

OXFORD BROOKES UNIVERSITY

## **The Under-recognition of Trauma in the Diagnosis of Borderline Personality Disorder (BPD)**

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## Abstract

BPD is a complex condition presenting with a wide array of features, making it difficult to diagnose and treat. Controversially, there is also concern about BPD misdiagnosis due to under-recognition of trauma and PTSD/CPTSD (Complex PTSD) because of common aetiology. PTSD/CPTSD has a better track record of successful treatment; as typically BPD treatment focuses more on symptoms, while PTSD/CPTSD treats underlying traumatic causes. **Aim:** The research objective is to assess if early screening for traumatic exposure and PTSD/CPTSD symptoms will enhance BPD diagnosis, and lead to improved treatment. **Methodology:** Following clinical and academic reviews, two stages were completed. **Stage 1:** Initially medical records of BPD (N=60) patients in three UK Mental Health Hospitals were examined for evidence of BPD, trauma, PTSD and CPTSD. **Stage 2:** Separate BPD outpatients (N=40) were screened for trauma, PTSD/CPTSD using a new simple 'BPD Trauma Exposure and Reactions Screen' (BTERS). Reliability and validity was then assessed using recommended reference instruments (CAPS and SIDES). **Results:** Trauma was recorded in 47% of the stage 1 medical records, 100% in stage 2, 92.5% trauma in childhood. Sixty percent of stage 2 patients suffered distressing non-life-threatening trauma consistent with Adjustment Disorder. High trauma percentages in BPD are explained by a combination of life-threatening trauma, requiring specialist PTSD/CPTSD treatment, and non-life-threatening, which is treatable using similar techniques by BPD clinicians without specialist training. **Conclusions:** Although insufficient evidence for BPD misdiagnosis was found, an under-diagnosis of comorbid PTSD/CPTSD was confirmed. Without initial screening (BTERS) of BPD patients, clinicians are missing PTSD/CPTSD diagnoses, and hence are losing the opportunity for early treatment for a significant percentage of BPD patients, which could be critical to improved recovery and reduced suicide rates.

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## **1 INTRODUCTION**

This chapter introduces the background to a very worrying mental healthcare problem of under-recognition of the history of traumatic experiences and the effects of trauma. Such an under-recognition can occur when patients with Borderline Personality Disorder (BPD) symptomatology are assessed and treated, which can lead to misdiagnosing/over-diagnosing BPD and or missing a comorbid diagnosis of Post Traumatic Stress Disorder (PTSD) or Complex PTSD (CPTSD). This can result in a fragmented approach to treatment. To address this problem – and using an extensive empirical and theoretical literature review, which is set out in chapter 2 – the principal research question and aim is formulated. The thesis structure is then developed, and a detailed description of each chapter is presented. Brief descriptions of the relevant disorders then follow, along with a discussion of the links between trauma and BPD. A description of the diagnosing dilemma is then presented. From this background, detailed research sub questions, aims and hypothesis are formulated. The chapter concludes by examining how the research can contribute to improving academic and clinical knowledge.

### **1.1 Background to the Problem, and why the Research is Important**

BPD is the most commonly diagnosed form of Personality Disorder (Shevin *et al.*, 2007). It has been recognised as a clinical condition that can be seriously disabling and often takes a huge toll on the individual (NICE, 2008). In the late twentieth century, interest in BPD seems to have exploded (Linehan, 1993). According to the UK National Institute for Clinical Excellence (NICE) there is currently a high prevalence of BPD, and Linehan asserts that over 30% of all psychiatry patients in the USA appear to meet the BPD criteria with treatment modalities appearing to be woefully inadequate (NICE, 2008; Linehan 1993). Suicide is a particular risk for BPD in the UK with up to 1 in 10 people with BPD committing suicide, 400 times higher than the national average suicide rate (NICE, 2008; Cailhol *et al.*, 2008). Effective BPD treatment is therefore a high [UK] Department of Health (DoH) priority. In order to provide effective treatment NICE has suggested that a more reliable diagnosis should be made of BPD patients to ensure they receive

appropriate intervention with the aim of reducing repeated hospital admissions, suicidal rates, and cost to patients, their family members, social relations, clinicians and the NHS (NICE, 2008).

Many highly respected organisations and authors have made sweeping but often unsubstantiated statements about this misdiagnosis. For example, the National Association for Mental Health has highlighted that '*there is a recognised and very worrying danger of misdiagnosing BPD*' (MIND, 2007). NICE (2008) also reported 'a high incidence of misdiagnosing BPD'. Authors such as Hodges have said that 'many women who have been exposed to chronic trauma are incorrectly misdiagnosed as having personality disorder, particularly BPD' (Hodges, 2003, p.413). Landecker noted that 'frequently a patient presenting [PTSD] symptoms is diagnosed borderline..... leading to inappropriate treatment approaches and the placement of a burdensome label' (Landecker, 1992, p.235).

That the diagnosis of BPD is problematic is a near universal view in the mental health community. A number of experts also believe that many cases of BPD should be re-conceptualised as PTSD associated with childhood abuse. This is related to a controversial link between BPD and both PTSD and CPTSD, with the possibility that PTSD/CPTSD may be under-recognised (or can be seen as a missed diagnosis) in patients with BPD presentations. CPTSD is also known as DESNOS (Disorders of Extreme Stress Not otherwise Specified), as identified in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition – Transcript Revised, DSM-IV-TR, 2000. Caution must be exercised, however, because, as will be shown in Chapter 2, there is limited empirical information currently available on the BPD misdiagnosis/over-diagnosing controversy.

The current research project will thus investigate and attempt to substantiate the relationship between BPD and trauma experiences from both theoretical and clinical perspectives. It will make concrete proposals that should lead to improved diagnosis by developing and using a streamlined trauma-screening instrument for BPD presentation that should ultimately result in higher recovery rates through the proven techniques of trauma-focused therapy. The research will also consider how best to treat the non-life-threatening trauma that affects many BPD patients,

traumatic experiences that are not symptomatic of PTSD/CPTSD. For these patients, treatment utilising techniques developed for Adjustment Disorder (AD) will be considered.

## **1.2 Structure of the Thesis**

Two structural extremes can be considered in the design of a thesis, *Focus Down*, and *Opening Out*; with a *Compromise Model* balanced between the two (Dunleavy, 2003; Silverman, 2005). The Focus Down Method consists of an exhaustive literature review followed by a substantive methodology and research design. Fieldwork in this method is relatively short in depth and analysis, and discussions of the results can be even shorter. For example, in a Focus Down structure, there may be little opportunity for making changes based on input from practicing BPD clinicians who could be influenced by the initial parts of the investigation.

The Opening Out Model is the reverse of Focus Down with a brief literature review and research design, for example confining the initial literature review to the empirical relationship between BPD and trauma, and thus potentially missing out on some important theoretical relationships. Similarly, the dilemma of BPD misdiagnosis could be downplayed in favour of greater attention to trauma diagnosis. This model focuses on what is seen to be the core of the research project, with a detailed commentary on the methodology, and the discussion includes an in-depth analysis. Literature references are initially close to the topic itself and then open out to wider literature based on research outcomes.

**Table 1-1 Thesis Structure**

<b>Structure Types</b>	<b>Main Areas</b>	<b>Reduced Areas</b>	<b>Advantages</b>	<b>Dis-advantages</b>
Focus Down	Wide literature review Extensive methodology investigation	Limited fieldwork and analysis Shorter discussions	Extensive theoretical scope	Less fieldwork and reporting Promotion of findings restricted Limited analysis/discussions
Opening Out	Detailed commentary on methodology In-depth analysis of results	Literature limited to close to topic, then opens out based on outcome	Researcher views and findings are presented up front	Risk of missing key relevant data and results Difficult to ensure that findings and proposals have not been previously considered

In order to capture the advantages of both approaches as shown above, a Compromise Model – an amalgamation of Focus Down and Opening Out – will be adopted as a framework for the research design. This approach thus introduces the core proposals concerning trauma in BPD at an early stage while including as comprehensive a review as possible of this important subject, which has to date received limited attention in academic literature. This method should hopefully ensure that the extensive range of theoretical analysis is balanced with a measured analysis of clinical studies. It also allows for a considered and critical analysis and discussion of research findings to aim for a balanced judgement of the diagnosis controversy (the prevalence of trauma in BPD), and the benefits of screening BPD patients for trauma and PTSD/CPTSD. The individual chapters in this research are then balanced between a comprehensive literature review, a detailed research design, then a full analysis and discussion of methodology, ending with a critical discussions and recommendations.

This thesis is divided into six chapters, each with its own opening and closing sections. The Introduction chapter first reviews the overlap between BPD and trauma, and then provides an introduction for the reader to the disorders. It moves

on by discussing the links between the disorders and how they are treated. This then provides the setting to develop a main research question divided into four detailed research sub questions with corresponding research objectives, from which four hypotheses are developed. The second Literature chapter starts by examining previous empirical studies of the relationship between trauma, PTSD/CPTSD and BPD, and the limited empirical information that is currently available to investigate the BPD misdiagnosis controversy. To complement the review of empirical evidence, the literature review also examines relevant publications that investigate the symptoms, causes or aetiology, and diagnosis of the disorders, BPD, and CPTSD, plus the effects and treatment options. Lastly, a review of available assessment and screening instruments for trauma in BPD is included. The Methodology begins with the third (Design) chapter, where an overall research design addresses ethical issues and how the hypotheses are effectively tested, resulting in two sequentially connected stages. The methodology continues with chapters four and five, which detail the data collection and analysis of the two stages as specified by the design, along with a review of threats to validity. Stage 1 is a quantitative review of BPD patients' records, followed by qualitative interviews with BPD clinicians and hospital management personnel. Stage 2 then develops and tests a new trauma screening instrument 'BPD Trauma Exposure and Reactions Screen' (APPENDIX 1 , BTERS) against accepted clinical standards. Finally, the Discussion (sixth) chapter compares and discusses all of the results in the light of the latest clinical knowledge, and details progressive recommendations for clinical trials.

This thesis has therefore been structured to focus down from the theoretical and the limited empirical studies, first by both quantifying and qualifying the presence of trauma and PTSD/CPTSD in BPD patients. It then opens out the controversy with a comprehensive design where the results are analysed and discussed prior to proposing and testing a trauma screening solution.

### **1.3 The Dilemma of Diagnosing BPD: should it be CPTSD?**

A major dilemma for clinicians is making the correct diagnosis between BPD and PTSD or CPTSD. In this field, clinicians include specialist consultants, general

practitioners and all mental health professionals. This dilemma can perhaps best be illustrated by two examples from clinical cases. Both examples have been taken from Gunderson's Clinical Guide (2008), which is a standard reference book for practitioners in BPD. The first example is of a patient who most likely would have received a diagnosis of BPD.

*In this case a forty four year old woman presented with flashback that disrupted her sleep and concentration, numerous admissions and suicidal attempts. Her childhood included eight hospitalizations, between ages 13–14 for treatment of a congenital disease. Twenty-six years later, she could still access the feelings of being “helpless and alone”. In response, she would become agitated with bursts of accusatory, offensive anger towards her husband and children, which she would later deeply regret as unfair to her family. This remorse then prompted self-destruction or suicidal impulses for this woman (Gunderson et al., 2008, p.48).*

As Gunderson noted, Herman's diagnosis of CPTSD is warranted when such patients have flashbacks or sustained dissociative experiences and an interpersonal style marked by weariness and fears of attachment, such that in adulthood, social isolation is usual, and only intermittently interrupted by brief, often alcohol-related social forays. He then goes on to say that if such a patient is very hungry for attention and protection, and expressive of intense angry feeling when hurt, the effect of the trauma is less likely to have been dominant, and the patient is better conceptualised as having BPD. Western (1990) pointed out that when patients are focused on their abuse experience (as in CPTSD), they are more likely to respond with paranoid accusations of malevolence within the context of ongoing relationships, whereas borderline patients are more likely to become accusatory when threatened by loss of their other relationships (Gunderson and Links, 2008).

In the second example, a thirty-four year old married woman sought psychotherapy because she needed 'support'. She then related this problem to a series of recent events.



*Although she loved her job, after becoming convinced that she was underpaid, she demanded more money from her employer, consequently lost her job. She also had a fight with her landlord insisting on her rights. This too resulted in her being kicked out. In both instances, she righteously perceived injustice was done. However, she experienced the injustice too personally and her intense anger was disproportionate. Not only was she depressed about her job and her flat, but she also worried about the prospect of having no husband and no children, she then moved back to live with her mother and with her forty year old brother. To add insult to injury, her brother had sexually abused her when she was between 6 and 10. And although her mother knew about this, her mother coped by alternating between helplessness and denial.*

In this case, the patient presented as an over-sensitive individual, wary, and hyper vigilant to rejection and criticism, with a very defensive response about everything. While she acknowledged fears of intimacy and attachments, this defensiveness made exploratory therapy very difficult. Even when a supportive therapist attempted to work with her, she resisted getting attached. Gunderson noted that this patient might easily have been given a BPD diagnosis by virtue of her anger and need for support. However, in his opinion she would better be identified as having CPTSD (as proposed by Herman). Such bleakness in interpersonal life and resistance to any attachment makes the effect of trauma distinctly different from the affect (emotion) of trauma that is seen in BPD.

#### **1.4 Diagnostic Criteria**

The diagnostic criteria for BPD, trauma, PTSD, and CPTSD are defined fully in DSM-IV-TR, produced by the American Psychiatric Association (APA, 2000), and DSM-5 (2013). Definitions are also presented in the International Statistical Classification of Diseases-10 (ICD-10) produced by WHO (1992). These are the established systems for classification of mental disorders, which have achieved widespread acceptance in psychiatry.

**Table 1-2 Diagnosis for different classifications**

	DSM	ICD
<b>CPTSD</b>	<b>DSM-IV-TR:</b> CPTSD is PTSD with the constellation of symptoms commonly seen in association with interpersonal stressors, e.g., childhood sexual or physical abuse, domestic battering	<b>ICD-10 F 62.0:</b> Enduring personality change after <b>catastrophic</b> experience
	<b>DSM-5:</b> PTSD in addition with either/or of the following depersonalisation and derealisation	
<b>BPD</b>	<b>DSM-IV-TR:</b> pervasive pattern of instability of interpersonal relationships, self-image and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts	<b>ICD-10 F 60.3:</b> Emotionally unstable Personality Disorder (Borderline Type)
	<b>DSM-5:</b> No significant change from DSM-IV-TR	

Both systems consider the disorders to be distinct, and in recent revisions the definitions in their respective manuals have converged to become broadly comparable, although some differences remain. A survey of over two hundred psychiatrists from different countries across all continents found that the current version of ICD (10) was the most frequently used system and most valued for clinical practice and training, whereas DSM was more valued for research. While DSM-5 is the current version approved in 2013, after this research commenced, the majority of available academic papers about BPD and trauma reference DSM-IV (1994) or DSM-IV-TR (2000), and some go back to DSM-III (1980) or DSM-III-R (1987). ICD emphasises the role of causes such as experiences where symptoms are not definitive. DSM on the other hand is a descriptive sociological system where definitions are based on signs and symptoms, and although this makes it more subjective, it is conducive to research (American Psychological Association, 2009). Consequently, this study will use DSM criteria.

## 1.5 Brief Description of the Disorders and Traumatic Stressors

NICE estimates that the prevalence of BPD in the general public could be as high as 2%, representing 20% of all psychiatric inpatients and 10-30% of outpatients (NICE, 2008). This is supported by epidemiological studies (Pinto *et al.*, 2000; Torgenson, Kringler and Cramer, 2001; and Coid *et al.*, 2006). BPD, which is described further in section 2.3.1.1, has a debilitating nature which makes it necessary for clinicians to address the disorder as early as possible to help assure positive outcomes. Effective assessment and the diagnostic process form an integral step towards determining appropriate intervention.

### 1.5.1 Traumatic Stressors

It would be remiss to discuss traumatic experiences that underpin the disorders of BPD, PTSD and CPTSD without a discussion of what constitutes a traumatic stressor. The traumatic stressor is the gatekeeper for the diagnosis of PTSD, and PTSD is the gateway for CPTSD. A life-threatening (or Criteria-A) traumatic stressor is a requirement for the diagnosis of PTSD (Cloitre *et al.*, 2013). Measurement of stressor dose however can be complex and must in part be subjective. The definition of a traumatic stressor is itself controversial. Initially defined (DSM-III, p.238) as 'a recognisable stressor that would evoke significant symptoms of distress in almost everyone', the definition was criticised for its lack of specificity and as a result it was expanded to 'an event that is outside the range of usual human experience that would be markedly distressing in almost anyone' (DSM-III-R, p.250). Subsequent research has demonstrated that traumas such as sexual and physical assault were not as rare as had been previously assumed and again challenged the definition (McNally, 2003). As a result the definition of a Criteria-A traumatic stressor was re-worded as 'an event that involves actual or threatened death or serious injury or a threat to one's personal integrity and includes learning about an unexpected or violent death, serious harm, or threat, or the unexpected death or injury to a family member or other close associates' (DSM-IV, p.463). Some have argued that the definition of a traumatic stressor should be broadened even further to include non-life-threatening (non-Criteria-A) experiences that are distressing but not necessarily directly associated with physical threat,

experiences such as sexual harassment (Avina and O'Donohue, 2002), and homophobic discrimination taking into account the person's subjective response to an event (Mascher, 2003).

In contrast, others have been critical of a broad based approach, stating that the definition is too inclusive, failing to differentiate between normal distress and psychopathology. McNally (2003) said that loosening the definition could impede our ability to accurately identify the mechanisms underlying PTSD (Gold, 2004). There are specific symptoms that arise and persist after life-threatening traumatic experiences such as rape and military combat (Resick, 2001; Pelcovitz *et al.*, 1997). Therefore, if the definition of a traumatic stressor is diluted, it may not be possible to identify causes and symptoms specific to PTSD/CPTSD, which requires life-threatening experiences. These symptoms arise from such experiences and treatment must be tailored accordingly. DSM-5 recognises a general category of 'Trauma and Stressor related Disorders', where the rationale is based upon clinical recognition of variable expressions of distress as a result of a traumatic experience (Canadian National Centre for PTSD, 2013). The diagnostic criteria for DSM-5 thus draw a clearer line detailing what constitutes a traumatic event, where (Criteria-A) qualifying events are narrowed, excluding events such as unexpected death of a family member (DSM-5). This category includes both PTSD and Adjustment Disorder and also the symptoms of CPTSD, although not specifically mentioned. Thus, PTSD would not be diagnosed after many upsetting situations that are described as 'traumatic' in everyday language, e.g. divorce, loss of job, or failing an exam. In these cases, a diagnosis of Adjustment Disorder may be considered (NICE, 2005; Gelder *et al.*, 2012).

### **1.5.2 Adjustment Disorder**

The term Adjustment Disorder (described more fully in section 5.13.1) refers to the psychological reactions involved in adapting to new circumstances. DSM-5 describes Adjustment Disorder as a heterogeneous array of stress response syndromes that occur after exposure to distressing (traumatic or non-traumatic) events. It is not merely an exacerbation of a pre-existing mental disorder, as in DSM-IV, but it also can include many PTSD and PTSD like symptoms, such as intrusions, avoidance

and sense of threat. Adjustment Disorders are commonly provoked by life changes, such as divorce and separation, a major change of work and abode. Also events such as transition from school to university or immigration, bereavement, and sexual assault, but not rape, which involves special kinds of adjustment (Gelder *et al.*, 2012).

### **1.5.3 PTSD**

Epidemiological data shows that PTSD is a psychological condition with characteristic symptoms that may develop in response to life-threatening traumatic events or stressors such as a road traffic accident or an assault. The diagnostic criteria for PTSD from both DSM-5 and ICD-10 draw a clear line detailing what constitutes a traumatic event, where qualifying events are narrow, excluding events such as the unexpected death of a family member (DSM-5, ICD-10). Individuals suffering from PTSD continue to re-experience the traumatic event after it is over in the form of flashbacks or nightmares. These are intrusive thoughts causing emotional/ psychological distress in the face of reminders of the event. A PTSD sufferer seeks to avoid reminders such as conversations about the event, specific people, places, and activities associated with the event. They also have difficulties in recalling aspects or the totality of the event, and have diminished interest in formally pleasurable activities. Other characteristic symptoms include feelings of detachment, a sense of a foreshortened future, and exhibiting signs of persistent arousal such as sleep difficulties, increased irritability, concentration problems, constantly being startled, and scanning the environment for problems (DSM-5 appendix, p.663). PTSD is thus the presence of a circumscribed trauma and its related symptoms accompanied by low diagnostic comorbidity and normal range personality functioning.

### **1.5.4 CPTSD**

CPTSD, which is described in further detail in section 2.3, has been defined as PTSD accompanied by marked personality dysfunction, with a broad array of symptoms including the domains of impaired emotional (affect) regulation, disturbed interpersonal relationships, identity disturbance and higher rates of psychiatric comorbidity (Miller and Resick, 2007). WHO refers to CPTSD as a lasting

personality change following catastrophic events that exceed the classic PTSD criteria, and typically comorbid with PTSD (World Health Organization, 1992). ICD-10, referencing Roth *et al.*, The DSM Field Trial (1997) defines CPTSD as a lasting personality change following catastrophic experience. Other experts see CPTSD as a complex condition encompassing a pervasive pattern of adjustment that may occur in response to trauma and across different settings and frequently involves numerous types of trauma, or trauma of long duration, which disrupts and alters developing and maturing biological and emotional systems (Luxemburg *et al.*, 2001).

The above approaches complement each other and simply examine CPTSD from different perspectives. They are also consistent with the inception of CPTSD as some of the pioneering specialists such as Herman (1992) and van der Kolk, Hostetler and Herron (1994) initially identified CPTSD as a syndrome of psychological disturbances related to early, chronic interpersonal trauma frequently associated with PTSD. From the patient's perspective, CPTSD sufferers have a negative view of themselves as helpless, permanently damaged and undesirable. This is the same theme observed in patients with psychological injuries that results from protracted exposure to social and interpersonal trauma with lack or loss of control, disempowerment in the context of either captivity or entrapment.

## 1.6 Comparisons between the Disorders

**Table 1-3 Short Definitions of Disorders**

<b>BPD</b>	Self-harming, often suicidal and other emotional behavioural problems due to attachment gone awry, and a variety of traumatic experiences ranging from neglect to those that are life-threatening
<b>PTSD</b>	Re-experiencing and avoidance behaviour following a discrete traumatic event
<b>CPTSD</b>	Self-harming, often suicidal, a feeling of being permanently damaged with re-experiencing caused by prolonged and repeated complex trauma often beginning in childhood
<b>AD</b>	Maladaptive behaviour, intrusions and difficult personal relationships caused by bio-psycho-social factors and non-life-threatening trauma

### 1.6.1 Similarities and Differences between PTSD and CPTSD

As CPTSD is often defined in relation to PTSD, it is worth highlighting the differences between the two conditions to show how CPTSD is distinct from, but similar to PTSD. The diagnosis of PTSD accurately describes the symptoms that result when a person experiences a short-lived trauma, such as a car accident, natural disaster and rape, all considered traumatic events of time-limited duration. However, following repeated and prolonged trauma for months or years at a time, clinicians and researchers have found that the current PTSD diagnosis often does not capture the severe psychological harm that occurs with such prolonged, repeated traumas (Herman, 1992; Whealin and Stone, 2008; Roth *et al.*, 1997).

For CPTSD:

- a) Symptoms are more complicated, diffused and persistent than Simple PTSD (as defined by the recognised 17 symptoms listed in the DSM-IV-TR), including somatic complaints, dissociation and dysregulation of affects;
- b) Marked personality disturbances including alterations in patterns of interpersonal relatedness and identity;

c) Heightened vulnerability to repeated self-harm.

### **1.6.2 The Links between BPD and Trauma, CPTSD**

As numbers of patients diagnosed with BPD increased in the 1980s, psychologists looked at different constructs to support diagnosis. This period coincided with increasing awareness of PTSD and knowledge about childhood abuse that was emerging 'from the closet'. It was within this clinical context that Judith Herman (1987), a pioneering research psychiatrist, posited the link between childhood trauma and BPD. Like so many scientific developments, there was no single eureka moment but a progressive coming together of interrelated theoretical and empirical knowledge. There are varieties of viewpoints regarding the connection between BPD and childhood trauma and this is demonstrated graphically in Figure 1-1. Herman (1987 and 1992) suggested that BPD might be a complex variant of PTSD because many core BPD features such as affect instability, anger, dissociative symptoms and impulsivity are present in individuals with chronic PTSD. BPD was initially conceptualised as a mild form of schizophrenia, later as a variant of an affect disorder, and more recently as a variant of a traumatic stress disorder (Golier *et al.*, 2003). Patients with BPD often present with so many symptoms of trauma that many American Psychiatrists were seeing it as a variant of CPTSD. This has been supported by Zimmerman (1999) and by Hodges (2003), who stated that BPD is actually a chronic form of PTSD that has become integrated into the personality framework. This theory maintains that prolonged and repeated stress can result in the development of behaviour patterns that are maladaptive and cannot readily be distinguished from personality traits. Thus, many people exposed to chronic trauma could be incorrectly misdiagnosed as having personality disorder, particularly BPD.

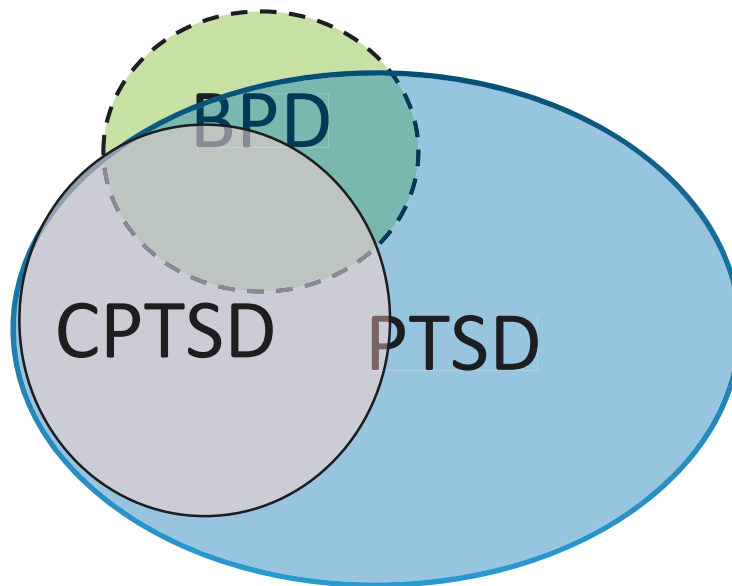
The theoretical link between BPD and trauma and between BPD and CPTSD has remained controversial since Herman's 1992 proposal to re-conceptualise BPD as PTSD associated with childhood abuse. This reconceptualization has not been universally accepted and van der Kolk has argued that while there is a large degree of overlap, and on the surface "these conditions appear to be quite similar, they only partially coincide and clear distinctions can be drawn between them as



separate diagnoses should be made” (van der Kolk, 1994; Haigh, 2003). Barnow *et al.*, (2005) found that 80% of BPD patients that they assessed reported to have experienced at least one traumatic event in their life and 30% met the criteria for CPTSD in addition to BPD. Also up to 80% of these patients experience at least some post-traumatic symptoms (McLeer *et al.*, 1992; Cuffe *et al.*, 1998).

This literature review has also confirmed the possibility that a very high percentage of cases of BPD can potentially be re-conceptualised as PTSD associated with childhood abuse and complex reactions (Herman, 1992). Potentially, the suggested re-conceptualisation could have very significant implications for the treatment and clinical management of these patients. Furthermore, a number of studies have shown that many who have been exposed to chronic childhood trauma are later diagnosed as having personality disorder, particularly BPD (Zimmerman and Mattia, 1999; Hodges, 2003; and Roth *et al.*, 1997). It has been argued that given effective treatment, patients with CPTSD may have a better prognosis than BPD patients (Harned *et al.*, 2012; Cloitre *et al.*, 2010; and Roth *et al.*, 1997).

Research has shown that if trauma is correctly diagnosed, then early intervention, especially trauma focused intervention, can be beneficial. Figure 1-1 graphically demonstrates the overlap between the three disorders. CPTSD is contained completely within PTSD, as it is not possible to have CPTSD without also having PTSD. PTSD is shown to exist independently, and has a comorbid relationship with both CPTSD and BPD shown as overlapping areas in the diagram. BPD is shown with a dotted outline in order to emphasise the uncertainty of its relation to PTSD and CPTSD, and in this particular diagram, BPD is shown to exist either independent of PTSD/CPTSD or in conjunction with PTSD and/or CPTSD.



**Figure 1-1 Overlapping Conditions**

### **1.7 The Problem with BPD Assessment and Diagnosis**

Although the reliability of diagnostic assessments for BPD has been considerably improved by the introduction of ‘standardized interview schedules’, no single schedule has emerged as ‘the gold standard’, as each has its advantages and disadvantages, with excessive length of interview time being a problem common to many of the schedules (NICE, 2008). There is still a heavy reliance on the diagnosis of BPD following unstructured clinical assessment, and there are many potential pitfalls, such as obtaining agreement in judgement among clinicians (Melsop *et al.*, 1982).

Although NICE have recently recommended that patients should routinely be asked about early childhood traumatic experiences, which might reveal some causal factors such as abuse or neglect, this does not appear to be a diagnostic criterion for BPD in their recommended assessment instruments (NICE, 2008, pp.20,300-1). Hence there appears to be a problem, recognised by specialist trauma clinicians, that primary and secondary care clinicians are not assessing or recording a history of traumatic experiences in patients given the diagnosis of BPD, and are perhaps missing vital information that may enable recovery, and also, the

level of agreement between interview schedules remains at best moderate (Zimmerman, 1994). In addition, there are divergences in clinical and research methods for diagnosing personality disorders, particularly BPD. Westen has found that although current instruments for diagnosing BPD rely primarily on direct questions derived from DSM-IV, clinicians tend to find direct questions only marginally useful when assessing for the presence of personality disorders. Instead, clinicians are inclined to arrive at the diagnosis of personality disorder by listening to patients describe interpersonal interactions and observing their behaviour (Westen, 1997).

To date, although research has investigated the link between traumatic childhood experiences and the development of BPD, and also the overlapping relationship between BPD and CPTSD, there does not appear to have been research into why there are so many BPD patients who are not considered for trauma treatment during the initial screening and diagnosis process. One reason could be that mental health professionals without in-depth and specialised training in trauma assessment and treatment may not recognise or diagnose the effects of trauma appropriately.

According to Saakvitne *et al.*, most diagnoses are descriptive and not exploratory, and seem to list behaviours and symptoms, but do not explain how or why a person may have developed their symptoms. For example, these symptoms could be as a response to traumatic stress, or a way of coping. Therefore, BPD diagnosis, like other diagnoses, fails to consider the role of abuse in people's backgrounds. These static and incomplete diagnoses have thus not helped therapists to provide appropriate care for abuse survivors (Saakvitne *et al.*, 2000).

There therefore exists a potential to consider the effective use of a screening diagnostic instrument that includes childhood and other significant traumatic experiences and/or PTSD in the assessment of BPD, as existing BPD screening instruments do not allow the screening of traumatic experiences. Also, there needs to be an assessment of the practicality and value of in-depth assessment of circumscribed or specific traumatic events connecting to current disturbing symptoms. Many researchers have advocated the need to examine the link

between traumatic history and memories that give rise to disturbances of affect (Herman, Perry and van der Kolk, 1989; Ogata *et al.*, 1990; van der Kolk, Hostetler and Herron, 1994; Landecker, 1992).

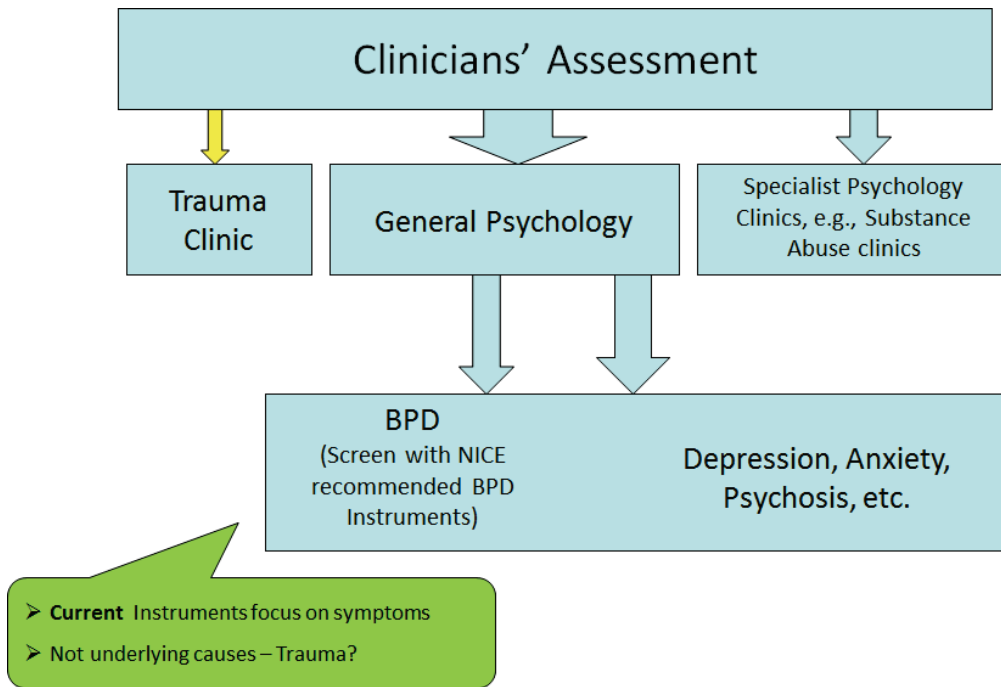
### **1.8 Research Concept and Question**

As with any investigation, it was first necessary to understand what has already been achieved by examining the latest academic and clinical literature. From this, it can be seen that the connection between BPD and trauma has been controversial since the late 1980s, when CPTSD was proposed as a specific disorder by Judith Herman (1992). It was important therefore to establish firm objectives or criteria for a solution by commencing with a principal research question.

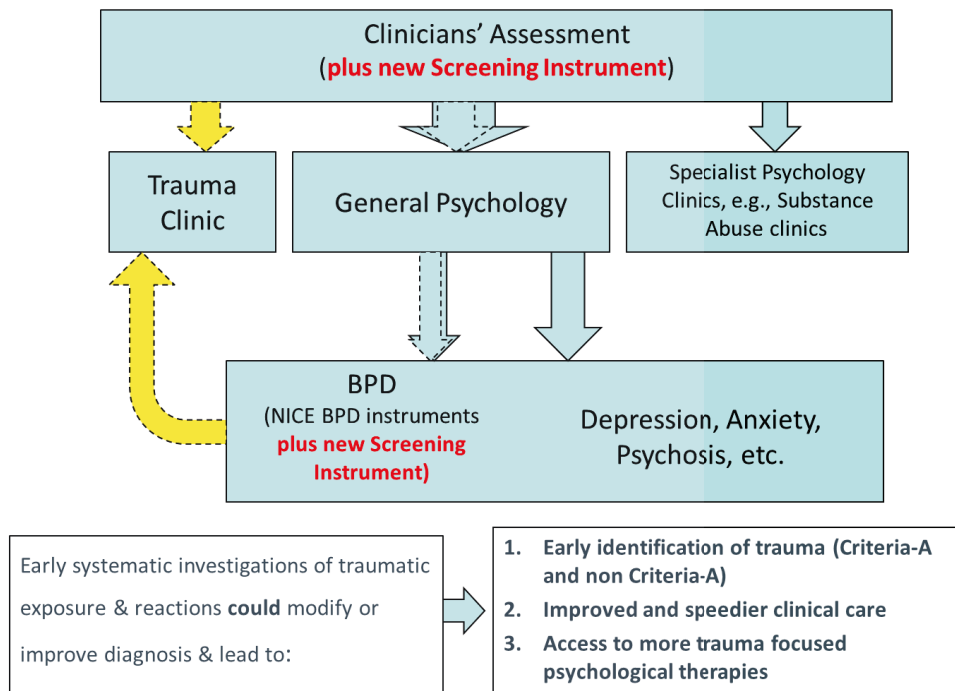
An overall research question is thus presented below:

*Can trauma screening optimise the identification of traumatic experiences/PTSD/CPTSD in patients with BPD, and resolve the misdiagnosis of BPD controversy?*

The theoretical and clinical controversy, where some patients with a diagnosis of BPD are thought to be more suitable for trauma treatment, underpins the research concept. The research concept thus foresees the early screening of patients with BPD symptomology for trauma, aiming to divert appropriate patients from BPD units for specialist trauma care. The research concept is thus visualised by Figure 1-2 and Figure 1-3, the first showing what happens today in our hospitals, and the second a vision of the future:



**Figure 1-2 What happens today in our Hospitals**



**Figure 1-3 Research Concept**

*All BPD patients will be screened for trauma with a new trauma in BPD screening instrument during initial assessments, and then the proportion of patients with PTSD/CPTSD symptoms can receive prompt treatment in specialist trauma centres.*

### **1.9 Secondary Research Questions, Objectives and Hypotheses**

To develop the research concept, it is necessary to examine in detail the BPD clinical environment, commencing with what can be expected according to currently accepted theory along with academic and clinical findings. The accepted theory can then be progressively investigated by critically analysing what actually happens, and by what should happen in clinical practice. Four secondary or research sub questions have therefore been formulated from the principal research question. To address the principal research question, it is necessary to first establish the facts relating to the BPD and the trauma underpinning the diagnosing dilemma. The first three sub questions therefore address the BPD diagnosing dilemma and the fourth aims for a solution.

- 1 *What is the proportion of BPD patients who have experienced traumatic stressors and what are the types of stressors?***
- 2 *What is the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis?***
- 3 *What is the extent or otherwise of BPD over-diagnosis or misdiagnosis?***
- 4 *Will a screening instrument reliably and sensitively discriminate BPD patients for trauma focused treatment?***

The research will therefore start by quantifying the trauma-BPD relationship as effectively as possible, and by measuring and challenging the comorbid relationship between BPD and PTSD/CPTSD from both theoretical and clinical perspectives. All findings will be quantified, comparing actual results with expectations and investigating any discrepancies from a comprehensive range of perspectives. Only then, with a strong quantitative and qualitative evidence base, will the controversial over-diagnosis or misdiagnosis of BPD be addressed from both academic and practical clinical perspectives. With a confident knowledge base of quantified findings and balanced clinical interpretation, a trauma screening solution to the BPD diagnosis dilemma will be developed, tested and refined for general clinical and academic acceptance. Four detailed objectives are mapped against the specific research sub questions, resulting in four corresponding hypotheses addressing the course of BPD, and these are listed below.

**Table 1-4 Research Objectives and Hypotheses**

No	Objective	Hypothesis
1	Quantify and qualify the proportion of BPD patients who have experienced traumatic stressors	A high proportion of BPD patients have had at least one highly distressing traumatic experience, either life-threatening or non-life-threatening
2	Quantify and qualify the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis	A high proportion of patients diagnosed with BPD also meet a comorbid diagnosis of PTSD and or CPTSD/DESNOS
3	Establish the extent of BPD over-diagnosis or misdiagnosis	BPD is over-diagnosed (or misdiagnosed) in patients in mental health care
4	Using a screening instrument, quantify and qualify BPD patients for trauma focused therapy by validation against gold standards	A short screening instrument can reliably, rapidly and sensitively discriminate which BPD patients are suitable for trauma focused treatment?

**Hypothesis 1** will investigate the underlying causes and symptoms of BPD, particularly examining the controversial impact and prevalence of trauma. Both life-threatening (Criteria-A) and non-life-threatening trauma are included in order to ensure that the effect of a wide range of causes and symptoms are considered

**Hypothesis 2** will attempt to quantify the clinical relationship between BPD and PTSD/CPTSD based on DSM diagnostic criteria, so that interpretations and recommendations are based as far as possible on unbiased facts

**Hypothesis 3** progresses to the heart of the over-diagnosing and misdiagnosing controversy, and will try to obtain a balanced interpretation of BPD diagnosis

Finally, **hypothesis 4** will address a potential solution to the BPD diagnosis dilemma by designing and clinically evaluating the reliability, validity and sensitivity of a trauma screening instrument which will enable patients to receive rapid proven treatment for debilitating trauma when presented.

### **1.10 Contribution to Academic and Clinical Knowledge**

This research project constitutes the first known systematic clinical attempt to quantify the presence of treatable traumatic events and post trauma reactions (PTSD/CPTSD) in a significant sample of BPD patients in a psychiatric population. To my knowledge, this research project constitutes the first known systematic clinical attempt to aid clinicians by utilising a simple screening technique prior to detailed diagnosis of BPD. This could hopefully lead to breaking the cycle of repetitive BPD hospital admissions. Ultimately, it could lead to a reduction in suicide rate in patients with BPD.

### **1.11 Concluding Remarks**

The idea for this research project came from practical clinical experience of BPD patients with persistent trauma presentations. It received tremendous support from all the participants throughout as they were all strongly motivated by the goal of improving assessment and treatment for the many BPD patients who suffer from the reactions of traumatic experiences. With reinforcement and clarification from the views and findings of academic and clinical expertise, trauma focused therapy was identified as a potential solution for at least some of the BPD patients. However, as this potential solution did not seem to be adopted in clinical practice, a research question is posed. This thesis is then structured in order to systematically explore the problem (stage 1) and to test a potential solution (stage 2). Three specific research sub questions and objectives were developed to try to establish the facts about trauma, PTSD and CPTSD in BPD patients, and to quantify and qualify the trauma history in BPD and the misdiagnosing dilemma. A fourth question and objective then draws on the initial results to develop and validate a screening instrument in order to identify which BPD patients are recommended for treatment for life-threatening trauma at specialist centres.



## 2 LITERATURE REVIEW

### 2.1 Introduction

The literature review chapter will now address the research question, first by examining key empirical evidence for the prevalence of trauma, PTSD/CPTSD in BPD patients, followed by an examination of complementary evidence from the theory of BPD and CPTSD in order to address the misdiagnosing/over-diagnosing controversy.

Detailed sub questions for the literature review are aligned to the four research sub questions that were presented in the Introduction Chapter, section 1.9, and these literature review sub questions are thus shown in Table 2-1 below. Initially each relevant empirical study is individually assessed for its relevance to the research question including the trauma screening and assessment instruments used. Then each study's relative theoretical and empirical merits and weaknesses are collated and compared.

**Table 2-1 Literature Review Sub Questions**

No	Literature Review Sub Questions based on the Overall Research Question
1	From analysis of academic literature, what is the proportion of BPD patients who have experienced traumatic stressors, and what is the nature of the trauma they have experienced?
2	From analysis of academic literature, what proportion of BPD patients also meet a PTSD/CPTSD diagnosis?
3	From academic literature, to what extent is BPD over-diagnosed, or is a trauma diagnosis being missed?
4	What is the suitability of existing instruments for screening the types of trauma that are presented by BPD patients?

An ideal literature review should examine all relevant published information, critically determining whether the research question has already been addressed in any form (Silverman, 2005). It is also important to examine other related work

to see what ideas can help to address the research sub questions. Search and update methodology is therefore organised in order to ensure the information gathered includes all relevant historical and ongoing studies as well as appropriate relevant theory. As knowledge was gained through the research process, supplementary searches were required in order to investigate the initial findings.

The search therefore commences addressing sub questions 1 and 2 concerning the prevalence of trauma and PTSD/CPTSD in BPD, where particular attention is paid to the methodology used in selecting patients, the quality of the assessors and the instruments used. To complement the empirical study findings, academic literature was interrogated providing a review of the symptoms and aetiology (causes) of BPD and CPTSD, their diagnosis and comorbidity. This provides the theoretical context for the third literature search question regarding the controversial overlap between the disorders, which is supported by empirical evidence derived from a large study (Westen) of US diagnosing practices. A review of prognosis, physical and brain effects, and trauma treatment then follows, in order to guide the direction of recommendations from that research.

Finally (for question 4), building on initial findings from the search findings from the empirical studies, a dedicated search was conducted to examine existing trauma screening and assessment instruments that could be suitable for BPD patients. These are reviewed, so that a proposal for future screening can build on the best available information.

## **2.2 Key Empirical Studies of Relationship between Trauma, BPD & CPTSD**

A number of authors have suggested a variety of causal mechanisms underlying the association between BPD and CPTSD, and there is an established resemblance and overlap between their presenting symptoms, e.g. McLean and Gallop (2003). While the association between general traumatic experiences and in particular childhood traumatic experiences and BPD appears well established (Yen and Shea, 2001), more recently Charles has cautioned that it is important to know that the experience of traumatic events in childhood is not enough for the diagnosis of BPD (Charles, Davies and Harris, 2008). These authors suggest that such a diagnosis should signpost clinicians to provide appropriate, trauma-focused psychological

treatments such as treatments resulting from the diagnosis of PTSD, encouraging them to provide patients with specific NICE mandated therapies, namely trauma-focused cognitive behaviour therapy (CBT) and/or EMDR (Eye Movement Desensitisation Reprocessing). One school of thought holds that BPD is best explained from a developmental theory perspective, maintaining that personality disorders manifest as the result of prolonged early experiences of childhood abuse, predisposing an individual to the development of BPD symptoms in reaction to stressors occurring in later life (Gunderson and Sabo, 1993).

A seemingly opposing view is that direct causal connections between childhood trauma and BPD are inaccurate. This is based on the premise that not all people with BPD report histories of childhood abuse (Zanarini *et al.*, 1997, p.203-4). There are also a number of relevant studies that do not report a causal link between childhood trauma and BPD (e.g., Vermetten and Spiegel, 2014). Perhaps typical of a researcher seeking 'the best of both worlds', Landecker (1992) advocates combining the diagnosis and treatment of dysfunction as in BPD with the trauma of PTSD. Researchers have also recognised that it is not enough simply to identify and diagnose abuse in BPD patients. Attention must be paid to the connection between abuse and behaviour, and which memories are related to which affect, etc. (van der Kolk, Hostetler and Herron, 1994; Linehan, Wagner and Cox, 1989). Any assessment of the association between childhood trauma and BPD must also consider Gunderson and Links (2008), who concluded that epidemiological data about BPD remains methodologically weak; pointing out that percentage on age of onset, history of traumatic abuse and prevalence should be considered best estimates. A descriptive but over-simplified explanation was given by Gunderson and Links (2008, p.48), who wrote that the interface between BPD and PTSD is 'complex'.

The role of childhood trauma in the aetiology of BPD has been tested both in theory and in practice by a number of different methods and designs. In particular, experts have focused on cases where high rates of childhood sexual abuse are reported by patients with BPD diagnosis (Bryer, Nelson and Miller, 1987; Herman, Perry and van der Kolk, 1989; Zanarini *et al.*, 2002; Briere and Zaidi, 1989; Goldman, Skodol and Lave, 1992). Furthermore, a degree of 'borderline pathology'

has been positively correlated with a degree of reported childhood trauma and with reports of more severe sexual abuse (Herman, Perry and van der Kolk, 1989; Landecker, 1992). The association with past trauma and the manifest similarities with PTSD have led some to suggest that BPD should be regarded as a form of delayed PTSD (Yen and Shea, 2001). Despite these concerns, BPD is a more uniform category than other personality disorders and is probably the most widely researched of the personality disorders.

Since the late 1980s, and in particular following the initial proposal by Herman, Perry and van der Kolk (1989), a small but fairly significant number of studies have been conducted by psychology researchers, usually exploring patients' history of sexual abuse. While none of these studies had exactly the same objective as the current research, all involved BPD patients where traumatic experiences were assessed. Therefore, data relevant to this review were extracted and presented in a consistent manner to address the main research question relating to the role of traumatic experiences in the development and diagnosis of BPD.

### **2.2.1 Search Methodology for Empirical Studies**

Three standard computerised mental health related databases (MEDLINE, PsycINFO and EMBASE) were initially searched in February 2011 for publications mentioning BPD and CPTSD, using combination Boolean logic from the University's 'Library Services' option. The databases were chosen because of their strong relevance to psychology. The other two sources searched were the Healthcare Database at the National Health Library in Prospect Park Hospital and Oxford Radcliffe Science Library. Searches were conducted with the help of librarians from:

1. Oxford Radcliff Science Library (Psychology specialist)
2. Mental Health Library in Berkshire Foundation Health care Library (Mental health specialist)
3. West London University (Psychology database specialist)

**Table 2-2 Search Methodology and Results**

	Database	Search Terms	Hits
1	MEDLINE	BORDERLINE PERSONALITY DISORDER/	3982
2	MEDLINE	(complex ptsd" OR "complex post-traumatic stress disorder" OR "complex posttraumatic stress disorder").ti,ab	75
3	MEDLINE	1 AND 2 [Limit to: English Language]	5
4	MEDLINE	trauma.ti,ab	121567
5	MEDLINE	3 AND 4 [Limit to: English Language]	4
6	MEDLINE	BORDERLINE PERSONALITY DISORDER/et [et=Etiology]	148
7	MEDLINE	6 AND 2 [Limit to: English Language]	3
8	PsycINFO	BORDERLINE PERSONALITY DISORDER/	2670
9	PsycINFO	("complex ptsd" OR "complex post-traumatic stress disorder" OR "complex posttraumatic stress disorder").ti,ab	214
10	PsycINFO	8 AND 9 [Limit to: English Language]	10
11	PsycINFO	("Disorders of Extreme Stress, Not Otherwise Specified" OR desnos).ti,ab	38
12	PsycINFO	8 AND 11 [Limit to: English Language]	2
13	MEDLINE	("Disorders of Extreme Stress, Not Otherwise Specified" OR desnos).ti,ab	20
14	MEDLINE	13 AND 1 [Limit to: English Language]	0
15	EMBASE	BORDERLINE STATE/	6774
16	EMBASE	("complex ptsd" OR "complex post-traumatic stress disorder" OR "complex posttraumatic stress disorder").ti,ab	98
17	EMBASE	("Disorders of Extreme Stress, Not Otherwise Specified" OR desnos).ti,ab	25
18	EMBASE	15 AND (16 or 17) [Limit to: English Language]	12

Free-text was used because there was no subject heading that was entirely appropriate. In addition, only PTSD was searched for, rather than CPTSD, in order to increase the hit numbers. No date restriction was required as BPD entered the psychiatric nomenclature within the publication of DSM-III only in the 1980s, because this was when reliable criteria for BPD were introduced by the American

Psychiatric Association (Gunderson, Kolb, and Austin, 1981). Because of the importance of the subject matter in North America, it was possible to obtain sufficient data by restricting the search to the English language. In order to capture the maximum numbers for BPD, full article contents were searched, revealing several thousand articles from the three databases: Medline 3,982, Psycinfo 2,670 and Embase 6,800.

To refine these numbers, an abstract only search for either CPTSD or DESNOS was conducted, resulting in smaller, but still somewhat unwieldy numbers: 95, 252 and 123, a total of 469. As PTSD and trauma will always be present in CPTSD, the refinement still adequately addresses both question 1 and 2. Combining the BPD and CPTSD searches using the AND logic function brought up three particularly useful articles. Once the major academic contributors were identified, additional searches then brought up further contributions from them. The reference lists from critical reviews were then manually scanned for additional references, in order to consolidate the range of investigation, and to ensure that key supporting investigations from leading experts were included. Due to the limited number of articles retrieved electronically (3), all abstracts were reviewed manually yielding 167 articles that met the criteria for the research. All the abstracts of the refined search were examined by the researcher and supervisor yielding 10 more articles, a total of 13 plus 3 dissertations. The others were rejected because they were not controlled studies. The references of these were scanned, yielding a further 29 making a total of 42 articles. These were divided into 5 categories:

- i. BPD and childhood trauma
- ii. BPD & CPTSD and childhood trauma
- iii. CPTSD, DESNOS and childhood trauma
- iv. Complexities and childhood trauma
- v. Related articles

All categories address the first and third research sub questions (trauma in BPD, and the misdiagnosis controversy), and categories ii, iii and iv also address the second research question (PTSD/CPTSD and BPD). The fourth research question (screen) is addressed by its own dedicated search (2.4). In each of the categories controlled studies were selected, and resulted in five initial articles. The rest were

added to the related article section. To support the investigation, Google searches for authors and titles proved a lively and efficient method of exploration. Many articles referred to three useful specialist books (Herman, 1992; Linehan, 1993; and Gunderson, 2008) and these books were often used to provide solid foundations. In one case, an online presentation by Herman from a trauma conference proved a useful adjunct to published articles and books.

### **2.2.2 Search Results of the Empirical Studies**

The search resulted in a solid database of 37 articles for a detailed study of previous empirical studies. Five articles were initially selected by excluding the following categories: Non-controlled trials; Self-assessment studies; Case Studies; and Treatment analysis without assessment information. Subsequently, a further article by Famularo, Kinscherff and Fenton (1991) was added as a result of continuous literature searches. Table 2-3 lists the six most relevant empirical studies as identified in the search methodology. More recently, three additional studies were also included. All studies are described in detail below in chronological order. The Table 2-3 heading follow a modification of the Diagnostic Checklist from CASP (Critical Appraisal Skills Programme which is designed as a guidance (CASP UK, 2013). Some headings from official DSM assessment instruments such as 'Are the benefits worth the harms and costs?' were omitted, as they were not relevant to the overall current research question. Others were added such the assessment of independence and relevance to the current study.

1. *Author(s), Location and Date*
2. *Study Objectives*, which addressed the relevance to current project
3. *Sample Size and Type*
4. *Selection Methodology*, as input factors in order to assess questions of precision
5. *Trauma Assessment Techniques and Instruments used*, to assess verification bias
6. *Questions Asked*, to check if there is sufficient detail
7. *Assessment of Independence*
8. *Results*

Table 2-3 Empirical Studies

Author, Location, Date (chronological order)	Empirical Study Objective	Sample Size & Type	Selection Methodology Sample Composition	Assessment Techniques Instruments Used	Questions Asked	Independence of Assessment Personnel	Result
Herman, Perry and van der Kolk, Harvard, Mental Health Center 1989	What is the role of childhood sexual abuse and physical trauma in BPD?	55 outpatients diagnosed with BPD Controlled - re-diagnosed BPD compared to non BPD group	Ongoing longitudinal study Mental health centre and adverts (paid)	DSM-III (BPD) Special '100 item semi-structured interview' (2 hrs) IES & DES	Encouraged to narrate trauma experiences/ events Perpetrator questions, separations, moves, violence, abuse, etc. No specifics/ PTSD	Authors, Blind to initial diagnosis	35% re-diagnosed BPD: 81% all types of trauma 33% sexual no increase in PTSD more childhood abuse
Ogata <i>et al.</i> , University of Michigan Medical Centre 1990	Can BPD predict sexual abuse?	24 BPD inpatients, drug free Controlled - compared to non BPD group (depression)	BPD (over 2 DSM-II criteria) 'Convenient' sample, Comprehensive exclusion criteria	DIB and Specially developed questionnaire (Familial Experiences Interview) Rated for severity	Sexual/Physical abuse, neglect, by sibling & family members Recollections of childhood & family events Caretakers vs. others	Researchers, Blind to DIB results	>70% sexual in BPD 22% in non BPD (83% response rate)
Famularo, Kinschiff and Fenton Harvard 1991	Do children with BPD also have PTSD?	19 children outpatients, 2 hospitals	Unknown	DICA-C-R child version, based on DSM-III	Queried abuse and neglect	Author interviews	37% PTSD, 80% trauma
Zanarini <i>et al.</i> , Harvard McLean Hospital 1997	What type of abuse causes BPD?	358 BPD inpatients Controlled trial with non BPD (High response rate)	BPD and other disorders	DSM-III, DIB-R (for BPD); DIBP Revised (childhood exp) questionnaire Specially developed (RCEQ)	Abuse (>1 mt) by caretakers, and others Trauma type: abuse, neglect, separation	Author trained, Clinically experienced (blind to clinical diagnosis)	> 92% were abused More physical than purely sexual BPD neither sufficient nor necessary
McLean and Gallop, University of Toronto 3 Mental Health Centres 2003	Will late or early abuse lead to BPD/CPTSD?	65 sexually abused women Controlled	"Convenient" sample Telephone response to flyers, with sexual abuse	DIB-R, SIDES (for CPTSD) - structured TQA	Assess lifetime experiences in 10 domains (e.g., neglect, physical trauma, sexual trauma) at four developmental periods	Researcher interview Plus PhD student Inter-rater 96%	>90%
Goller <i>et al.</i> , Veterans Centre Mount Sinai, NY 2003	What type of abuse causes BPD and did it occur in childhood or later?	180 outpatients with at least one disorder, 72 with BPD (High response rate)	One or more personality disorders, Adverts (paid) Must be '40% Borderline'	Structured Interview: DSM-III (with PTSD module), and Green (23 types) trauma self questionnaire	Broad range of Trauma using instrument(s)	Psychologist (part of team?)	25% of BPD have PTSD 29% child sexual, 53% physical 24% adult sexual, 18% sexual
Barnow <i>et al.</i> , Heidelberg Inpatients, German Hospital, 2010	What are the treatment requirements for BPD patients with CPTSD?	51 inpatients	Selection methodology unspecified, but 51 could represent all available patients in on hospital	SCID	Temperament, character, prevalence and type of traumatic events	Unknown	80% Trauma 68% PTSD 31% CPTSD
Harned <i>et al.</i> , USA various, 2010	What are the underlying causes for suicide?	94 outpatients with 3 suicide attempts	Pre-existing randomised controlled study	SCID and Trauma Life Event Questionnaire	Trauma history, suicidal tendencies	Independent clinicians trained by instrument developers	56% PTSD
Pagura <i>et al.</i> ; Grant <i>et al.</i> , USA <i>from longitudinal survey 2010</i>	What is the comorbidity of BPD and PTSD?	70% response from 34,653 1290 BPD (3.7%) <b>(5.9% in general pop)</b>	National Epidemiologic Survey on Alcohol and Related Conditions	DSM alcohol instrument (AUDADIS-IV), 'similar to SCID'	Interrogated other's data	Trained lay interviewers Face to face	33% PTSD (12 months) <b>39.2% lifetime</b>
<b>Abbreviations</b>							
IES	Impact of Event Scale		DICA-C-R	Diagnostic Interview for Children and Adolescents, Revised			AUDADIS
DES	Disorders of Extreme Stress		SCID	Structured Clinical Interview for DSM Disorders			Alcohol instrument
DIB	Diagnostic Instrument for Borderline		TA	Trauma Antecedents			



### 2.2.3 Chronology of Articles

All of the earliest empirical studies of trauma and BPD came about due to the link between childhood sexual abuse and BPD. American psychiatric academics such as Herman, Perry and van der Kolk in 1989, followed by Ogata *et al.*, and Famularo's team in 1991 all tested different types of abuse, and thus provided the first numerical evidence for the link between trauma and BPD. The Zanarini *et al.*, study in 1997 then expanded the study population size to 356, and along with the subsequent studies confirmed 80% to 100% levels of trauma in BPD patients. In all of these studies, the requirements for satisfying a trauma condition were often quite loose such as the withdrawal of a caretaker. Famularo, Kinscherff and Fenton in the 1991 brief study were the first team to specifically test for PTSD with its requirement of a life threatening traumatic stressor. This was then confirmed by the major Golier *et al.* study in 2003, and by the later (2010) large studies by Harned *et al.*, Pagura *et al.*, and Grant *et al.* Although the quantification of comorbidity between CPTSD and BPD was first investigated by McLean and Gallop (2003), they did not fully report the assessment data that they conducted. The only usable investigation using DSM recommended assessment data into CPTSD was the 2010 German hospital study by Barnow *et al.*

### 2.2.4 Location, Timing of Studies and Participant Selection

All but one of the studies were conducted in North American medical health centres or hospitals, with both inpatients and outpatients. The studies spanned the period from 1989, when the link was first proposed, up to 2010. Subjects were generally selected from existing outpatients, though two studies (Zanarini *et al.* and Barnow *et al.*) were conducted only with inpatients. The overall sample numbers ranged from 19 (Famularo, Kinscherff and Fenton), to 1290 from the longitudinal study analysed by Pagura *et al.*, and by Grant *et al.* In three studies (Golier *et al.*, Herman, Perry and van der Kolk, and Harned *et al.*), numbers were supplemented by advertising and subjects were (at least on one occasion) paid for their interview time. For the first important review of the link between BPD and PTSD (Famularo, Kinscherff and Fenton), all the participants were children between the ages of 7 and 14. Written permission was invariably obtained, and consistent with the captive clinical environment, response rates were high.

Researchers usually tested for racial, social and sexual bias. Selection criteria for all studies were generally derived from DSM-III/DIB criteria, which is the closest thing to a widely accepted standard for mental health work. Strict inclusion and exclusion criteria appear to have been applied.

### **2.2.5 Assessment Personnel for Traumatic Histories**

With the exception of the large US Alcohol study (Pagura *et al.*; Grant *et al.*), interviewers were fully trained psychology professionals. Studies strove to eliminate bias as much as possible, and on two occasions, interviewers were blind to the original diagnosis. Frequently, however, those who conducted the interviews were also the authors of the papers, which could lead to researchers assessing data to accord with expected outcomes. It should be noted, however, that all the diagnosis in the longitudinal alcohol study (Pagura *et al.*; Grant *et al.*) was independent of the research objectives.

