

**How do general hospitals respond to patients diagnosed with a  
personality disorder who are distressed**

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Submitted in accordance with the requirements for the degree of Doctor of  
Philosophy

The University of Leeds  
School of Healthcare

August 2019

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## **Dedication**

To my capable daughter.

## Acknowledgements

My sincere gratitude to my fantastic PhD supervisors, Professor John Baker and Dr Jane Cahill. I could not have asked for better support and guidance. I am grateful to Dr Kathryn Berzins and Dr Krysia Canvin for commenting on draft chapters, with special thanks to Dr Kathryn Berzins for mentoring and supporting me during my PhD journey. I am indebted to the people who took part in my research. I realise how difficult it was for some of you to take part. My thanks to the people who voluntarily took time to help with the study design and to those who kindly shared the study information on social media.

I owe a big thank you to my closest friend Sara Hamilton for her unwavering support, to my PhD buddy Haley Jackson for being there, and to a wonderful group of local mums, especially Jennifer Brown, who kept me going during the very difficult early days of this project.

Last but not least, my utmost thanks to Amit Sharda, who has always believed in me.

## Abstract

Patients with a diagnosis of personality disorder are at risk of poor physical health outcomes and reduced life expectancy. To date, research in the area of personality disorder and physical health has mostly been epidemiological. There has been very little research on what happens when patients with a diagnosis of personality disorder are admitted to NHS general hospital wards. This PhD thesis aims to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed.

An explanatory sequential design was used to integrate mixed methods data from: 1) a scoping review of the literature (n=10<sup>1</sup>); 2a) a QUAN<sup>2</sup> web-based survey of patients diagnosed with a personality disorder (n=65) and carers (n=5); 2b) embedded [QUAL] telephone interviews with patients diagnosed with a personality disorder (n=12); 3a) QUAN web-based survey of general hospital professionals (n=58); and 3b) QUAL telephone interviews with mental health liaison professionals (n=13). The primary data were analysed using QUAL framework analysis and QUAN descriptive statistics. The findings were integrated through mixed methods triangulation.

This research identified that general hospitals respond iatrogenically to patients diagnosed with a personality disorder. Five themes were identified across the integrated data: Workforce, Service delivery, Service design, Organisational stress, and Adverse events. There were three overarching meta-themes: Systems and logistics, Structures, and Outcomes. An explanatory framework of the interrelationship between the themes and meta themes is proposed. Considerable efforts are required to reduce organisational stress and to ensure

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<sup>1</sup> n= refers to the number of studies included in the scoping review of the literature

<sup>2</sup> QUAN and [QUAL] refers to the notational system used in mixed methods research to denote the study design. Brackets indicate an embedded design

that patients with a diagnosis of personality disorder are not subject to adverse experiences in NHS general hospitals.

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## **List of Abbreviations**

- AOR Adjusted Odds Ratio
- AOIR Association Of Internet Research Ethics
- AMA Against Medical Advice
- BOS Bristol Online Survey
- CI Confidence Interval
- CASP Critical Skills Appraisal Programme
- CAQDAS Computer Assisted Qualitative Data Analysis Software
- DOH Department Of Health
- EBM Evidence Based Medicine
- EBP Evidence Based Practice
- GRAMMS Good Reporting of A Mixed Methods Study
- HSCIC Health and Social Care Information Centre
- IQR Interquartile Range
- NHS National Health Service
- NICE National Institute for Health and Care Excellence
- NMC Nursing and Midwifery Council
- NRES National Research Ethics Service
- OR Odds Ratio
- SMR Standardised Mortality Ratio
- UK United Kingdom
- USA United states of America

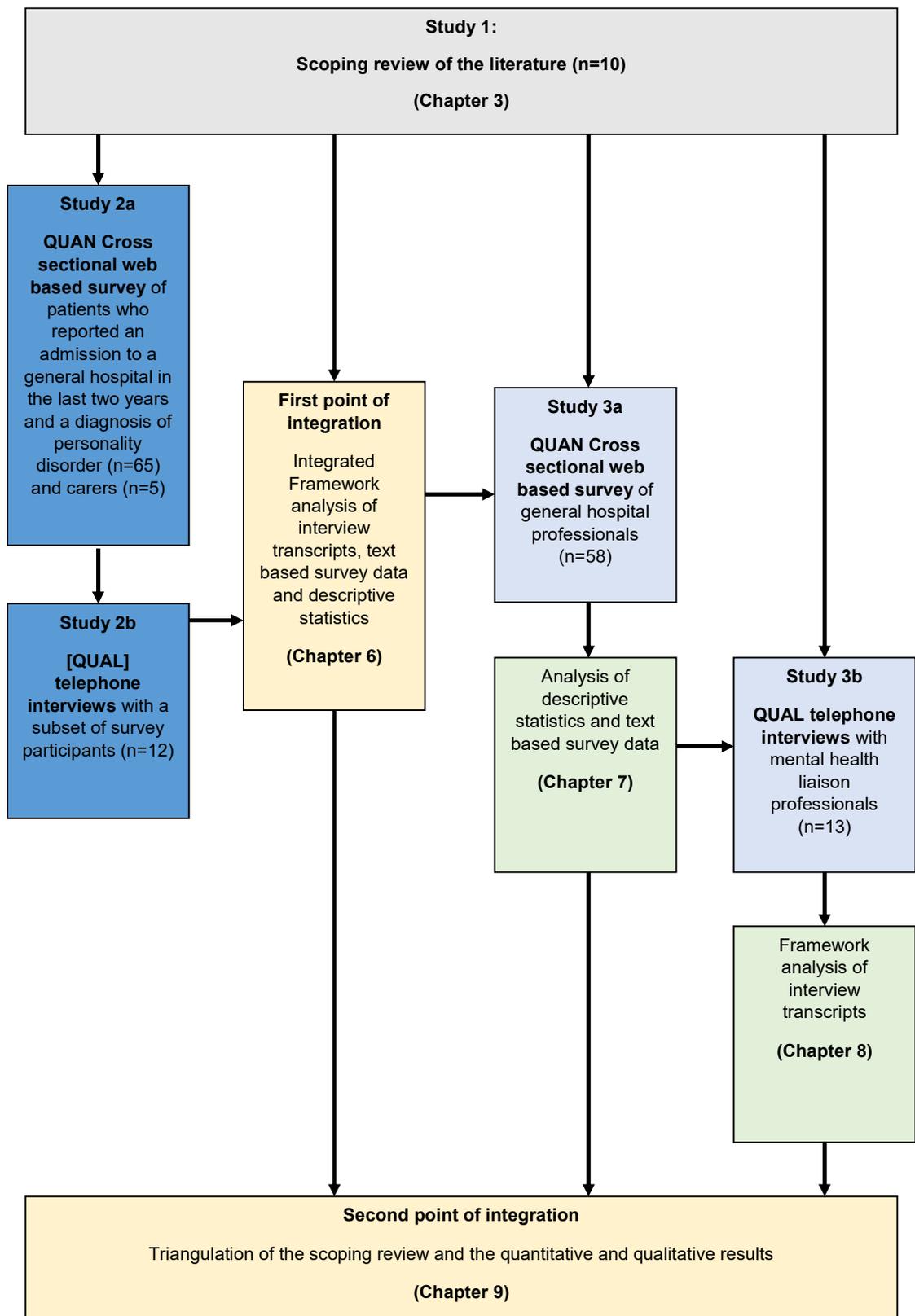
# **Chapter 1 : Introduction**

## **1.1 Thesis overview**

This thesis aims to explain how general hospital wards, outside emergency settings, respond to patients diagnosed with a personality disorder who are distressed, using a mixed methods explanatory sequential research design. This thesis is grounded in the pragmatic paradigm, and sets out three strands of work (Figure 1): study one, a scoping review of the literature; studies 2a and 2b, a cross sectional web based survey with patients and carers and embedded interviews with patients; study 3a, a cross sectional web based survey with general hospital professionals; and study 3b, interviews with mental health liaison professionals. The findings have been integrated and used to develop an explanatory framework of how general hospitals respond to patients diagnosed with a personality disorder who are distressed.

The thesis has been organised into ten chapters. Chapter Two discusses the diagnostic controversy around the personality disorder diagnosis and provides a background to this research. Chapter Three presents a scoping review of the literature (Study 1). Chapter Four sets out the philosophy and the methodological framework, which informed studies 2a, 2b, 3a, and 3b. Chapter five outlines the working methods used. The findings are reported in chapters six to eight before being integrated in Chapter nine – where an explanatory framework of how general hospitals respond to patients diagnosed with a personality disorder who are distressed has been proposed. This thesis concludes in Chapter Ten, with a summary of the research findings and the recommendations for practice, commissioning, policy, and future research.

**Figure 1 The study design and structure of the thesis<sup>3</sup>**



<sup>3</sup> QUAN and [QUAL] refers to the notational system used in mixed methods research to denote the study design.

## 1.2 Thesis aims and objectives

- **To conduct a scoping review of the literature (Study 1)**

The scoping review aimed to map and review the literature on personality disorder, violence, disruption, and the barriers and enablers of general hospital care. The review aimed to highlight methodological constraints in the current evidence base and to identify appropriate research designs to undertake the subsequent strands of the research. The findings of the scoping review were used to develop strand two. The aims of studies 2a and 2b were:

- **To conduct a QUAN web-based survey of patients diagnosed with a personality disorder and carers (Study 2a)**
- **To conduct [QUAL] telephone interviews with patients diagnosed with a personality disorder (Study 2b)**

The objectives of the patient web based survey (study 2a) were to explore the views and perspectives of patients and carers on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. Telephone interviews were undertaken with a sub section of the survey sample (study 2b) to provide additional insight into the findings of the web based survey (study 2a). The integrated findings of studies 2a and 2b were used with the findings of study 1 to develop the subsequent work. The aims of studies 3a and 3b were:

- **To conduct a QUAN web-based survey of general hospital professionals**
- **To conduct QUAL telephone interviews with mental health liaison professionals**

The objectives of the general hospital web based survey (study 3a) were to explore the views and perspectives of general hospital professionals on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. A final set of telephone interviews were undertaken with mental health liaison professionals (study 3b) to explore the findings of all of the previous studies 1, 2a and 2b, and 3a.

The results of all of the studies (1, 2a and 2b, 3a and 3b) were integrated through mixed methods triangulation, to connect, interpret and explain the results.

### **1.3 The contribution of this thesis**

This thesis contributes new knowledge by proposing an explanatory framework of how general hospital wards outside the emergency setting respond to patients diagnosed with a personality disorder who are distressed. The findings have been used to make practical recommendations for practice, commissioning, policy, and future research.

## **Chapter 2 : Background**

This chapter summarises the background to this PhD thesis. Section 2.1 provides a brief overview of general hospitals in the United Kingdom and the service provision for patients with mental health needs. Section 2.2 moves on to discuss the personality disorder diagnosis: exploring the historical basis of normal and abnormal personality; the controversy associated with the personality disorder diagnosis; and the long-standing discrimination of people diagnosed with a personality disorder. Section 2.3 explores the emerging evidence, which suggests that people with a diagnosis of personality disorder have poor physical health. Section 2.4 summarises policy in England to address the exclusion of people diagnosed with a personality disorder. The key contextual issues, which underpin this PhD thesis, are summarised in section 2.5.

### **2.1 General hospital care of patients with mental health needs**

In the National Health Service (NHS) general hospitals provide secondary healthcare to residents of the United Kingdom (UK). General hospitals vary in size, ranging from small district general hospitals to larger city teaching hospitals, depending on the local health economy. Patients occupy a bed to receive medical, surgical, and other types of specialist care (NHS, 2019). Specialist mental healthcare is typically provided to general hospital inpatients by mental health liaison services, which operate at the interface between general hospitals and mental health trusts (Fossey and Parsonage, 2014). There are inconsistencies in the size and scope of mental health liaison services in both England (Walker et al., 2018) and Wales (Tahir et al., 2019). No recent reliable data could be identified that depicts the state of mental health liaison in Scotland

and Northern Ireland. Generally, mental health liaison services are commissioned to provide care and treatment to patients with physical and mental health needs. They respond to patients experiencing a mental health crisis and provide support and education to general hospitals around mental health (NHS England; The National Collaborating Centre for Mental Health; and the National Institute for Health and Care Excellence, 2016).

The term 'parity of esteem' came into use in England to communicate governmental ambitions of treating mental and physical health problems equally and to the same standard (HM Government, 2011). Achieving parity of esteem in the National Health Service (NHS) has been mandated in the *Health and Social Care Act (2012)* and the *NHS constitution for England* (Department of Health and Social Care, 2015). Investment in mental health liaison services has been recommended as part of the government agenda to achieve parity of esteem, and a purported commitment to promoting health and wellbeing at the population level (NHS England, 2016). Aspirations to expand the liaison workforce in order to deliver high quality NICE recommended care, twenty four hours per day (NHS England; The National Collaborating Centre for Mental Health; and the National Institute for Health and Care Excellence, 2016) in more general hospitals, featured heavily in the *Five year forward view for mental health* (NHS England, 2016).

The literature outlining high quality mental health care in general hospitals has flourished in recent years. A substantial body of high quality evidence has been published on self harm in general hospitals (Kapur, 2009; Tsiachristas et al.; Hawton et al., 2016) and what constitutes best practice in the emergency department has been established (The Royal College of Emergency Medicine, 2017; Care Quality Commission, 2015). However, to date, guidance on general hospital inpatient care, particularly around expressions of distress other than self harm, has been lacking.

## 2.2 The personality disorder diagnosis

In the eleventh revision of the International Classification of Diseases (ICD), personality disorder has been described as *'characterized by problems in functioning of aspects of the self (e.g., identity, self-worth, accuracy of self-view, self-direction), and/or interpersonal dysfunction (e.g., ability to develop and maintain close and mutually satisfying relationships, ability to understand others' perspectives and to manage conflict in relationships) that have persisted over an extended period of time (e.g., 2 years or more). The disturbance is manifest in patterns of cognition, emotional experience, emotional expression, and behaviour that are maladaptive (e.g., inflexible or poorly regulated) and is manifest across a range of personal and social situations (i.e., is not limited to specific relationships or social roles). The patterns of behaviour characterizing the disturbance are not developmentally appropriate and cannot be explained primarily by social or cultural factors, including socio-political conflict. The disturbance is associated with substantial distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.'* (World Health Organisation, 2019, p.6 D10)

The history of this diagnosis has particular ontological relevance (Pickersgill, 2009). Since antiquity, there has been intense debate about personality and the appropriate distinction between normal and abnormal personality. The discussion began during the eras of ancient Chinese medicine and Greek philosophy. Confucius (551-479 BCE) proposed that personality was constructed based on a combination of physiological and psychological characteristics. Confucius believed that personality was not fixed but variable with age. By contrast, Theophrastus (c 371 to c 287 BCE), asserted that there were 30 distinct personality types, linked to fixed behavioural patterns. The book, written by Theophrastus was influential during the 17<sup>th</sup> and 18<sup>th</sup> century and is believed to be the first typology of personality. By the 18<sup>th</sup> century, psychiatry, and the study of personality in the context of psychiatric practice was well underway (Crocq,

2013). However, thinking about what constitutes normal and abnormal personality has continued to change (Table 1).

**Table 1 The evolution of the personality disorder diagnosis** adapted from Crocq (2013)

<p><b>Personality in the 18<sup>th</sup> century</b></p>	<ul style="list-style-type: none"> <li>• By the 18th Century terms such as temperament and personality had gained popularity. The French language encyclopaedia, which was edited between 1751 and 1772 by Denis Diderot and Jean d'Alembert, described phlegmatic, sanguine, melancholic, and choleric temperaments.</li> <li>• At the end of the 18th century, Phrenology had become popular. Phrenology was associated with Franz Joseph Gall (1758-1828). However, it was an associate Johann Caspar Spurzheim who provided the name. In Phrenology, personality was said to be derived mainly from the cerebral cortex, and it was hypothesised that personality facets could be identified with precision on the cranium. Phrenology is now discredited; however, the attention brought to the role of the cerebral cortex was considered to be a significant milestone.</li> </ul>
<p><b>Personality and now depleted psychiatric practice</b></p>	<ul style="list-style-type: none"> <li>• The first personality disorder diagnosis was said to have been 'manie sans delire' (mania without delusion). Philippe Pinel (1745-1826) gave this diagnosis to patients who exhibited impulsive violence in response to minor setbacks. This work inspired interest in the study of emotion and behaviours.</li> <li>• In the late 19th and early 20th century attempts to define normal and abnormal personality had begun. Theodule Ribot (1839-1916) reported that character was a stable entity, which appeared in childhood and lasted throughout life. Normal personality was defined by Ribot as i) sensitive or emotional ii) active iii) apathetic.</li> <li>• The first empirical study of personality was credited to Gerard Heymans (1857-1930) and co-author Enno Dirk Wiersma (1858-1940). The authors proposed three bipolar dimensions: activity-level, emotionality, and primary vs secondary functioning. The dimensions were used to determine amorphous, sanguine, nervous, choleric, apathetic, phlegmatic, sentimental, and passionate personality types.</li> </ul>

	<ul style="list-style-type: none"> <li>• Lazursky (1874-1917) proposed 'Endopsychic' and 'Exopsychic' personalities. The interaction between these distinct domains was said to determine the level of individual functioning. Those with inferior functioning were reported to be influenced more by external events.</li> <li>• At the beginning of the 20th century, Emil Kraepelin (1856-1926), who primarily focused on forensic patients; introduced the psychopathic personality. In the 8th edition of his book, pathological personalities were categorised as i) the excitable; ii) the irresolute; iii) persons following their instincts; iv) eccentrics; v) pathological liars and swindlers; vi) enemies of society; vii) the quarrelsome.</li> </ul>
<p><b>Personality and the development of contemporary psychiatric practice.</b></p>	<ul style="list-style-type: none"> <li>• Sigmund Freud (1856-1939) identified the impact of early life on personality. 'Character and anal erotism' (1909) was the first paper to discuss a psychoanalytic perspective of a 'faulty personality'. Freud described orderly, parsimonious, and obstinate traits, which he believed were interrelated. Freud's views informed early thinking about a range of personality types.</li> <li>• Kurt Schneider (1887-1967) built on ideas about psychopathy. Schneider gave the label to those who experienced distress or caused society distress due to personality traits. Schneider identified the following subcategories (i) the hyperthymic; (ii) the depressive; (iii) the insecure; (iv) the fanatical; (v) recognition-seeking; (vi) with labile mood; (vii) explosive; (viii) emotionally-blunted; (ix) the weakwilled; and (x) the asthenics. Schneider criticised the clinical relevance of deriving classification systems from apparently normal personality dimensions. The debate surrounding this remains relevant today.</li> <li>• Bernard Cattell (1905-1998) was the pioneer of the modern dimensional classification system. Catell used statistical measurement of adjectives to describe personality to characterise sixteen 'source traits'.</li> <li>• In more recent times, personality has been classified using various dimensional systems. The most popular dimensional system was the empirically developed, five factor model of personality, which informed the descriptors within DSM-5.</li> <li>• In subsequent revisions of the DSM and the ICD, distinct categories of personality disorder were adopted, using an approach most similar to the work of Schneider. Categories were determined based</li> </ul>

	on precedence, experience and consensus (Mulder et al., 2016). The categories have been heavily contested (Tyrer et al., 2019).
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In England, the ICD has generally been used to diagnose personality disorder. The eleventh and latest revision of the ICD has reverted to using a dimensional system of classifying 'personality disorder'. In ICD-11, a two stage process of assigning severity (Table 2) and traits (Table 3), with the optional use of descriptors, e.g., borderline pattern (Table 4) has been adopted (Bach and First, 2018). The domain traits in ICD-11 are considered broadly comparable with the fifth edition of the Diagnostic and Statistical Manual (DSM-5), with the exclusion of schizotypy and the inclusion of anankastia (Tyrer et al., 2019). As this PhD was undertaken in England at the University of Leeds, this chapter focuses on ICD-11, rather than DSM-5.

**Table 2 ICD-11 Essential features of personality disorder severity in Bach and First (2018 p.3)**

<b>Mild personality disorder</b>	<b>Moderate personality disorder</b>	<b>Severe personality disorder</b>
Disturbances affect some areas of personality functioning but not others (e.g., problems with self-direction in the absence of problems with stability and coherence of identity or self-worth) and may not be apparent in some contexts.	Disturbances affect multiple areas of personality functioning (e.g., identity or sense of self, ability to form intimate relationships, ability to control impulses and modulate behaviour). However, some areas of personality functioning may be relatively less affected.	There are severe disturbances in functioning of the self (e.g., sense of self may be so unstable that individuals report not having a sense of who they are or so rigid that they refuse to participate in any but an extremely narrow range of situations; self view may be characterised by self-contempt or be grandiose or highly eccentric).
There are problems in many interpersonal relationships and/or in performance of expected occupational and social roles, but some relationships are maintained and/or some roles carried out.	There are marked problems in most interpersonal relationships and the performance of most expected social and occupational roles are compromised to some degree. Relationships are likely to be characterised by conflict, avoidance, withdrawal, or extreme dependency (e.g., few friendships maintained, persistent conflict in work relationships and consequent occupational problems, romantic relationships characterized by serious disruption or inappropriate submissiveness).	Problems in interpersonal functioning seriously affect virtually all relationships and the ability and willingness to perform expected social and occupational roles is absent or severely compromised.
Specific manifestations of personality disturbances are generally of mild severity.	Specific manifestations of personality disturbance are generally of moderate severity.	Specific manifestations of personality disturbance are severe and affect most, if not all, areas of personality functioning.
Is typically not associated with substantial harm to self or others.	Is sometimes associated with harm to self or others.	Is often associated with harm to self or others.
May be associated with substantial distress or with impairment in personal, family, social, educational, occupational or other important areas of functioning that is either limited to circumscribed areas (e.g., romantic relationships; employment) or present in more areas but milder.	Is associated with the marked impairment in personal, family, social, educational, occupational or other important areas of functioning, although functioning in circumscribed areas may be maintained.	Is associated with severe impairment in all or nearly all areas of life, including personal, family, social, educational, occupational, and other important areas of functioning.

**Table 3 ICD-11 Trait domain qualifiers that contribute to the expression of personality dysfunction in Bach and First (2018 p.5)**

Trait domain	Core definition	Specific features
Negative Affectivity	A tendency to experience a broad range of negative emotions with a frequency and intensity out of proportion to the situation.	Anxiety, anger, worry, fear, vulnerability, hostility, shame, depression, pessimism, guilt, low self-esteem, and mistrustfulness. For example, once upset, such individuals have difficulty regaining their composure and must rely on others or on leaving the situation to calm down.
Detachment	A tendency to maintain interpersonal distance (social detachment) and emotional distance (emotional detachment)	<i>Social detachment</i> including avoidance of social interactions, lack of friendships, and avoidance of intimacy. <i>Emotional detachment</i> including being reserved, aloofness, and limited emotional expression and experience. For example, such individuals seek out employment that does not involve interactions with others.
Dissociality	Disregard for the rights and feelings of others, encompassing both self-centeredness and a lack of empathy.	<i>Self-centeredness</i> including entitlement, grandiosity, expectation of others admiration, and attention-seeking. <i>Lack of empathy</i> including being deceptive, manipulative, exploiting, ruthless, mean, callous, and physically aggressive, while sometimes taking pleasure in others' suffering. For example, such individuals respond with anger or denigration of others when they are not granted admiration.
Disinhibition	A tendency to act rashly based on immediate external or internal stimuli (i.e., sensations, emotions, thoughts), without consideration of potential negative consequences.	Impulsivity, distractibility, irresponsibility, recklessness, and lack of planning. For example, such individuals may be engaged in reckless driving, dangerous sports, substance use, gambling, and unplanned sexual activity.
Anankastia	A narrow focus on one's rigid standard of perfection and of right and wrong, and on controlling one's own and others' behaviour and controlling situations to ensure conformity to these standards.	<i>Perfectionism</i> including concern with rules, norms of right and wrong, details, hyper-scheduling, orderliness, and neatness. <i>Emotional and behavioural constraint</i> including rigid control over emotional expression, stubbornness, risk-avoidance, perseveration, and deliberativeness. For example, such individuals may stubbornly redo the work of others because it does not meet their standards.

**Table 4 Borderline pattern qualifier** in Bach and First (2018 p.6)

The Borderline pattern qualifier may be applied to individuals whose pattern of personality disturbance is characterized by a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, as indicated by five (or more) of the following:

- A pattern of unstable and intense interpersonal relationships, typically characterized by alternating between extremes of idealization and devaluation.
- Identity disturbance, manifested in markedly and persistently unstable self-image or sense of self.
- Impulsivity manifested in potentially self-damaging behaviours (e.g., risky sexual behaviour, reckless driving, excessive alcohol or substance use, binge eating).
- Recurrent episodes of self-harm (e.g., suicide attempts or gestures, self-mutilation).
- Emotional instability due to marked reactivity of mood. Fluctuations of mood may be triggered either internally (e.g., by one's own thoughts) or by external events. As a consequence, the individual experiences intense dysphoric mood states, which typically last for a few hours but may last for up to several days.
- Chronic feelings of emptiness.
- Inappropriate intense anger or difficulty controlling anger manifested in frequent displays of temper (e.g., yelling or screaming, throwing or breaking things, getting into physical fights).
- Transient dissociative symptoms or psychotic-like features (e.g., brief hallucinations, paranoia) in situations of high affective arousal.

Other manifestations of Borderline pattern, not all of which may be present in a given individual at a given time, include the following:

- A view of the self as inadequate, bad, guilty, disgusting, and contemptible.
- An experience of the self as profoundly different and isolated from other people; a painful sense of alienation and pervasive loneliness.
- Proneness to rejection hypersensitivity; problems in establishing and maintaining consistent and appropriate levels of trust in interpersonal relationships; frequent misinterpretation of social signals.
- Frantic efforts to avoid real or imagined abandonment.

Many patients and professionals firmly refute that personality disorder exists, rejecting the acceptability and validity of the diagnosis (Johnstone, 2017). Some authors, leading the critical psychiatry movement, have vehemently argued that the personality disorder diagnosis has profoundly obstructed the understanding of human distress and behaviour (Johnstone et al., 2017), reasoning that the difficulties deemed to be psychiatric symptoms are logical responses to adverse situations and threats (Johnstone and Boyle, 2018). The tentative historical background suggests that a consensus on the existence of normal personality and the distinction between normal and abnormal personality is unlikely to be reached in the near future. However, for many patients diagnosed with a personality disorder, there have been ethically undesirable consequences, because of the vast assumptions, which have accompanied this indeterminate diagnosis (Pickersgill, 2009).

Patients with a personality disorder diagnosis have consistently been treated pejoratively by healthcare professionals (Tyrer et al., 2015). Several studies, which have described negative attitudes to people, with a diagnosis of personality have focused on the borderline type (Dickens et al., 2016a; Bodner et al., 2015; King, 2014; Kendal and Weight, 2013). Before encountering healthcare professionals, patients who are ultimately diagnosed with personality disorders have commonly already endured adverse life experiences such as neglect, abuse, and prolonged misery (Craissati et al., 2011). Invalidating responses from healthcare workers and institutions risk replicating those early adverse experiences (Raven, 2009; Aiyegbusi and Tuck, 2008). Relationships with care providers have been described as fraught with difficulties (Dowsett and Craissati, 2008). A diagnosis of personality disorder may limit access to services and treatment, and increase the inequity faced by individuals already struggling - equally the diagnosis may be the only means of accessing services and resources in the current healthcare system (Lamb et al., 2018).

The decision to diagnose people with a personality disorder may be biased by gender (Paris, 2007). Borderline personality disorder particularly, has been

diagnosed more in females (Schulte Holthausen and Habel, 2018; Sansone and Sansone, 2011). A ratio of three females has been reported to be diagnosed with a borderline personality disorder to every one male (Association of American Psychiatry, 2013). Although the supporting research has been inconsistent, with some studies reporting no statistically significant relationship between borderline personality disorder and gender (Torgersen et al., 2001; Grant et al., 2004). Kaplan (1983) argued in her seminal work that misogynistic assumptions about healthy behaviour in women have shaped the diagnostic and treatment patterns related to personality disorders. Kaplan (1983) maintained that merely expressing overt female traits has been sufficient in some cases to attract a diagnosis.

### **2.3 Personality disorder and physical health**

Personality disorder has been reported to be highly comorbid with physical illnesses (Yang et al., 2010; Quirk et al., 2015; Quirk et al., 2017). However, the physical health of people with a diagnosis of personality disorder appears to be overlooked in comparison to other serious mental illnesses (Sanatinia et al., 2015). A number of large cohort studies have found that people diagnosed with a personality disorder have higher rates of conditions such as cardiovascular disease (Moran et al., 2007), arteriosclerosis, hepatic disease, hypertension, gastrointestinal disease, arthritis (El-Gabalawy et al., 2010), and pain (Powers and Oltmanns, 2012). Patients diagnosed with a personality disorder may experience worse health outcomes (Powers and Oltmanns, 2012; Frankenburg and Zanarini, 2004; Fok et al., 2014), and reduced quality of life (El-Gabalawy et al., 2010).

The relatively poor physical health of patients diagnosed with a personality disorder has been attributed to problems such as: polypharmacy, failure to provide adequate physical health screening, treatment for cardiometabolic side

effects (Sanatinia et al., 2015); lifestyle factors (Frankenburg and Zanarini, 2004); fragmented healthcare; a lack of communication between care providers (Sanatinia et al., 2015); and interpersonal difficulties impeding self-management of illnesses (Powers and Oltmanns, 2013). People diagnosed with a personality disorder may also be deterred from having contact with professionals, services, and treatment (Sanatinia et al., 2015) due to the risk of discrimination (Fok et al., 2014). However, conversely some authors have claimed that people diagnosed with a personality disorder have high rates of general hospital admissions (Frankenburg and Zanarini, 2004; Fok et al., 2019; Keuroghlian et al., 2013; Cailhol et al., 2016).

One UK study suggested that general hospital admissions, related to circulatory, respiratory, digestive, musculoskeletal, nervous and endocrine systems were three times higher in people diagnosed with a personality disorder compared to the general population (Fok et al., 2019). While the retrospective cohort design used by Fok et al. (2019) was reliant on the accuracy of NHS records and did not address potentially confounding variables, such as lifestyle and psychiatric comorbidity; the study highlighted a potential area of concern, which to date, has received very little attention. More high quality research on the general hospital admissions of people diagnosed with a personality disorder appears to be needed, to explore this issue fully.

To date, there appears to be no quality research into the economic impact of people diagnosed with a personality disorder using UK general hospitals. It has been suggested that patients diagnosed with a borderline personality disorder may be more likely to need costly health services (Frankenburg and Zanarini, 2004). Personality disorder has not been independently associated with an increased economic burden in the absence of additional psychiatric morbidity (Rendu et al., 2002). Contact with mental health and emergency services in England by people diagnosed with a personality disorder has been estimated to cost 704 million pounds per year (McCrone et al., 2008). A recent economic evaluation of a personality disorder clinical network in Leeds, England, estimated

treatment as usual costs for this group were approximately £14,860 (n=45) per head (Kane et al., 2016). However, a systematic review on economic evaluations for the borderline descriptor suggested that currently, cost and effect descriptors in this area lack validity. The authors considered a more robust approach to measurement in the economic context was required before costs could be fully understood (Brettschneider et al., 2014).

However, the human costs of a personality disorder diagnosis appear stark. The life expectancy of a cohort of people diagnosed with a personality disorder, using secondary mental health services has been estimated to be 18.7 years shorter for males (95% CI: 2.17–5.47) and 17.7 years for females (95% CI: 3.15–7.45) than the general population in England and Wales with an overall standardised mortality rate (SMR<sup>4</sup>) of 4.2 (95% CI: 3.03–5.64) (Fok et al., 2012). Björkenstam et al. (2018) calculated slightly higher standardised mortality ratios for people diagnosed with a personality disorder, reporting the SMR at 6.1 (95% CI 5.8–6.4) for women and 5.0 (95% CI 4.7–5.2) for men (Björkenstam et al., 2018). About half of the deaths were reported to be from ‘natural<sup>5</sup>’ causes. To address the increased mortality rates in people with mental illnesses, improving physical healthcare has been considered to be vital (Chesney et al., 2014). The fact that people diagnosed with a personality disorder diagnosis have generally been excluded from such initiatives (Sanatinia et al., 2015) appears inexplicable.

## 2.4 Policy to address exclusionary practice

A strategic milestone in addressing attitudes to people diagnosed with a personality disorder was the landmark publications: ‘*Personality Disorder no longer a diagnosis of exclusion*’ (National Institute for Mental Health in England,

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<sup>4</sup> The standardised mortality ratio refers to the ratio of the observed number of deaths in the study population compared to the general population

<sup>5</sup> Björkenstam et al., 2018 categorised infections, cancer, endocrine, substance misuse, nervous system, cardiovascular, respiratory, gastrointestinal and other deaths as ‘natural causes’ excluding suicide, undetermined intent, homicide, traffic accidents and other deaths.

2003b) and the accompanying '*Personality Disorder capabilities framework*' (National Institute for Mental Health in England, 2003a), which set out capabilities required to respond compassionately to people diagnosed with a personality disorder. While the personality disorder capabilities framework was developed for mental health services, the framework has been considered relevant to a wide range of healthcare providers (National Institute for Mental Health in England, 2003).

### **Personality disorder capabilities framework (National Institute for Mental Health in England, 2003a)**

- Promoting social functioning and obtaining social support.
- Improving psychological wellbeing.
- Assessing and managing risk to self and others.
- Suitability of management and leadership.

The publication of '*Personality disorder no longer a diagnosis of exclusion*' (National Institute for Mental Health in England, 2003b) and the '*Personality disorder capabilities framework*' (National Institute for Mental Health in England, 2003a), in addition to the cross government strategy '*No health without mental health*' (Department of Health, 2011) signalled a fundamental shift in the expectations of care and treatment of patients diagnosed with a personality disorder in England. However, progression with the agenda to address exclusionary practices has been slow. Recently, a consensus statement was issued to highlight the continued neglect and exclusion of patients with a diagnosis of personality disorder (Lamb et al., 2018). To date, there has been no mention of mainstream general hospital inpatient care and general hospitals inpatient wards appear to remain grossly overlooked in the national policy.

## 2.5 Summary

The distinction between abnormal and abnormal personality and 'personality disorder' has been debated since antiquity. Despite many people refuting the personality disorder diagnosis, it is the only means of accessing some services and resources in the current healthcare system (Lamb et al., 2018). Patients diagnosed with a personality disorder have been subjected to substantial discrimination. Patients diagnosed with a personality disorder appear to be at risk of poor physical health outcomes (Powers and Oltmanns, 2012; Frankenburg and Zanarini, 2004; Fok et al., 2014) and reduced life expectancy (Fok et al., 2012). To date, research in the area of personality disorder and physical health has mostly been epidemiological. There has been very little research on what happens when patients with a diagnosis of personality disorder are admitted to NHS general hospital wards.

Intentional space

## **Chapter 3 : Personality disorder, violence, disruption, and the barriers and enablers of general hospital care: A scoping review of the literature (Study 1)**

This chapter documents the literature review undertaken as part of this PhD research. The review aims to explore the extent, range and nature of the published literature on personality disorder, violence, disruption, and the barriers and enablers of providing general hospital care on inpatient wards. An abstract is provided in section 3.1. Section 3.2 describes the types of evidence review typically undertaken in healthcare, the rationale for undertaking a scoping review of the literature as part of this PhD research, the recommended procedures for undertaking scoping reviews, and the rationale for selecting the scoping methodology. Section 3.3 details the methods. The results of the scoping review are reported in section 3.4. The chapter concludes in section 3.5, with a discussion of the findings.

### **3.1 Abstract**

A systematic search of nine bibliographic databases was conducted from 2005-2015 using a combination of key words related to violence, personality disorder and hospital settings. The searches were repeated in December 2017 and in May 2019. Titles, abstracts and full papers were screened against the eligibility criteria. Quality appraisal was conducted using the Joanna Briggs critical appraisal tools. The review used thematic analysis, which involved an iterative process of charting, collating and summarising the results. Ten studies were located. These were identified to be methodologically weak. Thematic analysis generated three central themes: The scope of violence and disruption, responses to patients considered to be violent or disruptive, and working with

patients considered violent or disruptive. No linkage between violence in general hospitals and a diagnosis of personality disorder was found. A gap in the research and grey literature on distress and personality disorder in general hospitals was identified. There was no evidence that support systems have been developed empirically.

### 3.2 Methodology

Evidence reviews synthesise the knowledge in a specific area, answer particular questions, support policy, programme and practice decisions (Canadian Institute of Health Research, 2016), identify gaps in knowledge, and inform future research (Noble and Smith, 2018). A typology of reviews (Grant and Booth, 2009), updated by Noble and Smith (2018), identified 16 different types of evidence review, used in the field of health and health informatics (Table 5).

**Table 5 A typology of reviews** in Grant and Booth (2009), updated by Noble and Smith (2018)

Review type	Key features
<p><b>Critical review</b></p> <p>Aims to research the literature extensively and evaluates quality. Goes beyond description to include a degree of analysis and conceptual innovation. Usually results in a hypothesis or model.</p>	<ul style="list-style-type: none"> <li>• Seeks to identify the most significant items in the field.</li> <li>• No formal quality assessment. Articles are evaluated based on contribution.</li> <li>• Typically, narrative, conceptual or chronological.</li> <li>• The analysis is the significant component, seeks to identify a conceptual contribution, add to existing theory or develop a new theory.</li> </ul>
<p><b>Literature review</b></p> <p>Examination of recent or current published material.</p>	<ul style="list-style-type: none"> <li>• May or may not include comprehensive searching.</li> <li>• May or may not include quality assessment.</li> <li>• Typically, narrative.</li> <li>• The analysis may be chronological, conceptual or thematic.</li> </ul>

Review type	Key features
<p><b>Mapping review/systematic map</b></p> <p>Maps out and categorises existing literature from which to commission further reviews/and or primary research by identifying gaps in the literature.</p>	<ul style="list-style-type: none"> <li>• Completeness of searching determined by resources.</li> <li>• No formal quality assessment.</li> <li>• May be graphical and tabular.</li> <li>• Characterises quantity and quality of literature, perhaps by study design and other vital features. May identify the need for primary or secondary research.</li> </ul>
<p><b>Meta-analysis</b></p> <p>A technique that statistically combines the results of quantitative studies to provide a more precise effect of the results.</p>	<ul style="list-style-type: none"> <li>• Exhaustive, comprehensive searching.</li> <li>• May use a funnel plot to assess completeness.</li> <li>• Quality assessment may determine inclusion/exclusion and/or sensitivity analysis.</li> <li>• Graphical and tabular with a narrative commentary.</li> <li>• Numerical analysis of measures of effect assuming the absence of heterogeneity.</li> </ul>
<p><b>Mixed studies review/mixed methods review</b></p> <p>Any combination of review approaches, e.g., combining quantitative with qualitative research.</p>	<ul style="list-style-type: none"> <li>• Requires a very sensitive search or separately conceived quantitative and qualitative strategies.</li> <li>• Uses a generic appraisal instrument or has separate appraisal processes.</li> <li>• Typically, narrative but may also employ graphical means of integrating quantitative and qualitative data.</li> <li>• The analysis may characterise both quantitative and qualitative literature, look for correlations between characteristics or use gap analysis. The analysis may be chronological, conceptual or thematic.</li> </ul>
<p><b>Qualitative systematic review/qualitative evidence synthesis</b></p> <p>Method for integrating or comparing the findings from qualitative studies.</p>	<ul style="list-style-type: none"> <li>• May or may not include comprehensive searching.</li> <li>• May employ selective or purposive sampling.</li> <li>• May or may not include quality assessment. Quality assessment typically used to mediate messages, not for inclusion/exclusion.</li> <li>• Qualitative narrative synthesis.</li> <li>• The thematic analysis may include conceptual models.</li> </ul>
<p><b>Rapid review</b></p> <p>Assessment of what is already known about a policy or practice issue by using systematic review methods to search and critically appraise existing research.</p>	<ul style="list-style-type: none"> <li>• Completeness of searching determined by time constraints.</li> <li>• Time limited formal quality assessment.</li> <li>• Typically, narrative and tabular.</li> <li>• Quantities of literature and overall quality/direction of the effect of literature.</li> </ul>

Review type	Key features
<p><b>Scoping review</b></p> <p>Assessment of potential size and scope of available research literature. Aims to identify the nature and extent of research evidence.</p>	<ul style="list-style-type: none"> <li>• Completeness of searching determined by resources. May include research in progress.</li> <li>• No requirement to undertake formal quality assessment.</li> <li>• Typically, tabular with a narrative commentary.</li> <li>• Characterises quantity and quality of literature, perhaps by study design and other key features.</li> </ul>
<p><b>State of the art review</b></p> <p>Addresses current matters, offers new perspectives, or points out issues for further research.</p>	<ul style="list-style-type: none"> <li>• Aims for comprehensive searching of the current literature.</li> <li>• No formal quality assessment.</li> <li>• Typically, narrative but may have tabular accompaniment.</li> <li>• Outlines the current state of knowledge and priorities for future research.</li> </ul>
<p><b>Systematic review</b></p> <p>Seeks to systematically search for, appraise and synthesise research evidence, often adhering to guidelines on the conduct of a review.</p>	<ul style="list-style-type: none"> <li>• Aims for exhaustive, comprehensive searching.</li> <li>• Quality assessment may determine inclusion/exclusion.</li> <li>• Typically, narrative with tabular accompaniment.</li> <li>• Outlines what is known, what remains unknown, uncertainty about findings, makes recommendations for practice, and future research.</li> </ul>
<p><b>Systematic search and review</b></p> <p>Combines the strengths of a critical review with a comprehensive search strategy. Typically addresses broad questions to produce 'a best evidence synthesis'.</p>	<ul style="list-style-type: none"> <li>• Aims for exhaustive, comprehensive searching.</li> <li>• May or may not include quality assessment.</li> <li>• Minimal narrative uses tabular summaries.</li> <li>• Outlines what is known makes recommendations for practice and the limitations.</li> </ul>
<p><b>Systematised review</b></p> <p>Stops short of a systematic review. Usually conducted by students for assignments.</p>	<ul style="list-style-type: none"> <li>• May or may not include comprehensive searching.</li> <li>• May or may not include quality assessment.</li> <li>• Typically, narrative with tabular accompaniment.</li> <li>• Outlines what is known; uncertainty around findings, limitations of the methodology.</li> </ul>
<p><b>Umbrella review</b></p> <p>Compiles evidence from multiple reviews. Focuses on a broad condition or problem for which there are competing interventions.</p>	<ul style="list-style-type: none"> <li>• Identification of component reviews but no search for primary studies.</li> <li>• Quality assessment of studies within component reviews and or of reviews themselves.</li> <li>• Graphical and tabular with narrative commentary.</li> <li>• Outlines what is known; recommendations for practice. What remains unknown; recommendations for future research.</li> </ul>

Review type	Key features
<p><b>Integrative reviews</b></p> <p>Uses a systematic approach to answer a focused question.</p>	<ul style="list-style-type: none"> <li>• Has a detailed search strategy.</li> <li>• Provides an objective critique of a range of study types, e.g., randomised controlled trials, observational studies and qualitative research.</li> <li>• Deploys systematic categorisation and thematic analysis.</li> </ul>
<p><b>Realist Reviews</b></p> <p>Focuses on whether an intervention works, identifies which mechanisms impact on the intervention, how the interventions works, and under what conditions.</p>	<ul style="list-style-type: none"> <li>• Has a clear aim and identifies relevant evidence</li> <li>• Extracts and synthesises the evidence, with the emphasis on explanation.</li> <li>• Stakeholder involvement is vital and the review outcomes are negotiated.</li> </ul>

### 3.2.1 Evidence based practice

Systematic reviews are considered to be the gold standard of evidence synthesis for evidence based practice (Higgins and Green, 2011; Moher et al., 2015). The rigorous scientific procedures, used in systematic reviews, enable similar types of evidence to be combined, and the effectiveness of interventions to be rigorously evaluated using reproducible methods (Cullum and Dumville, 2015). However, evidence based practice requires clinicians to think beyond ‘if healthcare interventions work; questions such as when, why, how, and the contextual factors, which influence practice have comparable importance in health care (Cullum and Dumville, 2015). Different types of evidence and different clinical questions require the use of alternative methods of evidence synthesis (Royal Pharmaceutical Society, 2011; Aromataris and Munn, 2017). Evidence based medicine and when to use the derived concept of evidence based practice is discussed in Chapter Four (section 4.1).

