

Understanding how best to respond to the needs of Australians living with personality disorder

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Abbreviations

ACT	Acceptance and commitment therapy
CAT	Cognitive analytic therapy
CBT	Cognitive behavioural therapy
DBT	Dialectical behavioural therapy
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th edition
ICD-10	International Classification of Diseases, 10 th revision
LHN	Local Hospital Network
MBS	Medicare Benefits Schedule
MBT	Mentalisation-based treatment
MHTP	Mental health treatment plan
NDIS	National Disability Insurance Scheme
PHN	Primary Health Network
STEPPS	Systems Training for Emotional Predictability

Key terminology

Personality disorder	<p>A condition characterised by pervasive and persistent patterns of thoughts, emotions and behaviour that significantly deviate from cultural expectations and cause clinically significant distress or impairment (American Psychiatric Organization, 2013). The following specific types of personality disorder are identified in DSM-5:</p> <p>Paranoid personality disorder (PPD)</p> <p>Schizoid personality disorder (SPD)</p> <p>Schizotypal personality disorder (SZPD)</p> <p>Antisocial personality disorder (ASPD; ICD-10 dissocial personality disorder)</p> <p>Borderline personality disorder (BPD; ICD-10 emotionally unstable personality disorder)</p> <p>Histrionic personality disorder (HPD)</p> <p>Narcissistic personality disorder (NPD)</p> <p>Avoidant personality disorder (AVPD; ICD-10 anxious-avoidant personality disorder)</p> <p>Dependent personality disorder (DPD)</p> <p>Obsessive-compulsive personality disorder (OCPD; ICD-10 anankastic personality disorder)</p>
Lived experience	Current or former experience of mental illness
Carer	A family member, friend or other person supporting someone living with a mental illness
Online forum	An internet-based discussion site where people can hold conversations in the form of posted messages, which are at least temporarily archived
Specialist service	A service providing support tailored to personality disorder, or providing a treatment which has demonstrated efficacy specifically for personality disorder

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Executive summary

Purpose

The purpose of this report is to review current evidence-based practice, service availability and experiences of treatment for Australians with lived experience of personality disorder, regardless of their circumstances. An overarching aim of this body of work is to improve management of and access to effective treatment and support services for these people.

Background

Personality disorder involves pervasive and persistent patterns of thoughts, emotions and behaviour that significantly deviate from cultural expectations and cause clinically significant distress or impairment. Personality disorder, particularly borderline personality disorder (BPD), is often misunderstood and stigmatised, and associated with challenges for both those with lived experience and their carers, families and other support persons.

This project was commissioned by the National Mental Health Commission to identify treatment and support availability and access through three components: a literature review, an environmental scan and a qualitative study.

Literature review

The literature review was conducted in two parts. Part 1 identified the prevalence of personality disorder in Australia. This review found that approximately 6.5% of Australian adults meet diagnostic criteria for at least one personality disorder, with obsessive-compulsive personality disorder (OCPD) the most common (3.2%), and around 1% of the general population meeting criteria for BPD. It was estimated that around 26% of people presenting to emergency departments for mental health purposes have personality disorder, while 25–43% of adult inpatients and 23% of adult outpatients meet criteria for BPD.

Part 2 involved reviewing current evidence-based treatments for personality disorder. Most research has focused on BPD, with consistent evidence supporting psychotherapy, including dialectical behaviour therapy (DBT), psychodynamic therapy, schema therapy and cognitive analytic therapy (CAT). In general, there was little research that looked into psychotherapy for other personality disorders. People living with avoidant personality disorder (AVPD), dependent personality disorder (DPD) and OCPD appear to benefit from cognitive behavioural therapy (CBT), psychodynamic therapy and social skills training. Results were inconsistent for antisocial personality disorder (ASPD), with some studies reporting benefits from CBT and mentalisation-based treatment (MBT). Treatment guidelines were identified which provide strong recommendations on how to provide best-practice services for people living with personality disorder, including building strong relationships between clinicians and consumers and advocating long term, intensive treatment.

Environmental scan

The environmental scan involved reviewing the Australian mental health system and its appropriateness to personality disorder. Each Australian state and territory government funds and delivers a variety of public sector mental health services, including those in public acute and psychiatric hospital settings (inpatient and outpatient services), community mental health services with specific geographical boundaries, and residential health services. Mental health services are also available in the private sector, which involve fees for service. The scan identified several initiatives that partially or completely fund treatment, including the Medicare Benefits Schedule (MBS) Better Access initiative that subsidises up to 10 individual and 10 group therapy services per calendar year with a psychologist. The scan also identified various specialist services providing evidence-based treatment services for personality disorder, although nearly all of these services were limited to capital cities.

Overall, the environmental scan identified that the current Australian mental health system is not meeting the needs of Australians living with personality disorder. The MBS Better Access initiative does not subsidise the number of sessions required for treatment of BPD (generally weekly individual sessions, plus group therapy, over a year). Few free or low-cost specialist services were identified, and anecdotally these are known to involve long waiting lists. It appears that many people living with personality disorder are engaging with mental health services but not accessing a level of care sufficient for their needs.

The scan also identified several advocacy, education, research and training initiatives underway in Australia. These include dedicated personality disorder training, advocacy and treatment services in Victoria and New South Wales, and national initiatives such as the Australian BPD Foundation and National Education Alliance of BPD Australia (NEA.BPD Aust).

Qualitative study

The qualitative study involved 12 semi-structured participant interviews and two online focus groups, involving people living with personality disorder and carers, families and support persons. The following six themes were identified:

- Identity and discovery
- (Mis)communication
- Barriers and complexities
- Finding what works (for me)
- An uncertain future
- Carer-specific issues.

Participants typically described long, non-linear journeys with treatment and support services, which they perceived to be impacted by stigma and discrimination. Participants reported frustration with financial barriers, waiting lists and availability of specialist support.

Recommendations

Based on the results of the literature review, environmental scan and qualitative study, 11 recommendations were developed. These recommendations relate to the availability of and access to support services; strategies to improve clinician training and reduce stigma from health professionals; and research directions.

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|---|--|
| Understanding the prevalence of personality disorder | 1. Conduct a national, representative survey to identify current prevalence of personality disorder in Australia, providing an update to the 1997 figures. |
| Research directions | 2. Consider funding further research into treatments for personality disorder other than BPD. |
| | 3. Conduct practical and applied research that fills current knowledge gaps for BPD and other disorders. |
| Prevention and early intervention | 4. Scale-up existing early intervention programs. |
| Clinician training | 5. Obtain national commitment to establish and disseminate the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the Management of Borderline Personality Disorder |
| | 6. Consider the feasibility of establishing training and treatment standards to better prepare clinicians to work with personality disorder in an evidence-based and trauma informed way, increasing consistency between clinicians. |
| Improving current care standards | 7. Create a summary resource providing an overview of evidence-based treatment recommendations and options for all personality disorders in collaboration with an appropriate organisation or organisations that can be disseminated to clinicians and people with lived experience. |
| | 8. Take meaningful actions towards system redesign with focus on efforts to streamline pathways, improve access and reduce financial burden carried by individuals with personality disorder. |
| | 9. Develop a holistic approach to meet the needs of families and friends supporting someone living with personality disorder, and scale this to benefit people across Australia regardless of location. |
| Stigma reduction | 10. Identify, implement and evaluate strategies to shift assumptions from health professionals that individuals with BPD cannot benefit from psychotherapy, and other myths utilising a partnership of the existing national advocacy organisations. |
| | 11. Design and conduct formative research into a multi-channel media campaign aiming to educate the Australian community and destigmatise personality disorder. |

Introduction

Personality disorder is a condition characterised by pervasive and persistent patterns of thoughts, emotions and behaviour that significantly deviate from cultural expectations and cause clinically significant distress or impairment (American Psychiatric Organization, 2013). It is estimated that 5–10% of people in western countries meet criteria for personality disorder (Lamont & Brunero, 2009). People living with personality disorder may experience a variety of psychosocial difficulties, including difficulties with maintaining fulfilling relationships; performing well at school, university or other studies; and maintaining employment and performing at work (Zanarini et al, 2010).

The evidence shows that there are a range of biological, psychological and social factors that are believed to contribute to the development of personality disorder. These include genetic factors, attachment insecurity, an invalidating environment (including high family expectations, chaotic family environment, poor match between temperament and environment, abuse and neglect) and other trauma experienced during key developmental periods (Yen, Zlotnick and Costello, 2002; National Health and Medical Research Council, 2012; Chanen et al, 2017; Ibrahim, Cosgrave and Woolgar, 2018).

A particular type of personality disorder, borderline personality disorder (BPD), is of key interest to this study. BPD is characterised by poor control of emotions and impulses, unstable interpersonal relationships and unstable self-image (National Health and Medical Research Council, 2012). People living with BPD often experience high levels of psychological distress and many engage in self-harming behaviour. BPD is conceptualised as a severe form of personality disorder (Sharp et al, 2015; Grenyer, 2017), resulting in personal and interpersonal distress, with many individuals presenting frequently to health services. BPD is also highly stigmatised, with many individuals reporting discrimination and invalidation from health professionals (National Health and Medical Research Council, 2012). It is likely that stigma and discrimination, and lack of access to evidence-based treatments, are contributing factors to the suicide rate for people living with BPD being up to 45 times that of the general population (Chesney, Goodwin, & Fazel, 2014).

Further, carers, families and support persons of people living with personality disorder also experience significant challenges. Carers, families and support persons have reported experiencing their own mental health problems including depression and anxiety, impaired empowerment, financial burden and other types of burden. These difficulties are significantly higher than those experienced by carers of inpatients with other serious mental illnesses (Bailey & Grenyer, 2013).

The National Mental Health Commission recently convened a meeting with several organisations working to improve the lives of those living with BPD. Following this meeting, the Commission identified that it would be useful to better understand the needs of Australians living with all forms of personality disorder, including BPD, to identify evidence-based approaches to prevention, early intervention, treatment and support for recovery and relapse prevention, and to

determine what changes are required to address poor outcomes for those living with personality disorder in Australia.

This discussion paper, prepared by SANE Australia with the support of the National Mental Health Commission, sought to understand how best to meet the needs of Australians living with personality disorder.

About SANE Australia

SANE is a national mental health charity working to provide four million Australians affected by complex mental illness with better support, stronger connections, less discrimination and longer lives.

Every day there are 690,000 Australians living with a complex mental illness, including schizophrenia, bipolar disorder, personality disorders, eating disorders, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and severe depression and anxiety. For every one of these people, there will be at least five family members, friends, colleagues or other people they know who are directly affected by their condition.

Over the past decade, as a nation, we have made great advances in reducing stigma around mild to moderate mental illness. Now more than ever people are seeking help, but there is still a great deal of work to be done to help those at the more severe, or complex, end of the spectrum.

SANE's programmatic offerings include:

- A telephone helpline service operated by trained health professionals
- The SANE Forums, online peer support forums, which enable individuals, families, friends and carers to share their lived experience in a safe, anonymous and supportive environment
- The SANE website, which provides resources and information for people affected by mental illness, to help improve their quality of life
- A suicide prevention guide and program, improving how people are supported in suicide prevention and bereavement through training workshops with mental health and community professionals
- An online media centre, promoting the responsible portrayal of mental illness and suicide in the media and helping health professionals engage with the media
- Policy and engagement programs, advocating for improved mental health and support services
- The Hocking Fellowship, which promotes better mental health by advancing public understanding of mental illness.

SANE provides much-needed support for Australians living with personality disorder, including BPD. For instance, in the 12 months to 31 July 2017, 22% (230,000) of all users (1,048,000) who visited SANE's online platforms accessed materials on BPD, including factsheets and other information.

The SANE Forums are often used by people living with BPD looking for help and support. In the financial year 2016–17, there were 2,464 individual posts on the SANE forums referencing BPD. A 2017 survey of 233 SANE forum users found that:

- Nine of 71 who identified as carers (12%) reported as caring for someone with a diagnosis of BPD
- 27 of 196 who identified as having lived experience (13%) reported having a diagnosis of BPD.

In the same year, the SANE Helpcentre had an estimated 1,350 contacts (12% of all contacts) regarding BPD across phone, email and web chat (based on a 9am–5pm service). This service now operates 10am–10pm and we anticipate the number of contacts increasing.

About this discussion paper

This project sought to understand how best to meet the needs of Australians living with personality disorder through three processes:

- A literature review examining the prevalence of personality disorders in Australia and identifying evidence-based approaches to prevention, early intervention, treatment and support for recovery and relapse prevention
- An environmental scan of key activities relating to improving wellbeing for people living with personality disorders in Australia
- A qualitative study engaging with Australians living with personality disorders and their carers, families and other support persons to examine their experiences with evidence-based approaches to prevention, early intervention, treatment and support for recovery and relapse prevention.

This discussion paper synthesises the findings from these activities.

Part A presents the findings from the literature review and answers the following questions:

- What is the prevalence of personality disorder in Australia?
- What are the evidence-based approaches to prevention, early intervention, treatment and support for recovery, and relapse prevention for specific personality disorders?

Part B presents the environmental scan and seeks to answer the following questions:

- What treatment and psychosocial support options for people living with specific personality disorders are available in Australia, through the private sector, the public sector, and non-government organisations?
- What educational, awareness-raising or workforce capacity-building activities are underway regarding personality disorders in Australia?

Part C presents the findings from the qualitative study. This study, conducted with individuals living with personality disorder and their carers, families and other support persons, seeks to answer the following questions:

- What types of treatment and support services are accessed by people living with personality disorders and their carers, families and other support persons?
- What are the perceived benefits and challenges associated with these services?
- What changes would these individuals like to see with regards to service provision and access?

Building on the findings from Parts A, B and C, this paper then presents 11 recommendations for research, policy and practice efforts to better support the needs of Australians affected by personality disorder.

Understanding personality disorder

Personality disorders are identified by two major classification systems: the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) and the International Classification of Diseases, 10th revision (ICD-10). An overview of how the disorders are classified within these systems is presented in Table 1. The DSM-5 is the dominant classification system within the Australian mental health system, although use of ICD-10 as opposed to DSM-5 differs by state and territory and by clinical service. The ICD is currently undergoing revision, and ICD-10 terminology is being used less frequently.

Within the DSM-5, the personality disorders are grouped into three ‘clusters’:

- **Cluster A** includes paranoid, schizoid, and schizotypal personality disorders. Individuals with these disorders can appear *odd* or *eccentric*.
- **Cluster B** includes antisocial, borderline, histrionic, and narcissistic personality disorders. Individuals with these disorders can appear *dramatic*, *emotional*, or *erratic*.
- **Cluster C** includes avoidant, dependent, and obsessive-compulsive personality disorders. Individuals with these disorders can appear *anxious* or *fearful*.

DSM-5 notes that in the American context, Cluster C disorders have been identified as the most prevalent personality disorders, with an estimated 6% of the population meeting diagnostic criteria (American Psychiatric Organization, 2013). The second most prevalent cluster is Cluster A (5.7%) followed by Cluster B (1.5%). The DSM also notes that 9.1% of the general population are believed to meet diagnostic criteria for any personality disorder, with more than one type of disorder frequently co-occurring. Of note, the ‘cluster’ system used in DSM-5 has been widely criticised and is not evidence-based (Herpertz et al., 2017).

In the forthcoming ICD-11, currently under consideration, the various specific personality disorder diagnoses will be replaced by a single diagnosis: ‘personality disorder’. ICD-11 will introduce specifiers called ‘prominent personality traits’ and the possibility to classify degrees of severity ranging from ‘mild’ to ‘moderate’ and ‘severe’ based on the individual’s level of

dysfunction in interpersonal relationships and everyday life. ‘Domain traits’ will also be included to personalise diagnosis, and a ‘borderline’ specifier will be available.

There are a few reasons for these changes. First, the 10 categories in the DSM create artificial boundaries between clusters of symptoms, resulting in many individuals meeting diagnostic criteria for several disorders. Second, there is evidence for more ‘general’ symptomology between different diagnostic categories, with a single ‘general’ disorder appearing to overlap most with BPD in terms of interpersonal problems and identity disturbance (Grenyer, 2017). The challenge will be for clinicians, researchers and consumers to reconceptualise previous diagnoses within the new ICD-11 system, and understand and identify with new diagnoses.

Table 1. Personality disorders, as identified by DSM-5 and ICD-10

DSM-5 Cluster	Personality disorder	Brief description
A	Paranoid personality disorder (PPD)	A pattern of distrust and suspiciousness such that others’ motives are interpreted as malevolent.
A	Schizoid personality disorder (SPD)	A pattern of detachment from social relationships and a restricted range of emotional expression.
A	Schizotypal personality disorder (SZPD)	A pattern of acute discomfort in close relationships, cognitive or perceptual distortions, and eccentricities of behaviour.
B	Antisocial personality disorder (ASPD; ICD-10 dissocial personality disorder)	A pattern of disregard for, and violation of, the rights of others.
B	Borderline personality disorder (BPD; ICD-10 emotionally unstable personality disorder – borderline or impulsive type)	A pattern of instability of interpersonal relationships, self-image and affects, and marked impulsivity.
B	Histrionic personality disorder (HPD)	A pattern of excessive emotionality and attention-seeking.
B	Narcissistic personality disorder (NPD)	A pattern of grandiosity, need for admiration, and lack of empathy.
C	Avoidant personality disorder (AVPD; ICD-10 anxious-avoidant personality disorder)	A pattern of social inhibition, feelings of inadequacy, and hypersensitivity to negative evaluation.
C	Dependent personality disorder (DPD)	A pattern of submissive and clinging behaviour related to an excessive need to be taken care of.
C	Obsessive-compulsive personality disorder (OCPD; ICD-10 anankastic personality disorder)	A pattern of preoccupation with orderliness, perfectionism, and control.

Part A: Literature review

The literature review aimed to answer the following questions, in relation to the specific personality disorders identified categorically in DSM-5, and their ICD-10 equivalents:

- What is the prevalence of specific personality disorders in Australia?
- What are the evidence-based approaches to prevention, early intervention, treatment and support for recovery and relapse prevention for specific personality disorders?

Methods

The literature review examined both grey and peer-reviewed literature to identify the prevalence of specific personality disorders in Australia. Purposive searches for prevalence were conducted by browsing the websites of mental health organisations, which are known to provide information about personality disorders and mental health in Australia. Further, PsycINFO and Medline were searched in January 2018. The database search strategy involved a combination of a term related to prevalence, a personality search term or subject term, and a location term. Titles and abstracts were screened by the first author, and citations that appeared relevant were downloaded to the reference management software Mendeley.

A similar search strategy was used for identifying approaches to prevention, early intervention, treatment and support for recovery and relapse prevention. In order to identify highest quality 'Level I' evidence (Merlin, Weston, & Toohar, 2009), the search was first conducted using search terms relating to systematic reviews or meta-analyses. As the search failed to identify systematic reviews relating to all personality disorders, searches were conducted again for specific personality disorders without the systematic review search terms. Searches involved both DSM-5 and ICD-10 terminology. All empirically supported treatments were considered for inclusion in the review, with focus placed on highest quality 'Level I' and 'Level II' evidence (that is, randomised control trials). In the event that no empirically supported treatments were identified, case studies and treatment guidelines were reviewed.

1. The prevalence of specific personality disorders in Australia

Population-wide estimates

Most studies identified in the literature review described prevalence estimates of personality disorders in specific populations or settings. A summary of this is available later in this section (see 'Special settings and populations'). The literature review identified only one study providing population-level data regarding the prevalence of personality disorders in Australia (Jackson & Burgess, 2000). This study drew its estimates from the 1997 National Survey of Mental Health and Wellbeing, conducted by the Australian Bureau of Statistics. It involved face-to-face interviews with over 10,000 Australian adults from randomly selected households. Participants completed a screening process, using the International Personality Disorder Examination ICD-10 Screener (IPDE). In order to generalise findings to the wider Australian population, statistical techniques were used to extrapolate data (see Table 2), although these estimates may be conservative.

Table 2. Estimated percentages of adult Australian men and women with specific personality disorders, from the 1997 National Survey of Mental Health and Wellbeing

ICD-10 personality disorder	Men (%)	Women (%)	Total (%)
Paranoid personality disorder	1.41	1.01	1.21
Schizoid personality disorder	1.93	1.50	1.71
Emotionally unstable personality disorder – impulsive type (BPD)	1.65	1.02	1.33
Emotionally unstable personality disorder – borderline type (BPD)	1.08	0.83	0.95
Histrionic personality disorder (HPD)	0.69	0.52	0.60
Anankastic personality disorder (OCPD)	3.73	2.71	3.21
Anxious personality disorder (AVPD)	1.75	2.30	2.03
Dependent personality disorder	0.72	1.13	0.93
Any personality disorder	6.83	6.13	6.47

Note: DSM-5 equivalent diagnosis is presented in brackets where ICD-10 diagnostic labels differ.

These findings estimate that approximately 6.5% of Australian adults meet diagnostic criteria for at least one personality disorder. This is similar to other large population studies in western countries, which estimate that 5–10% of people meet diagnostic criteria for personality disorder (Lamont & Brunero, 2009). With regards to the sample-level data only, Jackson and Burgess (2000) found that 3.76% met criteria for one specific personality disorder, 1.46% met criteria for two diagnoses, 0.58% three diagnoses, 0.41% four diagnoses, and 0.31% five or more diagnoses. The authors found no statistically significant gender differences when examining population-level data, estimating that neither men nor women were more likely to experience any particular disorder when looking at the general community.