### **2.2.6 Assessment Techniques and Instruments in the Empirical Studies**

Because of their sensitive nature, all assessments are based on the patient's own recollection of events. Also, the retrospective nature of patients' recollections adds an additional element of uncertainty to the results (Torangeau, Rasinski and Rips, 2000). Memory involves reconstructive elements and can be influenced by present beliefs and expectations in the subject as well as in the researcher or clinician (Fossati, Madeddu and Maffei, 1999). Most of the studies employed their own specially designed or modified diagnostic instruments to acquire more information about traumatic histories; details of these are found in the summary table. Only Mclean reported exclusively using a structured interview with standard assessment criteria (Structured Interview for Disorders of Extreme Stress, SIDES), which is designed for a full-scale assessment of CPTSD symptoms by specially trained qualified trauma specialists. Golier *et al.* used the comprehensive self-assessment 'Trauma History Questionnaire' (Greene, Caracelli and Graham, 1989). None of the articles used a BPD trauma screening instrument. There is however, a potential for bias due to the semi-structured interview approach, where so much depends on the interviewer. If the objective of the research is to confirm the

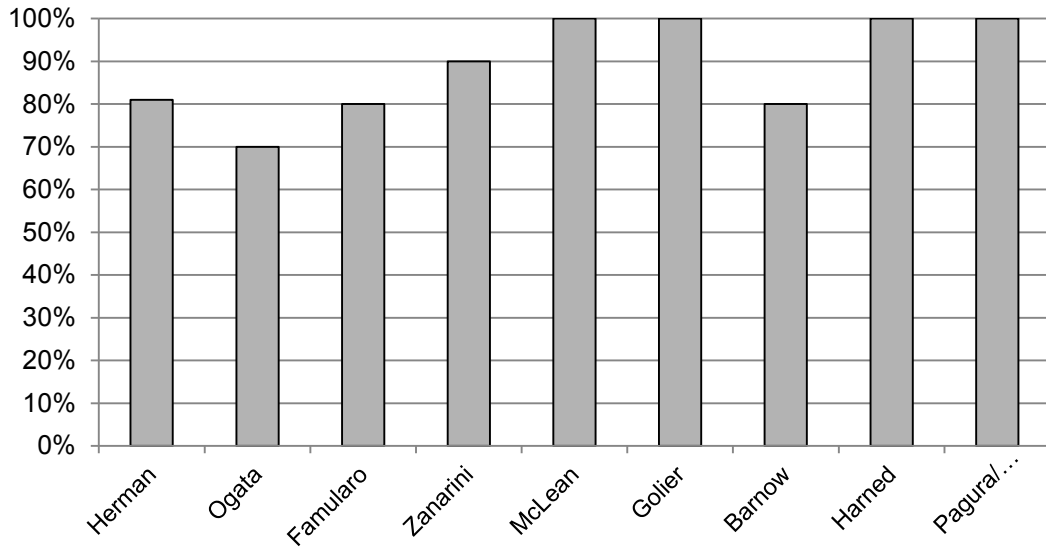
presence of trauma, then the use of a semi-structured questionnaire can be problematic.

In several studies (e.g., Ogata *et al.*; Golier *et al.*; Zanarini *et al.*), it was not possible to merge all the results to come up with a single traumatic experience percentage. For this reason, the type of trauma recording the highest percentage has been noted (Figure 2-1). In addition, some of Golier *et al.*'s results included information from a close associate such as a relative. According to Fossati, Madeddu and Maffei (1999), this practice may reduce the number of recorded incidences.

### **2.2.7 Findings from Empirical Studies**

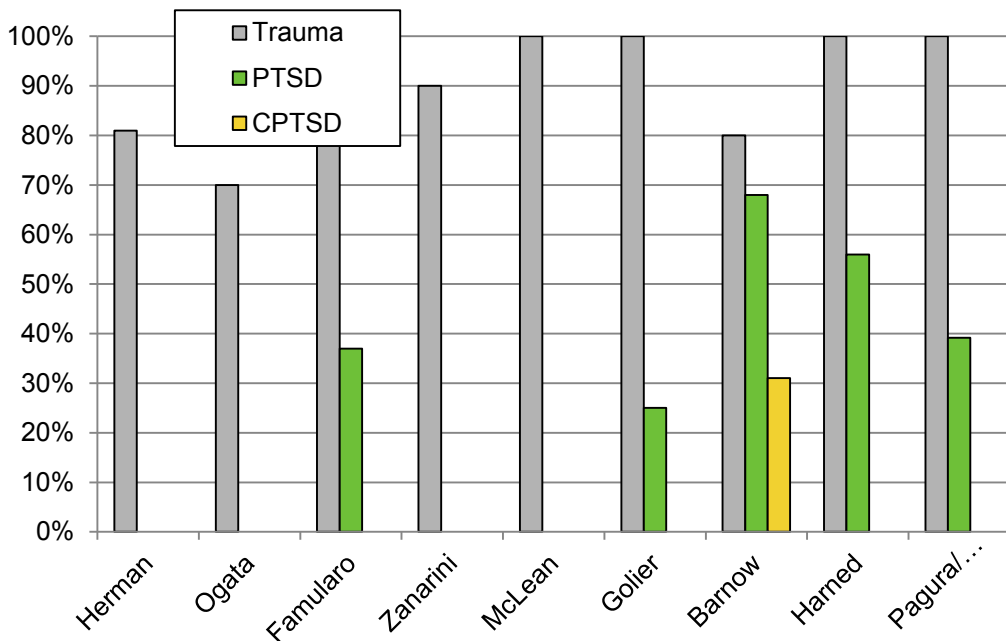
The findings from the empirical studies address the first two literature review questions about the prevalence on Trauma, PTSD and CPTSD in BPD patients. In line with Herman's proposed link, all studies, no matter which detection method was used, showed a high correlation between trauma and BPD. This correlation is significantly higher when compared with data from non BPD patients (Zanarini *et al.* and Golier *et al.*) No clear distinction could be detected in the results between paid and unpaid participants. It was notable that Barnow *et al.*, who limited their analysis to inpatients, noted much higher rates of PTSD/CPTSD in BPD patients (68%/31%). In summary, therefore, there appears to be little controversy in identifying the presence of trauma amongst BPD patients in a general sense. However, none of these studies correlated the recorded trauma with the patients' presenting symptoms, such as dissociation, self-harm, intrusive imagery, etc., as advocated by Landecker (1992) and DSM-IV recommendations. Also, from available data, it is not possible to establish an exact percentage of BPD patients with PTSD or CPTSD; however a number between 25% (Golier *et al.*) and 40% (Pagura *et al.*, Grant *et al.*) seems representative of the BPD population as a whole. A high PTSD comorbidity in BPD is also consistent with the 30% to 50% noted by Harned *et al.* Some of the studies that report higher percentages, however, may have been biased in their selection process. A representative percentage of BPD patients with comorbid CPTSD is harder to establish as only one study (Barnow *et al.*) reported results (31%), and this was based on inpatients only.

The graph below summarises the percentages of trauma recorded for each of the studies.



**Figure 2-1 BPD Studies that have Reported Trauma**

In addition, as shown on the chart below, trauma percentages can be compared with the records of PTSD and CPTSD.



**Figure 2-2 PTSD/CPTSD & Trauma in BPD**

A limitation to the Herman *et al.*, (1989) and Ogata *et al.*, (1990) studies is that they relied on self-report data from the participants. Yet the remaining studies used patients with other psychiatric diagnosis as comparison groups. One might

argue that there is no reason to assume that patients with BPD would manufacture historical information at differing rates from those with other personality disorders or Axis 1 diagnoses. Nonetheless, inferences drawn from studies using self-report data without corroboration remain problematic. Another possible limitation was the use of advertising for paid participants (Herman and Golier *et al.*) This process can lead to compliant outcomes if not carefully managed. Possibly the most difficult aspect to assess is the potential for researcher bias. When the researcher is the prime interrogator and is applying a semi-structured interview technique, there is the potential for confirmation bias. If an author expects a high trauma outcome and then does the interviews him or herself, then the outcome might be too high.

### **2.3 Theoretical Studies for the Mis/Over-Diagnosing Controversy**

Academic literature was then investigated to examine the current state of knowledge about the disorders themselves, and why the misdiagnosing/over-diagnosing controversy exists. It is important first to understand the theories and recommendations of experts in order to assess and understand what happens within clinical practice, and why individual clinicians make their diagnosis. This part of the literature review starts by reviewing what is known about the symptoms and aetiology of BPD and CPTSD. This review therefore provides the theoretical context to address diagnosis and comorbidity (question 3), which is then supplemented by a key empirical study of US BPD practice (Westen). In order to give guidance for any recommendations that may result from this study, the discussion then moves to prognosis, both the physical effects, and the effect of the brain, and in particular to the types of treatment that are suitable for BPD patients with trauma, linking treatment and prognosis.

#### **2.3.1 Symptoms**

##### **2.3.1.1 BPD Symptoms**

BPD portrays heterogeneous conditions with overlapping symptoms of depressive, schizophrenic, impulsive and dissociative identity disorder and problems with hostility and anger and bipolar features. There is a prolonged disturbance in personality. Disturbances in identity and relationships with others

is the hallmark of BPD, which arises from Attachment Disorder. BPD is characterised by rapid changes of mood with striking fluctuations from periods of confidence to times of absolute despair accompanied by fears of abandonment and rejection. BPD sufferers have strong tendency towards suicidal thinking and self-harm. In extreme cases, they experience transient psychotic and paranoid symptoms with strong fluctuations and variability. These are usually brief and linked to times of extreme emotional instability. In these cases, people can experience both visual and auditory hallucinations and clear delusions, but these can be distinguished from the core symptoms of schizophrenia and other related disorders (Links, Steiner and Mitton, 1989).

#### **2.3.1.1.1 CPTSD Symptoms**

DSM-IV-TR refers to CPTSD as a 'constellation of symptoms' more commonly seen in association with an interpersonal stressor (such as childhood sexual or physical abuse, domestic battering and torture). Its symptoms can be summarised as follows: impaired affection modulation, dissociation, feelings of ineffectiveness, feelings of permanent damage, shame, guilt, social withdrawal, impaired relationship with others or a change from previous personality characteristics. It is common in individuals exposed to extreme social and/or interpersonal trauma, especially childhood sexual abuse. These very much resemble the symptoms of BPD in terms of poor affect regulation, attachment problems and dissociative symptoms with a poor sense of self (de Zulueta, 2009). It is therefore possible to understand that making such a differentiation could be problematic for clinicians.

#### **2.3.2 Aetiology**

##### **2.3.2.1 BPD Aetiology**

All Personality Disorders arise out of childhood /adolescent experiences, and it is not something that can occur de novo in adults. Therefore any consideration of its aetiology, including BPD, must consider childhood experiences and their interaction with childhood biological factors. While the validity of a BPD diagnosis is now generally accepted, the aetiology or cause of the disorder is still a controversial subject of hot debate (Zanarini *et al.*, 1997), despite several decades of research. Establishing the etiological factors leading to its development is quite

significant given its prevalence, morbidity and mortality from suicide (one in ten, NICE, 2008), and NICE (2009) also acknowledges that the causes are complex and remain uncertain. They note that to date, although no model is able to integrate all the available evidence, many contributing factors have been advanced. The list of causes is long and includes genetic/epigenetic factors and constitutional vulnerabilities, neurophysiological, neurobiological and psychosocial factors. Other critical causes include a history of high incidence of childhood trauma, both sexual and physical abuse, maltreatment and abuse and neglect (Zanarini *et al.*, 1997).

Patients with BPD report many negative events (e.g. trauma, and neglect) during childhood and substantially more adverse events than do patients with other personality disorders (Leichsenring *et al.*, 2011, p.75). However, they go on to note that no close association between these experiences and the development of psychopathological changes in adulthood has been identified. For this reason, they expect that an interaction between biological (e.g. temperamental) and psychosocial factors (e.g. adverse childhood events in an invalidating environment) will probably provide the best explanation for how the condition develops. This is consistent with their results from recent studies of gene-environment interaction for the disorder. While some people with BPD come from stable and caring families, deprivation and instability in relationships are likely to promote borderline personality development and should be the focus of preventive strategies.

#### **2.3.2.1.1 Genetic/Epigenetic and Neuro-transmitting Factors**

According to Zanarini, the biological factors that influence the development of BPD include genetics and epigenetics, harmful intra-uterine events and effects on the development of the brain and nervous system (Zanarini, 1997, p.206). Leichsenring notes that although current evidence suggests that genetic factors have an influence on the development of BPD, no specific genes have been clearly identified as causative (Leichsenring, 2011, pp.39-41). In studies of twins, hereditary factors for BPD were less than 1% (Torgensen, Kringler and Cramer, 2001). This however contrasts with the 40-60% hereditary estimates for personality disorders in general (Leichsenring, 2001, pp.39-42). Current evidence

suggests that genetic influence on personality disorders generally, not specifically on BPD, acts both individually and in combination with environmental factors (White *et al.*, 2003; Capsi *et al.*, 2002). However, more recent studies on heredity suggest that the hereditary factor for Cluster C disorders (i.e., anxious and fearful factors such as avoidance, dependent and obsessive compulsive disorders) lies within the range of 27% to 35%. This would imply that genetic factors play a less important role than previously thought (Kendler, Torgensen, and Rechborn-Kjennerud, 2008).

Data from a candidate gene study shows an association between BPD and a haplotype containing a short allele in the serotonin transporter gene (the serotonin transporter-linked promoter region). Serotonin is thought to be a significant neurotransmitter in the aetiology of BPD (Leichsenring *et al.*, 2011, p.45). Impulse aggression, which is common in BPD, is associated with reduced seretogenic responsiveness and some genes that might be linked to the psychopathological changes in the disorder are involved in the seretogenic system (Leichsenring *et al.*, 2011, p.44). NICE (2009) noted that the regulation of emotional state is a core problem in BPD. Neurotransmitters have been implicated in the regulation of impulses, aggression and affects. Serotonin has been shown to have an inverse relationship with the level of aggression. Although the causal pathway remains unclear, reduced serotonergic activity may inhibit a person's ability to modulate or control destructive urges. For dysregulation of affects, little evidence exists for the role of catechlolamines (norepinephrine and dopamine neurotransmitters). Compared with controls without BPD, people with BPD have lower plasma-free methoxyhydroxyphenylglycol, a metabolite of noreadrenaline. This regulates the body's response to stress when amphetamine is administered to people with BPD. Coccaro, Lee, and McCloskey (2003) and also Schulz, Schulz, and Dommisse (1985) reported that they are uniquely sensitive and demonstrate greater behavioural sensitivity than control subjects.

A number of studies have reported evidence of structural and functional deficit in brain areas central to affect regulation, attention and self-control and executive function in BPD. These include the amygdala, hippocampus and the orbitofrontal regions, (Rusch, van Elst and Ludaescher, 2003; Stein *et al.*, 1997, cited in Judd and



McGlashan, 2003; De La Fuente *et al.*, 1997). People with BPD also show increased activity in the dorsal-lateral prefrontal cortex and in the frontal part of the brain and a reduction in activity in the right anterior cingulate (Schmahl, Vermetten, and Elzinga, 2003). They also show greater activation of the amygdala while viewing emotionally aversive images (Herpertz, Dietrich and Wenning, 2001) or emotional faces (Donegan, Sanislow, and Blumberg, 2003). Epigenetic alterations are also reported as being hallmarks of altered gene expression and could be involved in the aetiology of BPD (Dammann *et al.*, 2011). Epigenetics refers to the modification of gene expression, resulting in changes in the function of and/or regulation of genes, without alteration in the primary genetic sequences. In some cases, epigenetic changes may be stable and heritable, but in other instances, they are dynamic and change in response to environmental stimuli. In 2011, Dammann *et al.* analysed the DNA methylation patterns of 14 neuropsychiatric genes in the whole blood samples of patients diagnosed with BPD, and in controls. Aberrant methylation (the principal mechanism of epigenetic change) signatures on several promoter regions were established and significantly, increased average methylation (1.7%) occurred in the blood samples of the BPD patients. The authors surmised that their data suggested that aberrant epigenetic regulation of neuropsychiatric genes may contribute to the pathogenesis of BPD.

#### **2.3.2.1.2 Neurobiological Factors**

Studies investigating neurobiology testing on BPD patients suggest that individuals with BPD may have neurological deficits perhaps affecting the frontal lobe. O'Leary *et al.* found that individuals with BPD had deficits linked to brain dysfunction. This affects the frontal and limbic regions and implies that the dysfunction of the front limbic circuit could underlie core symptom clusters in patients with BPD, such as affect dysregulation self-injurious behaviours and dissociative symptoms (Wolf *et al.*, 2011). Similarly, Judd and McGlashan themselves reported that outpatients with BPD had deficits in recalling complex information as well as visual-spatial tasks measuring discrimination, speed and fluency. It is important to note, however, that other research has failed to find neurobiological differences between individuals with BPD and patient populations in general (Zanarini *et al.*, 1997, p.206). Most relevant is the well-established fact

that extreme environmental events and conditions can modify neural structures, most notably the effect of childhood trauma, abuse, and sexual abuse specifically on neurobiological development (Zanarini *et al.*, 1997, pp. 206-207).

A proposed information-processing model of the effects of sexual abuse asserted that the limbic system plays a key role in the perception of trauma and in the short and long-term effects of trauma (Wagner and Linehan, 1997). The authors argued that the limbic system is a primary neurological system for the integration of incoming information. When intensely activated or overwhelmed, which is assumed to happen in many cases of sexual abuse, numbing or dissociation occurs. Chronically, this can lead to alterations in the interaction between the limbic system and the prefrontal cortex, kindling it to respond intensely to stimuli. In turn, this can produce emotional dysregulation, which disrupts the development of the neocortical pathways that affect meaning systems and the integration of experiences. Sexual abuse can therefore lead to patterns of heightened emotional arousal, emotional dysregulation in response to events and conditions, which affects subsequent perceptions, interpretations and reaction to events or situations. This model can account for dissociative experiences, startle responses, avoidance, disrupted memories, difficulties in sexual relations, and other typical post-traumatic stress behaviours. In a sense then, childhood trauma, and sexual abuse specifically, may actually create biological emotional vulnerability by permanently altering the central nervous system of abused children (Wagner and Linehan, 1997).

#### **2.3.2.1.3 Social Factors**

Family studies for BPD were addressed by NICE in their clinical guidelines. They identified a number of social factors that may be important in the development of BPD, for example, a history of mood disorders and substance misuse in other family members. These studies point to recent evidence, which suggests that neglect, including supervision neglect, and emotional under-involvement by caregivers, are important. They point out that prospective studies in children have shown that parental emotional under-involvement contributes to a child's difficulties in socialising and perhaps to a risk of suicide attempts (Johnson, Cohen and Gould, 2002). Also that some people with BPD, significantly more often than

people without the disorder, see their mother as distant or over-protective, and their relationship with her conflictual, while the father is perceived as less involved and more distant. They infer from this that problems with both parents are more likely to be the common pathogenic influence in this group rather than problems with either parent alone. Physical, sexual and emotional abuse can all occur in a family context and high rates are reported in people with BPD (Johnson *et al.*, 1999). Zanarini reported that 84% of people with BPD retrospectively described experience of bi-parental neglect and emotional abuse before the age of 18, with emotional denial of their experiences by their caregivers as a predictor of BPD (Zanarini *et al.*, 2000). NICE suggests that these parents were unable to take the experience of the child into account in the context of family interactions. Thus abuse alone is neither necessary nor sufficient for the development of BPD and predisposing factors and contextual features of the parent-child relationship are likely to be mediating factors. The critical factor is therefore the family environment.

Some studies suggest that people are made more vulnerable to highly stressful bio-psychosocial experiences by early inadequate mirroring and disorganised attachment. Mirroring is when someone does not learn their worth as a child before adulthood, and is always looking to others for self-validation (Kohut, 1971). NICE proposes that this is likely to be associated with a more general failure in families, such as neglect, rejection, excessive control, unsupportive relationships, incoherence and confusion. Attachment is the bond that develops with the mother/ caregiver, predominantly based on infants' need for safety, security and protection. Attachment provides the context for growth and maintenance of many of developmental competencies, such as self-regulation, affect modulation, behaviour modulation, inter personal regulation, and cognitive aspects of the self and other. It thereby creates an infant who learns to control and modulate the exposures to environmental stimuli and develops internal homeostasis (a child's ability to maintain internal equilibrium by adjusting its psychological processes). Research shows that people who develop BPD due to disruption of the attachment process tend to go off track, as the attachment process is disrupted and disorganised. Lack of attachment has a negative impact on neurobiology, i.e., the

functions, growth and structure of the brain, which leads to psychological factors such as negative changes in personality traits (Kohut, 1971). BPD is strongly associated with attachment and there are indications of disorganisation (unresolved attachment and inability to classify category of attachment) in interviews, and also fearful avoidant and preoccupied attachment in questionnaire studies (Levy, 2005). According to NICE (2009) in about 94% of BPD patients, early insecure attachment is a relatively stable characteristic, particularly in conjunction with negative life events.

NICE (2009) also identifies evidence of the continuity of attachment from early childhood in adverse environments. The evidence fits with two longitudinal studies following children from infancy to early adulthood that reported associations between insecure attachment in early adulthood and BPD symptoms. This leads them to propose that disrupted childhood attachment may be an important factor in the development of BPD. Fonagy *et al.*, (2003) suggest that adverse effects arises from insecure and/or disorganised attachment relationships. These may have been disrupted for many reasons, are mediated via a failure in the development of mentalising capacity – a social cognitive capacity to do with understanding and interpreting one's own and others' actions as meaningful on the basis of formulating what is going on in one's own and other people's minds. NICE then infers that this formulation overlaps with the importance of the invalidating family environment that was suggested by Linehan (1993) as a factor in the genesis of BPD. This is further developed by Fruzzetti and Fruzzetti (2003), and by Fruzzetti and Boulanger (2005). They also report that parental invalidation, in part defined as the undermining of self-perceptions of internal states and therefore anti-mentalising, is not only associated with the young person's reports of family distress and their own distress and psychological problems, but also with aspects of social cognition, namely the ability to identify and label emotion in themselves and others.

#### **2.3.2.1.4 Bio-Psychosocial Factors**

Wagner and Linehan (1997) presented the theory according to which BPD arises from a combination of biologically based difficulties in the processing of emotions and specific environmental circumstances as well as their transaction. The

biological components in this model arise from a combination of genetic, intra-uterine and developmental factors affecting physiological development. The environmental contributors can be any circumstance involving neglect, trauma or severe punishment. The outcome of combined biological vulnerability to emotions, an invalidating environment and adverse childhood events is thus seen as a fundamental disruption of the emotional regulation system. Linehan views emotional dysregulation as the core pathology of BPD and views all problematic behaviours in individuals with BPD as functionally related to regulating emotions or as natural outcomes of dysregulated emotions (Wagner and Linehan, 1997).

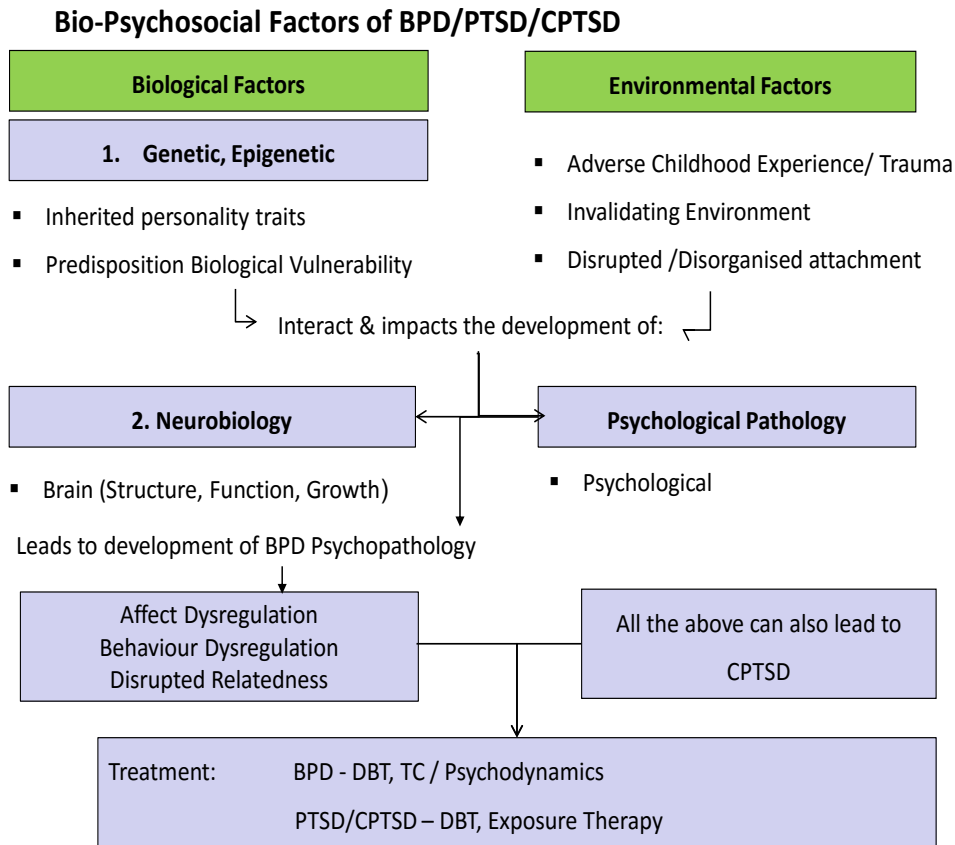
According to this theory, emotional regulation in individuals with BPD consists of two factors. The first factor is called Emotional Vulnerability whose components are hypothesised to be high sensitivity to emotional stimuli, elevated emotional intensity and a slow return to an emotional baseline. In other words, in emotionally vulnerable individuals, it does not take much to provoke an emotional reaction. These individuals have the tendency to pick up emotional cues easily and to react quickly with intense and extreme reactions. The second factor identified by these authors is a deficit in the ability to regulate emotions. This trait in turn leads to attention towards mood incongruent aspects of the environment, biased memory and biased interpretation. All of which contribute to maintaining the original mood state and a heightened state of arousal.

Linehan's theory asserts that invalidating environments disrupt the normal learning of emotional meanings, discrimination and modulation. An Invalidating Environment is one that consistently communicates to the individual that his actions or reactions, both cognitive and emotional, are not appropriate or valid responses to events (Linehan, 1993). It is an environment in which the child's communication of private experiences, i.e. thoughts and feelings, are responded to with erratic, inappropriate and extreme responses from caregivers. The expressions of private experiences, particularly emotional reactions, are not validated; instead, they are disregarded, trivialised or punished. Linehan then hypothesised specific consequences of invalidating environments:

- a) When a child's emotional expressions fail to be validated, the child does not learn how to label private experiences, and may actually come to experience emotions differently;
- b) When emotions are not acknowledged, the environment does not teach the child how to regulate them or to solve problems, therefore extreme emotional displays becomes necessary in order to evoke helpful environmental responses;
- c) When those around the child do not tolerate negative emotions, and oversimplify the child's ability to solve problems, the child does not learn how to tolerate emotions or form realistic expectations;
- d) The invalidating environment does not teach the child to trust his or her own reactions as valid, and the child therefore distrusts or invalidates personal experiences and relies on the environment to provide information on how to feel, think or act.

Bio-psychosocial Theory asserts that the effect of invalidation is not the sole cause of BPD. BPD arises from a combination of, and interaction with biological and environmental circumstances. Trauma is probably one of the primary influences on the biology of individuals with BPD (Wagner and Linehan, 1997, p.201). Bio-psychosocial Theory can thus be seen as a transactional theory, in which the child and the environment are hypothesised to influence each other. The above explanation describes many ways in which the environment can influence the child, but there are also several ways in which the child may influence the environment. The biological predisposition to emotional vulnerability may manifest itself in ways that puts the child at risk of abuse. Compared with other children, the emotionally vulnerable child may initially cry more, may have more tantrums, may seek affection more, and in general may engage in behaviours that make him or her a more salient and likely target for abuse. As the invalidating environment teaches the child that his or her thoughts, feelings and emotions are irrelevant, the child may become less likely to complain or to disclose abuse. In turn this child is at a higher risk of continued abuse than other children (Wagner and Linehan, 1997). The interrelation between the bio-psychosocial factors is shown in **Figure 2-3**. Not all children who have been abused or born with emotional sensitivity or vulnerability develop BPD. Thus Bio-Psychosocial theory

asserts that the biological predisposition to emotional vulnerability becomes problematic in an environment that does not take the vulnerability into account.



**Figure 2-3 Bio-Psychosocial Model (Modified Leichsenring *et al.*, 2011)**

There are thus three important factors in this model. These are the biological component of constitutional vulnerability, an invalidating social environment, and the psychological development of the individual. All these undermine the development of the individual’s cognitive, emotional and social capacities. These factors, with or without further trauma, exemplified by severe neglect, abuse and other forms of maltreatment, may cause changes in the neural mechanisms of arousal and lead to structural and functional changes in the developing brain, and unless early adequate remedial measure are taken, BPD may develop (NICE, 2009).

**2.3.2.2 CPTSD Aetiology**

Simply speaking, the cause of CPTSD is complex trauma. Courtois refers to CPTSD as ‘Developmental Trauma’, a type of stressful event that occurs repeatedly and

cumulatively, usually over a period of time and within specific relationships and contexts (Courtois, 2004). Childhood abuse (sexual, emotional, physical and neglect) constitute typical forms of chronic traumatisation. Families with dysfunctions such as affect-dysregulation among family members can also be developmentally traumatising (Ozturk and Sar, 2005). Courtois also highlights traumatic stressors that are interpersonal, i.e. premeditated, planned and caused by other human beings, involving intrusion upon, violation or exploitation of the child (Courtois, 2011). Interpersonal violence can be a onetime event that occurs without warning, perpetrated by a stranger (i.e. robbery, rape, physical assault). When such violence occurs within the family, between family members or in other closed contexts that involve significant roles and relationships, it is usually repeated, prolonged and can become chronic over time. Child abuse within the family is the most common form of chronic interpersonal victimisation (Courtois, 2014). Such abuse is often founded on problematic and insecure attachment relationships between parent and child or others who have primary caretaking responsibilities (Courtois, 2011). Also, the cumulative adversities faced by many people, communities and ethno-cultural religious and political groups around the globe can constitute forms of complex trauma, some of which occurs throughout life from childhood onwards, and can have the same effects (Courtois, 2011). Such complex stressors are often extreme, and due to their nature and timing may actually be life-threatening. Most threaten the individual's emotional mental health and physical well-being (emotional and physical integrity) because of the degree of personal invalidation, disregard, deprivation and coercion, and meet the DSM-IV criterion A for PTSD (Courtois, 2011).

### **2.3.3 Diagnosis**

In essence, BPD represents a disorder of attachment, while CPTSD can be better understood as a disorder of self-regulation (Luxenberg, Spinazzola and van der Kolk, 2001). This assertion supports other studies which suggest that many patients diagnosed with BPD should be assigned another more discriminating developmental diagnosis such as CPTSD (Vaillant, 1992; Herman, 1992).



### **2.3.3.1 BPD Diagnosis**

Although the prognosis of BPD can be relatively good, with most people not meeting the criteria for BPD diagnosis after 5 years, it is important to note that a minority of people have persistent symptoms into late in life. Recurrent self-harm possibly due to BPD may occasionally be a problem in the elderly. However, the condition is much less prevalent in the elderly than in the young and one of the encouraging features about remission from the condition is that it is less often followed by relapse than is the case with most other psychiatric disorders.

The reliability and validity of the diagnostic criteria have however been criticised, and the utility of the construct itself has been called into question (Tyrer, 1999). Moreover, it is unclear how satisfactorily clinical or research diagnoses actually capture the experiences of people identified as personality disordered (Ramon, Castillo, and Morant, 2001). There is a large literature showing that BPD overlaps considerably with other categories of personality disorder, with 'pure' BPD only occurring in 3 to 10% of cases (Pfohl, Coryell and Zimmerman, 1986). The extent of overlap in research studies is particularly great with other so-called cluster B personality disorders (histrionic, narcissistic and antisocial). In addition, there is considerable overlap between borderline personality disorder and mood and anxiety disorders (Tyrer, Gunderson, and Lyons, 1997; Zanarini *et al.*, 1998).

#### **2.3.3.1.1 Onset and Prognosis of BPD**

There is some controversy over the possible age of onset of BPD. Many believe that it cannot, or should not, be diagnosed in people under 18 years of age, while the personality is still forming (although diagnosis is possible in DSM-IV-TR based on the same criteria as adults, though with additional caveats). Nevertheless, borderline symptoms and characteristics are often identifiable at a much earlier age, and sometimes early in adolescence (Bradley, Jenei and Westen, 2005). More attention is now being paid to its early manifestations in adolescent groups (see Famularo, Kinscherff and Fenton). The course of BPD is very variable. Most people show symptoms in late adolescence or early adult life, although some may not come to the attention of psychiatric services until much later. The outcome in young people who have received treatment or formal psychiatric assessment is much better than was originally thought, with at least 50% of people improving

sufficiently not to meet the criteria for BPD 5 to 10 years after first diagnosis (Zanarini, 2003). This may be a consequence of treatment; however, evidence suggests that a significant proportion of improvement is spontaneous and is accompanied by greater maturity and self-reflection.

### **2.3.3.1.2 BPD Diagnostic Criteria**

DSM-IV-TR sees BPD as a pervasive pattern of instability in interpersonal relationships, self-image and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following):

1. Frantic efforts to avoid real or imagined abandonment, but not including suicidal or self-mutilating behaviour
2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation
3. Identity disturbance: markedly and persistently unstable self-image or sense of self
4. Impulsivity in at least two areas that are potentially self-damaging (for example, spending, sex, substance abuse, reckless driving, binge eating), but not including suicidal or self-mutilating behaviour
5. Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour
6. Affective instability due to a marked reactivity of mood (for example, intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days)
7. Chronic feelings of emptiness
8. Inappropriate, intense anger or difficulty controlling anger (for example, frequent displays of temper, constant anger, recurrent physical fights)
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

The key features are instability of interpersonal relationships, self-image and affect, combined with marked impulsivity beginning in early adulthood (Gelder *et al.*, 2012).

### **2.3.3.1.3 BPD Diagnosis in Practice**

A major survey of American clinicians by Westen in 1997 found a low rate of compliance with DSM criteria for BPD diagnosis (Westen, 1997). He surveyed 52 Harvard clinicians by email. The first finding was that of all the Axis II disorders, BPD represented the highest diagnosis at 85%, and that no mention was made of trauma related disorders such as PTSD/CPTSD. He then established that 44% of clinicians were satisfied with a single (BPD) diagnosis and did not wish to consider a second or comorbid Axis II diagnosis such as CPTSD. 14% did not consider their BPD diagnosis as a primary diagnosis. Another significant finding from the Westen study was the resistance by clinicians to the use of DSM recommended structured instruments. When surveyed, clinicians indicated that they preferred to observe patients' behaviours and appearance and to listen to their narratives. Some of the responses indicated that semi-structured instruments were often too probing and excessively time consuming. Other complaints were that such instruments tended not to discern between differing presentations and thus tended to over predict comorbidity. Although Westen extended his survey from his original dataset of 52 Boston practitioners to over 8,000 nationwide (25% response rate), the only applicable numerical results they present relate to their comorbidity rates, which confirmed previous findings.

### **2.3.3.2 CPTSD Diagnosis**

The findings of the 'DSM-IV Field Trial for PTSD' suggested that trauma has its most profound impact when its onset occurs during early childhood or adolescence and becomes less pervasively damaging with later onset. The trial also reported that almost half of the traumatised sample in the research had experienced a Criterion-A traumatic stressor before age 11. Also the high rates of current DESNOS in the individuals provided compelling evidence for the enduring impact of exposure to trauma during childhood (Luxenberg, Spinazzola and van der Kolk, 2001). Findings from the DSM-IV trial supported the CPTSD concept as a complex adaptation to chronic interpersonal violence, in both children and adults. One reason why DSM did not assign a separate diagnostic character is due to the comorbid nature between CPTSD and PTSD. DESNOS criteria were included among the associated features of PTSD. This reflects the view that DESNOS characteristics are not a

unique feature of survivors of childhood sexual abuse or other prolonged trauma, but instead apply to varying degrees to most PTSD sufferers. Brett (1996) commented that although it was suggested for inclusion as a separate DSM disorder by Herman in 1994, the debate surrounding the exclusion noted that the diagnosis of PTSD gave specific criteria for post-traumatic symptoms and fostered the appreciation of the generic features of a traumatic stress syndrome. However, CPTSD is included in DSM as DEPNOS and ICD has a similar code 'personality change due to classifications found elsewhere' (31.1), and both parameters accommodate CPTSD (Herman, 1997).

Many PTSD researchers and clinicians have proposed that most of the symptoms that DSM-IV lists as associated symptoms actually provide a description for CPTSD, and that this collection of symptoms clearly delineates the enduring developmental effects of trauma, and is helpful in conceptualising complex adaptations to trauma over a lifetime (van der Kolk and Courtois, 2005, p.386). Early research revealed that there were severe problem areas associated with interpersonal trauma at a young age (Herman, 1992). Although sometimes controversial, a growing number of empirical studies have supported the validity of CPTSD and its distinction from 'simple PTSD' (Roth *et al.*, 1997; Zlotnick *et al.*, 1996; Ford, 1999; Yen and Shea, 2001; Miller and Resick, 2007). While constituting the main psychopathological dimensions of CPTSD, these diverse features led to elevated levels of general psychiatric comorbidity, from a point of view of the existing psychiatric nosology and classification both in cross-sectional evaluation and in longitudinal course.

The comorbidity of CPTSD and PTSD reflect the view that CPTSD characteristics are not unique features of survivors of childhood sexual abuse or other prolonged trauma, but instead apply in varying degrees to most of PTSD sufferers (NICE, 2004; 2007, p.35). There is also a high incidence of comorbidity with trauma in general, other Axis I (mood or bipolar) and Axis II (personality) disorders such as BPD (Luxenberg, Spinazzola and van der Kolk, 2001).

**2.3.3.2.1 The DESNOS Criteria**

According to Roth *et al.*, 1997:

***I. Alterations in Regulation of Affect & Impulses (A and one of B-F required)***

- |                                   |  |
|-----------------------------------|--|
| <i>A. Affect Regulation (2)</i>   | <i>D. Suicidal Preoccupation</i>           |
| <i>B. Modulation of Anger (2)</i> | <i>E. Modulation of Sexual Involvement</i> |
| <i>C. Self-Destructive</i>        | <i>F. Excessive Risk Taking</i>            |

***II. Alterations in Attention or Consciousness (A or B required)***

- A. Amnesia*
- B. Transient Dissociative Episodes & Depersonalization*

***III. Alterations in Self-Perception***

- |                                      |                                 |
|--------------------------------------|---------------------------------|
| <i>A. Ineffectiveness</i>            | <i>D. Shame</i>                 |
| <i>B. Permanent Damage</i>           | <i>E. Nobody Can Understand</i> |
| <i>C. Guilt &amp; Responsibility</i> | <i>F. Minimizing</i>            |

***IV. Alterations in Perception of the Perpetrator (Not required)***

- A. Adopting Distorted Beliefs*
- B. Idealization of the Perpetrator*
- C. Preoccupation with Hurting Perpetrator*

***V. Alterations in Relationships with Others (One of A-C required)***

- A. Inability to Trust*
- B. Re-victimisation*
- C. Victimizing Others*

***VI. Somatization (Two of A-E required)***

- |                                    |                               |
|------------------------------------|-------------------------------|
| <i>A. Digestive System</i>         | <i>D. Conversion Symptoms</i> |
| <i>B. Chronic Pain</i>             | <i>E. Sexual Symptoms</i>     |
| <i>C. Cardiopulmonary Symptoms</i> |                               |

***VII. Alterations in Systems of Meaning (One of A-B required)***

- A. Despair and Helplessness*
- B. Loss of Previously Sustaining Beliefs*

The top DESNOS resembling criteria in DSM-IV–TR and still valid for DSM-5 are:

1. Impaired affect modulation
2. Self-destructive and impulsive behaviour
3. Dissociative symptoms

4. Somatic complains
5. Feelings of ineffectiveness
6. Shame
7. Despair and hopelessness
8. Feeling of permanently damaged
9. Loss of previous sustained beliefs
10. Hostility, social withdrawal
11. Feeling constantly threatened
12. Impaired relationship with others or change from individuals' previous personality character.

#### **2.3.4 BPD Comorbidity**

Either as a result of its position on the 'border' of other conditions, or as a result of conceptual confusion, BPD is often diagnostically comorbid with depression and anxiety, eating disorders such as bulimia, PTSD, substance misuse disorders and bipolar disorder (with which it is also sometimes clinically confused). The overlap with psychotic disorders can also be considerable. The level of comorbidity has been said to be so great that it is uncommon to see an individual with 'pure' BPD (Tyrer, 1999). Because of this overlap with other disorders, many have suggested that BPD should not be classified as a personality disorder, but should be classified as mood disorders or as disorders of identity. In clinical practice, it is sometimes difficult to determine if the presenting symptoms are those of BPD or a related comorbid condition. The main differences between the core symptoms of BPD and other conditions are that the symptoms of BPD undergo greater fluctuation and variability. These psychotic and paranoid symptoms are transient, depressive symptoms and change dramatically over a short period. Suicidal ideas may be intense and unbearable but only for a short time, doubts about identity may occur but are short-lived, and disturbances in the continuity of self-experiences are unstable. For each of the equivalent comorbid disorders there is much greater consistency of these symptoms.

### **2.3.5 Physical & Structural Effects of Trauma pre Treatment**

Trauma can have significant effects on the body (Luxenberg, Spinazzola and van der Kolk, 2001). There is also evidence that repeated traumatic experiences impact the body via numerous mediating models. The first is a Biological Model that includes neuro-anatomical factors and reduced hippocampal volume. Second is the Physiological or neurohormonal effect. This can affect the limbic system, causing excessive response in the nervous system and excessive activity in the sympathetic and parasympathetic system. Finally, there are somatic difficulties that also damage physical health and in extreme cases can lead to premature death (Luxenberg, Spinazzola and van der Kolk, 2001).

### **2.3.6 Treatment of the Disorders**

What has been written about the treatment of the disorders is now presented. This starts with classical BPD treatment, explaining why this is not enough, and addresses how trauma treatment can benefit BPD. CPTSD treatment is then addressed in more detail as these techniques could be applied to BPD.

#### **2.3.6.1 BPD Treatment**

APA guidelines recommend psychotherapy as the main treatment for BPD, with pharmacotherapy as an adjunctive component of treatment that targets current symptoms during periods of de-compensation and trait vulnerabilities (Leichsenring *et al.*, 2011; NICE, 2009). NICE also recommends that psychotherapy should be used as the cornerstone of treatment for BPD and identified several methods of psychotherapy. The outcome in young people who have received treatment or formal psychiatric assessment is much better than was originally thought, with at least 50% of people improving sufficiently not to meet the criteria for BPD 5 to 10 years after first diagnosis (Zanarini, 2003). This may be a consequence of treatment; however, evidence suggests that a significant proportion of improvement is spontaneous and is accompanied by greater maturity and self-reflection (NICE, 2009). DBT (Dialectical Behaviour Therapy) is a broad-based cognitive behavioural therapy (CBT) developed specifically for BPD (Linehan, 1993). It was the first type of psychotherapy shown via controlled clinical trials to be effective with BPD (Linehan *et al.*, 1991). DBT including skills training,

is based on the Bio-psychosocial theory of the development of BPD, where neglect in early relationships leads to an impaired ability, both to represent and to moderate affect and control attentional capacity. These factors may cause changes in the neural mechanisms of arousal and lead to structural and functional changes in the developing brain.

However, research on the treatment of BPD, such as that conducted by Marsha Linehan has largely ignored the traumatic origins of BPD and instead focused on symptom stabilisation (van der Kolk, 2001). As a comprehensive treatment for BPD, this is problematic, as it fails to intervene prior to the development of BPD psychopathology. The Bio-psychosocial model emphasises that we cannot change an individual's genetics or some of the environment that they grow up in, nor can we even know what is happening in an individual's environment. We can however intervene to reverse some of the adverse neural mechanisms of arousal, and thus lead to structural and functional changes in the developing brain. These changes happens in the environment due to adverse childhood traumatic experiences. The Bio-psychosocial model therefore informs the treatment of BPD in order to improve or sustain functional and affect long-term outcome. This model allow us to understand aetiology in terms that explain variations in long-term course, and it elucidates, or throws light on where to intervene for the most beneficial treatment. The model also shows that the etiological pathway is the same as for CPTSD, and therefore BPD can benefit from treatment that is designed for CPTSD as will be discussed in the next section (2.3.6.1.1).

Shea *et al.*, (2004) reported that treating PTSD due to the effects of traumatic experiences in BPD could, over time, lead to improvement in BPD because the latter shares some, but not all, the dimensions of PTSD. Leichsenring *et al.*, (2011, p.79) reviewed 24 randomised controlled trials (RCTs) on psychotherapy alone for BPD using the gold standard 'Cochrane' criteria. For those studies that used CBT, the authors compared its effectiveness with treatment as usual and found that behaviour therapy was in general more effective in several outcome measures than 'treatment as usual', i.e. DBT and pharmacotherapy. Following treatment, however, a number of patients still met the diagnostic criteria for BPD. The authors also compared the effectiveness of various non-behaviour therapies with



behaviour therapy, and came to similar conclusions, noting that even brief CBT, which looks at the origins of dysfunctional behaviours, but does not focus specifically on possible underpinning traumatic histories can be beneficial. While these benefits are recognised, the authors noted that at present there is no clear evidence that one specific form of psychotherapy is superior to another and that the available forms of psychotherapy do not yet lead to remission of BPD for most patients.

#### **2.3.6.1.1 Trauma Treatment for BPD Patients**

In addressing the question of why most psychotherapy treatment does not yield remission for BPD, Landecker (1992) proposes that this could be due to the treatment being focused on borderline characteristics rather than the comorbid PTSD/CPTSD. Van der Kolk (1987) also suggests that it could be due to the fact that, in clinical settings, diagnosis has been made on presenting BPD symptoms, and treatment is consequently focused on behavioural skills training and development, and not on PTSD/CPTSD or underline traumatic histories. NICE has recommended several types of treatment for trauma. One is Exposure Therapy, and a subset of this – trauma focused exposure therapy – applied in conjunction with CBT (TF-CBT), an evidence-proven treatment for PTSD recommended by NICE (2005). This treatment focuses on how patients interpret aspects of their traumatic experiences that have become problematic for them. It also improves response techniques for coping with problems such as thought suppression, rumination or selective attention to threat (Ehlers *et al.*, 2009). There are two main recommended types of exposure therapy: cognitive restructuring and prolonged exposure (PE), both of which incorporate cognitive behavioural structures, focusing on patients' cognitions and attributions about both the traumatic event and themselves. They also allow both the extinction of conditioned fear and the regulation of emotions. This regulates the dysfunctional neural circuits involved with negative emotions and fear. PE was designed to be added to Dialectic Behaviour Therapy (DBT) to treat PTSD symptoms in suicidal and self-injuring individuals with BPD, and in the hands of therapists such as BPD clinicians with minimal CBT experience, it was found to be as efficacious as treatment by CBT experts (Foa, 2011).

The advantage of focusing BPD treatment on trauma and PTSD/CPTSD follows from studies that have found that treatment of PTSD leads to the integration of traumatic memories, (associated with PTSD) and reduces the symptoms of BPD (van der Kolk, 1987, pp.111-119). This is a precondition for the development of improved tolerance, impulse control, defensive organisation, and for the restoration of an integrated self-identity. Also in 1987, the same authors noted that clinical literature on the treatment of PTSD repeatedly cites the importance to recovery of the integration of traumatic memories with their associated affect, and the necessity for the patients' traumatic experiences to be validated. This approach is consistent with the recommendation that there should be early, rapid and appropriate recognition of the connections between patients' current symptomatology and their origin.

Caution must always be employed, as intervening too early for PTSD/CPTSD could be problematic. Bryer, Nelson and Miller (1987) looked at sexual and physical abuse as factors in adult psychiatric illness and suggested that instituting psychological and pharmacological therapies without knowing about the original trauma would be like treating the varied and chaotic symptoms of Vietnam veterans without knowing about Vietnam or what happened there. In addition, it has been suggested that early intervention into PTSD symptoms by non trauma clinicians could lead to attrition and exacerbate symptoms (Grubagh *et al.*, 2011). Bryer also found that many clinicians were uncomfortable about discussing abuse, because of suppressed or repressed trauma memories, but also because most clinicians have not had the appropriate training, especially when dealing with the difficult subjective reactions that can be evoked in themselves.

Some researchers have concluded that a combination of early intervention with Trauma Focused CBT and treatment as usual will be beneficial (Deblinger *et al.*, 2006; Cloitter *et al.*, 2010). In addition, Clarke, Rizvi and Resick (2008) demonstrated that PTSD focused CBT treatment may positively affect BPD symptomatology, although this tends to contradict the 2011 Lancet study, which concluded that the prevalent assumption is that individuals with BPD will not benefit from evidence-based treatment for PTSD (Leichsenring *et al.*, 2011). However, it is inconsistent with Mueser *et al.*, (2008) who demonstrated that with

16 weeks of CBT, severely ill BPD patients with PTSD could be treated successfully in conjunction with treatment as usual. One interesting point in this research was that they found that the burden of PTSD can be reduced in this population and that Exposure Therapy may not be necessary.

Shea *et al.*, (2004) conducted a prospective study, which included 223 BPD patients, 38% of whom had a comorbid PTSD diagnosis. They showed that patients with a high PTSD remission rate exhibited an even higher BPD remission rate over time. This could imply that when PTSD treatment is working well, it also has a beneficial effect on BPD symptoms. Remission from PTSD can also be associated with the increased probability of remission from BPD. Harned *et al.*, (2012) treated PTSD in suicidal and self-injuring women with BPD. Their study focused on the development and pilot testing of a protocol based on Prolonged Exposure (PE) designed to be added to DBT to treat PTSD in suicidal and self-injuring individuals with BPD. Women with BPD, PTSD, and recent and/or imminent serious intentional self-injury (N=13) received one year of DBT compared with the DBT PE Protocol, plus three months of follow-up assessment. The treatment was associated with significant reductions in PTSD, with the majority of patients no longer meeting criteria for PTSD at post-treatment (71.4% of DBT PE Protocol completers, 60% of the intent-to-treat sample). Improvements were also found for suicidal ideation, dissociation, trauma-related guilt cognitions, shame, anxiety, depression, and social adjustment. Overall, the results indicate that successful integrated BPD and PTSD treatment can be achieved within one year of treatment starting. This is highly acceptable to both patients and therapists, safe to administer, and has showed promise as an effective intervention for PTSD in this complex and high-risk patient population.

#### **2.3.6.1.2 Consequences of not Screening and Treating for Trauma**

Failure to screen for trauma in BPD has the consequence of patients not being diagnosed with a trauma related syndrome, and therefore only receiving a diagnosis such as BPD, with the result that treatment is less effective (Tucker, 2002). For BPD comorbid disorders, NICE recommends referral to a special plan addressing the core difficulty as well as the comorbid disorder. A failure to refer for trauma treatment denies effective and evidence validated treatment: e.g.,

trauma focused CBT and/or EMDR (NICE, 2005; Mueser *et al.*, 2008 and Cloitre *et al.*, 2010). The failure to treat long-term disorders (PTSD/CPTSD) also perpetuates poor self-rated health and personality changes (Al-Saffer, Borgå and Hällström, 2002; Canadian PTSD Association, 2004-2011). The greater the understanding of the developmental origins of psychological mechanisms underpinning disorders, the better the chance of at least partially effective psychological treatments which challenge traditional views of BPD as immutable (NICE, 2008, p.30). The phase based treatment approach that is recommended for CPTSD, combines a skills focused with an exposure-focused treatment, is discussed below.

### **2.3.6.2 CPTSD Treatment**

The treatment of Simple PTSD and CPTSD (DESNOS) requires different approaches (van der Kolk, 2001). Effective treatment of complex post-traumatic problems needs amongst other things to address the imprint of trauma on the experience of the self as helpless and in danger. Trauma recovery needs to include dealing with defensive efforts that helped ensure survival, incorporate physical experiences that counter feelings and sensations associated with helplessness and disconnection, as well as an effective way of integrating fragmented memories of trauma. Experiencing physical mastery (as in yoga and specific body based techniques) is often necessary in order to initiate new ways of perceiving reality and to promote the types of behaviour patterns that are useful in dealing with trauma. Helping every aspect of the human organism to bring the traumatic experience to an end is the goal of treatment. The treatment recommended by the International Society for Traumatic Stress Studies (ISTSS) and many experts in the field is a Phased Oriented Treatment and advises a three-phase treatment model (ISTSS, Expert Consensus Guidelines for CPTSD, Cloitre *et al.*, 2011):

- Stabilisation and skills reinforcement;
- Reappraisal of traumatic memory;
- Greater engagement in community life.

Cloitre *et al.*, (2010) conducted a head-to-head comparison of this phase-based treatment with an exposure-focused treatment and a skills focused treatment. The results of this study indicated the superiority of the phase-based approach

as compared with exposure-focused treatment, while the skills-only approach fell in the middle (ISTSS).

#### **2.3.6.2.1 Phase One - Stabilisation and Skills Reinforcement**

This can be conceptualised as helping to maximise frontal lobe activity by learning to observe and attend to day-to-day activities, thereby diminishing the power of trauma-related physical sensations, emotions and perceptions. In this phase, DBT approaches are recommended as they can assist patients in developing skills to deal with affect regulation. DBT, which includes both skills training and individual work, can be extremely helpful as an adjunctive or sometimes preparatory treatment for individual trauma treatment (van der Kolk, 2001).

#### **2.3.6.2.2 Phase Two - Reappraisal of Trauma Memory/Trauma Processing**

Here, exposure-based treatments are applied, e.g. PE, Cognitive restructuring and Eye Movement Desensitization and Reprocessing (EMDR), all of which are cognitive behavioural in nature and focus on patients' cognitions and attributions about both the traumatic event and themselves. EMDR is a technique that is thought to facilitate rapid adaptive associative information processing by integrating sensations, affects and self-attribution. In this way, it may share some qualities with REM sleep, which has been posited to help process day-to-day experiences (Stickgold, 1999, cited in van der Kolk, 2001). However, at this point there is no specific evidence of why EMDR works (van der Kolk, 2001).

#### **2.3.6.2.3 Phase Three - Greater Engagement in Community Life**

The purpose is to re-establish secure social connections and interpersonal efficacy, accumulating restorative emotional experiences (van der Hart *et al.*, 1989; Herman 1992, cited in van der Kolk, 2001). Because so little systematic research has been done on both BPD and CPTSD patients, many questions remain about what constitutes optimal treatment. Some writers such as McCann and Pearlman (1992) and Herman (1992) emphasise the importance of a restorative therapeutic relationship with therapy and of building coping skills, with the formation of loose associations. Particular sensations then lose their power to evoke entire traumatic scenes and the patient learns to attach new meanings to old sensations and to process traumatic memories. What can be most important for these patients is to

learn to have a subjective sense of mastery and competence that will allow them to live in the present without constantly being pulled back into experiencing the present as a recurrence of the past (van der Kolk, 2001).

### **2.3.6.3 Impact on the Brain following Treatment**

A meta-analysis, and a systematic review by Porto *et al.* of neuroimaging of emotional processing in PTSD and social anxiety disorder revealed that CBT was able to make quantifiable changes in functional brain response is empathetic and forgiving in judgement, and also shows that PTSD has been resolved (Porto *et al.*, 2009). The study also shows that CBT helps in the remission of PTSD symptoms as well as to promote activation of the brain areas related to social cognition of empathy and forgiveness. Neuroimaging also found structures that participated both in the brain circuits involved with fear extinction and in those involved with cognitive regulation of emotion. In addition, CBT regulated dysfunctional neural circuits involved with the regulation of negative emotions and fear extinction. This is because CBT treatments contain specific techniques of exposure, and cognitive re-structuring, which allows for both the extinction of conditioned fear, regulates behaviour, and the cognitive regulation of emotions (Porto *et al.*, 2009).

### **2.3.6.4 Treatment Conclusions**

Linking causes of BPD with trauma and proven treatment can improve or sustain functional day to day life and affect long-term outcome for BPD patients. Although trauma treatment has been proven for CPTSD patients, this can only happen if it is identified early by screening during assessment when patients initially present with BPD symptomatology. To manage these patients effectively, one first has to recognise the disorder (Paris, 2012). The principle disadvantage however of trauma treatment, is the requirement for trained clinicians competent in trauma screening and in the application of trauma focused therapies.

## **2.4 Question 4: Existing Screening and Assessment Instruments**

The fourth (trauma screening instrument) literature review question is addressed by a specific literature search, which addresses instruments that could be used to screen BPD patients by BPD clinicians for trauma prior to a detailed assessment by trauma specialists. BPD instruments are first examined.

### **2.4.1 BPD Screening and Assessment Instruments**

Three principal instruments were identified.

IPDE, International Personality Disorder Examination consists of a self-administered questionnaire that contains 77 DSM-IV or 59 ICD-10 items (Loranger, Janca and Sartorius, 1997). It is recommended by NICE and contains questions that assess for any DSM-IV or ICD-10 personality disorder. IPDE is written so that a 9-10 year old can complete it in 15 minutes or less. Qualified clinicians can then quickly score the questionnaire and identify those patients whose scores suggest a personality disorder. 9 questions of the 77 are relevant for the screening of BPD. IPDE has been developed as the most comprehensive instrument for the diagnosis of any personality disorders, and has been proved to have good inter-rater reliability when applying either the DSM or ICD diagnostic system ( $\kappa=0.8$ , Mann *et al.*, 1999). It has also been proven to be user-friendly and to be a meaningful instrument for clinicians throughout the international psychiatric community. Although IPDE can be used as a valid screen to detect BPD symptoms, it can be lengthy, and more importantly does not identify the presence of traumatic experiences, or the reactions of trauma. Most BPD patients seek help for trauma reactions but often go unrecognised in the initial screening and or assessment interviews. It is therefore important to discuss the patient's background, but for this it is recommended to use other instruments that could enhance the questioning, probing and scoring process. IPDE is also not intended for subjects below the age of 18 years, although with slight modification it could be used with those as young as 15 years. As IPDE is self-reporting, it assumes that a person is capable of providing a valid description of their disturbances. Also IPDE is designed for experienced practitioners, including clinical psychiatrists and those with

comparative training capable of making independent psychiatric diagnosis; it is not intended for use by clinicians in the early phase of their training.

SAPAS (Standardised Assessment of Personality – Abbreviated Scale, Moran *et al.*, 2003) is also a recognised screen for BPD, but currently it is not commonly utilised in the Trust.

SCID (BPD module) is a commonly used assessment instrument. However the level of agreement between interview schedules is at best moderate (Zimmerman, 1994). Nevertheless, the questions in SCID meet the criteria for both the DSM-IV and ICD-10 classification systems.

#### **2.4.2 Assessment Instruments for PTSD and CPTSD (DESNOS)**

The Structured Interview for Disorders of Extreme Stress or SIDES for DESNOS (Pelkovitz *et al.*, 1997) is the only instrument that has been validated as a diagnostic assessment instrument for CPTSD (Luxenberg, Spinazzola and van der Kolk, 2001). The SIDES instrument consists of a 45 item structured interview comprising six sub-scales corresponding to the 12 symptom of DESNOS. It was developed by CAMH to measure current and lifetime presence of complex post-traumatic stress and response severity. Instructions for SIDES recommend its use after recording a patient's trauma history. It elicits information regarding the overall effects of trauma and is valuable in identifying the most critical areas of psychological impairment, which need to be addressed for effective treatment planning. SIDES measures the presence of the clinically most relevant issues associated with complex trauma. Zlotnick and Pearlstein (1997) supported SIDES as a valid measure of the associated features of PTSD in survivors of childhood sexual abuse. DSM field trials for PTSD found that SIDES prove a reliable and valid measure to assess the alterations in functioning that result from response to extreme stress (Roth *et al.*, 1997; Perry and Herman, 1993). The SIDES instrument is also a valid measure for the associated features of PTSD in survivors of childhood sexual abuse (CSA). The principal limitation of SIDES is that it is long and very time-consuming, so clinicians do not find it easy to use. In addition, the instrument does not itself elicit traumatic experiences but devolves this activity to another instrument, making the process very lengthy.



The Traumatic Antecedent Questionnaire (TAQ) is suggested to be used prior to SIDES. TAQ is a 78-item questionnaire to identify exposure to traumatic life events. A variation is TAQ-S (self-rated version) is recommended by (Herman, Perry and van der Kolk, 1989). The TAQ-S assessment instrument gathers information about lifetime experiences in 11 different domains: competence, safety, neglect, separation, emotional abuse, conflict resolution, physical trauma, sexual trauma, witnessing trauma relating to 4 different age periods, exposure to drugs and alcohol. Although it discusses all of trauma it is very long, time consuming and very detailed, and hence daunting for clinicians not qualified to treat trauma.

The CAPS (Clinical Administrated PTSD Scale by Blake, Weathers and Nagy, 1995) is considered to be the best measure for PTSD using DSM criteria (1994). Also the US Veterans National Centre for PTSD considers it the gold standard instrument for assessing PTSD (U.S. Department of Veterans Affairs). It consists of a 30 item structured interview that corresponds to the DSM criteria for PTSD by assessing the frequency and severity of the 17 DSM symptoms, and can be used to assess both lifetime and current PTSD. CAPS assessment is designed to be administered by clinicians and clinical researchers who have a working knowledge of PTSD, i.e., trauma trained Mental Health Professionals who have experience in conducting diagnostic interviews. It has been validated with good inter-rater and test-retest reliability (Brewin, 2005, p.153; Blake, Weathers and Nagy, 1995). One of the limitations of CAPS is that it is scored for symptoms rather than causes, one or more for frequency, and two or more for intensity. CAPS also evaluates trauma requesting three incidents. A full CAPS interview takes up to 45–60 minutes for a clinician competently trained to administer it; for untrained or inexperienced clinicians, it can take up to 90-120 minutes, and scoring is long and complicated.

### **2.4.3 Trauma Screening Instruments**

To ensure a trauma screening technique did not already exist, a comprehensive search was made for existing screening instruments for trauma, and several existing screening instruments were identified. These instruments screen for the presence of PTSD but appear to focus only on traumatic stress symptoms, without asking about the trauma itself. They are also designed to be used following a known involvement in a major single-incident traumatic event called a 'type 1

trauma', ranging in type from 9/11 to a mugging, rape, car crash or heart attack (Terr, 1991). Terr divides childhood trauma into two basic types and defines the findings that can be used to characterize each of these types. Type 1 trauma includes full, detailed memories, "omens" and misperceptions. Type 2 trauma includes denial and numbing, self-hypnosis and dissociation, and rage. No single short screen was found that could be used for individuals with a history of complex traumatic experiences (type 2 trauma as described in section 1.5.1) and its complex reactions. Brewin (2005) had already completed a systematic review of PTSD screening instruments and found that several screening instruments aimed at identifying patients who have PTSD, prior to formal diagnosis by clinical interview, have been developed. The review identified 13 screening instruments (with mean diagnostic efficiency of 86%) that were used to identify the presence of PTSD following major traumatic events. The most relevant ones as presented in Brewin (2005) and in Walters, Bisson and Shepherd, (2007) are summarised below and are detailed in APPENDIX 2 .