### 3.2.2 Scoping reviews

The scoping methodology was selected to undertake this review. Scoping reviews answer questions related to the 'what and why' (Davis et al., 2009). Scoping reviews have been recommended to explore the extent, range, and nature of the literature in a chosen field, to identify research gaps and to disseminate research findings (Arksey and O'Malley, 2005; Levac et al., 2010). Scoping reviews have been undertaken as standalone projects, or to determine the suitability for a future systematic review (Arksey and O'Malley, 2005; Levac et al., 2010). Scoping reviews should adopt rigorous, replicable and transparent methods (Peterson et al., 2017; Pham et al., 2014; Colquhoun et al., 2014). Scoping reviews share some procedural characteristics with systematic reviews (Pham et al., 2014). However, scoping reviews differ from systematic reviews and other types of evidence synthesis (Colquhoun et al., 2014) because scoping reviews are hypothesis generating, rather than hypothesis testing (Tricco et al., 2016). The function of scoping reviews is to provide a comprehensive overview of a broad topic (Pham et al., 2014; Tricco et al., 2016).

As scoping reviews provide a systematic approach to summarising all the available evidence, they have particular value in areas where there is a paucity of published literature (Colquhoun et al., 2014; Levac et al., 2010; Tricco et al., 2016). Scoping reviews have the advantage of not being bound by epistemological tradition, accommodate the inclusion of both qualitative and quantitative studies (Levac et al., 2010; Arksey and O'Malley, 2005), and are compatible with heterogeneous data (Mays et al., 2001). Scoping reviews are well suited to exploring new topics and can be used to report a summary of the evidence, in advance of clinical guidelines being available (Peterson et al., 2017). Scoping reviews are clinically relevant. They are useful for developing programmes of research (Tricco et al., 2016), developing policy, and advancing clinical practice (Colquhoun et al., 2014).

The different terminology relating to the scoping methodology i.e., 'scoping review', 'scoping study', 'scoping exercise' (Pham et al., 2014), illustrates the lack of a universally accepted definition (Rumrill et al., 2010; Davis et al., 2009; Levac et al., 2010; Peterson et al., 2017). The considerable variation in the intent, procedures and rigour, seen in the scoping literature (Levac et al., 2010; Colquhoun et al., 2014) has resulted in the controversy surrounding scoping reviews (Peterson et al., 2017). As with any other method of evidence synthesis, the scoping review needs to be conducted appropriately (Peterson et al., 2017; Arksey and O'Malley, 2005). The Arksey and O'Malley scoping framework (2005), which was enhanced by Levac et al. (2010) and Daudt et al. (2013) has responded to any procedural concerns relating to the methodology, by offering a methodologically rigorous structure for conducting scoping reviews. Building on prior work, the definition suggested by (Colquhoun et al., 2014) provides clarity about the intent, procedures, and rigour expected from scoping reviews:

*'A scoping review or scoping study is a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesising existing knowledge'* (Colquhoun et al., 2014 p.1294).

### **3.2.3 Reporting scoping reviews**

Until recently, there has been no consensus on the reporting of scoping reviews (Colquhoun et al., 2014). Some authors have opted to use the Preferred Reporting for Systematic Reviews and Meta-Analysis (Moher et al., 2009) checklist, to report scoping reviews (Pham et al., 2014; Peterson et al., 2017), but there has been debate about the suitability (Tricco et al., 2018a). Some items on the Preferred Reporting for Systematic Reviews and Meta-Analysis (PRISMA) checklist have been considered unsuitable, while other relevant items are not included. The Preferred Reporting for Systematic Reviews and Meta-Analysis:

extension for scoping reviews (PRISMA-ScR) was published in September 2018 (Tricco et al., 2018b). Although the review was completed before the publication of EQUATOR guidance for reporting scoping reviews, this chapter has been reported using the PRISMA–ScR reporting guidance as recommended (Tricco et al., 2018b).

### **3.2.4 Quality appraisal in scoping reviews**

The Arksey and O'Malley (2005) framework reports no requirement to undertake quality appraisal as part of a scoping review. However, debate was encouraged by Arksey and O'Malley (2005) to advance the methodology and more recent discourse has indicated that quality appraisal should be an essential part of scoping reviews (Levac et al., 2010; Daudt et al., 2013). However, as considerable resources may be required to carry out a systematic and comprehensive search of a broad topic, the decision to also undertake quality appraisal has been considered pragmatic (Daudt et al., 2013; Pham et al., 2014). A scoping review of 344 scoping reviews found that only 22.38% of authors had performed quality appraisal (Pham et al., 2014). The authors emphasised that by not undertaking quality appraisal, gaps in the literature as a result of poor quality research may be undetected, limiting the practical application of the findings (Pham et al., 2014). The PRISMA-ScR guidance describes quality appraisal as optional (Tricco et al., 2018b).

### **3.2.5 Objectives of the review and selection of the scoping methodology**

This review aims to explore the extent, range and nature of the published literature on personality disorder, violence, disruption, and the barriers and enablers of general hospital care on inpatient wards. This broad review topic was selected as it was anticipated that the main body of knowledge in this area would

be located in the literature on violence. This review explored a new topic and a broad research question was considered to be appropriate. The review objectives could not be met using a systematic review process. It was anticipated that the published literature in the field would be disparate and fragmentary, and a review type that could accommodate diverse types of evidence was needed. Scoping reviews are an appropriate methodological approach when the literature is disparate and fragmentary (Cacchione, 2016; Davis et al., 2009). The inclusion of diverse evidence within the review was considered valuable.

This review provides a synthesis of the findings, identifies gaps in the research literature, and makes recommendations for further research and practice. This review was also used to inform the methodological approach and the methods used in this PhD research. Therefore, a decision was taken to undertake quality appraisal as part of this scoping review. It was essential to capture variation in the type and quality of study designs in order to establish the strength of the current evidence base. Identifying methodological constraints within the evidence base was considered to be useful in identifying appropriate research designs to target this population.

### **3.3 Methods**

The Arksey and O'Malley scoping framework (2005), enhanced by Levac et al. (2010) is a methodologically rigorous framework which aims to mitigate concern about the intent, procedures, and rigour of scoping reviews (Colquhoun et al., 2014; Levac et al., 2010). The five compulsory stages of the Arksey and O'Malley scoping framework (2005), as enhanced by Levac et al. (2010) underpinned the methods used to undertake this review. The scoping review definition provided by Colquhoun et al. (2014), cited in section 3.2.2, has been adopted.

### **3.3.1 Developing the research question**

An initial environment scan, which preceded development of the search strategy, focused on personality disorder and district general hospitals. However, there were few hits. Most of the articles that were identified were related to violence and disruption. There was insufficient published material to identify interventions, comparators or outcomes from which to develop a focused review question. Therefore, key facets of the review topic were identified. The facets were determined to be: a) violence, b) personality disorder, and c) hospital to maximise the retrieval of articles. It is possible that this pragmatic decision, limited the range of papers and narrowed the scope of the review. Although, a range of other terms, including impulse control, agitation, behavior\*, abuse and distress were included in the search (Section 3.3.4).

Scoping review questions are deliberately broad to explore the breadth of research activity (Levac et al., 2010; Arksey and O'Malley, 2005; Daudt et al., 2013). Identification of the research question was an iterative process, informed by the latter stages of the review (Arksey and O'Malley, 2005).

### **3.3.2 Eligibility criteria**

Papers from developed economies and those in the English language were included. It was considered that exclusion of studies from outside the developed economies would facilitate more meaningful synthesis of the review findings and also in the empirical component of the thesis, due to the vast differences in healthcare practices globally. All studies in which personality disorder or personality difficulties were a feature of the study were included in the review. All articles relating to children and adolescents and older adults of 65 years or more were excluded. Violent and disturbed behaviours amongst children and adolescents, i.e., those under 18 years old, were considered likely to be subject

to alternative clinical management. In an older adult population, it was deemed more likely that violent or disturbed behaviours would have alternative aetiology in a general hospital setting.

A broad definition of violence and disturbance was applied to decisions about inclusion. Any descriptor, intervention or combination of interventions to reduce violent or disruptive behaviours including conflict, distress, abuse, and refusal of treatment was included. No comparison was used with any treatment as usual. There is limited evidence regarding 'treatment as usual' relating to this population, in this setting. It was not assumed that there would be parity with psychiatric settings and a broad range of outcomes was sought, including but not restricted to: knowledge of professional practice, service provision in the general hospital setting, and understanding patient experiences.

### **3.3.3 Information sources**

Medline, PsycINFO, EMBASE, AMED, BNI, Cochrane Library, Cinahl, Sociological Abstracts, and ASSIA were searched for terms relating to the key facets of the review topic.

### 3.3.4 Search strategy

In order to scope the breadth of the literature, a search was constructed using key words and subject headings, which were combined using Boolean operators:

*Violence (AND) impulse control OR violence OR disrupt\* OR behavio\* OR conduct OR anger OR angry OR threat\* OR aggress\* OR disturb\* OR impulsiv\* OR hostil\* OR violat\* OR combative OR agitat\* OR assault OR antagonis\* OR rage OR attack OR danger OR intimidat\* OR abuse OR distress\* (AND) personality disorder OR antisocial personality disorder OR borderline personality disorder OR compulsive personality disorder OR dependant personality disorder OR histrionic personality disorder OR paranoid personality disorder OR passive aggressive personality OR schizoid personality disorder OR schizotypal personality disorder OR antisocial OR asocial OR dissocial OR psychopath OR sociopath OR anankastic personality disorder OR hyster\* OR disordered personality OR difficult (AND) hospital OR clinic OR ward OR district general OR inpatient OR general hospital OR infirmary.*

The search took place between January and March 2015 and was limited to English language publications. Comprehensive searching was undertaken for subclassifications of personality disorders. The search terms attached to the personality disorder facet were adopted from a previous systematic review, conducted by eminent researchers in the field (Duggan et al., 2008). Whilst, the review may have been limited by the focus on violence, all sources were searched with and without the 'violence' facet. The searches were repeated in December 2017, and May 2019.

A record of the most recent search is available is Appendix 1. One additional study was found. This study is discussed in section 3.4.2.1.

### 3.3.5 Selection of sources of evidence

The search identified 62,741 articles (Figure 2, reported in the results in accordance with PRISMA-ScR). 19,730 duplicates were removed. Additional records were excluded if irrelevant to the review topic. This included: children and adolescents (1,276), diagnoses other than personality disorder or personality difficulties (1,417), older adults (264), papers published in journals of no relevance to the topic (4,530), discussion, news articles and letters (142) and theses and dissertations (530). Papers published outside the developed economies were also excluded (329). The inclusion of articles from comparable health economies was deemed to facilitate the meaningful synthesis of the findings. The remaining citations were filtered by date. The first publication of guidance in the short term management of violence and aggression (NICE, 2005) represented a significant change in the United Kingdom (UK) policy. However, 2005 was also a pragmatic cut off point, given the volume of citations identified at the search stage, and resources available to undertake the review. Citations prior to 2005 (16,789) were removed. Title and abstracts were screened for the remaining 17,735 papers. Full texts were obtained for 126 articles.

Although, a wide-ranging definition of violence and disruption was used when selecting articles for inclusion, the search might have located different articles, had the review been focused on distress or alternatively had more synonyms for 'distress' been included in the search terms. However, inclusion of the term 'distress' generates hits on psychological distress and emotional distress, so this appears to be unlikely. It is recognised that a minority of people with a personality disorder diagnosis are violent and that experiencing distress in hospital is more commonly reported by people with a personality disorder diagnosis. However, little is known about how professionals perceive psychological and emotional distress in the general hospital. It was considered highly likely that professionals working in UK general hospitals held stigmatising views related to personality disorders and that people diagnosed with a personality disorder would be

characterised in the context of violence and disruption in the general hospital literature.

### **3.3.6 Data charting process**

Charting is a recognised technique used in scoping reviews which involves: sifting, charting, sorting data thematically (Arksey and O'Malley, 2005), and collating descriptive statistics (Arksey and O'Malley, 2005; Levac et al., 2010). A data charting spreadsheet was devised in Microsoft Excel (Appendix 2). Suitability of the spreadsheet was discussed with the academic supervisors. There were only minor amendments made to the data charting spreadsheet during the extraction stage. Brief notes were made about any critical points, which were contained in each paper. However, an attempt was made to extract standardised data from each study, where possible. This accepted scoping review method builds on 'the descriptive analytical method' (Pawson, 2002). Twenty percent of data extraction was checked for accuracy by the academic supervisors and this was found to be detailed. Further statistical detail was extracted on the advice of the primary supervisor.

### **3.3.7 Data items**

A range of data was extracted: author and professional discipline, year of publication, origin of the study, setting, study population, antecedents to the study, aims of the study, methodology, methods, a description of violence and disturbance, a description of the impact of violence and disturbance, how violence and disturbance was addressed in the study, study outcomes, study limitations, and important results.

### **3.3.8 Critical appraisal and individual sources of evidence**

The use of critical appraisal tools increases transparency (Akobeng, 2005), and enables greater scrutiny of the review process (Ham-Baloyi and Jordan, 2016). There are several critical appraisal tools, e.g., Crombie (2004) and the Critical Skills Appraisal Programme (CASP, 2013). Tools similar to CASP are considered well suited to undergraduate students needing to develop skills in appraising validity and methodological quality but have been criticised for lacking depth (Hannes et al., 2010). The use of appraisal checklists from the same source has been considered optimal for consistency and synthesis of review findings (Crowe and Sheppard, 2011). At the time of undertaking this scoping review of the literature, the only checklists suitable for appraising narrative work as well as offering design specific tools for the quantitative papers were by The Joanna Briggs Institute (2014).

Quality appraisal was therefore undertaken using the Joanna Briggs critical appraisal tools (The Joanna Briggs Institute, 2014). This collection of tools offered a design specific tool for each of the studies included in this review. All of the studies were individually appraised using the relevant Joanna Briggs appraisal tool: narrative studies, comparable cohort and case control studies, and descriptive and case series studies. Quality appraisal was undertaken,

tabulated, and discussed with the academic supervisors. Table 7 (3.4.3) provides a summary of the strengths and limitations of the included studies.

### **3.3.9 Synthesis of results**

Thematic analysis is an established method used to identify, interpret and report themes (Braun and Clarke, 2006). It aids cross comparison and identification of linkages within the data (Arksey and O'Malley, 2005; Levac et al., 2010). The review articles were read several times, which enabled familiarisation with the data. The data were searched for dominant patterns relevant to the review question (Braun and Clarke, 2006). This process involved highlighting pertinent extracts of the data, making notes, and developing a commentary on the main facets of the review, i.e., personality disorder, perceptions of violence and disruption, and the general hospital. An initial commentary was discussed with the academic supervisors. The data were organised into preliminary themes. Searching for themes was an iterative approach and involved moving between charting, collating and summarising results. The themes were reviewed and revised following discussions with the academic supervisors about overlapping, relevance to the review question, interpretation, and reporting of the themes. The themes were subject to additional refinement during the writing of this chapter.

## **3.4 Results**

### **3.4.1 Selection of sources of evidence**

All 126 articles were read in full. After familiarisation with the literature, it was evident that perspectives relating to violence and disruption in the general hospital were diverse. A broad definition of violence and disturbance was applied to decisions about inclusion. Any article which reported conflict, distress,

violence, abuse, refusal of treatment, or interventions to address violent or disturbed behaviour within a general hospital setting were included; when personality disorder or personality difficulties were a feature of the study.

The articles excluded at this stage were those: unrelated to personality disorder or personality difficulties (44), related to non-general hospital settings (47), opinion or discussion (12), unrelated to violence and disturbed behaviours (7), conference abstracts with full paper unavailable (3), related to lateral and horizontal violence (1), and outside the developed economies (1). Where there was ambiguity regarding inclusion, this was discussed with the academic supervisors. On each occasion when articles were discussed, they were subsequently excluded. All study designs were eligible. No article was excluded due to quality. One study was excluded at the charting stage, as it was deemed to be less relevant to the definition of violence and disruption described in the previous paragraph. Ten articles were considered eligible for inclusion.

### **3.4.2 Hand searching**

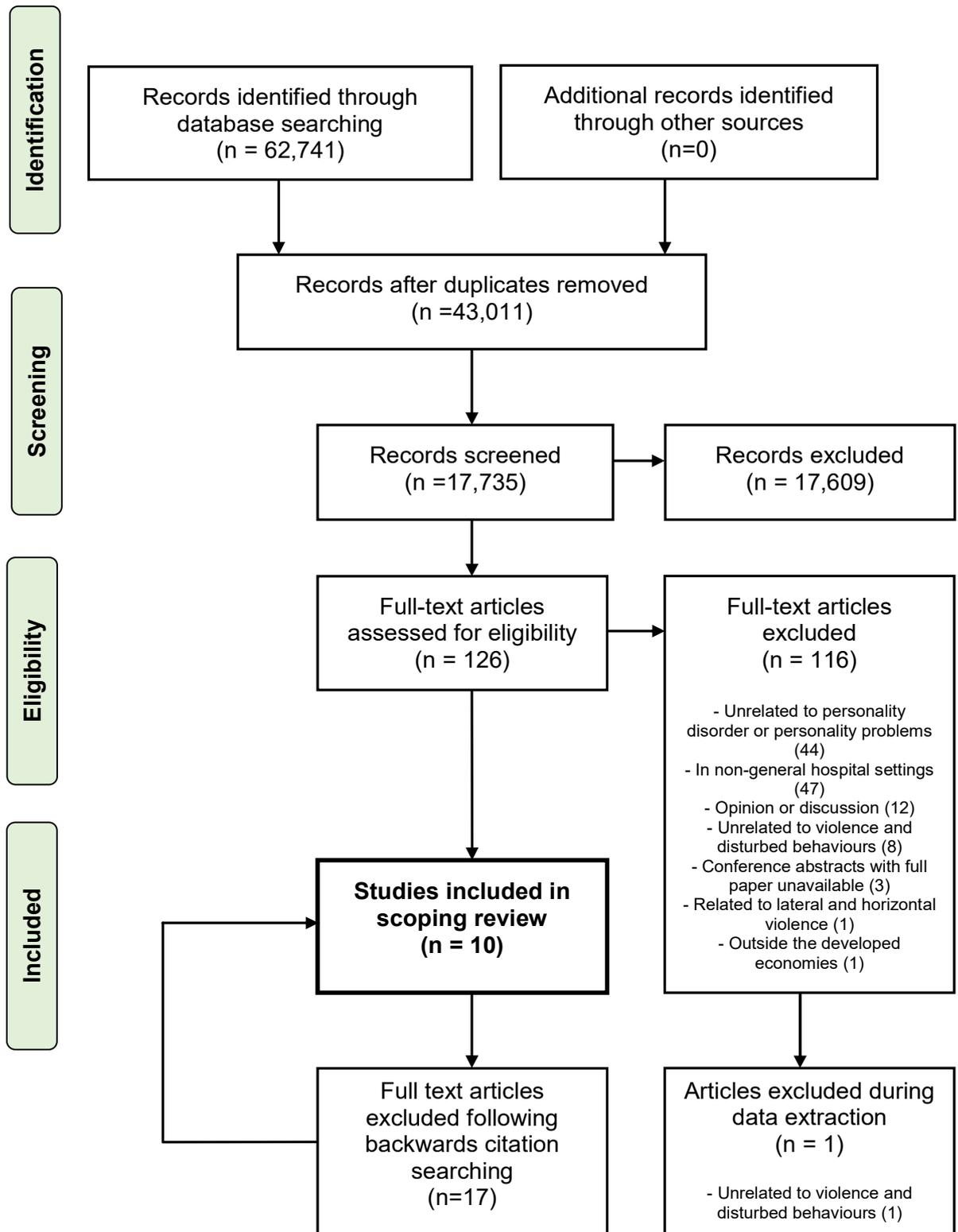
First authors of the ten included studies were contacted via email. No additional data or studies meeting the eligibility criteria were identified. Backward citation searching identified a further 45 titles and abstracts. Full texts were sought for 17 articles, however, none were eligible for inclusion. The United Kingdom Clinical Research Network (UKCRN) and Open Grey databases returned no records of any additional relevant studies or literature.

#### **3.4.2.1 Recently published literature not included in the review**

*Treat as One, Bridging the gap between mental and physical healthcare in general hospitals* (NCEPOD, 2017) was published after this review was completed and was not included in study 1. The authors collected data from

questionnaires and case notes to *'identify and explore remedial factors in the overall quality of mental healthcare provided to patients with significant mental health conditions who were admitted to the general hospital'* (NCEPOD, 2017 p.11). Data were collected retrospectively and related to hospital admissions for one month of 2014. Of the 552 patients in the study sample, 43 were reported to have a diagnosis of personality disorder. While this study did not exclusively explore issues related to the personality disorder diagnosis, one of the findings was that the diagnosis of personality disorder automatically triggered a referral to liaison psychiatry on only 4.3% of occasions (n=7), compared to 12.5% (n=20) in people with severe depression. The authors also presented a complex case study about a patient diagnosed with a personality disorder who attempted to leave the hospital against medical advice. The authors concluded that general hospital care was generally lacking for people with mental disorders.

**Figure 2 Prisma flow diagram**



### **3.4.3 Characteristics of sources of evidence**

An overview of the selected studies is provided in Table 6. The ten articles included two case controlled studies (Rocheffort et al., 2011; Kling et al., 2011), two surveys (Kannabiran et al., 2008; Tawk et al., 2013) and six case studies (Magidson et al., 2012; Navines et al., 2013; Mezzini and Crawford, 2009; Maytal et al., 2006; Saper, 2008; Taylor and Stern, 2013). Half of the studies were published in the United States of America (USA), (Magidson et al., 2012; Maytal et al., 2006; Saper, 2008; Tawk et al., 2013; Taylor & Stern, 2013). Only two of the included papers were European (Kannabiran et al., 2008; Navines et al., 2013), with one study undertaken in the UK (Kannabiran et al., 2008). The remaining studies were published in Australia (Mezzini & Crawford, 2009) and Canada (Kling et al., 2011; Rocheffort et al., 2011).

**Table 6 A summary of the characteristics of sources of evidence**

Author and origin	Aim	Study design	Sample characteristics	Data Collection	Data Analysis
Kannabiran et al. (2008) UK	To describe disturbed behaviours experienced by nurses.	Survey	87 adult inpatient wards. Sample of 42 male and 26 female patients (n=68).	Semi structured survey.	Descriptive statistics.
Kling et al. (2011) Canada	To assess if the alert system (risk tool) could be used to prevent violent incidents.	Case control	109 cases and 634 controls.	Phase 1 – data were extracted from hospital incident reports and records of staff working hours. Phase 2 - manual data extraction from patient charts.	Phase 1 – A Poisson regression model was used to calculate risk characteristics. Conditional logistical regression was used to calculate odds ratios of risk status.
Rochefort et al. (2011) Canada	To assess if patient and staff characteristics could be associated with increased sitter costs.	Case control	1,151 patients allocated a sitter from a cohort of 43,212 medical and surgical patients. Controls were selected randomly based on admission date (no further detail reported).	Data were extracted from clinical and administrative databases.	Descriptive statistics. Multivariate logistic regression was also used to measure associations between patient health conditions, nurse staffing and high sitter cost.
Tawk et al. (2013) USA	To understand associations between medical and mental illness and discharge against medical advice.	Survey	46261 discharges against medical advice from a cohort of 4499760 hospital records.	National discharge data.	Multiple logistic regression was used to estimate discharges against medical advice by year and mental illness.
Magidson et al. (2012) USA	To discuss challenges, strategies and theoretical perspectives of working with people with a diagnosis of narcissistic personality disorder in a medical setting.	Multiple case study	Three case studies, one relevant to this review. A female admitted with abdominal pain, diagnosis of narcissistic personality disorder, with 'behavioural outbursts'.	Unreported	Unreported
Maytal et al. (2006) USA	To demonstrate that understanding the aetiology of nudity can support healthcare staff to modify responses.	Multiple case study	Three case studies, one relevant to this review. A 53 year old male, admitted for an exacerbation of chronic obstructive pulmonary disease,	Unreported	Unreported

			reported to have comorbid features of dependant and narcissistic personality disorder. Presented with 'persistent nakedness'.		
Mezzini and Crawford (2009) Australia	To demonstrate emotional difficulties relating to malignant illness and offer guidance in reducing conflict.	Single case study	A 45 year old female admitted with breast carcinoma and chronic obstructive airways disease, diagnosed with borderline personality disorder and dependant personality traits. Reported to exhibit confrontational behaviour and misuse opioids and sedatives.	Unreported	Unreported
Navines et al. (2013) Spain	To highlight gaps in the literature, discuss the possible function of ingesting foreign bodies and the challenges of providing care.	Single case study	A 35 year old female, admitted for surgical removal of ingested items, with a diagnosis of borderline personality disorder. Presented with anger and hostility. The female reopened incision sites and ingested further items on the ward.	Unreported	Unreported
Saper (2008) USA	To offer guidance on identifying the 'problem patient', those who abuse medicines and to offer advice on how to 'approach' a patient with a cluster B personality disorder.	Single case study	The case was a headache unit rather than an individual. The unit had a specialist remit to treat patients with comorbid personality disorder diagnoses and disturbed behaviours.	Unreported	Unreported
Taylor and Stern (2013) USA	To demonstrate the impact of communication break downs amongst physicians. To suggest strategies to avoid this situation and to make recommendations in the event that communication broke down.	Single case study	A 26 year old female admitted to a medical ward for treatment of abdominal pain. Diagnosed with borderline personality disorder. Presenting with tightness in the throat and neck stiffness. There was no consensus re aetiology.	Unreported	Unreported

**Table 7 Critical appraisal and results within sources of evidence**

Author	Results	Strengths	Limitations
Kannibiran et al. (2008)	Disturbed behaviour was reported in 4% of hospital patients. Of the < 65 age group with disturbed behaviour, 73% of patients engaged in acts, which put others at risk. Disturbed behaviour in < 65 age group was attributed to personality disorder.	Primary data.	The sampling strategy raises questions about validity. Inclusion criteria was poorly defined. The study sought to 'understand experiences', but no qualitative data was reported.
Kling et al. (2011)	20 cases of mood or personality disorder were identified within the sample. Conditional logistic results did not demonstrate any statistically significant impact of violence prevention on the risk of patient violence for this group. Bivariate OR 95% CI 2.71 (0.87-8.35) and multivariate OR 95% CI 2.81 (0.79-9.94).	Follow up over five years.	The study aims were not well matched to the case control design. No protocol was in situ for reporting incidents or using the alert tool, which seemed likely to have resulted in the inconsistent allocation of cases and controls.
Rocheffort et al. (2011)	Personality disorders were included in the other psychiatric conditions group. This group did not demonstrate statistically significant sitter use, 21 patients were reported to have low sitter use (n=3.1%), and 23 patients were reported to have high sitter use (n=4.5%). Regression univariate OR 1.47 95% CI (0.80-2.71) and multivariate OR 0.71 95% CI (0.29 – 1.75).	The use of secondary data provided a wealth of data regarding a vulnerable population, with minimal intrusion.	No clear hypothesis. No findings were reported for the control group. There was no policy for sitter use in situ and relevant prescribing data reported within a second paper was not reported.
Tawk et al. (2013)	Mental illness was identified in 34% of against medical advice discharges. Personality problems were reported to be amongst the most common diagnoses. Injury and poisoning were identified in a further 8.3% discharges against medical advice. Patients aged 18-44 were discharged against medical advice most frequently. Single patients had 62% higher odds of discharge against medical advice. 60% of discharges against medical advice were male. 68.6% of patients left within three days.	The use of a large national dataset provided access to extensive data, which would not have otherwise been accessible.	The type of ward could not be identified from the dataset. Therefore there appears to be validity issues as some data may have been from psychiatric wards. Patients were excluded when there was no recorded diagnosis or when the patient was deceased. There was no discrete data to support claims that patients diagnosed with personality disorder were leaving against medical advice.
Magidson et al. (2012)	An individualised treatment plan was found to facilitate patient engagement. Healthcare professionals reported participating in a psychodynamic 'process group' was useful and improved practice.	The interests of patients and workers were pivotal to this study.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. A decline in the patient's health provided unconvincing evidence of good practice.

Maytal et al. (2006)	A behavioural treatment plan was found to be effective in reducing persistent nakedness. Healthcare professionals became less avoidant, and the quality of care improved.	The interests of patients were central to this study. The presenting argument was logical and argued. The paper described a clear rationale for completing detailed assessments, including the process of considering differential diagnosis and developing individualised plans.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. Some of the language used was controversial, i.e. 'when confronting such a patient'.
Mezzini and Crawford (2009)	Patients with a cancer diagnosis and borderline personality disorder required early detection and coordinated treatment responses.	This study provided a logical and analytical account of the need to improve care for patients on a palliative care pathway, with a comorbid personality disorder diagnosis.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. More robust research was needed to support the recommendations.
Navines et al. (2013)	Professionals had greater empathy for abdominal pain than any psychiatric need. The patient changed healthcare providers repeatedly and often discharged against medical advice.	The case study provided a logical, analytical and well referenced debate about the biopsychosocial aetiology of personality disorder and the ingestion of foreign bodies.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. The commentary was limited by the modest evidence available.
Saper (2008)	Patients with cluster B personality disorders were challenging to treat neurologically. Doctors may make unwise decisions and concede to unreasonable requests. Some patients had a level of complexity, which meant they were unwilling and unable to benefit from inpatient care.	An authentic account of issues as seen by the author, working clinically, within an inpatient environment.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. The study did not convey any sense of responsibility for clinicians to manage their frustrations. Instead, the patients were identified to be frustrating. No logical argument, minimal analysis and own thoughts and observations provided as evidence. The study cited 13 references, 11 were written by the author.
Taylor and Stern (2013)	The patient was discharged from the general hospital with inadequate follow up from mental health services. Collaborative working was considered to be fundamental to avoiding poor treatment outcomes.	This case study was presented logically and congruently within the extant literature. This was the only paper to explore the impact of violent and disturbed behaviours in the context of team dynamics.	No details provided about the selection of cases, data collection or analysis. There was no reflexive discussion. The case study adopted a psychodynamic perspective. The recommendations may not appeal to a global general hospital community.

### **3.4.4 Synthesis of results**

Three broad themes were identified from the data synthesis. The themes related to: The scope of violence and disruption in the general hospital setting (theme one), responses to patients considered to be violent or disruptive (theme two) and working with patients considered to be violent or disruptive (theme three). The themes were centred around violence and disruption in keeping with the aims of the review. Patient distress was implicit across the identified themes but because of the focus of the review, was not at the forefront of the findings. There is a risk, therefore, that the findings of this review could be construed to contribute to the negative stereotyping of people diagnosed with a personality disorder, due to the parameters of the literature search and the selection of articles that were identified in by the search.

However, it was important to highlight that patients diagnosed with a personality disorder might be interpreted as being violent or disturbed in the general hospital setting when they are deeply distressed and Theme one, the scope of violence and disruption, emphasised the low threshold for patients to be deemed violent and disruptive in the general hospital setting. Despite the overarching focus on violence and disruption, the key findings of this review were broadly comparable to patient experiences reported in other settings. Patients received discriminative responses from healthcare professionals (Theme two) and professionals were reluctant to work positively with people with a personality disorder diagnosis (Theme three). A summary of the empirical findings has been reported in Table 7.

#### **3.4.4.1 Theme one: The scope of violence and disruption in the general hospital setting**

On reviewing the literature, no data were found to support a relationship between violence and personality disorder in general hospitals. A minority of the studies explored violence in this context (Kannabiran et al., 2008; Kling et al., 2011; Magidson et al., 2012). However, the literature clearly portrayed people with a diagnosis of personality disorder to be disruptive because of: refusal to maintain socially expected norms (Maytal et al., 2006), hostility, impulsivity and rigidity (Mezzini & Crawford, 2009), agitation, wandering and suicidality (Rocheftort et al., 2011) and being so called 'problem patients' (Saper, 2008). Acts such as seeking discharge against medical advice (Tawk et al., 2013), sabotaging treatment attempts (Navines et al., 2013), or expressing strong disagreement with medical treatment or diagnosis (Navines et al., 2013; Saper, 2008) were identified as to cause disruption. Healthcare professionals response of frustration provoked additional conflict (Taylor & Stern, 2013).

Disturbed behaviours were present in an estimated 4% of all hospital inpatients (Kannabiran et al., 2008). There were 1.6 incidents found per 100,000 worked hours (Kling et al., 2011) and 1,151 out of 43,212 patients were allocated a sitter following 'deterioration of behaviour' during a two year study period (Rocheftort et al., 2011). No correlation was found between personality disorder and incidents of violence when assessed by the 'alert' risk assessment tool (Kling et al., 2011) or personality disorder and high cost sitter use (Rocheftort et al., 2011); However, personality disorder was not examined as a discrete category in any of the quantitative studies (Kling et al., 2011; Rocheftort et al., 2011; Tawk et al., 2013). Personality disorders were categorised with mood disorders (Kling et al., 2011) or included with 'other psychiatric conditions' (Rocheftort et al., 2011). Diagnostic data were not collected to substantiate claims that disturbed behaviour in under 65's was related to personality disorder (Kannabiran et al., 2008).

Leaving against medical advice was five times more likely when patients had a mental illness compared to those who did not (odds ratio (OR) = 4.928; 95% confidence interval (CI) 4.759-5.104; P= 0.0001) Tawk et al. (2013). The odds ratio was reduced when patients with substance misuse issues were excluded (OR = 3.295 95% CI 3.101-3.502 p= 0.0001). After controlling for patient, hospital related variables, and medical diagnosis, Tawk et al. (2013) reported the odds of leaving the hospital against medical advice were three times higher compared to the population not deemed to have a mental illness (Adjusted Odds Ratio (AOR) =3.110). Alcohol and drug dependence (approximately 38% of mental disorder subcategories), along with personality problems, were the most common subcategory of those leaving against medical advice (Tawk et al., 2013). No data on personality problems was reported. It appeared that Tawk et al. (2013) considered that alcohol and drug dependence was concomitant with 'personality problems'.

#### **3.4.4.2 Theme two: Responses to patients considered to be violent or disruptive**

The case studies described a culture of discrimination which included; patients being treated differently, being denied treatment for mental ill health, workers repeatedly paging the psychiatrist instead of providing treatment, premature discharge from hospital and frequent readmissions (Maytal et al., 2006). Patients also experienced; deficient care when professionals lacked knowledge and understanding (Magidson et al., 2012; Maytal et al., 2006; Mezzini & Crawford, 2009), substantial levels of distress (Mezzini & Crawford, 2009) and dissatisfaction with care provided (Magidson et al., 2012).

The literature described economically inefficient practices such as the organisation of the staff rota to avoid working more than two consecutive shifts with a patient diagnosed with a personality disorder (Magidson et al., 2012). There were examples of incomplete episodes of care, repeated hospital

attendances and non-adherence to treatment (Mezzini & Crawford, 2009; Navines et al., 2013). Patients were reported to be exploiting hospital admissions in order to access pharmaceuticals or gain respite (Mezzini & Crawford, 2009).

Poor care was contextualised by reports that healthcare workers felt threatened, perceived professional invalidation, and had a sense of working beyond their capabilities (Magidson et al., 2012). Workers reported high levels of distress (Mezzini & Crawford, 2009), were avoidant (Maytal et al., 2006), became emotionally drained (Mezzini & Crawford, 2009) and engaged in interprofessional conflict (Taylor & Stern, 2013). Psychodynamically orientated discussions were used to support workers to explore the emotions and behaviours, which underpinned professional challenges (Magidson et al., 2012; Taylor & Stern, 2013). Hospital workers were able to recognise that patients were incorrectly labelled as difficult because of the poor team working (Taylor & Stern, 2013) and were able to reflect on their practice (Magidson et al., 2012). Other ideas to support workers included; daily meetings to discuss care (Mezzini & Crawford, 2009) and conflict resolution training (Taylor & Stern, 2013).

The quantitative studies all advocated increased resources to address violent and disturbed behaviours. These included: the commission of specific wards to treat comorbid psychiatric and medical issues (Kannabiran et al., 2008), developing policy to target individuals at risk of treatment non completion (Tawk et al., 2013), and ensuring psychiatric liaison services were boosted to provide targeted interventions and education (Rochefort et al., 2011). The quality of the evidence, which was presented, was insufficient to justify the additional investments which were described.

#### **3.4.4.3 Theme three: Working with patients considered to be violent or disruptive.**

There were polarised opinions on best practice in working with this patient group in the literature: the most common recommendation was to work cohesively using a multidisciplinary and collaborative approach (Magidson et al., 2012; Mezzini & Crawford, 2009; Taylor & Stern, 2013) in conjunction with psychiatric consultation (Maytal et al., 2006). However, it was also claimed that clinicians should adopt a 'no-nonsense approach, based on 'frank talk and expectation' (Saper, 2008 p.825). In contrast, another study described promoting engagement by encouraging the 'need to be admired, highlighting the medical celebrity that she had achieved' (Magidson et al., 2012 p.199). The use of psychotherapeutic education around 'problem solving or 'distress tolerance' was also recommended (Navines et al., 2013 p.69).

The use of 'behavioural management plans' was identified in the case study literature although commentary about practical application was absent (Magidson et al., 2012; Maytal et al., 2006; Mezzini & Crawford, 2009). While success in using a behavioural management plan was reported (Magidson et al., 2012), the death of the patient prevented full implementation of the behavioural plan described in the study. There was no indication that coercive behavioural plans were acceptable to patients. Contractual agreements that treatment be withdrawn in the event patients failed to stop behaviours deemed undesirable (Saper, 2008) lacked any acknowledgement of professional responsibilities.