Anankastic personality disorder (OCPD) was estimated to be the most prevalent personality disorder, with 3.73% of men and 2.71% of women estimated to meet diagnostic criteria. No participants in this study met diagnostic criteria for dissocial personality disorder (ASPD). It is possible that this may have been due to social desirability bias, as adults participating in face-to-face interviews may have under-reported antisocial behaviour, and people living with antisocial traits may be unlikely to agree to participate in the study. The study also did not screen for narcissistic personality disorder (NPD) as it is not included in the IPDE screener. Hence, this study did not provide estimated prevalence for these two diagnoses.

Although this study provides the ‘most generalisable’ data identified in the literature review, it has notable limitations. It utilised a self-report, brief screening tool, limiting its validity. A broader discussion of limitations by the authors can be found in their publication (Jackson and Burgess, 2000).

Other community estimates

Two Australian studies were identified in the literature review that provided more recent prevalence estimates drawn from the community. The first of these provides estimates drawing on a cohort of 1,145 young Australian adults (mean age 24.1 years) who were followed in 2001–03 (Moran, Coffey, & Mann, 2006). Informants (a friend, sibling or partner) completed a semi-structured telephone interview with a research psychologist. The assessment tool was the ICD-10 version of the Standardised Assessment of Personality, a validated tool. The study reported that 18.6% of participants met diagnostic criteria for at least one personality disorder. The study found the following prevalence rates of personality disorders, in descending order of prevalence: 6.6% PPD, 5.8% OCPD, 4.6% AVPD, 3.6% NPD, 3.5% BPD, 3.1% ASPD, 2.4% HPD, 2.3% SPD, 1.0% DPD, 0.9% SZPD. Female participants were more likely than male participants to meet diagnostic criteria for Cluster A disorders. However, as this study also used a screening tool, and relied on information from informants rather than reports from participants themselves, its findings should be interpreted with caution.

A second cohort study was found which provided community-based prevalence estimates. In this study (Quirk et al, 2017), data was collected from 768 women aged 25 and over enrolled in an age-stratified ongoing cohort study. Participants were originally selected at random from the electoral roll. Participants completed a widely used and comprehensive structured interview (Structured Clinical Interview for DSM-IV Axis II personality disorders) with interviewers with postgraduate qualifications in psychology. Results were standardised to the general Australian population of women, finding an overall prevalence of 21.8% for any personality disorder. In descending order, prevalence was: 10.3% OCPD, 9.3% AVPD, 3.9% PPD, 2.7% BPD, 1.7% SZPD, 1.0% SPD, 0.8% DPD. Too few cases of NPD and ASPD were found in the sample to calculate standardised prevalence estimates ($n = 4$ and $n = 1$ respectively), and no participants met criteria for HPD. Comorbidity was common, with those with Cluster C disorders (particularly AVPD) most likely to meet criteria of at least one additional disorder, followed by those with Cluster A disorders.

Special settings and populations

There is a variety of research that has focused on establishing personality disorder prevalence among specific populations and settings. Key findings are described below:

- The Australian Institute of Health and Welfare reported that in 2015–16, <5% of emergency department presentations for mental health difficulties were related to principal diagnosis of personality disorder (Australian Institute of Health and Welfare, 2014). It is estimated that 26% of those presenting to emergency departments for a mental health bed have a personality disorder (Grenyer, 2015).
- It is estimated that up to 23% of adult outpatient populations and 25–43% of adult inpatient populations meet diagnostic criteria for BPD (Grenyer, 2015; National Health and Medical Research Council, 2012). Among youth aged 15–25, it is estimated that 11–22% of outpatient populations and 42–49% inpatient populations meet diagnostic criteria for BPD (Chanen et al, 2004, 2008).

- Among Australian forensic populations, an estimated 40–43% of prisoners meet diagnostic criteria for any personality disorder, with 27% meeting criteria for a Cluster A disorder, 31% for Cluster B and 28.6% for Cluster C (Butler et al, 2006, 2007). The estimated prevalence of ASPD among Australian prisoners varies considerably, between 3–30% of prisoners (Tye and Mullen, 2006; Butler et al, 2007; Shepherd, Campbell and Ogloff, 2018). The prevalence of other personality disorders among prisoners is estimated to be 15–33% PPD, 11–17% SPD, 13–26% BPD, 12% NPD, 3–8% HPD, 13–20% AVPD, 6–13% DPD, and 12–15% OCPD (Butler et al, 2006; Tye and Mullen, 2006).
- Among Aboriginal and Torres Strait Islander (ATSI) populations, community prevalence surveys report that 4–16% of these populations meet diagnostic criteria for personality disorder (Parker & Milroy, 2010). Based on hospital data from 2005–06 (Pink & Allbon, 2008), the ratio of Indigenous men with personality disorder compared to non-Indigenous men was 1.8:1. The ratio of Indigenous women with personality disorder compared to non-Indigenous women was 0.8:1. These data indicate that the rates of personality disorder in ATSI communities are slightly higher for men and slightly lower for women, although data are not very recent. Complicating matters, there are difficulties associated with diagnosing personality disorder in cross-cultural contexts and it is difficult to obtain clear prevalence estimates for ATSI populations in remote areas.
- The prevalence of personality disorder among older Australians appears to be under-researched. However, data collected by Stevenson et al (2011) that compared data from different age groups found that for those aged 65 and over (n = 98), 60% met criteria for at least one personality disorder. Comparatively, Quirk et al (2016) found that women aged 55–64 were most likely to meet criteria for a personality disorder in their study, with 21.7% of this age group meeting diagnostic criteria. Further, 14.8% of those aged 75 or older met diagnostic criteria for a personality disorder in this study.

Discussion and conclusions

With consideration of available evidence, it is clear that there is no comprehensive or recent data on personality disorder prevalence in the general Australian population. Based on the most representative, available data, it appears that the most common specific personality disorders are Cluster C disorders (OCPD, AVPD and DPD) and the least common are certain disorders belonging to Cluster B (NPD, HPD and ASPD). It is common for individuals to meet diagnostic criteria for more than one specific personality disorder, which emphasises the common risk factors for these disorders and overlap in symptomology between diagnoses. However, the prevalence rate of 6.5% identified by Jackson and Burgess (2000) – although conservative – is broadly aligned with international research about personality disorder prevalence (Lamont & Brunero, 2009).

An interesting finding is that neither men nor women appear to experience personality disorder more frequently. This finding is particularly relevant to BPD, as it is understood that women are three times more likely than men to receive the diagnosis (American Psychiatric Organization, 2013), and some studies have found clinicians exhibit a slight gender bias towards diagnosis in

women (Sansone & Sansone, 2011). This is likely to be a result of several interacting factors including different patterns in BPD symptoms between men and women, misconceptions from health professionals, and women's generally higher help-seeking behaviours (Sansone & Sansone, 2011).

Individuals living with personality disorder, particularly BPD, appear to frequently present to mental health services, including inpatient, outpatient and emergency departments. This is aligned with understandings of the lifetime course of BPD, with many individuals presenting to services across adolescence and adulthood (Biskin, 2015). It is understandable that individuals with BPD frequently attend services, considering the presence of life-threatening behaviours, such as suicidality and self-harm.

Individuals with ASPD tend to be over-represented in forensic settings, but estimates of ASPD in Australian forensic populations varied significantly. A large systematic review of international studies found that around 21% of prisoners meet diagnostic criteria for ASPD, concluding that prisoners were about 10 times more likely to have ASPD than the general population (Fazel & Danesh, 2002). However, community-based studies are likely to underestimate the prevalence of ASPD in the general community due to social desirability bias.

Community-based studies that have explored prevalence of personality disorder in young people and women have found substantially higher estimates than Jackson and Burgess (2000). This may be due to a number of factors. First, Jackson and Burgess (2000) involved a representative sample, and it is possible (although unlikely) that personality disorder was over-represented in smaller samples using different sampling methods. Second, community-based studies are more recent, and it is possible that in the context of decreasing stigma around mental illness, individuals are more able to recognise and report symptoms of personality disorder. Alternatively, it is possible that personality disorder is more prevalent within a younger population (Moran et al., 2006) or is becoming more prevalent in general. Third, methods differed between studies with regard to self-reported as opposed to informant-based data and selection of measures. Considering these factors, it is important not to take any of these prevalence statistics as being particularly representative of current personality disorder prevalence.

Of note, there is no evidence that looks specifically at personality disorder prevalence from the perspective of the most recent and most widely used diagnostic criteria (DSM-5), although DSM-5 and DSM-IV are similar. Given that the diagnostic criteria will change with the introduction of ICD-11, it is timely that further research is conducted examining prevalence in an Australian context. Such research would need to include a sample that is as representative as possible of the Australian population, and include a measure that is up-to-date with current diagnostic criteria. The National Survey of Mental Health and Wellbeing was repeated in August–December 2007. Methodological changes were made between the two surveys; personality disorder screening questions were not asked in the 2007 survey (Australian Bureau of Statistics, 2008). Further, the most recent Young Minds Matter survey (a national survey of Australian children and adolescents in 2013-2014, also conducted through the Australian Government Department of Health) also did not assess personality disorder, instead focusing

on 'common' mental disorders. At the time of writing, a more recent version of the adult survey has not yet been conducted. This means that the most recent population-level data for personality disorder prevalence in adults is over 20 years old. Australia is still lacking population-wide estimates for adolescents, adults of different age groups, and for personality disorders using DSM-5 criteria (including ASPD and NPD).

Limitations

Although the literature review aimed to be comprehensive, it was not a systematic review and it is possible that studies were missed.

2. Current evidence-based treatments for specific personality disorders in Australia

2A. Prevention, treatment and support – overall principles

It is known that evidence-based psychotherapy can provide at least some degree of symptom relief (Rudick, 2017), with many individuals ‘recovering’ or ‘remitting’ from their experience of personality disorder. The concept of ‘recovery’ may involve no longer meeting DSM-5 or ICD-10 diagnostic criteria, or may be based on a more holistic approach involving a personal understanding of functioning and symptomology (Ng, Bourke, & Grenyer, 2016). The most common psychotherapies that have been studied for personality disorder are dialectical behaviour therapy (DBT), integrationist, psychodynamic and psychoanalytic therapies (Rudick, 2017). See Appendix A for a brief summary of psychotherapy approaches.

Treatment efficacy may be influenced by therapist type, gender, age and other factors (Rudick, 2017). In general, it is recommended that individuals with personality disorder participate in psychotherapy that is evidence-based and designed specifically for treatment of personality disorder, if available (National Health and Medical Research Council, 2012). However, it is critical that treatment involves development of a strong therapeutic alliance and takes into account overall treatment principles (see Table 3 for treatment guidelines adapted from: National Health and Medical Research Council, 2012; Bateman, Gunderson and Mulder, 2015; Project Air Strategy for Personality Disorders 2nd ed, 2015). Although trauma therapy may be useful for individuals with a history of trauma, such therapies are not recommended as frontline treatments for personality disorder (Lewis & Grenyer, 2009). However, individuals may benefit from *trauma-informed practice*, which is sensitive to the impact of trauma, emphasises physical and psychological safety, and empowers survivors to rebuild a sense of control and empowerment (Kezelman & Stavropoulos, 2012).

Table 3. Overall personality disorder treatment principles

Domain	Principles
Clinician approach	<ul style="list-style-type: none"> • Be compassionate, empathetic, open, non-judgemental, consistent, reliable, validating, and encouraging. • Foster trust and convey hope. • Take individuals’ experiences seriously. • Be aware of and comfortable with the spectrum of interpersonal challenges that can be present in the therapeutic relationship (such as hypersensitivity, ambivalence, verbal aggression). • Engage in reflective practice and seek supervision or consultation. • Clearly explain processes and work collaboratively with consumers regarding treatment choices, where feasible • Be consistent, clear and predictable.
Assessment	<ul style="list-style-type: none"> • Conduct a comprehensive semi-structured interview and consider use of formal diagnostic instruments such as the Structured Clinical Interview for DSM-5 (SCID-5). • Communicate diagnoses, share formulations, acknowledge strengths and convey optimism about prospects of treatment. • Offer post-assessment support – particularly important when sensitive or traumatic material has been discussed – including out-of-hours phone support

Domain	Principles
Risk and crisis	<p>and crisis numbers.</p> <ul style="list-style-type: none"> • Sit with anxiety associated with chronic risk relating to suicidal and parasuicidal behaviours (and recognise the challenges associated with this). • Conduct thorough risk assessments and distinguish between chronic and acute risk (in context of risk to self and risk to others, where applicable). • Develop collaborative care plans to identify self-management strategies to reduce distress, and emergency contacts. • In the context of chronic personal risk, aim to engage in community-based treatment with continuity of care (if possible). • In the context of acute personal risk, consider brief hospital admissions, establish a care plan, inform others and gain support (for example, through a crisis team, family member or colleague).
Hospital settings	<ul style="list-style-type: none"> • Hospital admissions should be brief and goal-directed – for example, with the goal of preventing exacerbation of symptoms and risk. • In many cases, it is preferable to engage a person in community-based care rather than admitting to hospital, particularly if community-based care is provided within 1–3 days of crisis presentation. • Planned, brief hospital stays may be a useful alternative to involuntary hospital admissions. • Physical restraint and seclusion should only be used for the most extreme behaviours that threaten life or property. • Create comprehensive discharge plans to reduce rates of readmission. • Refrain from reinforcing self-harming behaviours and focus on the course of events that led to self-harm. • Provide referral to a follow-up service prior to discharge, and crisis contact information. • Enhance collaboration with carers by contacting carers within 48 hours of admission, provide information about diagnosis and management strategies, and involve them in discharge planning.
Medication	<ul style="list-style-type: none"> • Pharmacotherapy is not generally recommended as a primary treatment for personality disorder and should generally only be used to target specific symptoms. • Ensure medications are trialled sequentially, in a systematic way, and regularly review risks and benefits. • Avoid polypharmacy (concurrent use of multiple medications).
Working with families and carers	<ul style="list-style-type: none"> • With written consent, meet with carers and provide education about the person’s diagnosis, prognosis and treatment. • Encourage self-care. • Offer regular feedback and review sessions (for example, every three months). • Validate carer stress and reduce blame. • Consider variation in challenges associated with parent, spouse or partner, child and sibling carers.
Ongoing community treatment	<ul style="list-style-type: none"> • It is to be expected that progress may be slow or varied in earlier stages of treatment and it can be helpful to communicate this to the person; celebrate steps consistent with treatment goals. • Psychotherapy is the treatment of choice. The minimum expected duration of treatment is one year with weekly appointments. • Select evidence-based approaches and consider the key aspects of treatment: a focus on the therapeutic relationship, an active therapist, attention to affect and emphasis on exploratory change-oriented interventions.

Domain	Principles
	<ul style="list-style-type: none"> • Adapt frequency of treatment sessions to the person’s needs (for example, twice-weekly if necessary). • In the event that psychotherapy comes to an end, prepare with sensitivity well in advance, consider using a symbolic ending (such as a card or letter), summarise the therapy and invite the consumer to also summarise. In the case of unplanned termination (for example, clinician changing jobs), handle with care and sensitivity.

Table 4 presents a summary of personality disorders psychotherapies supported by evidence. Other important principles to note with regards to prevention, treatment and support of personality disorder include the following:

- A range of factors are believed to contribute towards the development of personality disorder, including genetic factors and developmental trauma. A major target for preventing development of personality disorder involves reducing young people’s exposure to trauma. A comprehensive discussion of personality disorder prevention is not within the scope of this review.
- Some people living with personality disorder do not present for psychotherapy, or tend to present only in the context of a crisis or a discrete issue, or at the insistence of someone else (Gabbard, 2014b). This can make early intervention and long-term treatment and support challenging. One factor influencing treatment challenges is the experience of ego-syntonic cognitions and behaviours, such that they are not perceived to be problematic, despite causing impairment or significant distress to others around them. Hence, individuals with personality disorder may demonstrate low levels of insight into their difficulties and neither desire nor present for assessment or treatment. However, individuals will certainly not present for treatment if it is not available (see Part B, which discusses the environmental scan).
- Personality disorder comorbidity is the norm rather than the exception, with common coexisting diagnoses including depression, anxiety, eating disorders, and substance use. The treatment of comorbid personality disorder and alcohol use can be challenging, as comorbidities contribute substantially to the severity of presentation, the challenges of management and the risk of self-harm and suicide. There is some evidence indicating personality disorder with comorbid disorders can be treated – for example, people living with personality disorder show a similar amount of improvement in alcohol-related outcomes compared to people without personality disorder (Newton-Howes et al, 2017). The presence of substance use or other comorbidities should influence treatment planning.
- Brief intervention programs have been developed by Project Air Strategy for Personality Disorders and Spectrum Personality Disorder Service for Victoria, and these are currently being evaluated.

Table 4. Personality disorders psychotherapies supported by Level I (systematic review/meta-analysis) and Level II (randomised control trial) evidence

Personality disorder	Level I	Level II
PPD	n/a	n/a
SPD	n/a	n/a
SZPD	n/a	n/a
ASPD	n/a ~	CBT; MBT
BPD	DBT; psychodynamic (MBT; transference-focused psychotherapy); schema; CAT; STEPPS	CBT, ACT
NPD	n/a	n/a
HPD	n/a	n/a
AVPD	n/a *	CBT; social skills training
DPD	n/a *	n/a
OCPD	n/a *	Supportive-expressive dynamic therapy; CBT; IPT

~ Meta-analytic evidence supports treatment for conduct disorder, a precursor to ASPD, using CBT and other behavioural interventions, family therapy and group therapy

* Studies combining Cluster C disorders have provided Level I evidence for treatment with CBT, psychodynamic therapy, and interpersonal social skills training

2B. Treatment and support for Cluster A personality disorders

Paranoid personality disorder

No known controlled studies have explored psychotherapy treatment efficacy specifically for PPD (Crits-Christoph et al, 2015). Therefore, it is unclear which treatment modes are effective in this population. Some case studies have explored cognitive analytic therapy and found positive results (Calvert & Kellett, 2014; Kellett & Hardy, 2014). Suggested therapeutic approaches include supportive therapy or CBT, although this is not supported by evidence (Stone, Gabbard and Gabbard, Glen O, 2014). Medications generally have little efficacy and little role in therapy, although antipsychotic medications may reduce anxiety in some. If paranoid cognitions are directed towards ingesting medications, these individuals may be resistant to pharmacotherapy (Stone et al., 2014).

Goals of therapy may involve increasing insight and reducing negative assumptions (such as 'People don't like me and want to take advantage of me'). Clinicians working with individuals with PPD need to be transparent regarding therapeutic decisions and aware that paranoid

cognitions may impact therapeutic processes (Stone, Gabbard and Gabbard, Glen O, 2014; Kellett and Hardy, 2014).

Schizoid personality disorder

No known controlled studies have explored psychotherapy treatment efficacy specifically for SPD (Crits-Christoph et al, 2015). As above, it is unclear which treatment modes provide consistent benefits. Suggested therapeutic approaches include supportive therapy, CBT or psychoanalytic therapy (Stone, Gabbard and Gabbard, Glen O, 2014; Wheeler, 2014; Beck, Davis and Freeman, 2015). Case studies have demonstrated some positive impacts of psychodynamic approaches (Viveier, 2012). Medication may be helpful in treating comorbid depression or anxiety, rather than treating 'pure' SPD (Stone, Gabbard and Gabbard Glen O, 2014).

Goals of therapy may include improving coping skills and social skills and increasing self-esteem (Stone, Gabbard and Gabbard, Glen O, 2014). Individuals with SPD attending psychotherapy may display aloofness and have difficulty volunteering information about themselves, and may display limited insight into their problems. People living with SPD typically appear comfortable with their detached lifestyle and may be resistant or indifferent to change (Beck et al., 2015).

Schizotypal personality disorder

People living with SZPD vary in presentation, with some displaying minor 'eccentric' behaviours and others displaying more severe or intrusive delusions, with symptomology closer to that of schizophrenia. Hence, there is no one-size-fits-all approach; therapists need to identify specific goals and target meaningful behaviour change (Ryan, Macdonald and Walker, 2013; Stone, Gabbard and Gabbard, Glen O, 2014). One major aim of treatment may be to prevent progression to psychosis, as individuals with this disorder have an estimated 20–30% chance of developing psychosis within two years (Ryan et al., 2013). Goals of therapy might involve improving communication and social skills, improving self-esteem, reducing obsessions and ruminations, improving interpersonal relationships, building mastery, and distancing from delusions (Stone, Gabbard and Gabbard, Glen O, 2014; Ridenour, 2016). Further, cannabis use is associated with more severe and earlier onset schizotypal symptoms, and may therefore be an important target for early intervention if relevant (Ryan et al., 2013).