**Table 2-4 Published Screens for PTSD**

Name	Description	Author	Items	Validation	By	Limitations
SPAN	Startle Physiological arousal Anger and Numbness	Meltzer- Brody <i>et al.</i> , 1999	4	Tested on varying independent populations	Chen <i>et al.</i> , 2003 Melzer-Brody <i>et al.</i> , 1999	Type 1 only. Complex replies required Limited questions
TSQ	Trauma Screening Questionnaire	Brewin, Rose and Andrews 2002	10	Consistent diagnostic prediction	Independent samples	Type 1 only
IES	Impact of Event Scale	Horowitz , Wilner and Alvarez 1979	15	Consistent diagnostic prediction	Independent samples	Type 1 only. Complex replies required

Brewin found that these ranged from simple four-item instruments to more complex scales (Foa *et al.*, 1997). He only found a few of these scales that have been validated in large and diverse populations or tested independently. Given the relative uniform results obtained, he argued that the ideal instrument should have few items, simple response scales, and simple scoring methods, and thus gives better results than longer and more complex instruments. He suggested that such instruments are likely to be more accepted and provide less scope for errors or uncertainty in terms of answering specific questions. Another consideration is that there is little information to date on acceptability for individuals who participate in the screening.

The major limitation of SPAN is the limited information that can be obtained from only 4 questions, and therefore it can add little about the construct (disorder). SPAN also focuses on one particular PTSD symptom (numbing). The questionnaire also requires severity and frequency levels that are not easy for sensitive patients to handle, and the scoring system is quite complicated for busy clinicians (Brewin 2005; Walters *et al.*, 2007). The two instruments that appeared more suitable were TSQ (Brewin's Trauma Screening Questionnaire) and IES (Horowitz's Impact of Event Scale), but both only addressed PTSD and did not consider BPD or CPTSD (APPENDIX 2 ). TSQ comprises 10 items with important questions on re-experiencing and arousing symptoms requiring straightforward yes/no answers, and it has the advantage of being validated. IES contains 15 questions about intrusion and avoidance relative to a specific event, which again are answered on a four-point scale. IES also has the advantage of having been validated on an independent sample. However, none of the existing screens proved suitable for non-specific traumas, such as those that typically experienced by patients with BPD/CPTSD often originating from childhood.

## **2.5 Literature Review Conclusions**

A clear connection emerges from the nine most relevant published trials relating to BPD and the prevalence of trauma, showing high levels of trauma consistent with theoretical evidence. Also within these trials, there are some significant indications of both PTSD and CPTSD as proposed by Herman, van der Kolk and more recently by Harned and Barnow. From the extensive academic reviews and

clinical discussions of BPD, PTSD, CPTSD and their relation to trauma, the remaining areas of concern cover causes, diagnosis and proposed treatments. In particular, the link between BPD and CPTSD is still topical and controversial, and no definitive conclusions can be reached based on current published data. The theoretical concept behind the misdiagnosis of BPD originates from Herman (1992) and Vaillant (1992) who have consistently promoted the adoption of BPD as a complex variant of PTSD as an alternative diagnosis. While such experts have investigated the BPD-PTSD/CPTSD relationship empirically, scientifically acceptable studies remain few, and many of these could be said to be biased in selecting subjects from those with known traumatic experiences and symptoms.

The empirical academic literature was also investigated to determine the reasons why BPD practitioners are not routinely diagnosing PTSD/CPTSD. In this case, answers were not so clear-cut, which therefore influenced the research design to investigate this area. Over-diagnosis of BPD was supported empirically by Westen (1997) in the examination of large-scale USA BPD practice when compared with the DSM requirements for at least five identified criteria. Westen found that the practice of diagnosing BPD with less than five DSM recorded symptoms was common throughout the US (section 2.3.3.1.3), and that clinicians supported BPD diagnosis based on a general observation of behaviour during interviews.

Finally, a review of existing instruments for screening and assessment of trauma confirmed that while large-scale assessment instruments such as SCID, CAPS and SIDES are appropriate for full assessments by specialist trauma clinicians, there was no simple screen that is appropriate for BPD clinicians. The only trauma screens available were designed for PTSD. This finding thus provides support to the development of such a screen.

**Table 2-5 Literature Review Conclusions**

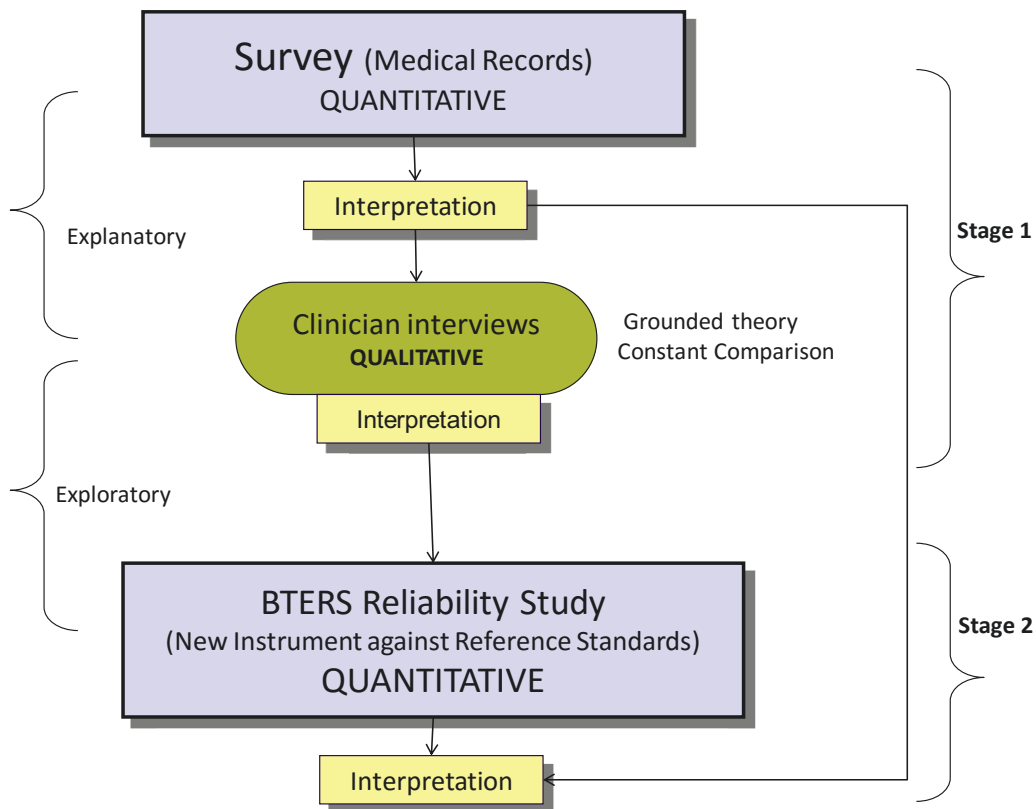
No	Literature Review Sub Questions	Theoretical Findings	Empirical Findings from review
1	From analysis of published literature, what proportion of BPD patients have experienced traumatic stressors and what type of trauma have they experienced?	While the link between trauma and BPD has been demonstrated, there are also a number of equally relevant biological and environmental causes of BPD.	More than 9 separate studies say that 70% - 100% of BPD patients experienced distressing trauma. Impact of trauma could have been exaggerated because sampling often encouraged inclusion of patients with existing trauma concerns.
2	From analysis of published literature, what proportion of BPD patients also meet a PTSD/CPTSD diagnosis?	Herman's proposed re-conceptualisation of BPD as PTSD associated with childhood abuse is not uniformly accepted, although overlap is generally agreed.	PTSD-BPD comorbidity: 25% (Golier) to 39% to 50% (Harned).
3	From published literature, to what extent is BPD over-diagnosis or is a trauma diagnosis being missed?	Herman and others have consistently promoted the adoption of BPD as a complex variant of PTSD as an alternative diagnosis. Hence, their view is consistent with the view of misdiagnosis.	Over-diagnosis as per DSM was supported empirically by Westen (1997) in his examination of large scale USA BPD practice when compared against the requirements for at least five identified criteria, however misdiagnosis was not supported by this study.
4	What is the suitability of existing instruments for screening the types of trauma that are presented by BPD patients?	N/A	The only trauma screens that were found were those designed for patients with known trauma and PTSD assessment. Detailed assessment instruments were unsuitable for BPD clinicians.



### 3 METHODOLOGY: DESIGN

#### 3.1 Introduction

The next step of the project is to select a suitable design in order to address the main research question, taking account of the knowledge gaps confirmed by academic and clinical literature. This chapter thus explains the design of chosen research methodology and the rationale for the choice. In practical terms, the nature of the research question being asked often determines the appropriateness of the methodology to be used in attempting to answer that question. Hence, a *two-stage sequential mixed method* design was selected and the rationale for its selection is presented in this chapter. The figure below illustrates the entire methodology.



**Figure 3-1 Research Design Flow Diagram**

The rationale for selection of the research methodology design must refer back to the main research question addressed via four sub-questions in order to explain why a *two stage sequential mixed method* design was chosen.

**Table 3-1 Sub-Questions**

No	Research Sub-Questions	How the Design addresses the Sub Questions
1	What is the proportion of BPD patients who have experienced traumatic stressors and what are the types of stressors?	Quantify proportions from stage <b>1</b> survey. Qualify stressor types and diagnosis reasons from clinician interviews.
2	What is the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis?	Repeat and crosscheck in stage <b>2</b> using BTERS and gold standards. Compare stage <b>1</b> and <b>2</b> results with empirical studies.
3	What is the extent or otherwise of BPD over-diagnosis or misdiagnosis?	Quantify BPD DMS criteria from stage <b>1</b> survey. Qualify using clinician interviews. Compare with empirical studies.
4	Will a screening instrument reliably and sensitively discriminate BPD patients for trauma focused treatment?	In stage 2, a screen is designed from literature and clinician interviews about stage <b>1</b> results. Check reliability/validity/sensitivity by comparison with gold standards. Compare results with empirical studies.

The chapter commences by explaining how and why this particular design was adopted, briefly highlighting the advantages and disadvantages of the selected quantitative and qualitative techniques. Then the required approach to data collection and analysis is discussed, including a full description of the mixed method methodology. Also to establish the most appropriate overall research design that will include feasibility, resources, time available, and ethical issues.

*Stage 1. To collect the necessary data, current BPD practice for addressing trauma in BPD is first determined using a survey technique. Then, based on the analysis of current practice using grounded theory and constant comparative approach, collate the requirements for a suitable 'trauma in BPD' instrument (BTERS).*

*Stage 2. A second stage develops BTERS, then addresses the reliability and internal validity of BTERS, including enhancement by the use of a pilot study and a statistical analysis. The instrument will subsequently be validated by comparison with gold standards.*



A dedicated section considers a range of threats to achieving validity in the research design in terms of types of bias, and discusses the mitigations adopted. Throughout the research, the process is guided and supported by a Project Steering Group (section 3.11.2), and a comprehensive quality control system is adopted. Finally, the different sections of the staged design are mapped against each of the research sub questions.

### 3.2 Rationale for the Design

A quantitative methodology therefore offers the opportunity to interrogate the documented evidence of trauma, PTSD, CPTSD and BPD diagnosis criteria in BPD patients' medical records. Subsequently, these results are integrated with qualitative feedback from practising clinicians as to why trauma is not being diagnosed. Thus, the first three research **sub** questions are addressed along with their corresponding objectives, which require results to be qualified. Both these elements comprise stage 1, the first sequential mixed stage of the overall research design. The principal disadvantage of stage 1 is that patients' traumatic experiences can only be accessed through the prism of clinicians who are dedicated to BPD treatments and are not trained in trauma assessment. Stage 1 does however offer a window on the disorders with minimum chance of being influenced by views of the researcher.

For the fourth research question, an additional research stage (stage 2) is required in order to develop and test a trauma screening instrument for patients with BPD symptomatology. The second stage will provide the opportunity to utilise the clinician interviews, building on the analysis of current practice using grounded theory and a constant comparative approach. Thus, a suitable 'trauma in BPD' instrument (BTERS) will be developed to both quantify and qualify BPD patients for trauma focused therapy by validation against gold standards. To achieve this final objective, a quantitative reliability study is selected in order to test BTERS against (DSM) standard assessment instruments. In addition, BTERS also provides the opportunity to **reassess research sub questions 1 and 2** utilising primary data, whereas stage 1 provides secondary information. Stage 2 will also examine the comorbidity of BPD with PTSD/CPTSD and thus could provide **further insight into the research question 3**, the misdiagnosing/over-diagnosing controversy.

Although both stages represent separate sequential elements, the quantitative results from stages 1 and 2 will subsequently be discussed concurrently in order to develop overall conclusions. Thus, the overall design can be classified as a two stage sequential mixed method. The flow diagram above (Figure 3-1) summarises the different elements of the research introduced above, which will be described in some detail in section 3.5.

### **3.2.1 Data Collection Rationale: Quantitative or Qualitative**

In quantitative research, results are deduced from observed data, but descriptive information can also be collected. This method is generally employed to test hypotheses such as relations between numerical variables that can be analysed statistically. Typical quantitative approaches used in health science are descriptive surveys, observational studies, case control studies, randomised controlled trials and time series designs (Creswell *et al.*, 2011). Qualitative research focuses on the context and meaning of human experiences such as trauma in a BPD clinical environment, in order to induce interpretations from research data. It uses data collection methods such as in-depth interviews, ethnological observations and document review. Typical qualitative approaches used in health science are case studies, grounded theory, ethnological exploration and phenomenology (Creswell *et al.*, 2011). While qualitative research does not give rise to mathematical abstractions, it should be systematic in its approach to data collection and analysis, and both approaches should be systematic and rigorous. Analysis of qualitative data can of course be subjective, so the design should include mechanisms to address this issue. The mixed method strategy of enquiry offers the opportunity to collect both quantitative and qualitative data to address all four research sub questions and hypotheses (Creswell *et al.*, 2011).

### **3.3 Types of Mixed Method Designs**

In order to select the optimum mixed method, the available options are first presented. Some types of questions can be answered only by using qualitative methods, whereas other types demand quantitative approaches. Some require mixed quantitative and qualitative methods, and there are other questions that are potentially open to either qualitative or quantitative approaches but which may be answered more efficiently, effectively or reliably by one approach than by

the other (Wellman, 2006). A simple definition of mixed methods in a research project is a combination of qualitative and quantitative components in the collection and/or analysis of research data (Bergman, 2008).

Such an approach has been shown to provide a more comprehensive, persuasive and rigorous understanding than adopting a single approach (Creswell and Plano Clark, 2007, p.5). A mixed or multi-level method therefore starts with the philosophical assumptions (ontology and epistemology) that guide the direction of data collection and analysis, and employs a mixture of qualitative and quantitative methods, both rigorously applied, in order to enhance contextual understanding in the various phases of the research process. Given that all approaches have limitations, in this way the biases inherent in any one single method can potentially neutralise or cancel out the bias in the other methods.

In the past, mixed methods were less common in research strategies compared with either exclusively qualitative or quantitative strategies (Creswell, 2003, p.15). Complex designs are now common place as they are driven by specific questions and aims in particular investigations (Creswell *et al.*, 2011). Creswell and Plano Clark (2011) simplified what became a complex set of mixed method classifications into a few basic types. Mixes can be made either concurrently in order to converge on a solution by triangulation, or sequentially by having one method build on the other, in a way that gives priority to one or the other or both. Sequential designs can involve exploratory or explanatory phases of data collection such as quantitative data collection followed sequentially by qualitative data collection or vice versa.

### **3.3.1 Triangulation Design**

Triangulation is a means of converging data across parallel qualitative and/or quantitative approaches (Jick, 1979). Triangulation Design can also be thought of as a concurrent mix which is considered central to qualitative analysis (Boeije, 2002). This offers a means of converging data across parallel qualitative and/or quantitative approaches (Jick, 1979). Triangulation enhances confidence in the ensuing findings, and assures validity through the use of a variety of methods on the same topic, which can involve different types of samples, as well as data

collection. In addition, it can capture different dimensions of the same phenomena (Kulkarni, undated).

For example, from a quantitative survey of patients' records and a qualitative review of clinicians' views, an overall view can be obtained by triangulating the results of these methodologies.

### **3.3.2 Other Mixed Methods**

Multiple methods can thus be adapted to different phases of a study and should direct the research plan so that a researcher makes decisions during its implementation. A further significant feature of mixed methods is in helping the researcher to decide whether the sequential detailed methodology should be allowed to emerge during the research, on the basis of initial results, rather than being predetermined at the outset of the study (Creswell *et al.*, 2011). Quality results can thus be achieved by intentionally integrating and combining separate methods to draw on the strengths of each, so that the investigation is framed within a philosophical and theoretical position (Creswell *et al.*, 2011). In any design, the focus can be weighted to quantitative or qualitative data, and emphasis can be given to the timing of data collection (Morgan, 2007; Creswell and Plano Clark, 2007).

Hall and Howard proposed a *synergistic* approach in which two or more options interact so that the combined effect is greater than the sum of individual parts. So instead of giving priority to one design over another, or weighting one approach within a mix of methods, they considered their value and representations as equal from an ideology of multiple points of view, balancing objectivity with subjectivity and collaboration, thus obtaining expertise in both qualitative and quantitative approaches (Hall and Howard, 2008).

### **3.4 Selected Approach for the Design**

The selected approach as represented in Table 3-2 below has thus been identified as a mixed method sequential design, which also incorporates Hall's synergistic approach. Stage 1 builds on the analysis of a database of BPD patients' medical records and the sub-sequential results of clinician interviews, connecting them together to gain a broader perspective by using different methods (Creswell,

2003). Thus, qualitative BPD clinicians' interviews about the results from the first part of stage 1 will be used to inform and describe aspects of the data that cannot be quantified. The second part of stage 1 will utilise the emerging data analysis and interpretations to help to give a more in-depth picture of some of the underlying clinical mechanisms, such as how trauma is considered during BPD assessments (Creswell *et al.*, 2011). In this way, the second quantitative data collection (stage 2) in the research is able to utilise the results of qualitative interviews to connect with the resulting stage 1 quantitative findings from the survey of patients' medical records.

**Table 3-2 Mixed Method Design**

	Stage 1		Stage 2	
<i>Parts</i>	Survey	Questionnaires Interviews	Instrument Development - Pilot	Main (BTTERS reliability) Study
<i>Type</i>	Quantitative	Qualitative	Quantitative	
<i>Process</i>	Design -> Collect Data -> Analyse -> Connect ->			
	Explanatory		Exploratory	
	Data Informs->	Data Emerges->	Data Informs->	
<i>Method</i>	Correlate symptoms with DSM criteria	Grounded Theory Constant Comparative	Correlate Trauma in BPD Screen (BTTERS) with DSM (Gold) standards	
<i>Participants</i>	Patients' Medical Records	Clinicians, Management	Patient interviews	
<i>Location</i>	3 Hospitals		Single Hospital	
<i>Literature</i>	Previous empirical surveys	International surveys of clinicians	Existing screening instruments	Previous empirical surveys
<i>Numbers</i>	N=60	N=28	N=13	N=40
<i>Validity</i>	Construct Validity	Content and Face Validity	Content, Construct and Face Validity	Content and Construct Validity

This approach will underpin the criteria applied in selecting items to identify types of trauma, in order to frame a trauma screening instrument for subsequent validity/reliability testing with BPD patients (stage 2). A trauma-screening instrument could alternatively have been developed using information from literature alone; however, in including a qualitative element from clinician interviews, the instrument can be made more useful. From a timing perspective, an emergent mixed design is more appropriate to this study, as from the outset it is important to obtain clinicians' views of the controversies, and these interviews should be able to lead either to the development of a new instrument or to the modification of an existing instrument. In addition, in the final discussions of the research, when the results of all sections are available, a synergistic approach will be used to decide on the relative weighting to be given to each part when considering recommendations for the future.

One of the strengths of the sequential design, beginning with a survey of patients' medical records followed by clinician interviews, is that it is relatively straightforward in nature and easy to implement and report. It also allows the researcher to view the problem from multiple perspectives, and to enhance and enrich the meaning of a singular perspective (Creswell *et al.*, 2011). The main weakness of this type of design however is the length of time it takes to collect data when working on sequential phases.

### 3.5 Design Concept

In the table below, the four individual hypotheses can now be considered against the two sequential research stages.

**Table 3-3 Staged Hypotheses**

No	Hypothesis	Stage 1	Stage 2
1	A high proportion of BPD patients have had at least one highly distressing traumatic experience, either life threatening or non-life-threatening	✓	✓
2	A high proportion of patients diagnosed with BPD also meet a comorbid diagnosis of PTSD and/or CPTSD	✓	✓
3	BPD is over- (or mis-) diagnosed in patients with symptoms of repeated self-harm, persistent risk-taking behaviour and marked emotional instability	✓	X
4	A short instrument (BTERRS) can efficiently screen for PTSD/CPTSD referrals during routine initial BPD assessment	X	✓

#### 3.5.1 Stage 1, Survey

To satisfy the first research objective of establishing current practice, the first step is to choose the most appropriate method between an experiment (trial) with patient interactions, and a survey of pre-existing data. In general terms, a *survey* is a technique employed to identify the presence of patterns in a defined environment such as the criteria used to make the diagnosis of BPD or the presence of trauma in patients with BPD (Gosall and Gosall, 2009). As such, a survey is suitable for establishing the current status of trauma in the understanding of BPD. The rationale for starting with a survey of the medical records of BPD patients reflects the recognition of the subjective nature of our knowledge (of trauma in BPD), or of reality, where the views of practising BPD clinicians can be incorporated into the study (Bound, 2011).

#### 3.5.2 Clinicians Interviews (Grounded Theory and Const. Comp.)

What a survey will not find out is what practising BPD clinicians and their departmental management personnel think about the world around them and in particular, what they think of the BPD/PTSD controversies as identified in the research objectives (Bound, 2011). In order to achieve this particular objective,

qualitative data collection and analysis is needed to understand and interpret behaviour, meanings, motives and other subjective reasoning. Therefore, the quantitative or objective approach inherent in the survey of patients' medical records is supplemented by anonymous questionnaires and face-to-face semi-structured clinician interviews. The intention of the interviews is to understand how trauma is being addressed in clinical settings by asking what clinicians do during BPD screening and assessment, and how they interpret their results, thus aiming for a more comprehensive and persuasive overall approach.

### **3.5.2.1 Grounded Theory**

Methodological options for ascertaining and interpreting complex feedback include phenomenology and grounded theories. A variety of different qualitative approaches, including grounded theory, offers a comprehensive empirical methodology that can identify the most useful questions to ask for the final research question and hypothesis about the screening instrument. These two models are presented together, as one can be seen as an extension of the other, and they use very similar data collection and analysis methods (Sayre, 2001). The main difference is that phenomenological theory begins with a research question, whereas grounded theory is conducted to discover a research question for testing, which in this case is the content of the trauma screening instrument. Phenomenology thus describes the meanings or interpretation of experiences about a concept or phenomenon, which in this case is the clinician-patient interface. Phenomenology also develops understandings of social and psychological phenomena from the cumulative perspective of the people involved, by listening to their stories (Welman and Kruger, 1999, p.189). These strengths of the phenomenological approach were thus integrated into how grounded theory was adapted for the examination of the research hypotheses.

Grounded theory contains an inductive loop where feedback from the clinician survey verifies the format of the final hypothesis concerning the design of the trauma screen for BPD. Questions that the researcher directly asks the clinicians in grounded theory are: "What is the effect of trauma?", "Are there any preconceptions of BPD diagnosis?", "What are the main challenges for participants", "Do you ask patients about traumatic experiences" and "How are



they trying to deal with trauma?” Grounded theory methodology does not aim for the absolute truth but conceptualises what is going on empirically, keeping an open mind as to the detailed formulation of hypotheses and thereby ensuring that they are grounded in real data. This technique results in information rich data, although any dataset can be subjective and value-laden, limiting the opportunity to make generalisations and compromising reliability estimates. Such an approach nonetheless encourages the freedom to interpret the behaviour of clinicians and presents the opportunity to generate explanations for that behaviour, an approach that is the essence of grounded theory (Glasser, 1988). As a cross validation, the analysis will also use techniques such as checking by an independent researcher, feeding back the findings to participants, and peer reviews such as a steering group to enhance the credibility of the overall interpretation of the data.

Giving voice to clinician participants allows for a more holistic analysis of complex clinical problems, and advances the development of the knowledge of trauma in BPD to provide a richer understanding of both the patients and the clinicians who serve them. The survey of clinicians’ views thus becomes a shared focal point, and thereby binds the relevance of the BPD assessment process to the clinicians themselves, making the phenomena more clearly articulated. To obtain a comprehensive outcome from the shared interaction between the researcher and clinicians and to explain clinician behaviour, both structured (simple anonymous questionnaires) and semi-structured interview methods will be employed. To interface efficiently with the clinicians, a number of questions relating to the information required will be generated, i.e. what data is required to make an effective assessment, which specialists will collect the data and from whom, what processes will be used to collect the data, and what other considerations are required to support this process? Feedback will be sought from BPD frontline clinicians and consultant psychiatrists, who assess, diagnosis and work with BPD patients, and also from management. Strauss and Corbin (1998) suggest that in grounded theory, the number of participants is less important than the quality and depth of examination, hence a minimum number of patients is not incorporated into the design.

Grounded Theory needs to move fast as the researcher is often limited by fieldwork constraints such as the requirement for rapid note taking during interviews. Ideas or concepts that fit with data need to be generated quickly so that they are relevant and work in explaining what clinicians do and why. Interviews will also quickly follow after project presentations, so that the subject matter and preliminary results are fresh. In all interviews, efficient note taking is an essential part of quality control (Taylor and Robert, 1984).

### **3.5.2.2 Constant Comparison Method**

A Constant Comparison Method is adopted which, together with theoretical sampling, constitutes the core of qualitative analysis within the grounded theory approach (Boeije, 2002). *Theoretical Sampling* is where the researcher decides what data will be gathered next. The objective of Constant Comparison is to find patterns within the words of the BPD practitioner's narratives, and to present those patterns by simultaneously coding and analysing data while at the same time staying close to the clinical environment as the participant practitioners experienced this environment (Taylor and Bogdan, 1984). Framed by a focus of inquiry, through both interviews and questionnaires, open-ended questioning will be employed to allow clinicians and management personnel articulate their perceptions and experiences freely and spontaneously. Although access to the front line clinicians should be relatively straightforward, it will also be necessary to explore and discuss the outcomes with the consultant psychiatrist(s), as they are responsible for making the initial diagnoses. In this respect, the views of managerial personnel are also significant. In analysing interview results, responses should not be grouped according to predefined categories; instead, salient categories of meaning and relationships between categories can be derived from the interviews through a process of inductive reasoning.

This should allow the perspectives of interviewees to be articulated and analysed, and thus integrated into the resultant BPD clinical model. Narratives of the interviews can thus be broken down into discrete items and then placed into categories (Glasser and Strauss, 1967; Lincoln and Guba, 2000). Categories take two forms:

- A. Those that are derived from the interviewee's customs and terminology;
- B. Those that the researcher identifies as significant to trauma within BPD.

The goal of the former is to construct categories used by the clinicians to conceptualise their own experiences and worldview of BPD. The goal of the latter is to assist in developing insights into how BPD is perceived in the clinical environment. This process stimulates thinking that leads to both descriptive and explanatory categories (Lincoln and Guba, 1985, pp.334-341). Categories can undergo content and definition changes as various items are compared, and as understandings of category properties and the relationship between them are developed and refined over the course of the analytical process. Information from interviews will therefore be analysed simultaneously in order to establish empirical relationships by continually comparing and refining specific items, exploring relationships between them and integrating them into a coherent explanatory model (Taylor and Bogdan, 1984, p.126).

An empirical approach can then be induced by comparing and connecting categories. Constant comparison goes hand in hand with Theoretical Sampling based on provisional empirical and theoretical ideas. This makes it possible to address questions that arise from the analysis of previous interviews. Such questions can include interpretations of findings as well as category boundaries, assigning segments of interviews or finding relations between categories. Data from practitioner interviews can then be analysed again and compared with subsequent interviews. Categories will be selected to ensure that both initial and supplementary interview questions were answered efficiently and effectively, thereby enhancing analysis and moving the comparative process forward. The cycle of comparison and reflection on previous and new interviews will be repeated several times, with each interview being conducted in the same manner. It is only when new interviews do not bring any significant new information to light that the categories would be considered to be saturated (Sayre, 2001). This means that subsequent new information will be easily assigned to one of the existing categories in the growing analysis.

Three sets of comparisons (comparative steps or moments) will be made to incorporate the two separate groups of participants that were interviewed: day-to-day clinicians and clinical managers. The process will start with a comparison

within a single interview and then compare that interview with the interviews with different clinicians. Interviews will consider the findings of the patient survey, how their views on trauma and BPD relate to one another, and the complexity of these relationships. The comparison between the clinicians and the management represents the third set. It is important to note that these steps do not constitute a strict linear process; instead, continual back-and-forth comparison maintains a cyclical process of reflection.

#### **3.5.2.2.1 Step 1: Comparison within a Single Interview**

The initial aim of internal comparison is to develop distinct categories and to label them from the most appropriate codes (open coding). Comparisons will first be conducted from within the first interview. During the process, the interview will be studied to determine what exactly was said, and common codes elicited. Comparing different parts of the interview allows the consistency of the codes to be determined. Thus, fragments that relate to the same idea can be given a common code, and in this way core messages will be developed.

#### **3.5.2.2.2 Step 2: Comparison between Interviews within the First Group**

There will then be a comparison between interviews within the first group – the BPD clinicians who conduct assessments – in order to assess the diversity of their views. All interviews will be conducted and handled in the same way, and as each interview is completed, outcomes will be compared. The first few interviews will therefore be selected with the aim of exploring the quantitative results and obtaining a meaningful variety of categories. Participants will be critically selected to answer any questions that are raised by the comparison process, and to ensure that the research hypotheses are being addressed. Items or segments from each interview will be compared so that themes that are common between the interviews are given the same coding (axial coding, Strauss and Corbin, 1998). Common themes will then be established by consolidating categories.

#### **3.5.2.2.3 Step 3: Comparison of Interviews from Different Groups**

The aim here is to compare the stage two interviews with a different group of people who hold the same knowledge and experience of trauma in a BPD clinical environment, that is, those responsible for the management of BPD patients, as opposed to those who assess and treat BPD patients, thus grouping participants

with same experiences. A data triangulation method will then be employed to gather interview segments through different types of sampling, or at different times and clinical situations. As these interviews will be conducted in the same way as the interviews with the clinicians, the process should therefore validate the information from clinicians, either confirming or challenging it. *Responder validation* is therefore adopted in preference to *investigator triangulation* in order to retain maximum engagement with raw data. This process representing an analysis of the clinician interviews concludes stage 1 of the research. The results from the clinician interviews will subsequently be used for the development of the screening instrument in stage 2.

### **3.5.3 Stage 2: Reliability Study for Screening Instrument**

Having designed a research methodology for addressing the stage 1 objectives and hypotheses, the stage 2 design then builds on the results of stage 1. The stage 2 design will thus test the efficacy and performance efficiency of a trauma screening instrument for patients diagnosed with BPD (hypothesis 4). It should also support and enhance the stage 1 design objectives of assessing trauma and PTSD/CPTSD in BPD (hypotheses 1 and 2). In so doing, the stage 2 design also refers back where knowledge (in this case, clinicians' perspectives) is acquired from stage 1 utilising the grounding process (Welman and Kruger, 1999, p.189). The updated knowledge base will allow the quantification of trauma and PTSD/CPTSD by empirical evidence to be re-examined using an alternative to the survey used in stage 1. The proposed screening instrument will be tested in a study (stage 2) by a simple *Reliability Study* where the results from BPD patients screened with the new instrument are correlated with the results from the use of gold standard assessment instruments.

### **3.6 Research Ethical Concerns**

Clinicians face many ethical dilemmas in their practice, so all research with human participants must consider the ethical concerns and rights of study participants. Studies should not expose people to harm and participants must be able to refuse participation (Polit, Beck and Hungler, 2001). Codes of ethics have thus been developed to guide the efforts of researchers and to help others evaluate their actions. "To do no harm" is embedded in the Helsinki Declaration adopted by the

World Medical Assembly (1964, revised 2013). Ethical responsibility is arguably even greater when dealing with a population which may be regarded as vulnerable, such as the mentally ill or those who are in some way victimised or abused, as is the case with any group of BPD patients. Because of the sensitive nature of this investigation, a staged approach to ethical approval will be adopted, allowing the approving authorities the opportunity to assess the effectiveness of researcher-patient interactions before granting approval for face-to-face interviews. In line with NICE guidelines, prior to all researcher-patient interactions, Patient and Clinician Information Sheets specifically designed for the research in question will be prepared, supported by a clear research protocol, patient consent forms and information posters. NHS approving authorities also require specific application forms and the option of a face-to-face ethics panel review.

Relevant ethics approval authorities examine all research proposals and either grant permission, rejects the proposal or request further clarifications and modifications. In this research, both university and NHS ethical approval is required. When granting approval, a number of constraints are usually applied, often including informed consent, freedom of choice, anonymity of data, security of data, etc.

### **3.6.1 Safeguarding of Vulnerable Patients**

For this research project, due to the nature of the patients' conditions, additional safeguards are also considered, such as what should happen in the event of the disclosure of past or present abusive events and relationships. Appropriate clinical referrals can then be made for those who may require help, either at the time of the screening and assessment interview, and/or later should subsequent reactions occur. Prior to data collection, therefore, discussions will take place with as many clinicians who work with BPD patients as possible. This is because, should participants experience difficulties, it is important they should be able to speak to a clinician whom they already have a therapeutic relationship with and have built up trust and confidence.

Patients must have effective contact information so that they can speak to their clinician or contact the clinic in an emergency. This is important, as it is possible that any discussions concerning trauma, particular for the first time, could trigger

traumatic memories that could cause great patient distress and even trigger flashbacks and/or nightmares. For this reason, complete familiarity with Trust Safeguarding Procedures (APPENDIX 19 ) is essential, through attendance at sufficient training courses and workshops. Access to safeguarding procedures must also be very clearly annotated as part of a Patient Information Sheet and this clause must be read to each patient prior to obtaining their written consent to be interviewed (APPENDIX 6), in order to ensure that patients are fully involved in any discussions of the action to be taken if abuse accusations are made.

Patients' clinicians will also be made aware of this clause and of the appropriate sections of the Trust procedures. To this end, the essential elements of the safeguarding procedures will be explicitly reproduced within the Patient Information Sheet and the (BTERS) screen itself. As an additional support for patients' clinicians, the researcher will be also available to assist in dealing with any and all distress generated by the assessment as and when it arises, so as not to impinge on clinical services. At all stages the researcher is backed by the project Steering group (section 3.11.2) and clinical supervisor. The screening instrument will not ask participants to identify past abusers, only to record the broad nature of their relationship with an abuser (i.e., stranger, friend, relative, parent or sibling). This is because information on the relationship with the abuser is required to differentiate between different types of abusive events associated with BPD and CPTSD. Participants will also be informed (Patient Information Sheet) that any information provided will have to be shared with clinical staff if there are any safeguarding and protection issues. Any information that gives concern regarding the safety of the participant or other people in the community must be raised with the Trust Safeguard Lead, and then with the Local Authority Safeguarding Team, which will log all relevant information as reported by the clinician. This will be done with or without the participant's permission, as there could be risk to other individuals. In addition, there is the possibility that participants could disclose information to someone else and claim that they had informed the clinician and that the authorities had failed to act on the information.

### **3.6.2 Grounding Techniques for Intense Anxiety**

Prior to starting potentially distressing discussions with patients (stage 2), it is important to obtain assurance as to the protection systems in place for

participants. These should include what are called 'grounding strategies', which are a set of simple strategies to help patients detach from emotional pain (such as anger, frustration, distress, cravings etc.) and to manage overwhelming feelings of intense anxiety (van der Kolk, 1996). These techniques will be discussed with patients at the beginning of (stage 2) screening.

### **3.6.3 Impact on Interviewers (Vicarious Traumatization)**

All research activity must also consider any adverse impact not only on the direct research participants (who can be considered as 'subjects' in the context of this research) but also on the research personnel themselves. This risk becomes particularly significant when interviewers are engaged in discussions about traumatic situations with vulnerable and potentially volatile patients. In this research, the greatest exposure to this risk will be the stage 2 screening process where interviewers have to assist volunteer patients to recall difficult traumatic experiences. The term applied to this situation is vicarious traumatization. Vicarious trauma is the negative change in one's thoughts, perception and interpretations as a result of repeated engagement with traumatic research-related materials and experiences (Sexual Violence Research Initiative, SVI, internet reference, not dated). Vicarious trauma is often difficult to recognise; symptoms may include feelings of anger, anxiety, depression, sadness, exhaustion, difficulty in concentrating and making decisions, headaches, body aches, sleeplessness, increase in drug and alcohol use and social isolation. For services and professionals to remain effective and to get the best possible outcomes for patients it is essential to make sure that practitioners have access to the help and support that they need to protect themselves (NSPCC, 2013). It will therefore be important to address the possibility that both the researcher and the clinicians who have volunteered to administer trauma screening may experience vicarious trauma. This will include acknowledging how emotionally difficult and sensitive trauma research can be, and each interviewer must be made aware of how they could be affected by distress. Recognising the importance of self-care and learning how to self-identify vicarious symptoms early are key in the management of vicarious trauma (SVI). To this end, a discussion with the clinicians will be arranged to familiarise the clinicians with vicarious traumatization and ways to recognise and prevent it.



The strategy to prevent and manage vicarious traumatisation will include the following: first, there will be adequate levels of managerial support or rigorous supervision and peer support (NSPCC, 2013). Then, for serious traumatic events, there would be a chance for the clinician involved to be fully debriefed. Finally, as exposure to trauma increases, there is an increasing likelihood that it could further negatively affect clinicians. Therefore, it is important to create the right working environment with strategies to improve clinicians' resilience and help them stay emotionally healthy by preventing them from becoming isolated from their teams (NSPCC, 2013).

### **3.7 Validity of the Research Design**

While no research design is perfect, all designs require a validation process to guide assessment of the design's effectiveness and to strengthen the overall research design (Campbell and Stanley, 1963). Internal validity means that the resultant research data can be shown to support the research concept (Campbell and Stanley, 1963). In the case of the current project, internal validity will be established when the methodology can be shown to validate the four hypotheses, according to statistically acceptable standards. External validity refers to a study being generalisable outside the research parameter results, and in the context of this research, it is not necessary to distinguish external validity from what can also be called construct validity (Shadish, Cook and Campbell, 2002, p.467 and Table 3.5).

This is because Construct Validity is the degree to which the instrument performs consistently in measuring what it claims to measure (Hardesty and Bearden, 2004). There are various structural ways to achieve a strong design, principally by controlling any threats to validity. Although there are inevitable compromises, if validity threats are not addressed in the design process, there is a risk that the threats may be confounded (Campbell and Stanley, 1963).

In any clinical trial, bias is one of the main threats to overall research validity. Bias may be defined as a systematic error or difference between the true value and that actually obtained due to all causes other than sampling variability (Friedman *et al.*, 2010). Depending on the type of bias, it can apply to internal or external validity (3.7.2, 3.7.3). Bias describes errors at any stage of a study that are not due

to chance, from the initial design through to data analysis and interpretation (Friedman *et al.*, 2010). Bias therefore cannot be effectively measured or controlled statistically, and can lead to a result in which there is a systematic deviation from the truth (Gosall and Gosall, 2009, p.34). It can be caused by conscious factors, subconscious factors or both (Gosall and Gosall, 2009). Types of bias range from the selection of participants, performance and observation, all the way through to the reporting of results (Campbell and Stanley, 1963; Bartlett, 2005). In particular, the analysis of qualitative data can be subjective, so mechanisms are included in the design to address this issue. Campbell and Stanley (1963) identified a number of areas of possible threat to research design validity. These may have particular relevance for the stage 2 trial, which included an important test-retest element, and threats are listed below with relevant examples, where a summary of the most important bias and proposed mitigations is tabulated followed by a more detailed review. These are arranged by the different stages of the research and are divided in internal validity threats and external validity threats. Table 3-4 below lists threats and mitigations for each of the major elements of the research design.

The following three types of validity capture the full range of validity that are required for instrument development: Face Validity; Content Validity and Construct Validity (Gosall and Gosall, 2009). If any of the various forms of validity are low, the overall validity of the conclusion of will be suspect (Black, 2005). Content and Face validity have often been used interchangeably even though there is an important conceptual difference (Gosall and Gosall, 2009; Black, 2005). Face validity concerns the appearance and usability of the instrument, whereas Content validity ensures that the instrument measures what it is supposed to measure. Face validity is necessary because inferences are made on the basis of final items of a screen, and therefore they must be deemed to be (face) valid if we are to have confidence in any inferences made from the final screen form (Hardesty and Bearden, 2004). Nunnally and Bernstein (1994) described content validity as the degree to which an instrument measured items represent a proper sample of the theoretical content domain of a construct.

**Table 3-4 Threats, Bias and Mitigations**

<b>Stages</b>	<b>Validity Threats/Bias: I - internal; E - External</b>	<b>Mitigations</b>
Stage 1: Medical Records	I: Selection/ Admission/ Recruitment	Accept all patients who consent from all Trust BPD hospitals. Create welcoming approach through ward presentations and group discussions.
	I: Attrition Bias due to stress	Analyse dropout causes and adjust recruitment. Consider impact of dropout during interpretation.
	E: Performance Bias, Expectancy Threat, Data Analysis Bias	Include study tool for consistent interpretations (interpretation protocol). Critical reviews/ peer group presentations Supervisor support.
	E: Observation Bias (favouring expected outcomes)	Compare results with empirical studies. Peer group presentations/ Steering Group reviews.
	E: Sample size	Quantify accuracy/reliability/ confidence intervals. Compare with empirical studies.
Stage 1: Clinician Interviews	I: Selection/ Admission/ Recruitment	Invite all clinicians and managers to participate.
	E: Performance Bias, Expectancy Threat, Data Analysis Bias	Playback results to participants. Rigorous 'Grounding Study'. Steering committee supervision.
Stage 2: Screening Study	I: Selection/ Admission/ Recruitment	Check if BPD patients in selected hospital are representative of general population.
	I: Attrition Bias due to stress	Analyse dropout causes and adjust recruitment. Consider impact of dropout during interpretation.
	I: Interviewer/ Researcher Bias, Pre- research Bias	Blinded inter-rater assessor.
	I: Data Analysis Bias	Test-retest, blinded inter-rater.
	E: Performance Bias, Expectancy Threat, Data Analysis Bias	Pilot reliability study. Face and content validity analysis. Scoring sheets. Test-retest, blinded inter-rater.
	E: Observation Bias (favouring expected outcomes)	Compare results with stage 1 and empirical studies. Peer group presentations/ Steering Group reviews.
	E: Sample size	Quantify accuracy/reliability/ confidence intervals. Compare with stage 1 and empirical studies.

### 3.7.1 Application of Validity to Screen Development

#### Explanation of Face and Content validity:

By way of example, a depression scale may lack content validity if it only assesses the affective dimensions of depression, but fails to take into account the behaviour dimensions (Black, 2005, p.193). One helpful way to distinguish between face and content validity is to picture the domains of a construct as a dartboard (Gosall and Gosall, 2009; Black, 2005). In order for the criterion of content validity to be established, darts must land all over the board to obtain a proper representation of the construct. If darts land on only the left hand side of the board (i.e. items measure only half of the domain of a construct), the measurement will not be content valid. Also if items are generated that are too similar and do not tap the full domain of the construct (i.e., cover the dartboard), content validity is not established. Using the dartboard analogy, an item has face validity if it actually hits the dartboard.

**Table 3-5 Validity of Instrument Development**

<b>Validity Types</b>	<b>Relevance to a diagnostic/screening instrument</b>	<b>Synthesised from refs:</b>
Face Validity	<ul style="list-style-type: none"> <li>i. The degree to which clinicians and patients judge that the questions are appropriate to the target Construct and the screening objectives</li> <li>ii. Items must 'hit the dartboard'</li> <li>iii. Predominantly a form of usability: simple, safe, and precise questions</li> <li>iv. Appearance and usability of the questionnaire in terms of feasibility, consistency of style, layout, formatting, font design and size and clarity of language</li> <li>v. Face can also include an assessment of External validity.</li> </ul>	Hardesty and Bearden, 2004
Content Validity	<ul style="list-style-type: none"> <li>i. Refers to how well the set of questions represents what content (or subject matter) the instrument is supposed to be testing</li> <li>ii. The content of the instrument must contain appropriate and sufficient clinical detail to measure all the Domains of the construct</li> <li>iii. The degree to which measured items represent a proper sample of theoretical content domain of a construct</li> <li>iv. Details must be relevant to the purpose</li> <li>v. It should contain a complete range of all the attributes of the construct</li> <li>vi. Must annotate the various traumatic events using proven techniques from PTSD/ CPTSD practice.</li> </ul>	Nasrin, 2009 Nurmally and Berstein, 1994 Allen, 1997 Anastasi, 1988 Nevo, 1985 Black, 2005
Construct Validity	<ul style="list-style-type: none"> <li>i. The degree to which the instrument performs consistently in measuring what it claims to measure</li> <li>ii. Provide reliable and repeatable results and ensure quality control</li> <li>iii. Construct Validity is also referred to as Test Performance.</li> </ul>	

### 3.7.2 Threats to Internal Validity

Selection bias is the identification and recruitment of an unrepresentative sample from the population, which results from the way in which subjects were chosen (Gosall and Gosall 2009; Bartlett, 2005, p.75). Such bias can be introduced by the researcher's selection of participants, or by third parties such as clinicians with vested interests in the research outcome. A particular version of selection bias can be labelled as *Admission Bias*, where a research programme can be limited to patients admitted to one particular institution without consideration of whether the sample is representative of the population; this is called a Berkson bias (Gosall and Gosall, 2009). This can lead to a result in which there is a systematic deviation from the truth. In a more general sense, it could also be called a *Convenience Sample* where respondents were chosen because of convenience and availability (Creswell, 2003). The selected sample has to be representative of the population, in this case patients with BPD symptomatology. The sample also has to comply with the strict ethical requirements set by health authorities for vulnerable patients, and such requirements may have other implications in terms of time limitations. To mitigate selection bias for stage 2, clinicians, not the researcher, will identify the patients. However, as clinicians are aware of the research objectives, selection bias cannot be totally excluded.

Threats to internal validity could occur if the content of a testing instrument is changed during the testing process, generating inconsistencies and misleading performance data. Similar inconsistencies can occur if changes are made to the calibration of measuring instruments.

Other threats to internal validity include attrition threats and performance bias. Attrition is the loss of study participants in the course of the testing period can undermine the accuracy of the results, as participants will be allowed to exclude themselves at any stage because of the stresses involved in addressing historical traumatic experiences.

Internal validity may suffer because of a poorly designed survey assessment protocol (study tool), or poorly designed questionnaires for clinicians or patients (screening instrument). To avoid this, the context created by written questions must be made clear and well defined. Also, the impact on how individual questions

are interpreted and answered will be enhanced by providing interesting questions to help reduce measurement error, and by encouraging respondents to answer questions carefully and to take the request for their participation seriously. In addition it is very important to ensure there are no leading or trigger questions (Schutt, 2011). Supervisors and Steering Group (section 3.11.2) support will be sought in devising all research documents.

### **3.7.3 Threats to External Validity**

1. **Expectancy Effect Threats:** In stage 2 participants may answer questions in a way that they believe the researcher wants them to, rather than according to their true beliefs. In this project, ethical considerations will require that prospective participants are familiar with the research objectives and expectations, and consequently participants' response may be unduly influenced by the research objectives. Similarly, if participants consider that certain responses could result in greater personal benefits such as extra attention, then outcomes may be invalid.
2. **Leakage between Participants Threat:** When participants are co-located where the research takes place, there is a concern that, in order to increase solidarity and empathy, participants may discuss the research amongst themselves, and agree responses to research questions before a testing process.
3. **Sample Size:** Reliability and accuracy are important for external validity, and can be compromised by an inadequate sample size. However, the selection of the samples must comply with practical and ethical considerations. For the quantitative analysis in both stage 1 and 2, the validity of a sample size can be tested by calculating confidence intervals for each of the results and then by comparing these results with the results of reliable clinical studies. If no comparison is available for qualitative methods, it is generally considered that the optimum sample size has been reached when no new themes arise in emerging data. That is, saturation occurs, a theme appears and no further insight can be gained from the data (Sayre, 2001).

A number of different types of bias can also impact on external validity. For example, an observation bias in this research would be the failure to classify

outcomes correctly, whether in the assignment of disorders, or the correct representation of clinician views. Such a bias can be caused either by the investigator (stages 1 and 2), or the participant(s) as in stage 2. This is particularly important when there is a large interpretist or subjective element to the analysis of research data (Karanicolas, Farrokhyar and Bhandari, 2010). Therefore a specialist checklist for trials such as Consolidated Standards of Reporting Trials (CONSORT, Moher, Schulz and Altman, 2001; or Standards for the Reporting of Diagnostic accuracy studies (STARD, Bossuyt *et al.*, 2000) can be used to maintain transparency.

Researcher, interviewer or ascertainment bias arises when the investigator has a vested interest in a positive outcome and can alter the approach to the patient (stage 2) and the recording of results (stages 1 and 2). In any analysis there is always a risk of selective use and reporting of qualitative and statistical tests, which may be a subconscious response by investigators eager to see a positive result, but which can have profound consequences. Common method bias can occur if the same investigator provides all the interpretations for all stages of a research project (Curry, Nembhard and Bradley, 2009). Recall bias can arise for stage 2 if participants selectively remember past details (retrospective memory) if they have a particular interest in the outcome. Similarly, response bias can arise in any study in which participants are asked questions and they answer in the way that they believe the researcher wants them to rather than according to their true beliefs. This can occur when it is not possible to blind participants to the research objectives for ethical reasons. In the case of the clinician interviews, it may prove problematic to fully articulate the subtleties and sensitivities of the research scope to all participants.

### **3.8 Mitigations for Threats to Validity**

In order to have confidence in the research results, how can threats to research design validity, both internal and external, be mitigated? Whereas it is not always possible to have full control of all threats, structured actions or mitigations must be put in place to minimise the impact of all threats on the validity of the research design. So what types of mitigation should be considered? For alternative methods such as reliability studies, other mitigations are required. In addition, as no



mitigations are ever completely effective, all weaknesses in the mitigations applied must be discussed and accounted for. The analysis will also be presented and discussed with the Steering Group (section 3.11.2), which includes members who are experienced in the topics that are being examined and in constant comparison methodology.

### **3.8.1 Blinding**

In research design, blinding is one of the most effective methods of counteracting bias. Blinding is a technique that keeps participants and investigators involved in the research blinded or masked from the processes of the research, so that their actions are not unduly influenced by anticipated outcomes (Karanicolas, Farrokhyar and Bhandari, 2010). Blinding can be addressed at different levels. Single blinding is usually used in situations in which the patient is unaware of the investigation he or she will be participating in. Double blinding is where both patient and investigator are kept blind to the intervention (Karanicolas, Farrokhyar and Bhandari, 2010). Blinded investigators are much less likely to transfer their attitudes to participants than un-blinded investigators (Karanicolas, Farrokhyar and Bhandari, 2010). In this research, blinding will be considered in the second stage to reduce confirmation bias where a comparison will be made between different assessments. It is however important to ensure that the blinding process itself does not introduce additional problems by impairing the ability to evaluate research outcomes effectively, for example when critical feedback is required following pilot studies. Ensuring that all patient information is made anonymous may also assist the blinding process when analysing data (Karanicolas, Farrokhyar and Bhandari, 2010). Nevertheless for ethical reasons clinicians may object to blinding during data collection; for example to protect participants' health, safety and security, it may become necessary to inform investigators about critical clinical diagnoses of particular patients, and thus either compromise the blinding process or cause particular tests to be excluded from the results (Freidman *et al.*, 2010, p.128).

The effectiveness of blinding can be tested by asking outcome assessors which outcome (disorder in this case) they think was assigned. Thus to check the effectiveness of blinding in the BTERS reliability study, a blinded screener will

make a statistical comparison of the screening results of the researcher, who should be unaware of the outcome of the full assessment.

### **3.8.2 Attrition Mitigations**

If a limited sample size is anticipated, one of the threats to maintaining a large enough sample is that too many patient participants drop out due to anxieties (attrition). To mitigate this particular risk for both stage 1 and 2, participants will be given assurances regarding any anticipated negative effects. In addition, aiming to complete all assessments soon after screening can minimise anxiety. Other mitigations for reducing participant anxiety is to minimise the total period over which sensitive issues are discussed by completing the study quickly and dealing quickly with any concerns as they appear. Additional methods to reduce anxiety include joining treatment groups where participants can obtain reassurance and build some trust and confidence should they find the process stressful. Large sample sizes however do not reduce bias although they have other benefits for enhancing validity, such as improving precision (Friedman *et al.*, 2010).

### **3.8.3 Researcher Bias Mitigations**

In order to identify and isolate potential researcher bias and expectations *bracketing* can be applied where the researcher tries to remain open-minded and to consider the perspective of participants by reviewing progress with supervisors and groups (Bound, 2011). Another technique to address researcher bias is to reassess results using independent experts to try to assure objectivity. In addition, a comparison will be made between research results and relevant findings from literature.

### **3.8.4 Other Mitigations**

The Constant Comparison method increases internal validity by describing and conceptualising the variety of views on trauma within BPD, comparing and looking for commonalities and differences in behaviour, reasons, attitudes, perspectives etc. In addition, assuming a reasonably homogeneous sample of practitioners, external validity is enhanced by providing a solid basis for generalising the results from patients' medical records to other BPD units by using ideas developed during the clinician interviews.

Another method to increase external validity is to obtain high statistical reliability, which can be achieved by a number of techniques including a pilot study, and quantifying repeatability by retesting with independent assessors. Threats to external validity can also be partially offset by comparisons with similar studies from the literature. Inevitably, however, as with any research, some residual threats will always remain to the overall validity, and these must be addressed in the final discussions, conclusions and recommendations.

### **3.9 Target Group and Recruitment**

As the ultimate aim of the research is to make an improvement to the diagnosis and treatment for all BPD patients worldwide, it would be ideal if there were no theoretical limit to the target group. However, in line with the design philosophy to verify findings by practical assessment, a target group must be limited to those patients and clinicians accessible by the researcher and supporting clinicians, which in turn restricts the pool of patients to specialist mental healthcare units. In addition, the practicalities of ethical approval could limit the opportunity to examine BPD patients' medical records and interview practising clinicians (stage 1) to a single NHS Trust. As the subsequent (stage 2) BTERS reliability study requires close collaboration between hospital clinicians and the researcher, restricting the trial to a single hospital ensures that the analysis of results benefits from consistency in clinical assessment policy. This also provides a sample size consistent with similar studies from literature. In both stage 1 and stage 2, the entire target group can be included in the study, thus providing what can be termed an *open trial*, although the grouping could alternatively be termed a *convenience sample* (Trochim, 2008).

For the stage 1 survey of medical records, both outpatient and inpatients can be asked by their attending psychiatric consultants for permission to be contacted about the study. Prior to contacting participants individually, presentations will be given to relevant clinicians to explain the study and the ethical approval process. Outpatients will be given presentations in their group sessions and inpatients will be seen individually by their clinicians. Any patient who shows willingness to participate will require a discussion with their clinicians for the clinicians' permission and to assess their eligibility to be recruited into the research. Willing

participants will then be seen by the researcher and informed consent obtained. For stage 1, a poster will be placed in all BPD outpatient clinics and wards, requesting people who are interested in participating in the research study to contact their clinicians and the researcher.

### **3.10 Data Analysis**

Data will be analysed from every stage of the research. A study tool will first be designed to collect relevant psychological attributes from patients' medical records according to DSM criteria. From this, interpretations of trauma, BPD, PTSD and CPTSD, can be made, and the frequencies of trauma and the disorders can then be calculated as well as comorbidity rates and treatments provided. From these results, frequency comparisons can be made with similar studies in the literature. Frequencies can then be compared graphically and in tabular form for presentation to clinicians. Questions for the qualitative semi-structured interviews with clinicians about different possible meanings concerning the recognition of trauma in BPD will be developed based on the findings of the survey of patients' records. The results of subsequent open-ended questions for clinicians will then be collated by triangulation as patterns appear in the interviewing process, in keeping with the interpretist method (Polit, Beck and Hungler, 2001, p.381). A 'constant comparative analysis' is thus applied by inducing individual interpretations from participants and comparing results of different interviews while editing, analysing and interpreting relevant information (Glaser and Strauss, 1967). In order to give the interview results internal validity, additional peer reviews will be conducted with the Steering group (section 3.11.2).

As part of the pilot study, the internal validity of the BTERS screen will be assessed by capturing the views of the participants (i.e. clinicians, subject matter experts and patients) on the appropriateness of the questions used to identify trauma and discern BPD, PTSD and CPTSD. From this, an internal consistency index can then be calculated using Cronbach's alpha where  $\alpha$  increases as the inter-correlations between the disorders increase. In addition, the pilot test results comparing the BTERS disorder assignment (PTSD or CPTSD) with gold standards can be analysed by calculating reliability and accuracy. A one-to-one comparison between the BTERS results and the gold standard assessments will be made with reliability and

accuracy rates calculated, including the use of area under the receiver operating characteristics curve (AUC, ROC, section 5.10). Reliability will be calculated with inter-rater and test-retest techniques by calculating Cohen's kappa coefficients.

### **3.10.1 Qualitative Software vs. Manual Analysis**

For the qualitative data analysis, software such as Computerised Assisted Qualitative Data Analysis (CAQDAS) can be utilised. This can provide discipline in logging data, coding patterns, and mapping categories. It can also render the various stages of a qualitative process more traceable and transparent, facilitating an audit trail. On the other hand, over-reliance on software can detract from the conceptual meaning, losing closeness to the data such as contexts, tones and emotions (Burton, 2000). For this reason, because of the risk of missing details of conceptual analysis, manual methodology will be utilised.

## **3.11 Quality Control**

Integral with every aspect of this project, overall quality will be controlled and assurance confirmed by adopting systematic methodologies that have been shown to be suitable. The following are considered:

### **3.11.1 QUADAS**

The development of the screening instrument will be adapted from the assurance system described in QUADAS (Quality Assessment of Diagnostic Accuracy Studies, Whiting *et al.*, 2003). The QUADAS process was selected because it is used by recognised experts in analysing the reporting of diagnostic studies (Streiner and Norman, 2012; Jaded *et al.*, 1996). It combines empirical evidence and expert opinion in a formal consensus method. The proposed stages (A-E) which were adapted from QUADAS will be applied directly to develop a trauma screening instrument as follows:

- A. Conceptual decision – screening instrument design and population selection for testing
- B. Generation of Items relating to both causes and symptoms of each of the disorders
- C. Assessment of Face validity and Content validity
- D. Pilot trial and refined instrument

## E. Field trial to assess consistency and Construct validity

**3.11.2 Steering Group**

The Steering Group will be set up in order to provide advice on research aims, methodology and the impartial interpretation of data. It will consist of clinicians, researchers and supervisors with a full variety of clinical interests, which will provide regular critical reviews.

This included the academic supervisor of this research, the clinical supervisor of the research who is also the former head of the Trust Trauma Centre, and the clinical director of the principal BPD Centre in Berkshire. Below is the list of the Steering Group members:

DT	Researcher
Professor NW	Supervisor, BPD and PTSD clinician and academic
NP	Clinician specialising in BPD
Professor SR	Academic and clinician CPTSD specialist, Clinical supervisor
Dr SM	Mental Health clinician. Nurse consultant
Professor GB	Mental health lecturer and clinician
Dr RH	Consultant psychiatrist, and psychotherapist (BPD specialist)
Dr DL	PTSD specialist Consultant clinical psychologist

Full Terms of Reference are given in APPENDIX 4 , and enhancements to the scope of the Steering Group will be made whenever required to meet the full objectives of the Project.

The group should form an important mitigation against many of the threats to research validity, as identified in section 3.7.2.

**3.11.3 STARD**

In this Project a 25 item quality checklist (STARD; Statement of Reporting Studies of Diagnostic Accuracy) will be applied (Bossuyt *et al.*, 2000, and APPENDIX 29 ).

### **3.12 Research Design Conclusions**

The main research question is to be addressed via four research sub questions and hypotheses concerning the relation between trauma and BPD, a mixed method design approach was chosen with two sequentially connected stages. The rationale for this selection requires both post positivistic and interpretist paradigms, allowing BPD clinicians the freedom to feed back their own interpretations of a quantitative survey of patients' records, where recorded trauma and BPD symptoms are correlated against DSM diagnostic criteria and the results of relevant empirical studies from literature. The results of qualitative questionnaires and interviews with clinicians will then be analysed using grounded theory, so that key information can emerge in order to inform and develop a new trauma-screening instrument (BTERS) for patients with BPD symptomatology. Stage 1 thus will consist of a survey of patients' records plus a sequential analysis of clinician interviews. Stage 2 will thus build on the stage 1 findings in order to develop BTERS, validating BTERS by interviewing BPD patients who have not been previously screened for trauma, where correlations can be made between the results of BTERS screening against full assessments for PTSD/CPTSD using gold (DSM) standards. A pilot study will first address validity concerns, and BTERS will be refined before the main screening study.

A number of threats to overall design validity have been recognised and have been analysed in terms of types of bias. Threats include restricted sample size, the potential for researcher bias, responder bias, as well performance and observation bias during the data collection and analysis process. As clinical practicalities limit the options to expand participant numbers, sample mitigations rely on a rigorous controlled selection process. Accuracy can then be carefully quantified and maximum use made of comparisons with similar studies. Blinding will be incorporated as much as possible to mitigate research bias; however ethical requirements reduce the opportunities to fully blind both patient and clinician participants to the research objectives and the consequences of the assessments. Also of importance to an effective design is the inclusion of a comprehensive range of critical statistical analysis.