Interventions for disturbed behaviour in the general hospital in Kannabiran et al. (2008) were identified as follows: additional staff time, given on 29 occasions (33%), additional medication given on 19 occasions (21.7%), increased observations, implemented on 17 occasions (19.4%), and asking security or police to intervene, which took place on 13 (14.8%) occasions. The researchers linked these type of interventions to self harm and interference with treatment,

which they related to personality difficulties. It was not possible to identify how many patients had a diagnosis of personality disorder from the data. It was reported that there were occasions when general hospital workers could not adequately meet the mental health needs of disturbed patients (Kannabiran et al., 2008). However, it was not possible to extract the supporting data from the report.

## **3.5 Discussion**

### **3.5.1 Summary of evidence**

Although this scoping review found no linkage between violence in general hospitals and a comorbid diagnosis of personality disorder, this has to date, not been robustly investigated, meaning that no firm conclusions can be made. Concern about the impact of violence was seen in the literature from the USA (Magidson et al., 2012), UK (Kannabiran et al., 2008), Australia (Mezzini and Crawford, 2009) and Canada (Kling et al., 2011). This scoping review raised important questions about the determinants of violence in this context, the difficulties faced by this patient group in general hospitals, and the types of behaviour, driven by distress, which are perceived to be, or manifest as violent, or disturbed behaviour in clinical practice.

This scoping review extends knowledge of the discriminatory practices experienced by this patient group in healthcare settings. However, the fundamental contribution of this scoping review is to provide a new understanding of the context of such practice. The scoping review revealed a lack of evidence to support clinical decision making and insufficient support structures in the general hospital (Taylor and Stern, 2013; Magidson et al., 2012; Mezzini and Crawford, 2009). Healthcare workers reported feeling threatened, unskilled (Magidson et al., 2012), and distressed (Mezzini and Crawford, 2009).

Taken together, these results suggest that there may be a risk to patients and healthcare workers alike if frontline workers are not supported at an organisational level. There seems to be room for improvement in clinical governance procedures to support all stakeholders.

Service delivery in general hospitals was shown to be easily derailed by overt distress (Maytal et al., 2006), non-adherence with treatment (Tawk et al., 2013; Navines et al., 2013; Saper, 2008), use of special observations (Rochefort et al., 2011) and conflict within teams (Taylor and Stern, 2013). Although it is difficult to be confident in the validity of these findings based on the quality of the studies, the findings are consistent with those that relate to supporting people with a diagnosis of personality disorder in other healthcare settings (Murphy and McVey, 2010). There are many unanswered questions about why this patient group has increased rates of comorbid physical health problems (Quirk et al., 2015; Frankenburg and Zanarini, 2004; Fok et al., 2014). More research is needed to understand the issues that are specific to general hospitals such as: the role of liaison psychiatry in reducing the distress that may be construed as violence and disruption; the interventions, which are feasible and acceptable in the general hospital setting; and the barriers and enablers to providing care.

A powerful finding to emerge was that no patient views or perspectives had been reported in the literature. Methodologically robust research, which reports the experiences of patients, is a priority. Additionally, there may be benefits of good quality research, which focuses on: the training and development of general hospital workers, treatment non-completion amongst people with a comorbid diagnosis of personality disorder, and the long term physical health needs of people with a comorbid diagnosis of personality disorder. Another key area for future research might be maternity settings. Research on antenatal care, attendance, the experience of pregnancy, and anticipation of birth conducted in Australia suggests that women with a diagnosis of borderline personality disorder experience birth as traumatic, request early delivery and have undesirable outcomes (Blankley et al., 2015). There were no studies relating to women's

services amongst the review literature. This may indicate an important area of unmet need.

### **3.5.2 Limitations**

The review contained no 'higher grade' research studies, such as systematic reviews or randomised controlled trials (The Joanna Briggs Institute, 2013). The studies included in this review were defined as lower grade. However, the worth of a study is dependent on contribution to practice (The Joanna Briggs Institute, 2013). This scoping review has provided a narrative account of literature in the field. This review has been used to highlight methodological constraints within the current evidence base and to identify appropriate research designs to target this patient group in the future. Only articles in English were included. There were insufficient resources available to include non English language articles. There may be articles written in a language other than English, which were excluded, limiting generalisability of the results. The optional sixth step of the Arksey and O'Malley (2005) framework was not undertaken because there were insufficient resources to enable a consultation exercise.

### **3.5.3 Conclusions**

The current evidence base was found to be limited to 10 studies of poor quality. The complexity of the patient group, the hospital setting, and the types of clinical interventions used were not sufficiently reflected, particularly in the quantitative literature. While the case study literature showed potential in understanding the many interacting components in the field; the case study methodology must be applied rigorously in order to be valid (Yin, 2014). When used correctly, case study research can be used to extend knowledge about systems (Thomas, 2016), organisational processes, decision making (Yin, 2014) and explore divergent views and influences in a real world context (Simons, 2009). It would be a natural progression from this review to undertake robust case study

research in this area; however, it may be that more innovative qualitative strategies are required to engage people diagnosed with a personality disorder.

This review has highlighted a gap in knowledge about personality disorder and general hospital care. The use of a scoping methodology to undertake the review has provided a pragmatic and practical mechanism for synthesising and disseminating the diverse and fragmented literature available in the field. This review has exposed a limited research base, with some inherent validity and reliability issues, and this is long overdue. Poor quality research has significant and profound ramifications for patient care and service delivery. The available literature does not provide an entirely convincing account of good practice in general hospitals. There are considerable implications of chaos, disruption, and weak care pathways. There is a lack of grey literature in Open Grey and no evidence that systems in place to support patients or healthcare workers have been developed empirically. This review has presented a strong case for initiating high quality general hospital research, to improve and strengthen the evidence based health care available for people diagnosed with a personality disorder.

This PhD thesis aims to explore manifestations of distress, other than self harm, for which, a body of good quality literature exists (Chapter Two). Therefore, on balance, it was useful to explore the problematic depictions of people diagnosed with a personality disorder in the general hospital literature as a precursor to undertaking primary research in this area. This scoping review has identified a need to collect primary data from patients and carers about their views and perceptions of general hospital services. However, the focus of this PhD thesis moves away from violence and disruption in subsequent chapters, as experiences of distress come to the forefront and some of the misperceptions described in this review are understood in more depth.

## **Chapter 4 : Methodology**

This thesis aims to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed, using a mixed methods explanatory sequential research design. Chapter Four will set out the philosophy and the methodological framework, which informed: studies 2a and 2b, a cross sectional web based survey with patients and carers and embedded interviews with patients; study 3a, a cross sectional web based survey with general hospital professionals; and study 3b, interviews with mental health liaison professionals.

This chapter is organised into the following sections: Section 4.1 provides a summary of evidence based medicine and the derived concept of evidence based practice (EBP), exploring the limitations imposed by traditional thinking about the hierarchy of evidence. Section 4.2 discusses research paradigms and explains why a pragmatic approach has been chosen to underpin this research. Section 4.3 provides an overview of mixed methods research, which informs a discussion about why a mixed methods approach is a rational methodological choice for this PhD research. Section 4.4 provides an overview of quality and rigour in mixed methods research and summarises the integration procedures used in mixed methods research and this thesis.

The framework underpinning the research methods is discussed in sections 4.5 – 4.7: Section 4.5 focuses on recruitment; Section 4.6 discusses the decisions taken regarding the study design in the quantitative strands 2a and 3a; Section 4.7 outlines the decisions taken regarding the study design in the qualitative strands 2b and 3b. Research governance is discussed in sections 4.8. The chapter concludes in section 4.9 with some reflexive discussion.

## **4.1 Evidence based medicine**

Evidence Based Medicine (EBM) has been defined as *‘the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research’* (Sackett et al., 1996 p.1). The concept of EBM was formulated in the 1980s and has been credited to epidemiologist Stanley Sackett and colleagues, based at McMaster University in Canada. Although Sackett et al. (1996) confined thinking about evidence to medicine, EBM has gained transdisciplinary popularity and provides the theoretical background for evidence based practice (Banning, 2005; Spring, 2007). The broader concept of evidence based practice (EBP) has been used in this PhD thesis.

### **4.1.1 Clinical expertise**

In their seminal paper, Sackett et al. (1996) were explicit about the importance of clinical expertise in making informed decisions about care. Clinical expertise, considered to be the competence and informed decision making that clinicians acquire by experience and practice (Sackett et al., 1996) is crucial to decision making, which takes place in the context of limited, inconclusive or contradictory evidence (Gerrish, 2015; Moule et al., 2017). However, considering the tacit knowledge of clinical experts to be ‘evidence’, has the potential to perpetuate unquestioning cultures of ‘custom and practice’ (Moule et al., 2017). Experience has not always been synonymous with proficiency and competence in healthcare (Closs, 2003; Greenhalgh, 1999) and the debate about the relationship between clinical expertise and evidence has endured (Gerrish, 2015; Spring, 2007).

### **4.1.2 Patient preferences**

Although Sackett et al. (1996) referred to respecting the rights and choices of patients, a more patient centric way of thinking was under represented (Spring, 2007). EBP in healthcare requires that patient choice has comparable weighting with research evidence and clinical expertise in the decision making process (Institute of Medicine, 2001). In nursing, for which individualised, patient centred, care forms the basis of professional practice, (Royal College of Nursing, 2016), the context, culture, choices, and characteristics of patients are central to EBP (APA Presidential Taskforce on Evidence Based Practice, 2006). *'Patients have the right to demand better evidence, better presented, better explained, and applied in a more personalised way with sensitivity to context and individual goals'* (Greenhalgh et al., 2014, p.3).

### **4.1.3 The best available research evidence**

The EBP mantra has been to use 'the best research evidence,' to inform clinical decision making (Ilic and Maloney, 2014). The origin of EBP in epidemiology has provided a strong emphasis on scientific measurement, and the discovery of facts (Greenhalgh, 1999). However, the original definition of EBM provided by Sackett et al. (1996), was at variance with this position and has been considered to be more expansive and cognisant of the potential for different types of evidence, to contribute to knowledge (Gerrish, 2015; Greenhalgh, 1999). The delicate balance between patient choice, expert knowledge and research evidence has required clinicians to develop a sophisticated and critical level of thinking about evidence based practice (Gerrish, 2015).

#### 4.1.4 Hierarchies of evidence

Hierarchies of evidence have been developed to support clinicians to interpret and evaluate the value of research evidence (Straus and McAlister, 2000). The traditional pyramid of evidence places systematic reviews, meta-analyses, and randomised control trials (RCT's), in the upper parts of the hierarchy, and 'weaker' studies such as case series or reports towards the bottom (Murad et al., 2016). However, traditional thinking about research evidence has been considered limited (Murad et al., 2016), and partisan to decision making around clinical effectiveness (Evans, 2003). In the context of EBP, many valid research approaches have been considered less favourably (Evans, 2003).

To support the interpretation and evaluation of a broader range of research evidence, other hierarchies have been developed, e.g., Muir Gray (1997), Windish (2013), Evans (2003), including a hierarchy of evidence for assessing qualitative research. The hierarchy of evidence for practice in qualitative research (Daly et al., 2007), identifies four types and corresponding levels of qualitative research: Level one, generalisable studies; level two, conceptual studies; level three, descriptive studies, and level four, single case studies (Table 8).

**Table 8 A hierarchy of evidence for practice in qualitative research: study types and levels in Daly et al. (2007)**

Level 1 Generalisable studies
Level 2 Conceptual studies
Level 3 Descriptive studies
Level 4 Single case studies

#### **4.1.5 Evidence based practice and this PhD thesis**

Health services are required to be delivered in line with the local context, considering the needs of the population (Dobrow et al., 2004), and based on the 'best available evidence' (Stevens et al., 2001). A lack of knowledge or competence impacts on the standard of care that patients receive (Royal College of Nursing, 2009). Evidence has naturally accumulated in practice areas, which have been funded by the government, targeted by the pharmaceutical industry, or which receive public support (Greenhalgh, 2014). Evidence has rarely amassed in practice areas regarded as unimportant, in areas which fail to attract public backing, or around conditions that have multi-morbidity or are hard to classify (Greenhalgh, 2014). This PhD thesis on personality disorder and general hospital care has a comparable research context. The evidence base on the general hospital care of people diagnosed with a personality disorder has been identified to be minimal and of low quality (Chapter three) and as such a case will be made for the use of an innovative research design.

#### **4.1.6 The use of an innovative research design to develop evidence based practice**

People with a diagnosis of personality disorder, have to date, represented a hidden population in general hospital settings, and consequently, the evidence base does not currently reflect the views, experiences, and needs of this patient group. We also understand very little about the knowledge and competence of general hospital workers in relation to this population. The scoping review reported in Chapter Three (study 1) suggested that traditional research methodologies have maintained the invisibility of this population. Research needs to be designed innovatively in order to access marginalised populations (De Leeuw, 2013; Royal College of Nursing, 2009). The decision to use an innovative and patient centric study design (Figure 6) has enabled this PhD thesis to make an original contribution to the evidence base. Improving the

evidence base has the potential to drive changes to policy and reshape contemporary health care funding and practice (Drisko and Grady, 2012).

## **4.2 Research Paradigms**

*'Paradigms are sets of beliefs and practices, shared by communities of researchers, which regulate inquiry within disciplines. The various paradigms are characterized by ontological, epistemological and methodological differences in their approaches to conceptualizing and conducting research, and in their contribution towards disciplinary knowledge construction'* (Weaver and Olson, 2006 p. 1).

As discussed in 4.1.3, in some disciplines, an over reliance on quantitative, population level research has been at the expense of other ways of knowing (Nolan and Bradley, 2008; Thorne, 2018). In nursing research, the paradigms used have included positivist, post-positivist, interpretative and critical social theory (Weaver and Olson, 2006). However, nursing research has been heavily criticised for primarily being qualitative, descriptive, and context specific (Hallberg, 2006). Nursing researchers have been considered to have a responsibility to develop knowledge, which has a practical application (Hallberg, 2005). Hallberg (2006) argued that to advance nursing research, the reliance on qualitative, person focused approaches should reduce. EBP benefits from the combination of a range of research paradigms (Weaver and Olson, 2006). The strengths and limitations of the different research paradigms and the different lenses, offered by the range of ontological and epistemological positions, support nursing researchers to ask questions and use the research methods most relevant to improving patient care (Richards and Borglin, 2011).

### **4.2.1 The objectivist paradigm**

Quantitative research uses statistical testing to establish laws, theories, and relationships deductively (Creswell, 2015). Quantitative research can be of an experimental or observational nature (Bowers et al., 2014). In health research, the dominant research methods have included Randomised Control Trials (RCT's) and longitudinal surveys, with the RCT being considered to be the gold standard of evidence in the traditional EBP context (Curtis and Drennan, 2013). The epistemology underpinning quantitative research is objectivism, the assumptions made in this type of research are that truth and meaning exist objectively and independently from the researcher, and that rigorous scientific methods can obtain that truth and meaning (Crotty, 2013; Curtis and Drennan, 2013). Objectivism underpins quantitative research undertaken in the positivist paradigm and since the late 20<sup>th</sup> century, in the post-positivist paradigm (Crotty, 2013).

### **4.2.2 The constructionist paradigm**

Qualitative research provides a means of accessing specific explanations, lived experiences (Peters 2010) and human variation, inductively (Thorne, 2018). In healthcare, qualitative research often involves the use of interviews, focus groups, analysis of documents, first person narrative accounts, or observations (Peters, 2010). The selection of methods commonly relates to the methodological approach used (Ormston et al., 2014). A dominant epistemology underpinning qualitative research is constructionism (Crotty, 2013). The assumption made in constructionist research is that truth and meaning are constructed and not discovered: the researcher is central to the construction of this type of knowledge, which is in direct contrast to the epistemological assumptions made by objectivists (Crotty, 2013). Constructionism underpins a range of theoretical perspectives, including interpretative and critical social theory paradigms, and qualitative methodologies such as grounded theory, ethnography, and phenomenology (Taylor and Francis 2013).

### **4.2.3 The pragmatist paradigm**

Pragmatism was first introduced to philosophy during a lecture given by William James at the University of California, towards the end of the 19<sup>th</sup> century (Bacon, 2012; McDermid, 2018). Although Charles Sanders Peirce is credited as the founder of pragmatism and what it entails, situating it within philosophical thinking, discussion relating to pragmatism can be traced back to the work of Descartes and Aristotle (Bacon, 2012). Pragmatism is a diverse philosophical tradition, and major contributions to pragmatism have been made by several philosophers, including John Dewey, Richard Rorty, and Cornel West (Hall, 2013). Pragmatism has become recognised as the third research paradigm (Denscombe, 2008; Johnson and Onwuegbuzie, 2004).

Pragmatists reject the traditional choice, which is made between constructionism and objectivism (Johnson and Onwuegbuzie, 2004; Borglin, 2015). Pragmatism offers a rich tradition of thought and recognises that there are several ways to know and that there are multiple truths (Nowell, 2015). Knowledge is shaped by objective and subjective values, and both theory generation and theory verification are possible (Borglin, 2012). The philosophy of pragmatism has been used widely to underpin applied health research (Pope and Mays 2006). The emphasis of pragmatic health research is on finding the methods, techniques, and procedures, which fit the research question (Creswell 2015). Pragmatic thinking is problem centred, grounded in real world practices, and focuses on the consequences of actions (Creswell, 2014).

### **4.2.4 Research paradigms and this PhD thesis**

This thesis is grounded in the pragmatic tradition. Pragmatism has informed the tradition of methodological pluralism (Creswell, 2014) and is linked with mixed methods research (Hall, 2013; Borglin, 2012). The combination of qualitative and quantitative research has been considered to offer a more inclusive view and

more data about a problem than only the quantitative or the qualitative perspective (Creswell, 2015; Doyle et al., 2009). The use of qualitative and quantitative data in a single study has been considered to capitalise on the strengths of both approaches and reduce the characteristic weaknesses (Johnson and Onwuegbuzie, 2004). This thesis draws on the benefits of quantitative and qualitative research to explain how general hospitals respond to patients with a diagnosis of personality disorder who are distressed. Mixed methods approaches are discussed in section 4.3

## **4.3 The mixed methods approach**

### **4.3.1 Defining mixed methods**

Mixed methods research has been considered a diffuse concept, which is a strength of the approach, accommodating flexibility, permeability, and complexity (Denscombe, 2008). Mixed methods is considered variously as a research method for collecting, analysing and interpreting qualitative and quantitative data; a methodology which underpins the research process and a philosophical stance undertaken by the researcher (Creswell and Tashakkori, 2007). Influential authors in the field of mixed methods research, (Creswell and Plano - Clark, 2017) have provided the following definition of mixed methods:

*'In mixed methods the researcher collects and analyses both qualitative and quantitative data rigorously in response to research questions and hypotheses, integrates (or mixes or combines) the two forms of data and their results, organises these procedures into specific research designs that provide the logic and procedures for conducting the study, and frames these procedures within theory and philosophy' (Creswell and Plano - Clark, 2017, p.5).*

### **4.3.2 The use of mixed methods in health services research**

Mixed methods research has been widely used in health services research, i.e., research into the acceptability, delivery, effectiveness, economics, and organisation of health care (Lohr and Steinwachs, 2002) for around 25 years (Borglin, 2015). Mixed methods has been a good fit for healthcare research because the approach which provides the 'best evidence' can be used (Johnson and Onwuegbuzie, 2004). Mixed methods research places importance on the research objectives and question and the methods that fit best can be used (Creswell and Plano - Clark, 2017; Borglin, 2015). Mixed methods research designs have successfully been used to investigate areas of new or poorly demarcated practice and have utility when neither quantitative and qualitative methods are considered sufficient to meet the aims and objectives of the research (Creswell and Plano - Clark, 2011).

### **4.3.3 Types and purpose of mixed method research**

Mixed methods research has been considered to offer a more comprehensive understanding of the complexities encountered in clinical practice (Johnson and Onwuegbuzie, 2004). The different purposes of mixing methods have been described by (Parahoo, 2006, p.89):

1. To develop and enhance the validity of scales, questionnaires and other instruments.
2. To develop, implement and evaluate complex interventions.
3. To further explore or test the findings of one method.
4. To study different aspects of the same topic.
5. To explore complex phenomena from a different perspective.
6. To confirm or cross validate data.

#### **4.3.4 Core mixed method designs**

Design typologies have been considered to enhance quality and rigour, providing a framework and a logical approach to the implementation of mixed methods research (Creswell and Plano - Clark, 2017). Although the use of mixed methods research typologies has been criticised, with some authors arguing for more tailored decision making about research design (Bazeley, 2009; Guest, 2012), the selection of a core design (Table 9) has been recommended to new mixed method researchers (Creswell and Plano - Clark, 2017). The core designs have been rationalised over time; at present, there are three core mixed method designs, as indicated in the far right hand column of Table 9. The three core designs are discussed in more detail in the next section (4.3.4.1 - 4.3.4.3). The mixed method research design may be fixed during the planning stages, but an advantage of this approach is that emergent designs can be used to overcome research issues (Plano-Clark and Ivankova, 2016; Creswell and Plano - Clark, 2017).

Intentional space

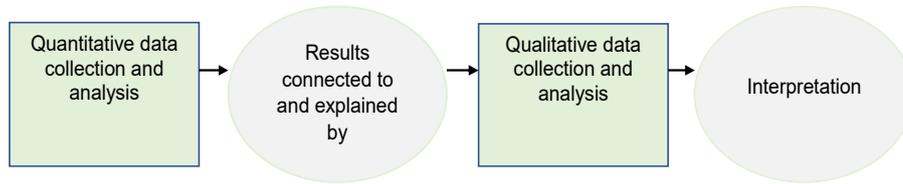
**Table 9 Changing typologies in Creswell and Plano - Clark (2017, p59)**

Creswell et al. (2003)	(Creswell and Plano-Clark, 2007)	Creswell and Plano - Clark (2011)	Creswell and Plano - Clark (2017)
Sequential explanatory	Explanatory design	Explanatory sequential design	Explanatory sequential design
Sequential exploratory	Exploratory design	Exploratory sequential design	Exploratory sequential design
Sequential transformative		Transformative design	
Concurrent triangulation	Triangulation design	Convergent parallel design	Convergent design
Concurrent nested	Embedded design	Embedded design	
Concurrent transformative		Transformative design	
		Multiphase design	

#### **4.3.4.1 The explanatory sequential mixed methods design**

The explanatory sequential design uses qualitative data to explain the quantitative findings (Figure 3). The researcher designs and implements an instrument in order to collect quantitative data, e.g., conducts a survey and the qualitative strand is used to explain the quantitative results (Creswell and Plano - Clark, 2017; Ivankova et al., 2006). Examples of the use of the explanatory sequential design in health have included: to explore ‘*Collaboration amongst clinical nursing leadership teams*’ (Lamont et al., 2015) and to evaluate ‘*Case management in primary care for frequent users of health care services*’ (Hudon et al., 2018).

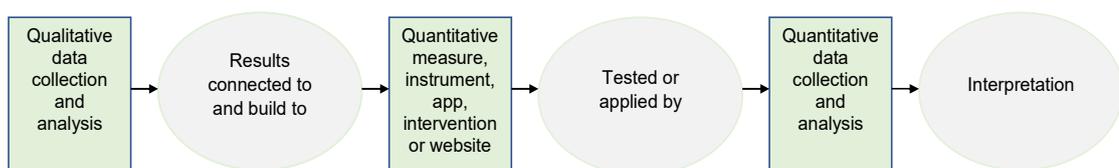
**Figure 3 Mixed methods explanatory sequential design** in Creswell and Plano - Clark (2017 p.66)



#### 4.3.4.2 The exploratory sequential mixed methods design

The exploratory sequential design uses quantitative data to explore qualitative findings (Figure 4). The researcher designs and implements a quantitative strand based on the findings of the qualitative strand (Fetters et al., 2013). The qualitative strand is used to develop items such as instruments, measures, interventions, apps, and websites, and these are tested, in a quantitative strand and interpreted along with the qualitative strand (Creswell and Plano - Clark, 2017). Examples of the use of the exploratory sequential design in health have included: to explore '*Perspectives in safety in home delivered health care*' (Jones, 2016) and the '*Provision of information about newborn screening antenatally*' (Ulph et al., 2017)

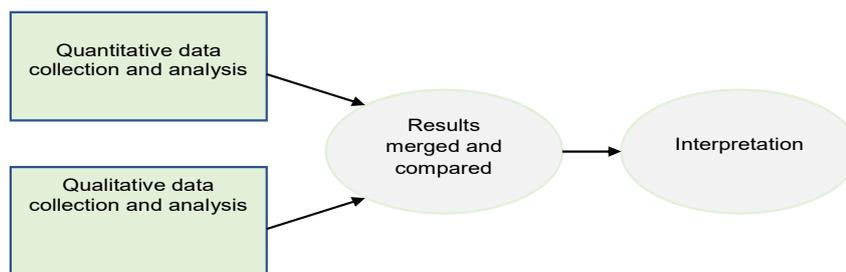
**Figure 4 Mixed methods exploratory sequential design** in Creswell and Plano - Clark (2017 p.66)



#### 4.3.4.3 The convergent mixed methods design

The convergent design uses quantitative and qualitative data to explore the same phenomenon (Figure 5) to: exploit the characteristic strengths of qualitative and quantitative research, gain a complete understanding of the research problem, and to compare and contrast the data (Greene et al., 1989). Data is commonly collected simultaneously (Fetters et al., 2013). Examples of the use of a convergent design in health have included: to explore '*Partners perspectives on participation in heart failure home care*' (Näsström et al., 2017) and to '*Evaluate a one-day mental health wellness intervention*' (Doyle et al., 2017).

**Figure 5 Mixed methods convergent design** in Creswell and Plano - Clark (2017 p.66)



#### 4.3.5 Complex applications of core mixed method designs

Core designs may be adapted as needed to fit the research question (Creswell and Plano - Clark, 2017). The core mixed method designs may be intersected, i.e., embedded, overlapped, or used in addition, to a range of study designs, methodologies and theories (Creswell and Plano - Clark, 2017). An example of an exploratory sequential design, which formed part of a larger programme of research, was Ulph et al. (2017), cited in section 3.3.6. Ulph et al. (2017) conducted six studies, combining multiple methods, including a realist review, qualitative interviews, a survey, observations, economic analysis, and focus groups. The authors reported that the mixed method design was pivotal to

advancing the field because the research design provided data, which captured the breadth and depth of the complex research problem.

#### **4.3.6 Priority in mixed methods research**

A notational system (Morse, 1991) has been used to describe the study design in mixed methods research. Brackets have been used to signify embedded methods, i.e., a qualitative component within a quantitative component (Creswell and Plano - Clark, 2017). Capital letters are used to indicate the priority, which is given to either qualitative and quantitative stands and the lower case is used to indicate the secondary methods. It is possible for equal priority to be given to both the qualitative and quantitative strands and in these circumstances, both strands will be capitalised. However, transparency about the purpose and intent of the data collection and the reason for integrating qualitative and quantitative data should be the focus, rather than the timing and priority of the qualitative and quantitative strands (Creswell and Plano - Clark, 2017).

#### **4.3.7 Integration in mixed methods research**

The term integration has been used to describe the interface between the qualitative and quantitative research (Creswell and Plano - Clark, 2017). Integration has also been known as 'mixing' or combining the data (Creswell and Plano - Clark, 2017). The stage of integration describes the point in which the quantitative and qualitative methods are merged, in order to best illuminate the findings (Bazeley, 2009). Integration has commonly been undertaken at the interpretation or the analysis phase, but depending on the aims and objectives of the research, integration may occur during the data collection, analysis or interpretation stages (Bazeley, 2009).

### **4.3.8 The use of a theoretical lens in mixed method research**

The theoretical lens informs thinking both informally and formally about the study design, the phenomenon to be studied, and the findings (Creswell, 2014). The mixed method core designs may be used with any theoretical lens and the theoretical lens may be explicit or implicit. Health services researchers have often taken an implicit position to undertaking mixed methods research; the research is said to be pragmatic, grounded in what can be done and in providing realistic solutions (Borglin, 2015). As discussed in section 4.2.3, the explicit theoretical stance, which has often been used in mixed methods research, is pragmatism (Turnbull and Lathlean, 2015).

### **4.3.9 The mixed methods design and this PhD thesis**

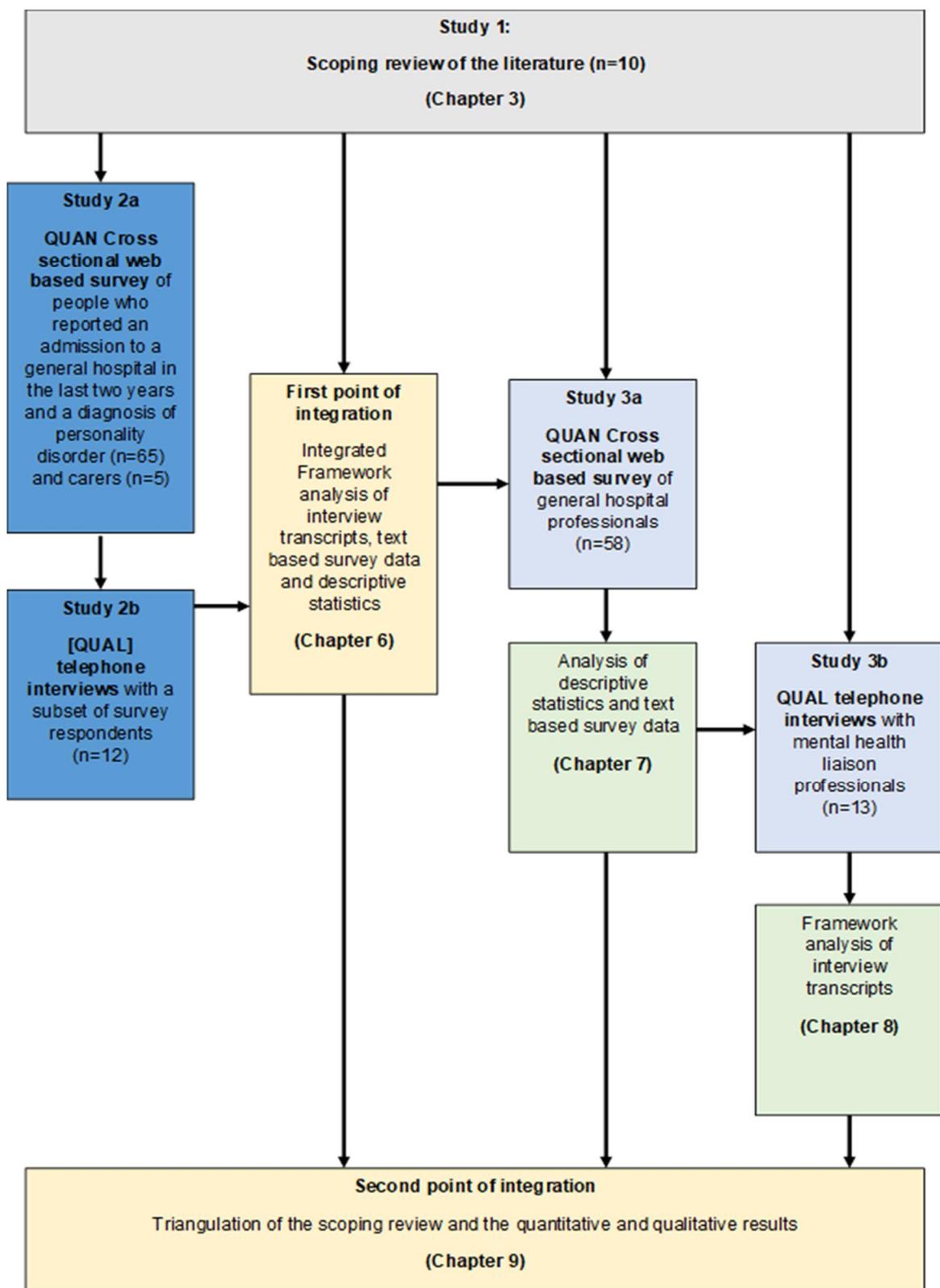
A mixed methods approach was selected because it has recognised utility in eliciting the views and perspectives of marginalised populations (O'Cathain et al., 2007). The use of a mixed methods explanatory sequential research design (Figure 6) enabled breadth and depth in the views sought. The mixed methods explanatory sequential design offered a means of exploring complex phenomenon from different perspectives, combining methods, and confirming the data (Parahoo, 2006). The Creswell and Plano - Clark (2017) definition of mixed methods was developed to express the design and conduct of mixed methods research in the context of the methods, design, and philosophical position, and will be used as a working definition in this PhD thesis.

In this research, an explanatory sequential design was intersected with a scoping review of the literature (Study 1), and a quantitative method with an embedded qualitative method (Studies 2a and 2b). Equal priority was given to the qualitative and quantitative methods. There were two points of integration: The first being the integrated analysis of studies 2a and 2b. The second stage of integration was at the end of the sequence of studies in order to connect and interpret the

findings (Figure 6). This study was conducted using an emergent design following research issues relating to the recruitment of participants (discussed in section 4.9). While there has been some suggestion that research projects require careful planning to enable robust conclusions to be drawn (Schoonenboom and Johnson, 2017), emergent designs have commonly been used in real world research (Creswell, 2015).

Intentional space

**Figure 6 The study design and structure of the thesis**



## **4.4 Quality and rigour**

### **4.4.1 Rigour in quantitative and qualitative research**

Rigour has been considered to be the extent to which the researcher takes steps to enhance research quality (Heale and Twycross, 2015). In quantitative research, there has been a consensus that validity and reliability form the basis of rigorous scientific procedures (Curry and Nunez - Smith, 2015). Reliability, referring to the consistency of measurements, and validity, referring to the extent to which, a study measures what it claims to (Lacey, 2010) has been explained in more detail in Table 10. The reliability and validity of a study underpins the integrity of the research methods, and the generalisability of the conclusions reached (Noble and Smith, 2015). Good quality, quantitative studies, provide evidence of how reliability and validity have been addressed (Heale and Twycross, 2015).

The parallel term of 'trustworthiness' (Lincoln and Guba, 1985) has been used to describe rigour in qualitative research (Taylor, 2013; Lacey, 2010). Trustworthiness provides an alternative concept (Table 10) for researchers opposed to using the positivist concepts of rigour in qualitative research (Horsburgh, 2003; Golafshani, 2003). Qualitative research may be underpinned by a distinctly different philosophical position or purpose to quantitative research (Noble and Smith, 2015). Trustworthiness may be preferred because it is considered to be free from the underlying assumptions, which relate to objectivity (Holloway and Wheeler, 2010). However, in qualitative research, methodological origins are diverse and epistemological, and ontological assumptions are not necessarily shared (Rolfe, 2006); the criteria for trustworthiness and the scope for generalisability or transferability, relates to the methodological approach used (Taylor, 2013).

The practices and terminology used to demonstrate quality and rigour have been much less clear in qualitative research and little consensus has been reached on how to address research quality (Pandey and Patnaik, 2014; Curry and Nunez - Smith, 2015). Some qualitative researchers maintain that the tenets of reliability and validity are central to producing generalisable qualitative research (Lewis et al., 2014). Although validity and reliability have different operationalisation requirements across the research paradigms (Lewis et al., 2014) in some qualitative methodologies, the broad principles of validity and reliability have been considered to have comparable utility (Rolfe, 2006; Long and Johnson, 2000; Noble and Smith, 2015). The nurse scholar has to appreciate this debate and make judicious decisions about the terminology and criteria used to determine research quality, in the context of their research practice (Sandelowski, 1993).

Intentional space

**Table 10 Rigour and quality in quantitative and qualitative research** adapted from Curry and Nunez - Smith (2015)

Quantitative	Qualitative
<p><b>Internal validity</b></p> <p>The degree to which the findings represent a true reflection of a causal relationship between the variables of interest in the population under study.</p> <p><b>Strategies</b></p> <p>Addressing and minimising bias and confounding. Randomisation. Identifying and controlling for confounding variables. Using a control in intervention groups. Developing instruments via systematic processes.</p>	<p><b>Credibility</b></p> <p>The degree to which the findings plausibly explain the phenomenon of interest or cohere with what is known.</p> <p><b>Strategies</b></p> <p>Triangulation, theoretical saturation, member checking, tactics to encourage truthfulness amongst participants, negative case analysis.</p>
<p><b>External validity (Generalisability)</b></p> <p>The degree to which observations, measures or results can be replicated.</p> <p><b>Strategies</b></p> <p>Random selection, clarity of inclusion and exclusion criteria and rationale, use of validated instruments, assessment of non-respondent bias, descriptions of statistical procedures including treatment of missing data and confidence intervals.</p>	<p><b>Transferability</b></p> <p>The degree to which findings or research protocols can be transferred to other settings, contexts or populations, as determined by the reader.</p> <p><b>Strategies</b></p> <p>An explicit statement of research aims, the rationale for methods, and supporting citations. A comprehensive description of the study, including contextual details, the procedures for sampling, data collection, and analysis, including transcription and coding.</p>
<p><b>Reliability</b></p> <p>The degree to which observations, measures or results can be replicated.</p> <p><b>Strategies</b></p> <p>Ensuring the consistency, stability, and replicability of observations or measures. Multiple measures of the same construct, testing and piloting of instruments, training data collectors, data cleaning, and using statistical procedures to adjust for measurement errors.</p>	<p><b>Dependability</b></p> <p>The degree to which the researcher accounts for and describes the changing circumstances and contexts during the study.</p> <p><b>Strategies</b></p> <p>A clear exposition of the research process and context.</p>
<p><b>Objectivity</b></p> <p>The degree to which researchers can remain distanced from the study so that the findings reflect the nature of the study rather than researcher, bias, motivation or interest.</p> <p><b>Strategies</b></p> <p>A detailed description of the design and methods decisions. Maximum transparency.</p>	<p><b>Confirmability</b></p> <p>The degree to which the findings of a study are shaped by the respondents and not researcher bias, motivation or interest.</p> <p><b>Strategies</b></p> <p>External audit, bracketing, reflexivity.</p>

#### 4.4.2 Rigour in mixed methods research

Mixed methods research, which has been designed to integrate quantitative and qualitative methods to produce a ‘whole greater than the sum of the parts’ (Barbour, 1999 p.40), has additional complexity with regards to ensuring rigour and quality (Curry and Nunez - Smith, 2015). Although quality in the quantitative and qualitative strands may be addressed separately, in accordance with the method used (Creswell and Plano - Clark, 2017), quality may also be addressed using criteria, analogous to both the qualitative and quantitative strands (Curry and Nunez - Smith, 2015; Mays and Pope, 2000). All decisions about quality must be made in the context of the integration between the qualitative and quantitative approaches (O’Cathain et al., 2008; Curry and Nunez - Smith, 2015). Use of the good reporting of a mixed method study (GRAMMS) framework (Table 11, O’Cathain et al., 2008) has been recommended, in order to demonstrate rigour in mixed method studies (Equator Network, 2013).

**Table 11 Good reporting of a mixed methods study (GRAMMS) in O’Cathain et al. (2008 p.97)**

<b>Good reporting of a mixed method study (GRAMMS)</b>	<b>Corresponding thesis section</b>
Describe the justification for using a mixed methods approach to the research question.	Chapter 4 Methodology 4.3.9
Describe the design in terms of the purpose, priority, and sequence of methods.	Chapter 4 Methodology 4.3.9
Describe each method in terms of sampling, data collection, and analysis.	Chapter 4 Methodology 4.5-4.7 and Chapter 5 Methods 5.4-5.7
Describe where integration has occurred, how it has occurred, and who has participated in it.	Chapter 4 Methodology 4.3.9 and Chapter 5 Methods 5.8
Describe any limitation of one method associated with the presence of the other method.	Chapter 4 Methodology 4.5-4.7
Describe any insights gained from mixing or integrating methods.	Chapter 9 Integration

### **4.4.3 Integration using triangulation**

In mixed methods research, the guiding principle has been that the integration of the quantitative and qualitative strands should produce a synergistic effect and without robust integration, the knowledge generated is limited, to that produced by the component studies (O' Cathain et al., 2010; Moran-Ellis et al., 2006). Integration techniques, which have been recommended in mixed methods research to enhance knowledge include: triangulation, following a thread, and the use of a mixed methods matrix (O' Cathain et al., 2010). Integration of data by following a thread involves identifying themes and analytic questions, which are followed up across multiple datasets (Moran-Ellis et al., 2006). Mixed methods matrices have been used to examine cases rather than variables or themes, with the matrices used to support cross case analyses (O' Cathain et al., 2010). In mixed methods research, triangulation describes the procedures for exploring convergence, complementarity, and dissonance across the qualitative and quantitative strands (O' Cathain et al., 2010).

#### **4.4.3.1 Triangulation**

The term triangulation can also be used more broadly to describe the combination of two or more theories, sets of data, methods, researchers (Denzin, 1989), or methods of analysis in the same study (Kimchi et al., 1991). Triangulation has attracted interest amongst nurse researchers because it supports the exploration of complex healthcare issues (Farmer et al., 2006). There are five distinct types of triangulation, which have been described in the literature; data triangulation, investigator or researcher triangulation, theoretical triangulation, methodological triangulation (Denzin, 1989) and analytic triangulation (Kimchi et al., 1991). The five types of triangulation are presented in Table 12. The use of more than one type of triangulation in the same study has been described as multiple triangulation (Denzin, 2009). Multiple triangulation has been used to enhance the rigour, confirmation, and completeness of research (Halcomb and Andrew, 2005; Breitmayer et al., 1993).