Few studies are available relating to SZPD (Crits-Christoph et al, 2015). The authors identified only one controlled trial specific to SZPD (Ridenour, 2016), a small study which involved modified assertive treatment, family treatment and social skills training within a multidisciplinary team. There were no significant benefits for the treatment group compared to the 'treatment as usual' group. However, more research is available which looks more broadly at schizophrenia spectrum disorders; such studies typically include individuals with SZPD within their samples. Importantly, meta-analytic evidence indicates that CBT may help prevent the development of psychosis among those with schizophrenia spectrum disorders (including SZPD) and can also help reduce symptoms of depression and anxiety in this population (Ryan et al., 2013). Other psychotherapeutic approaches that may be used include supportive therapy, psychodynamic

therapy, cognitive training, social skills training, family therapy and motivational interviewing (Salam et al, 2013; Stone, Gabbard and Gabbard, 2014; Ridenour, 2016). Mixed evidence supports the use of antipsychotic medication to reduce positive symptoms such as delusions and improve mood (Jakobsen et al, 2017). Omega-3 fatty acids have been demonstrated to reduce conversion to psychotic disorders among young people living with schizophrenia spectrum disorders, with further trials currently underway (Ryan et al., 2013).

2C. Treatment and support for Cluster B personality disorders

Antisocial personality disorder

Research has explored interventions for ASPD, with a particular emphasis on prevention and early intervention. A recent meta-analysis indicated that overall, the impact of treatment in adult populations is consistently minimal (Rudick, 2017). However, meta-analyses indicate that early intervention is possible for those demonstrating antisocial traits in childhood and adolescence. A large overview of meta-analyses (Litschge, Vaughn, & McCrea, 2009) found that for children and adolescents with conduct problems, treatments generally have a small to medium effect relating to reducing conduct problems, improving academic performance and reducing substance use. CBT and other behavioural interventions, family-based therapies and group therapies tend to be moderately effective. Stimulant therapies were found to produce relatively large effects relating to reducing aggression. Mentoring programs generally produced small effects, and 'boot camps' were generally found to be ineffective, despite their popularity.

For adult populations, treatments typically involve targeting criminality and antisocial behaviour or substance use (Meloy & Yakeley, 2014; Wilson, 2014). CBT and social learning techniques are most frequently used for treating this disorder (Meloy & Yakeley, 2014). Based on current evidence and expert consensus, guidelines from the UK-based National Institute for Health and Care Excellence (NICE) suggest that those with ASPD and a history of criminal behaviour should be offered group-based cognitive and behavioural interventions that focus on reducing offending and other antisocial behaviour (National Institute for Health and Care Excellence, 2009). Treatment principles should allow opportunity for informed decision-making if within the individual's capacity. Services should offer clear treatment pathways, avoid unnecessary transfer of care, and utilise a positive and rewarding (rather than punitive) approach to improve retention. Those with comorbid psychopathic traits may be unlikely to benefit from treatment due to difficulties with foreseeing long-term consequences of actions, difficulty reflecting on the past, and difficulty inhibiting behaviours when faced with punishment (Meloy & Yakeley, 2014; National Institute for Health and Care Excellence, 2009).

Overall, the evidence base is inconsistent. Types of treatment empirically studied include CBT, integrated dual disorder treatment through assertive community treatment (including a focus on substance use), therapeutic communities, and short-term rehabilitation for substance use. A meta-analysis of studies (Wilson, 2014) exploring treatments found that only one randomised control trial found evidence for treatment effectiveness in relation to recidivism. This study assessed the effectiveness of a modified therapeutic community compared to standard mental health services for male inmates diagnosed with ASPD, involving CBT, medication, peer

support, psychoeducation and other interventions tailored to the consumer. The study found that 12 months after treatment, those who received the intervention were 26 times less likely to be re-incarcerated compared to the control group; however, criminal arrests did not differ between the groups. A systematic review (Gibbon et al, 2009) involving 11 studies found that three interventions had benefits on at least one outcome (contingency management plus standard maintenance, CBT, and a 'Driving Whilst Intoxicated' program with incarceration and motivational interviewing). However, across these interventions, significant improvements were mainly related to substance use, with no studies reporting significant change in a specific ASPD trait.

More recently, research has begun to explore mentalisation-based therapy (MBT) for treatment of ASPD, with benefits identified relating to reduction in anger, interpersonal problems, self-harm and suicidality among those with comorbid BPD and ASPD (Bateman, Bolton, & Fonagy, 2013). DBT has been adapted to correctional settings and may also prove beneficial for those with psychopathy or ASPD (Galietta & Rosenfeld, 2012; Neacsiu & Tkachuck, 2016), although no controlled studies are known that examine DBT for a specific ASPD population.

Two large meta-analyses have confirmed that there is no consistent evidence for use of pharmacological intervention to treat ASPD or its symptoms (Meloy & Yakeley, 2014). NICE guidelines (2009) thereby report that pharmacological interventions should not be routinely used for treatment of this disorder, but be used instead for comorbid disorders in line with other recommendations.

Borderline personality disorder

BPD is undoubtedly the most researched of all the personality disorders (Rudick, 2017), and arguably the most well understood. Of all the personality disorder diagnoses, BPD has the most solid evidence base for treatment and recovery. One study found that among treatment studies with a follow-up period of five years or longer, after this period of time 33–99% of participants no longer met diagnostic criteria for BPD (Ng et al., 2016), although this may be partly due to the natural course of BPD involving symptom improvement over time (Newton-Howes, Clark, & Chanen, 2015).

BPD is understood to be the most diagnosed personality disorder, most likely because individuals with BPD often utilise treatment and support services, and because some symptoms of this disorder are 'high risk' (for example, for suicide attempts and self-harm) and thereby readily identified or visible. Despite this, many clinicians report hesitancy in diagnosing individuals with BPD due to concern about causing distress for the individual. After thorough assessment, the NHMRC recommends informing individuals of the diagnosis, explaining symptoms and formulation, and emphasising the possibility of effective treatment. Communication of a BPD diagnosis is generally recommended for adults and adolescents in order to inform treatment pathways, but is not recommended for prepubescent children (National Health and Medical Research Council, 2012).

In accordance with comprehensive NHMRC guidelines, it is recommended that people living with BPD are provided with structured psychotherapies that have been specifically designed for

BPD, but tailored to an individual's preferences and availability. Treatment for BPD typically involves enhancing emotion-regulation processes, fostering a more coherent self-identity, and fostering self-agency (Links, Shah, & Eynan, 2017). In general, psychotherapy yields significant benefits for those with BPD, with individual studies ranging from small to large effect sizes (Rudick, 2017). Evidence-based therapeutic approaches tend to result in similar benefits (Cristea et al., 2017). The three major treatments for BPD are understood to be DBT, MBT and transference-focused psychotherapy, all of which require a minimum of one year of treatment with at least weekly contact (Gunderson, 2016).

DBT is probably the most well known treatment for BPD and has been supported by meta-analyses, typically with small to medium effect sizes across a range of symptoms (Cristea et al., 2017; Panos, Jackson, Hasan, & Panos, 2014). DBT is designed to be a comprehensive program with individual and group therapy components. DBT has also been adapted for inpatient settings and forensic settings (Bloom, Woodward, Susmaras, & Pantalone, 2012; Eccleston & Sorbello, 2002). Treatment for PTSD can be incorporated into DBT, if necessary (Links et al., 2017). DBT has demonstrated benefits for reducing substance use and suicidal and parasuicidal behaviours, thereby leading to a reduction in hospital admissions and use of emergency services; however, there is no strong evidence indicating changes in depressive symptoms or negative emotions such as anger, guilt, anxiety and shame (Lee, Cameron, & Jenner, 2015; Links et al., 2017; Panos et al., 2014). Individuals undertaking DBT have reported their perceptions that DBT has generally improved insight, hope and acceptance, increased positive coping skills and self-efficacy, and validated their experiences (Little, Tickle, & das Nair, 2017). Challenges reported by these individuals include conflict with group therapy members, overuse of technical language, and coping with interpersonal conflict as their communication skills increase (Little et al., 2017). Hence, DBT may not be suitable for all individuals, such as those with cognitive impairment or severe interpersonal problems. Some therapists may practice DBT-informed therapy rather than a full DBT program; however, no known studies have reported benefits of this modified approach.

Other psychotherapies supported by research include psychodynamic approaches (including MBT and transference-focus psychotherapy) via meta-analysis (Cristea et al., 2017); schema therapy and cognitive analytic therapy via systematic review (Calvert & Kellett, 2014; Sempertegui, Karreman, Arntz, & Bekker, 2013); and Systems Training for Emotional Predictability and Problem Solving (STEPPS) across multiple randomised controlled trials (Gunderson, Weinberg, & Choi-Kain, 2014). CBT has not proven to be a consistently effective treatment for BPD (Cristea et al., 2017), and ACT needs further research to determine its efficacy with this population, although recent studies have provided some support (Morton, Snowdon, Gopold, & Guymer, 2012; Öst, 2014).

As symptoms of BPD typically emerge during adolescence and young adulthood, early intervention is strongly recommended where feasible (National Health and Medical Research Council, 2012). Programs such as DBT STEPS-A (DBT Skills in Schools: Skills Training and Emotional Problem Solving for Adolescents) aim to teach DBT skills in schools; however, there is no known data that indicates benefits of this program in preventing development of BPD. DBT

has recently been modified for pre-adolescent children experiencing emotion dysregulation, with an initial randomised control trial demonstrating benefits and treatment satisfaction (Perepletchikova et al, 2017). Treatment of adolescents with emerging BPD traits should consider adolescents' autonomy, developmental age, and functional impairment, and should be delivered in youth-oriented services where possible (National Health and Medical Research Council, 2012). The authors of this review are aware of two evidence-based structured and specific interventions. First, Helping Young People Early (HYPE), developed by Orygen Youth Health, is a program based in Melbourne. HYPE is an integrated intervention involving cognitive analytic therapy, case management and general psychiatric care for youth aged 15–25 who are experiencing emotional instability and interpersonal difficulties. A quasi-experimental study found that compared to manualised good clinical care, HYPE demonstrated significant improvement in internalising and externalising psychopathology at 24-month follow-up (Chanen et al., 2009). Second, an adolescent version of DBT has been developed and has demonstrated efficacy in improving treatment retention and reducing psychiatric hospitalisations in adolescents (Rathus & Miller, 2002).

In general, pharmacotherapy does not appear effective in altering the nature or course of BPD, and it should only be used to manage specific symptoms such as depression (National Health and Medical Research Council, 2012). Evidence from a systematic review and meta-analysis indicates that the most beneficial effects are found for mood stabilisers and second-generation antipsychotics for treating core BPD symptoms such as emotional dysregulation (Lieb, Völlm, Rucker, Timmer, & Stoffers, 2010).

Narcissistic personality disorder

No known controlled studies have explored psychotherapy treatment efficacy specifically for NPD (Crits-Christoph et al., 2015). The only known systematic review of this topic (Dhawan, Kunik, Oldham, & Coverdale, 2010) found no studies of NPD meeting its inclusion criteria relating to either psychotherapy or medication, although this review is a decade old at the time of writing. Hence, it is unclear which treatment modes provide consistent benefits based on the current state of the literature, although a significant body of case studies have been published on various forms of psychotherapy, including DBT, transference-focused psychotherapy, metacognitive interpersonal therapy and functional analytic psychotherapy. Recommended treatments include CBT, schema therapy, psychoanalytic and psychodynamic therapies, DBT, MBT, meta-cognitive interpersonal therapy and psychoeducation (Beck et al., 2015; Dimaggio & Attinà, 2012; Ronningstam, 2014).

Targets for treatment may involve understanding narcissistic defences, increasing daily functioning, and reducing distorted assumptions and all-or-nothing thinking and perfectionism (Ronningstam, 2014). A major challenge involved in treating individuals with NPD include building a therapeutic relationship, which can be slow and difficult due to the consumer's perfectionism, low insight and sense of superiority. It is important for the clinician to identify the difference between 'healthy' and 'pathological' narcissistic traits present in the individual, which can also be challenging (Ronningstam, 2014).

Histrionic personality disorder

No known controlled studies have explored psychotherapy treatment efficacy specifically for HPD (Crits-Christoph et al., 2015). As above, it is unclear which treatment modes provide consistent benefits. Case studies have demonstrated some support for cognitive analytic therapy and functional analytic psychotherapy. Recommended treatments include psychodynamic and psychoanalytic therapies and CBT. Symptoms tend to overlap with BPD, NPD and DPD, meaning approaches used to target these disorders may also be useful in the context of HPD (Gabbard, 2014a).

Targets of therapy may relate to improving sense of self, identifying defensive patterns, and reducing interpersonal conflict. Cognitive approaches may aim to analyse core beliefs associated with HPD, such as 'Unless I impress people, I am worthless', and 'In order to be happy, I need other people to pay attention to me'.

2D. Treatment and support for Cluster C personality disorders

Based on available literature, individuals with Cluster C personality disorders tend to experience benefits from treatment. Much of the literature discusses Cluster C personality disorders – AVPD, DPD and OCPD – in combination. One meta-analysis was identified which explored psychotherapeutic outcomes for individuals with Cluster C personality disorders (Simon, 2009). The review found that across 15 studies, individuals with Cluster C disorders display significantly more improvement at the end of treatment compared to controls, with the exception of those undertaking brief dynamic therapy. The authors noted that on most measures, Cluster C individuals had more favourable treatment outcomes compared to those with Cluster A or Cluster B disorders. No consistency was found as to whether those with AVPD, DPD or OCPD benefit more from therapy in general. CBT and psychodynamic therapy both appear to be efficacious, as does interpersonal social skills training, which may be strengthened when combined with cognitive modification (Simon, 2009). More specific discussion regarding these disorders is provided below.

Avoidant personality disorder

For AVPD, controlled trials support the use of CBT, graded exposure, and social skills training, while uncontrolled studies have demonstrated support for group behavioural treatment (group systematic desensitisation, behavioural rehearsal, self-image work), schema therapy, and supportive-expressive dynamic therapy (Bernecker, Coyne, Constantino, & Ravitz, 2017; Crits-Christoph et al., 2015; Taylor, Bee, & Haddock, 2016). Pharmacology studies have typically looked at AVPD traits in social phobia rather than exploring AVPD specifically, with many assuming a significant overlap in symptomology and response to pharmacotherapy (Drago, Marogna, & Søggaard, 2016). Several medications have been tested and shown to be effective for social phobia, including monoamine oxidase inhibitors, a benzodiazepine, and antidepressants, although more controlled studies with well-defined groups of AVPD subjects are needed to provide strong clinical evidence for pharmacotherapy (Drago et al., 2016).

Individuals with AVPD may have difficulty committing to and engaging with psychotherapies due to high levels of anxiety and a perceived threatening environment (Perry, 2014). Therapists

must foster a warm and safe environment that allows in-vivo experimentation and testing of reactions. Targets of therapy may involve exploring anxiety, self-criticism and sensitivity to rejection, and learning to tolerate discomfort, with a general aim of increasing social contact (Perry, 2014).

Dependent personality disorder

No known controlled studies have specifically studied DPD, although participants with DPD have been included in studies with general Cluster C populations (Crits-Christoph et al., 2015; Perry, 2014). Recommended psychotherapies include psychodynamic therapy, CBT and graded exposure (Beck et al., 2015; Perry, 2014).

Psychotherapy with individuals with DPD may be complicated, as these individuals may form a dependent relationship with the therapist; however, this can be addressed in a manner that promotes emotional growth. Treatment goals may include promoting self-expression, assertiveness, decision-making and independence. Pharmacotherapy is generally only recommended in the context of concurrent depression or other disorders (Perry, 2014).

Obsessive-compulsive personality disorder

Few controlled studies are available specifically for OCPD, although two controlled trials suggest benefits of supportive-expressive dynamic therapy, CBT and IPT (Crits-Christoph et al., 2015). Treatments for OCD do not seem to generalise to OCPD and the two should not be conflated (Perry, 2014). Evidence for pharmacotherapy is limited, with a lack of controlled studies and inconsistent findings (Perry, 2014).

Individuals with OCPD may have difficulty engaging in psychotherapy due to rigidity, excessive orderliness, parsimony and scrutiny of therapeutic processes and relationships (Perry, 2014). They may only seek support during a crisis and have limited insight into OCPD symptoms that are affecting their quality of life, as their worldview is ego-syntonic. Treatment goals may include challenging rigidity and increasing cognitive flexibility, and identifying defences and maladaptive relationship patterns (Perry, 2014).

2E. Carer treatment and support

Few studies have explored treatment and support for carers, family, friends and other support persons of people living with personality disorder, despite this population experiencing significant grief and objective and subjective burden (Bailey & Grenyer, 2014). Carers, family and friends are ideally involved in treatment of the individual with personality disorder and offered access to psychoeducation and other supports early (see Table 4).

Formal initiatives exist which aim to provide further support for carers and families of people living with BPD. Manualised programs are available, based on DBT programs and involving psychoeducation components about BPD, mindfulness skills, validation and interpersonal skills. Naturalistic studies and non-randomised controls have demonstrated the benefits of these programs for carers and families, including improvements in experiences of burden, grief, depression, mastery, hopelessness and interpersonal sensitivity (Flynn et al., 2017; Miller &

Skerven, 2017). A recent randomised control trial found support for a group BPD psychoeducation program (Grenyer et al., 2018).

Discussion

While the current prevalence of personality disorder is not well understood in the Australian context, it also appears that treatment approaches are not well understood overall. Our review of the literature has found that many treatment approaches rely on anecdote, consensus and case studies without high-quality evidence. This is particularly the case for disorders that are not as readily identified or studied, such as PPD, SPD and DPD. However, an exception to this is BPD, which has been a focus of most research in the personality disorder field, most likely due to the severity of symptoms and frequency of presentations in mental health settings. The literature reviewed presents generally positive findings for the treatment of BPD with psychotherapy.

It follows that if prevalence data is unreliable, and health professionals are unable to identify these disorders, or are reluctant to diagnose them due to the stigma and discrimination these individuals may face, these conditions are not systematically studied. These factors influence both the desire by researchers to understand these conditions and the funding allocated by governments and philanthropy to research in these areas.

It is clear that many of the principles for providing high-quality treatment to people living with personality disorder are common to treating other mental disorders as well. For example, providing services in a compassionate, empathetic, open and non-judgemental way is recommended for personality disorders, and is also appropriate when working with anyone experiencing a mental health difficulty. Similarly, a recovery-oriented approach that fosters hope and trust is also key.

The lack of evidence for treatment approaches has resulted in there being few known treatment manuals available, particularly for conditions outside of BPD, and even fewer controlled studies of interventions. There are limited guidelines for treatment for a number of disorders, such as those devised by Gabbard and colleagues (Gabbard, 2014b); however, further work needs to be completed to ensure that information about evidence-based treatments and how to apply them is readily available. This is particularly relevant for sole practitioners (such as psychologists working in private practice) and for those working in geographic areas where specialist guidance is unavailable.

BPD has received significant attention due to the high risk of suicide in this population; most of the research into treatment approaches has focused on DBT, but there is also good evidence for other treatment approaches. In fact, no one treatment approach appears superior (Cristea, 2017). Treatment for BPD can be cost-effective, with a mean cost-saving for treating BPD with evidence-based psychotherapy of US\$2,987.82 (approximately AUS\$3,900) per consumer per year, despite variation in health-related costs across studies and countries (Meuldijk, McCarthy, Bourke, & Grenyer, 2017). In terms of other personality disorders, there is also fairly consistent

evidence suggesting that Cluster C traits are treatable with CBT-based approaches, and mixed evidence relating to the treatment of ASPD.

In considering research priorities, it appears that most funding appears to go towards BPD research, which is understandable considering its severity. However, it is also important to consider that there are more prevalent (although less visible) personality disorders that also need research to understand how best to improve outcomes for people experiencing these conditions. This may involve further study of third-wave therapies in these populations, including DBT and the recently manualised 'radically open DBT' (RO-DBT; see Lynch, 2018), as well as further studying CBT, schema therapy, MBT and other approaches.

Limitations

It should be noted that while the search strategy employed for this review was comprehensive, it was not a completely systematic review. It may be possible that there are some studies that have not been included. Further, we did not review all case studies or treatment manuals and guidelines. We have tried to mitigate this risk through the involvement of the Project Advisory Committee that includes experts in personality disorder research and others very familiar with current and emerging evidence in this field.

Part B: Environmental scan

Purpose and scope

The environmental scan aims to answer the following questions:

- What are the available treatment and psychosocial support options for people living with specific personality disorder in Australia, with regards to the private sector, the public sector, and non-government organisations?
 - How many people living with specific personality disorders are accessing services?
 - What are the barriers to treatment access in Australia?
 - What are the roles of Primary Health Networks and other regional coordinating bodies (such as Local Health Districts) in this context in Australia?
- What educational, awareness-raising and workforce capacity-building activities are underway regarding personality disorder in Australia?
 - What activities are underway with regards to public awareness, stigma reduction and workforce development?
 - What are their aims and target audiences?
 - What is their reach and impact (if known)?

Methods

The environmental scan involved reviewing grey literature and, where available, peer-reviewed literature. Purposive searches were conducted by browsing mental health organisations' websites, which are known to provide information about personality disorders and mental health in Australia. Snowballing was also used to identify further information. Members of the Project Advisory Committee were also asked to share their knowledge of personality disorder resources in Australia.

Results – treatment and psychosocial support

Generalist mental health system overview

Each Australian state and territory government funds and delivers a variety of public sector mental health services, including those in public acute and psychiatric hospital settings (inpatient and outpatient services), community mental health services with specific health districts, and residential health services. Mental health services are also available in the private sector. Anecdotally, people living with personality disorders are known to access generalist services as well as services more specific to personality disorder. Various general mental health-related initiatives funded through the Australian government include:

- Medicare Benefits Schedule (MBS)
- Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)
- Chronic Disease Management services (formerly Enhanced Primary Care)
- programs that provide essential social and financial support:

- financial services (such as Centrelink)
- housing assistance
- social and community support
- disability services.