**Table 3-6 Design Conclusions**

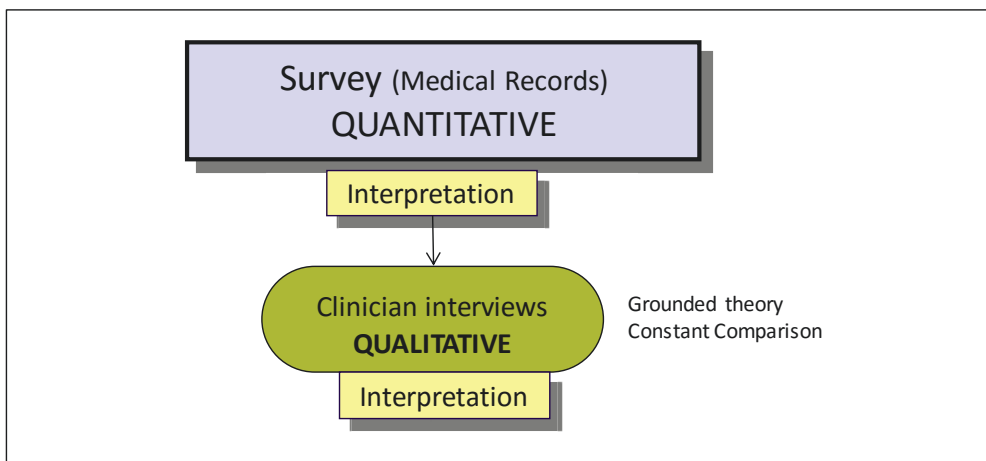
<b>No</b>	<b>Research Sub Questions</b>	<b>How the Design addresses the Sub Questions</b>
1	What is the proportion of BPD patients who have experienced traumatic stressors and what are the types of stressors?	Quantify proportions from stage <b>1</b> survey. Qualify stressor types and diagnosis reasons from clinician interviews.  Repeat and crosscheck in stage <b>2</b> using
2	What is the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis	BTERS and gold standards. Compare stage <b>1</b> and <b>2</b> results with empirical studies.
3	What is the extent or otherwise of BPD over-diagnosis or misdiagnosis?	Quantify BPD DMS criteria from stage <b>1</b> survey. Qualify using clinician interviews. Compare with empirical studies.
4	Will a screening instrument reliably and sensitively discriminate BPD patients for trauma focused treatment?	Design (stage <b>2</b> ) screen from literature and clinician interviews about stage <b>1</b> results. Check reliability/validity/sensitivity by comparison with gold standards. Compare results with empirical studies.



## 4 METHODOLOGY: STAGE 1, MEDICAL RECORDS & CLINICIAN INTERVIEWS

### 4.1 Introduction

This chapter develops the first stage of the research project in accordance with the research design, addressing the first three of the four sub questions and associated hypotheses. The principal feature is a survey of medical records of (N=68) BPD patients in a single NHS Trust over a period of one year for evidence of traumatic experiences and PTSD/CPTSD. This stage consists of two parts, a quantitative survey of BPD patients' notes, followed by a qualitative analysis of BPD clinicians' views of the results.



**Figure 4-1 Stage 1 Methodology**

As indicated above, the quantitative methodology chosen is first described, along with the mitigations against the identified threats to the design validity. Specific objectives for the survey are first established in accordance with three of the four overall objectives as shown below.

**Table 4-1 Objectives of Quantitative Review**

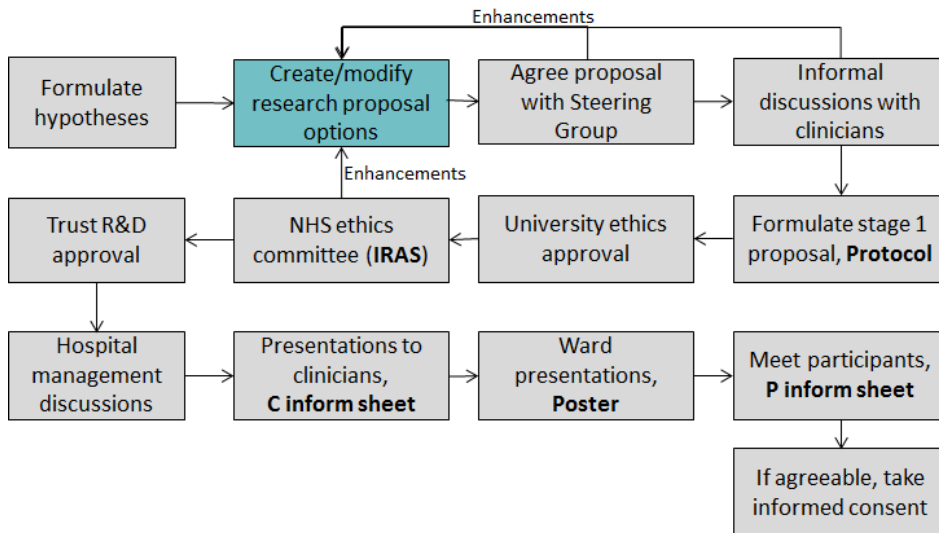
No	Objective	Hypothesis	Objectives of Quantitative Survey
1	Quantify and qualify the proportion of BPD patients who have experienced traumatic stressors	A high proportion of BPD patients have had at least one highly distressing traumatic experience, either life threatening or non-life threatening	Identify any trauma recorded and its frequencies
2	Quantify and qualify the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis	A high proportion of patients diagnosed with BPD also meet a comorbid diagnosis of PTSD and/or CPTSD/DESNOS	% of BPD patients with comorbid PTDS/CPTSD and standard deviation
3	Establish the extent of BPD over-diagnosis or misdiagnosis	BPD is over-diagnosed (or misdiagnosed) in patients in mental health care	Identify information on which current diagnoses were based. Interrelation between variables (e.g., DSM diagnostic criteria) and assigned clinical diagnosis

This survey interrogated BPD patients' records to map current practice for diagnosing BPD, and to obtain support information relevant to BPD, trauma, PTSD and CPTSD, and the assessment of trauma. The results of the survey were then analysed and compared with the relevant empirical studies obtained in the literature review. The detailed methodology for the qualitative part of the stage 1 design is then presented, where BPD clinicians are asked for interactive feedback on the results of the survey and their comments are collated and compared in accordance with the research design. Finally, the validity of both quantitative and qualitative results is considered in terms of the identified threats and research bias. Relevant supplementary information was also obtained during the review. This included the frequency of the different assessment instruments used, the

variability of the results against demographics, clinical history, types of treatments received by the patients, and a comparison with hospital from previous years.

**4.2 Patients’ Medical Records Survey Methodology**

Figure 4-2 Recruitment Process shown the overall process flow followed to obtain participants.



**Figure 4-2 Recruitment Process**

In order to ensure a sound clinical and academic approach to a potentially sensitive subject, a series of professional discussions were held with academics and operational clinical professionals. Initially the results were reviewed with the Research Project Steering Committee (APPENDIX 4 ). During these discussions, questions that were considered included how and when to differentiate between BPD and CPTSD, and what is the optimum time to make this selection. Also of importance was to consider the effectiveness of PTSD and CPTSD treatment in the event that an increased number of referrals are made. To aid these discussions, a brief review of historical discharge records (APPENDIX 9 ) showed that approximately 14% of patients discharged had a BPD diagnosis, confirming the overall significance of the disorder in the NHS Trust. The next requirement was a review and approval of the research ethics by the university Ethics Committee. Before any discussions with hospital authorities, approval from NHS ethics was obtained (APPENDIX 10 ). The main outcome of the ethical approval process was the requirement to obtain prior informed consent of patients to have their records

included in the survey. The next step was to obtain R&D approval from the Healthcare Foundation Trust for all three principal hospitals containing units which treat BPD (APPENDIX 12 ). The approval process began in September 2009 and was completed in June 2010. At this stage, all Trust BPD consultants were contacted by e-mail, followed by face-to-face meetings with four consultants from the largest (Prospect Park) hospital, two from Heatherwood hospital and two from Wexham Park hospital. Each consultant was issued with a *Clinician Information Sheet* and a Project Protocol and the objectives of the project and agreed ethics were discussed (APPENDIX 7 , APPENDIX 5 ). Then, with consultant support, participant recruitment posters were placed in the three hospitals (APPENDIX 8 ). Depending on individual involvement in different cases, and often the personal preferences of particular consultants, follow-up meetings took place on several occasions.

Discussions then commenced with hospital BPD clinicians. On several occasions, the researcher was invited to take part in ward meetings and group treatment sessions with patients, where the research process was discussed. Over the period from October 2010 to April 2011 a number of formal and informal presentations were made to both clinician-only and to joint clinician/patient groups in all three hospitals. These presentations covered the substance of the Protocol, the Clinician and Patient information sheets, and all presentations included active question and answer sessions that were well received by hospital authorities, clinicians and patients. In all, over 10 such presentations were delivered. Based on discussions with clinicians, the full range (both inpatient and outpatients) of BPD patients in all of the trust (3) hospitals – Prospect Park, Heatherwood and Wrexham Park – was established, giving a total of 77 patients. This number compares well with the total of BPD patients discharged from the same institutions in the period from June 2008 to May 2009.

Medical records of all admissions in the psychiatric departments were first screened against the inclusion criteria (listed below) by the relevant clinicians who agreed to participate.

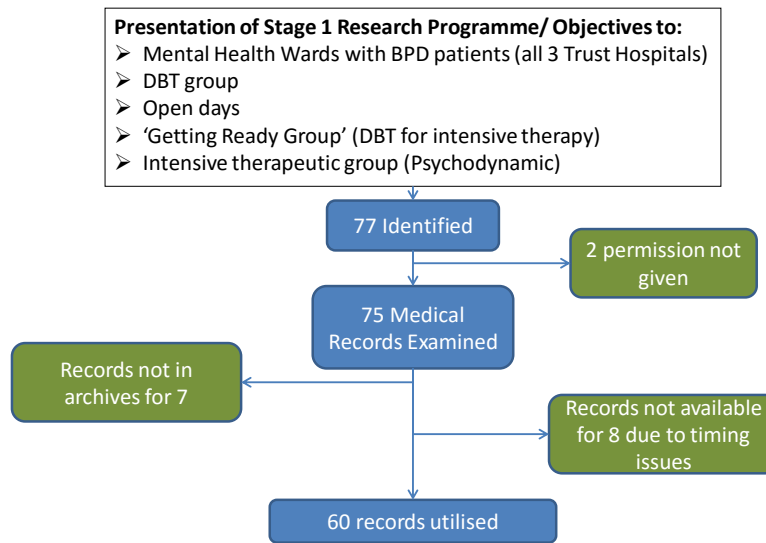
**Inclusion criteria**

- All potential participants must have the diagnosis of BPD, and they must know and understand their diagnosis
- Age between 18 and 65 years old
- Able to give informed consent to participate in the study
- Must have a good command and understanding of the English language

**Exclusion Criteria**

- Currently acutely disturbed / psychotic
- Unable to give informed consent.

Potential participants who met the criteria were then approached by the healthcare team. This was done by informal discussion about the research project and about how they could help. The method for obtaining patient agreement was in accordance with the Ethical Procedures specified within the agreed Research Protocol. Of this complete dataset of 77 patients, nobody needed to be excluded on grounds of age or understanding of English, and only two patients did not give permission for their medical records to be examined. However, it was not readily possible to obtain complete records for eight of the patients (due mainly to time constraints), resulting in a usable dataset of 68, or 88% of potential participants. Seven medical records were not available in the archives, further reducing the database to 60. A summary of the exclusions made is given in Figure 4-3 below. As no adult patient was excluded by the researcher, this eliminated the potential for selection bias.



**Figure 4-3 Stage 1 Recruitment**

Overall, a substantial proportion (approximately 60%) of the medical records from all of the three relevant hospitals of all patients diagnosed with BPD was examined to extract relevant information. The medical records were investigated using a specially developed Study Tool designed by the researcher (APPENDIX 13 ). This tool records relevant medical and demographic information from BPD patient records.

#### 4.2.1 Sample Frame

The 77 BPD patients' records considered in this research represents almost the entire BPD population of one NHS Foundation Trust. As a crosscheck, the Trust Annual Report for 2014-2015 shown annual BPD new interventions of 109 (Berkshire Healthcare NHS Foundation Trust, 2013-2014). The Berkshire NHS Trust is one out of 46 UK Mental Health Trusts, 1.7% of the English population. The English annual BPD (ICD-F60) admissions for 2008-2009 was 6,370, 1.7% of which (107) can be compared with the Trust mental health admission rate (HSCIC, 2007-2008). Like many English NHS Trusts, Berkshire includes both rural and urban areas, and is not untypical for the UK.

### 4.3 Results of Patients' Records Survey

#### 4.3.1 Demographics

The average age of participants was 37, with a range from 19 to 67, and a standard deviation of 11. Additional tests were conducted to see if there was any significant variation in age for any of the conditions and no significant variation was noted. 9% (N=6) were men which can be compared to 30% of national BPD admissions (HSCIC, 2007-2008). 91% were white with 5 patients of Indian origin and only one of Afro Caribbean origin. Whereas the samples are representative of the UK as whole (87% white), the percentage of white patients in the survey is higher than the white population in Berkshire (74%). Based on clinician diagnosis in the medical records, 4% (N=3) of patients were assigned a comorbid trauma related Axis II diagnosis (Figure 4-4 Primary Clinical Diagnosis of Participants).

#### 4.3.2 Clinician's Diagnoses

(Percentages rounded to whole number)

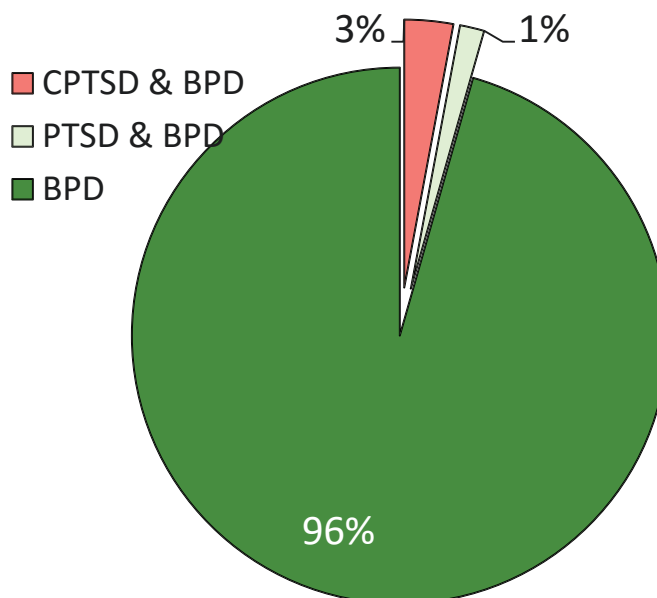


Figure 4-4 Primary Clinical Diagnosis of Participants

It should be noted, however, that of the three<sup>1</sup> patients assigned by their clinicians a comorbid PTSD or CPTSD diagnosis in their records, only one met DSM criteria. An additional observation was that once a diagnosis was recorded, it was rare that a reassessment was made for the diagnosis.

### 4.3.3 Recorded Symptoms

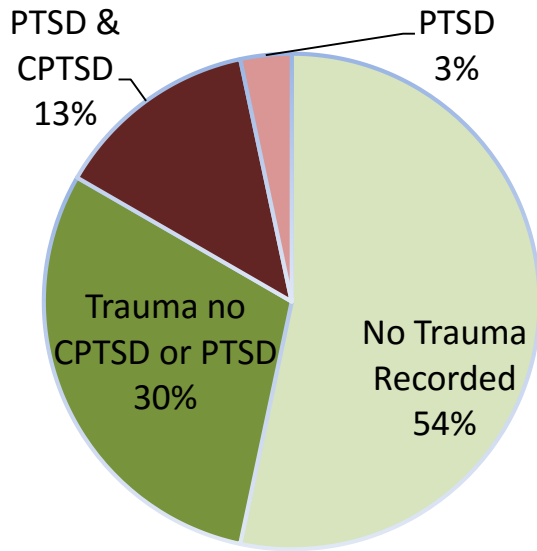
Using the Study Tool, recordings were made of the initial clinical primary diagnosis and then of the DSM criteria from the available medical records of each of the participants. The clear recording of the presence of DSM criteria within the patient's notes allowed these records to be examined for specific characteristics identified by DSM for both PTSD and CPTSD. It should be noted that the criteria for trauma, PTSD and CPTSD did not change between DSM-IV-TR and DSM-5. According to DSM, any patient with Trauma and with Re-experiencing can be given a PTSD diagnosis (NICE, 2004). Similarly, patients with both Trauma, Re-experiencing and Affect-Dysregulation can be assigned as CPTSD (van der Kolk *et al.*, 2001; Brewin *et al.*, 2013). References to the presence of trauma were recorded from the medical records (46%, N=28). On this basis, the records were then reassessed to identify comorbid PTSD and CPTSD using the data for trauma and the results presented in the figures below. This analysis therefore shows that 17%<sup>2</sup> (N=10) of all patients in this study could realistically be assigned either a comorbid PTSD or CPTSD diagnosis as per DSM (DESNOS), a situation that could be called a '*missed diagnosis*'. Figure 4-5 below is a summary chart which uses this data to highlight the diagnosis of PTSD and CPTSD based on the DSM criteria.

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<sup>1</sup> Two patients were assigned a CPTSD diagnoses (2.94% rounded to 3%), one PTSD (1.47% rounded to 1%). All summary results are given as integers, in order to be consistent with the small sample numbers which can only represent indicative results.

<sup>2</sup> The PTSD and CPTSD percentages do not add up to 17% due to rounding errors,  $13.333+3.333=16.666$ . Percentages are preserved as integers so as not to give the impression of high statistical accuracy.

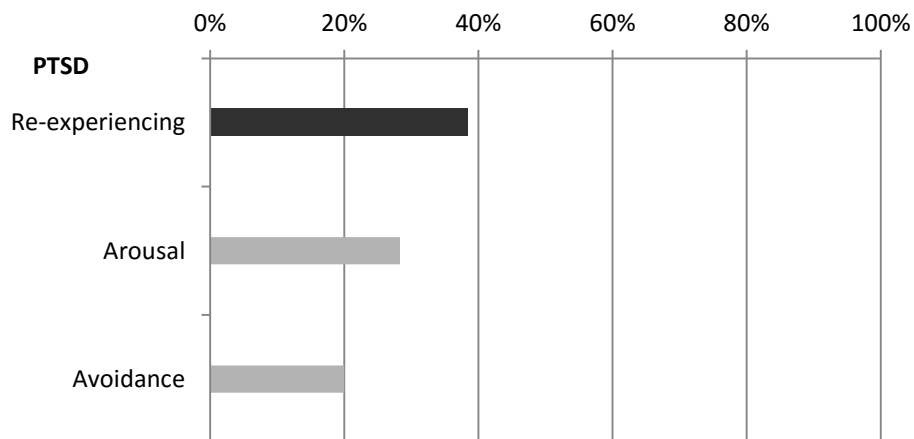




BPD: 46% trauma; 54% no trauma

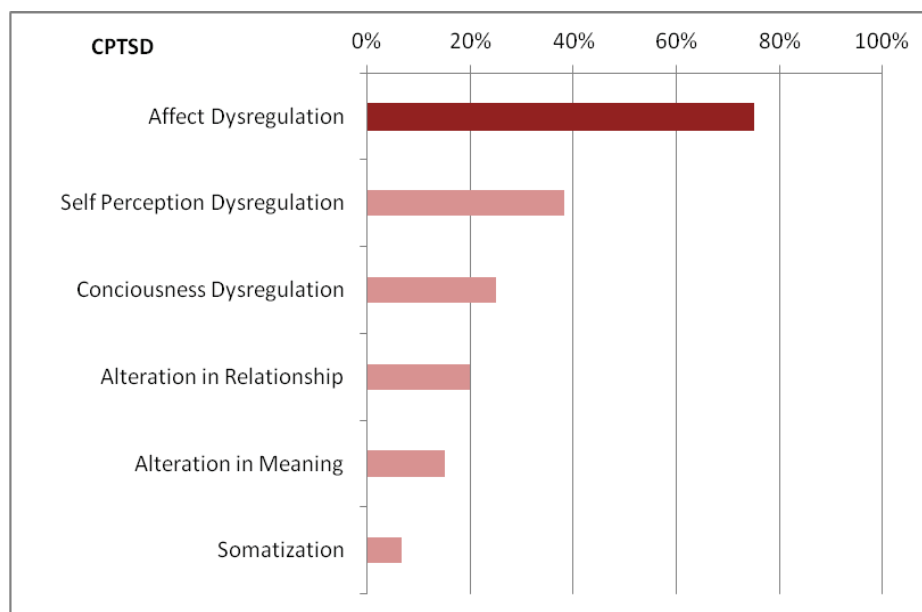
**Figure 4-5 Diagnoses as per DSM Criteria**

In most of these cases, the trauma was experienced in childhood as physical or sexual abuse and neglect. The records were then reassessed to identify underlying symptoms of comorbid PTSD and CPTSD (Figure 4-6 and Figure 4-7). It was also noted that only 2 patients had a record of an in-depth examination of their traumatic experiences.



**Figure 4-6 PTSD Criteria as per DSM**

Re-experiencing is the core characteristic of PTSD; so it is critical that the content of the re-experiencing is explored. The re-experiencing recorded could range from unwanted memories which could have a relatively mild impact, to disturbing flashbacks and nightmares. However, although 38% (N=23) of patients had records of re-experiencing in their medical records, on only one occasion was the content of this re-experiencing recorded. Similarly, on only 10 occasions was there a record of trauma with re-experiencing. This could therefore indicate that trauma is being under recorded. For CPTSD, affect dysregulation was selected as a critical parameter.

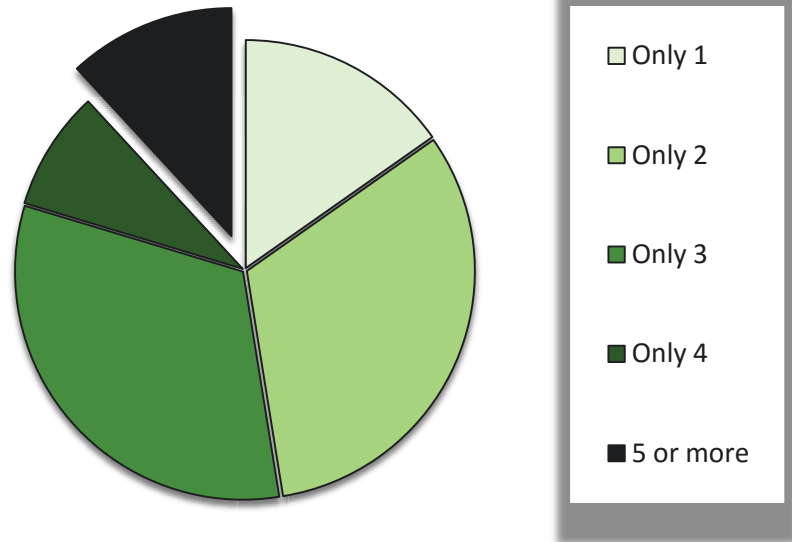


**Figure 4-7 CPTSD/DESNOS Criteria (in addition to PTSD) as per DSM**

#### 4.3.4 DSM Criteria for BPD

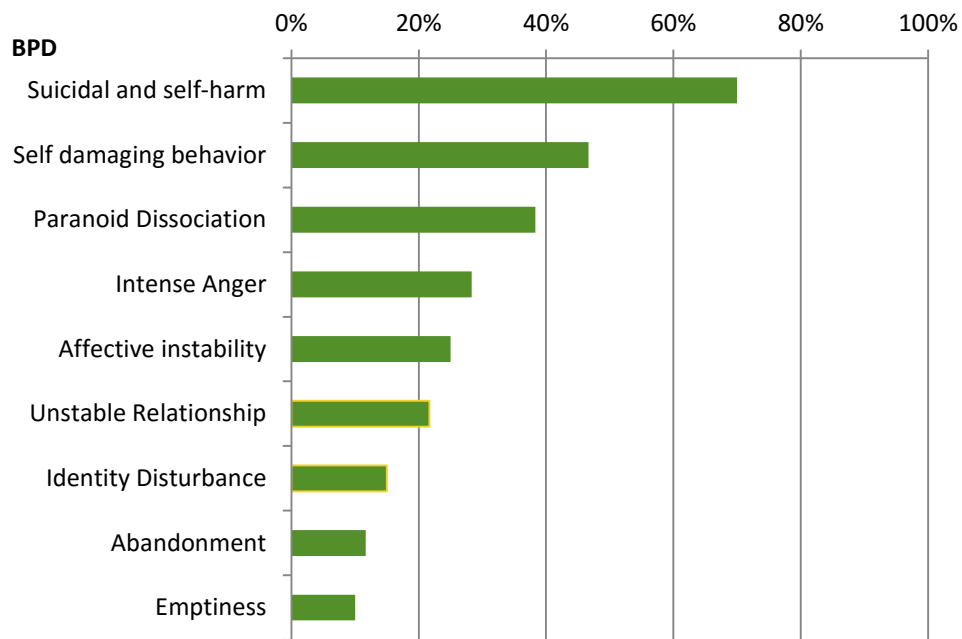
Although all patients were assigned a BPD diagnosis by their clinicians, Figure 4-8 shows only 12% (N=7) satisfied the full DSM criteria for BPD which states that at least 5 symptoms must be present (DSM-IV and DSM-5).

**Number of DSM symptoms present**  
(At least 5 required for BPD diagnosis)



**Figure 4-8 DMS Criteria for BPD**

The distribution of the 5 symptoms in Figure 4-9 shows that suicidal ideas or self-harm are the predominant symptoms identified, along with self-damaging behaviour. The dataset was then interrogated to see if the presence of trauma or PTSD/CPTSD influenced the proportions of DSM BPD criteria. One might speculate, for example, that patients with PTSD/CPTSD would exhibit higher percentages of BPD criteria. Although this dataset did permit percentages to be calculated, the small sample size on this occasion did not allow meaningful conclusions to be drawn. Another aspect of the comparison between BPD and PTSD/CPTSD is the severity of symptoms. Unfortunately, while the number of differing criteria was recorded, there was insufficient information in the recorded medical records to estimate severity.



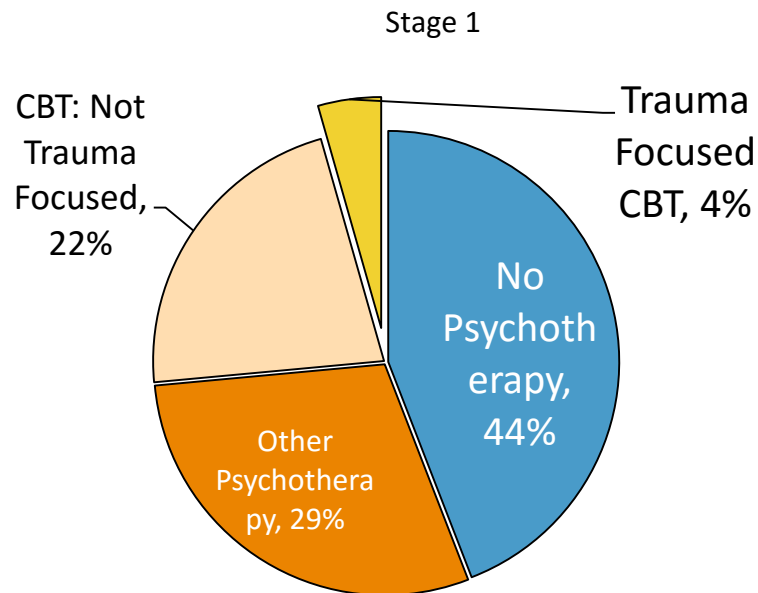
**Figure 4-9 Percentage of DSM BPD Symptoms**

#### 4.3.5 Instruments used

In the medical records there are records of two instruments being used, IPDE (International Personality Disorder Examination) in 22 cases (37%), SCID-II (Structured Clinical Interview for DSM Disorders) for only 2 patients (3%). For the other diagnoses there are no references to a specific assessment instrument.

#### 4.3.6 Psychotherapy Treatment

The pie chart in Figure 4-10 below illustrates the percentages that were offered psychotherapy of different kinds. While high proportions were given psychotherapy (56%, N=38) of differing types, and CBT in particular (26%, N=18), only a small proportion (4%, N=3) was related to trauma focused therapy. The high percentage of CBT in particular was for comorbid Axis I presentations such as Anxiety, Depression, etc.



**Figure 4-10 Psychotherapy Documentations**

It should be noted in addition that no evidence could be found in the medical records of the three trauma-focused CBT patients taking up the trauma treatment offered. This may explain why these patients are still being treated as BPD patients.

#### **4.3.7 Validation of the Stage 1 Survey Results**

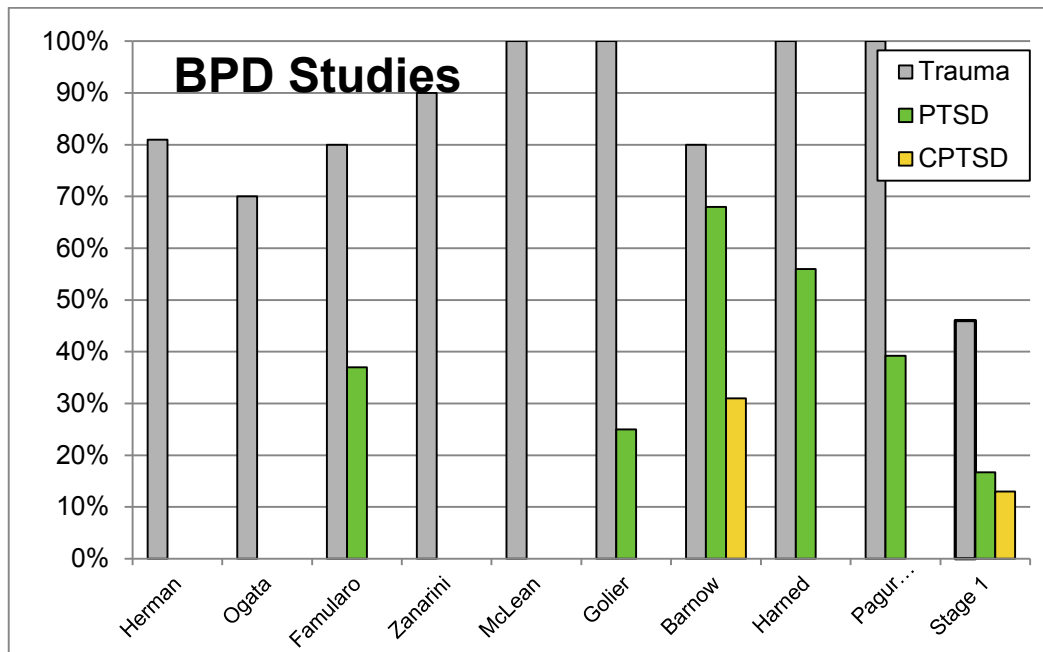
To help check the external validity of the results, a comparison with previously published empirical data was completed, as recorded in the literature review. The reason that these particular studies were selected was because they represented the only trial-based information. These 9 reviews all recorded the percentage of trauma found in BPD datasets, while some of the studies also recorded the presence of PTSD and CPTSD. The results from this review were then plotted alongside the published data for comparison in Figure 4-11, and Table 4-2. Table 4-3 lists the plus or minus error limits calculated from standard deviation at the routinely quoted confidence interval of 95% (Gosall and Gosall, p.76). This shows that the Trauma, PTSD and CPTSD results for the survey fall below the range of average results from the empirical studies. The reason for this is investigated during the clinician interviews. The reason for this is investigated during the clinician interviews (section 4.4).

**Table 4-2 Comparison of Results with Empirical Studies**

Study	Trauma		PTSD		CPTSD		BPD	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Empirical Studies	89%	12%	45%	17%	31%	N/A	N/A	N/A
Diagnosis by clinicians	Not diagn.	N/A	3.3%	18%	1.7%	13%	100%	N/A
Researcher Analysis	47%	50%	17%	38%	13%	34%	12%	32%

**Table 4-3 95% Confidence Intervals**

Study	Trauma	PTSD	CPTSD	BPD
Empirical Studies	8%	15%	N/A	N/A
Diagnosis by clinicians	N/A	5%	3%	N/A
Researcher Analysis	13%	10%	9%	8%



**Figure 4-11 Validation of Stage 1 Findings**

The 49% trauma presence in this survey can be compared to an average of 79% from the surveys in the literature. Although results initially appear lower than the previous selected studies, it should be noted that in all the previous studies the selection criteria were biased towards trauma. A situation that is especially true when findings have to rely on retrospective memory that can be influenced by

expected outcomes. In addition, on all occasions (except possibly for Ogata) the authors themselves were either leading the assessment process or were taking a major part in it, and thus may have been inclined to find the results they were looking for. In several cases, traumatic experiences were a pre-requisite of participation. Direct mathematical comparisons between the various trauma percentages recorded are therefore problematic. One reason could be because the clinical significance of these traumatic experiences has not been consistently recorded in the literature, as it is possible that in some studies the type of trauma recorded may not represent the type of life-threatening experiences required for a diagnosis of a disorder such as CPTSD, whereas on other occasions, all types of trauma may be recorded. CPTSD results for stage 1 (13%) do not compare particularly well with the 31% of inpatients with CPTSD reported by Barnow *et al.*, (2005). There is an even greater contrast, however, with the less than 2% of the stage 1 patients (in fact, a single patient) assigned a CPTSD diagnosis by the clinicians in the BPD clinic. Similarly, the 17% figure for stage 1 patients with PTSD symptoms is significantly less than the average of 47% from empirical studies, although much higher than the 3% (2 patients) assigned a PTSD diagnosis by their clinician.

#### **4.3.8 Limitations**

The principal limitation is the potential for researcher bias. As only the researcher examined the patients' records, it is feasible that interpretations of the data were biased towards the expectations of the Project. One potential mitigation could be to get an uninvolved party (blind examiner) to review a sample of the patients' records and to compare the results with those of the researcher, and thus complete an independent validation of the results. Another potential limitation for generalising the numerical results is the small sample size. The numbers of some of the resultant categories were very low. For example, there were only 2 patients assessed from the analysis of symptoms as having a 'PTSD Only' diagnosis, and only 7 patients with five or more BPD symptoms. The statistical significance of these data in terms of drawing general conclusions is therefore open to question. One possible way of improving statistical accuracy would be to repeat the exercise. This could be achieved by examining patient records at national scale.

However, before such a large undertaking, the results could be checked against stage 2 results.

In the case of individual research projects investigating trauma, there is also the potential for bias in the sampling and assessment process. The lower PTSD results (17%) could again be explained by reluctance of BPD clinicians to address life-threatening trauma. As one clinician suggested, clinicians tend not to discuss details of early childhood traumatic experiences, as they do not have the skills to manage this condition.

#### **4.3.9 Validation of Interpretations of Survey**

Although the criteria for assigning BPD, PTSD and CPTSD were obtained from the DSM-IV-TR, it is possible that working clinicians, academics and other relevant professionals could interpret DSM criteria in different ways. For example, some records that were written as *re-experiences* could perhaps be reinterpreted as *unwanted memories* rather than flashbacks and nightmares that are core to PTSD pathology and therefore PTSD results could be over-estimated.

#### **4.3.10 Discussion on Quantitative Survey Results**

Clinicians were recording adequate clinical information as per DSM-IV-TR and ICD-10 requirements to undertake DSM diagnosis for any of the three disorders. That is, a comprehensive range of symptoms was found in the medical records for more than 82% of the BPD patients. Thus the DSM criteria for CPTSD/PTSD are being clearly recognised and annotated, but this information did not result in any significant comorbid trauma-related diagnosis, and therefore detailed assessment was not requested by the BPD clinicians. Moreover, from the analysis above, there was an apparent under-diagnosis of CPTSD (DESNOS) and PTSD in the sample examined. There could be several reasons for this. Detailed discussions and references for both the theoretical and empirical relationships can be found in the Literature Review Chapter (section 2). Although according to DSM (IV and 5), five or more criteria have to be present (for ICD, a minimum of 3 are required) in order to adequately diagnose BPD, on 88% of occasions clinicians in the Trust appear to be satisfied with fewer than 5 BPD criteria, and on 15% of occasions were willing to assign a BPD diagnosis with only a single (although not any particular) BPD criterion present. Another explanation for the high diagnostic rate of BPD could



relate to professional clinicians' interpretations of DSM criteria. However, the DSM requirements were designed by committee to act as structural guidelines, making it easier for individual clinicians to make broad interpretations. Although the 1994 DSM-IV conditions were subject to constant interpretation, the recent DSM-5 BPD guidelines do not make any significant changes in this area.

The BPD results are consistent with the major (Westen) survey of American clinicians discussed in detail in the Literature Review, where a similarly low rate of compliance with the strict DSM-IV criteria for BPD diagnosis was found. These clinicians tended to make their diagnosis not on DSM criteria, but on the basis of observation and patient narratives. While it is logical to suggest that the patient narrative is led by thoughtful questioning by clinicians, a mapping of the clinician-patient interface would be difficult to achieve without recording assessment sessions. Similarly, although DSM symptoms for CPTSD and PTSD are routinely recorded, less than 1% of these 60 BPD stage 1 patients had been assigned a PTSD or CPTSD comorbid diagnosis. This contrasts with the 17% of patients who satisfied the DSM criteria for either comorbid PTSD or CPTSD when the records were examined (Figure 4-4 and Figure 4-5). This concludes the first part of stage 1.

#### **4.4 Stage 1, second part, Clinician Discussions: Qualitative Review**

To fully understand the underlying reasons, the above stage 1 quantitative results were presented to a variety of clinicians and consultants. These events included a Hospital Research Club Presentation, Steering Group Presentation, ward meetings, and informal discussions. This constituted the initial step in allowing the professionals to validate the results. It also provided a forum for clinicians to discuss alternative views. The objectives for this part of the study refer back to the overall objectives as shown below.

**Table 4-4 Objectives of Clinician Discussions**

No	Objective	Objectives of Quantitative Survey	Objectives of Qualitative Discussions
1	Quantify and qualify the proportion of BPD patients who have experienced traumatic stressors	Identify any trauma recorded and its frequencies	BPD clinicians' and management interpretation of trauma in patient presentations
2	Quantify and qualify the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis	Percentage of patients with PTDS/CPTSD diagnostic criteria and its statistical significance	<b>Why identified trauma does not appear to be fully assessed and treated</b>
3	Establish the extent of BPD over-diagnosis or misdiagnosis	Identify information on which current diagnoses were based. Interrelations between variables (e.g., DSM diagnostic criteria) and assigned clinical diagnosis	What do clinicians consider the essential criteria to diagnose BPD

#### 4.4.1 Interview Methodology

In order to build on group sessions and facilitate open discussions, a questionnaire was then prepared for a more comprehensive evaluation of clinician and management views. The questionnaire below was developed from the experience of the researcher, supervisors, peers, Steering Group and the literature on BPD, taking into account the link with trauma, PTSD/CPTSD:

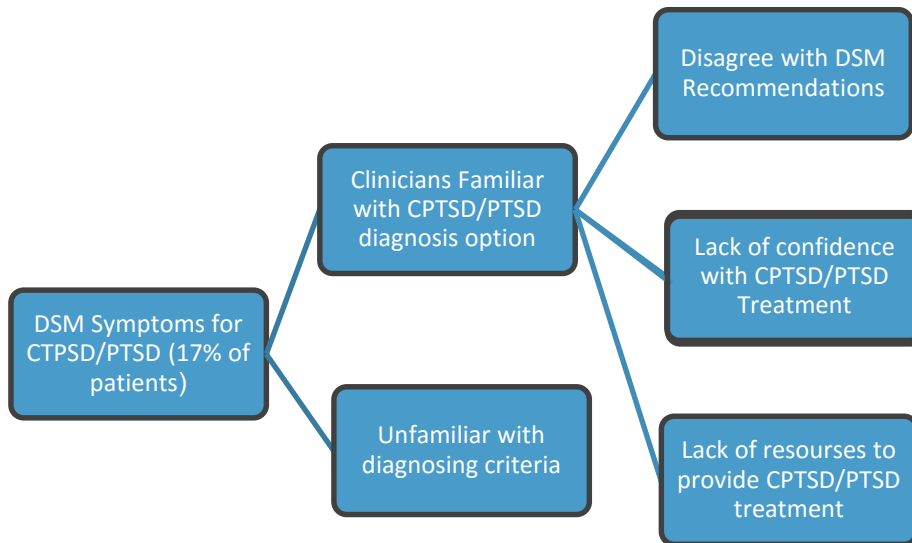
1. *How do you diagnose BPD, and do you use an assessment instrument for this?*
2. *What do you ask about childhood trauma and do you do a detailed examination of this?*
3. *Are you aware of the concept of CPTSD?*
4. *How do you differentiate between BPD and CPTSD?*
5. *Would a screening instrument used during the assessment help, and what would you like to see in such a screening instrument?*

6. *What is your usual treatment for BPD, and do you do anything about trauma if it occurs?*
7. *Do you find this treatment effective?*
8. *How is it evaluated?*
9. *Do you think referral to a Trauma clinic would be helpful to the patient?*
10. *Which would be better (easier); Trauma clinician to come to the patient or patient to go to the clinician?*

The questionnaire attempts to balance the potential benefits of trauma treatments for BPD patients against the inherent stresses that could be involved in this study. It was then either discussed during the semi- structured interviews or distributed to participants who were not interviewed. In particular, it was important to find out if clinicians ask all their patients about abusive histories as per current Department of Health Policy, Refocusing the Care Programme: Approach and Practice Guidelines, Department of Health, 2008). To quote directly from this document:

*'Childhood experience of sexual and other abuse is known to be more frequent in the histories of individuals with both mental illness and personality disorders (MNMSF, 1999). Research indicates that around 50% of women service users have been sexually victimised as children, notwithstanding further abuse in adulthood and a significant number of men service users have also experienced abuse. It is now DH policy that, following appropriate training for staff, exploration of violence and abuse is routinely undertaken in all mental health assessments. Questions should be asked by suitably trained staff at assessment about the experience of physical, sexual or emotional abuse at any time in the service user's life. The response, with brief details, should be recorded in the case records/care plans. If the specific question is not asked, the reason (s) for not doing so should be recorded.'*

Based on these initial informal discussions, the steering group considered a number of potential explanations for the stage 1 quantitative results. Figure 4-12 below illustrates these possibilities.



**Figure 4-12 Stage 1 interpretation Options**

A selection of clinicians' views on trauma, BPD, PTSD and CPTSD was then recorded based on the findings of the quantitative survey. The principal methodology for this review was the constant comparison method described fully in the design chapter (section 3.5.2.2). In line with the interpretist paradigm, this process considers the clinicians' opinions of BPD patient presentations that informed their diagnosis, and the formulation of patients care plans which guide treatment.

#### 4.4.1.1 Constant Comparison

This (qualitative) part of the study interviews two professional groups, practising clinicians (N=28) and medical directors/managerial personnel. The main focus area for the constant comparison technique was the second research objective: 'why identified trauma does not appear to be assessed and treated'. This was because there was most uncertainty about this particular issue. Clinicians' views on trauma (Objective 1) and on BPD assessment (Objective 3) were also recorded, but as there was not a sufficient variety in views, the full constant comparison methodology was not required for these objectives. Comparisons were made by coding and categorising the narratives of both individual day-to-day BPD clinicians and BPD management according to the three constant comparison steps.

1. Comparison within a single interview
2. Comparison between interviews of different clinicians
3. Comparison between the clinician and management interviews

#### 4.4.1.1.1 Step 1 Aims and Methodology

In order to make systematic comparisons, common codes from the initial interview narrative of one day-to-day clinician were developed, and the interviewee was asked about the survey findings and their views on trauma assessment and treatment in BPD.

#### 4.4.1.1.2 Step 1 Results

Consistent codes and tentative categories emerged quite quickly. Four codes which were identified from the first interview are presented below.

**Table 4-5 Codes from First Interview**

1	Trauma resources	<i>"We are very aware of trauma underpinnings - but we have no resources. Also we are stressed out with the lack of trauma specialists to see these patients."</i>
2	Trauma training	<i>"Trauma is not part of our BPD brief. We are not skilled enough to go into the past without the skills to deal with it."</i>
3	Trauma screening	<i>"Agree with the need for trauma screening during assessments as our patients are usually not actively disturbed when they were referred to us"</i>
4	Fear of BPD patients' reaction if pushed to explore past trauma	<i>"Fear of trauma. We do not ask about trauma as we do not want to open up things that patients might not be able to deal with without help."</i>

For example, fragments of an interview that were given the code "Fear" were then subjected to further comparison within the same interview to find out what they had in common, how they differed, in what context the interviewee made the remarks, and which dimensions or aspects of fear were highlighted. Some examples are as follows:

*"There is perhaps a fear of opening a can of worms"*

*"There is a fear of what to do with the information, and a worry about the possibly lack of services to deal with the information"*

*Trauma does not appeared to be considered, perhaps it is due to not wanting to open a can of worms".*

#### 4.4.1.1.3 Step 2 Aims and Methodology

Then, in order to confirm a meaningful variety of categories, comparisons were made between the initial interview and individual clinician interviews (N=26) as shown in APPENDIX 15 . From these free ranging discussions, common occurrences of the above codes were recorded. The optimum number of interviews was realised as the emerging data became saturated and no further insight could be gained from the data. However a number of additional clinicians were added for confirmation. Restricting the number posed another challenge, because a high number of clinicians had expressed an interest in the outcome; there was therefore a risk of a sample snowballing effect, which had to be sensitively managed by using clinicians who were in daily contact with the patients.

#### 4.4.1.1.4 Step 2 Results

A total of eight categories emerged as listed below.

**Table 4-6 Categories from Interviews**

1	Fear of opening Pandora's Box
2	Lack of resources for trauma treatment
3	Lack of clinical competence to deal with distressing trauma
4	Clinicians not aware of the need to assess for trauma
5	Instruments currently in use do not offer the opportunity explore trauma and its reactions
6	Not skilled enough to go into patients' past without the skills to clinically manage any results, disclosures and distress
7	A simple trauma screening instrument would help to know which patients can be referred on to trauma specialist(s) thus reducing the fear of dealing with trauma
8	Existing BPD screens do not help to identify trauma

Clinicians were fearful about discussing trauma, and felt that they did not have the skills to manage the life-threatening trauma typical of PTSD that they anticipated

would be brought out during the assessment process. Consequently they either did not talk about it at all, or they skirted around the subject. Interviews generally confirmed that clinicians were in fact familiar with PTSD but not CPTSD. A common concern was the fear of ‘opening Pandora’s Box’, that is, if delicate and sensitive traumatic experiences such as child sexual abuse were to be explored, additional unknown problems might be exposed. One ward manager said *“We do not ask about trauma as patients in the wards are in acute stress stage and are on the ward for a short time so we do not want to open things that cannot be dealt with.”* This reaction has previously been noted by (Bryer, Nelson and Miller, 1987). The item most requested by clinicians however was brief and effective screening for the early identification of trauma, PTSD/CPTSD in BPD patients, so that they could obtain an in-depth assessment as early as possible for their patient. As expressed by one clinician: *“Trauma must be explored in order to effect the treatment plan and to map a course through the mental health system with trauma screening the first step”*. Some clinicians requested more specialist trauma support and more training for dealing with trauma and its consequences. *“Clinicians are afraid to open trauma difficulties as they are not trained to deal with it. A screen would be good at the common point of entry, for referral for assessment of trauma component. Such a screen must be meaningful and clinicians must be trained in its use during formulation”*.

However, as the role of providing a full PTSD/CPTSD assessment is already being performed by specialist clinics, it could be more efficient for busy BPD clinicians to simply screen their patients for potential PTSD/CPTSD and to refer them appropriately for in-depth trauma exploration. In these circumstances, a simplified Screening Instrument should be considered for use by BPD clinicians. Screening instruments are commonly utilised prior to full clinical assessment.

#### **4.4.1.1.5 Step 3 Aims and Methodology**

Management participants (N=3) were independently asked to give their opinion on how they thought clinicians manage trauma and their reactions in BPD presentation, based only on the quantitative results, without access to results from the clinician interviews. This was done to obtain a comprehensive picture from a variety of perspectives. Categories identified were then presented to

management participants and to some of the clinicians in order to verify the results to make sure that the important issues that they had raised were not missed.

#### 4.4.1.1.6 Step 3 Results

From all of the results, four themes emerged in the reasons given for not assessing and treating trauma.

**Table 4-7 Step 3 Results**

	Clinicians	Management (with quotes)
1	Recognise and explain the presence of traumatic past histories	Assume that clinicians were adequately managing trauma <i>"We must ask clinicians to pay more attention to trauma"</i>
2	Trauma not explored by clinicians due to fear of 'Pandora's Box'	Based on quantitative results, fear of addressing trauma was suspected as the root cause <i>"There appears to be a fear of dealing with trauma"</i>
3	Not treating trauma underpinnings due to lack of resources and lack of competence for doing so	Appropriate training should be provided <i>"We have a lack of resources"</i> <i>"Clinicians must be trained to take away the fear of approaching trauma"</i>
4	Need a simple screening instrument that will help just to raise the issue and then refer on for an in-depth assessment by a trauma specialist, thus reducing the fear factor	Recommend screening and referral to specialist clinic(s) <i>"A meaningful and uncomplicated trauma screen should help clinicians feel confident in making a referral to trauma clinics"</i>

Management participants generally presented the same themes as the clinicians, but went further to suggest how they could help in terms of resources and training, as fear of 'not wanting to open the Pandora's Box' could be due to lack of training and resources. They also felt that it was unethical not to screen and treat for trauma.



#### **4.4.2 Additional Results from Clinician Interviews**

The relatively low reporting of trauma (47%) in patient medical records in comparison with empirical studies was explained by the BPD clinicians, who reported that discussing childhood trauma in particular with patients was a daunting experience. In general the criteria applied in making a BPD diagnosis in clinical practice were less strict than recommended by DSM and ICD, and typically patients were diagnosed and treated for BPD based on fewer symptoms. Avoidance of alternative diagnosis by BPD clinicians was also noted by Westen (1979) in his wide survey of US practitioners.

A number of authors have reported on the reasons why clinicians do not ask patients about their abuse histories. Gallop *et al.*, (1995) and Young *et al.*, (2001) have concluded that uncertainty about how to respond to revelations of abuse was one of the main reasons why clinicians do not ask about this. Similarly Read, Hammersley and Rudeffear, (2007) have reviewed this area. They then concluded that one of the reasons that clinicians do not enquire about abuse is because of 'lack of training in how to ask and how to respond'.

#### **4.4.3 Follow-up of Stage 1 Patients**

A number of months after the completion of stage 1, an investigation was made into the treatment response of these patients. Of the (N=16) patients where information was available (N=3) 14% showed improvements resulting from their BPD as usual treatment.

#### **4.5 Stage 1 Conclusions**

The quantitative and qualitative parts of stage 1 are now brought together to address three of the four research sub questions. The findings from the survey of patients' medical records formed the basis of the questions for the survey of BPD clinicians, views. The results were then assessed against the research objectives.

**Table 4-8 Stage 1 Result Summary**

No	Quantitative Objectives	Survey Results	Qualitative Objectives	Interview Results
1	Identify any trauma recorded and its frequencies	Trauma was recorded on 47% of patients' medical records	BPD clinicians' interpretation of trauma in patient presentations	Trauma not always recorded as not recognised as highly significant for BPD
2	% of patients with PTSD/CPTSD diagnostic criteria and statistical significance	17% had PTSD and/or CPTSD symptoms based on interpretation of patients' medical records	Why identified trauma does not appear to be treated	Lack of trauma training Consequences to patient of reliving stressful experiences
3	Identify information on which current diagnoses are based. Interrelationship between variables (e.g., DSM diagnostic criteria) and assigned clinical diagnosis	Only 12% satisfied at least five DSM symptoms	What do clinicians consider as the essential criteria to diagnose BPD	Focus is more on symptoms rather than aetiology Many clinicians recommend diagnosis on fewer symptoms

While the stage 1 results largely confirm NICE expectations, the urgent need now is to examine the value of the proposed changes in assessment techniques with systematic in-depth patient interviews.

## Stage 2

### **5 METHODOLOGY: STAGE 2, TRAUMA, PTSD & CPTSD SCREENING TRIAL**

#### **5.1 Introduction**

This chapter presents the objectives, methodology and results of the second or principal research stage of the project, and follows directly from the main recommendation arising from the findings from the stage 1 BPD patients' medical records. When presented with the findings, BPD clinicians requested a streamlined but effective trauma screening instrument that would prove easy to use when new patients present with BPD psychopathology. Stage 2 develops and trials this screen.

Specific objectives for the stage are first clarified, followed by a description of the stage 2 research methodology employed as sketched in the stage 2 Roadmap, Figure 5-1. Central to stage 2 is the development and trialling of a 'BPD Traumatic Experiences and Reactions Screen' (BTERS), a new trauma screening instrument for people who present with BPD-like symptoms. The process commenced with the development of the instrument, concentrating on how the instrument was validated, where validity was divided into a number of key elements. First, the conceptualisation of the instrument and the overall methodology are discussed. The next section then covers the creation of a pilot instrument, and the testing of the pilot version, leading to the trial of the final instrument. Finally, statistical analysis and results are presented in terms of validity and reliability, together with discussions on the limitations of the trial.

## Stage 2

### 5.1.1 Stage 2 Objectives

**Table 5-1 Stage 2 Objectives**

No	Research Objective	Specific stage 2 objectives
1	Quantify and qualify the proportion of BPD patients who have experienced traumatic stressors	Identify and specify the type of trauma experienced by BPD patients Establish the % of patients with the criteria for in-depth trauma assessment and treatment in BPD
2	Quantify and qualify the proportion of BPD patients who also meet a PTSD/CPTSD diagnosis	Detect PTSD/CPTSD in BPD patients using gold-standard clinical instruments Compare % of Trauma, PTSD, CPTSD identified with stage 1 results and with literature
3	Establish the extent of BPD misdiagnosis or over-diagnosis	(Misdiagnosis was addressed in stage1) Establish BPD over-diagnosis by calculating PTSD/CPTSD comorbidity
4	Using a screening instrument, quantify and qualify BPD patients using BTERS for trauma-focused therapy by validation against gold standards	Develop and trial a trauma screening instrument for clinicians for early identification of trauma and PTSD/CPTSD

### 5.2 Stage 2 Methodology

Clinical diagnostic instruments such as BTERS are commonly used methods for screening and validation and are reported in the professional literature. The methodology summarised in the Roadmap was based on QUADAS, as described in section 3.11.1, and comprised the following steps:

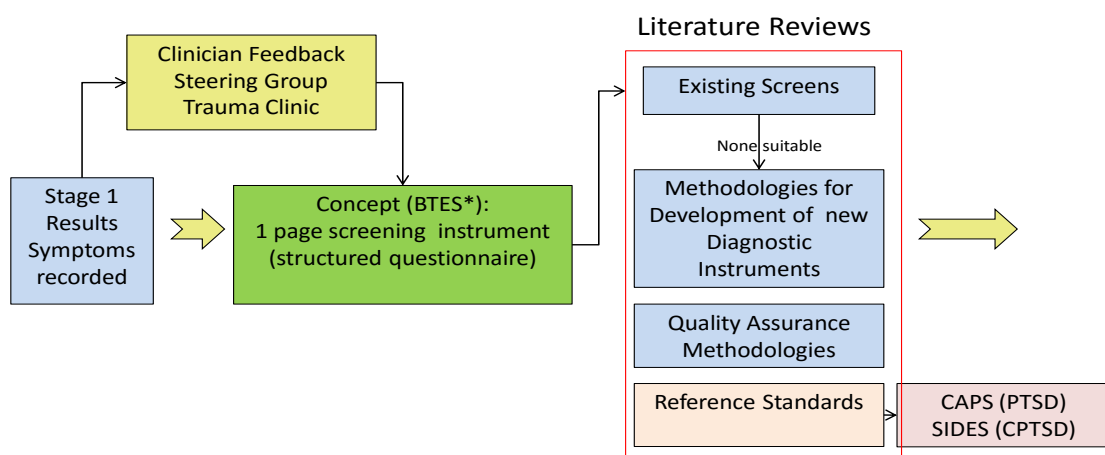
- A. Conceptual decision – screening instrument design and population selection for testing
- B. Generation of Items relating to both causes and symptoms of each of the 3 disorders
- C. Assessment of Face validity and Content validity

## Stage 2

- D. Pilot trial and refined instrument
- E. Field trial to assess consistency and Construct validity

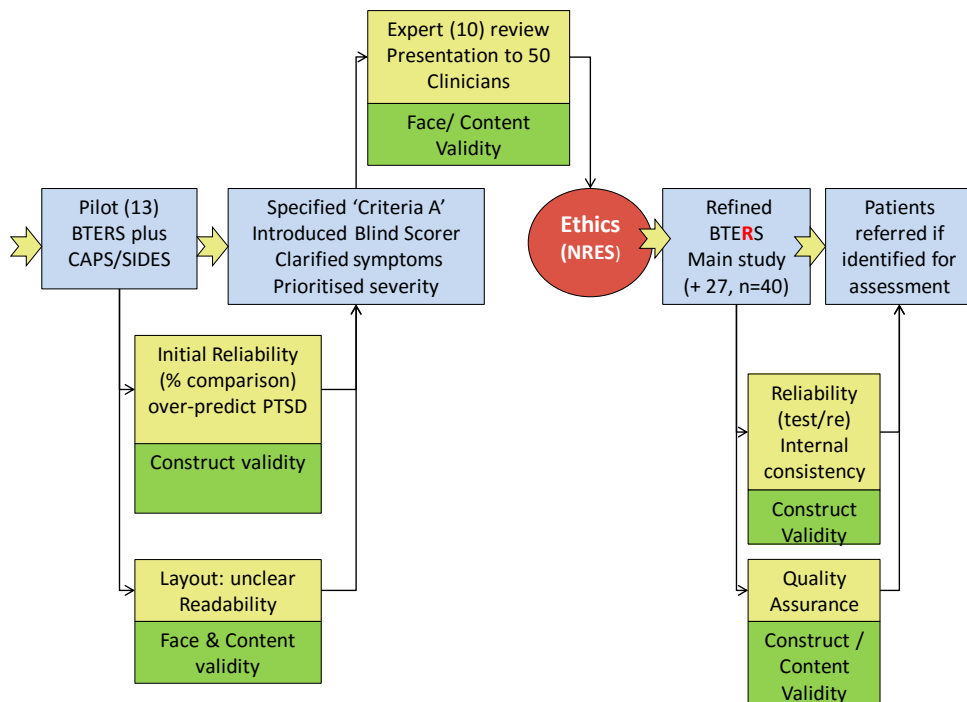
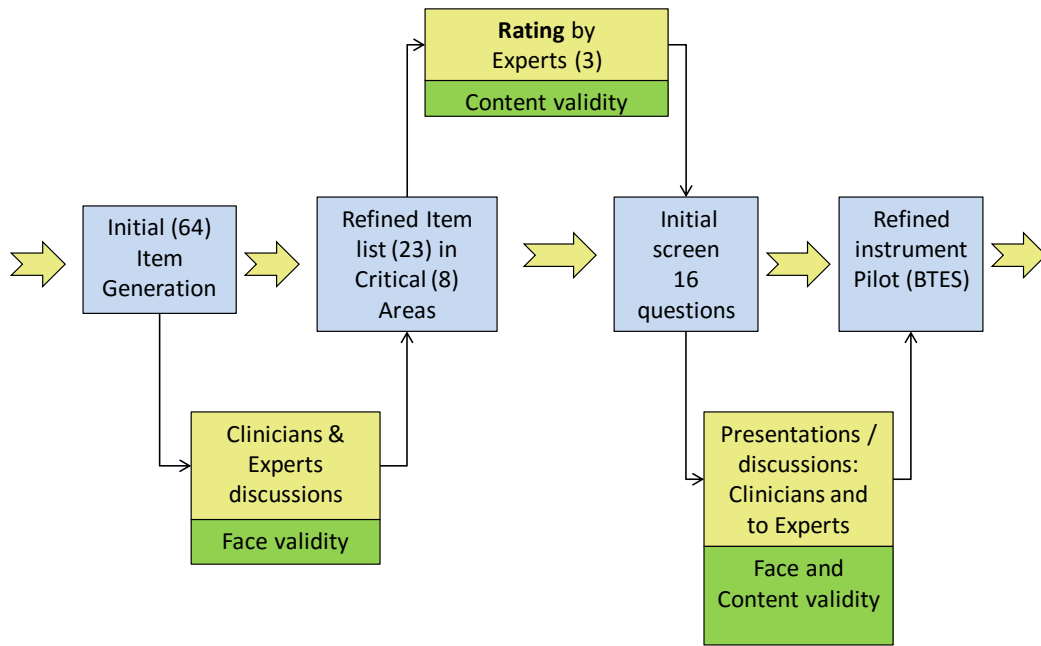
This development process also follows the approved Research Protocol and any deviations were noted and approved by the Supervisor and the Steering Group members whenever appropriate. First the overall methodology and conceptualisation of the instrument (A) is discussed. A list of items were then generated (B). The next sections then cover the creation of a pilot instrument (D) that deals primarily with Face and Content validity (C). Face validity concerns the appearance and usability of the instrument, whereas Content validity ensures that the instrument measures what it is supposed to measure. The data analysis used to calculate Construct validity (E) and the results are presented following the pilot study. Several statistical techniques were utilised throughout, and these are described in detail within the individual sections. In particular content validity index (CVI) and a discerning analysis using Cronbach's alpha was used to fine tune the items on the screen (section 5.2.2), then sensitivity and specificity was used for the pilot (section 5.7). For the main study, again sensitivity and specificity was used, along with the evaluation of repeatability (Cohen's kappa, 5.10). As in stage 1, the statistical program SPSS (version 19) was utilised to manipulate and present the data.

**Figure 5-1 Screen Development and Trial Roadmap**



\*BTES subsequently changed to BTERS

## Stage 2



### 5.2.1 Screen Concept Decision (A)

A new screening instrument was conceptualised in response to the results of stage 1, medical records survey, the clinician survey, and feedback from the Steering group (section 3.11.2). Stage 1 thus highlighted the need for a streamlined but effective trauma screening instrument that would prove easy for busy clinicians to

## Stage 2

use when new patients present with BPD symptomatology. Such an instrument would allow patients who could potentially benefit from PTSD/CPTSD treatment to be identified. It must, however, include sufficient clinical detail to annotate the various traumatic events including PTSD/CPTSD in order to provide repeatable results and ensure quality control. Thus BTERS (APPENDIX 1 ) was conceived as a single page form with a limited number of simple questions relating to traumatic experiences and patients’ reactions to the experiences, which could identify patients for subsequent detailed assessment of BPD or PTSD/CPTSD. To support the goal of simplicity, a structured interview was the preferred format; however, in recognition of the time pressures in the clinical environment and, in particular, the sensitive subject matter, the study also considered the effectiveness of self-completion. The literature search confirmed that none of the existing screens were suitable for non-specific traumas, such as those typically experienced by patients with BPD/CPTSD often originating in childhood.

### 5.2.1.1 Generating the Items for Screen Questions (B)

To create relevant questions for the screen, a comprehensive list of items relating to the disorders was systematically developed, edited and refined. The list included traumatic experiences that have been repeatedly described in the literature on individuals exposed to both type 1 and type 2 trauma.