**Table 12 Types of triangulation** Denzin (1989) and Kimchi et al. (1991) in Baker (2007 p.44)

Types of triangulation	Subtypes			
Data triangulation	Time (same thing different times)	Space (same thing different site)	Person (different levels of person)	
			Individuals	Groups
Investigator/researcher	Multiple researchers involved all with differing knowledge and experiences			
Theoretical/theory	Differing theoretical backgrounds			
Methodological	Two or more research methods at the time of data collection or analysis	Within method - two or more research methods at the time of data collection or analysis from the same paradigm	Across (or between) method. Two or more research traditions, i.e. Qualitative and quantitative	
Analysis	Two or more methods of analysis of the same data to validate			
Multiple triangulation	The use of two or more of the above			

#### 4.4.3.2 The strengths and limitations of triangulation

Researchers need to demonstrate a clear purpose for triangulating data; explicit consideration needs to be given to the underlying paradigm; the philosophical approach; the research questions and the methods, and the sampling strategy (Thurmond, 2001; Halcomb and Andrew, 2005). Triangulation has attracted criticism when researchers have omitted to discuss the reason and procedures for triangulating data and have given limited consideration, to the strengths and limitations of the approach (Farmer et al., 2006). The key strengths and weaknesses of triangulated research have been described in Table 13 (Redfern and Norman, 1994 p.51-52)

**Table 13 The strengths and limitations of triangulation in Redfern and Norman (1994 p.51-52)**

<b>Strengths</b>	<b>Limitations</b>
Overcomes the bias of a single method, single observer, single theory studies.	No guarantee of internal and external validity.
Increases confidence in the results.	May compound sources of error.
Allows the development and validation of instruments and methods (Confirmation).	Methods selected may not be the right ones.
Provides an understanding of the domain (Completeness).	Unit of analysis might not apply to all methods.
Ideal for complex social issues.	Cannot compensate for researcher bias.
Overcomes the elite bias of naturalistic research.	Expensive.
Overcomes the holistic fallacy of naturalistic research.	No use with the wrong question.
Allows divergent results to enrich explanation.	Replication is difficult.

#### **4.4.4 Quality and rigour and this PhD thesis**

This research into how general hospitals respond to patients diagnosed with personality disorder who are distressed has required the collection and integration of data from several strands: 1) scoping review of the literature 2a and 2b) QUAN web based survey and [QUAL] telephone interviews with patients; 3a) QUAN web based survey of general hospital professionals; and 3b) QUAL telephone interviews with mental health liaison professionals. In this PhD thesis, the qualitative and quantitative stands have been designed and implemented with due consideration of the key methodological assumptions, principles, and practices underpinning each strand (Curry and Nunez - Smith, 2015). This research has been reported in accordance with GRAMMS (O'Cathain et al., 2008) and provides a transparent and defensible account of the decisions taken in order to demonstrate quality and rigour.

In accordance with GRAMMS, the justification for using a mixed methods approach has been summarised in 4.3.9 along with the purpose, priority, and sequence of the research. The sequencing and integration are illustrated in Figure 6. Integration has been undertaken using mixed methods triangulation in order to produce a synergistic effect between the component studies (O' Cathain et al., 2010). Triangulation has also been used in this thesis in the broader sense to explore complementarity, convergence, and dissonance and was considered to provide a logical process to facilitate quality and rigour. The research will use methodological triangulation, data triangulation, analysis triangulation, and investigator triangulation (multiple triangulation). The next section discusses the research methods in terms of sampling, data collection, and analysis, and the limitations associated with each method (O'Cathain et al., 2008).

## **4.5 Rationale for working methods**

This section describes the rationale for the working methods selected. The methods have been chosen to fit with the methodological approach and to cohere with the research aims and objectives.

### **4.5.1 Recruiting research participants in the general hospital**

Study one, a scoping review of personality disorder, violence, and the barriers and enablers of general hospital care, demonstrated that people with a diagnosis of personality disorder have to date, not been recruited to take part in a study about their experiences of distress in general hospital settings. Study one also highlighted challenges and methodological constraints of conducting research with this population in a general hospital setting. The barriers that were considered to impede the recruitment of patients with a diagnosis of personality disorder to research about general hospital care have included precarious use and acceptance of the diagnosis and preconceived ideas about the suitability of

people with a diagnosis of personality disorder to take part in the research. Recruiting participants via a gatekeeper in a general hospital setting was deemed prohibitive to the successful completion of this research in the time frame available and this is discussed further in section 4.9.

#### **4.5.2 Using social media to recruit 'hard to reach' research participants**

Social media offers a profile on a website or application, on which users can create and share content, or participate in social networking (Oxford Dictionaries, 2018). The practice of using social media to conduct research has gained popularity and credibility (Batterham, 2014). Social media offers a rich source of naturally occurring data (Brooks and Churchill, 2010) and provides a cost effective (Batterham, 2014; O'Connor et al., 2014; Park and Calamaro, 2013), and useful platform for accessing research participants (Lohse, 2013; Brooks and Churchill, 2010). However, disadvantages which have been reported include a lack of representation in users of social media and an exclusively younger demographic (Frandsen et al., 2016). However, in 2017, 90% of UK households were reported to have internet access (Office for National Statistics, 2017), with three in four (76%) internet users having a social media profile on platforms such as Facebook, YouTube, Snapchat, and Twitter (Ofcom, 2017).

Facebook has become the most popular social media platform (Ofcom, 2017). Facebook has a considerable reach, which extends across diverse geographical locations (Gu et al., 2016) and socioeconomic groups (Ofcom, 2017). In March 2018, Facebook reported an estimated 1.45 billion people worldwide were active on the Facebook platform, daily (Facebook, 2018). The average Facebook user has approximately 229 'Facebook friends' (Hampton et al., 2011) and subject to the privacy settings of the user, Facebook friends and friends of friends can see user posted content, and a range of other interactions with the Facebook platform. Trust in Facebook has been high, in 2007, a survey of Facebook users found that 79% of respondents considered the platform was committed to

protecting their personal information; although, media reporting suggests confidence in the site reduced following a widely reported data breach (Kuchler, 2018). Nevertheless, Facebook groups and online communities relating to specific interests or causes have become well established (Brickman Bhutta, 2012) and Facebook<sup>6</sup> has been flagged as a useful tool to access a range of potential research participants (Park and Calamaro, 2013; Gu et al., 2016).

Twitter has become the most successful microblogging platform, with an estimated 336 million monthly active users (Statista, 2018). Twitter use has been reported to be higher amongst adults in the AB <sup>7</sup> socioeconomic groups (Ofcom, 2017). Twitter has most commonly been used in combination with other social media platforms (Ofcom, 2017). Twitter operates by dispersing content, which has been posted by users, across extended user networks (Gu et al., 2016). The reach of posts on the Twitter platform has been considered to follow established communication theories (Katz, 1957; Katz and Lazarsfeld, 1955), with posted content, being picked up and disseminated by 'opinion leaders' in the field (Gu et al., 2016), i.e., individuals with a higher number of links, interactions in a particular network, and a higher number of followers, retweets and mentions (Borge Bravo and Esteve Del Valle, 2017).

The UK based Mumsnet site attracts 12 million unique visitors each month and 120 million pages are viewed on the site monthly (Mumsnet, 2018a). Mumsnet has predominantly been used by women seeking parenting advice, entertainment, and to connect with other women, and has become known as a forum for strong debate and opinions (Pedersen and Smithson, 2013). Mumsnet has been used to conduct research targeting women, in areas such as postnatal healthcare (Mumsnet, 2018b n=1200) and postnatal depression (Mumsnet, 2015 n=631). Mumsnet offer a freely available, not for profit survey board, which

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<sup>6</sup> The implications of using Facebook to conduct this PhD research has been described in more detail in Chapter 5.

<sup>7</sup> The high or intermediate, managerial, administrative or professional groups IPOS Media CT. 2009. *Social grade, a classification tool* [Online]. [Accessed 16/07/2018]. Available from: [https://www.ipsos.com/sites/default/files/publication/6800-03/MediaCT\\_thoughtpiece\\_Social\\_Grade\\_July09\\_V3\\_WEB.pdf](https://www.ipsos.com/sites/default/files/publication/6800-03/MediaCT_thoughtpiece_Social_Grade_July09_V3_WEB.pdf).

seems to be used with regularity, although no supporting data were identifiable on the Mumsnet site.

Social media has been successfully used to recruit participants, in several published studies related to a range of mental disorders, including: screening for suicide risk (Batterham, 2014), perinatal mental health (Haga et al., 2013; Maloni et al., 2013), bipolar disorder (King et al., 2014), depression (Morgan et al., 2013; Youn et al., 2013) and psychosis (Thornton et al., 2013). The internet has been considered to provide an innovative means to access traditionally hard to reach populations (O'Connor et al., 2014; Haigh and Jones, 2005). A systematic review on reaching the hard to reach in health and social care research recommended more innovative strategies should be used in health and social care research in order to maximise representation of marginalised groups (Bonevski et al., 2014). There appears to have been no previous study in the English language, which has used social media to recruit research participants with a diagnosis of personality disorder.

#### **4.5.3 Views about using social media as a tool for research**

In a qualitative study of 34 members of the public, Beninger et al. (2014) identified three overarching themes relating to attitudes to social media research: acceptance, ambivalence, and scepticism. Some members of the public felt that the use of social media to conduct research was less valid and less reliable than more conventional research methods and that there was a risk that people portrayed themselves differently online, views may be impulsive, exaggerated, or lack context (Beninger et al., 2014). However, while the authors make a clear distinction between the use of social media to access naturally occurring social media data and the use of social media as a recruitment tool, it was clear from the report that the participants in Beninger et al. (2014) did not understand the difference between the two data collection approaches. More peer reviewed research is needed about the acceptability of social media as a research tool.

#### **4.5.4 Social media recruitment and this PhD thesis**

While there are methodological and practical disadvantages to recruiting research participants via social media, there are benefits, and the challenges of online recruitment have been considered comparable to more traditional research methods (Batterham, 2014). Social media profiles and accounts relating to the personality disorder diagnosis are visible and active, on a range of social platforms. Accessing the views and perspectives of people who have a diagnosis of personality disorder has been considered central to this research. Social media was deemed to be the most pragmatic means to access people with lived experience in the context of this PhD research.

#### **4.6 Quantitative strands 2a and 3a: The use of web based cross sectional surveys**

Surveys provide a systematic method of collecting data from a sample of the population to generate quantitative description (Groves et al., 2009). Survey methods answer research questions relating to 'who' or 'what' (Gillham, 2008).

##### **4.6.1 The use of a web based cross sectional survey design**

Surveys are typically observational and have been used to undertake descriptive research into the frequency and characteristics of specific populations (Sue and Ritter, 2012). Surveys have been used to make inferences about specific populations (Gillham, 2008) and to collect preliminary data, in order to develop further programmes of research (Sue and Ritter, 2012). Surveys can be cross sectional, undertaken at a single point or over a short period, or used over a longer period to observe change, using repeated cross sectional or longitudinal designs (Caruana et al., 2015). The longitudinal design enables the collection of rich and sequenced information because the same research participants are

followed up (Callegaro et al., 2015). Although the longitudinal design has been considered useful for identifying new relationships between events and exposures, the longitudinal design has been considered resource intensive; participants are required to remain involved for a prolonged period of time, increasing the risk of attrition (Caruana et al., 2015).

Despite society having become better connected, research participants have become more challenging to reach using conventional survey methods, and the use of web based surveys has burgeoned (De Leeuw, 2013; Martinsson et al., 2013). Historically, surveys were administered by an interviewer in person or over the telephone or posted out, and then completed, and returned by the respondent (Callegaro et al., 2015). However, web based surveys can be undertaken quickly and economically, compared to the more traditional methods of survey data collection (De Leeuw, 2012). The methodological issues relating to coverage, sampling, response rate, and measurement can be addressed at the design stage (De Leeuw, 2012). Web based surveys have been shown to be effective in supporting the disclosure of sensitive information (Beninger et al., 2014; De Leeuw, 2012; Braunsberger et al., 2007; Callegaro et al., 2015).

#### **4.6.2 The use of a web based cross sectional design and this PhD thesis**

Recruiting research participants who have experienced invalidation from society has historically been challenging (Sadler et al., 2010). The use of a web based cross sectional survey was considered to provide an economical means to access primary data covering a broad geographical area. Insufficient resources were available as part of this PhD research to consider undertaking either a repeated cross sectional design or a longitudinal survey design. Although the cross sectional design has been criticised for providing a 'snapshot' (Caruana et al., 2015), the mixed methods research design and the integration of the quantitative and qualitative methods to produce a 'whole greater than the sum of the parts' (Barbour, 1999 p.40) was considered to mitigate the critique. The use

of the mixed methods design (4.3.9) was considered to support multiple triangulation (4.4.4) and enhance the quality and rigour of this PhD thesis.

The University of Leeds provides access to the Bristol Online Survey platform (BOS). The use of a web based survey via BOS has provided an anonymous platform for patients and workers, to provide feedback about their experiences, and the resources that have been available to them. It was anticipated that healthcare workers would find gaps in their practice uncomfortable to disclose and that the use of a web based survey would support disclosure. The next sections discuss the limitations of web based surveys in relation to the key quality characteristics: coverage, response, measurement (4.6.2.1–4.6.2.3), and sampling (4.6.3 & 4.6.4) (De Leeuw, 2012).

#### **4.6.2.1 Survey coverage and this PhD thesis**

A limitation of research online is that it can only include people who have access to the internet, use the selected platforms, and are willing and able to take part (De Leeuw, 2013). One in ten households in the UK is reported not to have access to the internet (Office for National Statistics, 2017). However, the same issues relating to survey coverage online are applicable to survey research, which has been conducted offline (Haigh and Jones, 2005; Batterham, 2014). In the UK, internet use and the use of social technology is extensive, 90% of households have access to the internet (Office for National Statistics, 2017) and three in four internet users have at least one social profile (Ofcom, 2017). Such is the extent of the use of social media that the profile of Facebook users is now considered to be representative of the population of Great Britain (Ipos Connect, 2018). The use of three social media platforms was deemed to provide sufficient coverage to meet the objectives of this study.

#### **4.6.2.2 Survey response and this PhD thesis**

Non-response impacts on the quality of the data and falls into three broad categories; failure to invite eligible participants to respond, refusal to participate, and the inability of the participant to provide the information (Groves et al., 2009). A number of decisions were taken during the design and conduct of the study to reduce the risk of non-response error, including: inviting participants across diverse social media platforms (Callegaro et al., 2015), ensuring a sufficient period of data collection, maximising attempts to reach respondents, ensuring the survey design did not burden participants, and offering an alternative to completing the survey (Groves et al., 2009). A pragmatic decision was taken not to offer any incentive. More detail is provided in Chapter Five, Methods.

#### **4.6.2.3 Measurement and this PhD thesis**

The use of a mixed methods explanatory sequential design ensured that survey measurement was as accurate as possible. To enhance content and face validity, the survey questions were developed sequentially. The patient survey 2a was informed by the scoping review (Study 1), and the general hospital professional survey 3a was informed by studies 1, 2a, and 2b. The survey questions were developed to correspond with the competencies outlined in the UK personality disorder capabilities framework (National Institute for Mental Health in England, 2003). Also, the patient survey 2a incorporated a nationally recognised and recommended patient experience measure, which was designed for use in mental health liaison services to assess the quality of care in general hospitals (NICE and NHS England, 2016).

### **4.6.3 The use of nonprobability (snowball) sampling in quantitative research**

Web surveys use probability and nonprobability sampling. As probability sampling facilitates statistical inference, results from surveys that use probability sampling are considered more readily generalisable (Callegaro et al., 2015). However, there are limited possibilities for undertaking probability sampling in real world web surveys because the required sampling frame is commonly unavailable, inaccessible for practical and ethical reasons, or the identified respondents may not be willing to participate (Gillham, 2008). In nonprobability surveys, the recruitment process is used to build the sample, and convenience sampling strategies are often used to recruit respondents, including invitations embedded in web pages, banner advertising, pop ups, and paid advertising. Quota sampling can be used to balance certain attributes of nonprobability samples such as gender or age in order to enhance representation (Groves et al., 2009). However, pragmatic decisions regarding sampling methods often need to be taken in accordance with the research question, study population, culture, and context of the study (Callegaro et al., 2015).

Chapter Two described a background of difficulties faced by people who have been diagnosed with a personality disorder. Snowball sampling has been shown to provide a useful approach for reaching specifically defined, highly targeted, and 'hard to reach populations' (Browne, 2005; Ritchie et al., 2014; Sue and Ritter, 2012; Sadler et al., 2010). Snowball sampling makes use of natural social networks and connections (Ritchie et al., 2014; Browne, 2005). Snowball sampling has been linked to improved cultural competence and provides a particularly useful sampling technique to engender trust amongst potential participants, improving the likelihood that people feel able to engage with the research (Sadler et al., 2010). The use of Snowball sampling via a web based survey enables the sample to be successfully located online and built up and has been considered to be a useful strategy to undertake research with 'hard to reach' populations (Callegaro et al., 2015; Groves et al., 2009).

#### **4.6.4 The use of nonprobability (snowball) sampling in the quantitative strands of this PhD thesis**

Access to marginalised groups can be particularly difficult if participants consider that identifying with specific factions will result in abuse or discrimination (Browne, 2005; Russell et al., 2008). Healthcare workers may also be reluctant to disclose practices considered personally or politically sensitive. The use of an online, nonprobability, snowball sampling method, via three different social media platforms, including Facebook, was deemed to be the most pragmatic option to recruit research participants in the context of this research.

#### **4.6.5 Determining sample size in nonprobability web based surveys**

There has been little guidance in the literature on determining the sample size of non-probability internet samples (Callegaro et al., 2015). Sample size in nonprobability samples has been recommended to be in the region of more than 30, and fewer than 500, and between 10 and 30 for exploratory studies (Hill, 1998). Saturation sampling has been used in corporate or professional settings, but this has been considered largely impractical in open populations (Sue and Ritter, 2012). The randomness and representativeness sought in probability samples should be approximated as much as possible and sample size calculations are ideally used (Bowling, 2014). However, calculating the sample size is problematic in exploratory research as the margins of variability cannot be meaningfully determined (Sue and Ritter, 2012).

#### **4.6.6 Determining sample size in the quantitative strands of this PhD thesis**

A pragmatic approach to achieving a research sample of sufficient size and diversity needed to be taken (Sadler et al., 2010). Decisions about sample size were guided by what could reasonably be achieved within the time frame, and the resources which were available to undertake this PhD project. The limitations of this approach are acknowledged. However, to some extent, the mixed method design and the use of mixed methods triangulation (4.4.4) mitigated concerns about sample size in the quantitative strands of this PhD project.

#### **4.6.7 Data analysis using descriptive statistics in this PhD thesis**

The use of descriptive statistics in the quantitative strands: patient survey 2a and general hospital survey 3a was considered to be compatible with the study design and the aims and objectives of the research. The aim of the quantitative analysis was to describe the characteristics of the survey responses and to inform the development of the subsequent studies in the sequence. The use of a web-based, non-probability sample precluded the valid use of inferential statistics. However, the quantitative studies 2a and 3a were not designed with the intent to extend the conclusions beyond the immediate data set or to establish cause and effect. A pragmatic decision was made to use Microsoft Excel to undertake the quantitative descriptive analysis due to accessibility.

## **4.7 Qualitative strands 2b and 3b: The use of qualitative telephone interviews**

### **4.7.1 The use of qualitative interviews**

Interviews alongside observation and focus group methods, interviews constitute a core qualitative research method (Peters, 2010). Interviews have some advantage over observations and focus groups in researching sensitive topics (Lewis and McNaughton Nicholls, 2014). The one to one interaction offered by interviews may increase rapport between the interviewee and the researcher (Yeo et al., 2014). One to one interactions enable the researcher to use and respond to paraverbal cues, which may enrich the data (Spencer et al., 2014a). Interviews have widely been used in qualitative research to produce descriptions and interpretations (Yeo et al., 2014) of experiences, motives, and opinions (Rubin and Irene, 2012). Qualitative interviews are conducted using a variety of approaches and with a variable degree of structure (Carr and Worth, 2001). Qualitative interviews have been considered to provide a valuable method to explore complex areas of which little is known (Ritchie and Ormston 2014).

### **4.7.2 Face to face versus telephone interviews**

In the quantitative and qualitative literature, telephone interviews have been tacitly presumed to be less desirable than face to face interviews (Trier-Bieniek, 2012; Novick, 2008; Ward et al., 2015). It has been suggested that participants are liable to become distracted during telephone interviews (McCoyd and Kerson, 2006), that the researcher could struggle to establish rapport (Sweet, 2002), and that the inability of the researcher to pick up visual cues and contextual information could compromise the data (Novick, 2008). It has also been suggested that emotionally sensitive information might be less forthcoming over the telephone because the researcher cannot be suitably responsive

(Sturges and Hanrahan, 2004). However, there has been insufficient research evidence to substantiate claims that telephone interviews produce qualitative interview data, which is inferior to the qualitative data collected via face to face interviews (Ward et al., 2015; Novick, 2008).

To date, methodological discussion related to qualitative telephone interviews has been limited (Ward et al., 2015; Novick, 2008; Carr and Worth, 2001). Although, qualitative telephone interviews have been considered to generate data that is at least comparable to face to face interviews (Carr and Worth, 2001; Sturges and Hanrahan, 2004; Mealer and Jones, 2014), supporting data has been limited (Novick, 2008). Researchers who have undertaken qualitative telephone interviews have judged that they offer less social pressure than face to face interviews (McCoyd and Kerson, 2006) and increased versatility (Carr and Worth, 2001). There have been specific scenarios identified in which telephone interviews may be preferable: some interview participants may feel more comfortable in their environment (McCoyd and Kerson, 2006; Trier-Bieniek, 2012) and prefer the anonymity afforded by the telephone (Sweet, 2002; Trier-Bieniek, 2012). Participants in telephone interviews may feel more relaxed and have more opportunity to talk freely, and therefore disclose more personal information (Carr and Worth, 2001; Holt, 2010).

Telephone interviews have been considered to promote inclusion: in a study of women who had overcome traumatic experiences, it was noted by the author, that the use of telephone interviews had enabled the participation of women with caring responsibilities (Trier-Bieniek, 2012). A further study which explored views about taking part in an interview over the telephone suggested that being 'phone savvy' has become part of modern life; telephone interviews were believed to focus concentration on the voice instead of the face, offer easy rapport, and feel non-judgemental and uninhibited (Ward et al., 2015). Telephone interviews have been considered to provide the opportunity to contact and interview people who would be otherwise inaccessible (Trier-Bieniek, 2012). The reduced cost and

travel time needed to undertake telephone interviews might also be an advantage (Lewis and McNaughton Nicholls, 2014).

The digital age has changed how communication takes place, technology is rapidly replacing face to face contact, and research participants may be more comfortable with the use of remote methods, and particularly around discussion of sensitive topics (Trier-Bieniek, 2012; Mealer and Jones, 2014). Recently some researchers have attempted to use Skype to conduct qualitative interviews, but technical issues such as dropped calls, inaudible segments (Seitz, 2015; Deakin and Wakefield, 2014; Hanna, 2012) and limited webcam reach (Weller, 2017) have been problematic. In one study, the researcher had to exclude two interviews on account of the technical hitches, experienced with Skype (Oates, 2015). As an interview mode, Skype may be less suited to exploring sensitive topics due to the unreliable technology.

#### **4.7.3 The use of qualitative telephone interviews in this PhD thesis**

The use of qualitative telephone interviews provided the opportunity to access the experiences and lives of participants (Yeo et al., 2014) from all over the United Kingdom and afforded the participants the option of anonymity. In the context of this mixed methods explanatory sequential study design (Figure 6), the purpose of qualitative interviews was to collect rich data, which could add depth to the breadth of data provided by a web based cross sectional survey. The use of qualitative telephone interviews also served an additional purpose, enabling the opportunity to build sufficient 'cultural competence' (Sadler et al., 2010). Building rapport and gaining depth of understanding from telephone interviews, particularly around patient perceptions of the diagnosis, enabled more culturally competent social media use, to grow the survey (2b) sample.

#### **4.7.4 Audio recording and transcribing of telephone interviews**

It has become commonplace for qualitative interviews to be audio recorded and transcribed verbatim (Wellard and McKenna, 2001). The process of verbatim transcription that is the conversion of the audio recorded interview, word for word, into text may lack emotional context such as silences, crying and sighs (Halcomb and Davidson, 2006; Wellard and McKenna, 2001). The use of verbatim transcription has attracted criticism based on the cost and time commitment, needed to undertake the task (Halcomb and Davidson, 2006). It has been recommended that the techniques used in the transcribing process are consistent with the philosophy, underpinning the research (Halcomb and Davidson, 2006).

#### **4.7.5 Audio recording and transcribing in this PhD thesis**

There are different types of qualitative interview and the degree of richness and depth, which is required in the research interview needs to determine the procedures (Smith et al., 2011). This study does not aim to explore what it is like to be a patient or healthcare professional in a phenomenological context (Ormston et al., 2014). Neither does it explore culture within an ethnographical context (Francis 2013). It is not the explicit aim of this work to generate theory as in grounded theory (Taylor 2013). Mixed methods research, which has been undertaken in the pragmatic tradition, does not have the same methodological traditions, which relate to immersion in the data, as in the purely qualitative approaches. Transcribing the data intelligently, using a professional transcription service has been considered to provide a pragmatic and robust process to manage the interview data in this PhD research.

#### **4.7.6 The use of snowball sampling in qualitative research**

Procedures for sampling in qualitative research have been varied and depend on the research tradition, which is employed (Gentles et al., 2015). Recruitment of a purposive sample has been recommended in qualitative research to increase the opportunity for capturing diversity and information rich data (Paton, 2015). However, this approach has been considered impractical with hard to reach groups (Paton, 2015). Snowball sampling has provided a cost efficient and practical sampling strategy (Ritchie et al., 2014), which has been commonly used in qualitative research (Noy, 2008). Additional detail about the use of a snowball sampling approach has been set out previously in section 4.6.3.

#### **4.7.7 Determining sample size in qualitative research**

The procedure for determining sample size in qualitative research has been described pragmatically as a compromise between design, time, and resources (Paton, 2015; Ritchie et al., 2014). Qualitative data has typically been information rich and sample sizes need to be small in order to be manageable (Ritchie et al., 2014). A sample size of somewhere between 12 and 60 has been suggested for individual interviews; a sample of between 6 and 12 has been described as sufficient for hard to reach groups (Adler and Adler, 2012). However, when asked about sample size in qualitative research, many experts have concurred that 'it depends' (Baker and Edwards, 2012; Back, 2012; Charmaz, 2012; Doucet, 2012; Mason, 2012; Ragin, 2012; Ten-Have, 2012). The researcher needs to be able to justify the sample size ethically (Cleary et al., 2014) and decision making about the sample size needs to be driven by the principles of adequacy and appropriateness (Sobal, 2001).

The gold standard for determining sample size in qualitative research has been reaching saturation or information redundancy (Trotter, 2012; Sobal, 2001). The term saturation, which has been derived from grounded theory, has a rich

methodological tradition, which involves concurrent data collection and analysis (Cleary et al., 2014; Ritchie et al., 2014). In broad terms, saturation has been used to describe the point when all questions have been explored, and no new concepts or themes have emerged (Ritchie et al., 2014; Trotter, 2012; Saunders et al., 2018). Also known as informational redundancy (Lincoln and Guba, 1985), saturation in the broad sense has been defined as the repetition of interviews until all concepts have been repeated multiple times and no additional themes or concepts can be identified (Trotter, 2012). Decisions taken about saturation or informational redundancy are advised to be made in the context of the research problem, taking into consideration the methods and the resources available (Sandelowski, 1995).

#### **4.7.8 The use of snowball sampling and determining the sample size in the qualitative strands of this PhD thesis**

Recruiting for qualitative interviews on social media has permitted access to a wider population and provided more opportunity to harness diverse views and perspectives when compared with conventional snowball recruitment strategies (Brickman Bhutta, 2012; Ritchie et al., 2014). The decisions which have been taken about the adequacy and appropriateness of the sample size in the qualitative strands 2b and 3b were informed by the resources available, the time frame for completion, and the achievement of informational redundancy (Sobal, 2001). A pragmatic decision to use the term informational redundancy has been used in this thesis to describe the point in which interviews reached the point of diminishing return, and the generation of new evidence ceased (Ritchie et al., 2014).

#### **4.7.9 Qualitative data analysis**

Data analysis in qualitative research has been described as substantive: including grounded theory and thematic analysis, focussing on 'what the text

says' (Spencer et al., 2014a p.271), and structural: such as conversation or discourse analysis, focusing on 'what the text does' (Spencer et al., 2014a p.271). The purpose of the qualitative data analysis in this PhD thesis was to achieve a breadth and depth of understanding about '*How general hospitals respond to patients diagnosed with a personality disorder who are distressed*', i.e., how the system works and the impact, in addition to explaining the findings of the quantitative strands, 2a and 3a. The purpose of the analysis was, therefore, to uncover 'what the text says'.

#### **4.7.9.1 Thematic analysis**

Thematic analysis provides a means of identifying, interpreting, and reporting themes (Braun and Clarke, 2006; Gale et al., 2013; Spencer et al., 2014a). An advantage of thematic analysis, compared to some other types of qualitative analysis such as grounded theory and interpretative phenomenological analysis has been considered to be the flexibility that it offers; thematic analysis has no bind with any epistemological or ontological position (Spencer et al., 2014a) and can be used with different research questions, sample sizes, study designs and to explore diverse meanings (Clarke and Braun, 2017). However, the flexibility of the method has generated criticism: Researchers have failed to recognise the role the researcher plays in the analytic process and there has been a lack of focus on the decision making, which is integral to thematic analysis, leading to concerns about quality and rigour (Braun and Clarke, 2006; Spencer et al., 2014a; Clarke and Braun, 2018).

#### **4.7.9.2 Framework analysis**

Framework analysis involves a process of familiarisation with the data, the identification of a thematic framework, and the indexing, charting, mapping and interpretation of data (Pope et al., 2006; Furber, 2010). Framework analysis has been extensively used in qualitative research (Gale et al., 2013) and is a type of

thematic analysis similar to the Braun and Clarke (2006) thematic analysis (Spencer et al., 2014a). The framework method is considered distinct because of the defining 'framework matrix' used (Spencer et al., 2014b; Gale et al., 2013). The analytical stages in the framework method are clearly defined and the use of a framework provides greater transparency and enhances rigour (Pope et al., 2006; Furber, 2010). The framework method generates a clear audit trail from the transcripts to the final themes (Spencer et al., 2014b) and has been considered beneficial to conducting analysis in teams because each stage can be scrutinized and discussed (Furber, 2010; Gale et al., 2013).

The systematic nature of the framework method has attracted criticism; some qualitative researchers consider that the procedures used in framework analysis emulate the deductive approach undertaken by quantitative researchers (Gale et al., 2013). However, like thematic analysis (Braun and Clarke, 2006), the framework method has no relationship with any philosophical, epistemological, or theoretical approaches (Spencer et al., 2014b; Gale et al., 2013). The framework approach provides an adaptable method, which supports the exploration of 'a priori' themes deductively, building on what is known, or the development of themes inductively, which are more data driven (Spencer et al., 2014a; Gale et al., 2013). Although the framework method may be considered less well suited to the analysis of some theoretically situated qualitative research (Spencer et al., 2014a); the framework method has been deemed compatible with a range of epistemological and methodological approaches, including mixed methods (Gale et al., 2013).

#### **4.7.10 Framework analysis and this PhD thesis**

The scoping review (Study 1, Chapter 3) used the Braun and Clarke (2006) method of thematic analysis. However, a decision was taken to use the framework method of analysis, following the steps described by Furber (2010), in the subsequent qualitative strands: patient interviews (2b) and mental health

liaison professional interviews (3b). Framework matrices offer systematic and transparent management and analysis of larger data sets (Yin, 2014; Gale et al., 2013). The research design involved the use of inductive and deductive analytical procedures and the sequential analysis of qualitative and quantitative strands (Figure 6). The framework method has the advantage of being more structured, which was considered to be compatible with the mixed methods explanatory sequential design, enabling consistency, synthesis and a staged process across the strands (Lalor et al., 2013; Creswell and Plano - Clark, 2011).

The use of the framework method was considered to enhance rigour because it enabled discussion and scrutiny of the analysis (investigator researcher triangulation, section 4.4.3.1). The combined use of framework analysis and descriptive statistics was considered to enhance the rigour of the study (analysis triangulation, section 4.4.3.1).

#### **4.7.11 The use of computer assisted qualitative data analysis software in this PhD thesis**

Computer assisted qualitative data analysis software (CAQDAS) has been widely used in qualitative research (Spencer et al., 2014a). The management of interview data represents a considerable undertaking (Halcomb and Davidson, 2006). CAQDAS assists with: data storage, linking information, structuring the analysis, indexing, and maintaining structure (Spencer et al., 2014a). While CAQDAS has been criticised for enabling short cuts and distancing the researcher from the data, the use of CAQDAS has been considered to support the construction of a clear audit trail and expedites the analysis process (Seale, 2010). There can be no substitute for the researcher; there has been no software developed that does automated qualitative analysis (Spencer et al., 2014a; Flick, 2009). Researchers need to decide whether to use CAQDAS based on the methodology and epistemology of the study (Spencer et al., 2014a). The Nvivo CAQDAS has specific functionality for undertaking framework analysis (Spencer

et al., 2014a). A pragmatic decision was made to use Nvivo (Version 11) to support the analysis of qualitative data.

## **4.8 Ethics and research governance**

The Nuremberg code and the declaration of Helsinki form the cornerstone of ethical research practices with human participants (Wang and Huch, 2000). The Nuremberg code, issued in 1947, while never formally agreed, has underpinned the protection of human research participants and provided the foundation of the ethical principles, formally agreed, in the declaration of Helsinki (Fischer, 2006).

### **Nuremberg code in Fischer (2006, p69)**

1. The results of the research must be useful and unobtainable by other means.
2. The study must be rationally based on knowledge of the disease or condition to be studied.
3. It must avoid unnecessary suffering.
4. The study cannot include death or disabling injury as a foreseeable consequence.
5. Its benefits must outweigh its risks.
6. The study must use proper facilities to protect participants.
7. The study must be conducted by qualified individuals.
8. Participants may withdraw from the study if they wish.
9. Investigators must be prepared to stop the study should participants die or become disabled as a result of participation.

Consequently, the professional requirement for nurses to ensure safe and competent care includes research practice (Royal College of Nursing, 2009). The code of practice issued by the Nursing and Midwifery Council (NMC) clearly states that nurses have a professional obligation to ensure that research is safe, robust and ethical (Nursing and Midwifery Council, 2015). The key ethical considerations for nurses have included informed consent, confidentiality, data

protection, the right to withdraw from research, the potential benefits of the research, and the potential for harm (Royal College of Nursing, 2009). Although the ethics of conducting research online has attracted additional discussion amongst nurse scholars (Haigh and Jones, 2005), to date the Association of Internet Research Ethics (AoIR) have not provided any distinct guidance, and the general view is that the ethical considerations, on and offline, can be considered comparable (Markham and Buchanan, 2012).

#### **4.8.1 Informed consent**

Researchers have been required to ensure that potential research participants are given transparent and accessible information and that the information given enables the aims and objectives of the research to be fully understood (Royal College of Nursing, 2009). Patients categorised as 'psychiatric' have been reported to require special attention in this context; it has been suggested that there is increased risk of this group lacking the capacity to consent to participate in research (Druml, 2004). However, most people with mental disorders have decisional capacity and people who have experienced mental disorders cannot be assumed to be legally incompetent or mentally incapable (Amer, 2013). Specifically, personality disorder has not been cited in the list of mental disorders considered to elicit cognitive disturbance, sufficient to impair this type of decisional ability, and researchers have been advised to assume capacity unless there is evidence to the contrary (Mental Capacity Act, 2005).

Potential research participants should be given sufficient time to consider the information and ask questions (Royal College of Nursing, 2009; Webster et al., 2014). Those who choose to participate need to be made aware of the potential risks and benefits and have decided to take part in the research voluntarily (Royal College of Nursing, 2009). The volume of information to be given has been the subject of debate (Bryman, 2016; Webster et al., 2014). A balanced decision needs to be made between information giving and enabling participation as too

much information may be considered burdensome and unappealing (Webster et al., 2014). It has been considered to be good research practice to give information in stages (Webster et al., 2014; Graham et al., 2007).

The practice of seeking informed consent needs to be driven by respect and be conducted in such a way that the process is meaningful to the participants (Webster et al., 2014). Although it has become common practice to ask research participants to sign a consent form to confirm that informed consent has been provided (Bryman, 2016) and professional guidance states that gaining written confirmation of consent is ideal, there is no requirement for signed consent forms (Royal College of Nursing, 2009). The signing of consent forms seems to provide little advantage to research participants (Webster et al., 2014), and many participants have preferred to not provide a signature (Singer, 2003). The practice of obtaining written consent can often be impractical (Royal College of Nursing, 2009) and has historically been driven by concerns about liability (Bryman, 2016; Webster et al., 2014). There have been no agreed standards for obtaining informed consent in online studies (Webster et al., 2014) and it has been deemed acceptable for respondents to online surveys to provide informed consent electronically in low risk studies (Haigh and Jones, 2005).

#### **4.8.2 Confidentiality and the duty to report**

Researchers are required to protect the confidentiality and anonymity of research participants, ensuring that participants are unrecognisable in the research report (Royal College of Nursing, 2009). Participants should be informed about how their data will be kept confidential and anonymous (Webster et al., 2014). However, participants should also be made aware of the requirement of the researcher to breach confidentiality agreements in specific circumstances, i.e., *'The researcher has become highly suspicious that an error is imminent; they believe it is highly likely that the error will result in direct, severe or irreversible harm; their immediate action or intervention will prevent or reverse some of the*

*negative effects of the error'* (World Health Organisation, 2013 p.27). As a registered nurse a duty of care prevails (Royal College of Nursing, 2009).

### **4.8.3 Data protection**

Since 23rd May 2018, researchers have been required to adhere to both European Union general data protection regulations and the UK data protection act, known collectively as the General Data Protection Regulation (GDPR). GDPR applies to all personal data (Health Research Authority, 2018).

*'Personal data' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person'* (Health Research Authority, 2018 p.3).

Universities or healthcare organisations may only collect personal data for research purposes when the research has been seen to be a 'task in the public interest'. Universities and healthcare organisations undertake a formal role under GDPR, as controllers of the research data. The data, which has been agreed for collection will be set out in the research protocol (Health Research Authority, 2018). The arrangements for safely securing data have to be set out in advance and data has to be managed by the principles of data protection set out in article five of the GDPR (Information Commissioners Office, 2018). The general principles of data protection in Bryman (2016, p.128) require that data has to be:

- Fairly and lawfully processed.
- Processed for limited purposes.
- Adequate, relevant and not excessive.
- Accurate and up to date.
- Not kept longer than is necessary.
- Processed in line with rights and regulations.
- Secure.
- Not transferred to other countries without adequate protection.
- Withdrawn on request.

Participants have the right to withdraw their data under GDPR. However, once research data have been anonymised, and this cannot be reversed, the data are no longer subject to GDPR (Health Research Authority, 2018). Research participants have to be informed of their rights and be supported to withdraw their research data without prejudice (Royal College of Nursing, 2009). In order to balance the rights of research participants with the practicalities of undertaking research, it has been recommended that a defined period for the withdrawal of research data is given to participants (Webster et al., 2014).

#### **4.8.4 The potential for harm and risk**

The requirements under GDPR, which state that the collection of research data has to be justified in the public interest, has been discussed in section 4.8.3. In practice, this means that researchers have to make ethical choices, which balance the contribution to knowledge and the research design, against the burden, which is placed on research participants (Webster et al., 2014). In research, which has explored sensitive topics, the potential for psychological risks such as stress and anxiety has been acknowledged and the probability and likely severity of psychological risk occurring has to be offset against the research design, and the contribution to knowledge (Boothroyd and Best, 2003). In order to minimise the potential for harm and risk, particularly if participants have been considered vulnerable, the researcher has to engage in '*responsive and responsible*' research practices (Royal College of Nursing, 2009,p.6).

#### **4.8.5 Ethics and this PhD thesis**

The '*dignity, rights, safety, and well being of participants*' (Royal College of Nursing, 2009 p.8) have been central to the decision making in this PhD thesis. While there was no immediate to medium term benefit to participants from taking part in this study, this research was considered to be of value, because it sought to report experiences and risks in the current care context, which were unknown. The study design was considered to minimise burden on participants. This PhD thesis provided a platform for people to provide feedback about their views and perspectives and the resources available to them. This PhD thesis aimed to make practical recommendations for practice, policy and future research.

Intentional space

## 4.9 Reflexivity

Reflexivity requires researchers to consider how their experiences and epistemological position may have introduced bias to the research process (Dowling, 2006). Reflexive practice has been considered integral to the research process and supports the researcher and the reader to appraise the conduct and reporting of the research, in light of the reflexive thinking and discussion (Allen, 2004). The views that I hold and my ideas will have inevitably shaped this PhD research. The role of researcher bias in the research process is acknowledged and it is recognised that this project may have been conceived differently and the data interpreted differently by somebody with a different set of experiences and views (Smith and Noble, 2014). I have worked in acute mental healthcare for most of my career. My last clinical role was in mental health liaison. I have had limited professional experience of people being well in the community and all of my nursing career has been spent thinking about crisis or distress.