For many people living with mental illness (personality disorder or otherwise), a general practitioner (GP) is the first point of contact with mental health services. An estimated 18 million mental illness-related GP encounters occurred in 2015–16, comprising around 12.4% of all GP encounters. More than 80% of GP visits incur no out-of-pocket costs due to the MBS (Australian Government Department of Health, 2018b). A survey of 153 people diagnosed with BPD found that nearly 50% reported receiving professional care by a GP; within this group, about 59% reported that their GP helped significantly or somewhat, and 39% reported that the GP was not helpful (Lawn & McMahon, 2015a). Among participants, GPs were typically rated as least helpful of all health professionals with regard to personality disorder treatment. No known statistics are available regarding Australian GP access for personality disorders other than BPD.

Psychological support is accessible in many settings (public and private, community-based and hospital) through psychiatrists, psychologists, mental health workers, mental health nurses, social workers and other mental health professionals. In Australia, access to psychiatrists is limited, particularly in outer regional and remote areas where there are only three psychiatrists per 100,000 people (Grenyer, Ng, Townsend, & Rao, 2017). Online directories such as the Royal Australian and New Zealand College of Psychiatrists' (RANZCP) 'Find a psychiatrist', the Australian Psychological Society's (APS) 'Find a psychologist' and the Australian Clinical Psychology Association's 'Find a clinical psychologist' may help users to find a mental health professional. In the survey mentioned above (Lawn & McMahon, 2015a), 76% reported receiving professional care from a psychiatrist and 60% from a psychologist. Further, 75% reported a psychiatrist to be somewhat or significantly helpful, and 74% found a psychologist to be somewhat or significantly helpful.

Health professionals working in public hospitals and community health services typically do not charge a service fee. Those operating in private clinics and hospitals typically charge a fee, although individuals may receive subsidised treatment. Through the MBS Better Access initiative, individuals may access up to 10 individual and 10 group therapy services in private settings per calendar year subsidised by the Australian government. These benefits are available to consumers with an assessed mental disorder who are referred by a GP managing the consumer under a GP mental health treatment plan (MHTP), under a referred psychiatrist assessment and management plan, or through a psychiatrist or paediatrician. Up to seven of 10 consultations may be provided through online channels such as Skype, aiming to improve access for those in rural and remote locations. All consumers with a diagnosable mental disorder included in ICD-10 Chapter V, including personality disorder, are eligible to access a MHTP (Australian Government Department of Health, 2018a).

Some clinicians may choose to bulk bill, in which case the consumer will not have to pay out of pocket, but it is common for the cost of a psychological therapy session to be greater than the Medicare rebate. The rebate amount per individual session is \$84.80 for a general psychologist

or \$124.50 for a clinical psychologist. These costs differ between services, but the recommended cost per 45–60 minute session is \$246 for a clinical psychologist, according to the Australian Psychological Society. Out-of-pocket expenses count towards the Medicare Safety Net, which is designed to protect high users of health services from large out-of-pocket expenses, with Medicare giving a higher benefit. Some consumers may be able to access up to five Medicare rebates with a psychologist within a calendar year through the Chronic Disease Management program, at the discretion of a GP. Medicare rebates are also available for sessions with psychiatrists, with psychiatrist fees and bulk-billing services differing significantly between services.

Carers, families and other support persons may also access Medicare rebates through Better Access if they are experiencing significant psychological distress. Further, MBS item 348 covers attendance involving an interview of a person other than the consumer for 20–45 minutes in the course of initial diagnostic evaluation (usually in the first month). Similarly, MBS item number 352 enables clinicians to engage with families up to four times per 12-month period.

Individuals with personality disorder experiencing a mental health crisis or severe symptoms may access psychological services at public or private hospitals, through inpatient admission, or outpatient or day-patient services. Anecdotally, most private hospitals with mental health services provide specialist psychotherapy appropriate for personality disorder, such as DBT programs. Those identified through the environmental scan are presented in Appendix B. In a study by Lawn and McMahon (2015a), participants who had stayed in hospital for reasons related to BPD reported their length of stay as ranging from 24 hours to 32 weeks in public hospitals, and 24 hours to one year in private hospitals.

There are a range of services and programs in the community for consumers with personality disorder, but many of these programs have limitations in scope, service number and regional accessibility that impact or impede evidence-based treatment. Consumers requiring more than 10 psychological services in a calendar year, or otherwise unable to access private services, may access services through Primary Health Networks (PHNs). The 31 PHNs operating in Australia since 2015 are region-based independent organisations, aiming to improve the efficiency and effectiveness of medical services and coordination of care. Since 2016, the Australian Government has begun to consolidate more flexible service funding through PHNs, with an expectation that PHNs will invest in appropriate mental health services to meet the needs of each region. Consistent with the expectations of the Fifth National Mental Health and Suicide Prevention Plan, PHNs – working with state jurisdictions – are expected to utilise a ‘stepped care’ approach to mental health, involving a hierarchy of interventions, from least to most intensive, matched to an individual’s needs (Australian Government Department of Health, 2016). In theory, this involves individuals with severe and complex mental illness being matched to mental health interventions that are evidence-based and maximise recovery, with coordinated care. Although some PHNs have implemented specialist services appropriate for personality disorder treatment (see Appendix B for those picked up in the environmental scan), it would appear the vast majority have not, though the sparseness of available and reliable data on service distribution and type make this difficult to assess at this formative stage of PHN service

commissioning. Absence of specifically-focused personality disorder services may be due to several factors such as funding and availability of specialist training by region, and understanding of community need for such services. The relative sparsity of current specialised personality disorder services in the publicly funded sector suggests that access to evidence-based care for people living with personality disorder across much of the country remains unacceptably challenged.

The National Disability Insurance Scheme (NDIS) provides support for eligible individuals with a permanent disability as a result of a mental illness, such as personality disorder. The NDIS is currently available in Victoria, New South Wales, Australian Capital Territory and South Australia and is being rolled out in Tasmania, Northern Territory, Queensland and Western Australia. The types of services provided through the NDIS may not quite address the needs of these individuals, as they are designed for those affected by intellectual disability; physical disability; and impaired functional capacity or psychosocial functioning relating to communication, social interaction, learning, mobility, self-care or self-management (The University of Sydney, 2018). However, the design of the NDIS may be appropriate for people experiencing severe and persistent psychosocial impacts related to personality disorder, or those experiencing comorbid problems such as physical disability. Services available through the NDIS include mainstream services and supports, community groups and clubs, and other supports. These services are typically designed for people who face permanent or significant temporary impacts to their functioning, or for early intervention, rather than being recovery-focused. This model may not be appropriate, given that there is considerable evidence that people living with personality disorder (particularly BPD) can 'recover' with access to appropriate treatment (see discussion of the literature review in Part A).

The NDIS has been criticised for being confusing and difficult to access based on inclusion criteria and long waiting periods. It is unknown how many individuals are accessing the NDIS for reasons relating to personality disorder; however, only 6% of participants access the scheme for reasons primarily related to psychosocial disability (The University of Sydney, 2018). It is too early to know what impact the NDIS is having on the experiences of those living with personality disorder, although there is concern that existing community-based mental health support services utilised by these individuals might be displaced by investment in the NDIS, and individuals may then fall through gaps if ineligible for the NDIS. Of note, only around 9% of people living with severe mental illness are expected to be eligible for the NDIS (The University of Sydney, 2018).

Some individuals with private health insurance may be able to access coverage for mental health services, including services at private hospitals, depending on individual policies. Many private hospital services require private hospital cover, although users still incur out-of-pocket expenses. However, many private health insurance companies choose to exclude mental health services from cheaper policies (LaFrenz, 2017), increasing financial burden experienced by the consumer.

Financial support may be provided by services such as Centrelink. Services designed for those with mental health conditions and on low incomes include the Disability Support Pension and

Youth Disability Supplement, and carers, families and support persons may access various financial payments and supplements. However, some Centrelink services have been widely criticised for not providing enough financial support to cover everyday needs, including rent, food and other expenses (Coady, 2017).

Other options for financial support are available for people who have survived violent crime or sexual abuse. For example, the Victims of Crime Assistance Tribunal may provide financial assistance (on average \$7,700, up to \$60,000) for victims of crime to access counselling and meet other expenses. The National Redress Scheme, launching in mid-2018, will provide services for those who have survived institutional sexual abuse, including access to counselling and/or monetary payments up to \$150,000.

Young people aged 12–25 experiencing personality disorder may access headspace, a youth mental health initiative established in 2006 which offers treatment and support for a range of mental illnesses and may provide support for those with personality disorder, at clinician discretion. Services accessed through headspace are typically free or low-cost, and there are more than 90 centres at the time of writing, including several in rural areas. The online counselling service eheadspace may also be useful to those in rural areas or otherwise unable or unwilling to attend a face-to-face session. Some headspace centres run DBT group programs regularly or on occasion – centres in Queensland (Meadowbrooke, Ipswich) and Victoria (Mildura, Knox) have been known to run DBT group programs in the past.

headspace opened a specialist youth early psychosis program in six centres across Australia, with individuals with SZPD eligible for treatment and support. However, the service's funding was transferred to PHNs in 2016, aligned with the Australian Government's decision to move funding from national programs (such as headspace) to PHNs (Lee, 2016). Individuals with SZPD may be eligible for other early psychosis treatment programs in various capital cities.

Several telephone information and counselling services operate nationally, including Healthdirect Australia, Lifeline, Kids Helpline, Mental Illness Carer Advisory Link, and the SANE Helpline. These services provide free crisis support, information and brief intervention services, all of which may be relevant to those living with personality disorder. The SANE Helpline specifically provides information and resources regarding complex mental illness, including personality disorder. Due to their time-limited nature, these services may not bring about therapeutic outcomes in the long term. National online support services such as the SANE Forums provide 24/7, anonymous support for people living with mental illness and their families and friends, including those affected by personality disorder.

The Fifth National Mental Health and Suicide Prevention Plan (Australian Government Department of Health, 2017), published in 2017, seeks to establish a national, collaborative government approach over the period 2017–22, focusing on achieving integrated regional planning and service delivery, improving suicide prevention, reducing stigma and discrimination, and improving supports for people living with severe and complex mental illness. Although this plan does not specifically refer to personality disorders, the following initiatives are planned in order to improve services for those with complex mental illness:

- Governments will negotiate agreements that prioritise coordinated treatment and supports for this population, including planning for the community mental health support needs of people who do not qualify to receive supports under the NDIS.
- Governments will require PHNs and local hospital networks (LHNs) to prioritise coordinated treatment and support for the population at the regional level.
- Governments will establish a time-limited Mental Health Expert Advisory Group to advise on implementation of the Fifth National Mental Health and Suicide Prevention Plan and provide advice.
- Governments will develop, implement and monitor national guidelines to improve coordination of treatment and supports for this population, involving clarifying roles and responsibilities across the health and community service sectors, specifying criteria to guide the targeting of service delivery to consumers, promoting roles of multi-agency area plans and pathways, and identifying opportunities for use of digital mental health and electronic health records in coordinating care.

Various mental health initiatives run within forensic settings. One program of note is the Real Understanding of Self Help (RUSH) program, a modified DBT program for prisoners who are at risk of suicide, self-harm and other concerning behaviours. The program has been implemented across Victorian, New South Wales, Queensland and Australian Capital Territory correctional environments. Preliminary evaluation supports the feasibility and acceptability of this program, but larger controlled trials are needed to provide rigorous evidence for its efficacy (Eccleston & Sorbello, 2002).

State and territory-specific specialist services

The results of the environmental scan suggest that there are a large number of specialist treatment services, but these tend to be clustered around the largest capital cities in Australia, and most of these services are in private settings. Most private hospitals providing mental health services offer DBT programs and other services that may be appropriate for people living with personality disorder. A summary of these specialist services is provided in Appendix B, and their geographic spread is shown in Figure 1.

For the purpose of brevity, only specialist services are presented in the environmental scan results. Many generalist community services and private practitioners may provide excellent treatment and support for people living with personality disorder and their carers. Many private practitioners are trained in evidence-based personality disorder psychotherapy but may not work at a specialist service identified within this environmental scan. Further, various general organisations, such as Mental Health Carers Australia (formerly ARAFMI) may provide excellent support that is not specific to personality disorder. Online directories such as dbtconnect.com may help individuals to find private practitioners with specialist training.

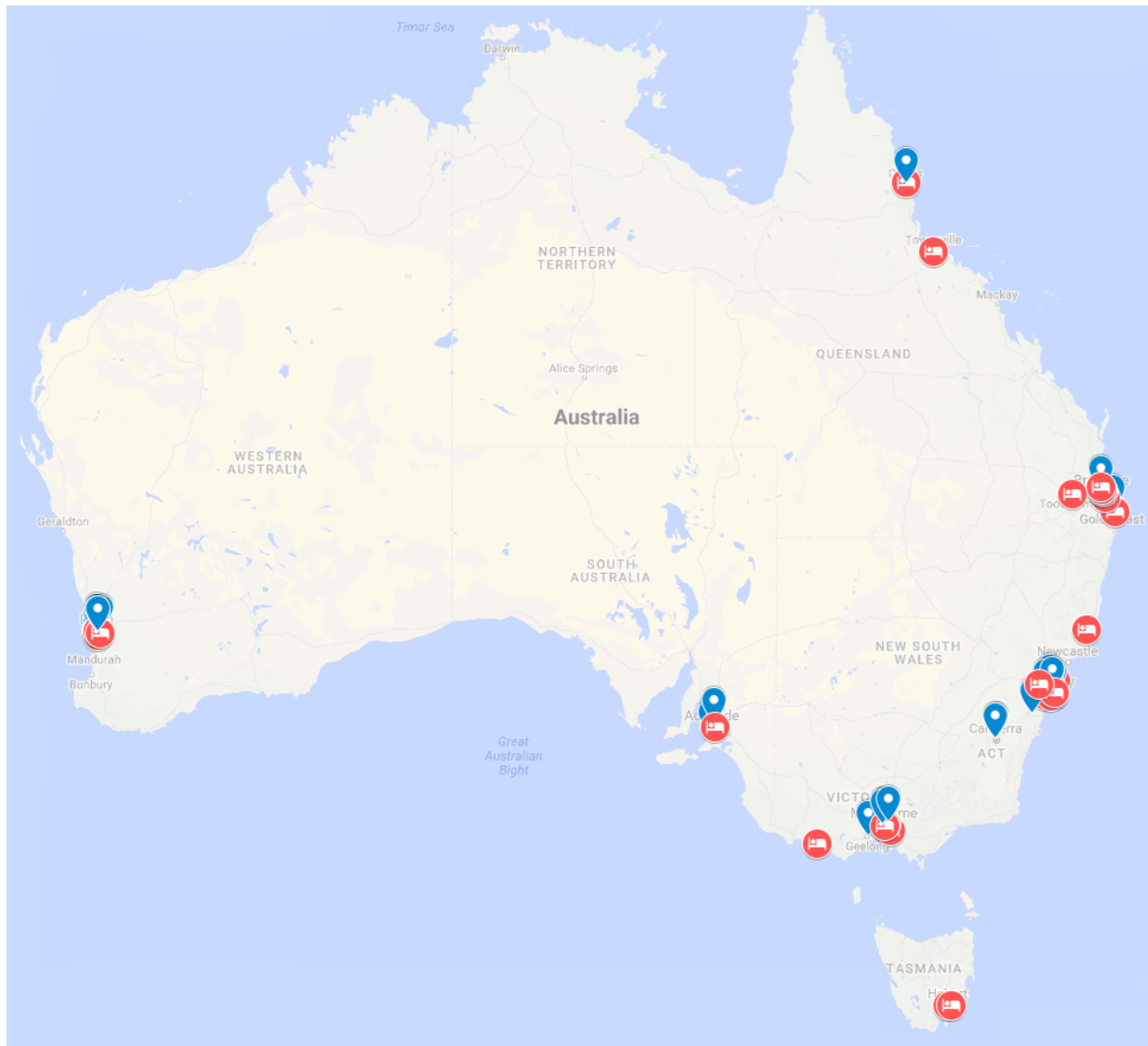


Figure 1. Locations of specialist services identified in the environmental scan

Results – advocacy, education, research and training

The results of the environmental scan suggest that there are several advocacy, education, research and training initiatives underway, mostly specific to or focusing on BPD. The following nationwide activities were identified:

- BPD Awareness Week, held each October, is organised by the BPD Awareness Week Collaboration Group, in collaboration with several BPD and mental illness organisations across Australia. The Collaboration Group is led by the Australian BPD Foundation and NEA.BPD Aust (see below). The week involves raising public awareness and reducing stigma and discrimination around BPD through BPD

awareness-raising activities in each state, promoted in local, state and national media.

- The Australian BPD Foundation is a charity supported by volunteer consumers, carers and health professionals which aims to raise public awareness, provide educational resources, and promote a positive culture for people living with BPD. It has branches in New South Wales, South Australia, Western Australia and Victoria. A branch is being set up in Queensland and plans are in process for branches in Northern Territory and Tasmania. Major outputs include the Annual National Borderline Personality Disorder Conference; development of a National Training Strategy (in process); and implementation of Stages 1 and 2 of the National Training Strategy in partnership with the Mental Health Professionals Network, Spectrum and Project Air; advocacy and awareness-raising activities; and information provision.
- National Education Alliance of Borderline Personality Disorder Australia (NEA.BPD Aust) aims to raise public awareness; educate professionals, families and schools; create a specialist BPD knowledge resource centre; address stigma; and partner with mental health entities to provide a strong platform for BPD advocacy. Major outputs include free Family Connections workshops for carers, families and friends of people living with BPD, and a free online training course for health professionals. Over multiple pre-post studies, Family Connections has demonstrated improvements related to feelings of burden, grief and empowerment (Krawitz, Reeve, Hoffman, & Fruzzetti, 2016).
- Orygen, the National Centre of Excellence in Youth Mental Health, is the largest personality disorder research program in Australia and provides national training in early intervention for personality disorder, alongside advocacy.
- The Private Mental Health Consumer Carer Network Australia has formed a BPD Expert Reference Group, which has conducted research into the experiences of people living with BPD and their carers in Australia.
- Project Air Strategy for Personality Disorders (University of Wollongong) provides training; research; online resources for carers, consumers and teachers; and advocacy relating to personality disorder. Major outputs include a comprehensive website including many fact sheets and a 'Find a service' directory for treatment services; treatment guidelines (described in Part A, above) and other guidelines; establishment and evaluation of brief intervention clinics; and the annual International Treatment of Personality Disorders Conference. Evaluation of the pilot implementation project has demonstrated benefits including reduction in emergency department presentations, reduction in admissions and length of stay in hospitals, and improvements in confidence and skills for carers and clinicians (Grenyer & Fanaian, 2015).
- SANE provides various education initiatives and resources relating to BPD and works with peer ambassadors, including individuals with BPD, to share stories and decrease stigma.
- Spectrum Personality Disorder Service for Victoria provides research, online resources and advocacy relating to personality disorder, in addition to clinical

services. Ongoing evaluation of clinical services has demonstrated reductions in personality disorder symptoms and reduction in medication misuse (Broadbear et al, 2016).

State and territory-specific initiatives

A summary of state and territory-specific initiatives is presented in Appendix B. These include training and education initiatives, advocacy groups, networking opportunities, major research groups, and groups advocating for system reform.

Discussion

The environmental scan identified significant gaps in the availability of high-quality evidence-based care for people living with personality disorder. The current mental health system involves a combination of programs, initiatives and schemes that appear to be more appropriate for Australians experiencing mild to moderate mental illness. For those requiring longer-term, intensive treatments, it is understood that individuals with personality disorder must utilise a combination approach, with referring practitioners needing to creatively ‘work the system’ to enable consumers to access maximum funding from various sources. In order to access timely evidence-based treatment, individuals with personality disorder generally need to be experiencing a mental health crisis and either presenting at a public hospital with available beds, presenting at a community health service with no waiting list, or able to pay for private services.

A major issue relates to the cost of accessing psychotherapy. Many individuals with personality disorder must access private programs. In order to reduce costs, they may receive treatment through a MHTP or receive some benefits through private health insurance. These options do not cover all costs related to accessing evidence-based treatments for personality disorder, as discussed in relation to the literature review (Part A). For example, major BPD psychotherapy programs need to be implemented over a minimum of one year with weekly or biweekly individual sessions and often with additional group therapy (Gunderson, 2016). It is not feasible to fit evidence-based treatments for personality disorder into 10 MBS-funded sessions, and this is further complicated in the context of comorbidities such as trauma or substance use. Public programs provide an alternative, but such programs are known to attract long waiting lists and are not available in every PHN.

Although people living with personality disorder are eligible for rebates under the MBS, anecdotally it is understood that some GPs do not list this diagnosis on consumers’ MHTPs. This may be due to a misconception that personality disorder is not an eligible condition for rebate. Since MHTPs are designed for treatment of mild to moderate mental illness, perhaps there has been miscommunication between certain practitioners. This confusion may be one reason why some health professionals do not assess for and diagnose personality disorder earlier, adding a layer of complexity to issues around stigma and discrimination.

Other services such as the NDIS may be suitable for some people living with personality disorder. The NDIS is designed to help eligible individuals with long-term psychosocial disability.

