMH 2017). This is due to a multitude of factors including poorer access to mental health services, stigma, and various other barriers (CRRMH 2017, p. 11).

It is difficult to find data on PD prevalence, including BPD, disaggregated to regional, rural, and remote areas, both in the international and Australian literature. There may be a case that BPD is more prevalent in these areas because there is more socioeconomic disadvantage. Grant et al. (2008) found that low income and education were associated with higher odds of BPD. However, they also noted that a longitudinal research design is needed to assess whether low SES status is a risk factor for BPD or vice versa. Australian census data indicates that the most disadvantaged local government areas (LGAs) are typically in regional and rural areas (ABS, 2018). Therefore, if low socioeconomic status is tied to higher rates of BPD, it is plausible that there would be higher BPD rates in these areas. However, research is needed to examine BPD prevalence in these areas. Until this happens, there is no clear picture of how these areas do or do not differ from metropolitan areas in terms of BPD prevalence.

2.5 Research methods

There are various research method related issues that impact on the reliability and validity of BPD prevalence estimates, both globally and within Australia.

As has been apparent, the significant heterogeneity in methodologies adopted between studies lowers the confidence that we can have in results and is an important factor behind the high levels of variance in estimates between studies. This has led various researchers (e.g. Quirk et al., 2016; Volkert et al., 2018; Winsper et al., 2019a) to urge for the adoption of standardised methods across studies so that there can be more confidence in the estimates obtained.

The variation in methods includes sampling methods and diagnostic assessment instruments. Many studies rely on self-report methods. These methods do have advantages insofar as they are easier and cheaper to use, whereas “diagnostic interviews require clinical expertise, intensive training and are more time consuming” (Volkert et al., 2018, p. 6). Indeed, Tyrer et al. (2015) have noted the lack of “quick and reliable instruments” in PD assessment, where even self-report measures are quite lengthy assessment methods in their own right (p. 720). However, self-report methods have been criticised for likely overestimating prevalence. Accordingly, various researchers (e.g. Carrotte & Blanchard, 2018; Volkert et al., 2018; Winsper et al., 2019) have urged for studies with expert-rated diagnostic assessment measures in place of self-report measures, to obtain more reliable estimates.

Volkert et al. (2018) have also noted that the complicated and resource-heavy nature of diagnosing PDs may be a factor behind the small number of epidemiological studies on PDs.

A further factor affecting confidence in prevalence estimates is the generally low amount of studies that likely impact the generalisability of the meta-analysis conducted by Volkert et al. (2018) and the global narrative review conducted by Winsper et al. (2019), in addition to other reviews. This low amount of studies also means that these reviews have been unable to analyse prevalence rates for subgroups based on age, gender, SES status, etc. in meta-analyses.

As noted earlier, diagnostic instruments used for some subgroups or settings are not necessarily well-suited for the group they are assessing, which may result in inaccurate prevalence estimates. Volkert et al. (2018) have highlighted that diagnostic criteria for non-Western countries may not be appropriate for these countries and may therefore underestimate prevalence. A 1996 review also highlighted this issue, nothing that current *DSM* diagnostic criteria appear to be unsuited for older adults due to the "unique physical, cognitive and social complications encountered by this segment of society" (Segal et al., 1996, p. 395. Despite this, Beatson et al. (2016) noted that there has still been little progress on this front.

The issue of dimensional versus categorical approaches has already been covered but is another significant research method related issue. These are all issues that need to be resolved in future studies.

2.6 Diagnosis/comorbidity-related issues

There are numerous important issues and challenges with the diagnosis of BPD that relate to prevalence:

2.6.1 Comorbidity

There are high levels of comorbidity and overlap between BPD and other PDs, PTSD, Bipolar Disorder, and various other mental and physical conditions (SAMHSA, 2011). A higher level of comorbidity is also associated with lower numbers of BPD symptoms, below the threshold for diagnosis (Zimmerman et al., 2012).

The overlap in symptoms and comorbidities means that GPs can fail to diagnose BPD (Wlodarczyk et al., 2018). Indeed, GPs report difficulties in diagnosing BPD, including due to "multi-morbid, complex presentations" in time-limited situations, especially for less experienced GPs (Wlodarczyk et al.,

2018, p. 5). One study conducted in the US found that in a sample of 210 patients from a general practice centre, for almost half of them their primary care physician (GP) failed to detect that they were having enduring emotional or mental health problems (Gross et al., 2002). This is unlikely to affect prevalence studies but is nonetheless a concern for clinical practice. Studies have found high rates of misdiagnosis of BPD as Bipolar Disorder (Ruggero et al., 2010; Zimmerman et al., 2010), and there can be confusion over whether diagnosis should be BPD with PTSD or Complex PTSD (Ford & Courtois, 2014). A further factor is that mental disorder comorbidities can overshadow BPD. Tyrer et al. (2019) have noted this concern and suspect that due to this, under the *ICD-11*, "only moderate or severe levels of PD will be recorded, and in some countries only the severe level will be".