The decision to ask the research question '*How do general hospitals respond to patients diagnosed with a personality disorder who are distressed*' was shaped by my most recent clinical experience, working as a mental health nurse, tasked with setting up a new mental health liaison service, with an amount of money, which could never fulfil the commissioning requirements. I began to think about what was important for mental health liaison services to provide, what quality care might look like, and the evidence needed to ask for additional funding while still in practice. I believed that the care and treatment given to patients diagnosed with a personality disorder in general hospitals was substandard before I commenced this PhD research. I anticipated that this view would be shared by other people who worked in mental health liaison teams.

My time working in the NHS and the use of a range of methods, techniques, and procedures, to solve a range of problems, along with my academic supervision has inclined me towards pragmatism. At the outset of my PhD my thinking was

heavily service led. I consider that stepping out of the NHS to undertake this PhD has encouraged me to think more broadly about health inequalities and the limitations of current service provision, particularly given the current political situation in the UK. I believe stepping out of the NHS to pursue a PhD has sharpened my thinking about the issues in practice and opened my mind to new ways of understanding and of doing things.

I spent a year of my PhD candidature designing and seeking permission to undertake a case study project. I planned to recruit patients in the general hospital setting and undertake interviews either on the ward or via telephone. I intended to interview the multidisciplinary team looking after the patient and undertake document research. However, the ethical necessity to use a mental health liaison service as a gatekeeper prevented me from recruiting to this project. The team could not be convinced to provide the study information to patients. I received many explanations including: that specific patients were not very nice, patients were 'known' and disinterested in research. One patient was considered 'too violent' for a telephone call. There were also challenges because the team suggested the eligibility criteria of 'personality disorder' was too specific.

The mental health liaison team were concerned that they may cause distress by handing out the study information if patients did not agree with their personality disorder diagnosis, despite providing reassurance that I was interested in how the diagnosis had impacted on general hospital care. Conversely, some members of the team made frequent comments about patients who had 'proper mental illnesses' referring to patients who did not have a personality disorder diagnosis as being more worthy. Ultimately, I made the pragmatic decision with the support of the academic supervisors to discontinue the case study project. Although I had support at a senior level to undertake the case study project, I was unable to convince front clinicians that patients diagnosed with a personality disorder should be offered the opportunity to take part in the research.

I have learned through reflecting on my own practice, undertaking this PhD project, and being on social media, that many of the barriers faced by people with a diagnosis of personality disorder evade the attention of the senior clinicians and are generally poorly understood by decision makers. I have referred to 'hard to reach' groups on numerous occasions in this PhD thesis. It has been my experience that people with a diagnosis of personality disorder themselves are not necessarily hard to reach but the correct methods must be used because the systems and structures that are there to protect people can ultimately introduce barriers. I believe the reason that people diagnosed with a personality disorder are 'hard to reach' is rooted in systemic discrimination.

My research question asked '*How do general hospitals respond to patients diagnosed with a personality disorder who are distressed*' and I placed most emphasis on the experiences of using the service, rather than the lived experience, which shaped the analysis and interpretation of the findings. Consequently, much of the detail about lived experiences was lost during the analysis and editing of this thesis. This was a difficult decision because I believe that the individual narratives were very powerful. However, my underlying belief that services require improvement underpins this decision making. It was my intention in undertaking this PhD to find practical recommendations for services.

I have become increasingly critical of the personality disorder diagnosis during my PhD research and I am deeply troubled by the harm this diagnosis causes. However, it is difficult to reconcile the need for research and to improve services with abolishing the diagnostic classification of personality disorder altogether. I am irresolute about the way forward and I believe there is no simple solution.

## **Chapter 5 : Methods**

This chapter provides details of the working methods used in studies 2a and 2b, 3a, and 3b. Section 5.1 reiterates the aims and objectives of studies 2a and 2b, 3a, and 3b. Section 5.2 describes the consultation undertaken with patients and professionals on the study design. Section 5.3 revisits the mixed methods explanatory sequential study design used. Section 5.4 discusses the snowballing method used to access participants on social media. Sections 5.5 – 5.7 describe implementation of the studies 2a and 2b, 3a, and 3b in sequence, describing each method in terms of the sampling, data collection, and analysis in accordance with GRAMMS (O'Cathain et al., 2008). The integration of all of the studies is described in 5.8. The chapter concludes in 5.9, with a description of the ethical and research governance processes.

### **5.1 Aims and objectives of the research**

This research aimed to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed. The aims of studies 2a and 2b were:

- **To conduct a QUAN web-based survey of patients diagnosed with a personality disorder and carers**
- **To conduct [QUAL] telephone interviews with patients diagnosed with a personality disorder**

The objectives of the patient web based survey (study 2a) were to explore the views and perspectives of patients and carers on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. Telephone interviews were undertaken with a sub section of the survey sample (study 2b) to provide additional insight into the findings of the web based survey (2a). The integrated findings of studies 2a and 2b were used with the findings of study 1 to develop the subsequent work. The aims of studies 3a and 3b were:

- **To conduct a QUAN web-based survey of general hospital professionals**
- **To conduct QUAL telephone interviews with mental health liaison professionals**

The objectives of the general hospital web based survey (3a) were to explore the views and perspectives of general hospital professionals on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. A final set of telephone interviews were undertaken with mental health liaison professionals (3b) to explore the findings of all of the previous studies 1, 2a and 2b and 3a. The results of all of the studies (1, 2a and 2b, 3a and 3b) were integrated using a mixed methods triangulation approach, to connect, interpret and explain the results.

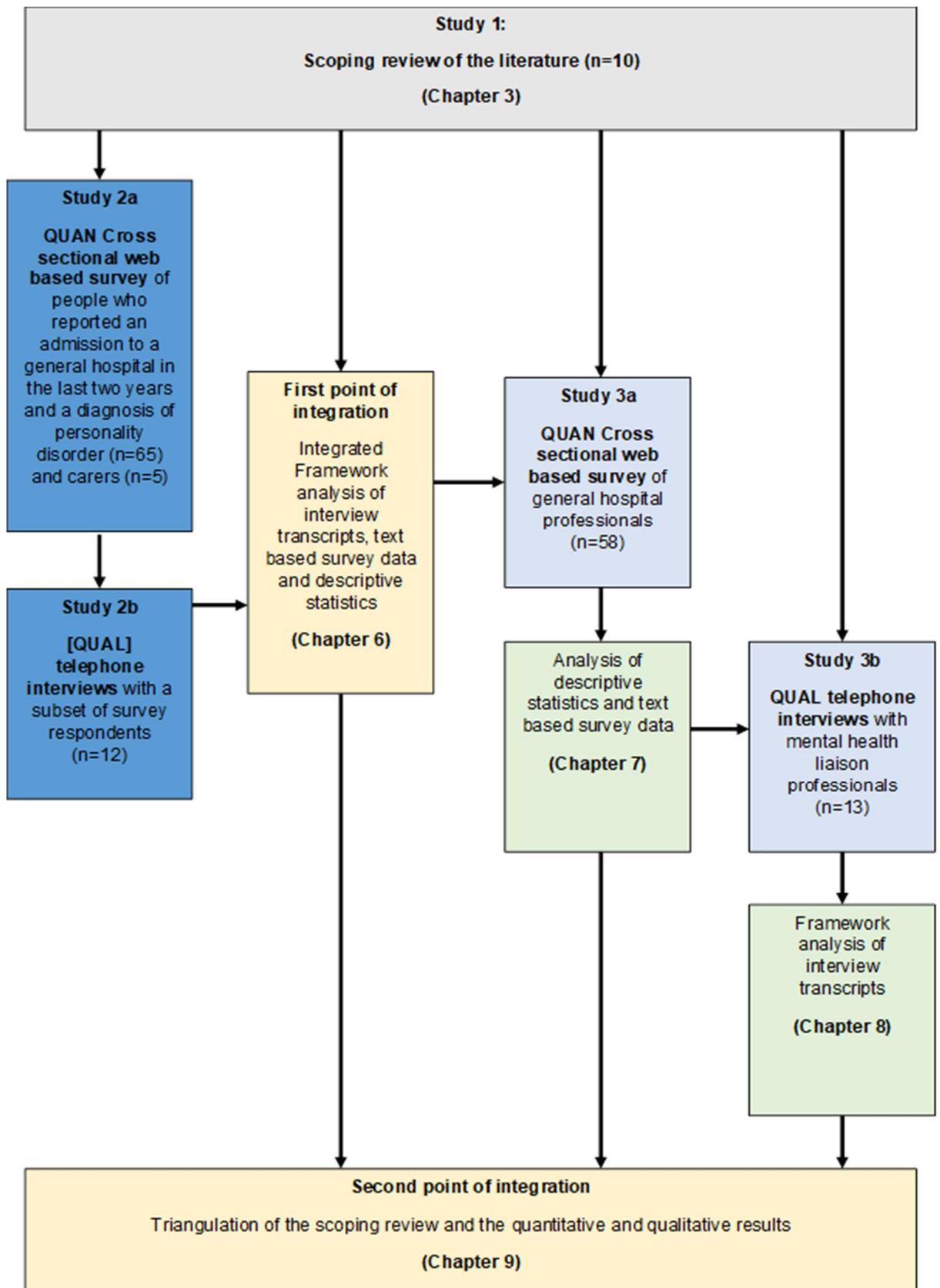
## **5.2 The mixed methods explanatory sequential design**

This research used a core explanatory sequential design (Creswell and Plano - Clark, 2017), which intersected with a scoping review of the literature (Study 1, Chapter Three), and a quantitative method with an embedded qualitative method (Studies 2a and 2b). Equal priority was given to the qualitative and quantitative

methods. There were two points of integration: The first point of integration was the integrated analysis of studies 2a and 2b. The second stage of integration was at the end of the sequence to connect and interpret the findings. The study design is shown in Figure 7.

Intentional space

**Figure 7 The study design and structure of the thesis**



The research design was emergent and evolved following difficulties collecting data. After initial difficulties recruiting to a case study project (Chapter Four, section 4.9), telephone interviews were planned with general hospital professionals. It was intended that general hospital professionals would be recruited via a cross sectional web based survey (study 3a). Unfortunately, despite study 3a being open from January 2018 to April 2018 only one midwife agreed to participate in a telephone interview. Some Facebook users in the nurses forums used the 'ha ha' emoji or made negative remarks in the comments section of the study recruitment message. Therefore, no qualitative interviews could be undertaken with professionals working in the general hospital.

### **5.3 Consultation with patients and professionals on the study design**

A third sector mental health organisation was visited to consult patients and professionals on the study design. An introductory visit was made to the team base, to meet professionals and the people using the community based mental health service. On agreement of the attendees, three community groups were visited. The groups were: a football group, with approximately 20 male service users in attendance; a 'good food' group, which was a mixed group of 10 mental health service users; and an art group, which was a mixed group of 12 mental health service users. The aims of the project were explained to the group and draft information leaflets were distributed. The options for researching the topic in a hospital or online were discussed.

The Facebook platform was popular among the group. Facebook was identified to be the platform most attendees used to interact with others. Attendees at the groups used Twitter, but more passively, i.e., for '*following celebrities*'. Some of the attendees said they did not have access to a computer or were '*not great*' with use. However, most attendees expressed a preference for taking part in

research after being discharged from hospital, e.g. by text message follow up, or via telephone interview. Participation in an online survey was considered ideal by some attendees because of the anonymity that would afford.

## **5.4 Accessing participants on social media using a snowballing approach: studies 2a, 2b, 3a, and 3b**

The Department of Health (DOH) and the Health and Social Care Information Centre (HSCIC), now known as NHS digital, were contacted at the start of the project to check whether there was a dataset related to 'personality disorder' and admissions to general hospitals. Both confirmed there was no relevant national data set. The diagnosis of personality disorder has been aggregated into the broader term 'psychiatric conditions' and no relevant public dataset exists. There was no readily available sample frame of people who have a diagnosis of personality disorder who have experienced admission to a general hospital setting, or their carers, or the health professionals that work with this population in a general hospital context. It was neither practical or ethical, to attempt to establish a sample frame or to undertake probability sampling in this PhD thesis.

Recruitment to studies 2a and 2b, 3a, and 3b was conducted on social media using a snowballing approach (Chapter 4, sections 4.6.3, 4.6.4, 4.7.6, 4.7.8).

### **5.4.1 The use of Facebook, Twitter, and Mumsnet in studies 2a, 2b, 3a, and 3b**

The social media platforms selected were Facebook, as the most dominant social media platform (Ofcom, 2017) and Twitter because there is an active community of opinion leaders in the health and social care field, including several survivors and activists. Mumsnet was also selected, based on the aims and

objectives of the study; it was the intention to recruit research participants that had experience of using women's services in the NHS. The gendered use of the personality disorder diagnosis (Chapter Two) made Mumsnet an appropriate third choice. It was not considered practical to research across any more than three social media platforms and therefore, no other social media platforms were considered.

Twitter and Facebook accounts were set up, and a Mumsnet log in was accessed by becoming a member of the site. The decision was taken not to use a pseudonym on any platform and all social media profiles and posts were identifiable. The Facebook page displayed the study name 'How do general hospitals respond to personality disorder?' due to the number of characters available. The Facebook page was set up as a business page and agreement was sought to display the University of Leeds logo. Visitors to the page were not able to send private messages or publish content. There were limitations to how the Facebook page could be shared due to it being set up as a page, rather than as a Facebook group, but this was considered necessary as the settings could then be restricted. The Facebook page was only visible to users in the UK. It was not the intention to use the page as a forum for discussion. The Facebook page was available at <https://www.facebook.com/shortsurvey/>

Studies 2a and 3a were constructed using the Bristol online survey platform. This survey platform was supported by the University of Leeds.

#### **5.4.2 Eligibility criteria of studies 2a, 2b, 3a, and 3b**

The eligibility criteria for the studies are shown in Table 14. Participants were able to decide if they met the eligibility criteria and self select. This study focused on having a label of personality disorder in the general hospital setting and patients were encouraged to take part if they had been given a diagnosis of personality disorder, regardless of the perceived validity of that diagnosis. This

research focused on receiving concurrent mental and physical healthcare on general hospital wards and accident and emergency was therefore excluded.

**Table 14 Eligibility criteria in studies 2a, 2b, 3a, and 3b**

	<b>Study 2a and 2b</b>	<b>Study 3a</b>	<b>Study 3b</b>
	<b>Patients and carers</b>	<b>General hospital professionals</b>	<b>Mental health liaison professionals</b>
<b><u>Inclusion</u></b>	<p>An admission within an NHS general hospital (including women's services) within the last two years and diagnosed with a personality disorder. Participants in this group had to be aged 18-65.</p> <p>A carer of somebody who met the above criteria</p>	<p>Working in an inpatient area in an NHS general hospital (including women's services).</p>	<p>Working in a mental health team providing in reach into a general hospital, e.g. a mental health liaison team.</p>
<b><u>Exclusion</u></b>	<p>Participants admitted solely to accident and emergency or outpatient areas.</p> <p>Participants unable to communicate fluently in English.</p>	<p>Participants working solely in accident and emergency or outpatient areas.</p>	<p>Participants working solely in accident and emergency or outpatient areas.</p>

## **5.5 Implementation of QUAN web-based survey of patients diagnosed with a personality disorder and carers (2a) and [QUAL] telephone interviews with patients diagnosed with a personality disorder (2b)**

Study 2a, the quantitative survey of patients with a diagnosis of personality disorder (Appendix 5) and carers was conducted online between May 2017 and August 2017. Study 2a aimed to achieve a pragmatic sample size of 50. Study 2a reopened in October 2017, for an additional one month period, ending in November 2017 to enable informational redundancy<sup>8</sup> in study 2b (5.5.3). The questions in the patient web based survey were developed using the findings of the literature review (Study 1) and mapped against the competencies set out in the UK personality disorder capabilities framework (National Institute for Mental Health in England, 2003a). The patient web based survey 2a included a patient reported experience measure (PREM), recommended to assess patient experiences of using mental health liaison services (NICE and NHS England, 2016).

### **5.5.1 The use of Likert scales in web based survey (2a)**

Five point Likert scales were used to collect ordinal data about the views and perspectives of the study participants. Likert scales have commonly been used in health research (Mathers et al., 2007) and were considered to be accessible to the research participants. Although a five point Likert scale was selected, there was no discernible evidence to support the use of a five point scale over a scale with any other number of points (Hartley, 2014) in the context of this PhD project. The decision to use a five point Likert scale was pragmatic. It was considered

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<sup>8</sup> The point of diminishing return was reached, and the generation of new evidence ceased Ritchie, J.A., Lewis, J., Elam, G., Tennant, R. and Rahim, N. 2014. Designing and selecting samples. In: Ritchie, J.A., et al. eds. *Qualitative research practice*. [Online]. 2nd ed. Los Angeles, London, California, New Delhi, Singapore: Sage.

that five point Likert scales would not burden participants. Free text boxes were provided to enable respondents to freely express their experiences and opinions.

## **5.5.2 Recruitment to web based survey (2a)**

The survey was distributed via Twitter, Facebook, Mumsnet, and professional networks. Patients and carers were able to self-select based on the eligibility criteria (Table 14), which was provided on the front page of the survey.

### **5.5.2.1 Mumsnet**

An invite was posted on 'Mumsnet Talk' on the not for profit survey board. Two people commented on the post; one person later asked Mumsnet to delete their comment, which, while not identifying, was related to personal experiences. This data was not captured as part of this research.

### **5.5.2.2 Twitter**

An invite to take part was first tweeted via Twitter on the 10<sup>th</sup> May 2017. There were 100 subsequent tweets, which related to the research project, which were tweeted during the study period. These tweets reached an audience of 103,410 twitter users. People engaged with the tweets on 2,856 occasions, which included retweeting information about the study on 556 occasions, and 'liking' the study on 230 occasions. Twitter users clicked on the survey link a total of 532 times during the study period.

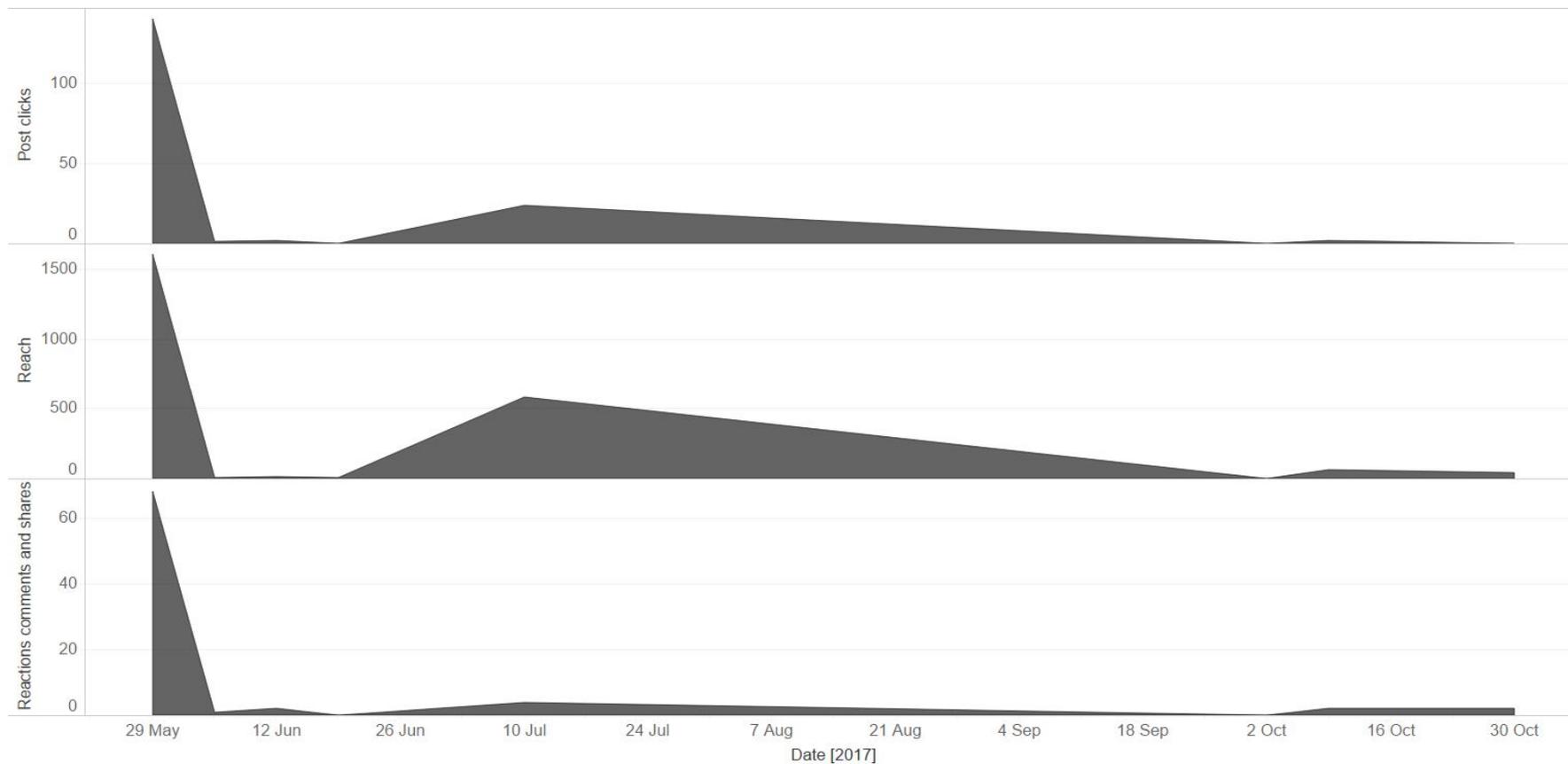
### **5.5.2.3 Facebook**

Details about participating in the survey were posted on the Facebook page. Visitors to the Facebook page were able to click on the 'learn more' button to view the study information. However, the primary function of the Facebook page was to access online community groups. Joining requests were sent to 22 Facebook groups related to mental health or personality disorder, which showed as having UK members. Four of the targeted groups had automated questionnaires in operation and the group administrators could not be contacted. None of the groups that had vetting systems in situ permitted membership.

Access to thirteen groups was permitted by the group administrators and permission was requested to post details about the research. Seven groups allowed details about the research to be posted. The combined number of members of those seven Facebook groups was 11, 268. All thirteen of the group administrators were contacted again five months later. This time nine online groups allowed details about the research to be shared amongst the members. Three of these Facebook groups did not share the research previously. The combined membership of the 9 Facebook groups, which were willing to share the details of the study on the second round was 36, 546.

Facebook recognised the research activity to be suspicious. Facebook continually restricted the research activity and suspended the Facebook account, making it inaccessible. Facebook required a personal photograph to be sent on three occasions and a passport on one occasion to prove identity. It was necessary to limit Facebook activity in order to keep the account active. Figure 8 shows that interest in the research peaked at the beginning of the study period, and again during July 2017, when posting from outside the UK appeared to open up the page to a new audience.

Figure 8 Engagement with the Facebook page (2a). Data extracted from Facebook 20th November 2017



### **5.5.3 Recruitment to qualitative telephone interviews (2b)**

Respondents to survey 2a were asked if they would be interested in taking part in a telephone interview (2b). Interested participants were asked to provide an email contact and they received an electronic participant information sheet via the email address provided. After running the survey 2a for the planned three months, a total of 25 people had expressed an interest in participating in a telephone interview and a total of 24 people had provided an email address. All 24 people who provided an email address were contacted and invited to participate in a telephone interview. A total of eight people agreed to participate in a qualitative interview. Seven interviews were conducted on the telephone and one was undertaken by electronic mail at the request of the participant.

As informational redundancy was not reached during the first round of interviews, a notice of change was given to the University of Leeds School of Healthcare research ethics committee to reopen the survey for an additional four weeks, to recruit more interview participants. A further ten people expressed interest in taking part in a telephone interview and were contacted via the email addresses provided. A further four telephone interviews were conducted, providing a total number of twelve qualitative interviews. Transcription of the audio recorded interviews was undertaken by a professional transcription company, that has a confidentiality agreement with the University of Leeds.

### **5.5.4 The use of topic guides in qualitative interviews (2b)**

The interview questions in study 2b were based on the scoping review of the literature and study 2a, the patient survey. A topic guide was used to focus the questioning. The topic guide was deemed fundamental to managing the extent of disclosure, and to leave participants feeling well (Webster et al., 2014). The interview topic guide used is available in Appendix 6.

### **5.5.5 Analysis of QUAN web-based survey of patients diagnosed with a personality disorder and carers (2a) and [QUAL] telephone interviews with patients diagnosed with a personality disorder (2b)**

The interview transcripts and the survey data were checked and identifying information was removed. The anonymised quantitative survey data was imported into a Microsoft Excel 2016 spreadsheet and cleaned, enabling the generation of descriptive statistics for the quantitative data items. Missing data was less than 5% for all QUAN items in study 2a, thus, the missing data were considered inconsequential to the research aims and objectives (Dong and Peng, 2013). Data from people who identified as a carer (n=5) were separated from the data from people who identified as patient diagnosed with a personality disorder (n=65). The excluded carer data (n=5) were printed out and the key points were highlighted and reported as found.

The patient survey responses (2a) and the interview transcripts (2b) were imported into Nvivo Version 11. The entire data set was read in full to gain an overview of the data. The transcripts and survey responses were re-read until the data was understood and became familiar. An attempt was made to classify the patient data by the type of hospital ward, for example, medicine, surgery, maternity, clinical decisions unit, however, there was no comparable difference in data between these settings, and the dataset was regrouped. The merging of results from the quantitative and qualitative data enabled a more complete understanding to be established than that which would be provided by the quantitative or the qualitative results alone (Creswell and Plano Clark, 2017).

### **5.5.6 Familiarisation with the data from studies 2a and 2b**

During the familiarisation stage of the analysis, notes about the recurring themes were made on a large sheet of paper and in the margins of the transcripts, and survey responses. Similar themes were grouped together and relevance to the aims and objectives of the project was considered (Furber, 2010). The ideas or themes, which were identified inductively from the data, were considered in conjunction with the themes which were identified deductively from the scoping review (study 1). A series of questions were identified (Appendix 7) and used to develop a draft framework (Spencer et al., 2014a).

### **5.5.7 Indexing the data from studies 2a and 2b**

The questions identified during the familiarisation stage were entered into Nvivo version 11 as a codebook and the related framework was assigned to nodes. Each survey respondent or interviewee was identified as a case. The entire data set was reread in Nvivo and indexed to the identified nodes. The questions and the draft framework were refined during this process, with new nodes being added, e.g. pain relief (later pain management and eventually merged to form the theme integration of services; missed care and treatment). On completion of the indexing, the data indexed to each node was re-checked to explore the fit with the framework, referring back to the original source, and ensuring the context of the data was not lost (Furber, 2010).

### **5.5.8 Charting the data from studies 2a and 2b**

The framework matrix function in Nvivo version 11 was used to automatically organise the indexed interview data into a thematic chart (Appendix 8). The summarised survey data was entered manually into the same chart as the survey data was not compatible with the automated function in Nvivo version 11. Rows were assigned to each case, either survey respondent (n=65), or interviewee

(n=12) and each column represented a node or theme. Once the corresponding cells were populated with the indexed data, it enabled the entire data set to be interrogated and further refined. It was easy to move between the chart and the original source in Nvivo, ensuring the fit of the data was maintained.

#### **5.5.9 Data validation in studies 2a and 2b**

The data chart was printed out and reviewed with the academic supervisors. The data summaries were compared and the themes were discussed. The themes were reviewed and revised following discussions with the academic supervisors, relating to overlapping, interpretation, and the reporting of the themes.

#### **5.5.10 Data interpretation in studies 2a and 2b**

The descriptive summaries were developed into explanatory accounts, which involved moving between the data summaries and the original data to ensure that the explanatory accounts remained grounded in the original data set (Spencer et al., 2014a). The findings of the patient study 2a and 2b informed the second part of the sequence, 3a and 3b. The study 2a and 2b themes were refined again during the writing of Chapter Six.

### **5.6 Implementation of QUAN web-based survey of general hospital professionals**

Study 3a, a survey of general hospital professionals (Appendix 9) was conducted online between January 2018 and April 2018 and aimed to achieve a pragmatic sample size of 50. The survey was distributed online using the Bristol Survey platform, over five screens, including the welcome and thank you messages. The number of questions per page ranged between five and twenty one. Participants

were able to review and change their responses to any of the questions using the back button. The majority of the questions were displayed on the third screen. Five point Likert scales were used as described in section 5.5.1.

### **5.6.1 Recruitment to web based survey (3a)**

The survey was distributed via Twitter, Facebook, Mumsnet, and professional networks. The general hospital professional participants were able to self-select based on the eligibility criteria provided on the front page of the survey (Table 14).

#### **5.6.1.1 Mumsnet**

An invite was posted on 'Mumsnet Talk' on the not for profit survey board. There were no comments posted on the Mumsnet platform about study 3a.

#### **5.6.1.2 Twitter**

An invite to take part in the general hospital professional survey (3a) was first tweeted on 19<sup>th</sup> January 2018. There were 53 subsequent tweets related to study 3a, tweeted during the study period. The tweets reached an audience of 6315 twitter users. People engaged with the tweets on 1450 occasions, which included retweeting information about the study on 251 occasions, and 'liking' the study on 123 occasions. Twitter users clicked on the survey link a total of 289 times during the study period.

### **5.6.1.3 Facebook**

A joining request was sent to 13 Facebook community groups, located using the Facebook search function. Ten of the groups located were nursing related, two were generic support groups for healthcare professionals, and one was for allied health professionals. No Facebook groups for doctors were located. Ten of the Facebook groups approved a joining request. However, one group did not approve the join request until after study 3a had closed and was therefore not contacted again. All nine groups, which approved the joining request, allowed information about study 3a to be posted on the group pages. The combined membership of the nine Facebook groups totalled 101,736 healthcare professionals.

The study information was reposted in groups in which members were more receptive, i.e., shared and liked the study. Each post was 'liked' a few days following the original post in order to keep the post active and visible in the group feed. Information about the study was posted across the nine groups on 13 occasions. Details relating to the study were reposted on to the study 3a Facebook page on two occasions during recruitment to ensure that the page appeared active. On the first update, on the 23<sup>rd</sup> January, the updated post was seen 4264 times by 2634 unique users. On the second update, on the 13<sup>th</sup> February 2018, the updated post was seen 192 times by 126 unique users. A total number of 121 unique users engaged with the Facebook page during study 3a, i.e., clicked on the page or the survey link during the duration of the study.

### **5.6.2 Analysis of QUAN web-based survey of general hospital professionals**

The interview survey data was downloaded from the survey platform and imported into a Microsoft Excel 2016 spreadsheet. Identifying information was removed and the data was cleaned. Descriptive statistics were generated in

Microsoft Excel. The free text items were exported into Nvivo Version 11. The free text responses were re-read until the data was understood and became familiar, and then the responses were coded using the framework developed during the integrated analysis of studies 2a and 2b, with the number of comments in each theme also being reported. When responses to individual questions lacked sufficient depth to be coded against the framework, the responses were aggregated and reported numerically. The new findings informed the next study, 3b.

## **5.7 Implementation of QUAL telephone interviews with mental health liaison professionals**

Healthcare professionals working in a liaison psychiatry role were sought on Twitter, Facebook and via professional networks to take part in study 3b. Mumsnet was not used to target this group, as mental health liaison is a small speciality and Mumsnet was not considered to be useful to target healthcare professionals working in specialist liaison psychiatry roles. Potential participants were able to express an interest via telephone or email, and an electronic participant information sheet was provided on contact. The interview topic guide used is available in Appendix 10.

### **5.7.1 Twitter**

A request for professionals working in mental health liaison was tweeted on seven occasions, seen by 11048 Twitter users, and received a total of 235 engagements. Four direct messages were received about the study.

### **5.7.2 Facebook**

Mental health liaison professionals were invited to take part via the study Facebook page, reaching 43 people and receiving four engagements. There were two relevant Facebook groups related to liaison psychiatry, which could be found on Facebook, both set up by allied health professionals. Only one of the groups (80 members) appeared active and responded to a request to share the study.

Topic guides were used to focus the questioning as described in 5.5.4. Transcription of the audio recorded interviews was undertaken by a professional transcription company that has a confidentiality agreement with the University of Leeds.

### **5.7.3 Analysis of QUAL telephone interviews with mental health liaison professionals**

The interview transcripts were checked, identifying information was removed, and then the transcripts were exported into Nvivo version 11. The interviews were read in full to gain an overview of the data and re-read until the data was understood and was familiar.

### **5.7.4 Familiarisation with the 3b data**

During the familiarisation stage of the analysis, notes about the reoccurring themes were made in the margins of the transcripts. Similar themes were grouped and the relevance to the aims and objectives of the project were considered. The ideas or themes which were identified inductively from the data were considered in conjunction with the framework developed during the

integrated analysis of study 2a and 2b, and the analysis of 3a. A series of questions were identified (Appendix 11), which were used to develop a framework (Spencer et al., 2014a), distinct from the framework identified in studies 2a and 2b.

### **5.7.5 Indexing of the 3b data**

The questions were entered into Nvivo version 11 as a codebook and the framework was assigned to nodes. Each interviewee was identified to be a case. The entire data set was re-read in Nvivo and indexed to the identified nodes. The questions and the draft framework were refined during this process, with nodes being merged and new nodes being added (e.g., organisational culture and practice, later separated to form organisational stress, and service delivery; alliances diplomacy and the care of patients diagnosed with a personality disorder. On completion of the indexing, the data indexed to each node was re-checked to explore the fit with the framework, referring to the original source, and ensuring that the context of the data was not lost (Furber, 2010).

### **5.7.6 Charting the 3b data**

The framework matrix function in Nvivo version 11 was used to automatically organise the indexed interview data into a thematic chart (Appendix 12). Rows were assigned to each interviewee (n=13) and each column represented a node or theme. Once the corresponding cells were populated with the indexed data, it enabled the study 3b data to be interrogated and refined. For example, it became apparent at this stage that the sub theme 'improvement' should be merged to form part of the theme 'service design; parity of esteem'. It was easy to move between the chart and the original source in Nvivo to ensure the fit of the data was maintained.

### **5.7.7 Data validation in study 3b**

The data chart was printed out and reviewed with the academic supervisors. The data summaries were compared and the themes were discussed. The themes were reviewed and revised following discussions with the academic supervisors, relating to overlapping, interpretation, and reporting of the themes.

### **5.7.8 Data interpretation in study 3b**

The descriptive summaries were developed into explanatory accounts. This involved moving between the data summaries and the original data set to ensure that the explanatory accounts remained grounded in the original data (Spencer et al., 2014a). The themes were refined again during this stage and once more during the writing of Chapter Eight.

## **5.8 Integration of studies 1, 2a and 2b, 3a, and 3b**

The results of studies 1, 2a and 2b, 3a, and 3b were integrated using a triangulation method (O' Cathain et al., 2010; Farmer et al., 2006). Checklists were developed (Appendix 13) based on the key findings of the patient studies. The checklists were used to systematically compare and scrutinise the findings across the strands, examining the findings for convergence, complementarity and dissonance. The integration of the patient survey (2a) and patient interview (2b) data at the analysis stage and the use of checklists based on the combined qualitative and quantitative patient data, ensured that the quantitative and qualitative results were given equal priority during integration of studies 1, 2a and 2b, 3a, and 3b. The integrated findings were initially organised into a large table but following discussion with the academic supervisors, the findings were ultimately reported thematically in Chapter Nine, to enhance readability.

## **5.9 Ethics and research governance**

Approval for this research was given by the University of Leeds, School of Healthcare, Research Ethics committee on the 25<sup>th</sup> April 2017 (2a and 2b, Appendix 3) and the 18<sup>th</sup> January 2018 (3a and 3b, Appendix 4). This study was conducted in compliance with the study protocol, the University of Leeds regulatory and monitoring requirements, and the National Research Ethics Service (NRES) guidelines (NHS Health Research Authority, 2017). This study was not undertaken in conjunction with any NHS Trust, participants were citizens recruited on social media and via professional networks, and therefore NHS Research Ethics Committee and Health Research Authority approvals were not required.

### **5.9.1 Ethical committee and research governance approval**

The ethical considerations were consistent across all strands of the research. Participants were not offered any incentives to participate, consistent with professional recommendations (Royal College of Nursing, 2009).

### **5.9.2 Identifying and accessing participants in studies 2a, 2b, 3a, 3b**

The use of social media enabled a range of people interested in the content to share the survey link amongst their networks. Potential survey respondents were able to look at the content and decide whether to click on the hyperlink to the survey or to share the content amongst their networks.

### **5.9.3 Informed consent: Surveys, 2a and 3a**

On clicking the survey link, all potential respondents were taken to the front page of the survey, which provided an overview of the study, and the details concerning eligibility. There was a drop box hyperlink, and on clicking the link, respondents were taken to the full electronic information sheet, written to the current research ethics service guidelines (NHS Health Research Authority, 2017). Potential respondents were able to make an informed decision, following reading the information provided, to complete and submit the survey. Respondents were reminded at the end of the survey that the completion and submission of electronic data implied consent to use the data in the project. Respondents were able to change their mind and withdraw from the survey at any point until the survey was submitted.

### **5.9.4 Informed consent: Telephone interviews, 2b and 3b**

Potential research participants were provided with an electronic information sheet, written to the current research ethics service guidelines (NHS Health Research Authority, 2017), via email, which provided information about the interviews and described the risks and benefits of taking part in the research. Participants were provided with contact details and were able to make contact with the postgraduate researcher with any queries before deciding to take part. It was important that potential interviewees were given sufficient time to consider the study information and that the information was provided using a staged approach (Webster et al., 2014; Graham et al., 2007). In the patient interviews (Study 2b), it was considered necessary to allow 48 hours between the potential interviewee receiving the information and the interview taking place, but this was reduced to 24 hours for the mental health liaison professionals study (3b) in an attempt to reduce attrition.

At the start of each interview, the purpose and process of the interview was explained again. After being given the information, participants were asked to confirm that they were willing to proceed. The participants were asked to consent to the audio recorder being switched on and verbal consent was taken using a checklist, and audio recorded. Consent forms were not returned as part of this study. However, the consent checklist was available for the participant to read before consent, and to re-read over the telephone during the consenting process. Interviewees were advised consent and data could be withdrawn up until 28 days after the interview. This time frame was considered ample to give interviewees a cooling off period in which to fully consider participation in the study.

#### **5.9.5 Discomfort, harm and burden in studies 2a, 2b, 3a, 3b**

All reasonable measures were undertaken to protect the health, safety and psychological welfare of all involved in this research in accordance with the University of Leeds health and safety regulations, UK health and safety legislation, and responsibilities as a registered health professional. The risk of people becoming distressed when describing difficult personal experiences was recognised and a distress policy was put in place (Appendix 14).

The survey and the interview questions were developed sequentially to ensure relevance. Voluntary completion of an electronic survey was considered to offer minimal inconvenience to respondents. Respondents were able to access the survey, from their electronic device. Respondents were able to remain in control and proceed through the survey at their own pace. At the end of the survey, a debrief statement was provided. The surveys were designed to be completed in less than 15 minutes and the interview was scheduled for completion in 30 minutes to maximise participation and to ensure that patients and professionals were not unduly burdened.

On the request of a potential participant, an amendment was submitted to the University of Leeds School of Healthcare research ethics committee, to enable the research to support participation in a qualitative interview via email.

### **5.9.6 Confidentiality and the duty to report in studies 2a, 2b, 3a, 3b**

Detailed participant information sheets were provided to participants before completing survey 2a or 3a or taking part in interviews 2b or 3b. The information sheet contained full details relating to confidentiality and anonymity. Disclosure of risk was addressed in the participant information sheet and explained during the consent process. With any research around patient care, there may be disclosures that researchers have a duty to report. Examples might include concerns about participant welfare (Distress policy – Appendix 14) or the conduct of healthcare professionals. The threshold for reporting is explained in guidance issued by the World Health Association (2013) as; information about an imminent error or action that could result in severe and irreversible harm, and that intervention from the research team may prevent or limit this harm. Interview participants were made aware of their rights to confidentiality and the circumstances in which they would be overridden, verbally, and in writing. Survey respondents received this information in writing.

### **5.9.7 Data protection: surveys 2a and 3a**

Survey responses were initially stored on the Bristol Online Survey account. When surveys 2a and 3b were completed, the responses were downloaded into a secure folder on the School of Healthcare server, and identifiable data were removed.

### **5.9.8 Data protection: interviews 2b and 3b**

Interviews were digitally recorded using an encrypted audio recorder, with the interviewee's consent, and transcribed verbatim, by a transcription company that has a confidentiality agreement with the University. All transcripts were anonymised and given a reference number. All files were uploaded and stored on a password protected server at the University of Leeds. There were no personally identifiable paper records generated.