It is known that people living with personality disorder may experience psychosocial impacts such as difficulty working or studying, lack of community involvement, physical disability and other challenges. Many people living with personality disorder respond well in terms of symptom reduction if provided with evidence-based psychotherapy, although psychotherapy may not result in functional improvements. NDIS may only be suited for individuals experiencing long-term disability. Services provided through the NDIS should address recovery prospects through engagement in evidence-based psychotherapy, as well as psychosocial support.

Another major issue is the availability of specialist services. The environmental scan also highlighted that most clinical specialist services are limited to major cities – mainly Melbourne, Sydney, Perth and Adelaide. There were no specialist treatment services identified in the Northern Territory, and only a few in the Australian Capital Territory and Tasmania. Even in states with relatively dense service provision, such as Victoria, some consumers from regional or rural settings must travel for hours to access a service, and most specialist services operate privately and would thereby require out-of-pocket costs as well as the cost of travel. Most of the specialist services provided relate to DBT, despite other treatments showing efficacy for BPD in particular, highlighting that the dissemination and uptake of other evidence-based approaches is lacking. Currently, only Victoria and New South Wales have state-based personality disorder initiatives – Spectrum Personality Disorder Service for Victoria and Project Air Strategy for Personality Disorders, respectively. South Australia is undergoing reform and movement is also underway in Western Australia to reform mental health services. Barriers here relate to funding of specialist services and specialist training, which the public mental health system cannot always support.

The movement of funding to PHNs comes with the expectation that PHNs are able to provide adequate ‘gap filling’ services for people living with complex and severe mental illness, such as personality disorder. However, it is difficult to see how this could be achieved with the limited resources available to PHNs for complex care treatment and management, and the limited role that PHNs hold in the broader mental health service system. It appears that few PHNs are currently providing specialist services appropriate for the comprehensive treatment and management of personality disorder, and this is most likely due to lack of funding. While a structured approach to the delivery of mental health services for the Australian community through approaches such as Stepped Care is clearly advantageous, barriers for people living with personality disorder remain. Because of limitations in services, funding and uneven distribution of clinical skill, it is likely that many people are accessing a level of support that is not sufficient for their needs – for example, accessing a style of psychotherapy that is not evidence-based for personality disorder, or accessing psychotherapy too infrequently to see meaningful benefits.

Little was found in relation to specialist treatment for personality disorder aside from BPD. Some services in Western Australia are providing specialist treatment for conduct disorder (multisystemic therapy) but no services for ASPD were identified in the community. No information was found about ASPD specialist treatment programs in forensic settings, although it is possible that this was simply not identified within the scan.

Further, few services were found that provide specific support for carers, family and friends of people living with personality disorder, and these were typically limited to capital cities. A major initiative was the NEA.BPD Aust's Family Connections program, with some of these workshops operating in rural areas. Many more general carer-support services, which may be beneficial to these individuals, were identified in the review.

Several advocacy, education, research and training initiatives were identified in the scan. Organisations that are advocating for personality disorder awareness and stigma reduction have conducted valuable work in the past decade, including advocating for consumers and carers and bringing together clinicians and researchers.

Although a variety of initiatives are underway, it appears that the current mental health system is not designed to adequately support individuals living with personality disorder – or other people living with complex mental illness. Guidelines identified in the literature review identified that treatment for personality disorder should occur in the community; however, the frequency of emergency department presentations suggests that there is a lack of appropriate community-based services. Coroner's reports have also identified that there are major gaps in continuity of care. For example, two reports (Coroner's Court of South Australia, 2018; Coroner's Court of Western Australia, 2015) have highlighted failings in discharge responsibilities when consumers are discharged from treatment services in the context of high suicide risk. This highlights the serious repercussions of system design issues and inadequate resourcing. System redesign is a critical step for improving suicide prevention efforts.

Organisations have been identified that are advocating for system redesign, such as the Western Australia Personality Disorder Subnetwork. This is in the context of other organisations, such as Australians for Mental Health, advocating for system design for mental illness in general. In a 2013 report, Medibank argued that system design is a critical issue in Australia, with new initiatives adding complexity to an already fragmented system and failure to address the critical issue of system design (Medibank, 2013). The report argued that people living with severe or very severe mental illness – including personality disorder – require similar services to those with less severe illness, but with more intensive case coordination. This was supported by the National Mental Health Commission's Review of Programmes and Services in 2014 (National Mental Health Commission, 2014).

Limitations

This environmental scan was not systematic in nature and relied mostly on snowballing and expert knowledge. Hence, it is possible that some services were not identified during the search. Further, as not all services were directly contacted for information, it is possible that information discovered in this scan may be outdated (for example, certain programs may no longer be running) or become outdated in coming months. It is also important to note that this search did not aim to identify private practitioners using evidence-based approaches; although specialist services may be lacking in certain areas, it is very likely that excellent private health professionals are delivering services in these areas. Many people living with personality

disorder may also be accessing excellent support through generalist settings that meets their needs.

Further, although many specialist services were identified, it was not within the scope of this project to determine how many of these services were adhering to evidence-based protocols. Of note, DBT skills training programs identified ranged in duration from eight weeks to 40 weeks or longer.

Part C: Qualitative study

Anecdotally, many individuals with personality disorders have reported long treatment histories, including emergency department presentations and other crisis-related care. Past research has identified barriers to treatment in the Australian context. For example, Lawn and McMahon (2015a) surveyed 153 people living with a diagnosis of BPD, finding that many of these individuals had accessed services including crisis lines, support groups, financial services and housing support. Participants reported experiencing challenges and discrimination from services. Carers have also reported frustrations with treatment services and experienced a lack of support for their own needs (Lawn & McMahon, 2015b).

There is a need to understand more about personality disorder treatment pathways in Australia. The surveys above provided interesting quantitative findings regarding experiences of BPD; however, qualitative research is needed to explore these processes in depth. Furthermore, there is a need to explore treatment experiences for individuals with other personality disorders, and their carers and support persons, as the majority of past research has focused solely on BPD.

Aims and objectives

This qualitative study aimed to answer the following questions, with regards to the Australian context:

- What types of treatment and support services are accessed by people living with personality disorder and their carers?
- What are the perceived benefits and challenges associated with these services?
- What changes would these individuals like to see with regards to service provision and access?

Methods

Design

This project involved 12 semi-structured participant interviews and two online focus groups. A sample size of 12 participant interviews was chosen as this number was sufficient to identify a range of experiences relating to various personality disorders, and was limited enough to be feasible within the study's timeline. The two online focus groups provided another avenue to capture and understand experiences. SANE moderates two online forums regarding complex mental illness – one designed for people with a lived experience, and one designed for carers (<https://saneforums.org/>). Members can participate in discussions with others to share their thoughts and experiences, which may involve regular discussion regarding personality disorders, particularly BPD. These forums involve many regular contributors who frequently share their personal experiences and views. Research has demonstrated that participants in online focus groups, compared to in-person focus groups, demonstrate a higher level of disclosure and ideas (Fox, Morris, & Rumsey, 2007). Furthermore, anonymity can reduce uneven power dynamics associated with in-person methods (Fox et al., 2007). Conducting

online focus groups allowed the researchers to use a pre-existing knowledge base, and removed barriers for participants who may be unwilling to share information in a setting where they are identifiable (such as a face-to-face interview). Ethical approval was granted by Bellberry Limited (Project Number 2017-12-977-A-1).

Participants

Interview participants were recruited through notices placed on the SANE Facebook and Twitter pages. Notices were also provided to representatives of SANE partner organisations involved in the Project Advisory Committee, for distribution. Interested participants were required to complete a brief (5–10 minute) online survey via SurveyMonkey. The survey remained open for two weeks in February 2018. The researchers then selected 12 participants using a maximum variation sampling approach to ensure participation from people from diverse backgrounds and a wide range of experiences (relating to age, gender, diagnosis, ethnicity, treatment access and perceived quality of treatment received).

In total, 133 people completed the online expression of interest form. The expressions of interest were largely from women from an Australian background reporting a diagnosis of BPD. Of the 12 participants initially contacted, two did not respond or confirm attendance, so two additional participants were then contacted. Of the 12 people who participated in the study, nine (75%) were female. The mean age for lived experience participants was 38.1 years ($sd = 10.4$), while carers were on average slightly older ($mean\ age = 41.8\ years, sd = 11.1$). Seven participants (58%) reported experiencing a personality disorder, three (25%) identified as carers of someone experiencing a personality disorder, and two (17%) identified as both.

Among participants with a lived experience, all self-reported a diagnosis or suspected diagnosis of BPD or BPD traits. Additional diagnoses received by participants included OCPD plus HPD traits; a mixture of Cluster B and C traits (specific to BPD, AVPD and DPD); SPD; and NPD traits. Among carers, one woman provided care for her daughter, another provided care for her brother, another ('Chloe') provided care for three relatives (her son, brother and sister), and two men provided care for their wives. All carers reported caring for someone with BPD, while Chloe also provided support for her son who had an additional diagnosis of NPD, and her sister, who had an additional diagnosis of OCPD. Although information was not systematically collected on participants' other diagnoses, throughout the interviews, some participants verbally reported receiving various other diagnoses. Diagnoses discussed included major depressive disorder, generalised anxiety disorder, bipolar disorder, schizoaffective disorder, dysthymia, anorexia nervosa, PTSD, substance use disorder, psychosis, dissociative identity disorder and agoraphobia.

Table 5. Summary of interview participant characteristics

Category	Sub-category	Lived experience (n)	Carer (n)
Gender	Female	6	3
	Male	3	2
Ethnicity (as reported by participants)	Australian	7	4
	British Australian	0	1
	Sri Lankan	1	0
	Australian Vietnamese	1	0
State of residence	Victoria	3	1
	New South Wales	1	2
	Western Australia	3	1
	South Australia	1	1
	Queensland	1	0
Overall treatment experience	Very negative	1	1
	Negative	4	1
	Neutral	0	0
	Positive	0	0
	Very positive	2	0
	Mixed	2	3

Note: N = 12; n (lived experience) = 9; n (carer) = 5; the total number within each category is 14 because two male participants identified with both lived experience and carer roles

Focus group participants were recruited through advertisements placed on the SANE Forums for lived experience individuals and carers, with the aim of recruiting existing forum members. Additional advertising occurred through SANE social media sites, including notices and advertisements on Facebook.

The anonymous nature of the SANE Forums meant that demographic details about focus group members were unable to be collected; unless their gender was specified during discussion, the pronouns ‘they’ and ‘their’ will be used to discuss individual members. In total, the lived experience focus group was attended by 13 forum members, with two of these forum members only attending at the tail end of the discussion to provide comments. Ten participants reported experiencing a personality disorder and thereby their comments were included in thematic analysis. Eight participants reported a diagnosis of BPD, with one participant reporting an unconfirmed diagnosis of DPD with BPD traits or ‘personality disorder not otherwise specified’, and another suspecting a diagnosis of OCPD. Other diagnoses reported by participants

included major depressive disorder, generalised anxiety disorder, dissociative identity disorder and PTSD.

The carers focus group was attended by four forum members, two of whom actively participated in the group and reported caring for someone with a personality disorder. The first participant reported caring for his wife, who has a current diagnosis of BPD, and the second participant reported caring for her husband, who has a current diagnosis of 'personality disorder not otherwise specified' (secondary to bipolar II disorder).

Procedure

Between February and March 2018, participants attended an interview with the project's Associate Investigator (EC) by phone, Skype or in person. Participants were required to sign a consent form prior to the interview's commencement. Interviews lasted 45–60 minutes and were semi-structured, with the interviewer following a discussion guide. At the end of the interview, participants were given a \$100 voucher. Participants who experienced distress during the interview were encouraged to contact their treatment team or were placed in contact with a SANE Helpline counsellor. All interviews were audio-recorded and transcribed.

Focus groups ran as part of 'Topic Tuesday', which occurs around once per month on the forums. The first post to the discussion was by a forum administrator, introducing the discussion ahead of the night and providing a link to an information form for participants. They were asked to read the form before deciding to participate, but were not required to sign any form. Participants were advised that if they posted in the discussion, it was assumed that they consented to participate and to have their (anonymous) information included in the thematic analysis. This removed a barrier for participation and allowed the focus group to function in a manner similar to standard forum discussions. It was also unlikely that participants would be willing to provide their real names and digital signatures in consent forms, considering that anonymous communication is an integral component of the SANE Forums and anonymity reduces uneven power dynamics.

On the night of the focus group, the Associate Investigator (EC) hosted the discussion while a moderator (a mental health professional) was also present. Discussions ran for an allotted two-hour timeframe and the Associate Investigator followed a discussion guide. Unlike the in-depth interviews, the focus group discussion aimed to focus more on experiences that members perceived to be useful or positive. Participants were thanked for their time but were not reimbursed.

Analysis

Analysis was conducted using a framework approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013), which incorporated both deductive and inductive analyses. The analysis began with reading and re-reading transcripts and listening to audio recordings if transcripts were unclear. This facilitated data immersion. The two authors then independently coded two transcripts (one lived experience, one carer) and developed an initial coding framework. The lead author then coded remaining transcripts using NVivo 13. The framework was altered

throughout the coding stage when new codes emerged or codes were refined. All participants were assigned pseudonyms.

Results – themes

Six overarching themes were identified throughout the qualitative analysis, with over 60 individual codes across the themes. These themes were **identity and discovery**, **(mis)communication**, **barriers and complexities**, **finding what works (for me)**, **an uncertain future**, and **carer-specific issues**. Themes are not mutually exclusive. The results are discussed below in relation to each theme, with relevant codes included in italics.

Common to all the themes was the impact of stigma, which was described as impacting on treatment and recovery pathways. One effect of stigma was that participants experienced *assumptions* made by others, including those relating to dishonesty, violence, capacity and functioning, level of dependence, and malicious intent. Further, participants described instances of *self-stigma*, whereby they internalised others’ blame and prejudice, resulting in self-blame for their symptomology and challenges in recovery. Discussion of stigma is incorporated within the themes, below.

Identity and discovery

Participants described their experience with personality disorder as being a journey characterised by fighting for themselves, fighting for others, and personal growth. The pathway to diagnosis was described by many participants as being fraught with confusion and misinformation, and there was generally a *long road to diagnosis*. Nearly all participants described some kind of *missed opportunity* for diagnosis and early intervention, including instances of being diagnosed with less complex but better understood mental illnesses such as anxiety and depression. Some participants, particularly those who did not report suicide attempts, described symptoms being attributed to other conditions (such as dysthymia), with personality disorder not being assessed or recognised for long periods of time. Many participants described *diagnosis as relief*, particularly those who had fought for a diagnosis themselves or who felt misunderstood or alone.

“ [The BPD diagnosis] *rocked me. I didn’t know what to do. Umm, but at the same time it was . . . cathartic in the long run.* ”

– Fiona, 36, BPD, traits of OCPD and HPD

For these individuals, a diagnosis offered a label that could help facilitate *self-discovery* and inform treatment. This fostered hope in those with lived experience and their carers; for instance, Abby (aged 36 years, diagnosed with BPD) and her mother shared a bottle of celebratory wine after Abby received her diagnosis in her early 20s. This *self-discovery* typically continued throughout treatment, particularly when engaging in treatments that facilitated exploration of factors that may have led to the development of the personality disorder (for example, schema therapy). Over time, many participants described their diagnosis forming part of their *identity*, as they engaged further with treatment over time and their *acceptance*

increased. For participants with more than one personality disorder diagnosis, this sense of *identity* was strongest with BPD. Participants implied that this was because BPD is more understood and talked about than other personality disorders, although it is still stigmatised. Some participants who did not meet full diagnostic criteria for a personality disorder diagnosis, or who were still seeking a diagnosis and had been labelled with *personality disorder traits*, described a disconnect with this label, with some feeling that a personality disorder label would be more meaningful and beneficial.



I need a box to put a label on it . . . I need that.



Lewis, 33, Cluster B traits

Although many participants experienced diagnosis as a relief, others found it upsetting. This was most evident for two participants: Daniel (37), whose former wife had a diagnosis of BPD and who was ‘devastated’ by his own diagnosis of BPD; and Vera (62, BPD), who had been told during her university studies that people living with BPD are ‘untreatable’ and who initially believed them to be ‘extremely manipulative’.

Throughout this process, nearly all participants described growth and development through becoming their own advocate, or someone else’s advocate, with some reporting increased *resilience*. Participants described the challenges of *learning their rights* and *trusting themselves* as they navigated process challenges and confusing service models. Many participants described taking on a *researcher role*, learning about symptoms, treatment evidence and availability, particularly when they felt information provided by health professionals was inadequate. This was particularly evident for participants who had minimal exposure to the Australian mental health system prior to their personality disorder diagnosis. Although participants described this advocacy process in terms of building personal strength, most resented feeling that the *onus is on them* and wished the process had been more straightforward from the start.



I was struggling . . . I guess it’s all a learning journey, but it would be helpful if, for me, if I had more access to stuff off the bat than having to search for it myself and figure it out myself.



Maggie, 41, traits of BPD, AVPD and DPD

The *language* surrounding personality disorder, including the diagnostic labels themselves, were disliked by some participants, who found the language around BPD in particular to be confusing and loaded. Although many reported identifying with their diagnoses, participants expressed concerns about being labelled and treated as a disorder rather than as a unique person. For some, the term suggested a fundamental flaw:



The term, borderline personality disorder, it sort of implies that there's something lacking in the individual. There's something defective in the individual. When, in fact, in my experience, a lot of it is a response to unacceptable levels of trauma.



Tess, 60, carer of daughter with BPD

The label itself was described as perpetuating stigma:



I think it prevents health professionals to be understanding because of that label. And the assumption that you're just attention seeking . . . not taking you seriously when you're feeling very suicidal.



Julie, 24, BPD

(Mis)communication

Participants emphasised the importance of clear, honest and sensitive communication throughout their treatment pathways. For many, the issue of miscommunication first emerged as health professionals exhibited *reluctance to diagnose* personality disorder, or reluctance to complete assessment in the first place. Although this is not aligned with general treatment guidelines (NHMRC), the choice not to diagnose may have been due to clinicians' concerns about labelling individuals and perpetuating stigma. Absence of diagnosis led to frustration for some participants, particularly those who actively researched and sought out a diagnosis. Some participants described moving between multiple health professionals as part of the process, only receiving a diagnosis after meeting with multiple clinicians. Some participants reported instances of seemingly *accidental communication* of diagnosis, for instance, seeing 'borderline personality disorder' or 'narcissistic traits' written on a form or report, rather than having this diagnosis communicated directly in person. Such occurrences were described as very distressing, resulting in confusion, mistrust and participants distancing themselves from the label.

Some participants also described a *lack of explanation* of treatment decisions, including therapeutic processes; many participants were unable to clearly answer what type of therapy their psychologists had used. Some participants believed their therapist used a CBT-informed approach but described elements of DBT, such as mindfulness and distress tolerance, included throughout their therapy. Some reported relief after finding a clinician who clearly communicated their choices and approaches, often not recognising this had been an issue with prior clinicians until faced with someone who communicated more clearly. For those being treated in a team environment, or seeing multiple professionals over time, some participants described receiving *conflicting information* and not always being sure which advice to follow. Some carers also reported receiving no information, or insufficient information, to support them, and having their views dismissed.

“ At the ED [emergency department] after a recent attempt (within the last month), while the level of care was high the attempt was not acknowledged as such, yet no one bothered to ask what I thought. She told them what they wanted to hear so she would be discharged and she was after a regulatory observation period, so I had to take her home fearing for her safety and there was nothing I could do about it. ”

Carer focus group participant, supports wife with BPD

Participants implied that *conflict resolution* was valuable, although challenging. This is in the context of mental illness that generally involves interpersonal issues as symptoms; hence, assertive communication of needs is not always easy for these individuals. Further, efforts from clinicians to repair ruptures were perceived as valuable. For example, Maggie (41, traits of BPD, AVPD and DPD) began writing down her perceptions of feeling invalidated or threatened by her psychologist to bring to her sessions, to try to ‘keep communication open’ and prepare in advance for difficult conversations. However, participants implied that there were not often opportunities for conflict resolution, as some relationships were deemed irreparable. Some participants described confronting clinicians by ‘lashing out’ or submitting complaints, or withdrawing from services after instances of conflict, invalidation, unprofessionalism or other issues.

Many described issues with a lack of understanding of personality disorders from family, peers and health professionals. Participants noted the lack of *visibility* of personality disorder in the public sphere having a flow-on effect, fostering misinformation and stereotypes. These stigmatising experiences impacted on participants’ *disclosure* choices, with some communicating their diagnoses widely (at least, to trusted family members and peers) and others limiting disclosure of their diagnosis – or full range of symptoms – in order to reduce experiences of prejudice and discrimination. For example, one participant, Anna (32, BPD), noted that she began withholding information about her diagnosis and the severity of her self-harm and suicidal ideation due to experiencing negativity from clinicians, and these symptoms being an exclusion criterion for service access, leading to a misdiagnosis of bipolar disorder. She also noted that she felt more respected when being treated for psychosis compared to treatment for BPD, noting that during an inpatient admission she found the nursing staff to be supportive, validating and generally ‘nice’.