Another factor that should be considered is the diagnosis of BPD in young people under the age of 18. There has been and continues to be a reluctance amongst the medical profession towards diagnosing BPD in this group (Grenyer et al., 2017). This caution stems in part from fears about stigma that may result from the diagnosis (National Health and Medical Research Council, 2013, p. 1). However, there is strong evidence that diagnosis and early intervention in this group produce better outcomes (Grenyer et al., 2017). Indeed, the National Health and Medical Research Council (2013) recommended that young people under 18 with "emerging symptoms" be assessed for BPD (Grenyer et al., 2017). The *ICD-11*, in a revision from the *ICD-10*, allows for the diagnosis of BPD at any age (Tyrer et al., 2019).

2.7 Prevalence and stigma & discrimination

Stigma, "defined as a mark of disgrace that sets a person apart" (SA Mental Health Commission, 2016, p. 11), is rife in the mental health system, and this has a number of relevant implications. Discrimination is the unjust or prejudicial treatment of different categories of people. Discrimination is the effect of stigma.

The comparative lack of research for BPD compared with many other mental health disorders raises the question of whether stigma and discrimination may play a part in this. Zimmerman and Gazarian (2014) noted that in the US, BPD has received under one-tenth of the research funding from the National Institute of Health that bipolar disorder has received over the 25 years before the study, with comparatively few grants funded. This is despite the public health costs being not just high for BPD, but also similar to, or perhaps even higher, than for bipolar disorder (Zimmerman & Gazarian, 2014). Accordingly, the authors noted that "the level of NIH research funding for borderline PD is not commensurate with the level of psychosocial morbidity, mortality, and health expenditures

associated with the disorder" (pp. 942-943). Therefore, the authors questioned whether the stigma emanating from the mental health system towards patients with BPD may be a factor in this, a suggestion that has been echoed by Carrotte and Blanchard (2018). It is of course difficult to confirm this, but it is quite a plausible factor. Furthermore, the paucity of research in general on BPD and other PDs, the failure to include PDs in Global Burden of Disease studies, the relegation of PDs to the other category in national reports in Australia, and the exclusion of PDs in national surveys suggest that BPD and other PDs may be implicitly viewed as less important than other mental health conditions.

3 Position statement

BPD Community's position statement details the policy and research implications of the existing prevalence data and the current state of prevalence research.

3.1 BPD Community accepts a BPD prevalence of 6%

The data that exists indicates that BPD is highly prevalent internationally and within Australia. BPD Community accepts a prevalence of 6% for BPD. This is based on the research of Grant et al. (2008). This is accepted because it supports the experience of BPD Community. The analysis above identifies the many challenges and difficulties with prevalence research and data, including the concerns of data that have lower prevalence figures. It is worthwhile noting that the prevalence of 5.9% is identified by the Substance Abuse and Mental Health Services Administration (SAMHSA) in its report to the USA Congress and was accepted by them (SAMHSA, 2011).

3.2 Sub-threshold BPD is also important

It has been highlighted in this paper that people with sub-threshold BPD also need to be considered in research and policy. Further, it is suggested that - given the challenges in diagnosis, the episodic manifestations of symptoms, the appreciation that sub-threshold BPD may develop into more severe BPD if left untreated, and the challenges of co-occurring conditions - a sub-threshold diagnosis today may be a severe condition tomorrow.

3.3 Need for up-to-date prevalence data

It is clear that the state of prevalence research for all PDs, including BPD, is poor, both internationally and within Australia. Quirk et al. (2016) has argued that when PDs aren't included in large-scale epidemiological studies, this may give the incorrect impression that PDs are not a significant public health concern. Extending this line of argument, the paucity of population-based data and subgroup data within Australia for BPD (and PDs in general) likely undermines perceptions of the importance of these conditions. It seems reasonable that this would translate into BPD receiving less attention from governments—and perhaps even researchers in a kind of feedback loop. It also is plausible that this would result in less attention to BPD and PDs from health care professionals. For these reasons, up-to-date research must be conducted in Australia. New population-level estimates for BPD are needed, as the only population-level data available is from the late 1990s and only covers adults (Jackson & Burgess, 2000). Up-to-date data is also needed for various subgroups, including at-risk groups.

The upcoming Intergenerational Health and Mental Health Study represents a valuable opportunity to provide up-to-date population prevalence estimates for BPD and other PDs. It is crucial that this occurs, and that this data continues to be updated frequently in future years. Furthermore, national mental health related-reports, such as those by the AIHW, should aim to collect and provide data in relation to PDs, including BPD, rather than placing them into an 'other' category. When this data is not collected and BPD is part of a broad 'other' category, this risks BPD being overlooked in policy responses and makes it difficult to gain more precise insights into relationships between BPD, comorbidities, health outcomes, health funding, etc.