## **Chapter 6 Results from patient and carer studies: 2a QUAN web based survey and 2b [QUAL] telephone interviews**

Chapter Six reports the integrated results of study 2a QUAN<sup>9</sup> web based survey of patients (n=65) and carers (n=5), and study 2b [QUAL] telephone interviews with patients (n=12). This chapter focuses on how general hospitals respond to patients diagnosed with a personality disorder who are distressed from the perspective of patients and carers. The participants were asked questions based on the scoping review of the literature (Chapter One) and the personality disorder capabilities framework (National Institute for Mental Health in England, 2003a). Study 2b provided additional insight into the findings of study 2a. The survey questions and the interview topic guide are available in the appendices (Appendix 5 and Appendix 6). Data were collected between May and November 2017. Participants were admitted to a range of wards including acute admissions wards, medical wards, obstetrics, gynaecology and maternity wards, and surgical wards. The integration of the patient results was considered to provide a more rigorous understanding of the data than that which would have been provided by the quantitative or the qualitative results alone (Creswell and Plano - Clark, 2017).

The chapter begins by briefly summarising the data collected from the participants in study 2a, QUAN web based survey (6.1) and the data collected from the participants in study 2b [QUAL] telephone interviews (6.2). Framework analysis was used to produce an overarching thematic framework of the integrated qualitative and quantitative data. The quantitative results are summarised using descriptive statistics and reported in the corresponding thematic context, alongside the qualitative results. The four themes identified: Workforce; Knowledge, understanding, skills, and discriminatory practice in the general hospital (6.3); Service delivery; missed care and treatment (6.4), Service

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<sup>9</sup> QUAN and [QUAL] refers to the notational system used in mixed methods research to denote the study design. Brackets indicate an embedded design.

design; integration of services (6.5); and Patient distress (6.6) are reported respectively. The carer results are reported in section 6.7. The chapter concludes with a summary of the integrated findings, which suggest that general hospitals respond adversely to patients with a diagnosis of personality disorder (6.8).

## 6.1 Data collected from the participants in study 2a QUAN web based survey

Patients and carers were asked to provide essential demographic information and to respond to a series of questions around their personal experiences of the general hospital and mental health liaison services. Participants were asked if they or the person they cared about had experienced distress, and how satisfied they were with the responses received. The patient demographic information from study 2a is shown in Table 15. Eighty three (n=54) percent of the patient participants were female, and the majority of participants were aged between 18 and 45.

**Table 15 Patient survey, study 2a: Demographic information**

Age group	Male	Female	Nonbinary	Total
18-25	2	13	3	18
26-35	0	20	1	21
36-45	2	12	2	16
46-55	1	6	0	7
56-65	0	3	0	3
<b>Total</b>	5	54	6	

## **6.2 Data collected from the participants in study 2b [QUAL] telephone interviews**

Interview participants were asked open questions and encouraged to talk in depth about the study 2a topics. No additional demographic details were captured during the telephone interviews (2b) in order to preserve anonymity. Eleven female patients and one male patient took part in the telephone interviews (2b). No carers chose to take part in the study 2b [QUAL] telephone interviews.

## **6.3 Theme one: Workforce; Knowledge, understanding, skills, and discriminatory practice in the general hospital**

Theme one describes the consensus among participants that the lack of knowledge, understanding and skills in the general hospital to respond to patients diagnosed with a personality disorder, resulted in discriminatory practice. Only a small number of participants reported being treated with kindness, empathy, and by professionals who were responsive to their needs. The participants, on the whole, believed that the workforce was not responsive to their healthcare needs and treated them unfairly. Participants suggested that professionals made assumptions about them, which focused on them being: untrustworthy, neurotic, manipulative, attention seeking and having anger issues:

*'I felt I was treated very well up until the point I told them about my PD diagnosis. After that, I was treated as a hypochondriac and dismissed.'* (Participant 43, 2a)

*'You know if they do a physical examination and they feel your reflexes and they feel your abdomen and stuff like that and I've got quite a lot of scars on my abdomen from self-harm, and he was like, oh, what's this. And I, sort of,*

*explained and I said, you know BPD and he was like, oh, okay. And then, from then on, I felt like he totally dismissed everything I was saying.'* (Participant 2, 2b)

Thirty six participants (55%) appeared to be under the impression that professionals working in the general hospital knew about their personality disorder diagnosis. Some of the participants described avoiding telling anybody at the general hospital about their personality disorder diagnosis and they reported feeling fearful of the professionals finding out:

*'I was too embarrassed to admit my BPD diagnosis, worried if my physical symptoms would be explained away as some sort of attention seeking'.* (Participant 72, 2a)

*'People in hospitals and doctors, they have no time to do anything, ever, for anything, let alone go to the bathroom. So when they're going into situations they're saving themselves time by just automatically judging based on a stereotype what a person is going to be like based on a diagnosis.'* (Participant 6, 2b)

A commonly held view among the participants was that professionals were disinterested and displayed dismissive attitudes. Participants expressed a sense of frustration. They wanted to be afforded comparable levels of care, compassion, and respect to people with other health conditions:

*'I would like to be taken seriously and treated the same as any other patient.'* (Participant 2, 2b)

*'The sense of judgement and feeling like I'm wrongly taking up people's time, energy and resources feels awful. I don't feel like I deserve help and the experience in hospital often confirms this.'* (Participant 46, 2a)

Commenting on being dismissed and discriminated against, one participant reported feeling deterred from returning to the hospital for treatment:

*'Because of the way I was treated, I haven't attended my follow up appointments on the ward, which has had an impact on my recovery.'* (Participant 39, 2a)

Intentional space

**Figure 9 BPD is a mental health condition**

This figure was created by participant 5. The meme challenges a view which this participant believed was ubiquitous amongst health professionals:



Participants generally believed the basic knowledge and skills, which would be helpful in caring for somebody with a diagnosis of personality disorder were absent, and they described a low level of knowledge, skill, compassion, and limited self-awareness among general hospital professionals:

*'She came up with these sheets of colouring paper and whatever. And I said to her look, I said I think you just don't get it. This isn't going to help me with my mood swings.'* (Participant 4, 2b)

*'The staff tried their best but weren't really equipped to cope with my mental state.'* (Participant 32, 2a)

Participants described receiving inhuman responses. The necessary skills, which participants considered would have made a difference to them appeared to relate to the 6 C's: care, compassion, courage, communication, competence, and commitment (Department of Health, 2012). The values relating to the 6 C's are not specific to mental health care and are fundamentally human principles, shared across the health and social care settings. The majority of participants did not believe that health professionals working in general hospital settings needed to develop sophisticated skills in mental health care; they wanted fundamental patient care:

*'Again, it's just down to some compassion and, rather than saying, well that's a stupid thing to do, or why would you do that, sort of, gosh you're having a really tough time at the minute. It's just about how you say things, that's all it is, you know. Maybe just saying, god, you know, you must have a tough time to need to do this, and...you know, is there anything else we can help...is there anything else we can do to make sure you're supported? It's much better than, well that was a stupid thing to do, wasn't it?'* (Participant 10, 2b)

Participants believed that professionals did not exercise professionalism or show any compassion or care following self harm or overdose, and they were perceived to be oblivious of what it might be like to be vulnerable in hospital, having experienced psychological trauma. Participants described feeling unsafe and dejected in the hospital as a result of the responses they received:

*'I was aware of something going on, but I wasn't...straight away I was shunted into an area and it was a male doctor that came and he basically wanted me to strip all my clothes off the top, and obviously straight away I was freaking out, I'm like there's no way I'm doing that.'* (Participant 9, 2b)

*'They didn't clean my arm or bandage it, or anything, it was just like we've had enough of you.'* (Participant 5, 2b)

Participants suggested that campaigns to raise awareness of mental health difficulties had done little to enhance understanding of personality disorders amongst health professionals working in the general hospital, as echoed by one participant:

*'There's increasing, sort of, exposure and understanding about depression and anxiety and I feel like the medical world is, sort of, a bit more accepting of those as real conditions and a bit more clued up about what an individual might be experiencing during that, whereas I feel like there's a lot of misunderstanding and possibly even stigma around other mental health conditions such as schizophrenia and especially personality disorders.'* (Participant 2, 2b)

The information sources used by professionals to inform practice on general hospital wards were presumed by some to be dubious. One participant reasoned that the lack of good quality information about personality disorders contributed to poor care and discrimination:

*'Staff need the correct information. Most staff in the general hospital will only have films and google to find incorrect information on personality disorders, which is all detrimental to our treatment.'* (Participant 6, 2a)

Participants suggested improvements to the training that professionals in the general hospital received around mental health problems. A few participants stated that more training delivered by experts by experience was needed to improve practice in the general hospital. Although one participant doubted how well training delivered by experts by experience would be accepted, another participant reported being welcomed, and the response was considered positive:

*'I just did a talk and I just said...I did talk about my experiences and what it was like, just to be left like that. You know, I think most medical staff sort of sit there and think, oh gosh, we don't want anyone feeling like that. So, you know, it's just about saying...just the humanness of it, really, and just going over and talking to people. So, it's been well received. I just think I've opened their eyes and raised their awareness. But, as I say, I kind of sit here thinking, I shouldn't need to really, it should just be there, but it obviously isn't. So, there may be people like me, do need to be doing what I'm doing.'* (Participant 10, 2b)

*'I'd like to go into the hospitals and educate them myself, but I don't think they'd accept me there.'* (Participant 9, 2b)

#### **6.4 Theme two: Service delivery; missed care and treatment**

This theme focused on missed care and treatment and included missed medicines, diagnoses, treatment, and nursing care. Seventy three percent (n=47) of the survey participants (2a) perceived their mental health was of equal or greater importance than their physical health at the time of admission to the

general hospital. However, participants also offered evidence of deficiencies in the mental health support, which was available. Participants reported that it was challenging to access pharmacological treatments, prescribed for their mental health on general hospital wards. Fifty four percent (n=35) of the survey (2a) participants reported being unable to access their usual treatment for their mental health.

Themes of missed, interrupted and omitted pharmacological treatments were echoed in the qualitative data (2b). The participant concerns regarding missed, interrupted and omitted pharmacological treatments were extensive. Participants described difficult circumstances, in which medicines prescribed for mental disorders were routinely unavailable. There was some suggestion that medicines were unavailable because the administration of psychotropic medicines was not part of the remit on some wards:

*'Usually my medication stops completely or for a few days.'* (Participant 1, 2b)

*'I was also not given my medication as they told me they "don't do psychiatric medication in this ward". The withdrawal effects were awful.'* (Participant 15, 2a)

Participants explained that admission to hospital during a period of crisis was often unplanned and their supply of medicines was commonly left at home. In the patient survey (2a), 37% (n=24) of patients reported that their specific treatment for their mental health was not available. A further 17% of patients (n=11) stated that their specific treatment was available, but they were unable to get it. The participants (2b) described substantial difficulties getting their regular medicines prescribed and considerable effort was needed to communicate the necessity to receive medicines for mental health:

*'I often carry that days worth of medication if I am out, but if you suddenly go to A&E you don't always think to take your medication, plus as I am only allowed a weeks supply of medication at a time, I often don't have enough anyway.'*  
(Participant 1, 2b)

*'I desperately needed my psychiatric medications but had to beg for it.'*  
(Participant 45, 2a)

A common view among the participants was that medicines prescribed for mental disorders were not a priority. Participants believed missed, interrupted and omitted pharmacological treatments led to the deterioration of mental and physical health. The term diagnostic overshadowing has been used to describe the incorrect assumption that physical complaints are attributable to a mental disorder (Nash, 2013). However, some of the scenarios described appeared to reflect an *inverse* diagnostic overshadowing, with mental health concerns ignored, while the professionals focused on physical health:

*'So I was going cold turkey in the hospital and feeling worse and worse. And I kept asking them where my medication was. And they just kept sort of brushing me off. So I wasn't getting anything, I wasn't getting my antidepressants, my anti-anxiety, I wasn't getting anything.'* (Participant 5, 2b)

*'What most distressed me was that my medications for other physical conditions were available immediately but it took 24 hours of polite 'hassling' for my psychiatric medications to become available. Without my tranquilisers, I was suffering from repeated, extreme panic attacks.'* (Participant 45, 2a)

Participants expressed frustration, reporting how healthcare professionals in the general hospital setting commonly failed to recognise personal expertise and lived experience in managing medicines:

*'They wanted to alter my antidepressant and I wouldn't let them because I said when the dose goes higher I go...the mood fluctuates. And it hurts me severely.'* (Participant 4, 2b)

*'We know our bodies, we know what drugs we react to, or won't react to in the way professionals expect the drugs to work.'* (Participant 1, 2b)

*'So we'd looked into the best balance before I got pregnant. And we kind of felt that actually, me being well would probably...versus being unwell and there not being medication in my system, on balance from the research, it seemed to be that the bigger impact on the baby was, if I was extremely unwell. So that was what we went with.'* (Participant 8, 2b)

Participants who were well informed about the medicines that they needed in a crisis described how they struggled to be heard, believing it was expected that they should be passive recipients of medicines. Participants revealed that the clinical decision making around medicines did not always make sense to them:

*'Apparently that's what people with BPD do, is they get given a PRN of something like a benzo or something like that. They'll just take it all the time which is not the case. Which is quite ridiculous and trying to treat you as if you're some sort of 12 year old as opposed to an adult who has the ability to make rational decisions.'* (Participant 6, 2b)

*'They wouldn't give me warfarin tablets in case I abused them, but yet they'd give me the Tinzaparin injection, and I was administering that myself at home, but one of the injections I had to take so much out so it was equal to the correct amount, so I could have easily just overdosed on that.'* (Participant 9, 2b)

Participants described several situations, where they believed a diagnosis of personality disorder imposed a barrier to an accurate diagnosis and prevented access to treatment. In the participant accounts of being an inpatient in the general hospital, diagnostic overshadowing was apparent:

*'I said I'm not here because of my mental health, I'm here because of suspected PE<sup>10</sup>s.'* (Participant 9, 2b)

*'The first thing they always say to me is oh, I see you've got a diagnosis of borderline personality disorder, and I said, yes, but I'm here about my gall bladder.'* (Participant 11, 2b)

Participants stated they and their relatives were frustrated and concerned about diagnostic overshadowing:

*'I would like my doctors to be able to understand that I'm there for my eye. That any psychiatric diagnosis I have has literally got nothing to do with it whatsoever.'* (Participant 6, 2b)

*'Eventually after my partner kicked up a fuss they did an x-ray and a couple of scans.'* (Participant 1, 2b).

The individual and organisational costs of diagnostic overshadowing were demonstrated by participant accounts of returning to the hospital because of health problems, which were overlooked because of this phenomenon:

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<sup>10</sup> Participant 9 referred to a suspected pulmonary embolism

*“He didn't give me any time to talk. He just literally smiled at me patronising, told me that basically I don't really have a problem, that it wasn't really true. It wasn't really an issue, they didn't really need to have done any of this stuff and I don't actually need the drops because I'm completely fine sort of thing(...) Three weeks later this I ended up back in A&E” (Participant 6, 2b)*

*‘So basically, they left having done nothing, but reported that they had done everything and that there was nothing wrong with my eyes or my eyesight. And then when I saw my neurologist after I was discharged, he was so concerned about what was happening with my eyes that he referred me to a specific neurological ophthalmology team. So, you know, and I told him what had happened and he just sort of raised his eyes and sighed, and said, oh, it doesn't surprise me.’ (Participant 5, 2b)*

A number of participants considered that trying to seek help for physical health problems and being ignored was adverse to their mental health. One participant experienced being belittled and denigrated before their physical health problem was recognised. An understanding of the interrelationship between pain and mental health was considered essential in the general hospital context to avoid diagnostic overshadowing:

*‘But, you know, there wasn't even anyone sort of saying, wow, so that's why you've been in so much pain, you know what I mean? I sort of was left...I was left there, me thinking, well I feel a bit vilified now, but that doesn't really help with, you know, what I've just been through for the past year.’ (Participant 10, 2b)*

Participants recounted some good experiences of receiving help to manage pain in the general hospital, in comparison with the help available on psychiatric wards, although a minority of participants believed general hospitals were responsive in managing pain. In many instances, participants reported that they were denied pain relief in the general hospital. Many of the participants believed

that having a diagnosis of personality disorder resulted in pain not being taken seriously in the general hospital setting:

*'I was so unhappy and so distressed and so scared and I was in so much pain, you know. Nobody was helping me, they wouldn't give me any pain relief.'* (Participant 10, 2b)

*'If they hadn't seen my scars it would have been very different.'* (Participant 2, 2b)

Participants believed they were denied pain relief because of assumptions relating to personality disorder and drug misuse. Participants also reported a sense that pain was dismissed, and that pain relief was denied, on a corrective basis:

*'When I asked for pain relief one of the nurses refused after she found out about my diagnosis because you did this to yourself, you have to live with the consequences.'* (Participant 75, 2a)

*'Admitted for hip op. They denied extra pain relief and tutted and sighed when I mentioned that I had issues with misusing prescription drugs. They joked about me tolerating the pain relief as I was coming round.'* (Participant 26, 2a)

Participants provided little evidence of parity of esteem in the pain context, suggesting that general hospital professionals did not understand the interrelationship between mental and physical health:

*'I was admitted due to severe abdominal pain linked to a urology problem and I have a long term indwelling catheter fitted due to urinary frequency problems. The increased pain was also fuelling my suicidal thoughts.'* (Participant 42, 2a)

One participant reported being unable to manage the pain, which led to lashing out verbally at a nurse:

*'I had a panic attack whilst stuck in my en suite and I also lashed out verbally at a nurse. Warned her I needed pain relief and she declined.'* (Participant 26, 2a)

Another reported issue was one on one nursing care, which elicited some negative comments from participants. Participants were commonly uncertain about the purpose of one on one support and believed there was often a lack of appropriate justification for the decision:

*'I was provided with 24/7 security at the door of my room because I have Multiple Personality Disorder which subsequently led to my being sectioned in a medium secure forensic unit for 2 years. I have lived peacefully in the community for the last 5 years'* (Participant 39, 2a)

*'A nurse I've encountered previously did the handover and, seemingly as a result of whatever was said, they refused to put in the cannula until the last minute and put me on one-to-one observations with a staff member while I received treatment, on the basis that they "wanted to guarantee blood was going in, not being taken back out!" This, in spite of having received blood transfusions cooperatively and peacefully twice in preceding weeks, with no such observations.'* (Participant 46, 2a)

Participants expressed concern about the lack of consistency and continuity when receiving one on one nursing care. Participants questioned the sense of somebody sitting watching them arbitrarily, without any meaningful engagement:

*I needed support and grounding. I had a nurse (rmn) with me at all times because they decided I needed 1:1 observations. However, this was a stranger each time and they offered no support.* (Participant 34, 2a)

*I was suppose to be on 1-1 on the ward while on a drip and I didn't receive a 1-1 until the 2nd night.* (Participant 21, 2a)

Commenting on their care plan, one of the participants stated: *'It seemed a little strange that they should go to the lengths of observing me overnight without offering any psych assessment the next day.'* (Participant 46, 2a)

When participants had multiple health needs, there were difficulties being seen by other physical specialities because they found that the existence of a personality disorder diagnosis diminished the referral. Clinicians and patients were required to pursue appointments actively, and there were instances when referrals had to be repeated:

*'He had to write to them both again and say, you know, you said this woman needs a follow up appointment, yet you've taken her off the system.'* (Participant 5, 2b)

*'I saw one of the other consultants there and he was actually furious because he looked through my notes and his face just darkened and he got really angry. And he was like right well, I know you've got an appointment next week now because I've put it in and I'm going to come along to it.'* (Participant 6, 2b)

## 6.5 Theme three: Service design; Integration of services

This theme described the integration of mental and physical healthcare in the general hospital setting, which included the role of mental health liaison services, information sharing, and patient satisfaction. Fifty five percent of participants (n=36) in study 2a with a reported diagnosis of personality disorder, stated mental health services did not see them during their general hospital admission. When participants were referred for specialist mental health input, this was usually provided by a mental health liaison service, but in pregnancy, women could be seen by mental health liaison or a specialist perinatal mental health service. Forty five percent of the total patient sample (n=29) completed the mental health liaison patient reported experience measure (PREM) as part of study 2a (Figure 10).

The qualitative data suggested that patients diagnosed with a personality disorder were not always considered for support from mental health teams. Participants reported not being able to self refer if additional support was needed and few participants described any collaborative decision making. There was a sense from participants that mental health services were ‘administered’, following perceived critical incidents, which may provide some explanation about why more than half of the participants were not seen:

*‘You know, and then when I said, can I see...I need to see someone from mental health, because I could feel myself going, and I said, I need to see someone from mental health urgently. And, you know, they said, you don't need to see anybody from mental health, there's nothing wrong with you.’ (Participant 5, 2b)*

*‘I was just getting more and more unsettled they would not phone my cpn/psychiatrist for support or let me talk to a Dr.’ (Participant 13, 2a)*

Participants wished services were better integrated and argued that there should be more joined up thinking between providers. However, even following critical incidents, participants reported that there was a lack of support from the mental health liaison service and the participants described an approach, which appeared crude and reductionist:

*'When I asked to see someone from mental health, nothing happened. I don't know whether the nurses forgot, whether they didn't have time, whether they did and nothing happened, you know, you just don't know. And as I said, the only time someone from mental health came was the day after I'd self-harmed because they were worried about discharging me and something happening to me.'* (Participant 5, 2b)

*'Their role is the risk assessment team. In which they can come down, they'll speak to you, and decide how much of a threat you are to...and this is the stupid thing, they should be better than this. Their basic role is to come in and go are you going to immediately kill yourself in the next 24 hours? If so...and how much will you do it in terms of will you actually get away with doing it? So will you actually lose your life or will it just be something that we can treat quite easily? That's my view of what they do.'* (Participant 6, 2b)

Only 20% (n=6) of the patient participants in the survey, study 2a, agreed they were treated with empathy, dignity, and respect by mental health liaison teams during treatment of a mental health crisis (Figure 10). Participants believed that mental health liaison teams were in an awkward position in the general hospital, with wider mental health services being under resourced, there was limited opportunity for onward referrals. One participant (6) stated that the lack of resources must be demoralising for mental health liaison workers and believed they were consequently becoming burnt out:

*'After suicide attempts the expectation is that they will actually do something useful, book you an emergency appointment with your outpatient psychiatrist, or refer you for therapy or something. But usually, they just refer you to the crisis team, even if I repeatedly tell them the crisis team make me feel worse and more distressed, they insist that is all they can do' (Participant 1, 2b)*

*'It must be the most demoralising job because you're sitting there seeing someone distressed but actually, your answer is well, I can't give you the response. And they're so stressed that their compassion and their empathy is just completely shot and it's not there anymore.'* (Participant 6, 2b)

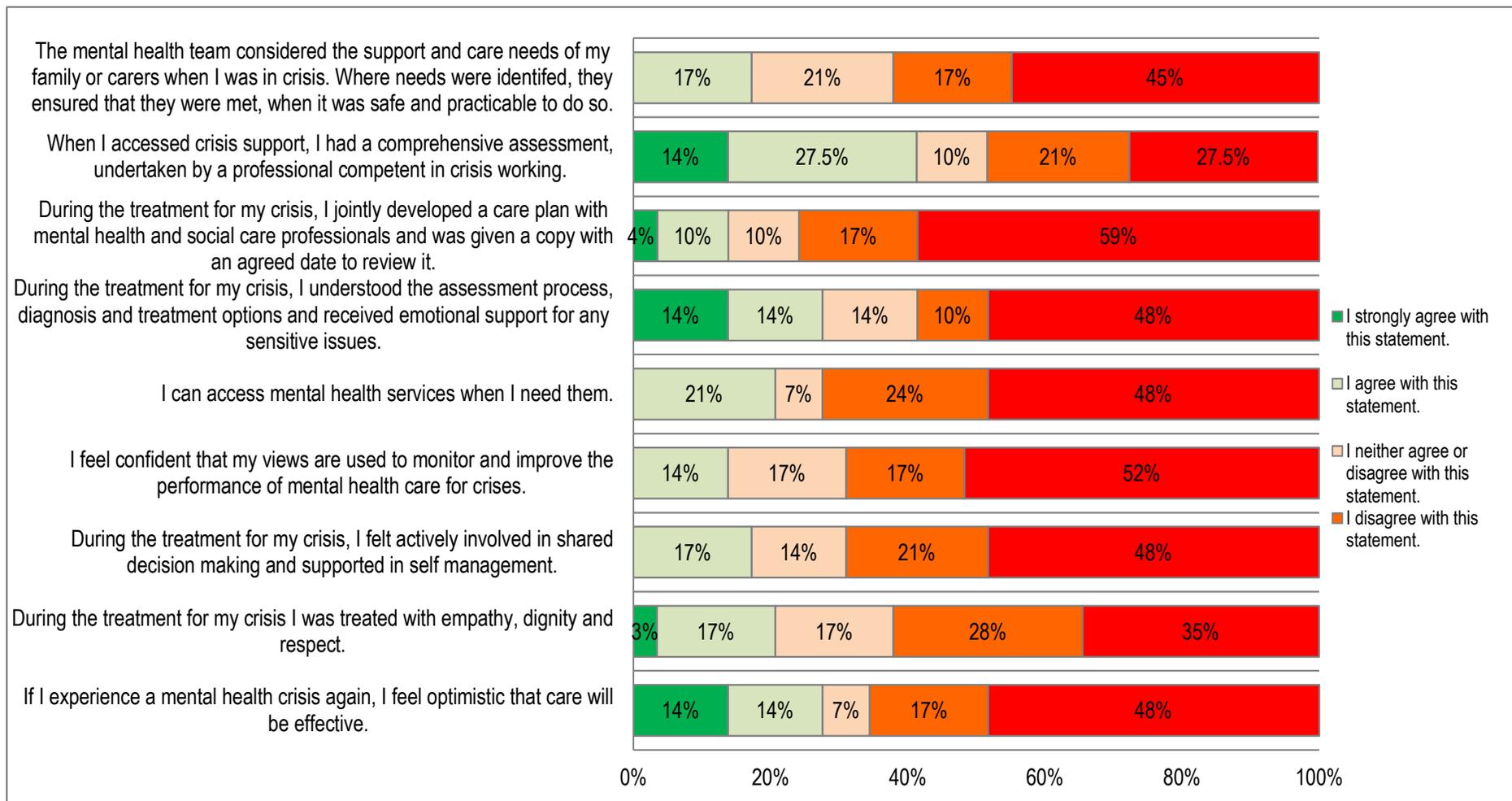
Only 17% (n=5) of the survey (2a) participants believed that the mental health liaison team considered the support and care needs of family or carers during a crisis (Figure 10) and this was echoed in the qualitative data (2b):

*'Nobody supports my parents' (Participant 4, 2b)*

Intentional space

**Figure 10 Patient survey, study 2a: Experiences of patients diagnosed with a personality disorder of using mental health liaison**

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Another reported issue was the paternalistic attitudes to information sharing. Participants stated that disclosure of information took place without permission. Some participants provided examples of feeling infantilised, with care coordinators being given sensitive information and involved in care, while the participants were assumed to be incompetent:

*'The doctor had given her loads of information about me and was telling her all this sort of stuff, and I got really annoyed because, afterwards she... the doctor handed over the phone to me and my care co-ordinator started talking to me and I was, sort of, like, why did you need to know all that information. He was telling her stuff that he hadn't told me yet. He talked about results, head CT scan results and... Then he was just telling her all this stuff and that she was telling him lots of stuff about me'* (Participant 2, 2b)

*'When my care coordinator called to ask for an update, they gave her a lot of information that I didn't believe was necessary for her to know. I was mostly angry because I had not given permission for this, and felt if I didn't have a PD diagnosis, this would not have happened.'* (Participant 43, 2a)

One participant reported experiencing an incredible violation of privacy, when an estranged parent was allowed access to the participant's information, and critically access to the participant:

*'About three days into that I was laid in the bed and one person watching who should have not even been near me, and that was my father. Not seen him in a long time. He'd found out through somebody else on Facebook, basically. What happened was, I was laid in the bed and he turned up and I'm like why are you here, what are you doing here, don't want you here, obviously, and the nurses were like well, it's your father so... Yeah, okay, I get that, but the annoying thing was they told him everything about my mental health issues plus the reason why*

*I was in the hospital, which ward I was on, without even telling me he'd even phoned up...'(Participant 9, 2b)*

Meanwhile, the same participant witnessed another patient, who did not have a diagnosis of personality disorder, being treated in accordance with the legal and ethical principles, which relate to maintaining confidentiality in hospitals:

*Half an hour before my dad turned up the lady in the next bed had a phone call, the nurse came to her and said we'd just like to show you that we think your daughter's on the phone, is there a password or a name we can give her to ask her to make sure it's your daughter. The woman gave a name. It turned out to be like the daughter's middle name. And they followed it through and she came back and said that's correct, we have now passed on the correct information to your daughter. But then I didn't get that, and the next minute my dad's turning up. So I just felt like I was an outcast, totally treated different all the way through the process.'* (Participant 9, 2b)

Participants were generally dissatisfied with the services for people diagnosed with personality disorder in general hospitals, and 58% (n=36)<sup>11</sup> of the patient participants in the survey study, 2a reported they were dissatisfied with their care. Participants described finding it challenging to let people know when they had received poor care and believed that responses from the patient advice and liaison service (PALS) were unsatisfactory when complaints were made. Participants who had experience of the complaints process found that it was invalidating. Participants provided examples of not being afforded the same considerations as other patients with regards to making complaints, and participants stated they were dismissed, based on unsubstantiated assumptions of mental disturbance:

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<sup>11</sup> There were three nonresponses to the study 2a question on satisfaction with being in a general hospital

*'I did consider, sort of, writing to PAL but I have had a similar experience, maybe two years ago, and...to this and, sort of, information being shared where it wasn't necessary and I wrote to PAL and they gave some sort of excuse. They just fobbed me off, saying it wasn't, you know... It was necessary and, you know, like, mental health' (Participant 2, 2b)*

*'It took ages for my complaint to go through. I got in touch with like PALS and [University Hospital], spoke to somebody there. Now, I never got a written response. I got a phone call and all I got was the people in question, especially the doctor himself, sends his apologies, and that was all I got.'* (Participant 9, 2b)

Participants considered that better funding and a more integrated mental health service would offer improvements and a more streamlined experience. Participants believed improvement was needed at the national policy level, to adequately fund mental health liaison teams, to achieve parity of care. Participants also expressed a desire to see changes at a local level and believed mental health support would be greatly enhanced if mental health liaison services were better integrated with the general hospital. Participants described feeling frustrated at the signposting and assessment, which was offered by mental health liaison teams and indicated that more practical interventions to support psychological wellbeing in the general hospital setting were needed:

*'There needs to be better mental health provision in hospitals, particularly for people with complex mental health needs, who struggle in a ward setting. Having a mh liaison service whose purpose is solely to check you don't need to be admitted to a mental health hospital is not good enough.'* (Participant 38, 2a)

*'We need to be able to think up a way of actually stopping them from going into distress in the first place, looking at more things to do with that.'* (Participant 6, 2b)

Participants called for overarching improvements to the interface between mental and physical health services. Participants commonly experienced a disruption in their mental health care, as contact with community mental health teams stopped during hospitalisation, a time when the participants believed they needed care coordination and enhanced mental health care the most. Participants were generally uncertain about what services were available and when, and they asked for more support to navigate the very complicated healthcare systems:

*'After they've been admitted, you know, or even if someone rings the day after, or two days after, and then to make sure to check that appointments have been made to relevant services and that they are getting that critical care that they need.'* (Participant 12, 2b)

*'CPN needs to be involved. A familiar face would make all the difference.'* (Participant 63, 2a)

*'We should be helped to navigate these things. But, as I say, I think even a...you know, on the inpatient leaflet that you get when you come into the ward or something, the ward information...if you need to have a chat with one of our nurses about...or have a chat with a member of staff, just let us know or...you know what I mean? Then, it doesn't matter if somebody says, look I'm busy at the minute, but I'll see you in half an hour, that's okay.'* (Participant 10, 2a)

## **6.6 Theme four: Patient distress**

Theme four focused on psychological distress, conflict, self harm, and leaving the hospital early or against medical advice. In the patient and carer survey, study 2a, 94% (n=64) of participants reported that they experienced distress

during their admission to the general hospital. The qualitative data emphasised that communication and organisational barriers heightened participant distress. Forty nine percent of study 2a participants who reported being distressed (n=30)<sup>12</sup> believed that professionals working in the general hospital had a very important role in supporting people with a diagnosis of personality disorder in crisis.

Sixty percent (n=39) of study 2a participants reported that they needed an emergency or crisis treatment at the time of their admission to the general hospital. However, the qualitative data indicated that the general hospital environment was typically not conducive to mental health. Participants explained that being admitted to hospital exacerbated psychological distress because of a perceived lack of privacy and support:

*'There were times there was a noise in my head and I couldn't shut down. I had no space. There were nurses in and out, by the bed. At times I had to just shut the curtain around my bed.'* (Participant 4, 2b)

*'It might still set off...you know, it just set off my kind of...you know how you can classify...you know, the intense emotions, that's what it set off in me. I wasn't able to manage them and I was upset and I was distressed. You know, it's very uncomfortable to also be in another ward with lots of people thinking, god, what's she, what's wrong with her, kind of thing? Yes, it was just very uncomfortable.'* (Participant 10, 2b)

Participants experienced a range of difficult emotions in the hospital, which were most commonly expressed as feeling distressed and fearful. Patients described a range of manifestations of psychological distress, which included becoming withdrawn, experiencing anxiety attacks, dissociation, shouting and screaming.

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<sup>12</sup> There were three nonresponses to the study 2a question on the importance of support from people who work in the general hospital.

Some participants recounted considerable barriers relating to communication and organisational processes, which heightened their distress:

*'I think, just that if somebody's willing to listen and validate and take at face value, what I'm saying, you can normally sort it out. If somebody tries to kind of dismiss or shut things down, that is when I tend to get extremely upset and find that really difficult.'* (Participant 8, 2b)

*'The food was awful and there was like a section for jacket potato and you ticked whether you wanted cheese or beans or, you know. So I ticked butter, but I hadn't actually ticked jacket potato. And all I got for dinner was a pack of butter.'* (Participant 5, 2b)

Participants explained that sometimes responses to distress in the general hospital were helpful. However, some participants felt more able to negotiate the hospital system than others, and some felt there were many more unhelpful responses to distress:

*'I think my...overall, my experiences have genuinely been quite good, but I think it's also because I'm reasonably well-educated, articulate. I don't tend to lose it unless I'm really pushed.'* (Participant 8, 2b)

*'I usually cannot manage my distress and this is usually due to how inaccessible hospitals and staff are. And any coping strategies I have are belittled (I was laughed at for having a cuddly toy).'* (Participant 35, 2a)

*'I was told to stop disturbing other patients.'* (Participant 77, 2a)

Participants considered that being able to acknowledge the distress and talk about it was useful. Figure 11 illustrates that gaining non-specialist support from professionals working in the general hospital was of comparable importance to using coping strategies, receiving medicines, and accessing a mental health professional:

*'We know what will calm us down, what will prevent us from getting distressed.'*  
(Participant 1, 2b)

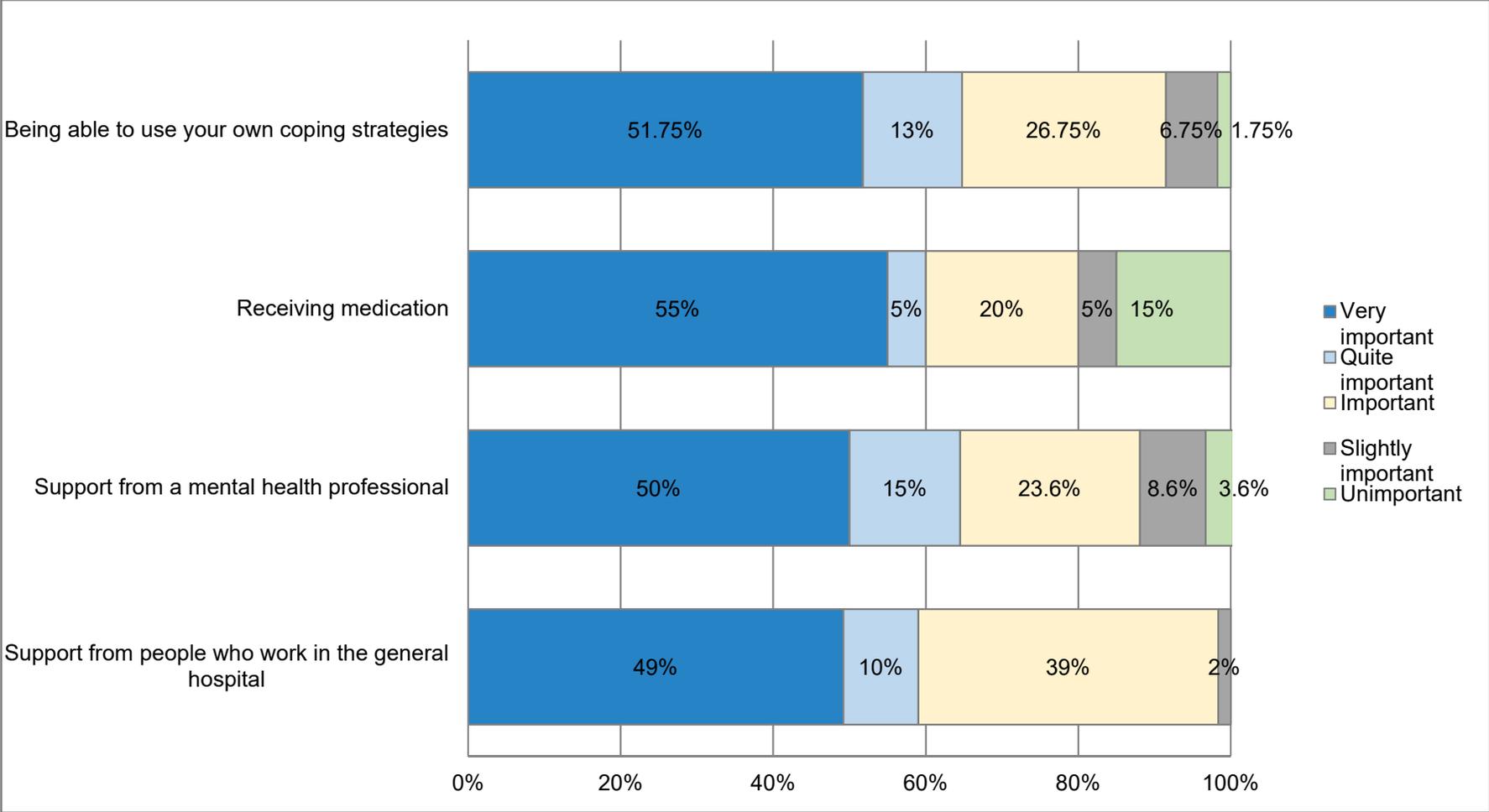
*'In certain circumstances, you might actually become really distressed and it might not be...you might not be able to communicate and it might not be particularly obvious why. But if someone's had a conversation with you about that already, then that will make life a lot easier.'* (Participant 8, 2b)

In the absence of support from professionals, distress could escalate and result in a deterioration of mental state. One participant (6) explained that to be taken seriously and gain help it was necessary to resort to extreme measures:

*'I struggled to manage my distress. I was offered very little support with it and ended up getting further distressed and as a result, I ended up sectioned.'*  
(Participant 34, 2a)

*"My response to that was to just make it worse the next time, if that makes any sense. They're actually making more problems for themselves because they're telling people that if you really want our help then you need to do something drastic.'* (Participant 6, 2b)

**Figure 11 Patient survey, study 2a: The needs of participants during distress**



There was a sense from participants of escalating distress in the general hospital and in some instances, increased self harm. The nature of the types of incidents described was severe, but participants reported there was minimal mental health support available during crisis. Participants described a range of expressions of self harm, including cutting, hitting, tying ligatures, vomiting and not eating in the context of considerable distress:

*'Urges to self harm became really strong.'* (Participant 19, 2a)

*'Sometimes I was able to manage were as sometimes I wasn't as I was wanting needing to harm myself the thoughts were too much!'* (Participant 51, 2a)

Two related reasons for distress were identified by participants in the context of self harm. First was that the participants engaged in self harm in the context of mental ill health:

*'I got very angry a couple of times and I cried a lot. I also didn't want to eat (I use this as a form of self harm).'* (Participant 29, 2a)

*'Tying ligatures because my brain can't cope.'* (Participant 58, 2a)

*'I cried a lot, wanted to escape and forced myself to vomit.'* (Participant 64, 2a)

Second patients identified that specific characteristics of the hospital environment increased distress and self harming was intensified:

*'I become very distressed, get defensive, go into sensory overload, can either have a meltdown or a shutdown, or become extremely upset, start sobbing, hitting myself.'* (Participant 1, 2b)

*'I jumped out of bed, I took the razor blade and, again, I ran out of the hospital. And I would find quiet places where I was hidden, where I could sit and I'd carry on cutting, and what have you. And then someone spotted me, so I kind of walked down this alleyway. And when I got to the other end of the alleyway, this car was there. And everywhere I was walking, it was as if they knew the area and they were following me. So again, the police got called.'* (Participant 5, 2b)

One participant described such severe distress that they attempted suicide. However, paradoxical to the level of support, which was available, patients believed self harm in the general hospital led to the professionals being hesitant to facilitate discharge, prolonging the experiences of being unsupported and of mental health needs not being met:

*'When I become distressed I would firstly start to hyperventilate and would hurt myself in some way. And sometimes try to attempt to take my life.'* (Participant 21, 2a)

*'Basically because I'd self-harmed, they didn't want to discharge me.'* (Participant 5, 2b)

Twenty six percent of participants in the patient survey, study 2a, (n=16)<sup>13</sup>, approximately one in four study participants, reported leaving the general hospital without waiting to be discharged by the general hospital team. The qualitative data offered insights into the possible reasons why. Leaving against medical advice was sometimes related to the mental state of participants. The mental state factors which participants reported compelled them to leave before completion of treatment included experiencing dissociation, psychosis, and paranoia:

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<sup>13</sup> There were three nonresponses to the study 2a question on leaving against medical advice.