Barriers and complexities

All participants identified challenges when seeking support and treatment for personality disorder. These challenges generally resulted in significant frustration, mistrust, anger and sometimes resentment and hopelessness; however, the severity of these challenges differed significantly between participants. For example, Abby (36, BPD) described challenges finding a trusted, youth-friendly clinician when she was in her early 20s, trialling several psychologists; after finding a psychologist she trusted she found treatment to be valuable and supportive. Her treatment journey appeared relatively linear, with frequent treatment access for three years resulting in a reduction in suicidality and increase in self-efficacy, and occasional contact with

psychologists in the last 10 years relating to less complex issues such as anxiety and stress management. In contrast, Daniel (37, BPD) described experiencing very high levels of stress while providing support to his former wife, who has BPD, for over a decade. He eventually received the diagnosis of BPD himself in middle adulthood after their separation. In the context of PTSD, physical disability and homelessness, he described the near impossibility of accessing housing and food, and noted that public waiting lists for free inpatient services (or other public psychotherapy) were excessively long in Perth, where he lived. He reported anger and hopelessness, feeling that he was out of options to cope with unrelenting crises. Other participants also described their frustration with services leading to a breakdown point where they felt unsupported and unable to cope, taking actions such as withdrawing from all treatments or refusing to take medication, generally resulting in an escalation of symptoms.

Participants described a number of clinician and process factors. Many participants described *crisis as catalyst*, with a suicide attempt or severe self-harm catalysing initial or new treatment access. Hence, most participants described emergency department presentations and inpatient stays. There was a general perception that many participants had experienced, or were at risk of, *falling through gaps*, particularly when they met exclusion criteria for service access (for example, due to current severe self-harm) or could not work around inflexible rules (for example, missing too many sessions). *Service availability* was a major issue, particularly in the context of *rurality*. Many participants reported a lack of mental health services, and when services are available they typically have long waiting lists (up to two years), particularly in the public healthcare system, but sometimes also in the private system.

Participants also noted a *lack of specialist resources*, as many participants accessed generalist services instead of specialist services. Although generalist services were perceived to be better than nothing, participants criticised the perceived lack of training, empathy and understanding by some clinicians at generalist services. Available specialist services were nearly universally directed towards BPD, alienating those with other personality disorder diagnoses. Many participants noted that their first point of contact with mental health services was typically a generalist service, often a GP, and felt that the lack of knowledge from GPs contributed to the length of time taken to receive appropriate treatment. Many reported *wrong or ineffective treatments*, with participants sometimes being given treatments that only addressed service-level problems or that are not evidence-based for personality disorder (for example, Fiona, 36, was given CBT for treatment of BPD, with no symptom reduction). These instances were usually in the context of generalist services and prior to a personality disorder diagnosis being made. Participants also noted that evidence-based treatments did not always work for everyone. For example, multiple participants noted that there is a focus on DBT, but felt it was not necessarily the best or most effective treatment for them. The full DBT program was not always accessible, and some had difficulty taking in the vast amounts of information during skills training. Regardless, many participants noted that DBT had been helpful in at least some ways, such as teaching distress-tolerance skills. Some participants emphasised difficulties working with services and professionals that did not give appropriate consideration to their history of trauma:

“ The MH [mental health] profession needs to shift away from talking about what is WRONG with a person and instead look at what HAPPENED to a person. The “symptoms” of BPD are perfectly normal reactions to extremely abnormal situations. The MH profession needs to shift to a trauma informed model rather than a medical model. ”

Lived experience participant, BPD

Participants also reported a number of issues with *clinicians behaving in unethical or unprofessional ways*. These anecdotes often provided a disturbing view into what can go wrong in psychotherapy. For instance, Maggie described her first psychologist yelling at her during a session; Tess described confidentiality violations in the hospital setting, with rumours spread about her daughter returning back to her; Julie described a doctor asking her if she was ‘stupid’ after she was hospitalised due to overdose. Several participants described not being believed by clinicians due to their diagnosis, reporting that some clinicians believed they were lying to seek attention. Other clinicians were confused or unaware of symptoms, for example confusing SPD with schizophrenia. At the most extreme, participants described *re-traumatisation*, with their experiences accessing treatment perceived as traumatic. For example, Tess noted an incident where her daughter was physically restrained and isolated during inpatient care:

“ You’d think that people would be trained in hospitals to actually react firstly with some empathy and secondly with a little bit of insight to know that then if you were going to get half a dozen burly nurses to hold down a young girl and shackle her, umm, it doesn’t solve the problem. And it just makes them feel like they’re worth nothing. ”

Tess, 60, carer of daughter with BPD

Participants also noted that *ceasing services* was an issue, with participants being ‘moved on’ when their clinician was going on leave, was leaving the service, or felt that the treatment they provided was not successful. Participants reported feelings of rejection, confusion and being disheartened by these instances. It is likely that the choice to refer elsewhere in the context of treatment being unhelpful was an ethical choice on the part of the health professional; however, some participants appeared to perceive these experiences as abandonment. Several participants discussed their perception that they were not ready to end treatment and were not adequately transferred to another service.

Participants also described individual factors that added complexities to the treatment process. Many participants described the *nature of their personality disorder* sometimes being a barrier, including difficulties setting boundaries with clinicians, interpersonal conflict and black-or-white thinking leading to challenges. The *emotional intensity* and *time commitment* of treatment were issues, with effective treatment generally understood to be long-term (years) and hard work.

Financial barriers were common, with most participants reporting their treatments to be very expensive, unless they were able to access a public or other free service. Many participants noted that the financial cost of treatment resulted in a flow-on effect, limiting other aspects of

their lives, such as their ability to engage in hobbies, go on holidays or eat out, sometimes resulting in significant debt. Challenges were exacerbated in the context of financial stress and rurality, if participants could not afford to travel. Mental health treatment plans (MHTPs) were valued but believed to reimburse not nearly enough sessions, considering the complexity and frequency of contact required for effective treatment. One participant, Daniel, described MHTPs as ‘a f—ing joke’ while a focus group participant described the session provision as ‘nothing’. Several participants reported that Centrelink had been critical for everyday survival, although difficult to access and often insufficient to cover needs. For example, Tony (42, BPD and SPD) reported receiving a reduction in payments after marrying his wife (who has BPD); he can no longer afford private health insurance, so he cannot access private specialist programs and now has to rely on a MHTP to access treatment. The NDIS was perceived to be very difficult to navigate, with its design confusing both clinicians and consumers, and limiting access to certain services, which participants felt they needed or found useful, and participants perceiving that people working within the NDIS were not appropriately qualified.

Some participants described further *demographic barriers*. Some reported older age as a barrier due to lack of familiarity with the mental health system or confusion from clinicians who believe personality disorder mostly affects younger people. Although asked, male participants in this study did not report perceived difficulties due to their gender. Participants of colour (Anna, 32, BPD and NPD traits; Julie, 24, BPD), both of Asian descent, noted that clinicians made assumptions about their families and had been hesitant to discuss cultural impacts and challenge their family dynamics. They both reported that their families did not understand mental health and struggled to understand and support their symptoms and treatment needs. Other participants noted extra challenges that presented in the context of *comorbidities*. For example, Fiona noted that after being on a waiting list for six months, she was then deemed unable to participate in a private hospital DBT program due to developing substance dependence during the wait.

“ [After the waiting list incident] *I nearly killed myself. I lost it really badly. . . And I couldn't go back to that practice afterwards . . . I won't even drive past it if I can help it.* ”

Fiona, 36, BPD, traits of OCPD and HPD

Finding what works (for me)

Many participants described a (usually long) process of determining which services, treatments and other supports provided the most benefit to their mental health. Most participants described ongoing connection with health professionals to this day, usually a GP, psychologist or mental health worker, with whom they had developed *rappor*t and who they perceived to be empathetic, professional, effective and willing to challenge them sensitively and appropriately. Community-based *specialist support* was seen by many participants to be invaluable, and better than generalist services, although some participants still accessed generalist services if they found them useful or if specialist support was unavailable at the time. For participants who accessed treatment in adolescence or young adulthood, youth-oriented services were generally

appreciated, although it was noted that some of these services do not accept consumers who are too 'complex'.

Typically, participants reported receiving the most benefits from goal-directed, long-term, in-person, evidence-based therapies such as DBT, schema therapy and mindfulness, although not all participants were able to access such treatments. Others reported engaging with self-help resources, or in-person counselling or supportive therapy rather than accessing more specific and structured treatments, finding the former valuable for working on daily life problems, and accessing other forms of treatment (such as telephone counselling, emergency departments) only in times of crisis. It was implied that for many individuals, treatment had been critical in improving quality of life. Inpatient stays were valued for surviving a crisis; psychiatrists and GPs were valued for managing medication; and psychologists, psychiatrists and other mental health workers (particularly if community-based) were valued for improving participants' coping skills and increasing their insight and self-efficacy. For several participants, a trauma-informed approach was identified as critical, starting with the basic idea of creating a feeling of safety in the room.

“ I think trauma work may just be the "key" to un-muddling [sic] me, which is a hope I've never really had before with any other treatment avenue . . . [my current therapist] very much works within an attachment-based framework. We are about 10 sessions in and thus far she barely knows anything about my story – the current focus is on creating a safe space in her room and with her. ”

Lived experience focus group participant, BPD

Finding what works often involved *meeting multiple needs*. For example, Maggie reported accessing a combination of DBT and schema therapy (specific to her personality disorder traits) but also a depression support group and generalist art therapy. Her 'needs' in this instance included learning distress-tolerance skills (DBT); gaining insight into childhood and adolescent factors which influence current cognitions and behaviour (schema therapy); *social support* from friends, family and peers (formal support group, informal support from family); and relaxation and fun (art therapy). Most participants reported accessing medication either currently or in the past, with mixed efficacy and side-effect profiles. Many participants continue to access Centrelink or other financial support.

Many lived experience participants reported strong appreciation for carers, family and friends and other support persons, including appreciation for social and more practical types of support, although several noted interpersonal difficulties getting in the way of long-lasting, healthy friendships, and others reported difficulties when their relationship with a carer was unhealthy or abusive. Carers also reported valuing support from family, friends and colleagues, including family members who were also able to provide care and support.

Participants identified the importance of self-care such as eating well and exercising. Also important was a combination of *pleasure and mastery*, with participants seeking pleasurable

activity such as engaging in hobbies, and obtaining mastery through study and work (which many participants had reduced, paused or ceased entirely at some stage during their treatment journeys). Some participants also reported valuing *professional opportunities* such as attending personality disorder conferences or accessing mental health first-aid training, and being involved in *advocacy* initiatives and campaigning for positive change. Participants also reported the value of *peer narratives*, experienced through meeting and talking to others with similar stories, normalising and validating their own journeys and learning from others' experiences. This was particularly evident in the context of online and offline forums and support groups.

“ I belong to a, umm, Facebook group . . . and again, it's a group who understands where you're coming from, understands the struggles in life. Umm, but literally just provide a social group, if you want to attend. Just to say, well you're a normal person, just like anyone else. We've got these, umm, conditions, but again, it doesn't define you. It doesn't mean you have to avoid life or avoid relationships. ”

Tony, 42, BPD and SPD

For some participants, however, ‘finding what works’ sometimes involved strategies that may vary in efficacy or have negative consequences in the long term. For example, one carer (Chloe, 46) described her son (20s, BPD and NPD) ‘doctor shopping’ in order to try different medications, eventually relying on misuse of prescription pain-relief medication to cope with daily distress. Other participants described self-medicating through illicit drug use either in the past or present, or continuing self-harm as a method of coping with intense distress.

An uncertain future

Most participants in the study were still heavily engaged with treatment and support services and had experienced rocky treatment trajectories. Although perceptions varied, many participants reported *worry* about future prospects, relating to the possibility of ‘recovery’, financial capacity, or – at an extreme level – meeting basic survival needs. Some participants reported a sense of *stagnation* with treatment, particularly those who had been engaged with services for a long time with little perceived progress. Many participants appeared to be *learning from past* negative experiences and fearing that the past would repeat itself, resulting in further stagnation or perhaps more negative experiences. Many participants spoke with *cynicism* and appeared to be sick of fighting what they perceived as a losing battle.

“ Fifteen years and I'm sort of back in the same spot, so it's kind of like . . . yeah, I don't know, it's very hard for me to say anything positive. ”

Lewis, 33, Cluster B traits

Even participants like Abby, who felt that their personality disorder symptoms were now minor or absent after a fairly linear treatment experience, reported concern about the future. For instance, Abby expressed concern that she will forever be vulnerable to environmental stressors and identified worries about relapse.

Regardless of her concerns, Abby’s narrative – and some others – tended more towards hope rather than cynicism. Participants were able to reflect on, and appreciate, positive experiences and their progress. However, despite varying experiences, nearly all participants strongly identified a *need for positive change* – with change needing to be timely, immediate and comprehensive. Suggestions included:

- Change in ‘personality disorder’ terminology, and ceasing the use of the term ‘borderline’ and using an alternative term such as ‘complex PTSD’ or ‘emotion dysregulation disorder’
- Significant increase in funding for specialist services, focusing on evidence-based service provision:
 - Increase in DBT services but also other evidence-based treatments such as schema therapy
 - Increase in specialist, comprehensive treatment and support services in rural and regional areas, for those experiencing personality disorder and for carers, family and support persons
 - For BPD, improved delivery of services in accordance with NHMRC guidelines
 - Significant reduction in service costs borne by consumers – such as the cost of having many more than 10 sessions in a MHTP to allow for intensive, long-term therapy
 - Increase in services which do not exclude individuals with comorbidities such as substance abuse
 - Increase or redesign of services to provide more comprehensive and practical support, such as career and study support, peer mentoring opportunities, social opportunities
- Increase in quality and consistency of training for GPs, psychologists, psychiatrists and other health professionals to ensure quality of care
- Increase in (sensitive and appropriate) public awareness campaigns – and also more education in schools to destigmatise and improve visibility of personality disorder, and to improve how teachers respond to students experiencing symptoms such as self-harm
- Removing mental health from the NDIS or redesigning the NDIS to improve functionality and access to services for people living with personality disorder
- Moving away from a medical model and towards a trauma-informed model of personality disorder.

As Fiona noted colourfully:

““ *Project Air’s, umm, treatment of personality disorders, umm, guideline . . . the NHMRC guideline. They are both evidence-based, effective ways of treating a personality disorder. Why the f— haven’t they been funded and implemented? It’s ludicrous . . . they keep putting all this money into research and it’s like, “Dudes, no, you’ve got all the research. F—ing fund it!” [laughs]* ””

Fiona, 36, BPD, traits of OCPD and HPD

Carer-specific issues

In addition to points raised above, carers reported additional challenges associated with their experiences. Carers in this study reported providing different levels of support ranging from practical and functional support to emotional support and friendship. Typically, carers reported *role fluctuation* over time, with the relationship described as reciprocal and neither individual purely passive or reactive. Their role also fluctuated depending on the severity of symptoms being experienced by the person they care for, with many care recipients experiencing fluctuations in symptom severity and level of support required. Typically, carers were able to provide a different *perspective*, providing advice and suggestions (which were not always agreed upon by all parties).

Carers reported significant *stress* and worry associated with their caregiving, particularly in the context of suicidal intent or attempts, or conflict with the care recipient. In some cases, carers felt that the stress of caregiving resulted in vicarious traumatisation and a decline in their own mental and physical health. However, carers generally reported that their support was fuelled by *love* and their resilience, knowledge and caring skills typically increased with time, so that they felt more skilful and more confident in their caregiving. Those with lived experience also reported strong appreciation for those who had provided support over their treatment and support journeys.

Carers noted some significant challenges worth mentioning in this report. First, some carers reported their perception that there is a *lack of specialist carer resources* available. This was most evident again for those residing in rural areas. However, when asked, not all carers reported actively seeking out carer services, which suggests that some carers were not aware of, or not willing to seek out, specialist support. Other carers reported varied experiences with specialist carer resources, sometimes finding them valuable and sometimes finding them inappropriate. Some carers reported receiving advice to end the relationship, or felt that they had been blamed by health professionals for the person's difficulties. This resulted in mistrust of health professionals and unwillingness to attend services again.

“ The solution the first psychologist I saw for support was for me to leave my wife and quit my job and all would be good. ”

Carer focus group participant, supports wife with BPD

Further, some carers noted a perception that *lip service* is paid to carers, without appropriate action. Some participants reported that they had not been sufficiently involved in the treatment of the recipient of their care, and had not been believed or consulted.



If I wasn't in addition to my full-time job spending hours and hours and hours sort of supporting my daughter, umm, you know, what would be the cost to society? I think people, you know, there's public statements about how important carers are. But, they really are undervalued.



Tess, 60, carer of daughter with BPD

Discussion

The qualitative data obtained through interviews and the online focus groups provided rich insights into the experiences of people affected by personality disorder – either through their own lived experience or through supporting someone in their life who lives with personality disorder. Participants typically described long, non-linear journeys with treatment and support services, impacted by stigma at various points along the way. Participants' experiences demonstrated that stigma and discrimination remain significant factors impacting the experiences of those with personality disorder, their families and friends. Their experiences reflected that there is very little understanding of personality disorders in the general community, and little positive representation of people living with these conditions. These findings are broadly aligned with previous research into experiences of people living with BPD and their carers, families and other support persons. For example, a study of Australians with BPD (Lawn & McMahon, 2015a) found that most participants reported feeling anxious or very anxious about discrimination due to BPD diagnosis, being treated poorly, not being taken seriously, and the prospect of losing a long-term therapist.

For those who described positive experiences of engaging with help and support, accessing evidence-based, professional and consistent treatment was key. Many reported that treatment and support had been invaluable for improving coping skills, increasing quality of life and – at a basic level – keeping participants alive through times of crisis. Many participants reported finding at least one health professional who they perceived to be ethical, warm, non-judgmental and empathetic. Positive experiences described by participants typically occurred in community-based specialist settings. This is not at all surprising and aligns with treatment recommendations that suggest that these services are best in the community (National Health and Medical Research Council, 2012).

In thinking about the types of treatment approaches that were most useful for them, participants and carers identified a variety of treatment strategies and psychosocial supports as being helpful. Treatments such as DBT, schema and supportive therapy were generally identified as helpful, while inpatient stays were described as important but often distressing. Trauma-informed therapy was typically described as being very challenging but critical, with several participants advocating for trauma-informed care. The patterns broadly support a past study which found that people living with BPD identified the following as being most helpful: DBT; community support groups; identifying early warning signs; crisis plans; education and information; and medication (Lawn & McMahon, 2015a). For those who experienced inpatient

settings, unfortunately, few appeared to have positive experiences and their experiences seem counter to the recommendations for optimal care identified in the environmental scan.

A key theme emerged in relation to the length of engagement with treatment services by people living with personality disorder. Nearly all participants reported having accessed treatment since late adolescence or young adulthood up to the present, sometimes with gaps in treatment access and changes in intensity. This is aligned with a past survey of people living with BPD, which found that 56% of participants reported accessing support for more than 10 years, although many also reported treatment being interrupted or inconsistent over this period (Lawn & McMahon, 2015a). Treatment length was despite the fact that most participants in this study had accessed at least one type of evidence-based treatment, such as DBT, supporting the notion that even evidence-based treatments do not necessarily result in full recovery after engagement. While many people spoke positively of their experience with DBT as a therapeutic approach, the perception was that DBT is not a 'cure', despite sometimes being heralded as one. This is aligned with research that indicates that DBT is not necessarily helpful for all symptoms – particularly depressive symptoms (Links et al., 2017). Regardless, DBT appears important for skill development particularly in areas such as distress tolerance. It is important for clinicians to have the skills to identify when DBT is or is not appropriate, and to consider other evidence-based treatment options and provide appropriate referrals as needed.

The financial impact of living with or supporting someone with a personality disorder was particularly salient in the study findings, and reflected the results of the environmental scan discussed in Part B of this paper. This is aligned with previous research by Lawn, where 70.3% of participants (who had BPD) reported feeling anxious or very anxious about the financial cost of accessing services. Individuals noted that the costs associated with accessing appropriate treatments for their personality disorder were high and it was difficult for them to access the range of services they needed. Treatment was often interrupted when the individual was no longer able to access free or subsidised services (for example, when their 10 sessions with a psychologist provided under a MHTP ran out). The cost factor forced some participants to rely on free services (which were not always specialist services) or on financial support from family or friends. Carers also discussed the considerable financial impact of supporting someone with a personality disorder as they often found themselves unable to work or underemployed. A near-universal suggestion from participants was a boost in funding to reduce costs borne by those with personality disorder and their carers.

Many participants described finding a warm, validating clinician and the huge benefits of developing a strong therapeutic alliance. It was implied that this was as important as, if not more important than, the type of psychotherapy undertaken. In contrast, many of those who participated in the study had experiences of frustration at what they perceived as unprofessional or unethical behaviour by health professionals. In particular, they cited examples of not having their mental health or related health concerns taken seriously; being actively discriminated against in seeking help and support; and not having their views or experiences respected. Unfortunately, some participants described narratives that were characterised by one negative experience after another. This is particularly the case in the context of rurality, financial stress,

long inpatient stays, and particularly complex cases (for example, a dual carer/care-recipient role, comorbidities such as PTSD or perhaps complex PTSD). Some participants described their experience of engaging with mental health services as traumatic and sometimes exacerbating past experiences of trauma.