**Table 5-2 Domain Set for 3 Disorders**

Disorder Pre-requisite	Traumatic experience	
Symptom set	Psychological	Re-experiencing - intrusions
	Behavioural	Avoidance
	Physiological	Hyper-arousal

The initial item list considered two Domains – Disorder Pre-Requisite and Symptom Set – for each of the disorders, which roughly correspond to the causes and symptoms of BPD, PTSD, and CPTSD as specified by DSM (Table 1-3). The first Domain deals with traumatic experiences, especially what is called ‘Criteria-A’ or Life-Threatening Trauma (see section 1.5.1 for further details) whereas the

## Stage 2

Symptom set can be divided into Psychological, Behavioural and Physiological symptoms. Symptom sets were generated from a review of the literature on the sequelae of childhood sexual abuse, physical abuse, crime, rape, incarceration in concentration camps and torture. Other items derived from feedback from clinicians after the presentations of the results of stage 1, and from comprehensive assessment instruments for the disorders (Gold Standards). From this review, an initial 'pool' of 64 items was created. A series of meetings followed and presentations were made to both clinicians and experts on psychological reactions to extreme stress and BPD in order to choose which specific criteria should be included or deleted in the item list. The format and language of the question set was also modified to improve face validity, which is important because, for the criterion of content validity to be met by the initial pool items, these items must be face valid (Hardesty and Bearden, 2004). At the end of this process a refined list of 23 items remained.



## Stage 2

### 5.2.2 Initial Content Validity of the BTERS Screen (C)

The Zaichkowsky (1985) system was employed to produce an initial assessment of Content Validity. For this assessment, a panel of 3 judges specifically chosen for their expertise in the field of traumatised populations was asked to review the 23 items. The judges consisted of the following:

1. CPTSD: Former Head of Trust Trauma Unit – Professor and consultant psychological trauma therapist with expertise in CPTSD. As a clinician and academic, has published extensively and spoken worldwide. World renowned for her work on Trauma. Founder staff member of the traumatic stress services at the Institute of Psychiatry. A founder and a very long term lead of a national traumatic stress services.
2. BPD: Head of the Trust BDP Unit - consultant psychiatrist specialist in the treatment and management of BPD. Member of BPD guideline development group for NICE clinical guideline 78 BPD: 'Borderline Personality Disorder: treatment and Management', NICE, 2009.
3. PTSD: Consultant clinical psychologist. Head of national trauma centre for PTSD, specialises in treating PTSD, and has widely disseminated her clinical knowledge in Europe and North America.

The most relevant items for the screen were chosen on the basis of the priorities assigned by each specialist in his or her field of expertise. Each specialist rated items as “completely representative”, “somewhat representative” or “not at all representative” of the construct for each of the 3 disorders, with scores from 1 to 3. For each disorder, the designated expert was given double points because of their speciality. Therefore the lowest score for one disorder is  $4 = 1$  (non-expert)  $+1$  (non-expert)  $+ 1+1$  (expert). The highest score is  $12 = 3$  (non-expert)  $+ 3$  (non-expert)  $+ 3+3$  (expert). These numbers are presented below in two tables, Table 5-3 below shows a Content Validity Index (CVI) where the numbers are represented by percentages (top score of  $12 + 12 + 12 = 36 = 100\%$ ).

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	<b>High CVIs are shaded</b>	CVI
1	Did you experience or witness TE in your childhood	89%
2	Was it before the age 13	86%
3	Was is after age 13	89%
4	Was it repeated	78%
5	Was it life-threatening	81%
6	Was it sexual abuse	100%
7	Was it physical abuse	92%
8	Was it non-life-threatening	61%
9	Was the perpetrator always a family member or a care -giver	33%
10	Was it inappropriate touching of your sexual parts	47%
11	Did you feel rejected	67%
12	Did you feel unloved	67%
13	Did you think you were no good enough	69%
14	Did you think you were permanently damaged	69%
15	Abandonment	69%
16	Did you lose trust in people	89%
17	Intense distress	94%
18	Flashbacks	94%
19	Nightmares	94%
20	Avoiding people and places that will cause you distress	89%
21	Intense anger	72%
22	Intense sense of fear	89%
23	Irritable and jumpy when unexpectedly startled	94%
	<b>Mean</b>	<b>79%</b>

**Table 5-3 Content Validity Index CVI**

It was also possible to identify items that discriminated between the disorders. In Table 5-4 below, colours highlight the differences in the scoring: dark green represents maximum value (12) for any particular disorder, and white represents minimum value (4), and the shade of green on all other cells is reduced proportionally using a built in Excel function.

An 'identifier' can be defined where one item is scored notably higher by the experts in only one particular disorder, and an 'excluder' is defined where an item is scored notably lower in only one disorder.

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**Table 5-4 Questions that Discriminate between Disorders**

Comparison for all experts, with double weighting for expert in specified area					2 Low one High		2 High 1 low	
	Best Disaerners	CPTSD	PTSD	BPD	Identifier		Excluder	
1	Did you experience or witness TE in your childhood	12	8	12		50%	PTSD	
2	Was it before the age 13	12	7	12		63%	PTSD	
3	Was is after age 13	8	12	12		50%	CPTSD	
4	Was it repeated	12	4	12		100%	PTSD	
5	Was it life threatening	11	12	6		69%	BPD	
6	Was it sexual abuse	12	12	12		0%		
7	Was it physical abuse	9	12	12		38%	CPTSD	
8	Was it non life threatening	6	4	12	BPD	88%		
9	Was the perpetrator always a family member or a care -giver	4	4	4		0%		
10	Was it inappropriate touching of your sexual parts	5	4	8	BPD	44%		
11	Did you feel rejected	8	4	12	BPD	75%		
12	Did you feel unloved	8	4	12	BPD	75%		
13	Did you think you were no good enough	8	5	12	BPD	69%		
14	Did you think you were permanently damaged	12	8	5	CPTSD	69%		
15	Abandonment	9	4	12	BPD	69%		
16	Did you lose trust in people	12	8	12		50%	PTSD	
17	Intense distress	11	11	12	BPD	13%		
18	Flashbacks	12	12	10		25%	BPD	
19	Nightmares	12	12	10		25%	BPD	
20	Avoiding people and places that will cause you distress	10	12	10	PTSD	25%		
21	Intense anger	8	8	10	BPD	25%		
22	Intense sense of fear	10	12	10	PTSD	25%		
23	Irritable and jumpy when unexpectedly startled	12	12	10		25%	BPD	

For example, non-life-threatening experiences (item 8) are indicative of BPD. Here we can see that BPD scores 12 points, PTSD scores 4 points and CPTSD scores 6 points, so item 8 is a clear identifier for BPD. Similarly the presence of repeated traumatic experiences (item 4) excludes PTSD as it scores high (12 points) for CPTSD and BPD, but low (4 points) for PTSD. Also the thought of being permanently damaged (item 14) is a major CPTSD identifier. On the right hand side of the table, each item is then assigned a percentage. 100% (dark red) is where there is a maximum contrast between the low and high values (item 4); here there is a definite exclusion of PTSD. On the other hand, 0% (white) represents the lowest contrast between the values (items 6 and 9), and so these questions do not help to discern any of the disorders. Where there is a moderate contrast such as item 18, (Flashbacks) the contract level is moderate and the percentage (25%) represents a lower ability of this particular question to definitely exclude BPD. Another example is items 13 to 15, where the percentage (69%) can be seen as a good identifier. If scores less than 25% were rejected, the lowest scoring 3 questions could be excluded, and thus 25% could be used as a cut-off value.

Nonetheless, the experts agreed with the selection of items with only a few exceptions (items 9/10). For simplicity, items were to be scored dichotomously,

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i.e. each question to be answered by each patient with either “yes” or “no”. The number of questions was reduced from 23 to 16 to make screening quick enough to be used easily in a busy clinical environment, while maintaining sufficient detail to differentiate between the 3 disorders. Items were then refined and arranged into a structured interview format ready for the pilot study. The actual questions in the instrument were not selected solely on the basis of statistical parameters. A judgement was made of the suitability of the questions both in terms of Face and Content Validity for screening and their usefulness as a focus for discussing treatment options. For example, whereas item 6 (Was it sexual abuse?) scored low, it was retained because it was combined with item 4 (Was it repeated?) because repeated sexual abuse is a recognised indicator of CPTSD. From this review, a list of 16 questions for the pilot screen was finalised. Whenever compatible, items were combined to ensure that the high scoring items were presented in clear and simple questions.

### **5.3 Stage 2 Ethical Approval**

NHS ethics placed a number of constraints, including informed consent, freedom of choice, anonymity of data, security of data, etc. As required by the NHS ethics committee and detailed in the Protocol and the Clinician Information Sheet (APPENDIX 16 and APPENDIX 18 ), prior to data collection, discussions took place with as many clinicians who work with BPD patients as possible. These included the Head of The Traumatic Stress Services Department responsible for possible referrals, key consultant psychiatrists, Medical Department Lead(s), the individual care coordinators for each patient participant, plus all clinicians in the crisis team. Prior to starting, assurance was obtained as to the protection systems in place for participants. These included what are called ‘grounding strategies’, and also the confirmation of efficient telephone contact numbers to be used in an emergency (Design Chapter, section 3.6.2).

It was also necessary to consider the consequence to individual patients should they be diagnosed with PTSD/CPTSD. When the assessment process was completed, therefore, and with the patient’s permission, the patient’s consultant/responsible clinician was informed of any clinically relevant findings. Subsequently, recommendations could be made as to which participants it would

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be appropriate to refer to the local traumatic stress services. In reality, as many of the patients were in BPD treatment, only a small number (N=7) of patients were referred to the Trauma Unit. BPD treatment continued unchanged for all patients, both those who were referred to the trauma services and those who were not, for as long as clinically necessary.

### **5.4 Patient Selection and Recruitment**

In order to field-test BTERS, the sample area needed to be restricted to a manageable and controlled environment with sufficient suitable patients available. The project thus concentrated on one BPD specialist centre in a UK Health Trust (BPD unit), where patients were recruited mainly from a psychological treatment facility on the basis of their BPD diagnosis. Patients either in treatment for BPD or new referrals for assessment of BPD were included. At the time, all were outpatients, although some had previous psychiatric hospitalisations.

#### **Inclusion Criteria**

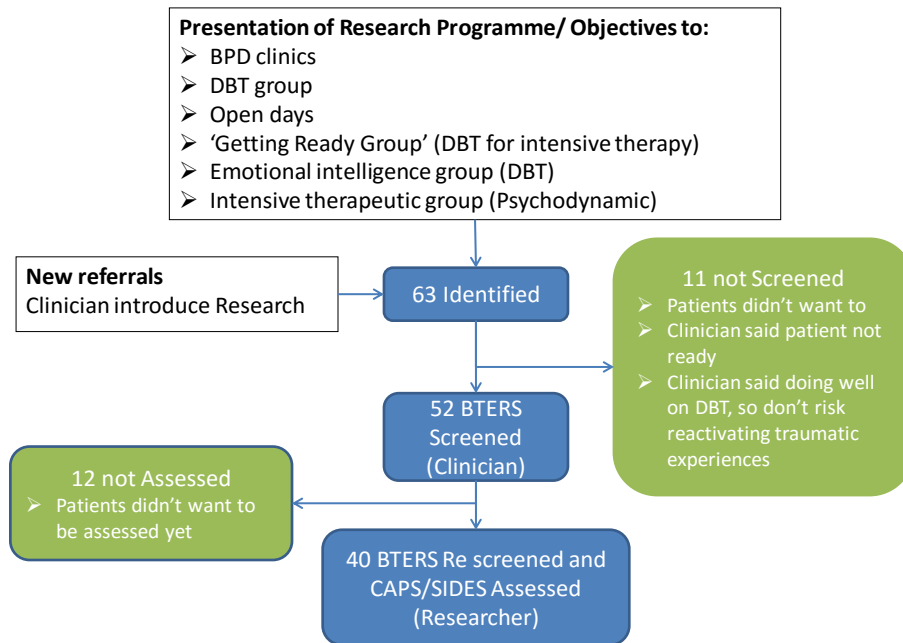
- Clinical diagnosis of Borderline Personality Disorder
- Age 18 or over (no upper age limit)
- Able to give informed consent
- Currently receiving psychiatric care from the participating NHS Trust
- Availability of professional support i.e. must have a key worker

#### **Exclusion Criteria**

- Age Less than 18
- Unable to speak English
- Acutely Distressed
- Significant learning disability
- Unable to give informed consent
- Alcohol or drug impairment
- Hospitalised
- A recent crisis condition such as self-harming
- Recent police involvement
- Missing three appointments in a row without a valid explanation

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A total number of (N=40) patients were targeted for the full study. This number was selected based primarily on practical clinical considerations for a single major treatment unit. For a single unit, a maximum of 60 prior to dropout can be expected based on annual discharge rates (APPENDIX 9 ). In addition, ethical considerations required a sensitive approach to recruitment, as many potential participants could not be included for clinical reasons.



**Figure 5-2 Recruitment Flowchart**

The treatment unit in question was for adults assigned a BPD diagnosis by their psychiatrist as per DSM (or ICD) criteria. The patients commonly had had different kinds of treatment for many years. Inclusion and exclusion criteria were based on both ethical and clinical factors. In this study therefore, no willing patient was excluded who satisfied the inclusion criteria. Previous published studies of trauma amongst BPD patients tended to suffer from bias, where participants were targeted from BPD patients who had experienced trauma. Therefore to reduce this bias during the recruitment process, patients were deliberately not asked if they had any traumatic experiences in their past.

A presentation was given to the BPD unit team to remind all clinicians of the results of stage 1 and of their request for a screening instrument, and to present the initial (Pilot) BTERS. This also included a training discussion on how to use the screen.

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Positive feedback was received when clinicians were asked about their willingness to help with the study, as they felt it would be beneficial for their patients. The clinicians recommended that this presentation should also be made to the patients in their therapy group sessions. While the intention stated in the stage 2 Research Protocol (APPENDIX 16 ) was to target the patients from stage 1, this did not prove to be practical as most of these patients were in the course of BPD treatment and introducing BTERS was seen as disruptive. Thus all other patients who attended the clinic during the study period (November 2012 - August 2013) were considered for enrolment into the study, which can therefore be considered a 'convenience sample'. During the presentations, the possibility of trauma triggers and their immediate management was explained to both clinicians and patients, and the Trust approved support system was discussed (incorporated into the Patient Information Sheet). Support was provided for all patient interfaces. After the presentations, a number of patients showed willingness to participate, so with their clinicians' permission they were recruited by the researcher who discussed the patient information documentation with them and obtained written consent. All other patients were recruited following recommendations by clinicians. In each case, formal written consent was obtained as per the process required for ethical approvals (the Patient Information Sheet and the Consent Form are shown in APPENDIX 17 and APPENDIX 14 ).

### **5.5 Pilot Study Objectives**

As BTERS is a new instrument, piloting was required to confirm its clinical acceptability and to make any necessary refinements. The main purpose of the Pilot Study, therefore, is to carry out an initial assessment of Construct Validity, or reliability, prior to the main testing programme. In addition, an initial assessment of Content Validity was made to ascertain whether the questions selected for the pilot version of the screen were appropriate and relevant and adequately reflected the theoretical relationship between trauma and the different disorders. The Pilot thus required a representative selection of subjects (N=13) and, to assist with Face Validity, a number of the BTERS forms needed to be completed both by a clinician and by the patients themselves.

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### 5.6 Pilot Study Methodology (D)

Patients were administered a BTERS screening interview (some for self-completion) followed by the reference assessment (Gold) standard. The SIDES instrument (Pelcovitz *et al.*, 1997) was selected as the gold standard for CPTSD and CAPS (Blake, Weathers, and Nagy, 1995) for PTSD (APPENDIX 24 and APPENDIX 25 ). Although both instruments are discussed in detail in the Literature Chapter (section 2.4.2 and 2.2.6), it is worth reiterating some of the weaknesses of these assessment instruments that led to the request for a short screening device. Both are complex and time consuming, often taking up to 2 hours to complete, and requiring specialist trauma training. As CAPS is designed for PTSD it addresses only Criteria-A trauma and tends to focus on symptoms. Similarly the SIDES for CPTSD/DESNOS focus on trauma symptoms rather than their causes.

The BTERS screening took about 10-15 minutes. To minimise the possibility of bias, the majority of screening was performed by clinicians or by the patients themselves. Thus an assignment of PTSD and/or CPTSD was made either by the patients' clinician (N=10) or by the researcher (N=3). On occasions when the patients themselves completed BTERS, their clinician made the assignment. Although the stage 2 Research Protocol (APPENDIX 16 ) proposed that the participants should be assessed straight after screening using the gold standard instruments, most patients requested a pause following the screening process. The reason for the pause was because patients frequently found the screening distressing and a number reported that this was the first time that they had been asked to discuss such intimate and painful experiences. In all cases however, assessment was completed within 3 weeks of the screening. The researcher assessed each patient with both Gold standards whether or not they met the criteria for trauma and PTSD/CPTSD as defined in BTERS. Checking against a gold standard was completed in order to facilitate a determination of reliability or Construct validity. The researcher was blind to the outcome of 10 (5 clinician and 5 patient) of the (N=13) pilot screens at the point at which she assessed these patients using the CAPS and SIDES.



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### **5.6.1 Impact on Interviewers (Vicarious Traumatization)**

Precautions adopted for managing vicarious traumatization (section 3.6.3) included the following:

- An initial presentation reminding clinicians about the risks and precautions
- Weekly peer supervision, joining group treatment and supervision sessions
- Making sure researcher is available during recruitment of clinicians
- Researcher available almost every day for consultation
- Researcher available for discussions and debriefing
- Looking for signs of vicarious traumatization
- Clinical supervision also assisted the researcher who is a trauma clinician

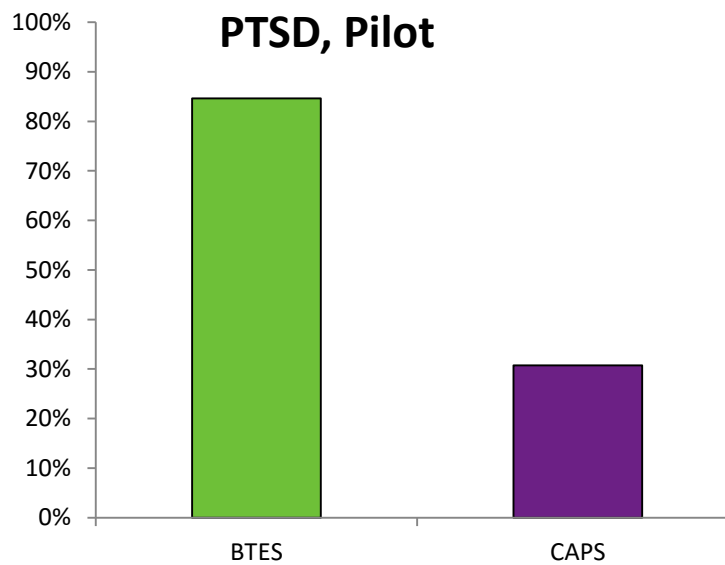
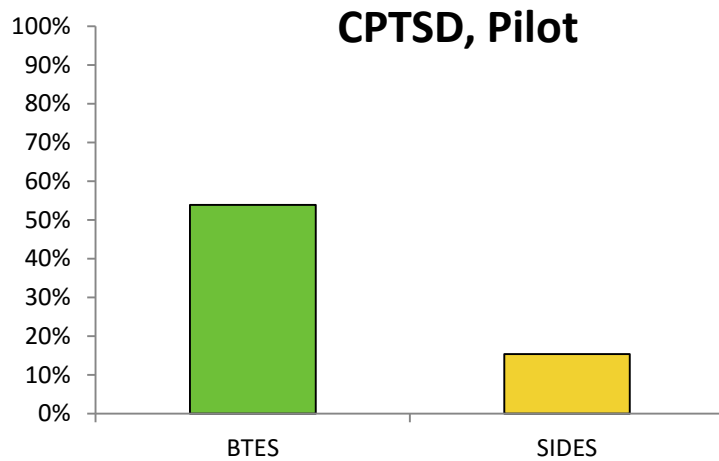
### **5.7 Accuracy of Pilot – Construct Validity (E)**

Construct Validity includes Diagnostic Accuracy which is an indication of how accurate BTERS (the Index Test) is at detecting traumatic experiences and the symptoms of PTSD/CPTSD when compared to the reference or gold standard (Reference Test). The most relevant terms used for assessing accuracy are: sensitivity, specificity; positive and negative predictive values, positive and negative likelihood ratios, diagnostic odd ratios, and receiver operating characteristics (ROC) curve.

- Sensitivity is the probability that someone who scores positive to CAPS, SIDES or to either CAPS or SIDES will have tested positive to BTERS, i.e., true positive
- Specificity is the probability that someone who scores negative to CAPS, SIDES or either will also have tested negative to BTERS, i.e., true negative
- The probability that someone with a positive BTERS will meet the criteria for PTSD/CPTSD, and that someone with a negative test will not receive the diagnosis of PTSD/CPTSD are respectively the positive and negative predictive power of BTERS (PPV/NPV)
- False positives and false negatives are also calculated.

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- **Figure 5-3 Pilot outcome, BTERS vs. CAPS/SIDES**



**Table 5-5 Pilot Accuracy**

Disorders	Sensitivity	Specificity	Positive predictive	Negative predictive	False positive	False negative	Efficiency/ Accuracy
PTSD	100%	22%	36%	100%	<b>78%</b>	0%	46%
CPTSD	100%	55%	29%	100%	<b>45%</b>	0%	62%
PTSD and/ or CPTSD	100%	22%	36%	100%	<b>78%</b>	0%	46%

The charts and table above show that when compared to either the gold standards, BTERS from the Pilot over-predicted both PTSD and CPTSD. Although the pilot showed excellent sensitivities (true positive) of 100%, the excessively

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high false positive (very low specificity of 22% to 55%) results give unacceptable accuracy figures (46% to 62%).

### **5.8 Changes following Pilot – Face & Content Validity Enhancement**

To enhance face and content validity, both patients and clinicians provided feedback about their experience during the screening, including the instructions given before the test, the items, item structure, and response options. Patients responded well to the order of the questions. They reported that they understood the questions and did not find the screening to be too intrusive. However, they also reported that the initial BTERS instruction was too abrupt, and the distinction between BPD and CPTSD was not clearly laid out. Both patients and clinicians were satisfied with the 'Yes' or 'No' response format, as this gave them a sense of control that they appreciated, not requiring them to discuss their past if they felt unable to do so. Some of the forms completed by patients themselves (N=3) were incomplete, these patients did not answer the question on the nature of the relationships of their abuser and as to whether they were still around. This did not affect the objective of BTERS which is to identify trauma, PTSD and CPTSD, therefore all three were included in the analysis. On these occasions, there was sufficient information to be able to make a PTSD/CPTSD assignment appropriately. Nevertheless based on this finding, it was recommended that on future occasions, forms must be completed by a qualified clinician.

Clinicians also reported that they appreciated the order of the questions which they found to be consistent with the clinical diagnosis. They requested more explanation of which experiences are defined as traumatic in DSM and ICD criteria and which are not. This was because they wanted the opportunity to record other traumatic experiences, since some of these were triggering the same responses as the (DSM and ICD) 'Criteria-A's. The clinicians requested an accompanying Scoring Sheet (APPENDIX 26) in order to align the replies from patients more closely with the elements of the disorders as defined in DSM-IV and ICD, and to reduce the subjective element in interpretations. Another finding was the need to ensure that a clinician should always conduct the screening interview, as some patients did not answer all the questions. There were also a few occasions when clinicians were reluctant to follow through with what they felt was intrusive questioning for

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patients who were successfully handling their current BPD treatment. In addition, it was noted that questions relating specifically to each disorder were not placed clearly together, and BTERS would therefore benefit from more definite demarcation. The clinicians also identified aspects of the construct that were not adequately covered.

Subsequently, with additional input from the Steering Group, while no items were eliminated, the following changes were made to BTERS in order to enhance face and content validity, while ensuring that the construct was not compromised:

- Clearer examples of which type of abuse related to each condition
- Examples of what was life-threatening trauma were given for clarity
- More direct and short questions with wording and phrasing selected to minimise ambiguity
- The order of the items was altered to introduce difficult questions gently and to keep items together as defined in the domain of the construct
- Traumatic experiences were grouped in a hierarchical order according to severity
- Items are scored dichotomously i.e. each question is answered with either 'yes' or 'no'
- The screen was divided into sections highlighting the screening of three separate disorders in a single instrument
- The diagnosis was removed from the form, and an additional Scoring Sheet was added
- A simple scoring sheet (APPENDIX 26) was required in order to foster consistency in the assignment of disorders.

On the basis of the face, content and an initial construct validity enhancement, the full test version of the instrument was developed. A number (N=10) of experts were then requested to assess the relevance of the items in the revised screen. These experts included BPD clinicians, trauma clinicians, and the Project Supervisors. They were requested to assign a yes/no answer to the relevance of each of the items. Although various attempts to apply weightings were made, this particular test did not prove to be helpful and had to be abandoned. The data, including the scoring mechanism, are shown in APPENDIX 27. The optimised instrument was then presented to some 50 clinicians who work with BPD, PTSD

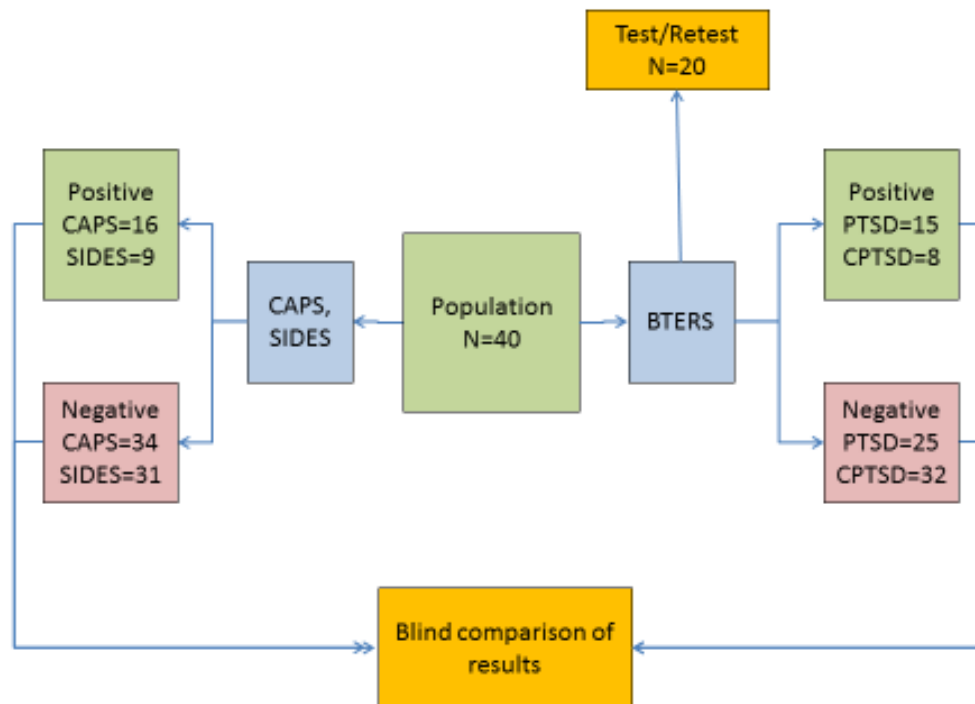
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and CPTSD patients. Their support for the revised instrument to be utilised for the main study was unanimous and they requested no further revisions.

### **5.9 Main BTERS Reliability Trial Methodology**

The updated version of the instrument was then used to systematically screen the remaining (N=27) patients. In addition, all the patients from the pilot (N=13) were rescreened. And again all were then scored by an independent researcher (blind to the patients' identity). As with the Pilot section, all patients were also given an in-depth PTSD/CPTSD assessment by the researcher. Following the request by the original pilot participants who felt that it was too stressful to follow BTERS immediately with CAPS/SIDES, the new patients were specifically offered the option for the CAPS/SIDES assessment to be done on another day (between one and three weeks later). To assist with reliability, (N=20) patients were re-tested. These patients were selected on the basis of clinical and logistical circumstances. These patients who were initially tested by a clinician where now retested by the researcher, and were scored by a separate researcher blind to the patients' identity. All of the screening and scored data is presented in APPENDIX 28 . The diagram below illustrates the flow of the reliability study.

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**Figure 5-4 BTERS Reliability Flow Diagram**

The principal outcome of the main study is an assessment of Construct Validity, which is the degree to which BTERS measures what it claims to measure. Although results must be accurate, they must also be reliable (repeatable), and overall quality control must be ensured. Two aspects of reliability are commonly used and were employed in this study, external and internal; both were used to examine the reliability of BTERS. Nasrin (2009) describes reliability as the ability of an instrument to consistently measure an attribute and how well the items fit together conceptually. Good research techniques entail commenting on the reliability of these measurements, that is, the consistency of test results on repeat measurements. For external reliability, repeatability tests were employed. These consisted of test-retest and inter-rater examinations.

Good reliability refers to the consistency of the results and conclusions drawn from the study (Gosall, p.61, 2009). Although reliability is necessary, it is not sufficient to validate an instrument, because an instrument may be reliable but not valid (Nasrin, 2009). Cronbach and Shavelson (2004) suggested that researchers should also consider the following issues when determining reliability:

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- Independence of sampling
- Heterogeneity of content
- How the instrument is used (Nasrin, 2009)

These issues are addressed in detail in the quality section (STARD, APPENDIX 29 ).

Two techniques were then utilised for assessing the repeatability of BTERS. One was an inter-rater test, where two raters (clinician and researcher) separately scored the outcome of each BTERS screening. The second was a retest (Test Retest), where the initial screening by a practicing clinician was followed by researcher rescreening so that the so that the level of agreement between the initial results and the retest results can be assessed (Gosall and Gosall, 2009). For the test re-test exercise it was not possible to include any of the patients involved in the Pilot study as they had already participated in two screening interviews, and an additional interview could have created unnecessary stress. Similarly, several other patients were not available due to hospital logistics such as over running treatment sessions and hospital transport not being able to wait. Overall, N=20 patients were re-tested. Both test-retest and inter-rater reliability can be quantified by a correlation coefficient (Cohen's Kappa). Kappa ( $\kappa$ ) coefficient is recommended for tests that measure categorical variables or nominal ordered data and it is weighted to allow for any near misses.

Kappa is also known as the 'chance correlated proportional agreement statistic' that accounts for measurements that can be agreed by chance. It indicates whether this agreement is more than can be expected by chance. If the agreement is no more than can be expected by chance  $\kappa=0$ , with a perfect agreement  $\kappa=1$  (Gosall and Gosall, 2009, p.61).

Internal consistency reliability or internal reliability is a test of the Validity of the Construct as previously discussed in section 3.7. It asks if the responses to the items are consistent across the construct (Creswell, 2003). Thus, while content validity was calculated before the pilot test by asking experts to judge the 23 items, the internal reliability of the items was re-evaluated using the actual responses of the (N=40) participants. This particular test was performed by analysing how each patient responded in the main study to each of the questions in BTERS. It determines how well the set of questions in BTERS represents the construct that

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the instrument is supposed to be testing or how well the items fit together conceptually (Nasrin, 2009). Internal consistency was then evaluated numerically using the Chronbach's Alpha coefficient, used because it is the most suitable when there are several variables in the measurement. In the case of dichotomous responses, this can also be called a Kuder Richardson test. If  $\alpha > 0.5$ , there is a moderate agreement, and if  $> 0.8$  there is a good agreement.

### 5.10 Stage 2 Results

Of the Stage 2 (N=40) patients, BTERS identified 15 (38%) with PTSD symptomatology and 8 (20%) with CPTSD. This compared with 40% and 23% respectively for CAPS and SIDES. The numbers of patients showing PTSD and CPTSD as identified by BTERS were compared with the gold standards and are displayed in the table below. Also shown are the BPD patients (52.5 %) who did not experience life-threatening trauma, but who reported that their particular traumatic experiences, mainly (45%) in childhood, were nonetheless highly distressing.

**Table 5-6 Patients Satisfying PTSD/CPTSD Symptoms**

N=40	Screen (BTERS)		Assessment (CAPS, SIDES)	
PTSD	15	38%	16	40%
CPTSD	8	20%	9	23%
PTSD and/or CPTSD	18	45%	16	40%
Life-threatening trauma	19	47.5%	16	40%
Non-life-threatening Trauma (only)	21	52.5%		

Accuracy and efficiency calculated by the test performance indicators of sensitivity, specificity, positive and negative predictive values, as well as false positives and negatives, are shown below (format from Gosall and Gosall, 2009, p.133; Brewin *et al.*, 2002).



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**Table 5-7 Main Study Reliability of BTERS vs. CAPS/SIDES**

Disorders	Sensitivity	Specificity	Positive predictive	Negative predictive	False positive	False negative	Efficiency/Accuracy
PTSD	81%	92%	87%	88%	8%	19%	88%
CPTSD	89%	100%	100%	97%	0%	11%	98%
PTSD and or CPTSD	100%	96%	94%	100%	4%	0%	98%

**Table 5-8 Means, Standard Deviations and 95% Confidence Interval: PTSD and CPTSD**

Study	PTSD			CPTSD		
	Mean	SD	95% CI	Mean	SD	95% CI
Stage 2 BTERS Screen	38%	49%	15%	20%	41%	13%
Stage 2 DSM Standards	40%	50%	15%	23%	42%	13%

Accuracy (see section 5.7) was thus calculated as 88% for PTSD and 98% both for CPTSD on its own and for when a patient has either of both of the disorders. This also shows the trade-off between sensitivity and specificity (any increase in sensitivity will be accompanied by a decrease in specificity).

**Table 5-9 Criteria-A Trauma Range based on 95% Confidence**

Criteria-A Trauma	Gold Standards		BTERS	
	Range	Numbers	Range	Numbers
Minimum expected	25%	10	32%	13
Expected value (mean)	40%	16	45%	18
Maximum expected	55%	22	58%	23

The above table thus shows the statistical analysis of the stage 2 data. Here there is a 95% probability between 25% and 55% of BPD patients in any future experiment will satisfy a diagnosis of PTSD or CPTSD based on CAPS and SIDES. At the same time we are also 95% confident that BTERS will screen between 32% and 58% the same BPD patients as suitable for PTSD or CPTSD assessment. Thus, we

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are 95% confident that BTERS will identify a range of Criteria-A Trauma amongst BPD patients similar to the gold standards. Of greater significance perhaps, is that the range for BTERS falls within the overall 95% confidence range of the published empirical studies.

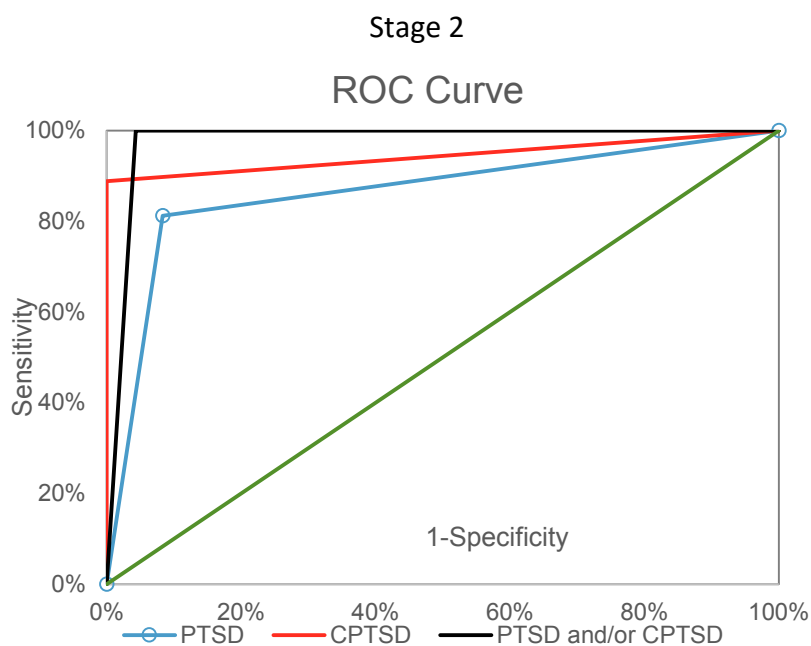
Sensitivity and specificity values were then supplemented by estimating the value under the ROC curve (AUC) where a value close to 1.0 confirms a high level of accuracy, which is a quality cross-check that was established using the standard parameters as recommended in SPSS (version 19).

ROC identifies the points of maximum sensitivity and specificity with respect to predisposing traumatic experiences and its accompanying post trauma reactions (AUDIT, Barbor *et al.*, 2001). ROC was originally developed from signal detection theory and has only recently been applied in psychiatric research (Slade *et al.*, 1998 p.85). In this case, it plots the proportion of individuals classified by BTERS and this plot thus represents the ability of the test to discriminate between those with and those without PTSD/CPTSD. The resulting curve which in this case is a line based on three points is called the Receiver Operating Curve (ROC). The area under the ROC curve (AUC) summarises the ability of the test instrument to discriminate. The computer program SPSS was used to calculate the (AUC) and the confidence intervals around this value to ensure that they were acceptable.

**Table 5-10 ROC Values**

	AUC	Confidence Interval	
		Lower	Upper
PTSD	.865	.734	.995
CPTSD	.984	.948	1.000
PTSD AND OR CPTSD	.984	.948	1.000

These figures calculated by SPSS compare well with a value greater than 0.5, which can be considered a poor match, and 1.0 for a perfect match. AUC values were also plotted below, and the values are equivalent to the calculations in the above Table.



**Figure 5-5 ROC PTSD and/or CPTSD**

Internal Consistency estimated by Cronbach Alpha as calculated for both PTSD and CPTSD was 0.80. Alpha increased to 0.91 and 0.89 respectively when only 4 of the 23 items were considered. These 4 were: life-threatening trauma, sexual abuse, flashbacks and nightmares.

The repeatability results of the test-retest and the inter-rater reliability analysis are shown below, where a Cohen’s kappa of 0.8 or higher defines an acceptable match (Gosall and Gosall, 2009, p.61).

**Table 5-11 Repeatability Results**

Cohen’s $\kappa$	PTSD	CPTSD	PTSD and/or CPTSD
Test-retest	.80	.86	1.00
Inter-rater	.95	1.00	.95

The performance of BTERS was also evaluated against the 25 STARD criteria for appraising the validity, effectiveness and appropriateness of a screening programme, and the results are shown in APPENDIX 29 .

### 5.11 Stage 2 Limitations

A range of potential limitations to stage 2 was considered and is discussed below.

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**Table 5-12 Limitations**

Bias	Limitation	Impact
Admission; Recruitment	Due to the limited numbers of available BPD patients, all (N=63) current patients were invited to participate	Thus admission bias was not an issue for this project as there was no sampling required
Diagnostic Purity	The BPD sample from the hospital may not meet the DSM BPD criteria	The BPD group was determined by hospital processes, not recruited by the project, and therefore was not influenced by the research objectives
Attrition	It is possible that some patients may have excluded themselves because they fear the stresses involved in addressing historical traumas	Again this possible exclusion would tend to lead to an underestimation of potential trauma patients
Sample size	N=40 may be too small to prove that BTERS will consistently identify CPTSD/PTSD	95% confidence interval calculations (Fig 5.8) shows sample is within range of empirical studies for either/or PTSD/CPTSD, but range is too wide to confirm exact percentages for individual disorders with confidence
Interviewer bias	The researcher scored both the retest (N=20) and the assessment, therefore these results may be influenced by previous knowledge	This potential bias may cause accuracy figures to be lower than those calculated
Response bias	Some patients may be over keen to present additional clinical conditions in order to seek attention	Such a risk is equally likely for any assessment, and thus must be addressed by the treatment clinician
Insufficient data collection	Optimum information may not have been obtained from participating experts	BTERS may not be fully optimised

The overall research limitations are again considered in the Conclusions section where a comparison is made with stage 1 results and with findings from published academic and clinical literature.

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### 5.12 Unanticipated Clinical Finding

*The majority of BPD patients (52.5%, N=21) did not experience life-threatening trauma, yet all BPD patients reported that their particular (life-threatening or non-life-threatening) traumatic experiences, particularly in childhood (45%, N=18), were nonetheless highly distressing.*

Non-life-threatening trauma symptoms include intrusions, avoidance and arousal, and are PTSD-like symptoms. A number of patients with such non-Criteria-A trauma (N=13) reported many of the CPTSD (PTSD) cluster symptoms required as per DSM (IV and 5):

- Intrusions in the form of highly distressing unwanted memories, images and nightmares all associated with the stressful events (5% experienced flashbacks)
- Avoidance
- Alterations in arousal and reactivity
- Negative alterations in cognition and mood.

Although this particular finding was not initially anticipated, it is supported by an assessment of psychopathology and exposure to traumatic events where individuals who were exposed to non-Criteria-A trauma reported the same amount of overall distress as those exposed to Criteria-A trauma (Gold *et al.*, p.263, 2005). The traumas listed by these authors included threats to personal integrity, learning about an unexpected or violent death, or the unexpected death or injury of a family member or other close associates. Although both Criteria-A and non-Criteria-A experiences can elicit symptoms of PTSD and PTSD-like symptoms, the two groups differ to some degree with respect to re-experiencing symptomatology. Stage 2 patient interviews indicated experiences reported as non-Criteria-A, such as bullying, inappropriate touching of sexual parts, family and relationship problems. These appeared to be linked with thought processes such as intense and chronic rumination, reflection, selective attention, irritable and startled; and these are similar to re-experiencing symptoms such as intrusive thoughts, and hyper-arousal.

Whereas such a category may be seen as somewhat new in a BPD environment, it is clinically equivalent to Adjustment Disorder (discussed in section 1.5.2), which

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is a well-established psychological condition, although not common in a clinical environment. Allowing for two separate trauma categories can, however, avoid the controversy of either widening or restricting the definition of a traumatic stressor. And while Adjustment Disorder places strong emphasis on symptoms, it also considers how patients perceive the impact of trauma. When these results were presented to BPD Management and clinicians, the initial feedback about incorporating such findings into treatment was positive.

### **5.13 Reliability Study Discussions**

While showing encouraging true positives and negatives for PTSD and CPTSD in comparison with the gold standards (accuracy 88% - 98%, sensitivity - 81% and 89%, and specificity - 92% and 100%), the false negative results (19% and 11%) mean that if the screen is utilised as an alternative to a full gold standard assessment, up to one case in five may be missed. BTERS of course was never designed as an alternative to CAPS or SIDES for diagnosing PTSD or CPTSD, and these results confirm that it is not suitable for this purpose. The effectiveness of correctly identifying either PTSD and/or CPTSD is therefore also assessed and presented, which shows a greater level of agreement with the gold standards. Thus if BTERS is used to determine if a patient has either PTSD, CPTSD or both, true positives and negatives are over 95% with no false negatives. To support this, reliability results as calculated by Cohen's Kappa (Table 5-9) are considered acceptable by statistical standards. The Cronbach Alpha test ( $\alpha=0.8$ ) confirmed that the optimised 16 questions in BTERS provides an acceptable level of internal consistency for the detection of PTSD/CPTSD. The analysis also indicated that reducing the number of questions from 16 to just 4 questions covering life-threatening trauma and sexual abuse, plus flashbacks and nightmares, would actually increase the internal consistency ( $\alpha=0.9$ ) for PTSD/CPTSD detection. However, in order to optimise the screen for non-Criteria-A trauma, items must be specifically identified that single out non-life-threatening trauma. So in order to identify items that satisfy tests for internal consistency of non-threatening trauma, additional internal consistency testing could be undertaken. Therefore, the full range of 16 questions in BTERS was appropriate for the requirement, i.e. to identify all trauma, BPD, PTSD and CPTSD.

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Out of the (N=40) BPD patients, there are 3 patients where BTERS identified CPTSD, but in each of these 3 patients, BTERS did not support a PTSD referral. For each of these three patients, CAPS assigned PTSD whenever CPTSD is diagnosed, because according to the DSM definition, CPTSD can only occur if PTSD is present. As CAPS/SIDES are considered the gold standards, all 3 BTERS cases were assigned as 'false' results, which is consistent with accepted DSM theory. Nevertheless, DSM theory could be challenged, possibly allowing CPTSD to be assigned without the strict criteria-A trauma requirement. In each of these cases, the possibility of a CPTSD diagnosis without PTSD is currently being considered by the relevant clinical specialists. It should be made clear however that this research does not seek to make such a proposal.

### **5.13.1 Adjustment Disorder**

Many of the problems facing those who suffer from non-Criteria-A trauma are quite similar to those associated with Criteria-A trauma, including substance dependence and suicidal behaviour. It is therefore possible that individuals who have been subjected to non-Criteria-A trauma (or can be identified as having Adjustment Disorder), should also be able to benefit from an exposure therapy such as Prolonged Exposure (PE) Psychotherapy, which currently appears to be available only to PTSD patients.

However, in order to make this proposal clinically effective, the PTSD patients who require specialist attention first need to be separated or identified. Using a simple trauma screening instrument such as BTERS, BPD clinicians can thus confidently identify non-Criteria-A trauma and its symptoms, and they could categorise such individuals as also suffering from Adjustment Disorder. Early screening also allows clinicians to progress all relevant treatment without having to wait for specialist trauma assessment for all patients with the symptoms of post trauma reactions. An additional concern noted during the trauma-focused screening was that patients who were not assigned a PTSD/CPTSD result felt somewhat undervalued when their particular distressing trauma was not assigned a prominent categorisation, a situation that often made them feel abandoned, as with the 'early abandonment' criteria. Assigning a valid clinical label such as Adjustment Disorder, with its specific and recognised treatment options, can help vulnerable

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and sensitive BPD patients to feel more included, enhancing therapeutic relationships. This helps them personally recognise and address all the difficult psychological conditions as an integral part of their personalised BPD treatment.

The symptoms of an adjustment disorder included anxiety, worry, poor concentration, irritability, automatic arousal such as palpitations and depression. There may also be outbursts of dramatic or aggressive behaviour, single or repeated episodes of deliberate self-harm, or the abuse of alcohol or drugs. Usually, social functioning is impaired. The onset is gradual and the course becomes prolonged. Stressful life events may precipitate anxiety, depression, and other psychiatric disorders.

### **5.13.1.1 Adjustment Disorder Criteria**

According to both DSM and ICD the symptoms generally start within three months of the stressing event.

*The development of emotional or behavioural symptoms in response to identifiable stress(es) occurring within 3 months of the onset of the stressor;*

*These symptoms or behaviours are clinically significant, as evidenced by one or both of the following:*

- A. Marked distress that is out of proportion with the severity or intensity of the stressor, taking into account the external context and the cultural factors that might influence symptom severity and presentation;*
- B. Significant impairment in social, occupational or other important areas of functioning.*

*The stress-related disturbance does not meet the criteria for another mental disorder and is not merely an exacerbation of a pre-existing mental disorder;*

*The symptoms do not correspond to normal bereavement;*

*Once the stressor or its consequence have terminated, the symptoms do not persist for more than a further 6 months.*

### **5.13.1.2 Aetiology**

Stressful circumstances are a necessary cause of an adjustment disorder, but individual vulnerability must be an important cause because not all people exposed to the same stressful circumstances develop an adjustment disorder. Although no systematic studies on prognosis have been carried out, Gelder *et al.*,



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(2012) suggests that most adjustment disorders last several months and a few persist for years. Adjustment disorder is thus classified as either acute or chronic, depending on whether it lasts more or less than six months. According to DSM-IV-TR and DMS-5, if the disorder lasts less than six months then it can be acute, but if it lasts more than six months then it must be considered chronic (Casey, 2001). The presence of a causal stressor is essential before a diagnosis of adjustment disorder can be made, and those exposed to repeated trauma are at greater risk, even if that trauma is in the distant past (Bisson and Sakhuja, 2006).

### **5.13.1.3 Differential Diagnosis**

The distinction between an adjustment disorder response and a normal stress response is based on the severity of symptoms and their duration, where the impact on everyday functioning is related to the nature of the stressor and how it is perceived. PTSD, with its very specific constellation of symptoms, requires the presence of a high magnitude stressor that would be traumatic for almost everybody. Not everybody exposed to such a traumatic event, however, responds by developing PTSD, and the possibility that other disorders can follow instead needs to be considered. For those not meeting the diagnostic criteria for PTSD, but with significant symptoms and/or functional impairment, Rosen suggests that Adjustment Disorder should be considered as a practical alternative (Rosen *et al.*, 2008, cited in Gelder *et al.*, 2012).

### **5.13.1.4 Treatment**

Adjustment Disorder treatment is designed to help with the resolution of the causal stressor problems if at all possible, but also to aid the natural process of adjustment by reducing avoidance of the stressful events, reducing maladaptive coping responses and encouraging problem solving. Counselling in problem-solving can encourage patients to seek solutions and to consider the advantages and disadvantages of various kinds of actions (Gelder *et al.*, 2012). The evidence base for the treatment of Adjustment Disorders is limited due to paucity of studies. A further problem is that the disorder is to a large extent a self-remitting condition, so that it may be hard to distinguish between the results of intervention and spontaneous resolution. However both this current study and Gold *et al.* have shown that effects can be long-lasting and debilitating. Three specific

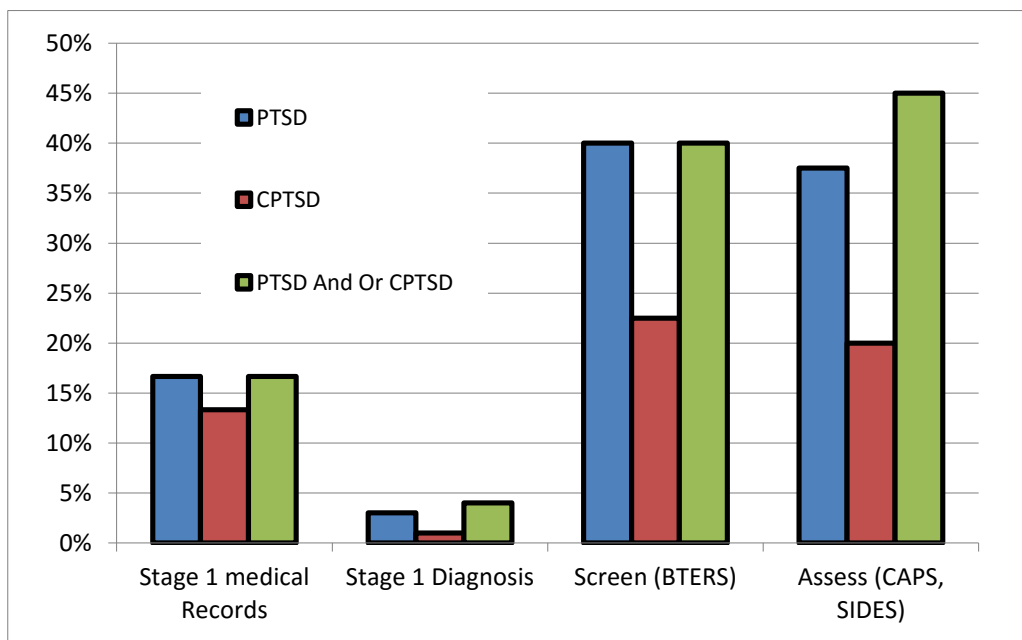
## Stage 2

psychological therapies, spanning the range of supportive, psycho-educational, cognitive and psychodynamic approaches, have been found to ameliorate Adjustment Disorder symptoms.

- *Dialectic Behaviour Therapy (DBT)* for example has been found to be beneficial to patients who engage in deliberate self-harm. The effectiveness of DBT was confirmed following two years of randomised controlled trials, which compared DBT with therapy by experts specialising in suicidal behaviour (Linehan, 2006)
- *Cognitive Behaviour Therapy (CBT)* was also shown to be helpful when administered to patients with adjustment disorder who experience work related stress (National Child Traumatic Stress Network, 2003)
- *Prolonged Exposure (PE) Psychotherapy* is designed to reduce psychological fear where patients intentionally address fear in otherwise safe objects, situations, thoughts sensations and memories. The goal is to reduce fear and other negative reactions to similar stimuli in the future (Foa, 2011).

### 5.14 Comparison of Stage 2 with Stage 1 Results

The stage 2 PTSD/BPD comorbidity rate of 40% is considerable higher than the 16% interpreted from patients' medical records in stage 1.



**Figure 5-6 Results Comparison for Stages 1 and 2**

In order to validate a comparison of the results between stages 1 and 2, a methodology comparison is presented below, where key differences are listed.

## Stage 2

**Table 5-13 Methodology Comparison Stages 1 & 2**

	Stage 1 (N=60)	Stage 2 (N=40)
Location	3 hospitals	1 hospital
Sample Selection	Existing BPD Patients Medical Records	Current and new BPD patients (not same as stage 1)
Assessment Technique	Analyse keywords from routine clinical recordings  Clinician interviews	Interviews utilising new 1 page (BTERS) structured screen then followed by CAPS/SIDES
Assessors	BPD Clinicians' records analysed by Researcher	BTERS by Clinicians, CAPS/SIDES by Researcher

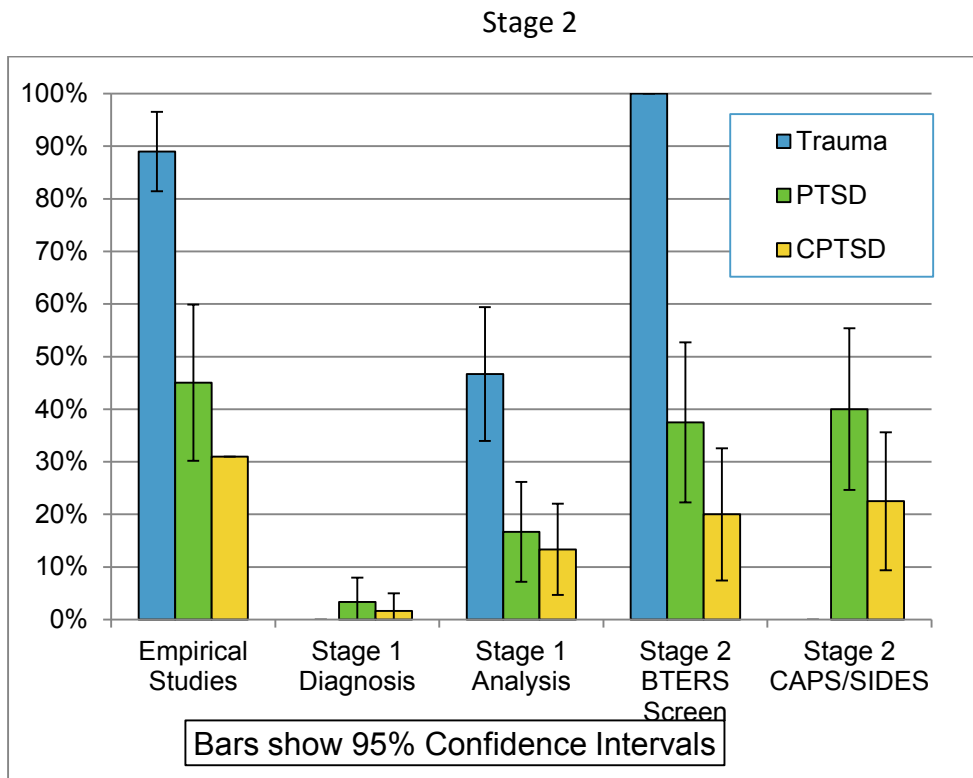
### 5.15 Comparison of Stage 1 and 2 with other Empirical Studies

As shown below, stage 2 with its combination of life-threatening and non-life-threatening trauma, compares more closely than stage 1 with the overall trauma records. Levels of PTSD and CPTSD are higher than stage 1 and are in line with the mean and standard deviations of the other studies.

**Table 5-14 Results Comparison**

Study	Trauma		PTSD		CPTSD	
	Mean	SD	Mean	SD	Mean	SD
Empirical Studies	89%	12%	45%	17%	31%	N/A
Stage 1 Diagnosis	N/A	N/A	3.3%	18%	1.7%	13%
Stage 1 Analysis	47%	50%	17%	38%	13%	34%
Stage 2 BTERS Screen	100%	N/A	38%	49%	20%	41%
Stage 2 DSM Standards	N/A	N/A	40%	50%	23%	42%

95% confidence intervals were estimated and results plotted below. This calculation utilises the standard deviations and the sample size so that a range of results from stages 1 and 2 can be compared with previously published empirical results.



**Figure 5-7 Comparison of Empirical Studies with Stages 1, 2**

The error calculations show that the stage 2 results for both BTERS and CAPS/SIDES are consistent with the mean results from empirical studies, although stage 1 results are not.

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### 5.16 Stage 2 Conclusions

Referring back to the specific stage 2 objectives identified in the chapter introduction, the table below summarises the quantitative results.

**Table 5-15 Stage 2 Conclusions**

No	Specific Stage 2 Objectives	Conclusions
1	<p>Establish the % of patients with criteria for in-depth trauma assessment and treatment in BPD.</p> <p>Identify and specify the type of trauma experienced by BPD patients.</p>	<p>100% (N=40) of the BPD patients interviewed identified significant traumatic experiences, 92.5% (N=37) in childhood.</p> <p>47.5% (N=19) were life-threatening.</p> <p>52.5% (N=21) non-life-threatening.</p>
2	<p>Detect PTSD/CPTSD in BPD patients using gold-standard clinical instruments.</p> <p>Compare % of Trauma, PTSD, CPTSD identified with stage 1 results and with literature</p>	<p>40% of BPD patients satisfied PTSD/CPTSD requirements based on CAPS/SIDES.</p> <p>PTSD-BPD comorbidity: 25% (Golier) to 39% to 50% (Harned), and 16% had PTSD and/or CPTSD symptoms based on an interpretation of patients' notes.</p>
3	<p>Establish the extent of BPD over-diagnosis.</p>	<p>High comorbidity PTSD/CPTSD is consistent with over-diagnosis of BPD</p>
4	<p>Develop and trial a trauma screening instrument for clinicians to discriminate BPD with possible PTSD/CPTSD.</p>	<p>BTERS field testing confirmed PTSD/CPTSD in agreement with gold standards CAPS/SIDES (98% accuracy).</p>

Stage 2 did not address the misdiagnosis of BPD as this was adequately discussed in stage 1; however, stage 2 results confirm that the opportunity to treat comorbid PTSD/CPTSD in almost half of the BPD patients is being missed.

The numerical results of the stage 2 tests have identified that BTERS could be a useful instrument for identifying trauma in BPD patient presentations, and in particular for differentiating between life-threatening trauma and non-life-threatening trauma.



## 6 DISCUSSION

### 6.1 Introduction

The overall project research question was:

*Can trauma screening optimise the identification of traumatic experiences/PTSD/CPTSD in patients with BPD, and resolve the misdiagnosis of BPD controversy?*

The research question was addressed by four sub questions. These sub questions were derived by breaking down the overall question. They were designed not only to establish the facts in a systematic manner, but also to find and test a contribution to the solution to the misdiagnosis controversy. Findings are synthesised by discussing the results from literature together with the results from stage 1 (BPD Patient Medical Records Review, N=60 and clinician interviews), and also from stage 2 where BPD patients from one hospital (N=40) were screened for trauma/PTSD/CPTSD using a newly developed 'BPD Traumatic Experiences and Reactions Screen' (BTERS), plus a full PTSD/CPTSD assessment according to DSM standards (CAPS and SIDES). The additional (5<sup>th</sup>) finding relating to the application of Adjustment Disorder for non-life-threatening trauma is also discussed. The principal findings are first listed below, and are then discussed in detail, before being presented in a summary which forms a conclusion to the research.

- Consistent with previous empirical studies, a high proportion of BPD patients in this study were found to suffer from at least one highly distressing traumatic experience
- A significant proportion of these patients also meet a comorbid diagnosis of PTSD and or CPTSD/DESNOS which is in line with generally, though not universally accepted, academic knowledge. For these patients therapies are available which improve outcome
- BPD is over-diagnosed, rather than misdiagnosed as interviewed BPD clinicians are reluctant to ask about trauma due to fear of triggering reactions for which they are not trained. Diagnosing BPD with less than the recommended number of criteria from the DSM/ICD diagnostic manuals was found to be an accepted

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practice, not only in this study, but also in a wide-ranging US survey of BPD clinicians

- The BTERS short screening instrument, although based on the results using a small sample, has reliably identified trauma and rapidly discriminated which BPD patients are suitable for specialised PTSD/CPTSD trauma focused treatment
- Almost half of interviewed patients suffer from only non-life-threatening traumatic experiences, a condition consistent with Adjustment Disorder, and treatable by simple trauma treatment techniques by BPD clinicians without PTSD/CPTSD specialist trauma training

A dedicated section then draws together the overall limitations to the project along with advantages and strengths. These were confirmed by both patient and clinician feedback as well as academic and clinical peer reviews, and the section also includes a review of the effectiveness of the Research Structure and Design. Implications and recommendations are then drawn together and discussed in terms of clinical, research recommendations and recommendations for the screen itself. Finally, the implications of the findings and recommendations for enhancements to clinical practice and for further research are discussed. This is followed by highlighting the unique contributions to academic knowledge.

### **6.2 Discussing the Research Findings**

This study has demonstrated that from the BPD patients whose records were reviewed in stage 1, and from those screened and interviewed in stage 2, a high proportion have had at least one highly distressing traumatic experience, either life-threatening or non-life-threatening. Trauma was recorded on 47% of BPD patients' records, and 100% (N=40) of stage 2 patients screened and interviewed had some traumatic experience. While the link between trauma and BPD has been previously demonstrated (section 1.6.2), there are also a number of equally relevant biological and environmental causes of BPD. Marsha Linehan (1997) presented the Bio-Psychosocial Model of BPD, and according to this theory, BPD arises from a combination of biologically based difficulties in the processing of emotions and specific environmental circumstances as well as their transaction. The biological components in this model arise from a combination of genetic



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vulnerability, intra-uterine and developmental factors affecting physiological development. The environmental (which she terms invalidating) contributors can be any circumstance involving neglect, such as emotional withdrawal by a carer, psychological trauma such as sexual abuse, or severe punishment. The outcome of combined biological vulnerability to emotions, an invalidating environment and adverse childhood events is thus seen as a fundamental disruption of the emotional regulation system and the development of BPD. More than 9 separate empirical studies (section 2.2.2) reported that between 70% and 100% of BPD patients have experienced distressing trauma, supporting evidence for the high percentage of trauma in BPD. These studies range from a limited inpatient study by Famularo, Kinscherff, and Fenton (1991) to a recent large-scale US longitudinal national study of BPD in the community by Pagura *et al.* (2010), and Grant *et al.* (2008). It is worth noting however that the impact of trauma could have been exaggerated in these studies because sampling often encouraged the inclusion of patients with existing trauma. In stage 2 of the current study where 100% (N=40) experienced trauma, of which 92.5% (N=37) identified specific distressing traumatic experiences in their life before the age of 13. While such a level of trauma may appear to be high, it was confirmed that the type of trauma encountered consisted of a combination of life-threatening (47.5%) and non-life-threatening (45%) childhood trauma.