*'When I get distressed, I dissociate and can cause serious harm to myself. I try and run away. My psychosis increases too.'* (Participant 34, 2a)

*I would disassociate and sometimes experience psychosis - seeing shapes, paranoid thoughts, hear voices. I would feel unable to cope and need to escape.'* (Participant 30, 2a)

However, overwhelmingly participants stated their reason for leaving was because they perceived their basic needs were not met. As reiterated throughout the data set, the situation in the general hospital was found to be unbearable, and participants described feeling distressed by paternalistic responses and the barriers to getting the treatment and care they needed:

*'I became very paranoid having a security guard sat at my door and escorting me to the toilet, to theatre and bringing me my meals. My focus should have been on my operation, but instead all I wanted to do was leave asap.'* (Participant 39, 2a).

*'Discharged myself as they refused to give me my normal medications and I was just getting more and more unsettled they would not phone my cpn/psychiatrist for support or let me talk to a Dr so began to withdraw off controlled drugs and couldn't take it any longer.'* (Participant 13, 2a)

Participants went to extreme lengths to avoid hospitalisation. One participant described spending the night in a police cell rather than being returned to the hospital. Another described feigning wellness to get discharged early:

*'I was walking in the road. I just couldn't cope with it anymore. And so, I mean, there wasn't much traffic, but basically I was hoping that I'd get run over, and I was like crying and I was distraught. After about a couple of hours, I got picked*

*up by the police. I'd taken my wristband off and they were asking me who I was, and I wasn't going to tell them because I didn't want to go back to that place, I didn't think it was fit to look after a guinea pig, let alone humans. And they phoned the hospital and asked if they had anyone missing and they said no. So I ended up being put in a cell.'* (Participant 5, 2b)

*'Had to convince them that I could manage without oxygen but was still acutely ill.'* (Participant 17, 2a)

Waiver or discharge against medical advice (AMA) forms were reported to be commonly used with patients diagnosed with a personality disorder. Participants provided accounts of disorganised and inconsistent decision making regarding the use of AMA forms. The way in which AMA forms were used unthinkingly, provided a sense that the practice would not withstand legal challenge (Devitt et al., 2000):

*'It was messy and unpleasant. Even though I'd signed the waiver form, staff called my boyfriend and brother asking them to persuade me to stay and even called the police who picked me up off the street (I was wearing a hospital gown and still had my drip in situ) and returned me to the ward, where I was treated as a troublemaking nuisance by the staff.'* (Participant 45, 2a)

*'I get a visit from the full complement of the mental health team, telling me they can't discharge me because I'm a risk to myself. And I just said to them, if you don't discharge me, I'll be more risk to myself here than at home, I need to get away for this godforsaken place. And in the end, they got me to sign a disclaimer and then they let me go.'* (Participant 5, 2b)

Some participants reported that conflict occurred when they tried to communicate individualised needs. When participants did not behave in the

manner, which was required by the system, then participants perceived that the professionals believed the behaviour must be 'managed', with correctional strategies such as behaviour plans and security guards. Participants described getting into conflict with healthcare professionals when they resisted being passive recipients of the care bestowed upon them:

*'It's really difficult because you're like actually, you're going to get really angry and you're going to get annoyed because you're not being listened to. You're basically being told that you're not actually worth being listened to or treated as a person, and I think that's the main issue with a lot of these things. That if you're going to treat someone like that, they're not going to respond well to it ever. No one will. It doesn't matter if they don't have a diagnosis of anything ever.'* (Participant 6, 2b)

*'I wasn't able to manage and I fear I may have been quite rude. I became quite disobedient when they told me I had to stay on the ward instead of going to get some fresh air, but this was the only way I could try to calm my mind.'* (Participant 15, 2a)

Participants also found themselves in conflict because the general hospital had fixed rules and regulations and despite the sound reasoning of the participants, the rules could not be relaxed:

*'They wouldn't let me put my soya milk in their fridge, it was ridiculous. And it took four days to get soya milk.'* (Participant 4, 2b talking about lactose intolerance)

*'I drew my curtains all the way round me because it made me feel safe. I felt too exposed. I mean, I don't really leave my house, so I felt really exposed without the curtains closed. And then about, I don't know, probably every shift change, a*

*nurse would walk onto the ward and pull back my curtains. And I'd say, no, please don't do that, you don't understand, I feel unsafe without them closed. And they were like, you can't have them closed all the time. And I'm saying, I need them closed all the time.'* (Participant 5, 2b)

One participant explained how difficult they found a request to transfer to another ward during the night:

*'I was fast asleep and at one o'clock they woke me up and they said to me, you're moving wards. And that just...number one, it was one o'clock in the morning. Number two, I hate change, I need time to process it and get myself accustomed to it. And that just tipped me over the edge.'* (Participant 50, 2a)

Participants described being dismissed until conflict escalated. General hospital professionals would commonly deal with conflict by calling for security:

*'The staff would just ignore it until they either needed to get a dr for physical examination or call security for 'management' of my behaviour'* (Participant 22, 2a)

*'They all had me on the floor for about half an hour. There must've been about five security guards at this time. But I was on the floor for half an hour, I was crying and screaming out. Everybody came out, even the nurse that put me in there said what are you doing to him, he didn't come here in an alarming, distressing way. He's come in calm, so why is he on the floor?'* (Participant 7, 2b)

Participants explained that they needed health care professionals to try to understand distress in the context of lived experience rather than perceive it as

conflict. However, participants believed there was minimal understanding and empathy for patients who were distressed:

*'I don't want someone to sit there and listen to us, I want someone to interact with me, about how I'm feeling, and words to, like, try and combat that way of feeling, and why am I feeling this way? You know, there's a reason why I'm feeling this way and there's a reason why I'm kicking off, but I can't feel I can't cope.'* (Participant 7, 2b)

*'The number of times I tried to explain I was in extreme distress before that one nurse actually took it on board'* (Participant 74, 2a)

One participant gave details of 'a behaviour agreement', which was put in situ and communicated, in order to enhance consistency, and it was interesting that a behaviour modification plan was seen to be required rather than care:

*Just that the nurses are not to be shouted at, and if there was a problem to ask to see the nurse in charge and they'll come (...) It was put in my folder and all the staff were told, even the agency staff. But everybody knew what was happening.'* (Participant 4, 2b)

These data demonstrate the urgency of making improvements: In study 2a, 46% (n=30) of patient participants stated there was a strong possibility of readmission to the general hospital in the next 12 months, a further 34% (n=22), stated they were unsure, indicating a strong possibility of readmissions amongst the participants.

## 6.7 Carers

Unfortunately, only five carers completed the survey. The demographic characteristics were one male and two females in the 26-35 age group and one male and one female in the 56-65 age group. One participant stated that caring responsibilities were in a professional capacity. None of the carers who took part in survey 2a provided a positive account of their experiences. One carer (female aged 26-35) stated they were somewhat satisfied with care at the general hospital but added: *'following the 'diagnosis being disclosed, the service slowed'*, and after the disclosure some of the staff were described as *'looking less enthusiastic.'* Two carers indicated that they were dissatisfied and two stated they were extremely dissatisfied with the experience the person they cared about had, in the general hospital.

A carer (female aged 56-65) described being *'frustrated and fearful'* after being told the general hospital *'didn't have enough staff to keep an eye'* on the person, they cared for, despite an imminent admission to a psychiatric hospital. A carer (female 26-35) expressed frustration because the *'staff attitudes were largely unsympathetic'*, stating the person they cared for was *'treated like a naughty child'*. A carer (female aged 56-65) believed the hospital staff reacted to the person they cared for as if they were *'some kind of monster'*. Some carers perceived they were unwelcome on the general hospital ward: *'they were annoyed I was there, despite this having 'been agreed with the consultant to help her manage her distress.'* Another stated, *'as a carer I was there for support and to advocate, but this had only slight bearing on the looks, despite polite reminders that I was a carer'*.

Carers expressed concern about the lack of understanding and knowledge, amongst general hospital workers, regarding personality disorders: *'they simply weren't educated'*; *'general healthcare staff urgently need to have training'* and there were risks highlighted, such as *'discharges without any care plans being*

*put in place.*' One carer (Male aged 56-65) expressed concern about the disparity between mental and physical health conditions generally:

*'The 'NHS is failing so many with MH issues; this would not be tolerated for patients with physical conditions.'*

No carers opted to take part in a [QUAL] telephone interview (2b).

## **6.8 Chapter summary: How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: the views and perspectives of patients and carers**

The integrated findings of studies 2a and 2b suggested that overall patients and carers believed general hospitals responded adversely to patients diagnosed with a personality disorder. There were concerns about the Workforce; Knowledge, understanding, skills, and discriminatory practice in the general hospital; Service delivery; Missed care and treatment; Service design; Integration of services; and Patient distress. The integrated results of study 2a and 2b suggested that participants were languishing in the gaps between mental and physical health services and that improvements were urgently needed.

Although evidence of caring, compassionate, and responsive health professionals was located in the data, the majority of participants described an unresponsive workforce, which responded to patients diagnosed with a personality disorder with disdain. Participants believed the professionals appointed to care for them, showed a low level of knowledge, skill, compassion, and little self-awareness. Participants perceived the unprofessional attitudes and behaviours, of some professionals, were the consequence of typecasting and inadequate information.

The majority of participants perceived that their mental health was of equal or greater importance than their physical health at the time of admission to the general hospital. However, participants supplied evidence of deficiencies in the mental health support, which was available. Participants reported they were subject to missed, interrupted and omitted care and treatment, specifically around receiving psychotropic medicines. Participants provided detailed accounts of diagnostic overshadowing. They also described an inverse diagnostic overshadowing, with mental health concerns ignored, while the professionals focused on physical health. Participants believed they were denied pain relief because of assumptions relating to personality disorder and drug misuse. There was little evidence of parity of esteem and participants expressed dissatisfaction with the services provided to them.

The participants believed mental health liaison services were not sufficiently integrated into general hospitals, or adequately resourced to offer satisfactory services to people with a personality disorder diagnosis. Patients reported that mental health liaison was difficult to access and 'prescribed' following critical incidents. The arrangements for sharing personal information between mental health and general health services were not explicit to the participants. Participants found it was challenging to let professionals know they had received poor care. The complaints process was perceived to be unsupportive, and some participants described complaints, which were dismissed, on unsubstantiated assumptions of mental disturbance. Participants considered that better funding and a more integrated mental health service would offer improvements and a more streamlined experience.

For many participants, admission to hospital was during a period of crisis and the majority of participants reported considerable psychological distress. Hospitals offered polarised responses and the professionals were both paternalistic and dismissive. Participants described cutting, hitting, tying ligatures, vomiting, and not eating in the general hospital. Some participants described getting into conflict with healthcare professionals, who in turn,

perceived their 'behaviour' must be 'managed', with correctional strategies. Approximately one in four survey (2a) participants reported leaving the general hospital without waiting to be discharged by the general hospital team. While the risk of adverse events may in part be explained by comorbidity in the study population, these results provide insight into the extensive obstacles faced by the study participants.

Key areas identified for further exploration in study 3a QUAN web based survey of professionals working in the general hospital and study 3b QUAL telephone interviews with mental health liaison professionals included: medicines, risk, discharge against medical advice, and access to mental health liaison services. Chapter Seven moves on to discuss the findings of study 3a.

Intentional space

## **Chapter 7 : Results from general hospital professional study: 3a QUAN web based survey**

Chapter Seven reports the results of the study 3a QUAN<sup>14</sup> web based survey of general hospital professionals (n=58). This chapter focuses on how general hospitals respond to patients diagnosed with a personality disorder who are distressed from the perspective of professionals, working in inpatient areas in NHS general hospitals. Survey 3a participants were asked a series of open and closed questions, derived from the previous studies: 1, 2a and 2b and the personality disorder capabilities framework (National Institute for Mental Health in England, 2003a). The questions were centred around: participant characteristics (7.1); frequency of contact with patients diagnosed with a personality disorder (7.2); emotional wellbeing (7.3); assessing and managing risk (7.4); supporting the workforce (7.5); the quality of the healthcare available (7.6) and improving the support available (7.7). Data were collected between January 2018 and April 2018. The survey questions are available in full in Appendix 9.

This chapter addresses each question in turn. The analytical framework, developed from studies 1, 2a and 2b was used to aid interpretation of the results<sup>15</sup>. When questionnaires were incomplete, nonresponse to numerical questions is reported in the relevant section. A summary is provided at the end of each section. The chapter concludes with the overall findings in 7.8. While the findings in this chapter echo the findings of studies 2a and 2b, this chapter identifies a struggling general hospital workforce, ill equipped with skills and knowledge, and reliant on unavailable, under resourced mental health services.

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<sup>14</sup> QUAN refers to the notational system used in mixed methods research to denote the study design

<sup>15</sup> This chapter has been edited to include the core results only due to the volume of data. Priority was given to reporting areas for improvement.

## **7.1 Participant characteristics**

Sixty three healthcare professionals responded to the survey. Five responses were excluded based on the eligibility criteria (section 5.4.2). Two were outside the UK, one was working in the community, one was based in the emergency department, and one was working exclusively with older adults. Fifty eight professionals working in the general hospital were included in the study. Ten of the participants were male, and 48 of the participants were female. Participants identified themselves as: Adult nurses (n=30), adult student nurses (n=9), a nursing assistant (n=1), midwives (n=4), a student midwife (n=1), pharmacists (n=2), allied health professionals (n=7) and doctors (n=4). Participants identified that they were practising in a range of areas, which included radiology (n=1), medicine (n=21), neurology (n=4), obstetrics and gynaecology (n=6), intensive care (n=3), anaesthetics (n=1), oncology (n=2), surgery (n=5), leadership and management (n=4), and pharmacy (n=1). Ten participants were not attached to a speciality as they were student nurses or in rotational posts. Fifty seven out of 58 participants completed the survey in full.

## **7.2 The frequency of contact with patients diagnosed with a personality disorder**

Sixty two percent of participants (n=36) surveyed, perceived that contact with patients diagnosed with a personality disorder was rare or occasional. Only thirty eight percent (n=22), believed they were in frequent contact with patients diagnosed with a personality disorder. There was no substantial difference between the frequency of contact and the reported area of clinical practice. Participants working in nursing, midwifery and nursing assistant roles reported more frequent contact compared to doctors and allied health professionals (Table 16).

**Table 16 The frequency of contact with patients diagnosed with a personality disorder**

<b>Frequency</b>	<b>Number of participants</b>	<b>Percentage %</b>
Rarely (less than once per month)	19	32.76
Occasionally (1-3 times per month)	17	29.31
Often (Once per week)	9	15.52
Frequently (1-2 times per week)	8	13.79
Very frequently (more than 3 times per week)	5	8.62

### **7.3 The emotional wellbeing of patients diagnosed with a personality disorder**

#### **7.3.1 Access to mental health professionals**

Participants were asked *how easy it is to access mental health assessment and support from mental health professionals to support patients with a diagnosis of personality disorder*. Only twenty one percent of survey participants (n=12) reported they found it was easy or very easy, to access mental health assessment and support for patients with a diagnosis of personality disorder. Participants were also asked: *how easy is it to access advice from mental health professionals to support the healthcare team*. Only 14% (n=8) of participants reported that it was easy to access advice. None of the participants considered it was very easy to access advice (Table 17).

**Table 17 Access to mental health assessment, support and advice**

<b>Ease of Access</b>	<b>Mental health assessment and support for patients</b>	<b>Professional advice from mental health specialists</b>
Very difficult	9 (15%)	9 (15%)
Difficult	25 (43%)	22 (38%)
Neutral	12 (21%)	19 (33%)
Easy	11 (19%)	8 (14%)
Very easy	1 (2%)	0

### **7.3.2 Interdisciplinary decision making**

Forty eight of the fifty eight participants (83%) provided 51 free text comments: *What happens in your clinical area when there are decisions to be made, which cut across your speciality into mental health services, what works well, what works less well.* Participants described 43 barriers and facilitators of interdisciplinary decision making, which were related to service design (43 comments, Table 18). The main service design issues reported were: slow moving and under resourced mental health liaison teams and a lack of practical support. Mental health liaison services were perceived to be reluctant to engage with patients before they were medically fit and were believed to be reluctant to work with patients diagnosed with a personality disorder. The lack of integrated decision making was perceived to compromise the care and treatment of patients diagnosed with a personality disorder (8 comments, Table 18).

**Table 18 Interdisciplinary decision making**

Theme	Number of comments	Sample quotes
<p><b>Barriers and facilitators to services for patients diagnosed with a personality disorder.</b></p> <p><i>(Service design)</i></p>	<p>43: 16 comments about what worked well and 27 comments about things which did not work well.</p>	<p>'Patients are kept waiting for weeks as an inpatient to be seen by the mental health liaison team.'(Participant 43, Nurse, Medicine)</p> <p>'Mental health leave all decisions and care plans to medicine, minimal support or suggestions for practical care.'(Participant 22, Nurse, Medicine)</p>
<p><b>Understanding care and treatment needs in the general hospital.</b></p> <p><i>(Service delivery)</i></p>	<p>8 comments about things, which did not work well.</p>	<p>'Mental health services insist on patients being "medically fit " before they will become involved (...) Therefore, they do not receive the support they need.' (Participant 10, Nurse, Oncology)</p> <p>'Mental health services don't want to know about personality disorders.'(Participant 50, Nurse, Medicine)</p>

### 7.3.3 Professional conflict

Forty three out of the fifty eight participants (74%) responded with 43 comments to the free text question: *Have you been involved in any situation where there was conflict amongst professionals involved in the care and treatment of a patient with a diagnosis of personality disorder, what works well, what works less well?* Ten of the forty three participants (23% of responses) reported no experience of professional conflict. Thirty three comments (77% of responses) were related to experiences of conflict. The data were organised into three themes (Table 19).

The service design, (i.e., the separation between services, and the reluctance for mental health liaison teams to get involved) was thought to be contributory to conflict. Communication was considered to be facilitative in avoiding conflict.

While a minority mentioned workforce issues in this context, what was interesting, was that several participants highlighted issues with their immediate colleagues, rather than with the mental health professionals. Participants described ‘*stigma*’ (Participant 35, Student Nurse) and ‘*a lack of understanding of PD by midwives and obstetricians*’ (Participant 52, Midwife, Obstetrics and Gynaecology). One participant (23) recalled witnessing another nurse refuse to administer pain relief to a patient. The patient was described as ‘*dramatic as they had a personality disorder*’ (Participant 23, Nurse, Medicine). The sample quotes in Table 19 highlight the impact of poor staff attitudes on patients. There was insufficient detail from which to understand the conflict in any depth.

**Table 19 Professional conflict**

Theme	Number of comments	Sample quotes
<p><b>Barriers and facilitators to services for patients diagnosed with a personality disorder</b></p> <p><i>(Service design)</i></p>	<p>6 comments about what worked well. 17 comments about things which did not work well.</p>	<p>‘Inpatient mental health units will not accept her as she has an NG tube for feeding, which will not be able to come out without mental health input. It’s all been a vicious circle and she is still not receiving the help she requires.’ (Participant 45, Allied health professional, Neurology)</p>
<p><b>Understanding care and treatment needs in the general hospital</b></p> <p><i>(Service delivery)</i></p>	<p>6 comments about things which did not work well.</p>	<p>‘The main areas of conflict occur with decisions regarding assessment of capacity. It can be very challenging for non-psychiatrists to assess capacity in patients, when we believe their mental illness is influencing their decision making. In situations where the patients have a personality disorder this is even more challenging, and when we have a busy ward round with 15-20 patients, we rely on the support from mental health services in making these decisions. However, the support in this type of scenario is not always readily available. We sometimes get answers such as ‘it is not our job to assess capacity’, ‘any doctor can assess capacity’ etc etc. Sometimes we just need a second opinion, and collaboration to come to a joint decision.’ (Participant 48, Doctor, Medicine)</p>

<p><b>How professionals respond to patients</b></p> <p><i>(Workforce)</i></p>	<p>4 comments about things which did not work well.</p>	<p>'I have seen qualified nurses attitudes and the way they care for a patient completely change due to their mental health status. They won't explain things properly to the patient. It scares the patient and then they become aggressive.' (Participant 33, Student nurse)</p>
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### **7.3.4 Strategies used to support patients diagnosed with personality disorder experiencing distress in general hospitals**

Participants were asked to rate: *What are you most likely to do to support somebody with a diagnosis of personality disorder who becomes distressed?* Participants reported that they were most likely to refer distress to mental health professionals (Figure 12). Arranging time with the consultant in charge of the patients care was shown to be the least likely option. Interestingly, the option 'arranging consultant time' attracted the highest number of nonresponses (Table 20), which might suggest that arranging consultant time was not an option.

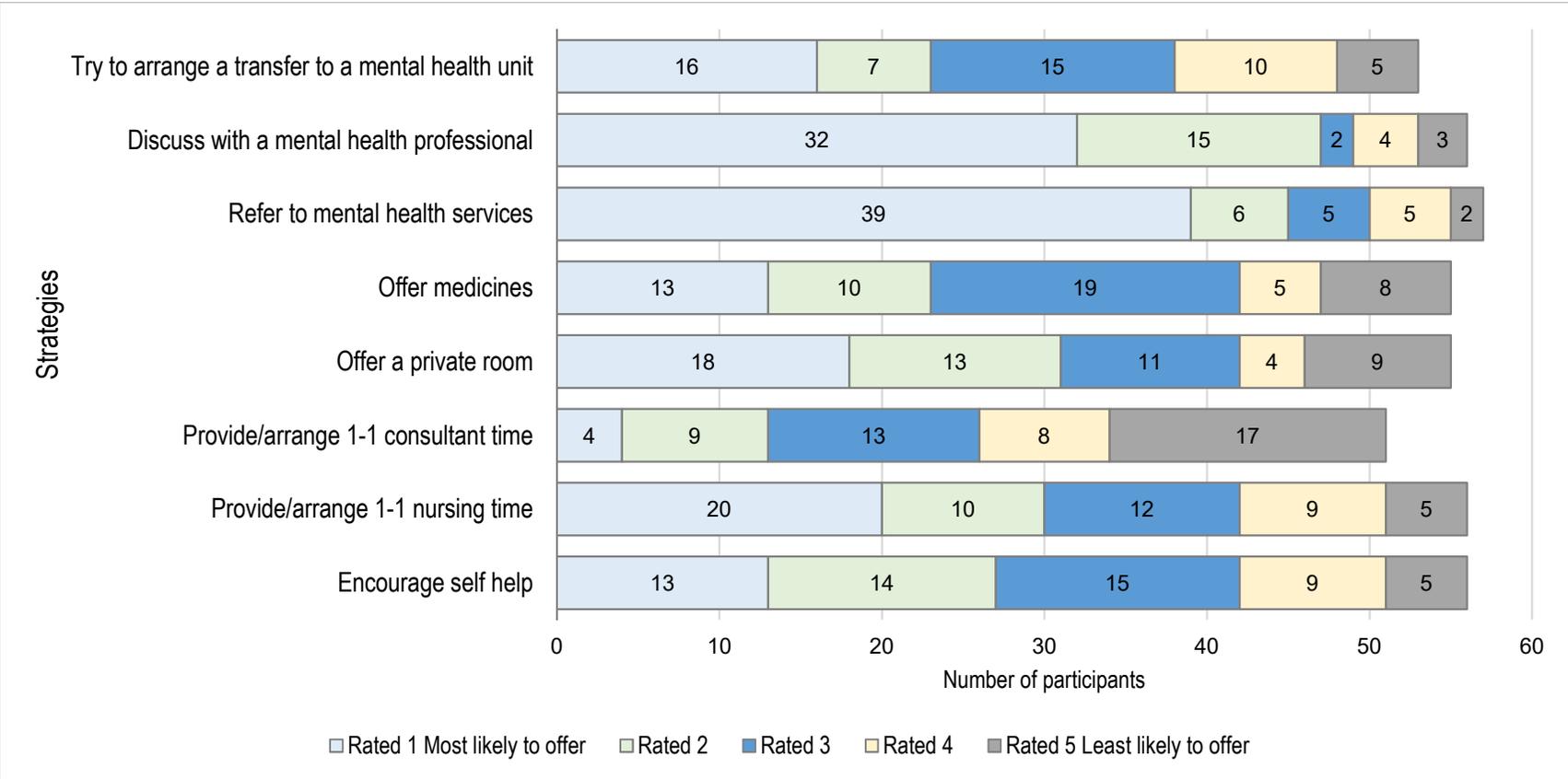
**Table 20 Nonresponses relating to the strategies to support patients diagnosed with personality disorder who are experiencing distress in general hospitals**

Survey option	Number of null responses (n=58)
Encourage self help	2 (3.4%)
Provide/arrange 1-1 nursing time	2 (3.4%)
Provide/arrange 1-1 consultant time	7 (12%)
Offer a private room	3 (5.2%)
Refer to mental health services	1 (1.7%)
Discuss with a mental health professional	2 (3.4%)
Try to arrange a transfer to a mental health unit	5 (8.6%)
Offer medicines	3 (5.2%)

Twenty four out of the fifty eight participants (41%) responded with 26 comments to the free text question: *Are you able to say anything about the strategies which are available in your clinical area. Do you have any good practice examples to share. Have you learnt anything about working with this patient group. Are there additional strategies which you have used, which have not been mentioned?* Participants suggested that basic communication skills were important, but they had mixed opinions about whether training general hospital professionals to work more effectively with distressed patients would be beneficial. Participants reported that interdisciplinary working was challenging. Comments about the use of one to one to one observations were conflated with security measures, which seemed counterintuitive, to supporting distressed patients. The findings are summarised in Table 21.

**Figure 12 Strategies used to support patients diagnosed with personality disorder experiencing distress in general hospitals**

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**Table 21 Strategies used to support patients diagnosed with personality disorder experiencing distress in general hospitals**

Theme	Number of comments	Sample quotes
<b>Barriers and facilitators to services for patients diagnosed with a personality disorder</b>  <i>(Service design)</i>	6	<p>We have 1 patient who self harms and regularly accesses acute medicine. Her behaviour is challenging but we have worked with her CPN/psychiatrist and her to create a bespoke management plan. At times it's very difficult to work together as we come from very different places but in this case we have been successful.' (Participant 39, Nurse, Medicine)</p>
<b>Understanding care and treatment needs in the general hospital</b>  <i>(Service delivery)</i>	5	<p>'I think what is good is that PRN meds aren't prescribed usually until psych input is gained.'(Participant 5, Allied health professional, Medicine)</p> <p>'One to one and use of security is very common.' (Participant 22, Nurse, Medicine)</p> <p>'Just properly explaining everything to a patient. Ensuring they understand all the info you're telling them. Including them in their care.' (Participant 33, Student nurse)</p>
<b>How professionals respond to patients</b>  <i>(Workforce)</i>	15	<p>'Training of staff to understand PD has helped. Staff can find it distressing as they don't feel empowered to help.'(Participant 51, Midwife, Obstetrics and Gynaecology)</p> <p>'This patient group is extremely challenging and in my work I'm constantly being bombarded with training sessions and new ideas that are supposed to make me view them as less challenging. That doesn't help. You need to know how to work with PD patients in order to provide the best nursing care, you also need to be prepared for them working against you. Whilst some fringe elements of</p>

		wider MH care and nursing are trying to beat this out of me with new approaches - you try prepping someone for surgery, for an injury they've inflicted upon themselves whilst waiting for labs to confirm the self reported OD was accurate.' (Participant 27, Nurse, Surgery)
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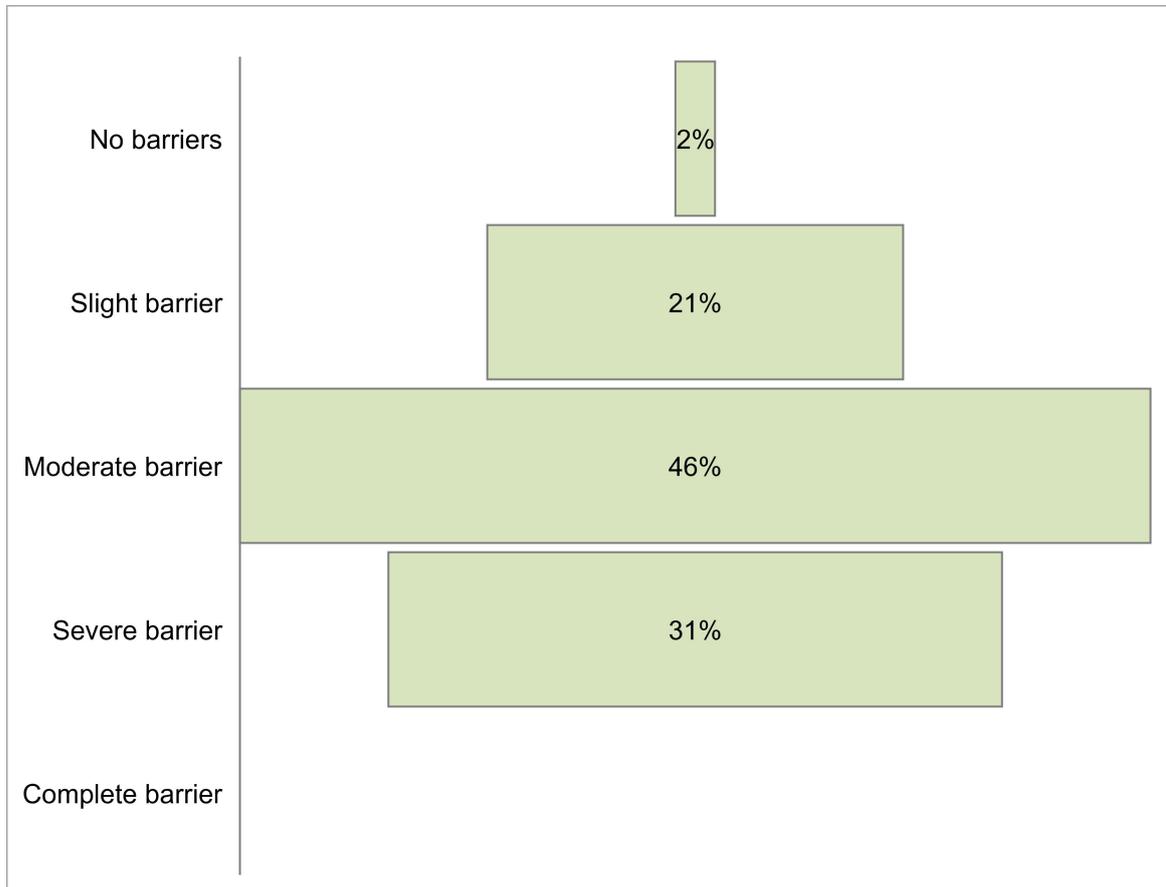
### 7.3.5 Barriers to care and treatment

Participants were asked: *Do you perceive there are any barriers to treating or caring for patients who have a comorbid personality disorder diagnosis?* Seventy seven percent (n=44) of the participants reported that there were moderate or severe barriers (Figure 13). There was one nonresponse to the question on barriers to care and treatment. When asked to explain the response to this question, forty eight out of fifty eight participants (83%) responded, inputting fifty three free text comments. The data were organised into three themes and is summarised in Table 22.

Common barriers included limited knowledge, understanding, and skills among the NHS workforce and stigma. Although one participant suggested patients were responsible for the presenting difficulties, these type of comments were in the minority. Few participants mentioned service delivery issues (6 comments). However, those who did described issues such as agreeing on treatment plans with patients and a need to understand if refusal of treatment was related to the diagnosis. There were mixed views about whether medicines were administered excessively, i.e., *'always push towards heavily medicating'* (Participant 8, Nurse, Medicine), or withheld, albeit for purported clinical reasons.

Participants were critical of current service models. The link between mental health teams and general hospitals was described to be *'virtually non existent'* (Participant 16, Student Nurse). Mental health liaison services were not believed to be sufficiently integrated, and there were perceived problems sharing information between the services. Two participants, a nurse working in intensive care (Participant 7) and a doctor working in medicine (Participant 48), considered the lack of *'out of hours'* mental health support was a substantial barrier, given wards were fully operational 24 hours per day, and it was reported to be *'lucky'* to have access out to of hours mental health liaison (Participant 49, Midwife, Obstetrics and Gynaecology). Physical resources, such as the lack of suitable rooms, were also identified as a barrier.

**Figure 13 Perceived likelihood of barriers to care and treatment of patients diagnosed with a personality disorder**



Intentional space

**Table 22 Barriers to care and treatment**

Theme	Number of comments	Sample quotes
<p><b>Barriers and facilitators to services for patients diagnosed with a personality disorder</b></p> <p><i>(Service design)</i></p>	<p>19 (No facilitators as per question)</p>	<p>‘At times it is very difficult to get a clear history. Records not shared between mental health/ physical health. Can make life harder, but it should not be an issue for the person in our care.’ (Participant 39, Nurse Medicine)</p> <p>‘Psyche reviews take a while and being put on a dementia ward was not always suitable for them but as we were the only secure unit in the hospital by the psych ward it was just the way it had to happen.’ (Participant 40, Nurse, Medicine)</p>
<p><b>Understanding care and treatment needs in the general hospital</b></p> <p><i>(Service delivery)</i></p>	<p>6</p>	<p>‘We just give their regular meds if we can’. (Participant 12, Doctor, Surgery)</p> <p>‘Can be very difficult to support if the patient has different views and ideas to those the professionals recommend.’ (Participant 37, Allied health professional, Leadership &amp; management)</p> <p>‘If the patient makes a decision about their care which may not reflect what the clinical team would advise in their best interests, it may be perceived that the decision making was influenced by their personality disorder rather than a measured decision taken with consideration of all the facts presented.’ (Participant 1, Doctor, Radiology)</p>
<p><b>How professionals respond to patients</b></p> <p><i>(Workforce)</i></p>	<p>28</p>	<p>‘Pts with a co-morbid Dx of PD are generally very hard to treat. They enjoy the experience in some way and often aim to escalate the difficulty. Any Pt presenting to me with a surgical need gets my care but unfortunately those with a Dx of PD like to take up time, energy and care with games.’(Participant 27, Nurse, Surgery)</p> <p>‘We are aware that people with such diagnosis are likely to try and play staff against each other. So we communicate more precisely. These pts therefore get an enhanced level of care.’ (Participant 32, Nurse, Medicine)</p>

		<p>'Staff in the acute clinical setting often have little experience of mental health care, and struggle to know how to help the person in the best way.' (Participant 31, Allied health professional, Neurology)</p>
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### 7.3.6 Prescribing practice

Participants were asked if they prescribed medicines and what (if any) the main issues were around prescribing for this patient group. Forty eight (83%) of participants stated they did not prescribe medicines. Ten participants (17%) stated they did prescribe. There were 16 textual comments on prescribing for patients with a personality disorder in the general hospital. It was unclear if more detailed information would have been obtained about prescribing practice if more participants had been prescribers. The comments encompassed a range of issues and were reported in full in Table 23, along with the professional group, and prescribing status of the participants. The majority of participants expressed hesitancy about prescribing for this group.

**Table 23 Prescribing concerns on general hospital wards related to patients with a diagnosis of personality disorder**

Area of practice	Professional group	Prescriber (Yes or No)	Comment
Medicine	AHP	No	'I advise on prescribing, the usual issues are the hesitancy/lack of hesitancy when to prescribe meds for acute symptoms of a behavioral nature. I worry that maybe sometimes symptoms are troublesome more for staff and so that becomes a factor for prescribing.'
Medicine	Nurse	Yes	'I would never prescribe a new medicine for anyone with a severe mental health condition as again they are out of my remit. I am able to check the BNF and discuss with pharmacy colleagues if I am prescribing new medication for a health condition and they are on medication for a MH condition. This would be for their safety to look at possible interactions to be fair just like any medications I'm not sure about.'
Medicine	Nurse	No	'Medications aren't always effective in personality disorder.'
Medicine	Nurse	Yes	'Same as any patient, check BNF if I am unsure and seek further advice if needed.'
Medicine	Nurse	No	'The doctors prescribe.'

Area of practice	Professional group	Prescriber (Yes or No)	Comment
Medicine	Pharmacist	Yes	'The first go to is a sedative. There is a lack of knowledge around mental health drugs generally particularly around choice of drug.'
Medicine	Doctor	Yes	'Knowledge about the common drugs used (dose, indication), and monitoring required post administration, particularly if concerns regarding cardiorespiratory comorbidity, and risk of respiratory depression.'
No speciality	Pharmacist	No	'Lack of confidence for prescribing in this area.'
No speciality	Student Nurse	No	'Family perception! Have been asked many times whether we can sedate people to stop her distress as that's what 'happens at home!!!'
Obstetrics and gynaecology	Midwife	No	'Pregnancy and breastfeeding contraindications and fears.'
Obstetrics and gynaecology	Midwife	Yes	'I think there may be issues around pain management and bad attitudes/stigma around attention seeking or drug seeking.'
Neurology	AHP	No	'Prescribing for this patient group is outside my scope of practice.'

Area of practice	Professional group	Prescriber (Yes or No)	Comment
Leadership/management	Nurse	Yes	'Interactions between medications and analgesics (e.g. serotonin syndrome).'
Leadership/management	Nurse	No	'Accessing a prescriber.'
Oncology	Nurse	No	'Incomplete medication history. Mental health drugs not stock on wards; however this is an issue for patients with all types of illnesses as a ward cannot stock every drug.'
Intensive Care	Nurse	No	'Unsure about previous prescription usage.'

### **7.3.7 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: a summary of emotional wellbeing**

Sixty two percent of participants (n=36) surveyed, perceived contact with patients diagnosed with a personality disorder was infrequent. However, there seemed to be a disproportionate amount of concern about the care and treatment of this patient group. Participants reported it was not easy to access mental health professionals to provide a mental health assessment or support for patients with a diagnosis of personality disorder in the general hospital or to access advice (Table 17). Participants were critical of current service models and reported that service design issues impeded shared care. Participants believed mental health liaison teams were slow moving and under resourced and provided a lack of practical support (Table 18). The separation between the services and the reluctance for mental health liaison teams to get involved was thought to be contributory to conflict. Although there was insufficient detail from which to understand the conflict described in any depth (Table 19), generally, participants highlighted issues with their immediate colleagues, rather than with the mental health professionals, who were considered in many instances to be inaccessible.

Participants described concerns about limited knowledge, understanding, and skills to promote psychological wellbeing in the general hospital. Participants reported they were most likely to try and refer distressed patients to mental health professionals (Figure 12). Opinions were mixed about whether training and education to work more effectively with distressed patients would be beneficial. It appeared that general hospital professionals were cautious about prescribing for patients diagnosed with a personality disorder (Table 23). Medicines used for mental health were reported to be omitted and potentially overused. Seventy seven percent (n=44) of the participants reported there were moderate or severe barriers to providing care and treatment to patients diagnosed with personality disorder in general hospitals (Figure 13).