Those who participated in the study who were carers or family of people living with personality disorder reported the significant impact of their caring experience. Their experiences were aligned with the findings of Lawn & McMahon (2015a) who identified significant stigma experienced by carers within the health system. The NHMRC guidelines for the treatment of BPD acknowledge that families, partners and carers play an important role and recommend that they be involved in the individual's care, with their consent. However, a number of those with caring experiences reflected that they found that their contributions were not valued by treatment teams, particularly once the person they supported was over the age of 18. Some felt that their concerns about the person's wellbeing were often not taken seriously. While carer support mechanisms were in place, it was noted that these were often not available at accessible times or locations.

The severity and nature of personality disorder – in particular, attachment-related difficulties, boundary-setting and other interpersonal challenges – mean that this population is particularly vulnerable to conflict with clinicians and an exacerbation of symptoms if they have a negative experience with a service provider or appear to fall through a gap. The instances of unethical or unprofessional clinician behaviour recounted by individuals could be related, in some instances, to transference. For example, individuals may interpret a psychologist ceasing a service as abandonment, based on their past experiences, although the psychologist may be resigning from their position in good spirits and carefully planning for handover. It is understandable that participants had experienced service cessation if they had been accessing services for a long time, as it is not always feasible for clinicians (or consumers) to stay at the one service for years. However, participants certainly described instances where services were cut very short without appropriate discharge or handover planning, which is against general recommendations.

Also important to consider is the role of clinician skills and countertransference. It is known, although not explored in this study, that clinicians face many challenges working in the field of personality disorder. These relate in particular to the chronicity of symptoms, interpersonal conflict, and coping with risk, which may interrupt the therapeutic alliance (Sansone & Sansone, 2013). These problems will be exacerbated in the context of lack of specialist training and resources. Although some of the ethical violations described in this study are clearly unacceptable (for example, violating confidentiality by spreading rumours about consumers), other instances of perceived unprofessionalism may be in the context of the clinician trying their best with their current knowledge and limits, particularly if working in a generalist service. Regardless, it is known that many health professionals make negative assumptions about people living with personality disorder. In previous research, clinicians have called for an increase in training and education; better support through supervision and leadership; clearer guidelines and protocols; and a reduction in stigma about personality disorder (Fanaian, Lewis, & Grenyer, 2013).

There was a strong perception amongst those who participated that the mental health system is failing to meet the needs of people living with personality disorder, particularly in relation to finances and public waiting lists. There was an expressed desire for GPs and health professionals to be upskilled in early identification of personality disorder, providing diagnoses, and guiding people through appropriate treatment pathways. This was considered necessary to address the many missed opportunities for diagnosis and treatment at the early stages of an individual's journey with personality disorder. Many participants found that they were 'forced' to become their own expert, to be proactive in seeking help through their own personal research into effective approaches, despite their mistrust in professionals.

Limitations

The authors acknowledge that the sample size of the qualitative study in this exploratory project may be insufficient to cover the full scope of experiences of people living with personality disorder, and hope that these findings may encourage more research in the future.

Given the exploratory nature of this work, the aim of this study was not to represent all people living with personality disorder but to capture a variety of experiences. We note, however, that no people from an Aboriginal or Torres Strait Islander background were involved in the research. While we cast the net widely to recruit people for the study, unfortunately no people identified as being from an Aboriginal or Torres Strait Islander background during the recruitment period. Further, only three men participated in the study, with responses to the recruitment notice being overwhelmingly from Australian women with a diagnosis of BPD. There were no participants from Tasmania, the Northern Territory or the Australian Capital Territory.

This study was also limited to adults over the age of 18. Young people living with personality disorder have unique experiences that should be reflected in efforts to improve responses to personality disorder in the community.

Further, it was not within the scope of this study to include clinicians. As described above, there are many challenges that clinicians may experience working with people living with personality disorder. Considering the perspective of clinicians is critical for future research endeavours.

Recommendations Overview

Reflecting on our findings, we have developed 11 recommendations to promote stronger research, policy and practice efforts to support Australians affected by personality disorder. The recommendations fall within six subject categories.

Understanding the prevalence of personality disorder	1. Conduct a national, representative survey to identify current prevalence of personality disorder in Australia, providing an update to the 1997 figures.
Research directions	2. Consider funding further research into treatments for personality disorder other than BPD. 3. Conduct practical and applied research that fills current knowledge gaps for BPD and other disorders.
Prevention and early intervention	4. Scale-up existing early intervention programs.
Clinician training	5. Obtain national commitment to establish and disseminate the NHMRC’s Clinical Practice Guidelines for the Management of Borderline Personality Disorder 6. Consider the feasibility of establishing training and treatment standards to better prepare clinicians to work with personality disorder in an evidence based and trauma informed way, increasing consistency between clinicians.
Improving current care standards	7. Create a summary resource providing an overview of evidence-based treatment recommendations and options for all personality disorders in collaboration with an appropriate organisation or organisations that can be disseminated to clinicians and people with lived experience. 8. Take meaningful actions towards system redesign with focus on efforts to streamline pathways, improve access and reduce financial burden carried by individuals with personality disorder. 9. Develop a holistic approach to meet the needs of families and friends supporting someone living with personality disorder, and scale this to benefit people across Australia regardless of location.
Stigma reduction	10. Identify, implement and evaluate strategies to shift assumptions from health professionals that individuals with BPD cannot benefit from psychotherapy, and other myths utilising a partnership of the existing national advocacy organisations. 11. Design and conduct formative research into a multi-channel media campaign aiming to educate the Australian community and destigmatise personality disorder.

Recommendations

Reflecting on the findings from the literature review, environmental scan and qualitative study, we have developed the following recommendations to promote stronger research, policy and practice efforts to support the wellbeing of Australians affected by personality disorder.

Understanding the prevalence of personality disorder

1. Conduct a national, representative survey to identify the current prevalence of personality disorder in Australia, providing an update to the 1997 figures.

The current body of literature does not provide comprehensive or recent data regarding the prevalence of personality disorder in Australia, with the most recent representative data being from 1997 (Jackson & Burgess, 2000). It is critical to update these figures in order to understand the size of this population, diagnostic trends and any changes in prevalence over time. The quality of outcomes for these individuals is driven by accurate collection and reporting of data. It is not enough to include personality disorder within an 'other' mental illness category in national surveys.

This survey should include a comprehensive measure of DSM-5 criteria, such as the semi-structured Structured Clinical Interview for DSM-5 Personality Disorders (SCID-5-PD). This is important because ICD-10 measures will soon be out-dated, and the ICD-11 will be redefining personality disorders, and it may take years before new measures are sufficiently validated. Further, prevalence data should be presented with consideration of age group, gender, ethnicity and other demographic variables. Ideally, this would involve inclusion of personality disorder screening in the next iteration of the National Survey of Mental Health and Wellbeing, which is currently in development.

The authors recognise the complexities and challenges of conducting such research, as identified in the literature review within this paper. It is expensive, time-consuming and labour-intensive to conduct national studies such as these, and it is near impossible to ever obtain a truly representative sample. For example, it will be difficult to obtain accurate estimates of ASPD within the general community, as participants would be unlikely to admit antisocial or illegal behaviours to researchers. Hence, it is important to carefully consider strategies to reduce the influence of social desirability bias (for example, anonymising certain responses) and also to conduct research in specialist settings, such as forensic populations, to support community-based data.

Consideration should also be given to how statistics relating to personality disorder in special settings and populations can be estimated and updated in systematic but culturally appropriate manners.

Research directions

2. Consider funding further research into treatments for personality disorder other than BPD.

Compared to BPD, there is very little research into treatment for other specific personality

disorders, and results of studies are often mixed. This was a major gap in the literature. However, considering that the prevalence of these disorders is similar to (or in some cases higher than) that of BPD, it is important not to forget these individuals, even though they do not present as often to services. This may be challenging, considering that many individuals with personality disorder are not routinely assessed or diagnosed, and do not seek treatment services as often as those with BPD. Hence, it is more feasible – and probably more necessary – to begin such efforts with more ‘visible’ diagnoses such as SZPD and ASPD. For example, SZPD treatment research could be conducted in youth early-psychosis settings, and ASPD treatment research could occur in forensic settings.

Such research would first require using systematic search strategies to comprehensively search available peer-reviewed and grey literature to identify any treatment evidence, and clinician consensus regarding treatment, prior to developing and testing manualised treatment approaches. Analysis of retrospective data may also be beneficial to provide initial directions. Replicating existing studies may also be necessary.

Such research may involve studying psychotherapy approaches that are typically recommended by clinician consensus, such as CBT and psychodynamic approaches. Research could also be conducted trialling third-wave therapies for treatment of personality disorders, such as the appropriateness of DBT for personality disorders other than BPD, or modified versions of these therapies specific for other personality disorder symptomology.

3. Conduct practical and applied research that fills current knowledge gaps for BPD and other disorders.

As this project has revealed, there are still some significant gaps in the evidence base. Research questions to be considered include:

- What is the cost-effectiveness of personality disorder treatment in the Australian context?
- How can attrition levels in treatment be reduced?
- How can existing psychotherapeutic approaches be successfully modified across different settings, such as self-help, digital therapy, and forensic settings?
- What are other options for early intervention and prevention, such as school-based mindfulness and distress tolerance programs? Are they effective?
- What are evidence-based approaches for people living with more than one personality disorder, or in the context of comorbidity (including substance use, eating disorder, and psychosis)?

Prevention and early intervention

4. Scale-up existing early intervention programs.

Programs such as HYPE and adolescent DBT have demonstrated efficacy for young people living with emerging BPD symptoms (Chanen et al., 2009). Further work and investment is needed to expand current programs to more settings (including rural and regional areas). This

would make a considerable contribution to ensuring that these young people have the best possibility of recovering, and reducing the risk that they will experience ongoing mental health challenges impacting their social and economic participation into adulthood.

Clinician training

5. Obtain national commitment to establish and disseminate the NHMRC's Clinical Practice Guidelines for the Management of Borderline Personality Disorder.

The NHMRC's Clinical Practice Guidelines for the Management of Borderline Personality Disorder, cited throughout this report, provide a comprehensive overview of management of BPD in the Australian context (National Health and Medical Research Council, 2012). However, the guidelines have not been systematically implemented across Australia. This is a critical step towards improving clinician knowledge of BPD, and also improving current care standards and models of care (see below). Strategies need to be developed to identify barriers to implementation and how to increase the usage of these guidelines. Such work may be best timed to coincide with the next review of the guidelines.

There is also a need to develop similar guidelines for other specific personality disorders in the Australian context, particularly ASPD. The UK's NICE guidelines for ASPD may be a useful resource for development of these guidelines (National Institute for Health and Care Excellence, 2009).

6. Consider the feasibility of establishing training and treatment standards to better prepare clinicians to work with personality disorder in an evidence based and trauma informed way, increasing consistency between clinicians.

Although health professionals are generally highly educated, mental health training differs significantly between universities and other clinical pathways. There is a need to utilise a range of educational resources to expand awareness of personality disorder, and of appropriate management and treatment approaches, throughout the sector nationally. There is a need to improve the skills and knowledge of health professionals so that those working in both specialist and generalist settings are equipped to work with individuals with personality disorder (Grenyer, 2017). Further, it is important to improve consistency of training standards for clinicians coming into contact with individuals experiencing the most severe symptomology, particularly clinicians working in emergency department and inpatient settings.

Core competency training for clinicians, based on the NHMRC guidelines, is currently offered by some services (such as Spectrum in Victoria). These training standards need to be expanded nationwide and become a requirement for clinicians who are likely to come into contact with individuals affected by personality disorder.

This work is currently underway through the National Training Strategy being developed by the Australian BPD Foundation. Currently Stages 1 and 2 have been funded through the National Mental Health Commission. Stages 1 and 2 include partnership with the Mental Health Professionals Network, Spectrum and Project Air. It is envisaged that Stages 3 and 4 will extend

the partnership to include Orygen/HYPE. As Stages 3 and 4 are developed, funding will be required for implementation.

The National Training Strategy will need to address undergraduate as well as workforce education. The training focuses on the needs of health professionals in the private and public sector and includes GPs, psychiatrists and allied health professionals (which includes mental health professionals).

Improving current care standards

7. Create a summary resource providing an overview of evidence-based treatment recommendations and options for all personality disorders, in collaboration with an appropriate organisation or organisations, that can be disseminated to clinicians and people with lived experience.

It is important to remember that, in the context of BPD, evidence-based interventions designed for BPD provide an average cost saving of US\$2,987.83 (approximately AUD\$3,900) per consumer, per year (Meuldijk et al., 2017).

A summary resource would allow individuals to quickly review and understand which psychotherapy approaches have the best research evidence for various personality disorder diagnoses. The research conducted as part of this project may form a helpful basis for such a resource. Such a resource may also need to account for clinical consensus when it comes to specific personality disorders that have not been as thoroughly researched as BPD.

8. Take meaningful actions towards system redesign, with a focus on efforts to streamline pathways, improve access and reduce the financial burden carried by individuals with personality disorder.

Specifically, this should involve:

- Reviewing and revising the MBS Better Access program to ensure adequate support for treatment options for people living with complex and severe mental illness (including personality disorder) as opposed to mild to moderate mental illness. These revisions must acknowledge that people living with personality disorder typically need 1–2 years of treatment at a minimum (with many individuals seeking treatment for more than 10 years; Lawn & McMahon, 2015). It should consider a minimum number of sessions required for treatment efficacy relating to diagnosis, per year, aligned with the evidence base. In the context of BPD, weekly individual psychotherapy plus group therapy are required (Gunderson, 2016). Individuals with less severe presentations may require fewer sessions, depending on the mode of treatment.
- An alternative proposal is to consider creating new Medicare item numbers, rather than modifying the existing Better Access scheme, providing more intensive forms of psychotherapy appropriate for complex mental illness. This would benefit not only those with personality disorders, but also those impacted by other complex mental illnesses such as eating disorders and PTSD.

- Another alternative is developing complex care packages involving psychosocial support alongside treatment. This could be aligned to the stepped care approach being adopted by Primary Health Networks, and the clinical staging model, in which the best available interventions are applied based on a person's stage of illness. Some Primary Health Networks are already exploring their role in supporting people living with personality disorder through targeted suicide-prevention activities. Further work with Primary Health Networks to develop this model of care is recommended.
- Increasing availability of evidence-based treatment services in rural, regional and remote areas. This could be achieved through a number of strategies, including:
 - Funding dedicated specialist services in rural settings, such as major rural cities. Where it is not feasible to implement a specialist service, consider implementing evidence-based brief interventions.
 - Increasing funding current training services to travel to these areas and conduct outreach training programs focusing on personality disorder treatment principles and evidence-based treatment methods such as DBT and schema therapy.
 - Reviewing the efficacy of current incentives to attract clinicians to rural and remote areas.
- Developing and funding evidence-based digital psychotherapy options. Digital platforms may offer opportunities to increase access in rural and remote settings. Consider increasing digital and phone-based options and modifying treatments to suit digital platforms. While telepsychiatry has proved promising in the treatment of some illnesses, comprehensive specialist programs are not always feasibly conducted via Skype or other online platforms. For example, it is quite difficult to provide group skills training online in real time. Hence, work in this field would need to involve a review of existing evidence and the feasibility of conducting such efforts in Australian settings.

9. Develop a holistic approach to meet the needs of families and friends supporting someone living with personality disorder, and scale this to benefit people across Australia regardless of location.

Family and friends supporting someone with personality disorder make a significant contribution, and their role is particularly valuable. Family and friends should be involved in treatment and support planning and decision-making and should also be supported in their role. This includes providing carers with information, education and support. Carers need to have information about the illness, prognosis and treatment, as well as how to respond positively in particular to self-harm and suicidal thoughts and behaviour as well as ongoing situations. They may also benefit from peer support in the forms of group education and ongoing support groups. Models such as the Family Connections program provided through NEA.BPD Aust show great promise. At present there are a variety of providers and different approaches are utilised; this needs to be done more systematically to ensure that this service is available wherever needed.

Given the complexity of diagnosing personality disorder, consideration should be given to extending MBS item 348, which covers attendance involving an interview of a person other than the consumer for 20–45 minutes in the course of initial diagnostic evaluation (usually in the first

month), to include follow-up interviews over the first few months of engagement. Similarly, MBS item number 352, which enables clinicians to engage with families up to four times per 12-month period, should be reviewed and increased to allow further visits as needed within a 12-month period.

Stigma reduction

10. Identify, implement and evaluate strategies to shift assumptions by health professionals that individuals with BPD cannot benefit from psychotherapy, and other myths, utilising a partnership of the existing national advocacy organisations.

Several strategies are already underway which provide BPD training and resources for health professionals, as identified in the environmental scan.

Large-scale initiatives are necessary. There is a need to include ‘myth-busting’ components in these initiatives to reduce stigmatising by health professionals. With regard to BPD, a major myth to address is the idea that people living with BPD do not benefit from psychotherapy. A likely consequence of this myth is that some clinicians focus on ‘managing’ BPD rather than ‘treating’ it with the aim of symptom reduction and improving quality of life.

Another important aspect is understanding the developmental and social learning aspects of personality disorder. This may be key to destigmatising – if people understand where the symptoms come from.

With regards to other specific personality disorders, the current body of literature does not provide strong evidence for the benefits of psychotherapy. However, considering the lack of research across these disorders, it is important not to conflate a *lack* of evidence for psychotherapy with *evidence against* psychotherapy. Hence, it is important that clinicians also understand that psychotherapy *may* be beneficial for other specific personality disorders as well.

Few evaluation reports were identified in the environmental scan (although these were not systematically searched for). Where feasible, training initiatives should be evaluated and modified if necessary to increase their acceptability and educational potential.

11. Design and conduct formative research into a multi-channel media campaign aiming to educate the Australian community and destigmatise personality disorder.

There is a need to improve awareness of personality disorder within the general community, including teachers and others working in schools. A significant component of this campaign may also involve ‘myth-busting’. Any such initiatives will need to be carefully designed, and to involve individuals with personality disorder, and carers, families and other support persons, throughout development (Grenyer, 2017), as well as input from health professionals and researchers.

This campaign may involve strategies to overcome the reluctance of some individuals to present for treatment, and the reluctance of some clinicians to diagnose and support people living with personality disorder.

This campaign must be disseminated alongside improvements to service availability; otherwise it risks widening treatment gaps for people requiring support for personality disorder.

Concluding statements

This body of work involved three major components: a literature review, an environmental scan and a qualitative study. The literature review identified that, based on best available estimates, at least 6.5% of Australians are living with personality disorder. It identified a number of evidence-based treatment approaches for BPD, but a lack of comprehensive research into other personality disorders. The environmental scan identified that the Australian mental health system is not currently designed to meet the needs of people living with personality disorder, due in particular to a lack of specialist services and rebates not designed to subsidise the intensive, long-term treatments typically required by these individuals. Finally, the qualitative study identified that many people living with personality disorder, and their carers, families and support persons, perceive that there is a lack of support available, with systems difficult to navigate and insufficient in scope. Many participants reported worrying about the future and having a strong desire for meaningful change.

The authors of this report echo the sentiments identified by the research participants. We wish to emphasise the seriousness of the current situation; many people living with personality disorder engage with services intensely, but do not have their needs met. They are also known to experience chronic suicidal ideation and are at much higher risk of dying by suicide compared with their peers. Evidence-based BPD treatment has the potential to save lives. Further, such treatments are known to be cost-effective in the long term, and it is likely that investment in other personality disorder treatments may also have these same benefits.

System redesign is absolutely necessary to meet the needs of people living with personality disorder and their carers, families and support persons. It is also necessary to meet the needs of other Australians impacted by complex mental illness.

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Appendix A: Brief summary of psychotherapy approaches relevant to this paper

Acceptance and commitment therapy (ACT) – involves noticing and accepting thoughts, emotions and other private events, and taking meaningful action aligned with values

Cognitive behaviour therapy (CBT) – focuses on the relationship between thoughts, feelings and behaviours. CBT helps the person to challenge and overcome automatic beliefs, and to use practical strategies to change or modify their behaviour

Dialectical behaviour therapy (DBT) – involves a combination of CBT techniques with skill development relating to mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness

Family therapy – styles of psychotherapy that involve working with families or couples through direct participation in therapy sessions

Integrationist therapy – involves integrating two or more psychotherapeutic approaches

Interpersonal psychotherapy (IPT) – emphasises current interpersonal and social contexts, such as relationship issues

Mentalisation-based therapy (MBT) – involves improving mentalisation, the process by which people implicitly and explicitly interpret their own actions and others' actions

Mindfulness – the psychological process of purposefully bringing attention to experiences occurring in the present moment. A key component of therapies such as ACT and DBT.