On the other hand, the relatively low recording of all references to both life-threatening and non-life-threatening trauma (47%) in patient records by BPD clinicians in stage 1 was explained by the BPD clinicians themselves, who reported that discussing trauma, particularly childhood trauma, with patients was a daunting experience, as they felt that they did not have the skills to manage the life-threatening trauma typical of PTSD that they anticipated would emerge during the assessment process. Avoidance of alternative diagnosis by BPD clinicians was also noted by Whealin and Stone (2009), and by Westen (1997) in his wide survey of BPD practitioners in the US.

However, direct mathematical comparisons between the various trauma percentages recorded can be problematic, not only because the clinical significance of these traumatic experiences has not been consistently recorded in the literature, but also because, if individual research projects were investigating

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trauma, this has the potential to bias the sampling and assessment process. This is especially true when findings have to rely on memory, which can be influenced by expected outcomes.

Nonetheless, the evidence found both in literature and in the current investigation strongly supports the hypothesis that a high proportion of BPD patients have had distressing traumatic experiences. Although BPD was originally defined in terms of presenting symptoms, trauma has been identified by many authors (such as Herman, Perry, and van der Kolk, 1989; Gunderson and Sabo, 1993 and DSM-5) as one of many equally relevant biological and other environmental causes such as attachment processes gone awry. This finding is valuable because addressing trauma during treatment has proven to be beneficial in promoting long term remission and improvement in prognosis of BPD (Shea *et al.*, 1997). This study has, however, demonstrated in addition that, from a treatment perspective, non-life-threatening trauma, as well as life-threatening trauma as defined by DSM, can be highly distressing and have a significant long-term impact.

The second finding from the study supports the notion that a high proportion of patients presently clinically diagnosed with BPD also meet a comorbid diagnosis of PTSD and or CPTSD (DESNOS). The low rates in patients' records are explained by the clinician themselves, who revealed that trauma is rarely discussed for fear of 'opening Pandora's Box' and disturbing existing treatment with volatile reactions to complex traumatic memories. The theoretical link between BPD and PTSD/CPTSD (DESNOS) has remained controversial since Herman's (1992) proposal to re-conceptualise BPD as PTSD associated with childhood abuse. This re-conceptualisation has not been universally accepted, and Roth *et al.*, (1997) have argued that that while there is a large degree of overlap, and on the surface these conditions appear to be quite similar, they only partially coincide. It was also recommended that clear distinctions be drawn between the disorders, requiring separate diagnosis (Haigh, 2003). This distinction was accepted by many Trust clinicians during clinical discussions. It is thus left to empirical studies to establish the level of comorbidity between BPD and PTSD/CPTSD.

The comorbid hypothesis is supported by this research, as 40% of the BPD patients in stage 2 were confirmed with a PTSD diagnosis by the DSM gold standard (CAPS)

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whereas a comorbid diagnosis was not previously identified. This percentage is consistent with comorbid PTSD in BPD as reported in comparable studies in the academic literature (section 2.2.2). These percentages range from 25% reported by Golier *et al.* (2003), to 39% reported in the major US longitudinal study analysed by Pagura *et al.* (2010) and also by Grant *et al.* (2008). High comorbidity rates of PTSD in BPD, ranging from 30% to 50%, are also noted by Harned *et al.*, (2012). The lower stage 1 PTSD results (16%) could again be explained by the reluctance of BPD clinicians to address life-threatening trauma. While according to Roth *et al.*, (1997), there is no direct theoretical link between CPTSD (as opposed to classical PTSD) and BPD, CPTSD in stages 1 and 2 (13% and 23%) could be seen as comparable with the 31% of inpatients with CPTSD reported by Barnow *et al.*, (2005). There is a marked contrast, however, with the less than 4.41% (N=3) of the stage 1 patients who were assigned a PTSD or CPTSD diagnosis by the clinicians in the BPD clinic. Both stage 1 and 2 results therefore confirm that a significant proportion of BPD patients could benefit from PTSD/CPTSD treatment. In practical terms, clinical leaders would first need to find a way to systematically introduce early trauma screening by practising BPD clinicians. Given the comorbid PTSD diagnosis and the reluctance to address potentially difficult memories, a dedicated treatment trial with associated trauma screening and assessment may prove beneficial in order to fully confirm and promote the benefits of PTSD/CPTSD treatment for BPD patients.

Although the evidence from this study was insufficient to support the hypothesis that BPD is misdiagnosis as noted by NICE (2008) and MIND (2007), the high comorbid PTSD/CPTSD rates confirmed by CAPS/SIDES in stage 2 identifies under-diagnosis of BPD-PTSD/CPTSD comorbidity as a significant finding, and arguably an over-diagnosis of BPD. The theoretical concept behind the misdiagnosis of BPD originates from Herman (1992) and, other trauma specialists such as Vaillant (1992). These pioneers have been consistently promoting the adoption of BPD as a complex variant of PTSD as an alternative diagnosis. A contrasting explanation is that trauma might not be a significant underpinning cause, supporting findings from literature that whereas trauma can cause BPD, other causes such as genetic/epigenetic factors and constitutional vulnerabilities, neurophysiological, neurobiological and psychosocial can be just as significant (e.g., Zanarini *et al.*,

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1997). Although approached from a completely different perspective, over-diagnosis of BPD was explained empirically by Westen (1997) in his examination of large scale USA BPD practice. These results were compared against the DSM requirements that specify the presence of at least five criteria for BPD. Westen found that the practice of diagnosing BPD with less than five DSM recorded symptoms was common throughout the US (section 2.3.3.1.3), and that clinicians supported BPD diagnosis based on general behaviour and observation during interviews. This is supported by the stage 1 BPD patients' medical records where only 12% of patients satisfied this strict DSM criterion for BPD. For ICD-10, a minimum of three criteria are recommended, so the BPD percentage would rise to 32%. Subsequent discussions with clinicians showed that the required criteria in clinical practice were less strict than recommended by DSM, and typically patients have been diagnosed and treated for BPD based on fewer symptoms, the most common indicators being suicidal and self-damaging behaviour.

While 12% compliance with strict DSM criteria would tend to support the misdiagnosis of BPD, such a definitive conclusion cannot be confirmed, as diagnosing BPD based on fewer DSM criteria is a well-established and accepted clinical practice. The 'high prevalence of BPD' noted by NICE could well be related to the willingness by clinicians to assign a BPD diagnosis when fewer symptoms than the DSM recommended criteria are presented. Of greater significance however, is that the opportunity to treat comorbid PTSD/CPTSD (16% in stage 1, and 47% in stage 2) in almost half of the BPD patients is being missed, as clinicians feel unqualified to deal with the consequences of disclosing life-threatening trauma. If, on initial presentation, patients receive the opportunity for PTSD/CPTSD treatment, then a higher recovery rate than with BPD treatment is likely to result, (Harned, 2012).

Currently the only RCT on treating BPD patients for trauma was conducted by Harned *et al.*, (2012) as a pilot, treating (N=7) BPD patients with PTSD with DBT and Trauma Focused CBT, and this indicated that the treatment was efficacious and effective in minimising PTSD. The majority of patients no longer met criteria for PTSD at post-treatment (71.4% of DBT PE Protocol completers, 60% of the intent-to-treat sample). Although a very small sample, it also indicated a large

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amount of reduction in suicidal ideation and intentional self-harm, with global social and emotional adjustments improving significantly, and the resolution of the trauma symptoms making these patients more able to manage and deal with their day to day life. Another limitation, which Harned also identified, was that patients may have reported a reduction in suicide tendencies because they received more attention from the trial clinicians. Nevertheless the treatment of BPD patients for trauma is recommended by a number of authors (Shea *et al.*, 2004; Foa *et al.*, 1997). Thus, while in many cases a BPD diagnosis may be valid, almost half of these patients may be better served by receiving immediate treatment for PTSD/CPTSD. A sole (BPD) diagnosis means the potential benefits of trauma treatment are being missed, either life-threatening (PTSD/CPTSD), or non-life-threatening (Adjustment Disorder), both of which can be addressed if identified on first contact with the system.

The stage 2 field trial (reliability study) supported the notion that a short trauma screening instrument can reliably, rapidly and sensitively discriminate which BPD patients are suitable for trauma focused treatment, although limitations such as the small sample size will have to be addressed in future trials. Although a number of PTSD screens are already available, screens such as SPAN, TSQ, IES and others (reviewed in

Table 2-4) focus on the psychological sequelae of discrete life-threatening traumas. These screens generally did not prove suitable for detecting the complex often repeated and frequently non-life-threatening types of (generally childhood) trauma typically experienced by patients with BPD/CPTSD.

When presented with evidence of significant percentages (47%) of trauma and comorbid PTSD/CPTSD from the stage 1 analysis of patients' medical records, practising BPD clinicians requested an effective trauma screening methodology – BTERS. A subsequent trial with (N=40) BPD patients confirmed the accuracy of BTERS in identifying trauma, PTSD and/or CPTSD when compared with DSM standards (CAPS/SIDES - 98% accuracy), and thus satisfies the objective as an efficient screening instrument for both Criteria-A and non-Criteria-A trauma. While the specificity of BTERS for predicting PTSD or CPTSD alone was acceptably high (92% and 100%), unacceptably relatively low sensitivities (high false negatives

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of 19% and 11%) in comparison the sensitivities experienced for predicting either/or PTSD/CPTSD (100%), confirms that BTERS, as currently designed, is not a suitable substitute for CAPS/SIDES assessments.

BTERS therefore should not be used for the diagnosis of PTSD/CPTSD as it was not developed as a diagnostic instrument. Nevertheless, the form and usability of this one page screen has been welcomed as efficient by practising BPD clinicians. In discussions however, clinicians confirmed that, once BPD treatment commences, they did not recommend diverting patients for alternative trauma assessment and treatment even if PTSD/CPTSD is identified during screening. The most effective opportunity for trauma/PTSD/CPTSD screening, therefore, would be to incorporate BTERS screening as an integral part of initial BPD assessment, at first contact with health professionals.

Early discussion at initial contact about trauma was discussed by Bryer, Nelson and Miller, where they advocate caution because of the potential danger of re-traumatising patients (see section 2.3.6.1.1). However this hasn't been borne out by Gaubagh *et al.* (2011). While recognising these concerns, they concluded that mental illness will almost certainly be exacerbated, and care hindered if trauma related treatment is not offered at an early stage. Mueser and Rosenberg conducted an extensive literature search from the past 31 years on PTSD treatment of people with severe mental illness (Mueser *et al.*, 2001). They were unable to locate a single published report that provided evidence that addressing the sequelae of trauma amongst severely mentally ill including PTSD was unsafe or clinically harmful. In addition, more than 150 clinicians suggested that inpatients receiving acute care as well as outpatients with severe mental illness can respond to assessment of trauma and PTSD without psychotic distortions that would invalidate their responses (Rosenberg *et al.*, 2011). Mueser *et al.* also demonstrated that with 16 weeks of CBT trauma focused therapy, severely ill BPD patients with PTSD could be treated successfully in conjunction with treatment as usual (Mueser *et al.*, 2008). Under these circumstances, the clinicians and managers interviewed expressed a willingness to adopt this form of trauma, PTSD/CPTSD screening.

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This study identified that the majority of BPD patients (52.5%, N=21) had not experienced life-threatening trauma, yet 45% (N=18) of all BPD patients reported that their particular non-life-threatening traumatic experiences such as being used as a sexual object, sexual organs inappropriately touched, or subjected to severe bullying particularly in childhood, were nonetheless highly distressing. The stage 2 results confirm the presence of non-life-threatening trauma (non-Criteria-A) in addition to life-threatening trauma in BPD patient presentations. Some patients presented with PTSD-like symptoms including intrusions, avoidance and arousal. Others (N=5) reported many of the CPTSD (PTSD) symptoms required as per DSM (IV and 5), including intrusions in the form of re-experiencing highly distressing memories, images and nightmares all associated with the stressful events (5% experienced flashbacks). This unanticipated finding is supported by a reported assessment of psychopathology and exposure to traumatic events where individuals who were exposed to non-Criteria-A trauma reported the same amount of overall distress as those exposed to Criteria-A trauma (Gold *et al.*, 2005, p.263). It has already been shown (section 1.5.2) that Adjustment Disorder can be considered as the clinical consequence of suffering from non-Criteria-A traumatic stressors. Although a well-established psychological condition, Adjustment Disorder is not currently a common diagnosis in a BPD clinical environment. However, allowing for two separate trauma categories can avoid the controversy of either widening or restricting the definition of a traumatic stressor. While Adjustment Disorder places strong emphasis on symptoms, it also considers how patients perceive the impact of trauma.

However, in order to make this proposal clinically effective, the PTSD cases that will require specialist attention first need to be identified and separated. Once the more challenging Criteria-A patients are screened and sent for specialist trauma care, BPD clinicians can confidently identify non-Criteria-A trauma and its symptoms, categorising such individuals as also suffering from Adjustment Disorder. As a result, with minimal additional training, all BPD clinicians could apply simple trauma-focused treatment such as PE (Prolonged Exposure Therapy) to their patients (currently only available for PTSD), without having to cope with the types of problematic life-threatening trauma that needs specialist care and that can be anxiety provoking for clinicians not specialised in trauma.

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PE develops a restorative therapeutic relationship, building coping skills, where patients learn to attach new meanings to old sensations and thus process traumatic memories (McCann and Pearlman, 1992). This process therefore complements established BPD treatment processes of building cognitive and behavioural skills and then re-establishing secure social connections. In this way, BPD clinicians, who welcomed the format and usability of BTERS for improving and optimising the identification of traumatic experiences, should not be required to cope with the types of problematic life-threatening trauma that need specialist care and that can cause anxiety for non trauma trained clinicians.

Early screening also allows clinicians to progress all relevant treatment without having to wait for specialist trauma assessment for all patients with the symptoms of post trauma reactions. Applying a valid clinical label such as Adjustment Disorder with its specific and recognised treatment options can also help vulnerable and sensitive BPD patients to feel more included, less abandoned, enhancing therapeutic relationships. This helps them personally recognise and address all of the difficult psychological conditions as an integral part of their personalised BPD treatment.

### **6.3 Conclusions**

In conclusion, the literature review and both stages of the study demonstrated that traumatic experiences, PTSD, and CPTSD are probably under-recognised in patients with the diagnosis of BPD. In stage 2, all patients who reported life-threatening trauma met the criteria for a diagnosis of PTSD/CPTSD as well as BPD. The high rates of trauma make a sharp contrast with low rates of comorbid BPD/PTSD or CPTSD diagnosis in the patients' records survey. These low rates were explained by BPD clinicians who revealed that trauma is rarely discussed for fear of 'opening Pandora's Box' and disturbing ongoing treatment with volatile reactions to complex traumatic memories. Although this apparent contradiction is problematic, low rates of PTSD and/or CPTSD diagnosis are consistent with internationally accepted practice for clinicians to diagnose and effectively treat BPD on less than the recommended criteria. Nevertheless, the high PTSD/CPTSD comorbidity in stage 2 emphasises an under-diagnosis of, or under-recognition of comorbid BPD-PTSD/CPTSD. A single (BPD) diagnosis means the potential benefits



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of trauma treatment are being missed, either life-threatening (PTSD/CPTSD), or non-life-threatening (Adjustment Disorder), both of which can be addressed if identified on first contact with the system.

The stage 2 reliability study showed that the newly developed screen (BTERS) can improve and optimise the identification of traumatic experience in this client group which may help to resolve the misdiagnosis controversy. The importance of non-life-threatening trauma then came to light as some interviewed patients reported no life-threatening experiences, but had non-life-threatening experiences that were nonetheless highly distressing. BPD clinicians considered Adjustment Disorder as a promising treatable option for such patients who do not require specialist trauma treatment.

### **6.4 Advantages and Limitations of the Research**

The advantages and limitations of the research design can be assessed in terms of the effectiveness of the thesis structure and the research design.

#### **6.4.1 Effectiveness of Thesis Structure**

The effectiveness of the selected Compromise Thesis Model combining Focus Down and Opening Out (section 1.2) can now be evaluated. From the beginning of the study, the research benefited from a comprehensive literature review focusing down on the relationship between trauma and BPD. This was complemented by a theoretical analysis of the disorders inherent in the Focus Down technique, without being overly diverted by the many findings about BPD and trauma that are so important to analysis. The Opening Out element then permitted the whole research programme to devote considerable efforts to the individual methodologies within the two stages, while remaining close to the initial research concept and question. The Opening Out approach also proved beneficial in developing the findings relating to non-life-threatening trauma. Finally, in order to complement the strong focus on the practical results, and not to risk missing any relevant academic findings, regular updates to the literature search were included and well as frequent reviews with subject matter experts.

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### 6.4.2 Evaluation of the Effectiveness of Research Design

The effectiveness of the selected methodology (chapter 3) which was designed in order to address the research sub questions can now be assessed by referring back and critically assessing the mixed method sequential design (section 3.3). In doing so, BPD practitioners were facilitated to make critical contributions to the detailed design of the instrument development. This may not have been possible without the mixed method approach involving the discipline of the patients' records survey and the screen pilot study. In this respect, the numerical results both from the survey of medical records and the comparison between BTERS and CAPS/SIDES provided the backbone for drawing the principal conclusions. Central to the success of the interviews with BPD clinicians and management was the grounded theory/ constant comparison. While this method proved to be useful, the constant comparison method of analysis did not reveal any new findings from what could have been deduced from a simple summary of the results of the individual interviews.

### 6.5 Overall Limitations

The limitations of each component of the research are discussed in detail within the individual chapters, with attention given to the various types of validity, threats to validity and bias; so that mitigations could be systematically applied. For an overarching perspective, threats to the validity of the conclusions and recommendations are now discussed. Two primary limitations appear to stand out: the relatively small number of available patients and the potential for a single researcher to unduly influence the results to fit with expectations. In each case, mitigations were put in place.

As numbers of patients involved were limited (N=60 in stage 1, and N=40 in stage 2) this meant that a precise percentage for trauma and for potential PTSD and CPTSD diagnosis cannot be predicted. As the sample was small, there is a larger error range (also called a 95% Confidence Interval). From stage 2, the Criteria-A trauma as identified by the Gold Standards was 40%, with an error range of  $\pm 15\%$  (Table 5-8). Similarly, Criteria-A trauma for BTERS was 45%  $\pm 13\%$ , (Table 5-9). Whereas utilising a larger sample would tend to reduce the error range, and result in more precise trauma, PTSD and CPTSD percentages, this would not alter the

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research conclusion that there is 95% confidence that a significant proportion of BPD patients would benefit from specialised (Criteria-A) trauma treatment. In order to establish a narrower error range it would be necessary to repeat the BTERS reliability study with a larger sample size.

An additional consequence of this range is that a future treatment trial (RCT) may have to plan for a consequently wider range of BPD patients that may require detailed assessment for Criteria-A trauma. For a successful treatment trial, higher sample numbers are likely to be required, and in this case the required sample numbers should be statistically confirmed during a treatment trial feasibility study. For budget control, such a programme may require a more precise prediction of the number of BPD patients expected to be treated at trauma centres. Nevertheless, the use of literature comparisons also provided significant robustness to the overall interpretation of the results. In addition, Steering Group reviews and regular discussions with clinical personnel at all levels confirm their support for a screening, assessment and treatment RCT based on their confidence in the suitability of BTERS. Similarly the risks due to undue researcher bias were mitigated by the use of blind scorers and analysts, and again by challenging group and individual feedback sessions.

### **6.5.1 Advantages and Disadvantages of the Research**

The advantages and disadvantages of the research design can be assessed in terms of the effectiveness of the thesis structure and the research design.

### **6.5.2 Evaluation of the Effectiveness of Research Design**

The effectiveness of the selected methodology (chapter 3) which was designed in order to address the research sub questions can now be assessed by referring back and critically assessing the mixed method sequential design (section 3.4). In doing so, BPD practitioners were facilitated to make critical contributions to the detailed design of the instrument development. This may not have been possible without the mixed method approach involving the discipline of the patients' records survey and the screen pilot study. In this respect, the numerical results both from the survey of medical records and the comparison between BTERS and CAPS/SIDES provided the backbone for drawing the principal conclusions. Central to the

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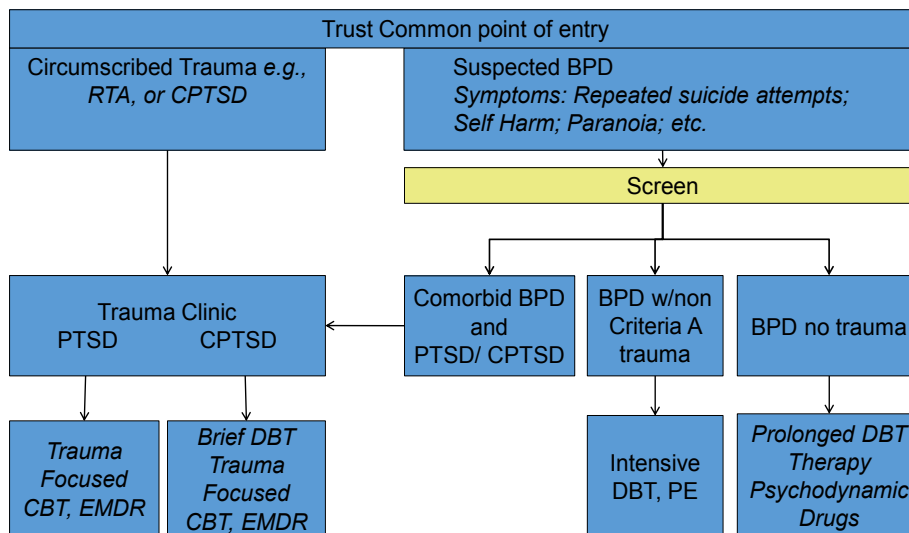
success of the interviews with BPD clinicians and management was the constant comparison/ grounded theory. While this method proved to be useful, the constant comparison method of analysis did not reveal any new findings from what could have been deduced from a simple summary of the results of the individual interviews.

### 6.6 Recommendations

The implications of the findings are now discussed for the clinical environment, which include specific recommendations. Recommendations are then presented for research and for BTERS.

#### 6.6.1 Clinical Implications and Recommendations

The underlying childhood trauma that has been demonstrated to cause significant distress should be routinely screened for each new BPD patient as represented in the revised clinical concept below, and reconsidered for existing BPD patients.



**Figure 6-1 Revised Clinical Concept**

Clinical policy should therefore be adjusted to require the BTERS simple trauma screening device to be formally incorporated into standard assessment procedures in BPD units ("Tier 3 Personality Disorder Services"). The implications are that this will permit BPD clinicians to both isolate comorbid PTSD/CPTSD and to identify distressing non-life-threatening trauma. Thus, at the common point of

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entry to the mental health system, as soon as potential PTSD/CPTSD comorbidity is identified, a referral programme should be developed with specialist trauma units for appropriate assessment.

NICE has highlighted that in the circumstances of any BPD comorbid disorder, it is necessary to refer the patient to a special treatment plan that addresses his or her core difficulty as well as the comorbid disorder (NICE, 2009). Not making these referrals could thus be denying patients effective and evidentially validated treatment such as trauma focused CBT and EMDR (Eye Movement Desensitization and Reprocessing; NICE, 2005; Mueser *et al.*, 2008; Cloitre *et al.*, 2010). In addition, not treating long term disorders such as PTSD/CPTSD can perpetuate poor self-rated health and personality changes, and PTSD symptoms can become worse. Indeed, this had been confirmed in recent studies (Grubagh *et al.*, 2011; Al-Saffer *et al.*, 2002). Some documented cases include addiction to drugs or alcohol; chronic pain; hypertension or physical maladies; self-injury; overwhelming fear of death; compulsiveness; personality changes and self-destructive incidents, to name a few (Canadian PTSD Association, 2004-2011). Also, as a number of studies have reported high health costs associated with BPD, overall costs could be reduced (Greenberg *et al.*, 1999; Solomon and Davidson, 1997).

To support the screening process, all BPD clinicians should receive sufficient basic training to become confident in addressing patients' non-life-threatening traumatic history. As a comorbid Adjustment Disorder diagnosis can legitimately be assigned to such BPD patients who are troubled by non-Criteria-A traumatic events. Adjustment Disorder Treatment consisting of clinically proven active psychotherapy treatment processes such as CBT/DBT, psychoanalysis and in particular PE, could become a more readily identifiable label. These techniques focus on the causal links in BPD and could be immediately integrated into individual treatment programmes without the requirement for dedicated trials. The results of this study can therefore be utilised to promote and highlight the adoption of Adjustment Disorder for all BPD assessments as a separate comorbid category. This is derived from the non-Criteria-A traumatic stressors that include experiences such as those identified by the patients in stage 2.

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No specific recommendation can be supported by the current study to re-diagnose or to declassify BPD patients either according to Herman's CPTSD proposal or by strict (DSM-IV and 5, or ICD) criteria guidelines. These patients were usually assessed by the clinically approved SCID assessment technique (section 2.4.1). However, this research has identified a significant weakness, in that clinicians are stopping with a single (BPD) diagnosis and not considering comorbid PTSD/CPTSD. And as recovery rates with treatment for these disorders is generally higher, in this sense BPD can be considered to be over-diagnosed.

Nevertheless, clinical evidence from professional practitioners from both stage 1 and stage 2 also supports the practical benefits of a BPD diagnosis, and patient improvement rates were confirmed using classical BPD treatment. However, the continuing high rate of readmission for BPD provides a constant incentive to seek out and adopt enhanced treatment methods such as PE with DBT, in addition to specialist treatment for comorbid PTSD/CPTSD. Ongoing academic and clinical debate about BPD diagnosis must, however, never lose sight of the priority of providing vulnerable patients with an effective range of treatment methods, commencing with therapeutic relationships.

### **6.6.2 Research Recommendations**

The initial requirement for future research is to replicate the BTERS screening with a larger sample. This should confirm the prevalence of trauma and reinforce the effectiveness of trauma focused treatment for BPD patients both with the DSM specified PTSD criteria, and without (but nonetheless with post trauma symptoms). An efficient approach to this objective could be to perform a two part trauma focused trial. The first part would repeat and consolidate the performance of BTERS utilising a larger number of participants by comparing BTERS results performed by practicing BPD clinicians, with trauma assessments using CAPS/SIDES performed by independent trauma clinicians. The second part then offers tangible benefits to Criteria-A participants by repeating the controlled treatment comparison trial (section 2.2.2) of BPD patients conducted by Harned *et al.*, (2012). This 2012 trial examined comorbid BPD/PTSD patients (N=13) with a history of suicide attempts, and over 50% of the patients showed a reduction in PTSD symptoms. Concurrently, a trial should be undertaken for patients who have

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been identified by BTERS as not been affected by life-threatening trauma (i.e., patients with non-Criteria-A trauma). A comparison should therefore be made between trauma-focused PE with DBT, against DBT on its own, both undertaken by a single team of BPD Clinicians.

In order to ensure that the benefits of all forms of treatment continue to be maintained, such a test would require critical clinical oversight from both BPD and trauma practitioners. For such a major controlled trial to be successful, it would require the participation of several specialist hospitals and significant professional clinical engagement by both specialist BPD and Trauma units as well as the patients themselves, and might take a number of years to reach its full conclusions. Once relevant findings and recommendations from this current research are published in topical clinical and academic literature, the publicity and exposure could assist in promoting such a treatment trial.

Further research should also be considered to distinguish between flashbacks (the intrusive symptoms and thought processes that are the hallmarks of PTSD), and distressing intrusive thoughts that may arise from non-life-threatening traumatic memories. This research should seek to better characterise and create a typology of these experiences and memories. The implication of such a programme is that clinicians could feel more confident about discussing signs and symptoms and differentiating between memories associated with life-threatening and those that are not, without having to discuss the causative traumatic events in detail.

### **6.6.3 BTERS Screen Recommendations**

BTERS should be used as a starting point to allow BPD clinicians to deal with non-life-threatening traumatic experiences. During this research, the BTERS screen has already been used in practice by a number of clinicians in initial BPD assessments, and its introduction in its current state as a practical day-to-day instrument has now been requested by a representative selection of clinicians who work with BPD patients. More importantly, its adoption has been strongly endorsed by BPD clinical managers working with BPD patients in the participating hospital. Moreover, it already has a significant track record among both patients and clinicians who found it useful. It must always be remembered however, that the proposed application of the screen is not to replace the full PTSD/CPTSD

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assessments (CAPS & SIDES) but to identify whether a patient should be referred to a specialist clinic where they will receive a full assessment of both disorders, or if they should receive trauma focused treatment such as PE for non-life-threatening trauma from their regular clinicians. In addition, as BTERS makes it possible to screen separately for Complex PTSD as well as (classical) PTSD, such an early indication is likely to be of assistance when referrals are made to trauma specialists. BTERS should also be tested in different clinical settings where BPD symptoms may be presented, e.g., primary care settings such as GP clinics, school's nurses, and common point of entry to hospitals. Discussions with BPD professionals concluded that using BTERS at an early stage, i.e., the common point of entry into hospital(s) can steer patients to the appropriate department for full and appropriate assessment without delays, so that they can receive the early treatment required. BTERS is a new instrument that has to date only been field tested in a single study, although it has been successfully used by several clinicians. Like any new screening instrument, BTERS has the potential for further improvement. No clinical screening device can be successful without the effective participation of both clinicians and patients. To achieve this, any enhancements should therefore be carefully aligned to changes in each specific clinical environment. In particular, as this project has clearly demonstrated, all new screening applications must be supported by comprehensive patient and clinician interaction and feedback.

### **6.7 Original Contribution to Clinical and Academic Knowledge**

This research project constitutes the first known systematic clinical attempt to quantify the presence of treatable PTSD and CPTSD in a significant sample of BPD patients utilising a simple screening instrument. It may therefore prove to be a significant contribution to psychiatric knowledge in aiding clinicians by means of a simple screening technique prior to detailed diagnosis. This could potentially break the cycle of repetitive BPD hospital admissions for BPD patients with CPTSD/PTSD comorbidity. In addition, it could be the first occasion where life-threatening and non-life-threatening trauma has been differentiated in a BPD population. Such a differentiation is a critical parameter in the potential for subsequent successful treatment of the trauma component in BPD.



### **6.8 The Future Outlook**

If replication studies support the value of the BTERS instrument, its routine use could offer hope of the provision of more effective treatment and thus a better quality of life for the many thousands of individuals who suffer from BPD and comorbid CPTSD/PTSD. To translate such aspirations into reality, the starting point following the proposed retesting and treatment trial, is for NHS Trusts to embrace the clinical recommendation for the introduction of the BTERS screen at common point of entry to the mental health system. The application of BTERS will then encourage high quality trauma focused treatment for BPD patients for both life-threatening traumatic experiences and non-life-threatening experiences (in parallel with existing BPD treatments) to become the norm. Treatments for PTSD/CPTSD (life-threatening trauma) and Adjustment Disorder (non-life-threatening trauma) already exist within the NHS. The distinctions between the different trauma types for patients with BPD symptomatology cannot be recognised and the correct treatment implemented without the dedication and collaboration of our excellent clinical and academic personnel, who work tirelessly with one of the most challenging and debilitating illnesses in modern society. Similarly, there can be no success story without the future contribution of a well-designed, well-funded and well-led treatment trial of the screening, assessment and treatment of BPD for underlying trauma. Such a research programme will make a vital contribution to credible and effective new ways of caring for some of our most vulnerable citizens.



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## Abbreviations

AD	Adjustment Disorder
APA	American Psychiatric Association
AUC	Area under the ROC curve (statistical accuracy)
AUDADIS	Alcohol instrument
AUDIT	Alcohol Use Disorders Identification Test
BPD	Borderline Personality Disorder
BTERS	BPD Trauma Exposure and Reactions Screen
CA	Criteria-A (for trauma)
CAMH	Canadian Centre for Mental Health
CAPS	Clinical Administrated PTSD Scale
CASP (group, 2013)	Critical Appraisal Skills Programme
CAQDAS	Computerised Assisted Qualitative Data Analysis
CBT	Cognitive Behaviour Therapy
CONSORT	Consolidated Standards of Reporting Trials
CPTSD	Complex PTSD
CSA	Childhood sexual abuse
CVI	Content Validity Index
DBT	Dialectical Behaviour Therapy
DES	Disorders of Extreme Stress
DESNOS	Disorders of Extreme Stress Not otherwise Specified
DIB	Diagnostic Instrument for Borderline
DICA	Diagnostic Interview for Children and Adolescents, Revised
DoH	UK Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMBASE	Biological document database
EMDR	Eye Movement Desensitization and Reprocessing

ICD	International Statistical Classification of Diseases
IES	Impact of Event Scale
IPDE	International Personality Disorder Examination
ISTSS	International Society for Traumatic Stress Studies
MEDLINE	Medical Literature Analysis and Retrieval System Online
MIND	National Association for Mental Health (UK)
NICE	National Institute for Health and Care Excellence, UK
NPV	Negative predictive value
NSPCC	National Society for the Prevention of Cruelty to Children
PE	Prolonged Exposure Therapy
PPV	Positive predictive value
PsycINFO	Psychology Information
PTSD	Post Traumatic Stress Disorder
QUADAS	Quality Assessment of Diagnostic Accuracy Studies
RCT	Randomised Controlled Trials
ROC	Receiver operating characteristics
SCID	Structured Clinical Interview for DSM Disorders
SIDES	Structured Interview for Disorders of Extreme Stress
SPAN	Startle Physiological arousal Anger and Numbness
SPSS	Statistical Package for the Social Sciences
STARD	Statement of Reporting Studies of Diagnostic Accuracy
SVI	Sexual Violence Research Initiative
TA	Traumatic Antecedent
TAQ	Traumatic Antecedent Questionnaire
TF-CBT	Trauma focused Cognitive Behaviour Therapy
TSQ	Trauma Screening Questionnaire

## APPENDIX 1 BTERS Screen

### BPD Traumatic Experiences and Reactions Screen (BTERS)

Patient Number:

**I am going to ask you some questions about some stressful things that sometimes happen to people. You may find it upsetting, as it may bring back uncomfortable feelings or memories. People sometimes find that talking about them can be helpful. If anything gets upsetting, we can slow down and talk about it.**

<b>Box 1</b>	<i><b>Before age 13</b></i>
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A. Did you experience or witness any events that were repeated and particularly highly upsetting, e.g. Physical abuse, domestic violence, bullying, emotional neglect etc.? YES , NO

B. Indicate the most upsetting event \_\_\_\_\_ and at what age?

C. Did any of these events make you feel not important, rejected unsure of yourself or abandoned? YES , NO

D. Did anyone repeatedly inappropriately touch your private parts, or made you touch theirs? YES , NO

E. Did anyone ever made you have any form of repeated sex against your will? i.e., rape YES , NO

F. Did you feel as if you were permanently damaged? YES , NO

G. Indicate your relationship with the abuser(s), e.g. stranger, family member. And is he/she still around?  
 \_\_\_\_\_

<b>Box 2</b>	<i><b>After age 13</b></i>
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A. Did you experience or witness traumatic event/s that was life threatening or a serious injury (e.g. stabbing, car accident, rape, torture, a sudden death of someone close), (not bullying, divorce, redundancy, etc.) YES  NO

B. Any other experiences? \_\_\_\_\_

<b>Box 3</b>	Which events above distressed you most at the time?	
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A. Box 1 YES , NO  Which letter in Box 1 \_\_\_\_\_

B. Box 2 YES , NO  Which letter in Box 2 \_\_\_\_\_

<b>Box 4</b>	
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A. When unexpectedly reminded of the worse event, is it very distressing for you? YES , NO

B. Worst than that, do you re-experience the event in the present, (like it is happening now) accompanied with the fear or horror that you felt at the time of the event? YES , NO

C. Do you get nightmares associated with the event/s? YES , NO

D. Are you startled, irritable, jumpy at something unexpected? YES , NO

E. Do you sometimes try to push the memory of the trauma and the feeling of fear away? YES , NO

<b>Box 5</b>	At the time, what aspect of the traumatic event did you find most upsetting?	
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A. Was it the event itself that upset you? YES , NO

B. Was it other aspects, such as parents / guardians not protecting you? YES , NO

**Advise Patient that:**

- a. Talking about upsetting events can bring back distressing memories and or nightmares
- b. Teach grounding techniques to be used at home if required
- c. If that does not work, to contact their care coordinator for further advice



APPENDIX 2 PTSD Screens

Horowitz's Impact of Event Scale

Below is a list of comments made by people after stressful life events. Please check each item indicating how frequently these comments were true for you during the past seven days. If they did not occur during that time, please mark the 'not at all' column.

	Not at all (0)	Rarely experienced (1)	Sometimes experienced (2)	Often experienced (3)
1 I thought about it when I didn't mean to.				
2 I avoided letting myself get upset when I thought about it or was reminded of it.				
3 I tried to remove it from memory.				
4 I had trouble falling asleep or staying asleep.				
5 I had waves of strong feelings about it.				
6 I had dreams about it.				
7 I stayed away from reminders of it.				
8 I felt as if it hadn't happened or it wasn't real.				
9 I tried not to talk about it.				
10 Pictures about it popped into my mind.				
11 Other things kept making me think about it.				
12 I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13 I tried not to think about it.				
14 Any reminder brought back feelings about it.				
15 My feelings about it were kind of numb.				

*Note:* Intrusion subset = 1, 4, 5, 6, 10, 11, 14;  
 and avoidance subset = 2, 3, 7, 8, 9, 12, 13, 15.  
 Reproduced by permission of Professor Mardi J. Horowitz, from Horowitz (1986).

### **SPAN (four-item Startle, Physiological arousal, Anger, and Numbness instrument)**

To use the PC-PTSD instrument ask the patient:

In your life have you ever had any experience that was so frightening, horrible, or upsetting that in the past month you:

1. Have had nightmares about it or thought about it when you did not want to?
2. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
3. Were constantly on guard, watchful, or easily startled?
4. Felt numb or detached from others, activities, or your surroundings?

Three or more "yes" answers to these questions represent a positive result for PTSD.

Finally, another four-item screening instrument was validated in a group of veterans with symptoms of depression. The instrument consists of an initial question ("Have you witnessed or experienced an event that involved threatened or actual serious injury or death?"), followed by three additional questions about symptoms (i.e., troubling memories, feeling distant or cut off, and feeling "super alert" or on guard). The overall likelihood of PTSD for patients experiencing trauma was 37 percent. The likelihood was 11 percent for those with none of the three symptoms, 27 percent for those with one symptom, 45 percent for those with two symptoms, and 71 percent for those with all three symptoms.<sup>8</sup>

Among the four instruments discussed above, Breslau's short screening scale and the PC-PTSD instrument have been validated in representative populations and can be recommended for use in the primary care setting.



## Trauma Screening Questionnaire (TSQ)

Your own reactions now to the traumatic event

Please consider the following reactions which sometimes occur after a traumatic event. This questionnaire is concerned with your personal reactions to the traumatic event which happened to you. Please indicate (Yes/No) whether or not you have experienced any of the following at least twice in the past week.

1. Upsetting thoughts or memories about the event that have come into your mind against your will
2. Upsetting dreams about the event
3. Acting or feeling as though the event were happening again
4. Feeling upset by reminders of the event
5. Bodily reactions (such as fast heartbeat, stomach churning, sweatiness, dizziness) when reminded of the event
6. Difficulty falling or staying asleep
7. Irritability or outbursts of anger
8. Difficulty concentrating
9. Heightened awareness of potential dangers to yourself and others
10. Being jumpy or being startled at something unexpected

Received July 5, 2001

Revision received January 2, 2002

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## APPENDIX 3 BPD Screens

IPDE

### East Berkshire Complex Needs Pathway



National  
Personality Disorder  
Development Programme

### Personality Questionnaire (IPDE)

Name	Date Completed
------	----------------

**DIRECTIONS**

1. The purpose of this questionnaire is to learn what type of person you have been during the past five years.
2. Please do not skip any items. If you are not sure of an answer, select the one-TRUE or FALSE- which is more likely to be correct. There is no time limit, but do not spend too much time thinking about the answer to any single statement.
3. When the answer is TRUE, circle the letter T and when the answer is FALSE, circle the letter F.

1	I usually get fun and enjoyment out of life	TRUE	FALSE
2	I trust people I know	TRUE	FALSE
3	I'm not fussy about little details	TRUE	FALSE
4	I can't decide what kind of person I want to be	TRUE	FALSE
5	I show my feelings for everyone to see	TRUE	FALSE
6	I let others make my big decisions for me	TRUE	FALSE
7	I get upset when I hear bad news about someone I know	TRUE	FALSE
8	Giving in to some of my urges gets me into trouble	TRUE	FALSE
9	Many people I know envy me	TRUE	FALSE
10	I give my general impression of things and don't bother with details	TRUE	FALSE
11	I've never been arrested	TRUE	FALSE
12	People think I am cold and detached	TRUE	FALSE
13	I get into very intense relationships that do not last	TRUE	FALSE
14	Most people are honest and fair with me	TRUE	FALSE
15	People have a high opinion of me	TRUE	FALSE
16	I feel awkward or out of place in social situations	TRUE	FALSE
17	I am too easily influenced by what goes on around me	TRUE	FALSE
18	I usually feel bad when I hurt or upset someone	TRUE	FALSE
19	I find it very difficult to throw out things	TRUE	FALSE
20	At times I have refused to have a job, even when I was expected to	TRUE	FALSE
21	When I am praised or criticized I let others know how I feel	TRUE	FALSE
22	I use people to get what I want	TRUE	FALSE
23	I spend too much time trying to do things perfectly	TRUE	FALSE
24	People often make fun of me behind my back	TRUE	FALSE
25	I have never threatened suicide or injured myself on purpose	TRUE	FALSE
26	My feelings are like the weather, they are always changing	TRUE	FALSE
27	To avoid being criticized I prefer to work alone	TRUE	FALSE
28	I like to dress so I stand out in a crowd	TRUE	FALSE
29	I will lie or con someone if it serves my purpose	TRUE	FALSE
30	I am more superstitious than most people	TRUE	FALSE
31	I have little or no desire to have sex with anyone	TRUE	FALSE
32	People think I am too strict about rules and regulations	TRUE	FALSE

33	I usually feel uncomfortable or helpless when I am alone	TRUE	FALSE
34	I will not get involved with people until I am certain they like me	TRUE	FALSE
35	I would rather not be the centre of attention	TRUE	FALSE
36	I think my spouse (or lover) may be unfaithful to me	TRUE	FALSE
37	People think I have too high an opinion of myself	TRUE	FALSE
38	I am careful about what I tell others about myself	TRUE	FALSE
39	I worry a lot that people may not like me	TRUE	FALSE
40	I often feel "empty" inside	TRUE	FALSE
41	I work so hard I do not have time left for anything else	TRUE	FALSE
42	I worry about being left alone and having to care for myself	TRUE	FALSE
43	I have tantrums or angry outbursts	TRUE	FALSE
44	I have a reputation for being a flirt	TRUE	FALSE
45	I feel very close to people I have just met	TRUE	FALSE
46	I prefer activities that I can do by myself	TRUE	FALSE
47	I lose my temper and get into physical fights	TRUE	FALSE
48	Some people think I am tight or stingy with my money	TRUE	FALSE
49	I often seek advice or reassurance about everyday decisions	TRUE	FALSE
50	To get people to like me I help them with unpleasant jobs	TRUE	FALSE
51	I am afraid to making a fool of myself with people I am close to	TRUE	FALSE
52	I often mistake objects or shadows for people	TRUE	FALSE
53	I am very moody	TRUE	FALSE
54	It's hard for me to get used to a new way of doing things	TRUE	FALSE
55	I daydream about being famous	TRUE	FALSE
56	I take chances and do reckless things	TRUE	FALSE
57	Everyone needs a friend or two to be happy	TRUE	FALSE
58	I discover hidden threats in what some people tell me	TRUE	FALSE
59	I usually try to get people to do things my way	TRUE	FALSE
60	When I am under stress things around me do not seem real	TRUE	FALSE
61	I get annoyed when people will not do what I ask	TRUE	FALSE
62	When a close relationship ends, I can hardly wait to start a new one	TRUE	FALSE
63	I avoid unfamiliar activities so I will not be embarrassed trying to do them	TRUE	FALSE
64	People find it hard to get the point of what I am saying	TRUE	FALSE
65	I prefer to associate with talented people	TRUE	FALSE
66	I have been the victim of unfair attacks on my character or reputation	TRUE	FALSE
67	I do not show much emotion	TRUE	FALSE
68	I do things to get people to admire me	TRUE	FALSE
69	I am usually able to start projects on my own	TRUE	FALSE
70	People think I am odd or eccentric	TRUE	FALSE
71	I feel at ease in social situations	TRUE	FALSE
72	I have held grudges against people for years	TRUE	FALSE
73	I find it hard to disagree with people I depend on a lot	TRUE	FALSE
74	It is hard for me to stay out of trouble	TRUE	FALSE
75	I go to extremes to try to keep people from leaving me	TRUE	FALSE
76	When I first meet someone I do not say much	TRUE	FALSE
77	I have close friends	TRUE	FALSE

**BORDERLINE PERSONALITY DISORDER**

**BORDERLINE PERSONALITY DISORDER CRITERIA**

A pervasive pattern of instability of interpersonal relationships, self-image, and affects and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

- |   |   |                |            |
|---|---|----------------|------------|
| <p>90. You've said that you have <i>(Have you)</i> often become frantic when you thought that someone you really cared about was going to leave you.</p> <p>What have you done?</p> <p><i>(Have you threatened or pleaded with him/her?)</i></p>  | <p>(1) frantic efforts to avoid real or imagined abandonment (<b>Note:</b> Do not include suicidal or self-mutilating behavior covered in item (5).)</p> <p>3 = several examples</p>  | <p>? 1 2 3</p> | <p>112</p> |
| <p>91. You've said that <i>(Do)</i> your relationships with people you really care about have lots of extreme ups and downs.</p> <p>Tell me about them.</p> <p><i>(Were there times when you thought they were everything you wanted and other times when you thought they were terrible? How many relationships were like this?)</i></p> | <p>(2) a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation</p> <p>3 = either one prolonged relationship or several briefer relationships in which the alternating pattern occurs at least twice</p> | <p>? 1 2 3</p> | <p>113</p> |

**? = inadequate information    1 = absent or false    2 = subthreshold    3 = threshold or true**



## **APPENDIX 4 Steering Group Terms of Reference**

### **Group Objective**

Provide informal advice on research aims, methodology and interpretation of data.

### **Commitments**

Reading a reasonable selection of provided information

Critically questioning interpretations and conclusions whenever practicable

Proactively suggesting improvements to methodology

Attendance at occasional meetings is not a requirement but could be considered

Members can resign from the Group due to conflicting commitments

Provision for anonymous participation will be provided

Group will comply with the Project agreed ethical procedures, (e.g., confidentiality will be respected).

Membership of the Group does not imply endorsement of the findings or conclusions of the research. However, if desired, acknowledgements will be made in the final report.

### **Methodology**

Primarily an e-mail sharing group

A shared web area can be included

I will act as group moderator

Moderator will provide regular summary updates

### **Participants**

I am looking for a small group of clinicians, researchers, supervisors, who could give a varied and intelligent view on the different aspects of this study.

Participants should not necessarily feel as passionately as I do about the study, nor should they be expected to contribute in all areas.







# A study of Life Experiences and the Diagnosis of Mental Health Problems

Protocol for: A study of Life Experiences and the Diagnosis of Mental Health Problems

REC No: 10/H0605/23

## Background

Borderline Personality Disorder (BPD) is the most commonly diagnosed form of Personality Disorder (Shevin et al., 2007) and has been recognised as a clinical condition that can be seriously disabling and often takes a huge toll on the individual (NICE, 2008).

The key diagnostic criteria of BPD (as presented in the Diagnostic and Statistical Manual of Mental Health disorders, DSM-IV) is an instability in interpersonal relationships, self-image and affect, combined with marked impulsivity beginning in early childhood and present in a variety of contexts. BPD patients also portray transient, stress related paranoid ideation, with recurrent suicidal behaviours, gestures, threats and self-mutilation.

NICE estimates that 0.7-2% of the general public could be suffering from BPD, with 20% of all psychiatric inpatients and 10-30% of outpatients (NICE, 2008). This is supported by epidemiological studies (Pinto, 2000; Torgenson, 2002; and Coid, 2006). Suicide is a particular risk in BPD with up to 1 in 10 people with BPD committing suicide, 400 times higher than the national average suicide rate (NICE 2008; Jeffrey et al., 2009; Cailhol et al., 2008). The UK Department of Health (DoH) and the National Association for Mental Health (MIND) have highlighted a worrying 'danger of misdiagnosing BPD'. Many experts also believe that most if not all cases of BPD should be re-conceptualized as Post Traumatic Stress Disorder (PTSD) associated with childhood abuse, (e.g., Lineham, 1993).

An initial literature review has confirmed the possibility that a very high percentage of cases of BPD can potentially be re-conceptualized as Post Traumatic Stress Disorder (PTSD) associated with childhood abuse (Lineham, 1993; Herman, 1992), usually called Complex Post Traumatic Stress Disorder (CPTSD). Potentially this may have very significant implications for the treatment and clinical management of these patients.

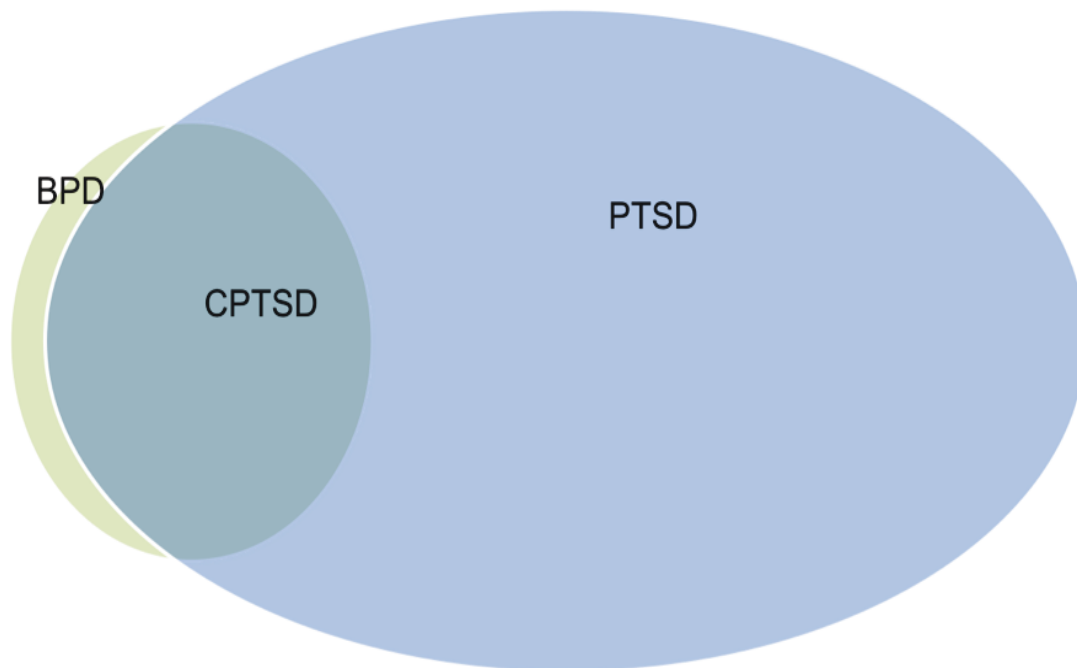
Furthermore, a number of studies have shown that many who have been exposed to chronic childhood trauma are diagnosed as having personality disorder, particularly BPD (Zimmerman et al., 1999; Hodges, 2003; and van der Kolk et al., 1994). Some studies have linked this to a causal effect (e.g., McLean, 2003), thus there is an established resemblance and overlap between the presenting symptoms of BPD and CPTSD. However according to van der Kolk, while there is a large degree of overlap and on the surface both conditions appear to be quite similar, these disorders only partially coincide and there is a clear distinction between them (van der Kolk et al., 1994). It has also been suggested that many of patients diagnosed with BPD can be assigned more discriminating diagnosis such as CPTSD (Valliant, 1992; Herman, 1997), which would signpost clinicians to provide appropriate psychological treatments.

NICE (2009) has suggested that failure to make the diagnosis sufficiently early may prevent appropriate early intervention to ameliorate the difficulties. Therefore reliable identification and assessment of BPD is required.

### **Assessment Instruments**

The reliability of diagnostic assessments for BPD has been considerably improved by introduction of 'standardized interview schedules'. However, no single schedule has emerged as 'the gold standard', as each has its advantages and disadvantages' (NICE, 2008). There is still a heavy reliance on the diagnosis of BPD being made following unstructured clinical assessments, and there are more potential pitfalls, such as obtaining agreement among clinicians, (i.e. inter-rater reliability) (Melsop, 1982).

The aim of this program of research is to develop more sensitive & specific tools to discriminate BPD from CPTSD



Although NICE have recently recommended asking patients about early childhood traumatic experiences, which might reveal abuse or neglect (NICE, 2008, p.300), this does not appear to be indicated in the recommended diagnostic criteria for BPD (NICE, 2008, pp.20, 301). Hence there appears to be an underlying problem that clinicians are not assessing or recording history of traumatic experiences and PTSD in patients given the diagnosis of BPD and perhaps missing vital information that may enable recovery.

To date, although research has investigated both the link between childhood traumatic experiences and the development of BPD, and also the link between the overlapping relationship between BPD and CPTSD, there is a clear need for a diagnostic Instrument that includes childhood traumatic experiences and PTSD in the assessment of BPD.

### **Recognised Area for Further Investigation**

NICE has suggested that a more reliable diagnosis should be made of BPD patients to enable the most appropriate interventions to be adopted, with the aim of reducing repeated hospital admissions, suicide, and cost to patients, their family members social relations, clinicians and the NHS (NICE, 2008).

### **Objectives**

The current project is the first stage of a planned doctoral program of research. The aim of this first stage is to map current practice in Berkshire Healthcare Foundation NHS Trust (BHFT) for diagnosing BPD/CPTSD. This mapping exercise will inform the later development of a new, trauma sensitive diagnostic instrument for assessing patients presenting in ways suggestive of BPD/CPTSD. To this end, the researcher will examine a selection of medical records of patients diagnosed with BPD to extract information on which life experiences clinicians have discussed with patients, and how that information has informed diagnosis and the formulation of the care plans which guide treatment.

## **Method**

### **Data Collection**

The medical records of all patients admitted to acute psychiatric inpatient wards in Berkshire over a 12 month period will be screened against the inclusion criteria by clinical staff. Potential participants who meet the criteria will be approached by the health-care-team. This will be done by informal discussion about the research project and how they could help. Written information about the voluntary nature of their participation will be given to those who express an interest in participation. All patients will be given the opportunity to discuss the study with the researcher if they wish and ask questions before making a decision. Patients will be given a minimum of 24 hours to consider if they wish to take part and to allow their medical records to be examined. Investigation of medical records using the Study Tool designed by the researcher of all BPD patients will then commence once consent has been obtained.

### **Data Analysis**

#### **AIMS:**

1. To identify information on which current diagnoses are based
2. To calculate the frequency of different assessment instruments used
3. To identify the nature of any trauma recorded and their frequencies. Establish the number and types of different treatments received to date
4. To determine, through a structured format, the percentage of patients with CPTSD, and also the index of variability, or standard deviation

5. To establish interrelationship patterns between variables such as demographics, clinical history and treatments received. This will be presented in frequency tables

The data analysis is essentially descriptive but statistical computer packages such as SPSS will be employed whenever required to calculate frequencies and percentages etc.

### **Inclusion criteria**

All acute in-patients diagnosed with BPD in a one-year period in Berkshire will be approached. (Based on 2008/2009 discharge statistics, this should be about, n=120).

- All potential participants must know and understand their diagnosis
- Age between 18 and 65 years old
- Able to give informed consent to participate in the study

### **Exclusion Criteria**

- Currently acutely disturbed / psychotic.
- Unable to give informed consent.

### **Risks to Participants**

The study of the medical records of patients in the sample group in Berkshire should not generate any significant risks to these patients.

### **Data Management and Storage**

The master-file which links names linked to unique code numbers will be kept in a secure location on an NHS computer according to NHS data security practices. All other data will be stored under anonymised code numbers in encrypted forms on password-protected computer (personal laptop and university computer). No hard copy will be created where a participant who could potentially be identified.

### **Proposed Security Procedures**

No data with names of patients or clinicians will be removed from its source location. However, a list of patient's names and hospital number etc. will be securely maintained at the source location. This is to aid good coverage, minimise the possibility of duplication, and the clearing of anomalies for external quality control.

Photocopying or scanning of information will be restricted to ensure any copies are stripped of all identifiers. Thus when collating records, a coded number will replace all names, where the index relating names to codes will reside only at the source location.

All (coded) records from the source will be kept in a secured electronic folder (i.e. kept on a password protected computer). Where separate patients records are kept in different hospital locations in Berkshire (BFT maintains acute psychiatric admission wards on three hospital sites – Prospect park Hospital in Reading, Wexham Park Hospital near Slough and Heatherwood Hospital in Ascot), then separate secure records will be maintained in each hospital.

The clinical team will have full access to all participants' personal data that will also be accessed by the researcher and the supervisor (who also has an honorary contract with the Trust) according to agreed ethical procedures.

### **Project Management**

This project will be overseen by my research supervisor Professor Nigel Wellman of Thames Valley University.

## APPENDIX 6 Patient Information Sheet, Stage 1

# Life Experiences and the Diagnosis of Mental Health Problems

Patient Information Sheet for: **Life Experiences and the Diagnosis of Mental Health Problems**

REC No: 10/H0605/23

You are invited to take part in a research study undertaken as part of a Doctorial study at Thames Valley University.

Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read this information carefully and discuss with others if you wish. If there is anything that is not clear, or if you would like more information, please feel free to contact the researcher using the contact number below. Please take time to decide whether or not you wish to take part.

Alternatively you may wish to speak to a representative for the Patients Advise and Liaison Services (PALS) who may also be able to answer questions and discuss with you about participating in NHS research.

### The Purpose of the Study:

The primary purpose of this study is to look at how mental health clinicians evaluate patients' life experiences, and the effects of these experiences on how patients cope with life.

We are also interested in how this information is used to guide the mental health services that patients are offered. We are doing this because we hope to use this information to develop new assessment tools such as questionnaires to help clinicians assess patients.

To this end I would like to ask your permission to look at your medical records and extract information on which life experiences doctors have discussed with you, and how that has informed your diagnosis and the care plan which guides your treatment.

### Why have I been invited?

You have been invited because you have received care for mental health issues from the Berkshire Healthcare NHS Foundation Trust. Many patients with similar mental health issues over a period of the next twelve months will also be invited to take part.

### Do I have to take part?

No, your participation is entirely voluntary. If you decide not to take part, this will in no way affect your treatment or entitlement to services. Furthermore, you can withdraw your consent at any time, without having to give a reason and this will not affect your treatment.

### What will happen to me if I decide to take part?

If you decide to take part, you will be given this information sheet to keep, and you will be asked to sign a consent form giving permission for the examination of your medical records.

### What do I have to do?

If you decide to take part, please sign the attached consent form giving permission for the examination of your medical records.

### What are the possible Risks or Disadvantages of taking part?

You will be giving up a few minutes of your time to read the information sheet and decide if you wish to let the researchers review your medical records.

### What are the benefits of taking part?

There may be no direct benefit for you in taking part in this study, but we hope that the development of improved assessment tools may help to improve the care of people who have similar mental health issues to you in the future.

### What happens when the research study is finished?

When the research study is finished and the information has been analysed, we will inform you of the results of the study if you wish.

### What if there is a problem?

If you experience any problems as a result of the study you should discuss this with the researcher, but the normal university and NHS clinical support as well as the NHS complaints mechanisms remain open to you.

### What if something goes wrong?

It is unlikely that anyone will be harmed by taking part in this study; however this study is covered by Thames Valley University's insurance policy. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

Regardless of this, if you have any concerns, you can speak to your clinical staff or the researcher. Or if wish to complain about the way that you have been approached for this



study, the normal Thames Valley University and NHS complaints mechanism will be fully available to you.

Will my taking part in this study be kept confidential?

If you decide to take part in the study I will inform the mental health clinicians involved with you about your participation. All information collected about you during the course of the research will be kept entirely confidential. Any information about you that leaves the NHS site will have your name removed so that you cannot be recognized from it.

What will happen to the results of the study?

When the study is finished, we hope to use the information to develop new assessment tools. We also hope to publish the results in academic journals, in various mental health publications, and to present the findings of the study at conferences and research meetings, but will ensure that no individual participant in the study can be identified.

Who is organizing and funding this research?

The researcher is not being paid; neither will there be any payment for your participation. However the study will form part of the researcher's thesis as part of a Doctorial study at The Thames Valley University.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called the Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

Before obtaining permission to distribute this Information Sheet, this study has been given a favorable ethical opinion for conduct by the Oxfordshire Research Ethics Committee B, and the Faculty of Health and Human Science Research Committee at Thames Valley University.

Contact for further information

For further information about the study, please contact:

1. Researcher: Doris Tallon, [doris.tallon@berkshire.nhs.uk](mailto:doris.tallon@berkshire.nhs.uk) 07977984758
2. Dr Gwen Bonner, 01344 874340, [gwen.bonner@berkshire.nhs.uk](mailto:gwen.bonner@berkshire.nhs.uk)

Thank you very much for taking the time to read this information sheet, which is now yours to keep.

If you agree to take part in the study, you will be asked to sign the consent form and you will be given a personal copy of this form.





## APPENDIX 7 Clinician Information Sheet, Stage 1

Researcher: Doris Tallon    tallondoris@googlemail.com    Phone 07779728985
---

### Life Experiences and the Diagnosis of Mental Health Problems

My name is Doris Tallon; I worked for many years with Complex PTSD patients in the Berkshire Traumatic Stress Clinic and I am currently undertaking research for a PhD at Thames Valley University.

The first stage of my research is a project entitled “Life Experiences and the Diagnosis of Mental Health Problems”, and it aims to map how clinicians in Berkshire make the diagnosis of Borderline Personality Disorder (BPD), including any questionnaires or clinical tools they use and what life experiences they consider in making this diagnosis

NICE estimates that 0.7-2% of the general public could be suffering from BPD, with 20% of all psychiatric inpatients and 10-30% of outpatients (NICE, 2008) and these figures are supported by epidemiological studies. Suicide is a particular risk in BPD with up to 1 in 10 people with BPD committing suicide, 400 times higher than the national average suicide rate (NICE 2008).