BPD Community also notes that it is important that the National Suicide Register, expected to be completed in 2022, links suicides with mental health diagnoses, including BPD and other PDs. This will help provide more data on suicide rates for people with BPD.

3.4 Desirable key criteria for prevalence research

BPD Community advocates that future research conducted on BPD prevalence within Australia be based on the *ICD-11*, as soon as this is possible. The *ICD-11*, unlike the existing classification systems, reflects the science that PDs are dimensional in nature. It allows for more nuance in diagnoses, allowing one to specify the severity of an individual's BPD. This also addresses the issue of clinically significant sub-threshold personality disturbances, which can go unrecognised under the *ICD-10* and *DSM* but can receive a diagnosis under the *ICD-11*. These factors mean that research using the *ICD-11* can identify not just the prevalence of BPD, but the prevalence of different levels of severity of BPD. Having this knowledge would be a highly desirable outcome, as it would enable more effective targeting of different types of treatment, social, and relational supports.

Unfortunately, as the *ICD-11* has not yet come into effect, and may take some time to be implemented in Australia, research in the meantime should use the *DSM-5*. Despite its flaws, this is the most current of the diagnostic systems until the *ICD-11* can be used. Ideally, until the *ICD-11* is ready to use, research should aim to extend the approach of ten Have et al. (2016) to Australian populations, by measuring the proportion of people with varying numbers of BPD symptoms from the *DSM*. This would enable prevalence research to assess BPD prevalence for varying levels of severity and to detect the proportion of Australians with clinically significant sub-threshold BPD. Once the *ICD-11* is ready, this would no longer be necessary.

All research should aim, where possible, to use larger sample sizes and to use expert-rated measures of PDs. Additionally, while studying clinical populations is of value, it is also essential that population data is obtained, as clinical population data does not generalise to the general population. More research that assesses BPD prevalence in subgroups including various demographics—particularly at-risk and marginalised subgroups—is also needed.

3.5 Stigma and discrimination

BPD Community suggests the paucity of research into BPD and prevalence is an example of the stigma and discrimination experienced by people with lived experience of BPD. To continue to exclude people with BPD from the data, to continue to ignore the complexity of co-occurring illnesses means to continue to stigmatise and discriminate against people with BPD. People with lived experience of BPD need to be accounted for, they need BPD-informed supports.

The work of BPD Community is to fill the gaps and to replace stigma and discrimination with hope and optimism by creating a community to support recovery and to provide up-to-date, accessible, accurate information for that purpose.

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5 Appendix 1. *ICD-11*: Prominent personality traits

Trait domain	Negative Affectivity	Detachment	Dissociality	Disinhibition	Anankastia
Core feature	The tendency to experience a broad range of negative emotions.	The tendency to maintain interpersonal distance (social detachment) and emotional distance (emotional detachment)	Disregard for the rights and feelings of others, encompassing both self-centeredness and lack of empathy.	The tendency to act rashly based on immediate external or internal stimuli (i.e., sensations, emotions, thoughts), without consideration of potential negative consequences	A narrow focus on one's rigid standard of perfection and of right and wrong, and on controlling one's own and others' behaviour and controlling situations to ensure conformity to these standards.
Common manifestations (not all of which may be present in a given individual at a given time)	Experiencing a broad range of negative emotions with a frequency and intensity out of proportion to the situation; emotional lability and poor emotion regulation; negativistic attitudes; low self-esteem and self-confidence; and mistrustfulness."	Social detachment (avoidance of social interactions, lack of friendships, and avoidance of intimacy); and emotional detachment (reserve, aloofness, and limited emotional expression and experience).	Self-centredness (e.g., sense of entitlement, expectation of others' admiration, positive or negative attention-seeking behaviours, concern with one's own needs, desires and comfort and not those of others); and lack of empathy (i.e., indifference to whether one's actions inconvenience hurt others, which may include being deceptive, manipulative, and exploitative of others, being mean and physically aggressive, callousness in response to others' suffering, and ruthlessness in obtaining one's goals).	Impulsivity; distractibility; irresponsibility; recklessness; and lack of planning.	Perfectionism (e.g., concern with social rules, obligations, and norms of right and wrong, scrupulous attention to detail, rigid, systematic, day-to-day routines, hyper-scheduling and planfulness, emphasis on organization, orderliness, and neatness); and emotional and behavioral constraint (e.g., rigid control over emotional expression, stubbornness and inflexibility, risk-avoidance, perseveration, and deliberativeness).

Adapted from the ICD-11 (World Health Organization, 2020)