Narrative therapy – focuses on the narratives people use about their identities and experiences to form new, helpful stories that allow them to live according to their values

Psychodynamic therapy – involves identifying and exploring unconscious experiences that cause difficulties in day-to-day life, based on psychoanalytic theory

Schema therapy – focuses on allowing people to meet their emotional needs by implementing adaptive coping styles and healing maladaptive schemas (patterns of thoughts and behaviour)

Transference-focused psychotherapy – a specialised form of psychodynamic therapy with an emphasis on reducing suicidality and self-injurious behaviours and improving relationships

Appendix B: Environmental scan results

Table A. Summary of known specialist services by state and territory (note: LE = lived experience)

State/territory	Service	Location	Target group	Notes
Australian Capital Territory	ACT Psychological and Counselling Services	Lyneham	LE	Private clinic DBT program
Australian Capital Territory	Family Connections	Canberra	Carer	12-week program for carers, families and others supporting someone with BPD
Australian Capital Territory	DBT Canberra	Canberra	LE	Private clinic DBT program
Australian Capital Territory	BPD Awareness ACT	Online	Carer	Community-based support groups for carers, family and others supporting someone with BPD; workshops based on DBT skills training
New South Wales	ARAFMI (Assisting Relatives and Friends of People with Mental Illness)	Hamilton East	Carer	Community-based support groups and one-day workshops for carers, family and others supporting someone with BPD
New South Wales	Bankstown Community Mental Health	Bankstown	LE	Community-based DBT program
New South Wales	Brisbane Waters Private Hospital	Woy Woy	LE	Private hospital services; inpatient BPD treatment and outpatient DBT program
New South Wales	Brookvale Community Health Centre	Brookvale	LE	Community-based DBT program
New South Wales	Campbelltown Community Mental Health	Campbelltown	LE	Community-based DBT program
New South Wales	Cumberland Hospital	Parramatta	LE	Public hospital outpatient personality disorder services
New South	DBT Psychology Clinic	Potts Point	LE	Private clinic DBT program

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State/territory	Service	Location	Target group	Notes
Wales				
New South Wales	DBT Sydney	Newtown	LE and carer	Private clinic DBT program and family and friends program
New South Wales	Family Connections	Wollongong, Hunter, Wairoonga, Newtown, Miranda	Carer	12 week program for carers, families and others supporting someone with BPD
New South Wales	Hunter New England Mental Health Service: Centre for Psychotherapy	Newcastle	LE	Community-based DBT program
New South Wales	Illawarra Community Mental Health	Wollongong	LE	Community-based clinic; includes DBT program, ACT, schema therapy, psychodynamic therapy, affect regulation clinic (BPD-specific), adult Gold Card Clinic (brief intervention; for evaluation see Grenyer & Fanaian, 2015)
New South Wales	Institute for Healthy Living	Bondi	LE	Private clinic DBT program and schema therapy
New South Wales	Lake Illawarra Community Mental Health – Gold Card Clinic	Warrawong	LE	Community-based brief intervention service for those with personality disorder diagnosis or traits; for evaluation see Grenyer & Fanaian (2015)
New South Wales	Mayo Private Hospital	Taree	LE	Private hospital DBT program
New South Wales	Mosman Private Hospital	Mosman	LE	Private hospital DBT program
New South Wales	Northside Group Hospitals	Wentworthville, St Leonard's, Macarthur, Cremorne	LE	Private hospital services; inpatient and supportive day programs for BPD (all locations), DBT program (Northside West and Northside Macarthur clinics)

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State/territory	Service	Location	Target group	Notes
New South Wales	Prince of Wales Hospital	Bondi	LE	Community-based brief intervention service for those with personality disorder diagnosis or traits – Lifeworks Program; for evaluation see Grenyer & Fanaian (2015)
New South Wales	Project Air	Wollongong, Sydney	Carer	Carer workshops and support groups
New South Wales	Royal North Shore Hospital – Lower North Shore Community Mental Health	Lower North Shore	LE	Community-based DBT program
New South Wales	Royal Prince Alfred Hospital	Camperdown	LE	Public hospital DBT program
New South Wales	Ryde Community Mental Health Centre	Ryde	LE	Community-based DBT program
New South Wales	Schema Therapy Sydney	Liverpool	LE	Private clinic schema therapy
New South Wales	South Western Sydney Community Mental Health	Liverpool	LE	Community-based DBT program
New South Wales	St John of God	Burwood, Richmond	LE	Private hospital personality disorder services; includes inpatient DBT and schema therapy programs, outpatient DBT program
New South Wales	St Vincent's Mental Health Service	Darlinghurst	LE	Private hospital outpatient DBT program
New South Wales	The Sutherland Hospital – Sutherland Community Mental Health Service	St George, Sutherland	LE	Community-based DBT program
New South Wales	Sydney South West Private Hospital	Liverpool	LE	Private hospital inpatient DBT program
New South	Taree Community	Taree	LE	Community-based DBT program

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State/territory	Service	Location	Target group	Notes
Wales	Health Service			
New South Wales	The Australian DBT Institute	Rozelle, Woollahra	LE	Private clinic DBT programs; includes adolescent and adult DBT and adapted-DBT programs, graduate program, young men's program, women's group, antenatal group, substance-use group
New South Wales	The Clinical Psychology Centre	Crows Nest, Manly	LE	Private clinic DBT program and schema therapy
New South Wales	The Hills Clinic	Castle Hill, Hornsby, Kellyville	LE	Private hospital inpatient and day DBT programs
New South Wales	The Hills Private Hospital	Baulkham Hills	LE	Private hospital inpatient personality disorder treatment
New South Wales	The Resilience Centre Psychology Services	Epping	LE	Private clinic DBT program
New South Wales	The Sydney Clinic	Bronte	LE	Private hospital DBT day program
New South Wales	Wesley Hospital	Ashfield, Kogarah	LE	Private hospital DBT day program
Northern Territory	n/a	n/a	n/a	No specialist services identified
Queensland	Belmont Private Hospital	Brisbane	LE	Private hospital DBT and trauma day programs
Queensland	Caboolture Hospital Adult Mental Health	Caboolture, Kippa-Ring	LE	Community-based DBT program
Queensland	Currumbin Clinic	Cairns	LE	Private hospital services; includes inpatient services for individuals with BPD; DBT and DBT-Lite day programs
Queensland	DBTBrisbane	Brisbane	LE and carer	Private clinic DBT programs; includes intensive DBT program, booster DBT program, and services for carers, families and other support persons (information sessions and individual sessions)

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State/territory	Service	Location	Target group	Notes
Queensland	Lakeside Rooms	Gold Coast	LE	Private clinic DBT program
Queensland	Logan Hospital Mental Health Care	Logan	LE	Public hospital inpatient personality disorder services; includes DBT program, psychodynamic and MBT services
Queensland	New Farm Clinic	Brisbane	LE	Private hospital day programs; includes adult DBT program, young adult DBT program, advanced DBT program and schema therapy
Queensland	Pine Rivers Private Hospital	Strathpine	LE	Private hospital DBT day program
Queensland	Royal Brisbane Women's Hospital Mental Health Service	Brisbane	LE	Public hospital DBT program
Queensland	St Andrew's Hospital Toowoomba	Toowoomba	LE	Private hospital DBT outpatient program
Queensland	The Australian DBT Institute	Southbank	LE	Private clinic DBT programs; includes adolescent and adult DBT and adapted-DBT programs, graduate program, young men's program, women's group, antenatal group, substance-use group
Queensland	The Cairns Clinic	Cairns	LE	Private hospital DBT day program
Queensland	The Prince Charles Hospital Mental Health Service	Brisbane	LE	Public hospital DBT program
Queensland	Townsville Hospital and Health Service	Townsville	LE	Public hospital personality disorders assessment clinic
Queensland	YETI (Youth Empowered Towards Independence)	Cairns	LE	Community-based clinic, involves DBT program for young people aged 12–25 years

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State/territory	Service	Location	Target group	Notes
South Australia	BPD Centre of Excellence	TBA	LE	Funding announced for development of BPD specialist clinic, to involve specialist clinicians, training and research
South Australia	Centre for Schema Therapy	Frewville	LE	Private clinic schema therapy for children, adolescents and adults
South Australia	Family Connections	Noarlunga, Bowden, Glandore	Carer	12-week program for carers, families and others supporting someone with BPD
South Australia	Kahlyn Day Centre	Magill	LE	Private hospital DBT day program
South Australia	Mental Illness Fellowship of South Australia	Wayville	LE and carer	Community-based services; mother-infant DBT program (currently being researched and evaluated), carer support program
South Australia	PsychMed	Adelaide city, Morphette Vale, Payneham, Salisbury, Seaview Downs	LE and carer	Community-based clinics; services include DBT, schema therapy, IPT, support groups for carers, families and others supporting someone with BPD
South Australia	Skylight Mental Health	Wayville	Carer	Sanctuary Support Group for carers, families and others supporting someone with BPD
Tasmania	St Helens Private Hospital	Hobart	LE	Private hospital DBT day program
Tasmania	The Hobart Clinic	Rokeby	LE	Private hospital DBT day program
Victoria	Albert Road Clinic	Melbourne	LE	Private hospital clinic, includes DBT day program for adults and modified DBT program 'LEAF' for adolescents, incorporating art and music therapy
Victoria	Alfred Health	St Kilda, South Yarra	LE	Community-based outpatient DBT program
Victoria	Alfred Hospital	Melbourne	LE	Public hospital, inpatient BPD services
Victoria	Banyule Community	Greensborough	LE	Community-based DBT program

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State/territory	Service	Location	Target group	Notes
	health			
Victoria	Barwon Health Deakin Psychology Clinic	Geelong	LE	Community-based DBT program
Victoria	Bouverie Centre	Brunswick	Carer	Community-based carer services; support groups and workshops for carers supporting a family member with BPD (Fostering Realistic Hope workshop series)
Victoria	BPD Community	Statewide	Carer	Community-based carer services; information nights and peer-led support groups for carers, families and others supporting a person with BPD
Victoria	Delmont Private Hospital	Glen Iris	LE	Private hospital DBT day program and inpatient program
Victoria	Epworth Clinic	Camberwell	LE	Private hospital DBT day program, DBT graduate day program, schema therapy day program
Victoria	Family Connections	Langwarrin, Box Hill, Sale	Carer	Community-based carer services; 12-week program for carers, families and others supporting someone with BPD
Victoria	Geelong Clinic	Geelong	LE	Private hospital DBT day program
Victoria	Melbourne DBT Centre	Murrumbeena	LE	Private clinic DBT programs; adult, adolescent, graduate and RO-DBT groups
Victoria	Mind Australia	Statewide	Carer	BPD Family and Carer Group; carer helpline

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State/territory	Service	Location	Target group	Notes
				Community-based and inpatient youth-oriented mental health services. Includes: HYPE (Helping Young People Early), a prevention and early intervention program relating to symptoms of BPD, involving case-management, psychotherapy, medication, family work; EPICC (Early Psychosis Prevention & Intervention Centre); PACE (Personal Assessment and Crisis Evaluation) for young people at risk of developing psychosis (may be appropriate for SZPD); psychosocial recovery program; carer services including family peer support, information sessions and financial support fund
Victoria	Orygen Youth Health	Parkville, Footscray	LE and carer	
Victoria	Schema Therapy Institute Australia	Carlton	LE	Private clinic, individual and group schema therapy
				Community-based and residential clinical services: DBT, ACT (Wise Choices), MBT, psychoanalytic treatment, complex care service, brief intensive group treatment, secondary consultation, residential treatment. See Broadbear (2016) for evaluation of residential treatment program and Morton (2012) for evaluation of ACT program.
Victoria	Spectrum Personality Disorder Service	Statewide with centres in Ringwood, Fitzroy, Richmond	LE	
Victoria	St John of God	Dandenong, Warrnambool, Ballarat	LE	Private hospital, inpatient and outpatient services with a personality disorder-specific program (may involve DBT program, schema therapy, CBT or mindfulness-based cognitive therapy depending on presentation)
Victoria	The Australian DBT Institute: Essentia Health and Wellbeing Centre	Brighton	LE	Private clinic DBT programs; includes adolescent and adult DBT and adapted-DBT programs, graduate program, young men's program, women's group, antenatal group, substance-use group

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State/territory	Service	Location	Target group	Notes
Victoria	The Melbourne Clinic	Richmond	LE and carer	Private hospital services including: DBT day program; Supporting Trauma and Recovery (STAR) day program incorporating DBT, CBT, mindfulness and trauma therapy; schema therapy day program; and family, friends and carers information/support sessions
Victoria	Victoria Clinic	Prahran	LE	Private hospital services, including: schema therapy inpatient program; schema therapy day program; DBT day program; Total Wellness Program incorporating DBT, schema therapy, mindfulness, exercise and other approaches
Western Australia	Alive 360 Health & Community	Guilford, Rockingham	LE	Community-based clinic; aimed towards people at increased risk of suicide or self-harm, including people living with BPD
Western Australia	Armadale Mental Health Service	Armadale	LE	Community-based DBT program
Western Australia	Child and Adolescent Mental Health Services MST program	Fremantle, Murdoch	LE and carer	Community-based program for young people living with conduct disorder or oppositional defiant disorder; involves multisystemic therapy (MST) program, intensive family intervention for young persons (12–16 years) working in home, school and with parents and caregivers; evaluation indicates reduction in behavioural problems and emotional difficulties (see Porter & Nuntavisit, 2016)
Western Australia	Clarkson Community Mental Health Service	Clarkson	LE	Community-based DBT program
Western Australia	Family Connections	Midland, Fremantle	Carer	12-week program for carers, families and others supporting someone with BPD

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State/territory	Service	Location	Target group	Notes
Western Australia	Fiona Stanley Hospital	Murdoch	LE	Public hospital services; includes specialist youth unit with high of percentage inpatients diagnosed with BPD or emerging BPD; planned admissions (72 hours) available; community-based Youth Community Assessment and Treatment Team (YCATT) also available
Western Australia	Fremantle Hospital Mental Health Service	Fremantle	LE	Community-based DBT program
Western Australia	Hollywood Hospital	Perth	LE	Private hospital services; DBT day program, schema therapy day program
Western Australia	Joondalup Community Mental Health	Joondalup	LE	Community-based DBT program
Western Australia	Marian Centre	Wembley	LE	Private hospital DBT day program
Western Australia	Open Borders – Hampton Road Service	Fremantle	LE	Public residential program for people living with BPD
Western Australia	Peel Mental Health Service	Mandurah, Peel	LE	Community-based DBT program
Western Australia	Perth Clinic	Perth	LE	Private hospital DBT day program
Western Australia	Royal Perth Hospital	Perth	LE	Public hospital inpatient BPD treatment; The Enhance Study identified that consumers receiving clinical care aligned with NHMRC BPD guidelines spent less time in hospital and reported greater satisfaction compared to consumers receiving treatment as usual, while maintaining average reductions in psychiatric symptomology (see Wilson 2017)
Western Australia	Sentiens Private Psychiatric Day Hospital and	Perth	LE	Private hospital DBT program

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State/territory	Service	Location	Target group	Notes
	Outpatient Clinic			
Western Australia	Swan Mental Health Service	Middle Swan	LE	Community-based DBT program
Western Australia	Touchstone (CAMHS)	Bentley	LE	Community-based service for young people aged 12–17 who have experienced intense emotional distress and self-harm, including BPD
Western Australia	Youth Axis Mental Health Program	Wembley	LE	Community-based assessment, treatment, outreach, consultation and community capacity-building for people aged 16-24 years; aimed at those with emerging mental health problems, particularly ‘ultra high risk’ of developing psychosis and/or emerging BPD

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Table B. Summary of known advocacy, education, research and training initiatives by state and territory (note: LE = lived experience)

State/territory	Service	Location	Target group	Notes
Australian Capital Territory	Borderline in the ACT	Statewide	Clinicians	BPD education and advocacy
Australian Capital Territory	DBT Institute	Statewide	Clinicians	Consultancy/supervision, DBT training
Australian Capital Territory	Expressive Therapy Clinic	Canberra	Clinicians	DBT training workshops
Australian Capital Territory	Schema Therapy Training	Canberra	Clinicians	Schema therapy training, including basic and advanced workshops
New South Wales	ARAFMI (Assisting Relatives and Friends of People with Mental Illness) Illawarra	Wollongong	Clinicians, carers, general public	Education and training workshops, advocacy and community awareness sessions
New South Wales	Australian DBT Institute	Sydney	Clinicians	DBT training workshops
New South Wales	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Sydney	Clinicians	BPD training and education
New South Wales	DBT Psychology Clinic	Potts Point	Clinicians	DBT program for health professionals aiming to reduce burnout and develop clinical skills
New South Wales	DBT Sydney	Newtown	LE and carers	Information and resources for people living with BPD and carers, families and other support persons
New South Wales	Expressive Therapy Clinic	Sydney	Clinicians	DBT training workshops

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State/territory	Service	Location	Target group	Notes
New South Wales	Mentalization Based Treatment Australia Association	Sydney	Clinicians	MBT training workshops and supervision
New South Wales	Project Air	Statewide	Academics, clinicians, carers, general public	Personality disorder training, education, resources and advocacy; many of these initiatives are nationwide, but in-person training is generally in New South Wales
New South Wales	Psychology Training	Sydney	Clinicians	DBT training workshops
New South Wales	Schema Therapy Centre of NSW	Drummoyne	Clinicians	Schema therapy training, including basic and advanced workshops
Northern Territory	Expressive Therapy Clinic	Darwin	Clinicians	DBT training workshops
Northern Territory	Northern Territory Mental Health Coalition	Darwin, Alice Springs	Clinicians	BPD training and education
Northern Territory	P&P Training and Consultancy	Darwin	Clinicians	BPD training and education
Queensland	Australian DBT Institute	Brisbane	Clinicians	DBT training workshops
Queensland	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Ipswich/West Moreton, Brisbane North	Clinicians	BPD training and education
Queensland	Expressive Therapy Clinic	Brisbane, Coolangatta	Clinicians	DBT training workshops
Queensland	Schema Therapy Training	Brisbane, Sunshine Coast	Clinicians	Schema therapy training, including basic and advanced workshops

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State/territory	Service	Location	Target group	Notes
South Australia	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Adelaide	Clinicians	BPD training and education
South Australia	Borderline Personality Disorder Support Services in SA (BPDSA)	Statewide	Clinicians, general public, LE, carer	BPD information, training, resources
South Australia	BPD Centre of Excellence	To be announced	Clinicians, academics	Funding announced to develop this service; to involve specialist clinicians, training and research
South Australia	Maternal and Neonatal Community of Practice Committee	Statewide	Clinicians	The Maternal and Neonatal Community of Practice Committee has published clinical guidelines for personality disorders and severe emotional dysregulation in the perinatal period
South Australia	Mentalization Based Treatment Australia Association	Adelaide	Clinicians	MBT training workshops and supervision
South Australia	PsychMed	Adelaide city, Morphette Vale, Payneham, Salisbury, Seaview Downs	Clinicians	Various training workshops (for example, on topics of trauma, schema therapy)
South Australia	SA Mental Health Commission	Adelaide	Clinicians, general public	The SA Mental Health Commission has published the South Australian Action Plan for People Living with Borderline Personality Disorder 2017–2020
South Australia	Schema Therapy Training	Adelaide	Clinicians	Schema therapy training, including basic and advanced workshops

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State/territory	Service	Location	Target group	Notes
Tasmania	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Hobart	Clinicians	BPD training and education
Tasmania	Expressive Therapy Clinic	Launceston	Clinicians	DBT training workshops
Tasmania	P&P Training and Consultancy	Hobart, Launceston	Clinicians	BPD training and education
Victoria	Australian DBT Institute	Brighton	Clinicians	DBT training workshops
Victoria	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Melbourne	Clinicians	BPD training and education
Victoria	BPD Community	Statewide	Clinicians, general public	BPD education, support and advocacy in Victoria, including information nights
Victoria	Forensicare	Fairfield	Clinicians, academics	Specialist forensic mental health research, including personality disorder research
Victoria	Myndscape	Melbourne	Clinicians	Training course in RUSH (Real Understanding of Self-Help) program – 20-session adapted version of DBT for correctional organisations
Victoria	Orygen Youth Health	Parkville, Brunswick, Mildura, North Melbourne, Wangaratta	Clinicians	EPPIC, HYPE and CAT training workshops
Victoria	Orygen, The National Centre of Excellence in Youth Mental Health	Parkville	Clinicians, academics	Personality disorder research group, collaborating with various universities across Australia and internationally
Victoria	Psychology Training	Parkville	Clinicians	DBT training workshops

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State/territory	Service	Location	Target group	Notes
Victoria	Schema Therapy Institute Australia	Carlton	Clinicians	Schema therapy training, including basic and advanced workshops
Victoria	Schema Therapy Training	Melbourne	Clinicians	Schema therapy training, including basic and advanced workshops
Victoria	Spectrum Personality Disorder Service	Ringwood, Fitzroy, Richmond	Academics, clinicians, carers, general public	Provides advocacy, support and training, carer information and resources; training workshops run throughout Victoria aligned with NHMRC guidelines
Western Australia	Borderline Personality Disorder (BPD) Mental Health Professionals' Network	Perth	Clinicians	BPD training and education
Western Australia	Consumers of Mental Health WA (CoMHWA)	Cannington	Clinicians, LE	Education and training, peer support and advocacy
Western Australia	Expressive Therapy Clinic	Perth	Clinicians	DBT training workshops
Western Australia	Mentalization Based Treatment Australia Association	Perth	Clinicians	MBT training workshops and supervision
Western Australia	P&P Training and Consultancy	Broome	Clinicians	BPD training and education
Western Australia	Psychology Training	Floreat	Clinicians	DBT training workshops
Western Australia	Schema Therapy Training	Perth	Clinicians	Schema therapy training, including basic and advanced workshops

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State/territory	Service	Location	Target group	Notes
Western Australia	WA Personality Disorders Subnetwork	Perth	Clinicians, general public, LE, carers	Network of people living with personality disorder, carers and health professionals aiming to improve quality of life for people living with personality disorder.
Western Australia	Western Australian Association for Mental Health	Perth	Clinicians, general public	Advocacy for systemic change, various workshops including DBT, Obsessions and Compulsions (relevant for OCPD), Understanding Personality Disorders