#### Assessment

The literature suggests the diagnosis of BPD is generally made following unstructured clinical assessment, and that there are often pitfalls, such as difficulty in obtaining agreement on diagnosis among clinicians (Melsop, 1982) and overlap with a range of other conditions. NICE have suggested that more reliable methods of diagnosis need to be developed for BPD and related conditions in order to enable patients to obtain speedy access to the most appropriate interventions and services. The current project aims to understand current practice in Berkshire with a view to building on this work to develop and test new diagnostic instruments and procedures.

## **Data Collection**

Medical records of all admissions in the acute inpatient wards will be screened against the inclusion criteria by clinical staff.

Potential participants will be approached by the health-care-team. This will be done by informal discussion about the research project and how they could help; written information about the voluntary nature of their participation will be given to those who express an interest in participation.

All patients will be given the opportunity to discuss the study with the researcher if they wish and ask questions before making a decision. Patients will be given a minimum of 24 hours to consider if they still wish to take part to allow their medical records to be examined. Investigation of medical records of the BPD patients, using a checklist designed by the researcher will commence once consent has been obtained.

## **Data Analysis**

### **AIMS:**

1. To identify information on which current diagnoses are based.
2. To calculate the frequency of, and different assessment instruments used
3. To identify the nature of life events recorded in the medical records and their frequencies. Establish the number and types of different treatments received to date
4. To determine, through a structured format, the percentage of patients with CPTSD, and also the index of variability, or standard deviation

### **Inclusion Criteria**

All acute in-patients diagnosed with BPD in a one-year period in Berkshire will be approached. (Based on 2008/2009 discharge statistics, this should be about, n=120).

- All potential participants must know and understand their diagnosis
- Age between 18 and 65 years old
- Able to give informed consent to participate in the study

**Exclusion Criteria**

- Currently acutely disturbed / psychotic
- Unable to give informed consent

**Risks to Participants**

The study of the medical records of patients in the sample group in Berkshire should not generate any significant risks to these patients. This project has been given a favourable ethical opinion for conduct by the Oxford B NHS Research Ethics Committee and the Faculty of Health & Human Sciences Research Ethics Committee at Thames Valley University.

If you require further information then please do not hesitate to contact me by e-mail [tallondoris@googlemail.com](mailto:tallondoris@googlemail.com) or phone 07779728985.


I will truly be grateful for your co-operation in this matter. Your time and the participation in this study will be greatly appreciated.

Thank you


Doris Tallon




## APPENDIX 8 Recruitment Poster, Stage 1



Thames Valley University  
London Reading Slough



Berkshire Healthcare   
NHS Foundation Trust

# Life Experiences and the Diagnosis of Mental Health Problems

How do mental health clinicians evaluate life experiences?

To answer this question and to potentially improve diagnosis, patient permission is needed to access medical records

**FULL CONFIDENTIALITY GIVEN**

For further information about the study please :  
contact  
Doris Tallon [doris.tallon@berkshire.nhs.uk](mailto:doris.tallon@berkshire.nhs.uk) 07977984758  
Or the ward staff

19/07/2014 v02 REC No: 10/H0605/23





## APPENDIX 9 Hospital Discharge Statistics

Diagnosis	ICD10 Codes	Total	Percentage
Brain damage	F06	3	0.6%
Brain damage	F07	2	0.4%
Alcohol	F10	23	4.8%
Drugs	F11	26	5.5%
Drugs	F13	1	0.2%
Drugs	F15	1	0.2%
Drugs	F19	8	1.7%
Schidoid	F20	47	9.9%
Delusion	F22	3	0.6%
Psychotic	F23	17	3.6%
Schidoid	F25	16	3.4%
Manic	F30	14	2.9%
Manic	F31	58	12.2%
Depression	F32	46	9.6%
Depression	F33	19	4.0%
Mood	F34	1	0.2%
Anxiety	F41	6	1.3%
OCD	F42	2	0.4%
<b>Stress inc. Trauma</b>	<b>F43</b>	<b>16</b>	<b>3.4%</b>
Eating	F50	1	0.2%
Puerperium	F53	1	0.2%
<b>Includes BPD</b>	<b>F60</b>	<b>66</b>	<b>13.8%</b>
Transexual	F64	1	0.2%
Faking	F68	1	0.2%
Unspecified	F69	1	0.2%
Developmental	F84	1	0.2%
Hyperkinetic	F90	1	0.2%
	NOT KNOWN	44	9.2%
	NOT RECORDED	51	10.7%
		<b>477</b>	<b>100.0%</b>



# APPENDIX 10 NHS Ethics Approval, Stage 1

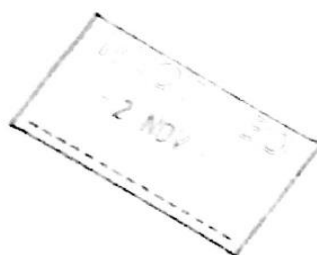


## National Research Ethics Service

Oxfordshire REC E

Northwick Park Hospital  
Level 7, Maternity Block  
Watford Road  
Harrow  
Midd:  
HA1 3U.

Tel: 020 8869 3804  
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29 October 2010

Ms Doris Tallon  
Research and Clinical Psychologicaltrauma Therapist  
Berkshire Healthcare Foundation Trust  
Research and Clinical Psychologicaltrauma Therapist  
25 Erieh Road  
Reading  
RG1 5LR

Dear Ms Tallon

**Study title:** A Study of Life Experiences and the Diagnosis of Mental Health Problems  
**REC reference:** 10/H0605/23  
**Amendment number:** Sub AM01-Oct 10-Version 02-2, 11 October 2010  
**Amendment date:** 12 October 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 22 October 2010 by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet	v01-1 - Original, Tracked	11 October 2010
Participant Information Sheet	v02-1 - Clean	14 April 2010
Protocol	v02-2 - Clean	11 October 2010
Notice of Substantial Amendment (non-CTIMPs)		12 October 2010
Covering Letter		11 October 2010
Protocol	v01-2 - Original, Tracked	16 April 2010

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H0605/23:	Please quote this number on all correspondence
--------------	--

Yours sincerely



**Mr Lawrence L Penez**  
**Assistant Committee Co-ordinator**

E-mail: [scsha.oxfordRECB@NHS.net](mailto:scsha.oxfordRECB@NHS.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Neelam Kaushal  
Thames Valley University  
Research Office, Graduate School, St Mary's Rd Ealing  
Ealing  
W5 5RF*

Ms Doris Tallon  
3 Chazey Road  
Caversham Heights  
Reading RG4 7DS  
13 April 2010  
Dear Doris

THAMES VALLEY UNIVERSITY  
Faculty of Health and Human Sciences  
Faculty Research Ethics Committee  
Paragon House  
Boston Manor Road  
Brentford TW8 9GA

**Re: Application for Ethical Approval No FREC24/March10**

Thank you for sending in your application for approval by the Faculty Ethics Committee. This is to confirm that the Committee has considered your application and approved the research without major amendment.

If you make any changes to your research proposal or methodology can you please inform the Committee in writing, as this may entail the need for additional review. A report on the progress/completion of the research is required in 12 months from the date of this letter, or on completion of the research, whichever is the sooner.

The Committee wish you well with the research and look forward to your report.

Yours sincerely



Heather Loveday

Principal Lecturer (Research)

Chair of the Faculty Research Ethics Committee



## APPENDIX 12 Foundation Trust Approval Stage 1



Berkshire Healthcare **NHS**  
NHS Foundation Trust

R&D Department  
Fitzwilliam House  
Skimped Hill  
Bracknell  
RG12 1BQ  
Tel: 01344 415825  
Fax: 01344 415666

25 June 2010

Doris Tallon  
3 Chazey Road  
Caversham Heights  
Reading  
RG4 7DS

Our Ref: 2009/24

REC Ref: 10/H0605/23

Study title: **A Study of Life Experiences and the Diagnosis of Mental Health Problems**

Start date: 25/6/2010 End date: 1/7/2011

Dear Ms Tallon

### Confirmation of Trust Management Approval

On behalf of Berkshire Healthcare NHS Foundation Trust, I am pleased to confirm Trust Management Approval for the above research on the basis described in the application, protocol and other supporting documents.

If there are any changes to the study protocol, the R&D Department must be informed immediately and supplied with any amended documentation as necessary, including confirmation that the amendments have been favourably reviewed by the Sponsor and the Ethics Committee.

If the end date changes from that shown above, then please inform BHFT R&D Manager. Trust approval will cease on the end date above and you will be requested to submit a final report. Please contact the R&D Manager to discuss and request any extension.

The R&D Department is required to monitor the progress of all research in the Trust under the Department of Health's Research Governance Framework, and as a co-sponsor of your research with Thames Valley University. You will be contacted in due course with a request for reports of progress, and for a brief final report of research findings.

If you have any questions about the above, or you require any other assistance, then please contact the R&D Department.

I wish you every success with the study.

Yours sincerely

*JW*  
Dr Justin Wilson  
Medical Director





## APPENDIX 13 Study Tool, Stage 1

Study Tool for: **A Study of Life Experiences and the Diagnosis of Mental Health Problems**

REC No: 10/H0605/23

### Study Tool (for medical records)

#### Objectives

- To obtain information regarding diagnosis of co-morbid psychiatry disorders and the severity of these disorders, i.e. duration, course treatment and use of acute services over a period of one year of the patients admitted to the acute wards
- To establish relationships between sets of data and to look for etiology and symptoms of BPD and CPTSD

Statistical measurements (e.g. percentages) will be made.

#### Procedure

The data required includes:

- a) Clinician (a code must be assigned)
  - a. Grading
  - b. Age
  - c. Experience
  - d. Location
  - e. Gender
  - f. Ethnicity
  - g. Qualification
  - h. Occupation
- b) Patient data (a code must be assigned):
  - a. General; Age, Sex, Nationality, Social Class
  - b. Marital Status, accommodation, occupation, ethnicity
  - c. Trauma History, and type including childhood trauma
  - d. Initial referral date
  - e. Age at first trauma symptoms
  - f. Previous number of referrals

- g. Previous diagnosis, location, by whom, including PTSD records
  - h. Previous kinds of treatment (e.g., psychotherapy and type)
  - i. Treatments offered
  - j. Effectiveness of treatment
  - k. Medications used
  - l. Admission history
  - m. Number of subsequent assessments
- c) Ward data
- a. Number of overall admissions throughout the acute wards within the Trust
  - b. Number of BPD admissions
  - c. Where they are discharged to

A draft is shown below:

---

Formulation:

Presenting symptoms:

Symptoms to look for when assessing for BPD are:

- Repeated self-harm:
  - Persistent risk taking
  - Marked emotional instability:
  - Risk of self-harm or to other
1. Assessment process used: Structured or semi-structured interview, self-assessment questionnaire, etc.
  2. Was there a Standard Assessment Instrument used?
  3. If so, which one or ones:
  4. If not, why not? Is the reason given?
  5. Was a family member present?
  6. Is there a recording of traumatic history?
  7. If no, was it asked and none was given?
  8. What exactly was the diagnosis recorded
  9. When was the diagnosis made?
  10. How many assessment sessions before diagnosis was made?
  11. Reasons for the diagnosis
  12. Treatment offered:

13. Prognosis:

- How long was, or has the patient been in hospital

14. Follow-ups

15. Referrals





**APPENDIX 14 Consent Form, Stage 1**

REC No: 10/H0605/23

Patient Identification Number for this trial:

**Please initial the box below**

Name of Researcher: Doris Tallon.

- I confirm that I have read and understand the information sheet dated ..... for the above study.
- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I wish to be sent a summary of the results of this study once completed
- I agree to take part in the above research study
- I give permission for the researcher to assess my medical records for the purpose of this study.


Name of Patient	Date	Signature

Name of Person taking consent (if different from researcher)	Date	Signature

Researcher	Date	Signature

When complete, 1 copy for patient: 1 copy for researcher site file: 1 (original) to be kept in medical notes



### APPENDIX 15 Interview results, Stage 1

No	Role	Trauma resources required	Trauma training required	Simple Trauma screening Required	Fear of BPD patients reaction if encouraged to explore past trauma
1	BPD Nurse therapist	x	x	x	Yes
2	BPD nurse therapist	x	x	x	Yes
3	BPD nurse therapist			x	Asks about trauma but no detail exam
4	Consultant Psychiatrist, BPD specialist			x	To ask about trauma
5	BPD specialist		x	Screen must be meaningful	Yes
6	Ward manger	x		x	
7	Clinical psychologist		x	Screen must be meaningful	
8	Director of nursing	x			Yes
9	Director of nursing	x			Yes
10	Psychologist	x	x		
11	Psychologist	x	x		
12	Ward manager	x	x		Yes
13	Ward manager				Yes
14	Consultant psychiatrist	x			Aware of trauma underpinnings
15	Doctor			x	
16	Ward manager				Clinician do no investigate underpinnings
17	Consultant psychiatrist			x	Worry about trauma not recorded in all the notes or treated
18	Professor trauma specialist		x		

19	Consultant nurse specialist				Yes
20	Trauma dept manager			x	Trauma must be explained
21	Doctor HO			x	
22	Crisis team lead				Yes
23	Mental health lecturer	x			Yes
24	Consultant psychologist	x		x	
25	Doctor			x	Patient need trauma pathway
26	Doctor SHO	x		x	
27	Lecturer mental health			x	Trauma must be explored to effect treatment plan
28	Clinical nurse specialist				Yes, fear of what to do with the information





# Protocol: Trauma in Borderline Personality Disorder

## “Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Diagnosing Borderline Personality Disorder (BPD)?”

REC No: 12/SC/0382

### Background

Borderline Personality Disorder (BPD) is the most commonly diagnosed form of Personality Disorder (Shevin et al., 2007) and has been recognised as a clinical condition that can be seriously disabling and take a large toll on the individual (NICE, 2008). The key diagnostic criteria of BPD (as presented in the Diagnostic and Statistical Manual of Mental Health disorders, DSM-IV) is instability in interpersonal relationships, self-image and affect, combined with marked impulsivity beginning in early childhood and present in a variety of contexts. BPD patients may also experience transient, stress-related paranoid ideation, with recurrent suicidal behaviours, gestures, threats and self-mutilation.

NICE have estimated that 0.7-2% of the general public could be suffering from BPD, with 20% of all psychiatric inpatients and 10-30% of outpatients meeting diagnostic criteria (NICE, 2008). This is supported by epidemiological studies (Pinto, 2000; Torgenson, 2002; and Coid, 2006). Suicide is a particular risk in BPD with up to 1 in 10 people with BPD committing suicide, a rate 400 times higher than the national average (NICE 2008; Jeffrey et al., 1985). The National Association for Mental Health (MIND, 2009) have highlighted a worrying ‘danger of misdiagnosing BPD’. A number of experts also believe that many cases of BPD should be re-conceptualised as Post Traumatic Stress Disorder (PTSD) associated with childhood abuse, (e.g., Lineham, 1993).

A literature review has confirmed the possibility that a very high percentage of cases of BPD can potentially be re-conceptualised as PTSD associated with childhood abuse (Lineham, 1993; Herman, 1992), which is usually called Complex Post Traumatic Stress Disorder (CPTSD). The proposed diagnosis of CPTSD is currently covered by the current DSM-IV diagnostic category of ‘Disorders of Extreme Stress Not Otherwise Specified (DESNOS)’. Potentially, re-diagnosis could have very significant implications for the treatment and clinical management of these patients. Furthermore, a number of studies have shown that many who have been exposed to chronic childhood trauma are diagnosed as having personality disorders, particularly BPD (Zimmerman et al., 1999; Hodges, 2003; and van der Kolk et al., 1994) and some studies have linked this to a causal effect (e.g., McLean, 2003).

There is a resemblance and overlap between the presenting symptoms of BPD, PTSD and CPTSD. However according to van der Kolk, while there is a large degree of overlap and on the surface these conditions may appear to be quite similar, these disorders only partially coincide and clear distinctions can be drawn between them (van der Kolk et al., 1994) as depicted in Figure 1 below.

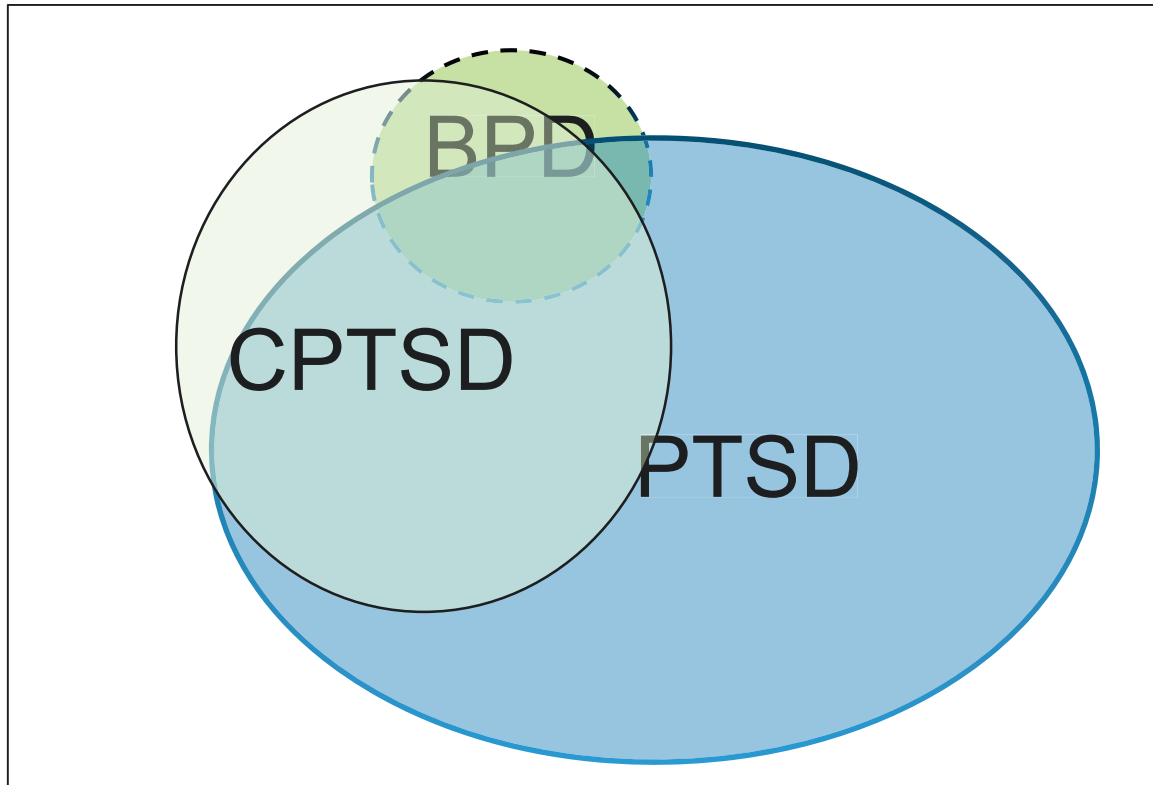


Fig 1: Model of relationship between disorders

It has also been suggested that many patients diagnosed with BPD can be assigned other and perhaps more discriminating diagnosis such as CPTSD (Valliant, 1992; Herman, 1992), which would signpost clinicians to provide appropriate psychological treatments such as trauma-focused cognitive behaviour therapy. NICE (2009) have suggested that failure to make the diagnosis sufficiently early may prevent appropriate early intervention to ameliorate the difficulties. Therefore reliable identification and assessment of BPD is required.

## Definitions of Disorders

### Post-Traumatic Stress Disorder (PTSD)

**Cause:**

Follows a sudden, unexpected event of a life threatening or catastrophic nature, “outside the range of usual human experiences” which engenders feelings of helplessness, fear or horror.

Recent research shows events qualifying for PTSD are quite common, (childbirth, car crashes, heart attacks, assaults, rapes, combat) and some traumas so powerful that the exposure typically leads to PTSD.

**Symptoms:**

Patients continue to intermittently re-experience aspects of the traumatic event after it was all over (e.g. flashbacks, nightmares, intrusive thoughts with emotional and physical distress in the face of reminders of the event). They seek to avoid reminders of the event, show diminished interest in formerly pleasurable activities, and display feelings of detachment and a sense of a foreshortened future.

In addition, patients typically can exhibit signs of persistent arousal, (e.g. difficulty with sleep, increased irritability, concentration problems, scanning the environment for danger and a heightened startled response. Impacts on relationships and ability to work are common, as are

### Complex PTSD

**Cause:** Follows catastrophic changes beyond classic PTSD criteria. It is common in individuals exposed to extreme social and/or interpersonal trauma (especially childhood sexual abuse).

**Symptoms:** PTSD, shame and guilt, anxiety and depression.

Lasting personality changes, with chronic mood dysregulation being the classic hallmark of CPTSD, characterised by difficulties in regulating impulses, affects, attention, consciousness, self-perception and relationships with others. They report significant dissociation symptomatology, ranging from episodic experiences of derealisation to lasting amnesia for all or portions of the traumatic experiences

CPTSD individuals have negative view of themselves as being helpless, damaged and undesirable with strong feelings of shame and guilt.

### Borderline Personality Disorder (BPD)

**Cause:** As with other mental disorders, the causes are complex and controversial. Childhood abuse and neglect have been found to be strongly associated.

Researchers have suggested diverse possible causes such as genetic predisposition, neurobiological factors, environmental factors and or brain abnormalities.

**Symptoms:** Heterogeneous condition with symptoms overlapping depressive, bipolar disorder, schizophrenic, impulsive, dissociative, and identity disorders with problems with hostility, anger and anger expression.

Prolonged disturbance in personality with disturbance in identity and relationships with others being the hallmark of BPD, (seen in Attachment Disorder), characterised by rapid changes of mood with striking fluctuations from periods of confidence to times of absolute despair with fears of abandonment and rejection.

BPD individuals have strong tendency towards suicidal thinking and self-harm. In extreme cases they experience transient psychotic and paranoid symptoms with greater fluctuations and variability with brief clear delusions and hallucinations, both visual and auditory. These are usually brief and linked

## **Assessment Instruments**

The reliability of diagnostic assessments for BPD has been considerably improved by introduction of 'standardised interview schedules'. However, no single schedule has emerged as 'the gold standard', as each has its advantages and disadvantages' (NICE, 2008). There is still a heavy reliance on the diagnosis of BPD being made following unstructured clinical assessments, with consequent pitfalls, in obtaining agreement among clinicians, (i.e. poor inter-rater reliability) (Mellsop, 1982).

Although NICE and the Department of Health have both recently recommended that clinicians should routinely ask patients about early childhood traumatic experiences, which might reveal abuse or neglect (NICE, 2008; DH, 2008), there still appears to be a problem that clinicians are not adequately assessing and efficiently recording histories of traumatic experiences and PTSD in patients given the diagnosis of BPD and hence may be missing vital information that potentially could help to facilitate recovery. To date, although research has investigated both the link between childhood traumatic experiences and the development of BPD, and also the relationship between BPD and CPTSD, there is a clear need for an instrument to efficiently map childhood traumatic experiences and PTSD in the assessment of BPD.

## **Recognised Area for Further Investigation**

NICE has suggested that a more reliable diagnosis should be made of BPD patients to enable the most appropriate interventions to be adopted, with the aim of reducing repeated hospital admissions, suicide, and costs to patients, their family members social relations, clinicians and the NHS (NICE, 2008).

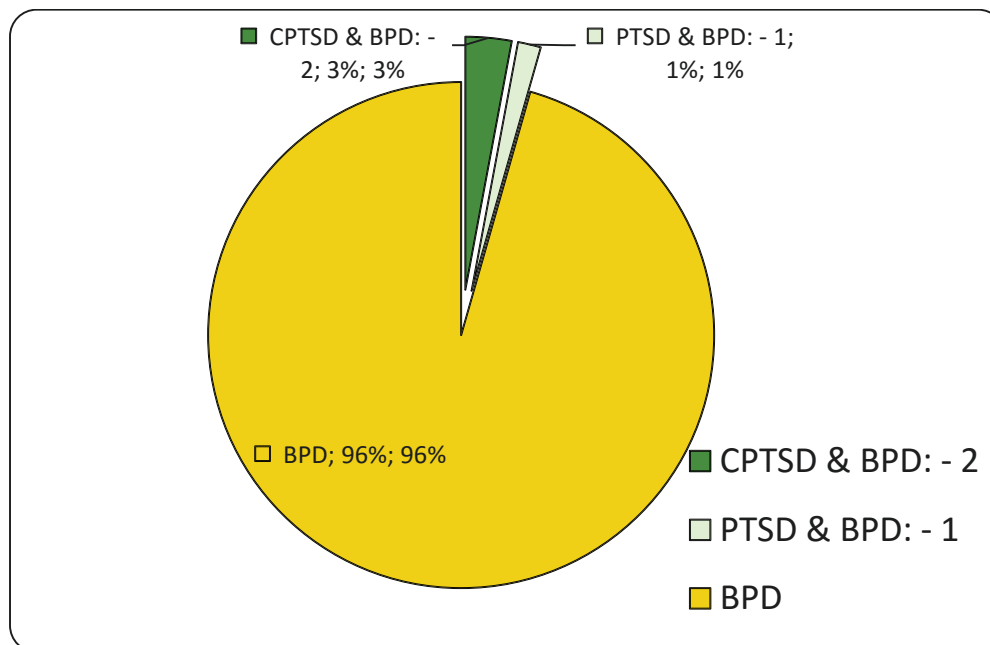
## **Stage 1 and Stage 1 Results**

The current project is part of a staged doctoral program of research, which will be completed in two stages. The aim of the first (completed) stage was to map current practice in Berkshire Healthcare Foundation NHS Trust (BHFT) for diagnosing BPD/CPTSD. That exercise was designed to inform the later development of a new, trauma sensitive screening instrument for assessing patients presenting in ways suggestive of BPD/CPTSD. To this end, a selection of medical records of patients diagnosed with BPD was examined to extract information on which life experiences clinicians have discussed with patients, and how that information has informed diagnosis and the formulation of the care plans which guide their treatment. This was supplemented by recording a selection of clinicians' views on BPD/CPTSD and how that information had informed diagnosis and the formulation of the care plans guiding treatment.

Records from BPD patients in psychiatric units operated by the Berkshire Healthcare NHS Foundation Trust were examined, and less than 3% of the patients did not give their permission for their notes to be examined, (Figure 2).

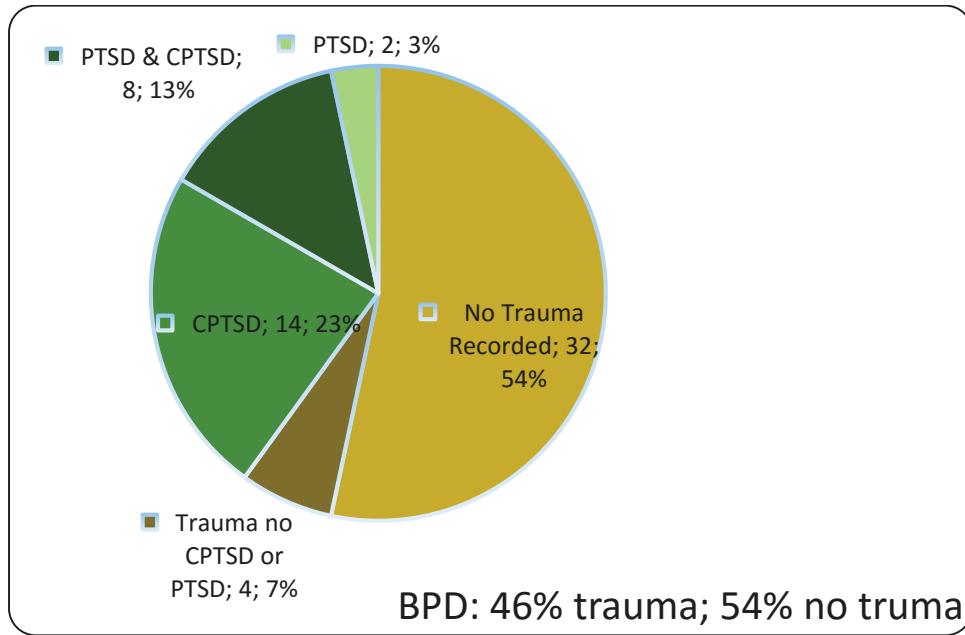
A usable dataset of n=60 or 78% of potential participants resulted, which covered a period of one year.

Based on clinician diagnosis, 4% (N=3) of patients were also assigned a comorbid trauma related Axis I and II diagnosis, however only one met DSM-IV criteria.



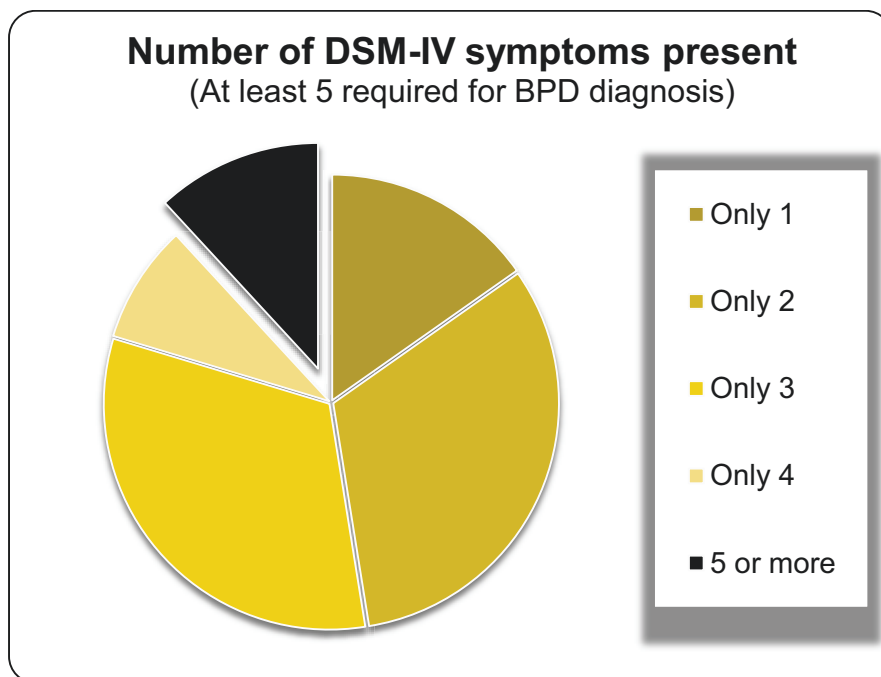
**Figure 2: Clinicians' Diagnosis from Medical Records**

References to the presence of trauma were recorded in 47% (N=28) of medical records. Medical records were reassessed to identify co-morbid PTSD and CPTSD based on recordings in the medical records of the symptoms presented. Any patient with Trauma and with re-experiencing in the records was given a PTSD diagnosis (NICE, 2004). Similarly, patients with both Childhood Trauma and affect-dysregulation were assigned as CPTSD (Luxenberg et al., 2001). This suggests that 40% (N=24) of all patients in this study could potentially be assigned DSM-IV diagnoses of either comorbid PTSD or Complex PTSD (DESNOS), see Figure 3.



**Figure 3: Trauma Recording, and Diagnosis as per DSM-IV Criteria**

Although all patients were assigned a BPD diagnosis by their clinicians, Figure 4 shows only 12% (n=7) satisfied the full DMS-IV criteria for BPD which states that at least 5 symptoms must be present (DSM-IV, 1994).



**Figure 4: BPD Criteria in Notes**

In the medical records there were records of two structured clinical instruments being used: the IPDE (International Personality Disorder Examination) (37%, n=22) and also the SCID-II (Structured Clinical Interview for DSM Disorders) which was used with only n=2 patients (3%). For the other diagnosis there were no references to specific assessment instruments being employed. However, it was also noted that only n=2 patients had a record of an in-depth examination of their traumatic experiences

It appears that clinicians are recording adequate clinical information as per requirements to undertake DSM-IV diagnosis. That is, a full set of symptoms was located within the medical records for more than 82% of the BPD patients. However, from the analysis above, there was an apparent under-diagnosis of CPTSD and PTSD in the sample examined, and an apparent over-diagnosis of BPD.

Although DMS-IV requires that 5 or more criteria to be present in order to assign a diagnosis of BPD, clinicians in Berkshire on 88% of occasions appear to be satisfied with less than 5 BPD criteria, and on 15% of occasions were willing to assign a BPD diagnosis with only a single BPD criterion present. This particular result is consistent with a recent large-scale survey of American clinicians (Westen, 1997)(Westen et al., 1997), and was not of undue concern to the Steering Group (p.11 below). The initial results largely confirmed expectations from literature that a significant proportion of cases of BPD can potentially be re-conceptualised as PTSD associated with childhood abuse (Lineham, 1993; Herman, 1992). There is a need now to examine the value of the proposed changes in assessment to include screening for trauma, PTSD and CPTSD.

## **Second Stage: Trauma Screening followed by Assessment**

### **Stage 2 Objectives**

At present there is no specific trauma screening instrument in regular use in patients with BPD in Berkshire.

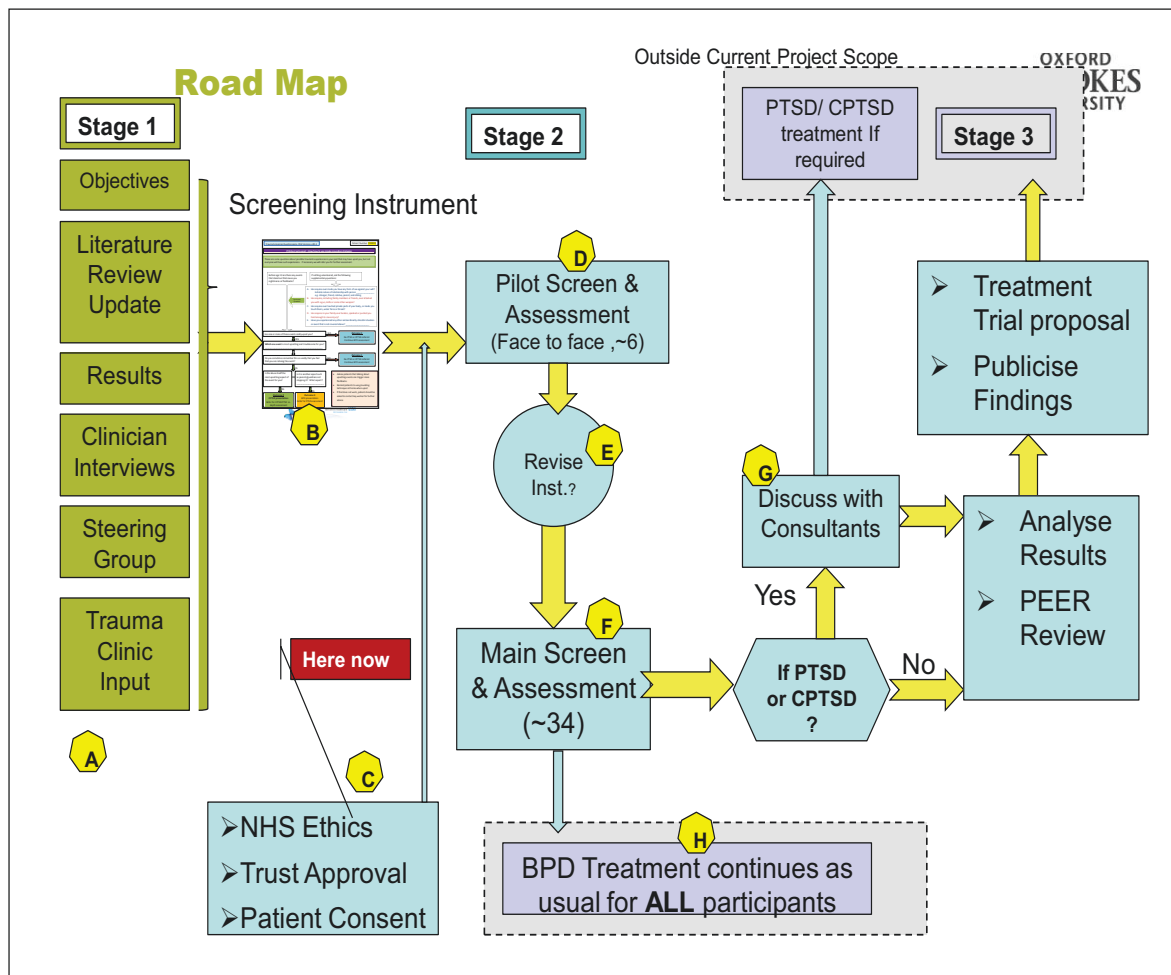
The aims of this second (PhD) stage are:

- To develop a brief trauma screening instrument for clinicians to facilitate the discrimination of BPD patients with possible CPTSD/ PTSD diagnosis.
- To test the new brief trauma screening instrument against the gold-standard clinical instruments for the identification of PTSD and CPTSD/DESNOS
- To compare the percentages of Trauma, PTSD, CPTSD and BPD identified in this screening trial with the results of Stage 1
- To compare all results with the latest information from academic literature

### **Stage 2 Data Collection Method**

The Second Stage methodology builds on the results of Stage One.

This Stage is described in Roadmap in Figure 5 (with elements marked A-H in line with the bullet points below).



**Figure 5: Stage 2 Roadmap**

- A. The programme starts by taking into account both the results of the clinician survey and all other feedback
- B. A new streamlined brief screening instrument has been developed in the form of a checklist to be used in a structured clinical interview (Appendix A - BTES). This is based on a modification of existing instruments, in particular the THQ (Trauma History Questionnaire, Green, 1996), TESI (Traumatic Events Screening Inventory, (Ippen, et al., 2002) and also the SIDES for DESNOS (Pelcovitz et al. 1997). The new instrument ensures the length of time for this screening is controlled and also annotates the various traumatic events using proven techniques from the PTSD/ CPTSD practice combined with a quality control element
- C. Once all ethical approvals have been obtained, BPD patients' consent will be obtained
- D. An initial pilot study of approximately n=6 patients will take place in order to confirm the clinical acceptability of the new screening instrument. This pilot study may be audio-recorded for completeness and quality control purposes to help to ensure the instrument is being used correctly. Clinicians will administer the new checklist (BTES). All patients will then be interviewed by the researcher using SIDES (Structured Interview for DESNOS questionnaire, Pelcovitz et al., 1997) and CAPS (Clinician-Adminstrated PTSD Scale, Blake et al., 1995), whether or not they meet the criteria for trauma and PTSD/CPTSD as defined in the Screening Instrument. Both CAPS and SIDES are in-depth PTSD/CPTSD 'gold-standard' instruments. As there will be only a single interview for each participant, as far as possible, the in-depth



assessment will take place immediately following the screening. After this the results will be compared

- E. Based subsequently on the clinical evidence that will be collected, and feedback from the clinical community and the Steering Group, the screening instrument will be refined if necessary
- F. Following the Pilot study, all remaining participants will then be systematically screened for trauma and PTSD/CPTSD, using the finalised screening instrument. And as with the Pilot section, all patients will also be given an in-depth PTSD/CPTSD assessment
- G. Following completion of the assessment process, with the patient's permission, the researcher will inform the patient's consultant/responsible clinician of any clinically relevant findings together with recommendations as to which participants it would be appropriate to refer to the Berkshire Traumatic Stress Service, which is headed by a member of the Project Steering Group
- H. BPD treatment will continue unchanged for all patients, both those who are referred to the trauma services and those who are not, for as long as clinically necessary

For all of Stage 2, an independent clinician will undertake the screening and the researcher will undertake the assessment of the participants.

### **Inclusion Criteria**

- Clinical diagnosis of Borderline Personality disorder
- Age 18 or over (no upper age limit)
- Able to give informed consent
- Currently receiving psychiatric care from the participating NHS Trust

### **Exclusion Criteria**

- Age Less than 18
- Unable to speak English
- Acutely Distressed
- Significant learning disability
- Unable to give informed consent
- 

### **Participants:**

All participants in the previous study were consented in person by the applicant. The original consent was just to allow the researcher to access participants' medical records but participants were told that this review of medical records would form the first part of a two-part study. Participants were asked whether they would be willing to be contacted about possibly participating in the second part of the study which would be likely to involve a more in-depth assessment. All participants without exception expressed an interest in being contacted about taking part in the second part of the study.

For the participants who expressed an interest in being contacted about the taking part in the second part of the study, The researcher will liaise with relevant clinicians to determine that these patients still meet the inclusion criteria and are

not currently acutely distressed before re-contacting them and ascertaining if they would still be interested in participating.

Contacting these patients will be in two forms.

1. At the start of stage 1 of this project, the clinical staff requested presentations to be given to potential participants in their BPD groups at their therapeutic treatment units. This was found to be very helpful to explain the project to the patients. This will be done again to explain the aims of the project and the nature of participation will also be explained. The PIS will be made available. As for stage 1, any patients who express interest in the study will then be given a copy of the PIS and will have at least 24 hours to consider whether or not they wish to take part. Once they agree verbally, the researcher will be available to provide a further verbal explanation of the study, answer patients' questions if requested and obtain consent. Once consent has been obtained the researcher will liaise with the patient and with relevant clinicians to arrange a date and time for the administration of the screening tool and the in-depth interview
2. For patients who still meet the criteria and are interested in participating but are either unavailable for presentations or did not want to join the presentation, the researcher will seek permission from their clinicians to re-contact them. Once re-contacted, the same procedure as above will be followed:
  - Explain the nature of their participation
  - Ascertain whether they are still interested in participating in the research
  - Give a copy of the PIS
  - As usual give 24 hrs. for patient to consider taking part
  - After that the researcher will be available to provide further explanation, answer any questions and obtain written consent
  - Once consent has been obtained the researcher will liaise with the patient and with relevant clinicians to arrange a date and time for the administration of the screening tool and the in-depth interview

If necessary, any new participants would be recruited using the methods approved by the Faculty Research Ethics Committee at Thames Valley University and by the Oxford B NHS Research Ethics Committee for recruitment of participants to stage 1 of this study (Application number 10/H0605/23). That is: if new participants are required, patients diagnosed with BPD who meet the inclusion criteria will be approached by a member of their own health-care team and given a verbal explanation of the study. Any patients who express interest in the study will then be given a copy of the PIS and will have at least 24 hours to consider whether or not they might wish to take part. Once they agree verbally, the researcher will be introduced to them and will provide a further verbal explanation of the study, answer patients questions and obtain consent. Once consent has been obtained the researcher will liaise with the patient and with relevant clinicians to arrange a date and time for the administration of the screening tool and the in-depth interview. For new patients it will also be

necessary, as in stage 1, to anonymously record key medical information from their notes. The Consent form accounts for this possibility.

## **Stage 2 Data Analysis**

The CAPS, SIDES and BTES will generate predominantly quantitative data. This will be supplemented by the use of descriptive analysis.

The predominant presentation of the results of the screening/interview process will be descriptive but we will also use linear discriminant and principal components techniques. The statistical analysis will be undertaken by the applicant aided by her supervisors. Any uncertainties about diagnostic or other issues relating to specific participants will be discussed first with the applicant's clinical supervisor Professor Suzanna Rose and then with other member of the Steering Group as required.

## **Risks to Participants**

All participants will be under current specialist psychiatric care and will have access to support from trained mental health clinicians. Discussing traumatic events which occurred in an individual's past may be temporarily distressing for some participants but some participants will undoubtedly receive benefit by being referred for appropriate psychological therapies and future patients may benefit from increased diagnostic precision. Other participants may receive benefit from feeling that they have been listened to and taken seriously and from knowing that they have contributed to a scientific research project.

It is also current Department of Health Policy as articulated in the 'Refocusing the Care Programme: Approach and Practice Guidelines' (DH, 2008), that mental health clinicians should ask all mental health service users about their abuse history. To quote directly from the above document: *'Childhood experience of sexual and other abuse is known to be more frequent in the histories of individuals with both mental illness and personality disorders (MHNFS, 1999). Research indicates that around 50% of women service users have been sexually victimised as children, notwithstanding further abuse in adulthood and a significant number of men service users have also experienced abuse. It is now DH policy that, following appropriate training for staff, exploration of violence and abuse is routinely undertaken in all mental health assessments. Questions should be asked by suitably trained staff at assessment about the experience of physical, sexual or emotional abuse at any time in the service user's life. The response, with brief details, should be recorded in the case records/care plans. If the specific question is not asked, the reason(s) for not doing so should be recorded.'*

In general, well-conducted research interviews are likely to be interesting, engaging and reassuring rather than distressing. In support of this, Griffin et al. (2003) have reported on the outcomes of 430 individuals including n=260 victims of domestic violence, n=108 rape victims and n=62 victims of physical assault who were subject to research trauma assessments including the CAPS interview

(Blake et al., 1995) which is to be used in this project. Griffin et al. (2003) concluded that *'Results indicated that participation was very well tolerated by the vast majority of trauma survivors. Participants generally found that the assessment experience was not distressing and was, in fact, viewed as an interesting and valuable experience. The findings suggest that trauma survivors are not too fragile to participate in trauma research even in the acute aftermath of a traumatic experience'*. Similarly, Jorm et al., (2007) conducted a systematic review of participant distress in psychiatric research including a number of studies relating to a range of traumatic and other distressing experiences and concluded that *'a minority of participants become distressed but there is no evidence of longer term harm'*.

The Screening Instrument starts by explaining to the patient that he or she might experience an increase in unwanted distressing memories and this is normal when one discusses adverse life experiences. If this occurs, the patient is advised to use what are called 'grounding techniques'. This is a common practice in any patient/clinician interface with this client group and these simple techniques will be discussed with patients at the beginning of the screening. If any memories become significantly distressing, participants will be advised to contact their keyworker who will offer support and advice. From the Information sheet and verbal explanation of the study, participants will know that they can stop the assessment and/or withdraw from the study at any time, without prejudice and without affecting their treatment in any way.

For every patient who discloses childhood sexual abuse or other forms of child abuse there must have been at least one abuser and it is possible that that person may still be alive and have access to children. The screening instrument does not ask participants to identify past abusers; only to record the broad nature of their relationship with the abuser (i.e. stranger, friend, relative, parent, and sibling). This is because the relationship with the abuser is required to differentiate between different types of abusive events associated with BPD and CPTSD respectively. This sensitive issue will be tackled according to normal trust policy and procedures, specifically, the Berkshire Healthcare NHS Foundation Trust's Safeguarding of Adults Policy and Procedures (2008). This policy stipulates that any information that gives concern regarding the safety of the participant or other people in the community must be raised with the Trust Safeguarding Lead, and then with the Local Authority Safeguarding Team who will log all relevant information as reported by the clinician. This will be done regardless of the participant's permission, as there could be risk to other individuals. This will be made clear to the patient at the beginning of the interview session. This has to be done because there is the possibility that the participant could disclose the information to someone else and claim that they have told the clinician about it and that the authorities did nothing about it.

If there is a disclosure of an abuse and or an abuser, Trust Policy is as follows:

- a. Clinicians are advised not ask probing questions, but must explain that any reported abuse will be recorded in their notes and to record information as it is given to them using patients own words
- b. Any disclosure of abuse must be entered as an incident via the official data recording system (Datix), which will be seen by the safeguarding lead. This requires the safeguarding lead to complete the safeguarding section of this form as well as updating the patient's notes.
- c. Concerns about abuse or actual abuse must also be raised formally with the Safeguarding team to the local Authority Safeguarding Team who will determine the next stage, as they do not get automatic notification.
- d. Where there is suspicion of a criminal offence the patient should be asked if they wish to report to the police.
- e. If they wish to report the alleged crime (to the police), they must be advised that this could lead to prosecution, although they do not have to prosecute if they do not wish to. However it is still the responsibility of the clinician (researcher) to report all concerns about abuse to the Safeguarding Adults team.
- f. This will then be reported to the Police who will deal with it as per Police procedures, such as any criminal investigation
- g. If the perpetrator could be a risk to others, then the police must always be made aware. If the perpetrator is not currently a risk to others (e.g. if they have passed away) and the patient does not wish to make a report, then it is acceptable not to inform the police
- h. Patients will be advised that they do not have to identify the abuser if they do not wish to. Patients should also be advised that once a report is made, it is likely that either the police or the local authority will request that the patient disclose the abusers' identity
- i. Patients must be asked if the perpetrator is still around and whether or not he/she is in a position to further abuse the participant or any other children or adults
- j. If the abuser is around, identified, and is in apposition to abuse again, this will be reported to the police whether or not the patient wishes to prosecute
- k. Patients will be advised that, where there is abuse or neglect, action will be taken, and they will be involved as sensitively as possible. This process must be explained to ensure their full understanding. However, it is not possible to explain every consequence as these are dependent on the outcome of any subsequent investigation and/or criminal proceedings)
- l. Once informed, the local authority are obliged to put safeguarding measures in place with the agreement of the patient

### **Proposed Ethical Procedures**

No data with names of patients or clinicians will be removed from its source location. However, a list of patient's names and hospital number etc. will be securely maintained at the source location. This is to aid good coverage, minimise the possibility of duplication, and the clearing of anomalies for external quality control.

When collating records, a coded number will replace all names where the index relating names to codes will reside only at the source location.

All (coded) records from the source will be kept in a secure electronic folder (i.e. kept in a file on a password protected computer). No paper records with participants' names will leave the Hospital.

No identifiable data will be stored any laptop computer. All data stored on laptop and university computers will be stored under research code-numbers. The file linking the research code number to patient identifiers will be stored only on a secure NHS computer. The data files will also be stored in encrypted form. Only one laptop will ever be taken to the source location and all files will be made available for inspection at any time.

No findings will be shared outside the Steering Group, and no publication will be attempted without Steering Group approval.

No professionals will be contacted unless the approach has been approved by the project supervisor(s). All professionals to be contacted will receive an e-mail describing the study, with all required details listed in an information sheet agreed by the Steering Group. No interviews will be conducted unless consent has been received in discussions with Departmental Heads and consultants.

### **Steering Group**

The Steering Group is an informal arrangement. It consists of a number of secondary care clinicians, specialist research development professionals, subject specialists as well as the course supervisor(s). The consent of the Berkshire Medical Director was obtained for Stage 1 and will be re-sought for Stage 2. As before, the Steering Group participants have received a full briefing concerning the aims, objectives and methodology proposed.

### **Patient Consent**

Every patient who is to be screened and assessed will give full informed consent. Consent will be sought after patients have had time to study the Patient Information Sheet and have also received a verbal explanation of the study from researchers. Consent will be taken in writing and participants will be free to withdraw at anytime.

### **Data Management and Storage**

The master-file which links names linked to unique code numbers will be kept in a secure location on an NHS computer according to NHS data security practices. All other data will be stored under anonymised code numbers on password-protected computer (personal laptop and university computer). No hard copy will be created where a participant could potentially be identified.

#### **Proposed Security Procedures**

All (coded) records from the source will be kept in a secured electronic folder (i.e. kept on a password protected computer). All records will be maintained on the secure NHS Master Global Intranet. The participant's clinical team will have full access to all participants' personal data.

#### **Project Management**

This project will be overseen by my research supervisor Professor Nigel Wellman, Oxford Brookes University.







## **Trauma in Borderline Personality Disorder**

### **Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Borderline Personality Disorder (BPD)?'**

1. You are invited to take part in the second stage of a Study about trauma in borderline personality disorder (BPD). This study is principally concerned with negative childhood experiences that may have caused you stress.
2. Before you agree to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please feel free to contact the researcher Doris Tallon using the contact number given at the end of this information sheet.
3. Alternatively you may wish to speak to a representative from the Patients Advice and Liaison Services (PALS), Trevor Lyalle, 0118 960 5027 who should also be able to answer questions and discuss participation in research with you. This study will form part of Doris Tallon's PhD research at Oxford Brookes University.
4. Purpose of the study  
The overall aim of this study is to test a new brief screening tool (questionnaire) designed to try and identify patients diagnosed with BPD who have experienced significant traumas and other distressing events in their lives. This information should help clinicians offer the most appropriate care and treatment to their patients. The screening tool is new and we do not know whether it will be useful or not, so we need to compare the results it gives with results obtained from assessing patients using well-established but longer questionnaires.
5. Why have I been invited? (For the patients that participated in stage 1)  
You have been invited because you have received care for BPD from the Berkshire Healthcare NHS Foundation Trust, and when you were approached about our previous study - *Life Experiences & the Diagnosis of Mental Health Problems* you expressed interest in hearing about the second stage of our research.

#### Why have I been invited? (For potential new Participants)

You have been invited because you are receiving care for Borderline Personality Disorder, and your healthcare team has identified you because you meet the inclusion criteria for this research.

6. Do I have to take part?

No, your participation is entirely voluntary. You do not have to take part if you do not want to. If you decide not to take part, this will not affect your treatment or entitlement to services. Furthermore, you can withdraw your consent at any time, without having to give a reason and this will not affect your treatment in any way.

7. What will happen to me?

You will be giving up about two hours of your time to attend the screening and assessment interview about your past experiences. This will be in two parts in the same session including a short break if required. This will take place at the hospital during your regular attendance.

8. Payment

There will not be any payment for your participation.

9. What do I have to do?

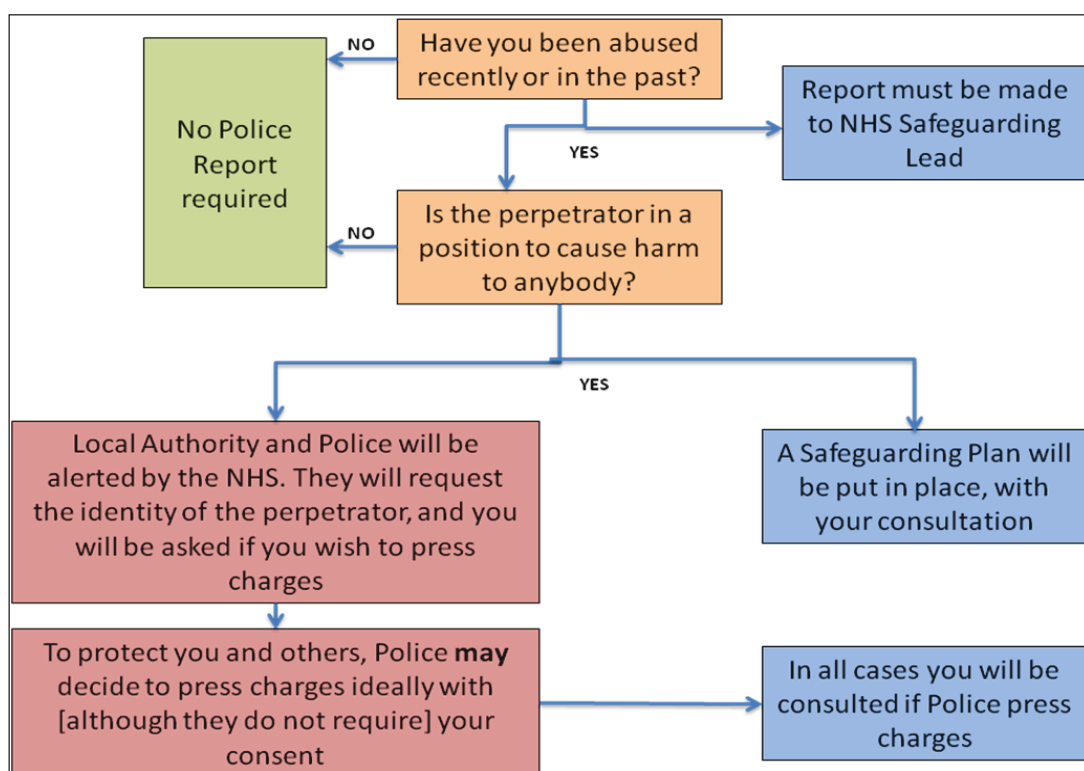
If you decide to take part, you will be asked to sign a consent form and we will then arrange a screening and assessment interview with you. The first part (screening) will be with an independent clinician using a new instrument for screening trauma in BPD patients. The second part will be an assessment with the researcher using standard assessment forms: CAPS (Clinician-Administered PTSD Scale) and SIDES (Structured Interview for Disorders of Extreme Stress Not Otherwise Specified).

10. What are the possible risks or disadvantages to me for taking part?

When you are asked about your past experiences, some of these experiences may be difficult to talk about because stressful and very upsetting things may have happened to you. Discussing these experiences may temporarily bring back uncomfortable and distressing memories or feelings. However, quite often people find that talking about past experiences can actually be helpful. It will be up to you to decide how much you want to tell the interviewer. As we go along, if you find yourself getting upset, or you don't understand anything, let the interviewer know and we can slow down and talk about it.

If you have experienced sexual or physical abuse in the past, you may also be concerned about the possibilities of disclosure of this abuse. As discussed in the confidentiality paragraph, our sessions will remain confidential. However we have a duty to report or share information with the Trust Safeguarding Team if we have concerns about your safety or that of others. The diagram below shows the disclosure process that has been put in place by the Trust to protect you and others who may be at risk.

## Disclosure Process



### 11. What are the benefits of taking part?

There is no direct benefit for you in taking part in this study, but we hope that the development of the screening instrument may contribute to the better treatment of mental health disorders in the future.

### 12. What happens when the research study is finished?

When the research study is finished and the information has been analysed, your consultant will be informed about any clinically relevant new information we have gathered that could influence your future care.

### 13. What if there is a problem?

If you experience any problems as a result of the study you can discuss this with the researcher, and the appropriate hospital procedures will be followed. The normal NHS clinical supports will be available to you as well as NHS and university complaints mechanisms.

### 14. Will my taking part in this study be kept confidential?

If you decide to take part in the study we will need to inform the mental health clinicians involved in your care about your participation. Any clinically relevant information about you collected during the course of the research will be discussed with your consultant who already knows about this research. Otherwise our sessions will remain confidential. However we have a duty to report or share information with the NHS Patient Safeguarding Team if we have concerns about your immediate safety or that of others.

### 15. What will happen if I don't want to carry on with the research?

It will be up to you to decide how much you want to tell the interviewer. Your participation in the research can be suspended or stopped altogether, at any time with no disadvantage to you.

16. What if something goes wrong? (What if there is a problem?)

It is unlikely that taking part in this study will harm anyone; however this study is covered by Oxford Brookes University's insurance policy. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it. Regardless of this, if you have any concerns, you can speak to your clinical staff or the researcher.

If you wish to complain about the way that you have been treated in this study, the normal NHS and Oxford Brookes University complaints mechanism will be fully available to you. If you have any concerns about the conduct of the study, please contact Hazel Abbott, the Chair of the Faculty Research Ethics Committee – [heabbott@brookes.ac.uk](mailto:heabbott@brookes.ac.uk).

17. What will happen to the results of the study?

When the study is finished, we hope to use the information to continue the development of the new screening tool for patients with problems similar to yours. We also hope to publish the results in academic journals, in various mental health publications, and to present the findings of the study at conferences and research meetings, but will ensure that no individual participant in the study can be identified. You may also request a copy of the findings.

18. Who is organising this research?

The study will form part of the researcher's thesis as part of her doctoral studies at Oxford Brookes University.

19. Who has reviewed this study?

All research in the NHS has to be looked at by an independent group of people called the Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been given a favourable ethical opinion by the National Research Ethics Service - Portsmouth Research Ethics Committee, and the Faculty of Health and Life Science Research Ethics Committee at Oxford Brookes University.

20. Contact for further information

For further information about the study, please contact: Researcher: Doris Tallon, [11117615@brookes.ac.uk](mailto:11117615@brookes.ac.uk) 07779728985 or Dr. Sue McLaughlin, Consultant Nurse [Sue.Mclaughlin@berkshire.nhs.uk](mailto:Sue.Mclaughlin@berkshire.nhs.uk) 0118 9605000 who is familiar with the Research. Thank you very much for taking the time to read this information sheet, which is now yours to keep.



## APPENDIX 18 Clinician Information Sheet, Stage 2

### Participant Information Sheet for Clinicians

#### **Trauma in Borderline Personality Disorder: 'Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Borderline Personality Disorder (BPD)?'**

Dear Colleague

My name is Doris Tallon; having worked for several years as a clinical trauma specialist in the Erleigh Road Trauma Services Centre, I am currently undertaking research at Oxford Brookes University. The research project is entitled "*A Study of Trauma in Borderline Personality Disorder (BPD); is Complex PTSD (CPTSD) under recognised in diagnosing BPD?*" This is the beginning of the second part of a doctoral programme of research aimed at assessing a reported weakness in BPD diagnosis. You may already be familiar with this project, as it has already been presented to a number of clinicians in February at Prospect Park.

The first stage of this research is complete. Using patients' medical records, and with full support and cooperation of clinical staff, I measured current practices in the diagnosis of PTSD/CPTSD for borderline patients in Berkshire. In particular, I measured the use of assessment instrument(s), the documentation of trauma history, and symptoms against the DSM-IV diagnostic criteria for BPD, PTSD and CPTSD (listed in the DSM as Disorders of Extreme Stress Not Otherwise Specified - DESNOS). I then recorded how this informed their care plan, and treatment(s). Preliminary findings support the research hypothesis that PTSD/CPTSD is under recognised in this patient group. Building on this work I have developed a screening instrument to facilitate delineating BPD from PTSD/CPTSD, using a subset of the same patients.

This second stage will now test the Screening Instrument for its reliability and sensitivity, and also its validity against gold standard PTSD & CPTSD/DESNOS assessment instruments. Patients from Stage 1 have already verbally agreed to participate in a subsequent assessment. All participants in Stage 1 will now be informed about the second stage of the study and invited to take part in it. Depending on the actual number of Stage 1 patients that grant their approval, a few new patients may be needed. Following consent, an independent clinician will use the new instrument to screen participants, and they will then be assessed by me in an interview which will use the CAPS for PTSD and SIDES for DESNOS tools and the results of the interview will be compared to the results from the screening instrument.

Ethical approval has been granted by the National Research Ethics Service and by Oxford Brookes University and Berkshire Healthcare NHS Foundation Trust has agreed to the project going ahead.

## **What do you have to do?**

You are requested to give your agreement for the researcher to approach Stage 1 participants who have already given verbal consent.

If sufficient Stage 1 patients do not provide consent, I may revert to you to approach new patients that meet the criteria below for inclusion. As with Stage 1, any new potential participants will initially be approached by a member of their direct healthcare team who should informally discuss the research project with them and explain how they could help. All patients (Stage 1 or new) who express an interest in the study will be then be given a copy of the Patient Information Sheet which emphasises the voluntary nature of their participation, and they will have at least 24 hours to consider whether or not they might wish to take part. Once they agree verbally then the researcher will be (re) introduced to them to answer any further questions they may have and take consent. Once consent has been obtained I will liaise with the patient and with you to arrange a date and time for the administration of the screening tool and the in-depth interview.

## **Inclusion criteria for all participants (already satisfied for Stage 1 participant)**

- Must know and understand their diagnosis
- Age 18 or over (no upper age limit), diagnosed with BPD
- Must be able to give informed consent to participate in the study
- Be an in or out patient of the participating Trust
- Able to speak English

## **Principal exclusion criteria**

- Acutely distressed
- Significant learning disability
- Not aware of their diagnosis of BPD

## **Administrating of Screening Tool**

An important part of this research is to have an independent clinician administer the new screening instrument. I would like to discuss with you if you are willing to participate in this activity

## **Further Information**

If you require further information then please do not hesitate to contact me by e-mail or phone (below). I am truly grateful for your co-operation in this matter both in the past and the future. Your time and the participation in this study will be greatly appreciated.

Thank you,



## APPENDIX 19 Trust Safeguarding Procedure

### Trust Policy Safeguarding of Adults Policy and Procedures (2008)

- Clinicians are advised not ask probing questions, but must explain that any reported abuse will be recorded in their notes and to record information as it is given to them using patients own words
- Any disclosure of abuse must be entered as an incident via the official data recording system (datix), which will be seen by the safeguarding lead. This requires the safeguarding lead to complete the safeguarding section of this form as well as updating the patient's notes.
- Concerns about abuse or actual abuse must also be raised formally with the Safeguarding team to the local Authority Safeguarding Team who will determine the next stage, as they do not get automatic notification.
- Where there is suspicion of a criminal offence the patient should be asked if they wish to report to the police.
- If they wish to report the alleged crime (to the police), they must be advised that this could lead to prosecution, although they do not have to prosecute if they do not wish to. However it is still the responsibility of the clinician (researcher) to report all concerns about abuse to the Safeguarding Adults team.
- This will then be reported to the Police who will deal with it as per Police procedures, such as any criminal investigation
- If the perpetrator could be a risk to others, then the police must always be made aware. If the perpetrator is not currently a risk to others (e.g. if they have passed away) and the patient does not wish to make a report, then it is acceptable not to inform the police
- Patients will be advised that they do not have to identify the abuser if they did not wish to. Patients should also be advised that once a report is made, it is likely that either the police or the local authority will request that the patient must disclose the abusers' identity
- Patients must be asked if the perpetrator is still around and whether or not he/she is in a position to further abuse the participant or any other children or adults
- If the abuser is around, identified, and is in apposition to abuse again, this will be reported to the police whether or not the patient wishes to prosecute
- Patients will be advised that, where there is abuse or neglect, action will be taken, and they will be involved as sensitively as possible. This process must be explained to ensure their full understanding. However, it is not possible to explain every consequence as these are dependent on the outcome of any subsequent investigation and/or criminal proceedings)
- Once informed, the local authority are obliged to put safeguarding measures in place with the agreement of the patient







**APPENDIX 20 Consent Form, Stage 2  
CONSENT FORM**

Patient Identification Number: \_\_\_\_\_ **Research Project: Stage 2, Trauma in Borderline Personality Disorder 'Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Borderline Personality Disorder (BPD)?**

**Please**

**Initial box**

- I confirm that I have read and understand the information sheet dated .....version..... for the above study
- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
- I understand that my participation is voluntary and that I am free to withdraw at any time, including during any assessment, without giving any reason, without my medical care or legal rights being affected
- I understand that sections of my medical notes may be looked at by responsible individuals from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I agree to take part in the study 'Trauma in Borderline Personality Disorder 'Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Borderline Personality Disorder (BPD)?'
- I agree to my consultant being informed of my participation in the study, and to be kept informed of all results
- I agree to have the session(s) audio-recorded
- I would like a summary of the research findings


\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher (Doris Tallon)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## APPENDIX 21 NHS Ethics, Stage 2



### Health Research Authority

#### NRES Committee South Central - Portsmouth

Bristol Research Ethics Committee Centre  
Level 3, Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT

Telephone: 0117 342 1334  
Facsimile: 0117 342 0445

23 August 2012

Mrs Doris Tallon  
PhD Student  
Oxford Brookes University  
Department of Clinical Health Care  
Jack Straws Lane  
Marston, Oxford  
OX3 0FL

Dear Mrs Tallon

**Study title:** Trauma in Borderline Personality Disorder - 'Is Complex Post Traumatic Stress Disorder (CPTSD) under recognised in Borderline Personality Disorder (BPD)?'  
**REC reference:** 12/SC/0382

Thank you for your letter of 10 August 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		19 June 2012
Covering Letter		
Evidence of insurance or indemnity		08 July 2011
Letter from Sponsor		11 June 2012
Other: CV Nigel Wellman		18 June 2012
Other: FREC reply February		20 February 2012
Other: FREC 2011 - 15 Tallon (resubmission)		25 June 2012
Other: 2011 - 15 Tallon (resubmission follow-up)		11 June 2012
Other: Project schedule	1.1	18 June 2012
Other: Ethical approval (Hazel)		11 June 2012
Other: Screen development flowchart	2	18 June 2012
Other: CV L Coombes		11 February 2011
Other: CV - Doris Tallon		
Other: CV - Dr Rex Haigh		
Other: CV - Suzanna Rose		
Participant Consent Form: Stage 2	8	18 June 2012
Participant Information Sheet: Clinicians	7.7	19 June 2012
Participant Information Sheet	18	01 August 2012
Protocol	18	18 June 2012
Questionnaire: CAPS form		
Questionnaire: SIDES form		
Questionnaire: BTES screening instrument	9.1	18 June 2012
REC application		18 June 2012
Referees or other scientific critique report		11 June 2012
Response to Request for Further Information		10 August 2012
Summary/Synopsis	1.1	18 June 2012

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/SC/0382**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

  
Mrs Jayne Tyler  
Vice-Chair

Email: [scsha.sehrec@nhs.net](mailto:scsha.sehrec@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

*Copy to: Mrs Hazel Abbott  
Ms. Sylvia Warwick, Berkshire Healthcare NHS Foundation Trust*

NRES Committee South Central - Portsmouth

Attendance at Sub-Committee of the REC held in correspondence

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>
Mrs Ita Berry	Retired Clinical Psychologist	Yes
Dr. Mary Saunders	Senior Lecturer	Yes
Mrs Jayne Tyler	Senior Fire Control Operator and Committee Vice Chair	Yes

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Thomas Fairman	Assistant Committee Coordinator

## APPENDIX 22 Trust R&D Approval, Stage 2



Berkshire Healthcare   
NHS Foundation Trust

*Doris Tallon*  
3, Chazey Road,  
Caversham,  
Reading,  
RG47DS

5<sup>th</sup> Floor, Fitzwilliam House  
Skimped Hill lane  
Bracknell  
Berkshire  
RG12 1BQ

Tel: 01344 415825

Fax: 01344 415826

<http://www.berkshirehealthcare.nhs.uk/>

Our Ref: 2012/23

29/10/2012

REC Ref: 12/SC/0382

Study title: Trauma in Borderline Personality Disorder – 'Is Complex Post Traumatic Stress Disorder (CPTSD) under recognized in Borderline Personality Disorder (BPD)?'

Start date: 17/09/2012

End date: 01/07/2013

Dear Doris Tallon,

### **Confirmation of Trust Management Approval**

On behalf of Berkshire Healthcare NHS Foundation Trust, I am pleased to confirm Trust Management Approval for the above research on the basis described in the application, protocol and other supporting documents.

Approval is conditional on reporting of up-to-date recruitment when requested and the submission of a brief final report of research findings. Failure to do so may result in approval being withdrawn.

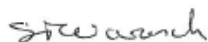
If there are any changes to the study protocol, the R&D Department must be informed immediately and supplied with any amended documentation as necessary, including confirmation that the amendments have been favourably reviewed by the Sponsor and the Ethics Committee.

If the end date changes from that shown above, then please inform BHFT R&D Manager. Trust approval will cease on the end date above. Please contact the R&D Manager to discuss any extension.

If you have any questions about the above, or you require any other assistance, then please contact the R&D Department.

I wish you every success with the study.

Yours sincerely



*JW* Dr Justin Wilson  
Medical Director

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The Community Health Services for Berkshire East and Berkshire West are part of Berkshire Healthcare  
NHS Foundation Trust as of 8 April 2011





# Oxford Brookes University

Faculty of Health and Life Sciences

Research Ethics Committee

Scientific Peer Review Form

**The Research Ethics Committee (REC) of the Faculty of Health and Life Sciences have undertaken an independent scientific peer review of the following research proposal:**

**Project Title:** Trauma and diagnosis of BPD: is CPTSD under-recognised in diagnosing BPD?

**Name of Researcher:** Doris Tallon

**Name of Research Supervisor:** Professor Nigel Wellman

**Faculty REC Application Number:** 2011/15

Following review on 09/02/12 and 18/05/12, the above research is considered to ethically and scientifically sound (see attached letters).

Signed: .....Hazel Abbott.....

Designation: Departmental Research Ethics Officer

(Signed on behalf of the Faculty of Health and Life Sciences Research Ethics Committee)

Date: ...11/06/2012 .....

Independent scientific peer review and ethics review undertaken by the following members of the Faculty REC:	
Mrs Hazel Abbott (Chair)	Ms Gail Lansdown
Professor David Foxcroft	Dr Mandy Plumb
Ms Morag Maclean	Dr Sally Richards



**APPENDIX 24 CAPS  
National Center for PTSD**

CLINICIAN-ADMINISTERED PTSD SCALE FOR DSM-IV

Name: \_\_\_\_\_ ID #: \_\_\_\_\_

Date: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Study: \_\_\_\_\_

Dudley D. Blake, Frank W. Weathers, Linda M. Nagy,  
Danny G. Kaloupek, Dennis S. Charney, & Terence M. Keane

National Center for Posttraumatic Stress Disorder

Behavioral Science Division -- Boston VA Medical Center  
Neurosciences Division -- West Haven VA Medical Center

Revised July 1998

**Criterion A. The person has been exposed to a traumatic event in which both of the following were present:**

- (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
- (2) the person's response involved intense fear, helplessness, or horror. Note: In children, this may be expressed instead by disorganized or agitated behavior

I'm going to be asking you about some difficult or stressful things that sometimes happen to people. Some examples of this are being in some type of serious accident; being in a fire, a hurricane, or an earthquake; being mugged or beaten up or attacked with a weapon; or being forced to have sex when you didn't want to. I'll start by asking you to look over a list of experiences like this and check any that apply to you. Then, if any of them do apply to you, I'll ask you to briefly describe what happened and how you felt at the time.

Some of these experiences may be hard to remember or may bring back uncomfortable memories or feelings. People often find that talking about them can be helpful, but it's up to you to decide how much you want to tell me. As we go along, if you find yourself becoming upset, let me know and we can slow down and talk about it. Also, if you have any questions or you don't understand something, please let me know. Do you have any questions before we start?

ADMINISTER CHECKLIST, THEN REVIEW AND INQUIRE UP TO THREE EVENTS. IF MORE THAN THREE EVENTS ENDORSED, DETERMINE WHICH THREE EVENTS TO INQUIRE (E.G., FIRST, WORST, AND MOST RECENT EVENTS; THREE WORST EVENTS; TRAUMA OF INTEREST PLUS TWO OTHER WORST EVENTS, ETC.)

IF NO EVENTS ENDORSED ON CHECKLIST: *(Has there ever been a time when your life was in danger or you were seriously injured or harmed?)*

IF NO: *(What about a time when you were threatened with death or serious injury, even if you weren't actually injured or harmed?)*

IF NO: *(What about witnessing something like this happen to someone else or finding out that it happened to someone close to you?)*

IF NO: *(What would you say are some of the most stressful experiences you have had over your life?)*

EVENT #1

<p><b>What happened?</b> <i>(How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</i></p> <p><b>How did you respond emotionally?</b> <i>(Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</i></p>	<p><i>Describe (e.g., event type, victim, perpetrator, age, frequency):</i></p> <p><u>A. (1)</u>  <i>Life threat? NO YES [self ___ other ___]</i>  <i>Serious injury? NO YES [self ___ other ___]</i>  <i>Threat to physical integrity? NO YES [self ___ other ___]</i></p> <p><u>A. (2)</u>  <i>Intense fear/help/horror? NO YES [during ___ after ___]</i></p> <p><i>Criterion A met? NO PROBABLE YES</i></p>
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## EVENT #2

<p><b>What happened?</b> (How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</p> <p><b>How did you respond emotionally?</b> (Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</p>	<p>Describe (e.g., event type, victim, perpetrator, age, frequency):</p> <p><u>A. (1)</u> Life threat? NO YES [self ___ other ___] Serious injury? NO YES [self ___ other ___] Threat to physical integrity? NO YES [self ___ other ___]</p> <p><u>A. (2)</u> Intense fear/help/horror? NO YES [during ___ after ___]</p> <p>Criterion A met? NO PROBABLE YES</p>
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## EVENT #3

<p><b>What happened?</b> (How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</p> <p><b>How did you respond emotionally?</b> (Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</p>	<p>Describe (e.g., event type, victim, perpetrator, age, frequency):</p> <p><u>A. (1)</u> Life threat? NO YES [self ___ other ___] Serious injury? NO YES [self ___ other ___] Threat to physical integrity? NO YES [self ___ other ___]</p> <p><u>A. (2)</u> Intense fear/help/horror? NO YES [during ___ after ___]</p> <p>Criterion A met? NO PROBABLE YES</p>
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For the rest of the interview, I want you to keep (EVENTS) in mind as I ask you some questions about how they may have affected you.

I'm going to ask you about twenty-five questions altogether. Most of them have two parts. First, I'll ask if you've ever had a particular problem, and if so, about how often in the past month (week). Then I'll ask you how much distress or discomfort that problem may have caused you.

**Criterion B. The traumatic event is persistently reexperienced in one (or more) of the following ways:**

- (B-1)** recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.

**Note:** In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.

<p><b><u>Frequency</u></b>  <b>Have you ever had unwanted memories of (EVENT)? What were they like?</b> <i>(What did you remember?)</i> [IF NOT CLEAR:] <i>(Did they ever occur while you were awake, or only in dreams?)</i>                  [EXCLUDE IF MEMORIES OCCURRED ONLY DURING DREAMS] <b>How often have you had these memories in the past month (week)?</b></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much distress or discomfort did these memories cause you? Were you able to put them out of your mind and think about something else?</b> <i>(How hard did you have to try?)</i> <b>How much did they interfere with your life?</b></p> <p>0 None                  1 Mild, minimal distress or disruption of activities                  2 Moderate, distress clearly present but still manageable, some disruption of activities                  3 Severe, considerable distress, difficulty dismissing memories, marked disruption of activities                  4 Extreme, incapacitating distress, cannot dismiss memories, unable to continue activities</p> <p><b><u>QV (specify)</u></b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime F</u></b></p> <p>_____</p> <p>I _____                  Sx: Y N</p>
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- (B-2)** recurrent distressing dreams of the event. **Note:** In children, there may be frightening dreams without recognizable content.

<p><b><u>Frequency</u></b>  <b>Have you ever had unpleasant dreams about (EVENT)? Describe a typical dream.</b> <i>(What happens in them?)</i> <b>How often have you had these dreams in the past month (week)?</b></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much distress or discomfort did these dreams cause you? Did they ever wake you up?</b> [IF YES:] <i>(What happened when you woke up? How long did it take you to get back to sleep?)</i> [LISTEN FOR REPORT OF ANXIOUS AROUSAL, YELLING, ACTING OUT THE NIGHTMARE] <i>(Did your dreams ever affect anyone else? How so?)</i></p> <p>0 None                  1 Mild, minimal distress, may not have awoken                  2 Moderate, awoke in distress but readily returned to sleep                  3 Severe, considerable distress, difficulty returning to sleep                  4 Extreme, incapacitating distress, did not return to sleep</p> <p><b><u>QV (specify)</u></b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime F</u></b></p> <p>_____</p> <p>I _____                  Sx: Y N</p>
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3. **(B-3)** acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). **Note:** In young children, trauma-specific reenactment may occur.

<p><b><u>Frequency</u></b>  <b>Have you ever suddenly acted or felt as if (EVENT) were happening again?</b> <i>(Have you ever had flashbacks about [EVENT]?)</i> [IF NOT CLEAR:] <i>(Did this ever occur while you were awake, or only in dreams?)</i>                  [EXCLUDE IF OCCURRED ONLY DURING DREAMS]  <b>Tell me more about that. How often has that happened in the past month (week)?</b></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much did it seem as if (EVENT) were happening again?</b> <i>(Were you confused about where you actually were or what you were doing at the time?)</i>  <b>How long did it last? What did you do while this was happening?</b> <i>(Did other people notice your behavior? What did they say?)</i></p> <p>0 No reliving                  1 Mild, somewhat more realistic than just thinking about event                  2 Moderate, definite but transient dissociative quality, still very aware of surroundings, daydreaming quality                  3 Severe, strongly dissociative (reports images, sounds, or smells) but retained some awareness of surroundings                  4 Extreme, complete dissociation (flashback), no awareness of surroundings, may be unresponsive, possible amnesia for the episode (blackout)</p> <p><b><u>QV (specify)</u></b>                  _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime F</u></b>                  _____                  I _____                  Sx: Y N</p>
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4. **(B-4)** intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

<p><b><u>Frequency</u></b>  <b>Have you ever gotten emotionally upset when something reminded you of (EVENT)?</b> <i>(Has anything ever triggered bad feelings related to [EVENT]?)</i> <b>What kinds of reminders made you upset? How often in the past month (week)?</b></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much distress or discomfort did (REMINDERS) cause you? How long did it last? How much did it interfere with your life?</b></p> <p>0 None                  1 Mild, minimal distress or disruption of activities                  2 Moderate, distress clearly present but still manageable, some disruption of activities                  3 Severe, considerable distress, marked disruption of activities                  4 Extreme, incapacitating distress, unable to continue activities</p> <p><b><u>QV (specify)</u></b>                  _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime F</u></b>                  _____                  I _____                  Sx: Y N</p>
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5. (B-5) physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

<p><b><u>Frequency</u></b>  <b>Have you ever had any physical reactions when something reminded you of (EVENT)?</b> <i>(Did your body ever react in some way when something reminded you of [EVENT]?)</i> <b>Can you give me some examples?</b> <i>(Did your heart race or did your breathing change? What about sweating or feeling really tense or shaky?)</i> <b>What kinds of reminders triggered these reactions? How often in the past month (week)?</b></p> <p>0 Never          1 Once or twice          2 Once or twice a week          3 Several times a week          4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong were (PHYSICAL REACTIONS)?</b>  <b>How long did they last?</b> <i>(Did they last even after you were out of the situation?)</i></p> <p>0 No physical reactivity          1 Mild, minimal reactivity          2 Moderate, physical reactivity clearly present, may be sustained if exposure continues          3 Severe, marked physical reactivity, sustained throughout exposure          4 Extreme, dramatic physical reactivity, sustained arousal even after exposure has ended</p> <p><b><u>QV (specify)</u></b>          _____</p>	<p><b><u>Past week</u></b>          F _____          I _____</p> <p><b><u>Past month</u></b>          F _____          I _____          Sx: Y N</p> <p><b><u>Lifetime</u></b>          F _____          I _____          Sx: Y N</p>
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**Criterion C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:**

6. (C-1) efforts to avoid thoughts, feelings, or conversations associated with the trauma

<p><b><u>Frequency</u></b>  <b>Have you ever tried to avoid thoughts or feelings about (EVENT)?</b> <i>(What kinds of thoughts or feelings did you try to avoid?)</i> <b>What about trying to avoid talking with other people about it?</b> <i>(Why is that?)</i> <b>How often in the past month (week)?</b></p> <p>0 Never          1 Once or twice          2 Once or twice a week          3 Several times a week          4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much effort did you make to avoid (THOUGHTS/FEELINGS/CONVERSATIONS)?</b> <i>(What kinds of things did you do? What about drinking or using medication or street drugs?)</i> [CONSIDER ALL ATTEMPTS AT AVOIDANCE, INCLUDING DISTRACTION, SUPPRESSION, AND USE OF ALCOHOL/DRUGS] <b>How much did that interfere with your life?</b></p> <p>0 None          1 Mild, minimal effort, little or no disruption of activities          2 Moderate, some effort, avoidance definitely present, some disruption of activities          3 Severe, considerable effort, marked avoidance, marked disruption of activities, or involvement in certain activities as avoidant strategy          4 Extreme, drastic attempts at avoidance, unable to continue activities, or excessive involvement in certain activities as avoidant strategy</p> <p><b><u>QV (specify)</u></b>          _____</p>	<p><b><u>Past week</u></b>          F _____          I _____</p> <p><b><u>Past month</u></b>          F _____          I _____          Sx: Y N</p> <p><b><u>Lifetime</u></b>          F _____          I _____          Sx: Y N</p>
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7. (C-2) efforts to avoid activities, places, or people that arouse recollections of the trauma

<p><b><u>Frequency</u></b>  <b>Have you ever tried to avoid certain activities, places, or people that reminded you of (EVENT)?</b> <i>(What kinds of things did you avoid? Why is that?)</i> <b>How often in the past month (week)?</b></p> <p>0 Never          1 Once or twice          2 Once or twice a week          3 Several times a week          4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much effort did you make to avoid (ACTIVITIES/PLACES/PEOPLE)?</b> <i>(What did you do instead?)</i> <b>How much did that interfere with your life?</b></p> <p>0 None          1 Mild, minimal effort, little or no disruption of activities          2 Moderate, some effort, avoidance definitely present, some disruption of activities          3 Severe, considerable effort, marked avoidance, marked disruption of activities or involvement in certain activities as avoidant strategy          4 Extreme, drastic attempts at avoidance, unable to continue activities, or excessive involvement in certain activities as avoidant strategy</p> <p><b>QV (specify)</b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____          I _____</p> <p><b><u>Past month</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p>
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8. (C-3) inability to recall an important aspect of the trauma

<p><b><u>Frequency</u></b>  <b>Have you had difficulty remembering some important parts of (EVENT)?</b> <b>Tell me more about that.</b> <i>(Do you feel you should be able to remember these things? Why do you think you can't?)</i> <b>In the past month (week), how much of the important parts of (EVENT) have you had difficulty remembering?</b> <i>(What parts do you still remember?)</i></p> <p>0 None, clear memory          1 Few aspects not remembered (less than 10%)          2 Some aspects not remembered (approx 20-30%)          3 Many aspects not remembered (approx 50-60%)          4 Most or all aspects not remembered (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How much difficulty did you have recalling important parts of (EVENT)?</b> <i>(Were you able to recall more if you tried?)</i></p> <p>0 None          1 Mild, minimal difficulty          2 Moderate, some difficulty, could recall with effort          3 Severe, considerable difficulty, even with effort          4 Extreme, completely unable to recall important aspects of event</p> <p><b>QV (specify)</b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____          I _____</p> <p><b><u>Past month</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p>
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9. (C-4) markedly diminished interest or participation in significant activities

<p><b><u>Frequency</u></b>  <b>Have you been less interested in activities that you used to enjoy? (What kinds of things have you lost interest in? Are there some things you don't do at all anymore? Why is that?)</b>                  [EXCLUDE IF NO OPPORTUNITY, IF PHYSICALLY UNABLE, OR IF DEVELOPMENTALLY APPROPRIATE CHANGE IN PREFERRED ACTIVITIES] <b>In the past month (week), how many activities have you been less interested in? (What kinds of things do you still enjoy doing?) When did you first start to feel that way? (After the [EVENT]?)</b></p> <p>0 None                  1 Few activities (less than 10%)                  2 Some activities (approx 20-30%)                  3 Many activities (approx 50-60%)                  4 Most or all activities (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong was your loss of interest? (Would you enjoy [ACTIVITIES] once you got started?)</b></p> <p>0 No loss of interest                  1 Mild, slight loss of interest, probably would enjoy after starting activities                  2 Moderate, definite loss of interest, but still has some enjoyment of activities                  3 Severe, marked loss of interest in activities                  4 Extreme, complete loss of interest, no longer participates in any activities</p> <p><b><u>QV (specify)</u></b>                  _____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b>                  F _____                  I _____</p> <p>Sx: Y N</p>
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10. (C-5) feeling of detachment or estrangement from others

<p><b><u>Frequency</u></b>  <b>Have you felt distant or cut off from other people? What was that like? How much of the time in the past month (week) have you felt that way? When did you first start to feel that way? (After the [EVENT]?)</b></p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong were your feelings of being distant or cut off from others? (Who do you feel closest to? How many people do you feel comfortable talking with about personal things?)</b></p> <p>0 No feelings of detachment or estrangement                  1 Mild, may feel "out of synch" with others                  2 Moderate, feelings of detachment clearly present, but still feels some interpersonal connection                  3 Severe, marked feelings of detachment or estrangement from most people, may feel close to only one or two people                  4 Extreme, feels completely detached or estranged from others, not close with anyone</p> <p><b><u>QV (specify)</u></b>                  _____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b>                  F _____                  I _____</p> <p>Sx: Y N</p>
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11. (C-6) restricted range of affect (e.g., unable to have loving feelings)

<p><b><u>Frequency</u></b>                  Have there been times when you felt emotionally numb or had trouble experiencing feelings like love or happiness? What was that like? (What feelings did you have trouble experiencing?) How much of the time in the past month (week) have you felt that way? When did you first start having trouble experiencing (EMOTIONS)? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>                  How much trouble did you have experiencing (EMOTIONS)? (What kinds of feelings were you still able to experience?) [INCLUDE OBSERVATIONS OF RANGE OF AFFECT DURING INTERVIEW]</p> <p>0 No reduction of emotional experience                  1 Mild, slight reduction of emotional experience                  2 Moderate, definite reduction of emotional experience, but still able to experience most emotions                  3 Severe, marked reduction of experience of at least two primary emotions (e.g., love, happiness)                  4 Extreme, completely lacking emotional experience</p> <p><b><u>QV (specify)</u></b>                  _____</p> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime</u></b>                  F _____                  I _____                  Sx: Y N</p>
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12. (C-7) sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

<p><b><u>Frequency</u></b>                  Have there been times when you felt there is no need to plan for the future, that somehow your future will be cut short? Why is that? [RULE OUT REALISTIC RISKS SUCH AS LIFE-THREATENING MEDICAL CONDITIONS] How much of the time in the past month (week) have you felt that way? When did you first start to feel that way? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>                  How strong was this feeling that your future will be cut short? (How long do you think you will live? How convinced are you that you will die prematurely?)</p> <p>0 No sense of a foreshortened future                  1 Mild, slight sense of a foreshortened future                  2 Moderate, sense of a foreshortened future definitely present, but no specific prediction about longevity                  3 Severe, marked sense of a foreshortened future, may make specific prediction about longevity                  4 Extreme, overwhelming sense of a foreshortened future, completely convinced of premature death</p> <p><b><u>QV (specify)</u></b>                  _____</p> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime</u></b>                  F _____                  I _____                  Sx: Y N</p>
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**Criterion D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:**

**13. (D-1) difficulty falling or staying asleep**

<p><b><u>Frequency</u></b>  <b>Have you had any problems falling or staying asleep? How often in the past month (week)? When did you first start having problems sleeping? (After the [EVENT]?)</b></p> <p>0 Never  1 Once or twice  2 Once or twice a week  3 Several times a week  4 Daily or almost every day</p> <p>Sleep onset problems?      Y    N  Mid-sleep awakening?        Y    N  Early a.m. awakening?        Y    N</p> <p>Total # hrs sleep/night        _____  Desired # hrs sleep/night      _____</p>	<p><b><u>Intensity</u></b>  <b>How much of a problem did you have with your sleep? (How long did it take you to fall asleep? How often did you wake up in the night? Did you often wake up earlier than you wanted to? How many total hours did you sleep each night?)</b></p> <p>0 No sleep problems  1 Mild, slightly longer latency, or minimal difficulty staying asleep (up to 30 minutes loss of sleep)  2 Moderate, definite sleep disturbance, clearly longer latency, or clear difficulty staying asleep (30-90 minutes loss of sleep)  3 Severe, much longer latency, or marked difficulty staying asleep (90 min to 3 hrs loss of sleep)  4 Extreme, very long latency, or profound difficulty staying asleep (&gt; 3 hrs loss of sleep)</p> <p><b>QV (specify)</b>  _____</p> <p><b>Trauma-related?</b>    1 definite 2 probable 3 unlikely  Current _____      Lifetime _____</p>	<p><b><u>Past week</u></b>  F _____  I _____</p> <p><b><u>Past month</u></b>  F _____  I _____  Sx: Y N</p> <p><b><u>Lifetime</u></b>  F _____  I _____  Sx: Y N</p>
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**14. (D-2) irritability or outbursts of anger**

<p><b><u>Frequency</u></b>  <b>Have there been times when you felt especially irritable or showed strong feelings of anger? Can you give me some examples? How often in the past month (week)? When did you first start feeling that way? (After the [EVENT]?)</b></p> <p>0 Never  1 Once or twice  2 Once or twice a week  3 Several times a week  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b>  _____</p>	<p><b><u>Intensity</u></b>  <b>How strong was your anger? (How did you show it?) [IF REPORTS SUPPRESSION:] (How hard was it for you to keep from showing your anger?) How long did it take you to calm down? Did your anger cause you any problems?</b></p> <p>0 No irritability or anger  1 Mild, minimal irritability, may raise voice when angry  2 Moderate, definite irritability or attempts to suppress anger, but can recover quickly  3 Severe, marked irritability or marked attempts to suppress anger, may become verbally or physically aggressive when angry  4 Extreme, pervasive anger or drastic attempts to suppress anger, may have episodes of physical violence</p> <p><b>QV (specify)</b>  _____</p> <p><b>Trauma-related?</b>    1 definite 2 probable 3 unlikely  Current _____      Lifetime _____</p>	<p><b><u>Past week</u></b>  F _____  I _____</p> <p><b><u>Past month</u></b>  F _____  I _____  Sx: Y N</p> <p><b><u>Lifetime</u></b>  F _____  I _____  Sx: Y N</p>
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15. (D-3) difficulty concentrating

<p><b><u>Frequency</u></b>                  Have you found it difficult to concentrate on what you were doing or on things going on around you? What was that like? How much of the time in the past month (week)? When did you first start having trouble concentrating? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>                  How difficult was it for you to concentrate? [INCLUDE OBSERVATIONS OF CONCENTRATION AND ATTENTION IN INTERVIEW] How much did that interfere with your life?</p> <p>0 No difficulty with concentration                  1 Mild, only slight effort needed to concentrate, little or no disruption of activities                  2 Moderate, definite loss of concentration but could concentrate with effort, some disruption of activities                  3 Severe, marked loss of concentration even with effort, marked disruption of activities                  4 Extreme, complete inability to concentrate, unable to engage in activities</p> <p><b><u>QV (specify)</u></b></p> <p>_____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely</p> <p>Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p>
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16. (D-4) hypervigilance

<p><b><u>Frequency</u></b>                  Have you been especially alert or watchful, even when there was no real need to be? (Have you felt as if you were constantly on guard?) Why is that? How much of the time in the past month (week)? When did you first start acting that way? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>                  How hard did you try to be watchful of things going on around you? [INCLUDE OBSERVATIONS OF HYPERVIGILANCE IN INTERVIEW] Did your (HYPERVIGILANCE) cause you any problems?</p> <p>0 No hypervigilance                  1 Mild, minimal hypervigilance, slight heightening of awareness                  2 Moderate, hypervigilance clearly present, watchful in public (e.g., chooses safe place to sit in a restaurant or movie theater)                  3 Severe, marked hypervigilance, very alert, scans environment for danger, exaggerated concern for safety of self/family/home                  4 Extreme, excessive hypervigilance, efforts to ensure safety consume significant time and energy and may involve extensive safety/checking behaviors, marked watchfulness during interview</p> <p><b><u>QV (specify)</u></b></p> <p>_____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely</p> <p>Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p>
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17. (D-5) exaggerated startle response

<p><b><u>Frequency</u></b></p> <p>Have you had any strong startle reactions? When did that happen? (What kinds of things made you startle?) How often in the past month (week)? When did you first have these reactions? (After the [EVENT]?)</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b></p> <p>How strong were these startle reactions? (How strong were they compared to how most people would respond?) How long did they last?</p> <p>0 No startle reaction 1 Mild, minimal reaction 2 Moderate, definite startle reaction, feels "jumpy" 3 Severe, marked startle reaction, sustained arousal following initial reaction 4 Extreme, excessive startle reaction, overt coping behavior (e.g., combat veteran who "hits the dirt")</p> <p><b><u>QV (specify)</u></b></p> <p>_____</p> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b></p> <p>F _____ I _____</p> <p><b><u>Past month</u></b></p> <p>F _____ I _____ Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____ I _____ Sx: Y N</p>
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**Criterion E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.**

18. onset of symptoms

<p>[IF NOT ALREADY CLEAR:] When did you first start having (PTSD SYMPTOMS) you've told me about? (How long after the trauma did they start? More than six months?)</p>	<p>_____ total # months delay in onset</p> <p>With delayed onset (≥ 6 months)? NO YES</p>
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19. duration of symptoms

<p>[CURRENT] How long have these (PTSD SYMPTOMS) lasted altogether?</p> <p>[LIFETIME] How long did these (PTSD SYMPTOMS) last altogether?</p>	<p>Duration more than 1 month?</p> <p>Total # months duration</p> <p>Acute (&lt; 3 months) or chronic (≥ 3 months)?</p>	<p><b><u>Current</u></b></p> <p>NO YES</p> <p>_____</p> <p>acute chronic</p>	<p><b><u>Lifetime</u></b></p> <p>NO YES</p> <p>_____</p> <p>acute chronic</p>
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**Criterion F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.**

20. subjective distress

<p>[CURRENT] Overall, how much have you been bothered by these (PTSD SYMPTOMS) you've told me about? [CONSIDER DISTRESS REPORTED ON EARLIER ITEMS]</p> <p>[LIFETIME] Overall, how much were you bothered by these (PTSD SYMPTOMS) you've told me about? [CONSIDER DISTRESS REPORTED ON EARLIER ITEMS]</p>	<p>0 None</p> <p>1 Mild, minimal distress</p> <p>2 Moderate, distress clearly present but still manageable</p> <p>3 Severe, considerable distress</p> <p>4 Extreme, incapacitating distress</p>	<p><b><u>Past week</u></b></p> <p>_____</p> <p><b><u>Past month</u></b></p> <p>_____</p> <p><b><u>Lifetime</u></b></p> <p>_____</p>
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21. impairment in social functioning

<p>[CURRENT] <b>Have these (PTSD SYMPTOMS) affected your relationships with other people? How so?</b> [CONSIDER IMPAIRMENT IN SOCIAL FUNCTIONING REPORTED ON EARLIER ITEMS]</p> <p>[LIFETIME] <b>Did these (PTSD SYMPTOMS) affect your social life? How so?</b> [CONSIDER IMPAIRMENT IN SOCIAL FUNCTIONING REPORTED ON EARLIER ITEMS]</p>	0	No adverse impact	<u>Past week</u>
	1	Mild impact, minimal impairment in social functioning	_____
	2	Moderate impact, definite impairment, but many aspects of social functioning still intact	<u>Past month</u>
	3	Severe impact, marked impairment, few aspects of social functioning still intact	_____
	4	Extreme impact, little or no social functioning	<u>Lifetime</u>

22. impairment in occupational or other important area of functioning

<p>[CURRENT -- IF NOT ALREADY CLEAR] <b>Are you working now?</b></p> <p>IF YES: <b>Have these (PTSD SYMPTOMS) affected your work or your ability to work? How so?</b> [CONSIDER REPORTED WORK HISTORY, INCLUDING NUMBER AND DURATION OF JOBS, AS WELL AS THE QUALITY OF WORK RELATIONSHIPS. IF PREMORBID FUNCTIONING IS UNCLEAR, INQUIRE ABOUT WORK EXPERIENCES BEFORE THE TRAUMA. FOR CHILD/ADOLESCENT TRAUMAS, ASSESS PRE-TRAUMA SCHOOL PERFORMANCE AND POSSIBLE PRESENCE OF BEHAVIOR PROBLEMS]</p> <p>IF NO: <b>Have these (PTSD SYMPTOMS) affected any other important part of your life?</b> [AS APPROPRIATE, SUGGEST EXAMPLES SUCH AS PARENTING, HOUSEWORK, SCHOOLWORK, VOLUNTEER WORK, ETC.] <b>How so?</b></p> <p>[LIFETIME -- IF NOT ALREADY CLEAR] <b>Were you working then?</b></p> <p>IF YES: <b>Did these (PTSD SYMPTOMS) affect your work or your ability to work? How so?</b> [CONSIDER REPORTED WORK HISTORY, INCLUDING NUMBER AND DURATION OF JOBS, AS WELL AS THE QUALITY OF WORK RELATIONSHIPS. IF PREMORBID FUNCTIONING IS UNCLEAR, INQUIRE ABOUT WORK EXPERIENCES BEFORE THE TRAUMA. FOR CHILD/ADOLESCENT TRAUMAS, ASSESS PRE-TRAUMA SCHOOL PERFORMANCE AND POSSIBLE PRESENCE OF BEHAVIOR PROBLEMS]</p> <p>IF NO: <b>Did these (PTSD SYMPTOMS) affect any other important part of your life?</b> [AS APPROPRIATE, SUGGEST EXAMPLES SUCH AS PARENTING, HOUSEWORK, SCHOOLWORK, VOLUNTEER WORK, ETC.] <b>How so?</b></p>	0	No adverse impact	<u>Past week</u>
	1	Mild impact, minimal impairment in occupational/other important functioning	_____
	2	Moderate impact, definite impairment, but many aspects of occupational/other important functioning still intact	<u>Past month</u>
	3	Severe impact, marked impairment, few aspects of occupational/other important functioning still intact	_____
	4	Extreme impact, little or no occupational/other important functioning	<u>Lifetime</u>

**Global Ratings****23. global validity**

ESTIMATE THE OVERALL VALIDITY OF RESPONSES. CONSIDER FACTORS SUCH AS COMPLIANCE WITH THE INTERVIEW, MENTAL STATUS (E.G., PROBLEMS WITH CONCENTRATION, COMPREHENSION OF ITEMS, DISSOCIATION), AND EVIDENCE OF EFFORTS TO EXAGGERATE OR MINIMIZE SYMPTOMS.	0	Excellent, no reason to suspect invalid responses
	1	Good, factors present that may adversely affect validity
	2	Fair, factors present that definitely reduce validity
	3	Poor, substantially reduced validity
	4	Invalid responses, severely impaired mental status or possible deliberate "faking bad" or "faking good"

**24. global severity**

ESTIMATE THE OVERALL SEVERITY OF PTSD SYMPTOMS. CONSIDER DEGREE OF SUBJECTIVE DISTRESS, DEGREE OF FUNCTIONAL IMPAIRMENT, OBSERVATIONS OF BEHAVIORS IN INTERVIEW, AND JUDGMENT REGARDING REPORTING STYLE.	0	No clinically significant symptoms, no distress and no functional impairment	<u>Past week</u>
	1	Mild, minimal distress or functional impairment	_____
	2	Moderate, definite distress or functional impairment but functions satisfactorily with effort	<u>Past month</u>
	3	Severe, considerable distress or functional impairment, limited functioning even with effort	_____
	4	Extreme, marked distress or marked impairment in two or more major areas of functioning	<u>Lifetime</u> _____

**25. global improvement**

RATE TOTAL OVERALL IMPROVEMENT PRESENT SINCE THE INITIAL RATING. IF NO EARLIER RATING, ASK HOW THE SYMPTOMS ENDORSED HAVE CHANGED OVER THE PAST 6 MONTHS. RATE THE DEGREE OF CHANGE, WHETHER OR NOT, IN YOUR JUDGMENT, IT IS DUE TO TREATMENT.	0	Asymptomatic
	1	Considerable improvement
	2	Moderate improvement
	3	Slight improvement
	4	No improvement
	5	Insufficient information



**Current PTSD Symptoms**

Criterion A met (traumatic event)?      NO    YES

\_\_\_\_\_ # Criterion B sx ( $\geq 1$ )?              NO    YES

\_\_\_\_\_ # Criterion C sx ( $\geq 3$ )?              NO    YES

\_\_\_\_\_ # Criterion D sx ( $\geq 2$ )?              NO    YES

Criterion E met (duration  $\geq 1$  month)? NO

YES Criterion F met (distress/impairment)?

NO YES

CURRENT PTSD (Criteria A-F met)?      NO    YES

IF CURRENT PTSD CRITERIA ARE MET, SKIP TO ASSOCIATED FEATURES

IF CURRENT CRITERIA ARE NOT MET, ASSESS FOR LIFETIME PTSD. IDENTIFY A PERIOD OF AT LEAST A MONTH SINCE THE TRAUMATIC EVENT IN WHICH SYMPTOMS WERE WORSE.

**Since the (EVENT), has there been a time when these (PTSD SYMPTOMS) were a lot worse than they have been in the past month? When was that? How long did it last? (At least a month?)**

IF MULTIPLE PERIODS IN THE PAST: **When were you bothered the most by these (PTSD SYMPTOMS)?**

IF AT LEAST ONE PERIOD, INQUIRE ITEMS 1-17, CHANGING FREQUENCY PROMPTS TO REFER TO WORST PERIOD: **During that time, did you (EXPERIENCE SYMPTOM)? How often?**

<b>Lifetime PTSD Symptoms</b>
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Criterion A met (traumatic event)?      NO    YES

\_\_\_\_\_ # Criterion B sx ( $\geq 1$ )?              NO    YES

\_\_\_\_\_ # Criterion C sx ( $\geq 3$ )?              NO    YES

\_\_\_\_\_ # Criterion D sx ( $\geq 2$ )?              NO    YES

Criterion E met (duration  $\geq 1$  month)? NO

YES Criterion F met (distress/impairment)?

NO YES

LIFETIME PTSD (Criteria A-F met)?      NO    YES

**Associated Features**

**26. guilt over acts of commission or omission**

<p><b><u>Frequency</u></b>  <b>Have you felt guilty about anything you did or didn't do during (EVENT)? Tell me more about that. (What do you feel guilty about?) How much of the time have you felt that way in the past month (week)?</b></p> <p>0 None of the time          1 Very little of the time (less than 10%)          2 Some of the time (approx 20-30%)          3 Much of the time (approx 50-60%)          4 Most or all of the time (more than 80%)</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong were these feelings of guilt? How much distress or discomfort did they cause?</b></p> <p>0 No feelings of guilt          1 Mild, slight feelings of guilt          2 Moderate, guilt feelings definitely present, some distress but still manageable          3 Severe, marked feelings of guilt, considerable distress          4 Extreme, pervasive feelings of guilt, selfcondemnation regarding behavior, incapacitating distress</p> <p><b><u>QV (specify)</u></b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____          I _____</p> <p><b><u>Past month</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p>
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**27. survivor guilt [APPLICABLE ONLY IF MULTIPLE VICTIMS]**

<p><b><u>Frequency</u></b>  <b>Have you felt guilty about surviving (EVENT) when others did not? Tell me more about that. (What do you feel guilty about?) How much of the time have you felt that way in the past month (week)?</b></p> <p>0 None of the time          1 Very little of the time (less than 10%)          2 Some of the time (approx 20-30%)          3 Much of the time (approx 50-60%)          4 Most or all of the time (more than 80%)          8 N/A</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong were these feelings of guilt? How much distress or discomfort did they cause?</b></p> <p>0 No feelings of guilt          1 Mild, slight feelings of guilt          2 Moderate, guilt feelings definitely present, some distress but still manageable          3 Severe, marked feelings of guilt, considerable distress          4 Extreme, pervasive feelings of guilt, selfcondemnation regarding survival, incapacitating distress</p> <p><b><u>QV (specify)</u></b></p> <hr/>	<p><b><u>Past week</u></b></p> <p>F _____          I _____</p> <p><b><u>Past month</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____          I _____</p> <p>Sx: Y N</p>
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28. a reduction in awareness of his or her surroundings (e.g., “being in a daze”)

<p><b><u>Frequency</u></b>  <b>Have there been times when you felt out of touch with things going on around you, like you were in a daze? What was that like?</b>                  [DISTINGUISH FROM FLASHBACK EPISODES]  <b>How often has that happened in the past month (week)?</b> [IF NOT CLEAR:] <i>(Was it due to an illness or the effects of drugs or alcohol?)</i> <b>When did you first start feeling that way?</b> <i>(After the [EVENT]?)</i></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong was this feeling of being out of touch or in a daze?</b> <i>(Were you confused about where you actually were or what you were doing at the time?)</i> <b>How long did it last? What did you do while this was happening?</b> <i>(Did other people notice your behavior? What did they say?)</i></p> <p>0 No reduction in awareness                  1 Mild, slight reduction in awareness                  2 Moderate, definite but transient reduction in awareness, may report feeling “spacy”                  3 Severe, marked reduction in awareness, may persist for several hours                  4 Extreme, complete loss of awareness of surroundings, may be unresponsive, possible amnesia for the episode (blackout)</p> <p><b><u>QV (specify)</u></b></p> <hr/> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p>
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29. derealization

<p><b><u>Frequency</u></b>  <b>Have there been times when you felt as if you were outside of your body, watching yourself as if you were another person?</b> [IF NO:] <i>(What about times when your body felt strange or unfamiliar to you, as if it had changed in some way?)</i> <b>What was that like? How often has that happened in the past month (week)?</b> [IF NOT CLEAR:] <i>(Was it due to an illness or the effects of drugs or alcohol?)</i> <b>When did you first start feeling that way?</b> <i>(After the [EVENT]?)</i></p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>  <b>How strong was (DEREALALIZATION)? How long did it last? What did you do while this was happening?</b> <i>(Did other people notice your behavior? What did they say?)</i></p> <p>0 No derealization                  1 Mild, slight derealization                  2 Moderate, definite but transient derealization                  3 Severe, considerable derealization, marked confusion about what is real, may persist for several hours                  4 Extreme, profound derealization, dramatic loss of sense of reality or familiarity</p> <p><b><u>QV (specify)</u></b></p> <hr/> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b></p> <p>F _____                  I _____</p> <p><b><u>Past month</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p> <p><b><u>Lifetime</u></b></p> <p>F _____                  I _____</p> <p>Sx: Y N</p>
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30. Depersonalization

<p><b><u>Frequency</u></b>                  Have there been times when you felt as if you were outside of your body, watching yourself as if you were another person? [IF NO:] (What about times when your body felt strange or unfamiliar to you, as if it had changed in some way?) <b>What was that like? How often has that happened in the past month (week)?</b> [IF NOT CLEAR:] (Was it due to an illness or the effects of drugs or alcohol?) <b>When did you first start feeling that way?</b> (After the [EVENT]?)</p> <p>5 Never                  6 Once or twice                  7 Once or twice a week                  8 Several times a week                  9 Daily or almost every day</p> <p><b><u>Description/Examples</u></b></p>	<p><b><u>Intensity</u></b>                  How strong was (DEPERSONALIZATION)? How long did it last? What did you do while this was happening? (Did other people notice your behavior? What did they say?)</p> <p>5 No depersonalization                  6 Mild, slight depersonalization                  7 Moderate, definite but transient depersonalization                  8 Severe, considerable depersonalization, marked sense of detachment from self, may persist for several hours                  9 Extreme, profound depersonalization, dramatic sense of detachment from self</p> <p><b><u>QV (specify)</u></b></p> <hr/> <p><b><u>Trauma-related?</u></b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b><u>Past week</u></b>                  F _____                  I _____</p> <p><b><u>Past month</u></b>                  F _____                  I _____                  Sx: Y N</p> <p><b><u>Lifetime</u></b>                  F _____                  I _____                  Sx: Y N</p>
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## APPENDIX 25 SIDES and TAQ

Only a part of SIDES can be displayed due to copyright requirements

SIDES February 13, 2003

### Structured Interview for Disorders of Extreme Stress-NOS

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NOTE: In view of the fact that some interviewees may be victims of interpersonal violence or other severe trauma very early in life, and essentially have no experience with pre-traumatic functioning, the preamble "since the experience" may not apply. Alternative wording is suggested where appropriate.

#### Instructions:

What follows are descriptions of typical reactions someone could have after traumatic experiences such as you have had. Please indicate if you had similar feelings soon after the experience or as long as you can remember.

After each reaction that you feel describes your behavior indicate how severely you felt that reaction in the past month. If the reaction is not one you feel describes you, enter a four, for not applicable, as the severity rating for the past month.

#### I) ALTERATION IN REGULATION OF AFFECT AND IMPULSES

##### I. a.) Affect regulation

1. Do small problems get you very upset? (For example, do you get too angry at a minor frustration? Do you cry too easily? Do you get too nervous about minor things?)

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all.		0
Sometimes overreacts a little.		1
Sometimes gets very upset.		2
Often gets extremely upset, or has tantrums.		3
Not applicable.		4

2. Do you have trouble letting go of things that upset you? (Do you have trouble getting upsetting things off your mind?)

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all.		0
Gets momentarily upset.		1
Upsetting thought keeps coming back hour after hour.		2
Gets completely consumed by upsetting thought.		3
Not applicable.		4

3. When you feel upset, do you have trouble finding ways of calming yourself down? (Does playing music, going out with friends, or sports help? How do you get yourself back on track?)

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all		0
Needs to make special efforts to calm down (e.g. talking, sports, listening to music )		1
Needs to stop everything and focus all energy on calming down.		2
Needs to resort to extreme measures, like getting drunk, taking drugs, or doing other harmful things to his/her body.		3
Not applicable.		4

#### I. b.) Modulation of anger

4. Do you feel angry a lot of the time?

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all.		0
Feels quite angry but able to shift to other matters.		1
Anger interferes with paying attention to daily tasks.		2
Anger dominates my daily life.		3
Not applicable.		4

5. Do you have thoughts or images of hurting somebody else? (Tell me more about that.)

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all.		0
Yes, fleeting thoughts.		1
Thinks about hurting people every day.		2
Can't stop thinking about hurting people.		3
Not applicable.		4

6. Do you have trouble controlling your anger? (What happens? What do you do? How often?)

After the experience or as long as you can remember	Yes	No
In the last month:		
None; not at all.		0
Snaps at people.		1
Yells or throw things.		2
Attack people physically.		3
Not applicable.		4



**The Traumatic Antecedent Questionnaire (TAQ)** is suggested to be used prior to SIDES.

TAQ Revised 3.2010, Bessel A. van der Kolk,

1. I generally felt safe and cared for
2. Someone made sure I got up in the morning and went to school.
3. I was really good at something (like sports, a hobby, school, work or some creative activity).
4. I had good friends.
5. I felt close to at least one of my brothers and sisters.
6. Somebody in my family had so many problems that there was little left for me
7. I felt that nobody cared whether I lived or died.
8. I had someone to talk with outside my family when something was bugging me
9. My parents confided things in me that made me feel uncomfortable.
10. My parents were divorced or separated
11. I lived with different people at different times (like different relatives, or foster families).
12. I had a serious illness and/or had to be hospitalized for a medical problem.
13. Someone I was close to was very sick, or in an accident for which they needed to be hospitalized.
14. I received news that someone close to me had been seriously injured or violently killed during an accident, a fight, or a crime.
15. In my parents' eyes, nothing I did was ever good enough.
16. People in my family called me insulting names.
17. The rules in my family were unclear and inconsistent.
18. The punishments I received were unfair.
19. My parents hurt each other physically when they argued and fought.
20. I spent time out of the house and no one knew where I was.
21. People in my family were out of control.
22. I witnessed physical violence in my family.
23. Someone in my family got medical attention because of violence.
24. Someone in my family had a problem with alcohol and/or drugs
25. I abused alcohol and/or drugs.

26. My caregivers were so into alcohol or drugs that they couldn't take care of me
27. I was beaten, kicked or punched by someone close to me.
28. I was in a situation in which I was convinced that I would be physically injured or lose my life.
29. Someone outside my family attacked me.
30. I saw dead bodies
31. I was involved in a serious accident.
32. I was in a natural disaster.
33. I saw sexual things that scared me.
34. Someone (older) touched me sexually, against my wishes or tried to make me touch them
35. Someone forced me to have sex against my will.
36. Someone threatened me with physical harm unless I did something sexual.
37. I believe that one of my brothers or sisters was sexually molested.
38. I have had another very frightening or traumatic experience where I felt intense fear, helpless, or horrified.
39. Something terrible happened to me that still remain a mystery to me.
40. How upsetting was it to answer these questions?

## APPENDIX 26 Scoring Sheet

### SCORE SHEET FOR BTERS

				Yes	No
		<b>CPTSD</b>	<b>(3 criteria must be met)</b>		
Main Criteria	Box 1, f must be met	(GATE)	if not met, move to BPD	<input type="checkbox"/>	<input type="checkbox"/>
	a	Box 3 a,b	<i>(all must be associated with 'f' in Box 1)</i>	<input type="checkbox"/>	<input type="checkbox"/>
	b	Box 4 b,c,d,e	<i>(all must be associated with 'f' in Box 1)</i>	<input type="checkbox"/>	<input type="checkbox"/>
	c	Box 5 a		<input type="checkbox"/>	<input type="checkbox"/>
CPTSD		Check: Box 1 f <b>must</b> be met or not CPTSD		(3 criteria must be met)	

				Yes	No	
		<b>BPD</b>	<b>(3 criteria must be met)</b>			
Main Criteria	Box 1 a and/or d	(GATE)	if not met move to PTSD	<input type="checkbox"/>	<input type="checkbox"/>	
	a	Box 3 a, b	<i>(must be associated with a,c,d in Box 1)</i>	<input type="checkbox"/>	<input type="checkbox"/>	
	b	Box 4 a, c, d or e or any combination of these			<input type="checkbox"/>	<input type="checkbox"/>
	c	Box 5 b		<input type="checkbox"/>	<input type="checkbox"/>	
BPD		Check: Box 1 a and/or c <b>must</b> be met or not BPD		(3 criteria must be met)		

				Yes	No	
		<b>PTSD</b>	<b>(all 4 criteria must be met)</b>			
Main Criteria	Box 2 a	(GATE)	must be met	<input type="checkbox"/>	<input type="checkbox"/>	
	a	Box 3 a, b	<i>(must be about Box 2)</i>	<input type="checkbox"/>	<input type="checkbox"/>	
	b	Box 4 a, b, c, d, e in any combination ( must de associated with Box 2)			<input type="checkbox"/>	<input type="checkbox"/>
	c	Box 5 a, b		<input type="checkbox"/>	<input type="checkbox"/>	
PTSD		Check Box 2 a <b>must</b> be met or not PTSD		(ALL 4 criteria must be met)		

Outcomes				
1	CPTSD	5	BPD/CPTSD	1,3,4,5,6,7
2	BPD	6	PTSD/CPTSD	Referral to specialist for
3	PTSD	7	ALL: BPD/CPTSD/PTSD	further diagnostic
4	BPD/PTSD	8	None of the above	evaluation and treatment

SCORING BOX	<table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">Date:</td> <td style="width: 50%;">Pt Ref.:</td> </tr> <tr> <td>Scorer:</td> <td>Outcome:</td> </tr> </table>	Date:	Pt Ref.:	Scorer:	Outcome:
Date:	Pt Ref.:				
Scorer:	Outcome:				

<b>To differentiate between CPTSD and BPD:</b> For CPTSD, the traumatic exposures are predominantly CSA and the most upsetting aspect of the experience will be about the trauma itself.
For BPD, the traumatic exposure is predominantly physical, neglect, emotional, sexual molestation. The most upsetting aspect of the experience will be about the environment.
For both CPTSD and BPD the most upsetting aspect is about both the trauma itself as well as the environment.



## APPENDIX 27 Internal Validity, 10 Experts Assessment

This appendix outlines one of the 2 exercises to improve the internal validity of BTERS. Here, a number of different specialists scored the selected sub items (Section 5.7) as to whether or not they considered the particular item to be important. Different weightings were then assigned to the various experts as shown below and the overall summary examined in order to see if a pattern emerged. Unfortunately, no discernible pattern emerged and this particular method was abandoned in favour of the 3 expert review described in (Section 5.7). In the tables below, Green represents a high score, red represents a low score, with yellow and orange representing intermediate values.

		Weighted			Unweighted	
		CPTSD	PTSD	BPD		
1	Did you experience or witness TE in your childhood	11	18	24	10	
2	Was it before the age 13	11	16	18	8	
3	Was it after age 13	11	18	24	10	
4	Was it repeated	11	18	24	10	
5	Was it life threatening	11	16	18	8	
6	Was it sexual abuse	11	16	18	8	
7	Was it physical abuse	11	18	24	10	
8	Was it non life threatening	3	9	20	7	
9	Always a family member, or carer	0	0	0	0	
10	Was it inappropriate touching of your sexual parts	9	13	17	7	
11	Did you feel rejected	9	15	23	9	
12	Did you feel unloved	9	15	23	9	
13	Did you think you were no good enough	9	15	23	9	
14	Did you think you were permanently damaged	9	13	17	7	
15	Abandonment	5	12	21	8	
16	Did you lose trust in people	9	13	17	7	
17	Intense distress	11	18	24	10	
18	Flashbacks	11	18	24	10	
19	Nightmares	11	18	24	10	
20	Avoiding people and places that will cause you distress	11	18	24	10	
21	Intense anger	4	10	19	7	
22	Intense sense of fear	11	18	24	10	
23	Irritable and jumpy when unexpectedly startled	11	18	24	10	
					Mean	8.43
					SD	2.21

Disipline	PTSD	CPTSD	CPTSD	BPD	BPD	BPD	All	BPD	BPD	BPD
CPTSD	2	3	3	0	1	1	1	0	0	0
PTSD	3	3	3	1	2	1	2	1	1	1
BPD	1	1	2	3	3	3	2	3	3	3
Sub items	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8	Expert 9	Expert 10
Did you experience or witness TE in your childhood	1	1	1	1	1	1	1	1	1	1
Was it before the age 13	1	1	1	1	1	1	1	1	0	0
Was it after age 13	1	1	1	1	1	1	1	1	1	1
Was it repeated	1	1	1	1	1	1	1	1	1	1
Was it life threatening	1	1	1	1	1	1	1	1	0	0
Was it sexual abuse	1	1	1	1	1	1	1	1	0	0
Was it physical abuse	1	1	1	1	1	1	1	1	1	1
Was it non life threatening	0	0	0	1	1	1	1	1	1	1
Always a family member, or carer	0	0	0	0	0	0	0	0	0	0
Was it inappropriate touching of your sexual parts	0	1	1	1	1	1	1	0	0	1
Did you feel rejected	0	1	1	1	1	1	1	1	1	1
Did you feel unloved	0	1	1	1	1	1	1	1	1	1
Did you think you were no good enough	0	1	1	1	1	1	1	1	1	1
Did you think you were permanently damaged	0	1	1	1	1	1	1	0	0	1
Abandonment	1	0	0	1	1	1	1	1	1	1
Did you loose trust in people	0	1	1	1	1	1	1	0	0	1
Intense distress	1	1	1	1	1	1	1	1	1	1
Flashbacks	1	1	1	1	1	1	1	1	1	1
Nightmares	1	1	1	1	1	1	1	1	1	1
Avoiding people and places that will cause you distress	1	1	1	1	1	1	1	1	1	1
Intense anger	1	0	0	1	1	1	0	1	1	1
Intense sense of fear	1	1	1	1	1	1	1	1	1	1
Irritable and jumpy when unexpectedly startled	1	1	1	1	1	1	1	1	1	1
	15	19	19	22	22	22	21	19	16	19

## APPENDIX 28 Detailed Results

Patient	Child Trauma	Trauma	PTSD	CPTSD	PTSD	CPTSD	CAPS	SIDES
			Researcher		Independent		PTSD	CPTSD
1	1	1	0	1	0	1	1	1
2	0	1	0	0	0	0	0	0
3	1	1	0	0	0	0	0	0
4	1	1	0	0	0	0	0	0
5	1	1	0	0	0	0	0	0
6	1	1	0	0	0	0	0	0
7	1	1	0	0	0	0	0	0
8	1	1	0	0	0	0	0	0
9	1	1	0	0	0	0	0	0
10	1	1	0	1	0	1	1	1
11	1	1	1	0	1	0	1	0
12	1	1	0	0	0	0	0	0
13	1	1	0	1	0	1	1	1
14	1	1	1	1	1	1	1	1
15	0	1	1	0	1	0	1	0
16	1	1	1	0	1	0	1	0
17	1	1	1	0	1	0	1	1
18	1	1	0	0	0	0	0	0
19	1	1	0	0	0	0	0	0
20	1	1	0	0	0	0	0	0
21	1	1	1	1	1	1	1	1
22	1	1	0	0	0	0	0	0
23	1	1	0	0	0	0	0	0
24	1	1	0	0	0	0	0	0
25	1	1	0	0	0	0	0	0
26	1	1	0	0	0	0	0	0
27	1	1	0	0	0	0	0	0
28	1	1	1	1	1	1	1	1
29	1	1	1	0	1	0	1	0
30	1	1	1	0	1	0	1	0
31	1	1	1	0	1	0	0	0
32	1	1	1	0	0	0	0	0
33	1	1	0	0	0	0	0	0
34	1	1	1	1	1	1	1	1
35	1	1	1	0	1	0	0	0
36	1	1	0	0	0	0	0	0
37	0	1	1	0	1	0	1	0
38	1	1	1	1	1	1	1	1
39	1	1	1	0	1	0	1	0
40	1	1	0	0	0	0	0	0





## APPENDIX 29 Quality Assurance Results

STARD

1	Title (Screen)	Screen not in title as only one of the 4 objectives
2	Objectives	Yes, objective number 4
3	Population description	Those already identified with BPD presentations
4	Recruitment description	Detailed in text and checked with Steering Group
5	Sampling description	Not sampled due to limited resource
6	Data collection	Methodology described
7	Reference standard and rationale	CAPS, SIDES identified and described
8	Technical specifications of material	BTERS validated with expert groups
9	Categorisation	Scoring sheet utilised
10	Qualification, training of interviewers	Qualified clinicians were all briefed on objectives
11	Blindness	Scorer was blind to patient's diagnosis
12	Diagnostics	Identified by CAPS/SIDES
13	Reproducibility	Test-retest performed
14	Reporting timing	Written reports were all completed and reported to clinicians and patients
15	Applicable population	One large psychiatric hospital
16	Results	Percentage identifies and compared with literature
17	Time between screen and standard	Break introduced to allow recovery
18	Severity	Patient suitability confirmed with clinicians,
19	Cross tabulation	Comparison with stage 1
20	Adverse events	Safeguarding procedure explained
21	Accuracy	Calculated by SPSS and discussed with Steering Group
22	What happened to those who dropped out	Well understood at group sessions
23	Subgroup Variability	No subgroups
24	Reproducibility estimates	Addressed in validity and limitations discussions
25	Clinical Applicability	For 'common-point-of-entry' and initial assessment in BPD clinics