## 7.4 Assessing and managing risk to self and others

### 7.4.1 Identifying and managing risk to self and others

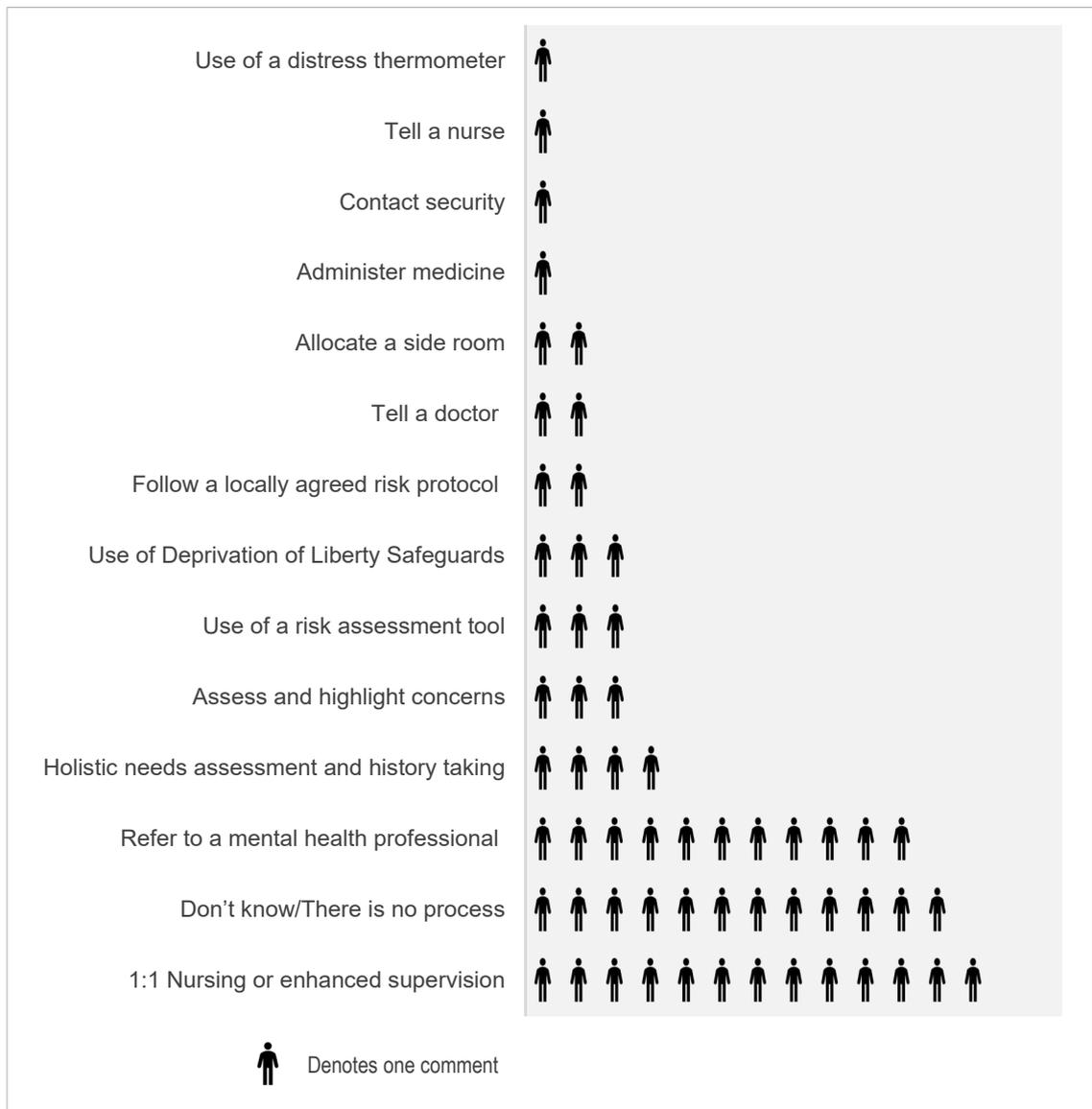
Participants were asked about patients who were considered to present a risk to themselves or other patients. Participants were asked: *is there a formal process for identifying risks and can you say a little about how risks are identified and managed?* Fifty nine comments were provided by forty three participants (74%). The comments were aggregated and are reported in Figure 14. One to one nursing care and increased supervision was reported with more frequency than any other strategy to manage risk. However, the number of comments identifying no process for managing risks to self and others were comparable.

An additional four comments described personal experiences of risk. There was a sense that the participants were frustrated about reactive responses to risk from hospital management and mental health services. One Nurse (21) alluded to general hospital resources being unjustly allocated to support patients diagnosed with a personality disorder, who were at risk:

*'We had a patient on the ward who was a danger to staff and other patients. Things used to get thrown at staff and patients. Management did nothing until one night shift the patient got up, hit an elderly man blacking his eye and breaking his nose.'* (Participant 42, Nursing Assistant, Medicine)

*'We do an assessment of risk and if high we implement 1:1 care. Our nurses are then unavailable to attend to patients.'* (Participant 21, Nurse, Medicine)

**Figure 14 Identifying and managing risk to self and others**



### 7.4.2 Mental capacity

Participants were asked if they were *confident in assessing mental capacity in patients diagnosed with a personality disorder*. All 58 participants responded. Forty participants (69%) stated they were not confident assessing mental capacity in this group. Six participants (10%) reported they were confident to some extent:

*'I sometimes require a second opinion by a psychiatrist, particularly if the person is making decisions with particularly serious consequences.'* (Participant 48, Doctor, Medicine)

Only five (9%) participants stated they felt entirely confident in assessing mental capacity. Of the five professionals who stated they were confident, three were nurses and two were midwives. The participants who stated they were confident were from a range of clinical specialities:

*'Nurses are very well versed and trained regarding capacity and DOLS if needed.'* (Participant 21, Nurse, Medicine)

#### **7.4.3 Leaving against medical advice**

Participants were asked: *how often do people diagnosed with a personality disorder leave against medical advice.* There were two nonresponses to the question on discharge against medical advice. Only 2 participants (5%) considered that patients with a diagnosis of personality disorder frequently left the hospital against medical advice. The majority of participants (n=28, 50%) reported that leaving against medical advice occurred only occasionally. However, more detail was provided by forty two participants (72%) via the related free text question. While leaving against medical advice was considered to be infrequent, a total of 19 free text comments communicated concern about patients diagnosed with a personality disorder leaving the hospital against medical advice. Among the thirteen comments, which indicated that leaving against medical advice was not concerning, the motivation for that view was sometimes questionable:

*'Being honest, it's easier when they leave as generally they create a lot of chaos.'* (Participant 7, Nurse, Intensive Care)

#### **7.4.4 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: a summary of assessing and managing risk to self or others in the general hospital**

Participants commented on the provision of one to one nursing care and increased supervision with more frequency than any other strategy to manage risk (Figure 14). However, a comparable number of comments from participants identified no process for managing risk to self or others (Figure 14). While patients were not considered to leave against medical advice regularly, when this did happen, there were serious concerns. All 58 participants responded to the question on mental capacity and only nine percent of professionals reported confidence in this area. As few workers believed they were competent to assess mental capacity, vulnerable patients diagnosed with a personality disorder were potentially at risk.

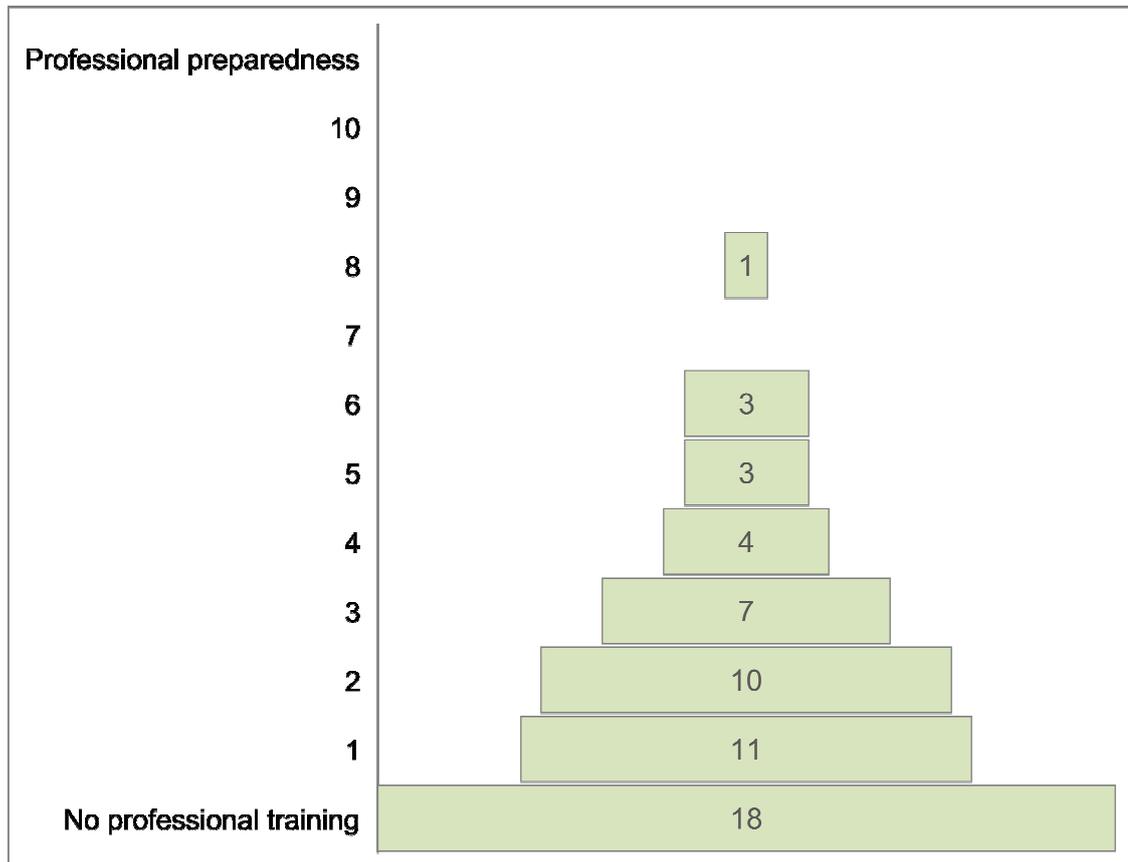
### **7.5 Supporting the workforce**

#### **7.5.1 How well professional training prepared the participants to work with patients diagnosed with a personality disorder**

Participants were asked: *How well do you think your professional training prepared you to work with patients who have a diagnosis of personality disorder?* Participants were asked to rate 'preparedness' between one and ten, with one being least prepared and ten being most prepared (Figure 15). There was one nonresponse to question 17 on professional training. Only four participants rated their level of training above five. A breakdown of the responses by the professional group showed that midwives rated their preparatory training between one and no preparatory training. Nurses rated their preparatory training between no preparatory training and six. Doctors rated their professional training between three and five. The most substantial variance was amongst the allied health professionals (AHP), who rated their preparatory training between no

preparatory training, and eight. Data was not collected in order to differentiate between professional backgrounds in the AHP group.

**Figure 15 How well multiprofessional training prepared the participants to work with patients diagnosed with a personality disorder (n=57)**



#### **7.5.1.1 Opportunities to enhance, knowledge, understanding and skills to work with patients diagnosed with a personality disorder**

Participants were asked: *what additional opportunities were available in the workplace to enhance knowledge and skills?* Participants reported that access to knowledge via formal education or training (n=10, 10%), or case by case consultation (n=11, 11%) was less widely available. Participants generally accessed knowledge to improve understanding and skills after incidents and complaints (n=22, 22%), and via peers (n=18, 18%). Only 15% of participants

(n=15) reported being able to access clinical supervision and 23% (n=23) of participants stated they were unaware of any opportunities. The data provides the impression that learning opportunities were less formalised and available on an ad hoc basis.

#### **7.5.1.2 Workforce development needs**

Participants were asked: *is there anything specific about the assessment and treatment of personality disorders that you would find beneficial to learn*. Twenty six out of fifty eight participants (45%) provided 31 free text comments. Eleven of the participants provided general statements about accessing training. Two of those were student adult nurses who suggested that this teaching should be added to their programme of study. A further eleven comments identified learning needs, which were broadly related to improving the psychological wellbeing of patients with a diagnosis of personality disorder. The comments ranged from *'how to avoid their manipulation* (Participant 7, Nurse, Intensive Care), to *'the appropriate way to respond and react'* (Participant 17, Nurse, Obstetrics and Gynaecology). The comments appeared to illustrate that general hospital professionals experience emotional challenges in their work. In context, only 15 of the participants reported being able to access clinical supervision (7.5.1.1).

There were six comments about the assessment and management of risk to self and others. Participants reported they wanted to know more about *'risk management'* (Participant 38, Nurse, Medicine) and *'de-escalation'* (Participant 30, Nurse Intensive Care), and promoting social functioning and obtaining social support for patients under their care (3 comments):

*'It can feel like these patients are left to bounce from crisis to crisis, which alongside being distressing for them is also difficult for HCP. Formalised pathways that can be accessed by non MH professionals would be helpful, not*

*just the black hole of a CMHT referral.*' (Participant 51, Midwife, Obstetrics and gynaecology)

### **7.5.2 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: a summary of supporting the workforce**

Participants did not believe they were well prepared to work with patients diagnosed with personality disorder (Figure 15). The learning needs identified were consistent with the skills identified in the personality disorder capabilities framework (National Institute for Mental Health in England, 2003a). Opportunities to gain additional knowledge, understanding and skills appeared to be ad hoc. The personality disorder capabilities framework may offer a useful starting point for developing professionals in the general hospital setting. Health professionals also seemed to require additional support to undertake emotionally challenging work.

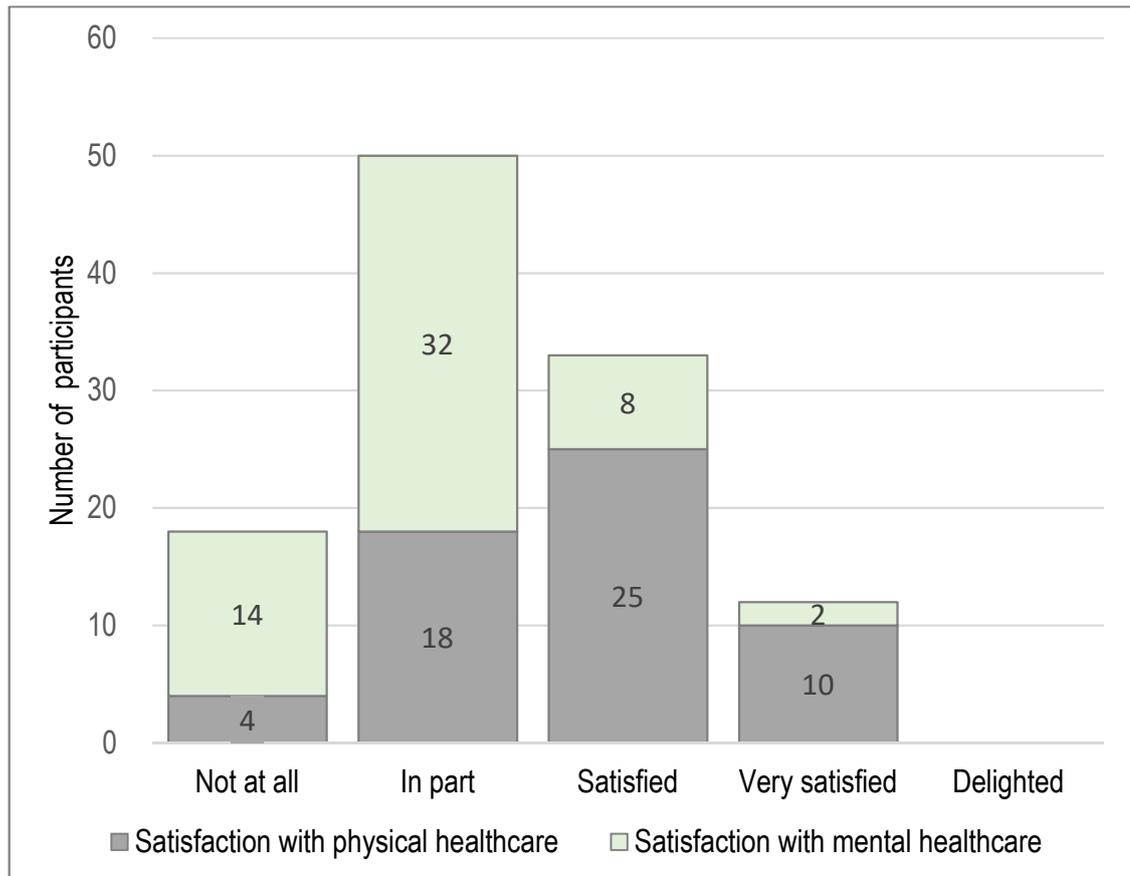
## **7.6 Quality of the healthcare available in general hospitals to patients diagnosed with a personality disorder**

### **7.6.1 Satisfaction with the mental and physical healthcare provided to patients diagnosed with a personality disorder in the general hospital**

Participants were asked to rate *satisfaction with the physical and mental healthcare* provided to patients with a diagnosis of personality disorder, using a five point scale. There were three nonresponses to the question on satisfaction with healthcare. Twenty two participants (39%) reported being less than satisfied with the physical healthcare available to patients diagnosed with a personality disorder. Forty six participants (82%) stated they were less than satisfied with the mental healthcare available (Figure 16). Although participants were not overly positive about the mental or physical healthcare available, the data

indicated the participants did not believe there was parity of esteem in the general hospital setting, with only 10 (n=56, 18%) participants reporting satisfaction with the mental healthcare, which was available.

**Figure 16 A comparison of satisfaction levels between mental and physical healthcare**



Fourteen out of fifty eight participants (24%) contributed 14 free text comments about the physical healthcare provided to patients with a diagnosis of personality disorder in the general hospital. One participant wrote 'dismal' (Participant 7, Nurse, Intensive care), but this could not be contextualised. Thirteen responses were organised into four themes (Table 24). Eight of the comments, related to the knowledge, understanding and skills of the workforce. Seven of the participants implied that there were areas of deficiency. One participant (27)

disagreed that the general hospital workforce lacked the knowledge, understanding and skills to fulfil their role.

**Table 24 Perspectives on the physical healthcare available in general hospitals**

Theme	Number of comments	Sample quotes
<b>Barriers and facilitators to services for patients diagnosed with a personality disorder</b>  <i>(Service design)</i>	1	'I am satisfied with the physical health care given, but it can be very time consuming to provide this in a very busy system. In my trust there are some 'frequent attenders' who have care plans formed by various specialities, and the patients themselves, this can make the patient journey smoother, and can work well.' (Participant 48, Doctor)
<b>Understanding care and treatment needs in the general hospital</b>  <i>(Service delivery)</i>	2	'Physical health seems to be well managed.' (Participant 30, Nurse, Intensive care)
<b>How professionals respond to Patients</b>  <i>(Workforce)</i>	8	<p>'Physical healthcare provided is not based on any Dx of a mental disorder. We treat people and we treat them with care, professionalism and responsibility. People with PDs kick back against that.' (Participant 27, Nurse, Surgery)</p> <p>'Poor awareness leads to a poor standard of care. This begins with frontline staff and continues throughout.' (Participant 24, Student nurse)</p>
<b>How patients respond to the hospital</b>  <i>(Distress)</i>	2	The 'higher level of self discharge is concerning and a possible area that could improve.' (Participant 10, Nurse, Oncology).

There were 16 free text comments on mental healthcare, contributed by fifteen out of fifty eight participants (26%). Most of the participants commented on

service design issues (Table 25). The dominant view was that mental health services were inadequate and poorly integrated (10 comments). However, some participants identified a need for additional training to respond to patient distress (4 comments).

**Table 25 Perspectives on the mental healthcare available in general hospitals**

Theme	Number of comments	Sample quotes
<b>Barriers and facilitators to services for patients diagnosed with a personality disorder</b>  <i>(Service design)</i>	12 barriers and 2 facilitators	'Poor support from MH liaison team due to them having no staff and unable to cover the whole hospital.' (Participant 43, Nurse, Medicine)  'I think we are very lucky as we have specialist perinatal mental health services and out of hours psych liaison.' (Participant 49, Midwife)
<b>How professionals respond to patients</b>  <i>(Workforce)</i>	4	'All staff members need more training on dealing with complex mental health issues and some de-escalation techniques.' (Participant 28, Student nurse)

### 7.6.2 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: a summary of the quality of healthcare available

82% of participants were less than satisfied with the mental healthcare available in general hospitals (Figure 16), raising concern for inpatients with both acute mental and physical health needs. Unsatisfactory service levels were the most commonly cited problem (Table 25).

## **7.7 Ideas for improvement to support patients diagnosed with a personality disorder on general hospital wards**

Participants were asked: *if resources were no object, what could be done differently, to support patients who have a diagnosis of personality disorder.* Thirty six participants (62%) provided forty one free text comments about what could be done differently. The comments were aggregated and are reported in Table 26. More than half of the comments were related to integrating mental health care and treatment in the general hospital and improving access to mental health professionals:

*'I don't think that patients need to be 'medically fit' before they are reviewed by a mental health care professional. For example, if that patient is simply waiting for a 16hr bag of Parvolex to finish, there is no need to wait for that to occur before they are reviewed.'* (Participant 48, Doctor, Medicine)

*'The patients could have regular contact and follow up by mental health professionals to ensure we are considering everything we should be from the mental health perspective.'* (Participant 5, Allied health professional)

Intentional space

**Table 26 Ideas for improvement to support patients diagnosed with a personality disorder on general hospital wards**

<b>Idea</b>	<b>No of comments</b>
Increased access to mental health specialists	12
Fully integrated interdisciplinary care and treatment	11
Available mental health beds/units	4
Additional training	4
Better staffing/More nurses	3
Supported activities/access to therapy	2
Dual trained nurses	1
Improved pathways	2
Designated quiet spaces	1
Availability of dedicated 1:1 nursing	1

### **7.7.1 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: a summary of ideas for improvement**

The data suggested that the general hospital workforce believed they lacked the knowledge and skills needed to deliver an acceptable service. Participants believed the solution was to improve access to mental health specialists and to integrate care and treatment fully (Table 26).

## **7.8 Chapter summary: How do general hospitals respond to patients diagnosed with a personality disorder who are distressed; the views and perspectives of general hospital professionals**

The findings of study 3a found that overall general hospital professionals believed that general hospitals respond to patients diagnosed with a personality

disorder adversely. The participants believed they lacked the knowledge and skills to respond to emotional distress. Participants reported they were unable to deliver a satisfactory service to patients diagnosed with a personality disorder. There was no evidence that adequate processes were in place to support patients who were a risk to themselves or others (Figure 14). As with study 2a and 2b, mental health liaison services were believed to be underresourced and understaffed and the separation between the general hospital and the mental health service was not considered to be conducive to the care and treatment of patients with a diagnosis of personality disorder.

Chapter Eight moves on to discuss study 3b, QUAL telephone interviews with mental health liaison professionals. Areas identified for exploration in study 3b included: perceptions of the mental health liaison role for patients diagnosed with a personality disorder, expectations of the general hospital, and training and education in the general hospital.

## **Chapter 8 : Results from mental health liaison professional study: 3b QUAL telephone interviews**

Chapter Eight reports the results of study 3b, thirteen QUAL<sup>16</sup> telephone interviews with mental health liaison professionals. This chapter focuses on how general hospitals respond to patients diagnosed with a personality disorder from the perspective of mental health liaison professionals. A series of open questions, derived from the findings of studies, 1, 2a, 2b, and 3a and the personality disorder capabilities framework (National Institute for Mental Health in England, 2003a) were asked. The interview topic guide is included in Appendix 10, but questions broadly focused on referrals, outcomes, the general hospital setting, education and learning, and ideas for improvement. The sample comprised: a consultant nurse and consultant psychiatrists (n=5), a mental health pharmacist (n=1), and liaison nurses (n=7). Data were collected between March and April 2018.

Framework analysis was used to produce an overarching thematic framework of the data (Appendix 12). The four themes: Workforce; Knowledge, understanding, skills, and discriminatory practice; Service delivery; Alliances, diplomacy, and the care and treatment of patients diagnosed with a personality disorder; Service design; Parity of esteem; and Organisational stress; Mismatched expectations and decision making are reported respectively. The chapter concludes in section 8.5, with a summary of the findings. This chapter introduces the new theme Organisational stress; Mismatched expectations and service led decision making, and builds on the previous findings, which suggest that general hospitals respond to patients diagnosed with a personality disorder adversely.

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<sup>16</sup> QUAL refers to the notational system used in mixed methods research to denote the study design

## 8.1 Theme one: Workforce; Knowledge, understanding, skills, and discriminatory practice

This theme focused on the lack of knowledge, understanding and skills among the general hospital workforce and the role of mental health liaison in addressing the discriminatory practices. General hospital professionals were perceived to be reluctant to use the diagnosis of personality disorder. It was considered by the participants that referrals were rare for this condition. In some instances, participants described being aware of patients being 'relabelled', with more socially acceptable diagnoses. Some participants explained that general hospital professionals were more forthcoming with the term 'personality disorder' when it was used to label patients who were hard to work with. One participant suggested that many professionals working in the general hospital considered psychiatry to be 'slightly dark' (Participant 5, Consultant). Participants provided a sense that many general hospital professionals were oblivious that their practice was condemnatory:

*'I get frustrated all the time, she's a PD, or they'll say, it's one of yours. It's absolutely mad, bonkers, yeah, that kind of terminology that's quite derogatory.'* (Participant 6, Liaison Nurse)

*'You know, with sort of words like manipulative bandied around where, you know, people are just finding someone really hard to work with and they kind of start using kind of pejorative terms in a way I think they wouldn't if they just knew a little bit more about the disorder.'* (Participant 1, Consultant)

Half of the participants and mostly those at consultant level emphasised the importance of establishing good working relationships, with their general hospital colleagues to develop the knowledge, understanding, and skills needed. A recurrent theme in the interviews was the sense that responding to people who were upset was nothing new to the general hospital workforce. The participants believed that caring for patients with a personality disorder diagnosis did not

automatically require sophisticated expertise. Participants talked about supporting their colleagues to develop confidence:

*'A lot of these, kind of, slightly lower level or less concerning situations might be managed now in house by the general nursing staff or they might request a little bit of assistance or for somebody to come across and perhaps just speak to the patient and often that would be enough, but I think my colleagues are really, really skilled in deescalating these situations.'* (Participant 3, Consultant)

*'Once the staff have got the knowledge and they've got the understanding, they can respond quite promptly to the needs of those patients.'* (Participant 6, Liaison Nurse)

It was concerning that one mental health nurse (Participant 2) had observed discriminatory practices in other mental liaison professionals. The participant questioned their professional knowledge, understanding, and skills. It was proposed that as a profession, mental health nurses had 'let themselves down terribly', concerning patients diagnosed with a personality disorder. There were no similar reflections about the other professional groups:

*'That tends to be the attitude that people have; they're coming here, they're wasting my time, people who deserve care should be having my time, not these people who are time wasters.'* (Participant 2, Liaison Nurse)

## **8.2 Theme two: Service delivery; Alliances, diplomacy, and the care and treatment of patients diagnosed with a personality disorder**

The care and treatment provided to patients diagnosed with a personality disorder and the role of the mental health liaison service will be expanded upon in this section. Participants were keen to point out that not all patients diagnosed with a personality disorder required a referral to mental health liaison services. However, the mandate on mental health liaison services in supporting people

with the difficulties associated with personality disorder was considered substantial. Mental health liaison was deemed essential to communicating the mental health needs of some patients. In all interviews, the participants considered the clinical work with patients diagnosed with a personality disorder was typical of the mental health liaison role. Examples of their work included: assessment of people following self harm or overdose, attending interface meetings, responding to patients in distress, and care planning. However, there was some suggestion from the participants that professionals in the general hospital believed that the mental health liaison role was to coerce patients to have physical health treatment:

*'In terms of referrals of patients who have got a definite personality disorder, probably are very low. However, they are very difficult to manage, you know, so they might consume a disproportionate amount of time in a way.'* (Participant 1, Consultant)

*'If the patient, for example, has come in with an overdose, and they're refusing treatment, the general hospital might ask us to come over and assist to try and make the patient agree to have the treatment that's required, for the overdose.'* (Participant 9, Liaison Nurse)

As patients were under the care of the general hospital, not mental health services, participants accepted that general hospital professionals would not necessarily elect to contact mental health liaison when there was a problem. The analysis indicated that participants were using high level influencing skills to persuade the general hospital to make referrals. Participants extensively explained how they used diplomacy and relationship building to promote the care and treatment of patients. Most of the participants described ongoing work in their services to establish sensible thresholds for referrals, balanced against the safety and comfort of patients. The alliances created with general hospital colleagues were used to subvert harm, and the impression was given that this interpersonal work was almost surreptitious:

*'It's a bit of a sort of diplomacy role (...) we're used to working with people with challenging personalities. So we're perhaps not quite as alarmed by some of the things that happen, as the more generic hospital staff would be.'* (Participant 1, Consultant)

*'So, we've got good relationships with all of the wards, and we know most of the staff on all of the wards, and because of that, we're normally the first port of call for any of those complex cases.'* (Participant 10, Liaison Nurse)

When asked about the assessment of mental capacity in the general hospital, most participants stated that the general hospital would assess decision making capacity, the same as they would with any other patient. However, some participants argued that determining decisional capacity was nuanced and complex with patients diagnosed with a personality disorder. There was some suggestion that inexperienced general hospital professionals might make ill informed decisions, and some participants argued that it was preferable for mental health liaison to be involved in capacity decisions when there were potential psychological difficulties:

*'In general we would say they should assess capacity in the first instance by themselves.'* (Participant 7, Consultant)

*'My only concern with a non-mental health clinician, so a staff nurse or a junior doctor, who's not experienced in mental health, assessing the capacity of a patient, with a mental health diagnosis is, it would probably be more difficult for them to pick up on the nuances of whether that patient's mental health needs are impacting on their capacity.'* (Participant 10, Liaison Nurse)

Some participants believed that understanding around legislative issues had improved in general hospitals, while others considered that understanding of the mental health legislation was lacking. Participants expressed concern about illegal detentions and tragic outcomes. The analysis indicated that more clarity about who should undertake capacity assessments, and the roles and expectations around legislation was needed:

*'She wasn't detained, she wasn't subjected to DoLS and she was quite young. She was in her late thirties. So she was denied to go out (...) I don't know how long that took for, but when we received the referral, she was admitted the day before, so probably two days.'* (Participant 6, Liaison Nurse)

*'I think this lady, part of the problem was she always believed that services would save her and unfortunately they didn't and as a consequence of her not taking that medication she did die, but that, again, we can't force...within the Mental Health Act, we can't force physical medication onto...and it's difficult, but she had the capacity to make that decision.'* (Participant 2, Liaison Nurse)

Another gap in service delivery was reported to be the management of medicines. Participants reported that general hospitals commonly stopped psychotropic medicines and while there was some suggestion that those drugs were not available, one participant (8) stated this was usually incorrect. Some participants concluded that psychotropic medicines were not a priority in general hospitals:

*Acute hospitals have a terrible habit, of just taking people off all their mental health medication when they come into hospital. That's not always a good thing to do.'* (Participant 4, Consultant)

*'In terms of the psychotropic medications, 95 per cent of them I would say are available to general hospitals, so there shouldn't be a delay.'* (Participant 8, Mental health Pharmacist)

*I think sometimes a popular misconception might be that if psychiatric medication isn't available, it's not as important as a blood pressure agent. Which is a misconception.'* (Participant 8, Mental health Pharmacist)

However, the opposite scenario, the administration of excessive medication was also described in people diagnosed with a personality disorder. Some of the participants believed general hospital professionals tried to medicate away personality disorder and distress. However, other participants disagreed and reported there were generalised prescribing problems for this group. Participants

raised concerns about the safe use of hypnotics, anxiolytics and opioids in patients diagnosed with personality disorder in the general hospital setting:

*'There was one patient in particular that got given a lot of benzodiazepines and subsequently, kind of, almost had respiratory arrest.'* (Participant 3, Consultant)

*'Some doctors won't prescribe anything at all. They're very reluctant to prescribe anything at all, especially because they say everything's behavioural, and then some will prescribe an awful lot of medication, such as benzodiazepines, sometimes at very high dosages which aren't really warranted (...) 'It's probably the way they're trained medically isn't it, and I think they think let's go with the highest dose, and it'll work the quickest, and the patient will calm down.'* (Participant 9, Liaison Nurse)

Experienced mental health liaison professionals were considered by participants to be requisite to support the general hospital with the safe and timely use of medicines, especially in the event of a mental health crisis or emergency. However, the nature of the liaison role was that the mental health team could only offer advice. One mental health liaison nurse participant (11) talked about their difficulties convincing the general hospital that a patient needed medicine because they were not a doctor. It was believed that all mental health clinicians had to be careful not to overstep their role:

*'Sometimes we will go up and you make recommendations of what to use and then they call us two days later that this person is still in crisis, but when we check the record that's not been done.'* (Participant 11, Liaison Nurse)

*'Even if you've rationalised and you've set the entirety of why you've come to a decision as to why a psychotropic would be prescribed, if you've taken that decision without actually discussing it with the medical team, that can be seen as stepping on their toes.'* (Participant 8, Mental health Pharmacist)

One participant (3) expressed uncertainty about how well quality measures such as clinician rated outcome patient measures (CROMs), the patient reported

experience measures (PREMs), and the patient reported outcome measures (PROMs) reflected the actual value of mental health liaison work:

*'So are they relevant to the group? Are they personal to the group? So I think that's the real tricky bit (...) I can demonstrate until the cows come home how cost effective we are as a, you know, liaison service, because it's not difficult to do that.'* (Participant 3, Consultant)

### **8.3 Theme three: Service design; Parity of esteem**

This theme focused on the integration of mental and physical health services and the implications for achieving parity of esteem for people diagnosed with a personality disorder. Participants reflected that there was little parity with other conditions. One participant (2) stated that patients diagnosed with a personality disorder were provided for inadequately in national policy and the expected standards of care. The NICE guidelines were perceived to be a barrier to accessing mental health care and treatment because of recommendations to minimise the use of inpatient services. Another participant echoed the difficulties in accessing mental health support for patients diagnosed with a personality disorder, who were admitted to the general hospital. The participant stated that it was difficult to access community support for patients in crisis as they were deemed too 'risky' and were refused psychological therapy:

*'Due to the nature and impulsivity of people with personality disorder, sometimes very difficult to signpost them because of the risks, especially for psychological services like IAPT who don't like to take anyone who is the most risky (...) For example we have this rule in this area that if somebody presents with an overdose, we were not able to refer them for psychological services, so they had to be clear of any risky behaviour for six months, let it be self-harm or impulsive overdoses (...) It's only recently in the last few months they changed the rule so now they consider cases on the individual basis.'* (Participant 11, Liaison Nurse)

Some clinical areas appeared to make little effort to respond to mental health needs. Participants considered their general hospital colleagues believed not being mental health trained justified their omissions. Participants advised that local policies on managing mental health crises in the general hospital setting were few and that the general hospital setting resorted to custom and practice approaches. Mental health assessment skills were deemed to be very poor among some general hospital professionals. Participants imagined those general hospital professionals were not uncomfortable in that position, as mental illness was a problem for somebody else:

*'You don't hear the mental health nurse saying, I'm not general trained. If there's a critical health problem that you come across during your assessment, you go and seek advice. You don't react in the same way. This is your patient.'* (Participant 13, Liaison Nurse)

*'I don't think they have guidance specifically on psychiatric crisis. So it would be a case of practitioner experience really, which is probably what it is throughout a lot of the country.'* (Participant 8, Mental health Pharmacist)

There was a sense from the participants that newly qualified health professionals were more educated about the issues related to parity of esteem, and that some trusts had excellent leadership, positively championing the treat as one agenda (NCEPOD, 2017). Regardless, achieving parity of esteem for people diagnosed with a personality disorder was considered to be a long way off:

*'There are lots of hurdles to overcome around treatment of patients with personality disorders, and attitudes and values towards patients with personality disorders. And we are a long way off parity of esteem, even in our hospital, we're a long way off that.'* (Participant 10, Liaison Nurse)

Many of the participants were involved in educational work to improve the integration of services in the general hospital. However, mental health training in some places was perceived to be an optional extra and general hospital professionals were not supported to attend training. Participants determined that

failure to integrate mental health training was likely to result in adverse outcomes. The current service model, which gives priority to accident and emergency over the inpatient wards, meant it was not feasible to wait until the mental health liaison team were able to attend:

*'They had some pretty bad suicides and there was a lot of anxiety around the people we work with (...) we'd deliver training for an hour at each ward, the training was routinely badly attended, as time went by, that hour, they tried to close it down to half an hour and then 15 minutes.'* (Participant 2, Liaison Nurse)

*A&E we've got an hour to respond, whereas maybe with the wards we've got 24 hours to respond (...) if someone is in crisis and then is in distress there and then, 24 hours is quite a long time.'* (Participant 12, Liaison Nurse)

*'I have this belief that we need to skill up people as much as we possibly can, to be able to deal with things in the moment. Because I think, when 70 per cent of people in an acute hospital, have got a mental health need, that's the kind of average statistic, there's no way that, even when you've got a team of X people, that you're going to be able to deal with all of those X beds, which is what we have. So we have to skill people up as best as we can, and actually, for me, it's about getting them to understand that it's not complicated stuff.'* (Participant 4, Consultant)

Participants reasoned that mental health liaison teams were under resourced. The participants provided a sense of the precarity of the relationships with the general hospital, and the importance of the interpersonal work, undertaken, which was not always recognised. Several participants stated that much of their work, i.e., the role modelling, relationship building, and offering peer support went unrecorded, and was difficult to demonstrate as a return on investment. Participants recounted how they were required to be considered and judicious in their negotiating, as they mostly relied on the general hospital referring patients and delivering the care and treatment they recommended. It was considered that commissioners required a good understanding of mental health liaison services in order to fund them adequately:

*'I've invested most of my time, in that time, trying to improve the relationships with the referrers, because it doesn't matter how psychiatrically literate the referrers are, if they don't pick up the phone and refer the patients, we can't do anything (...) So, knowing our place, is the first thing, and then negotiation at other times, is important.'* (Participant 5, Consultant)

*We've got commissioners that buy into the whole psych liaison system, which is fortunate for us (...) I'm aware that it's not all sweetness and light in other hospital.'* (Participant 10, Liaison Nurse)

#### **8.4 Theme four: Organisational stress; Mismatched expectations and service led decision making**

Organisational stress; Mismatched expectations and service led decision making will be discussed in this section, which focuses on the stress and strain observed in individual professionals and at an organisational level. Participants explained that general hospital professionals were intensely anxious about working with people diagnosed with a personality disorder and were afraid. Participants had observed that the general hospital was easily overwhelmed by people diagnosed with a personality disorder due to a complete lack of understanding. Participants identified that supporting the general hospital workforce to manage collective anxieties was as important as supporting the patients. These views surfaced mainly concerning the indirect impact of organisational stress on patients diagnosed with a personality disorder:

*'I think that patients perceive that they are treated slightly differently. I suspect that many of them perceive that sometimes the wards are a bit anxious about them. I think they perceive that the wards are slightly less interested in them. And I strongly suspect that the patient's perceptions of that approach, simply drives any of the communication difficulties, which were already there, and a vicious circle is very quickly begun.'* (Participant 5, Consultant)

*'With a bit of education around, potentially what that patient's been through, why they're behaving in the way they're behaving, what we can do to try and help manage their emotions, to help validate what they're going through, more often than not that helps the staff and the patient, it helps the patient calm down, it*

*makes them feel better, which is more beneficial for the whole ward really.'* (Participant 10, Liaison Nurse)

Participants reported that anxiety and fear amongst the general hospital professionals elicited over and under reactions to presenting situations. Participants considered it was in the interests of the general hospital workforce to be able to respond appropriately to people presenting with distress. Some participants stated it was not uncommon for general hospital professionals to become frantic, seeking advice and support from the mental health liaison service, with desperation. While no participants disputed that supporting anxious and fearful general hospital professionals was part of the liaison role, they reported it was not practical to respond to continuous phone calls or provide one on one care to all distressed patients, which was sometimes the expectation:

*'I don't think that people don't want to look after someone who's upset, I think that people haven't got the adequate skills to be able to deal with that, and that makes them panic, and so they avoid it.'* (Participant 4, Consultant)

*'Sometimes you'll have them calling up numerous times, the general hospital, they want you to be there on a one to one with the patient.'* (Participant 9, Liaison Nurse)

*'They are very, very scared as I said, even approaching them when they're self-harming or being chaotic because they just don't know what to say because they're worried that they'll make the situation worse.'* (Participant 11, Liaison Nurse)

Participants explained that there was an expectation grounded in the anxiety of professionals, that mental health liaison services would assume responsibility for patients with personality disorder diagnoses, with the perception being that mental health units were for mental health patients, and not the general hospital. It appeared that mismatched expectations and unresolved anxiety and distress sometimes grew into interprofessional conflict:

*'I'd come back from days off and this lady hadn't been seen for a couple of days, I walked onto the ward and there was two doctors and the nurse in charge shouting at me up the corridor, that's the kind of thing that we have to avoid.'* (Participant 2, Liaison Nurse)

*'Conflict you get it quite often I'd say, and again, I think it's to do with people's lack of understanding, lack of willingness to want to understand.'* (Participant 9, Liaison Nurse)

Mental health liaison nurses, in particular, reported that they clashed with the general hospital over patient care. One participant (12) described how a 'vicious cycle' began when a care plan was implemented, which was aspirational and unrealistic, and offered no support to anybody. Given the importance placed on relationships, the results indicated that there was a strong possibility that organisational stress was contributing to this type of service led decision making:

*'When you've got the Doctors saying that this is not a medical issue, this is a psychiatric issue. And you've got that battle. That's the main one that we get to be honest.'* (Participant 13, Liaison Nurse)

*'There was this professionals' meeting and a care plan was put in place which basically stated that she doesn't need to remain on the general ward (...) but what would quite frequently happen is if then she perceived her needs weren't being met in terms of the pain relief, she would either say she was going to self harm, or she would self harm. And that would then result in the care plan not being followed and her remaining on the ward for longer than she needed; which was this vicious cycle that was very difficult to break.'* (Participant 12, Liaison Nurse)

## **8.5 Chapter summary: How do general hospitals respond to patients diagnosed with a personality disorder who are distressed; the views and perspectives of mental health liaison professionals**

The findings of study 3a supported the idea that general hospitals responded to patients diagnosed with a personality disorder adversely. However, in study 3b, the impact on patients, demonstrated by the analysis was less explicit in contrast to the results of studies 2a, 2b and 3a. The mental health liaison professionals tended to talk about the general hospital professionals and the interface between the services. The participants described some responsive practice, in some general hospitals, after input from mental health liaison services. However, the accounts provided by the participants suggested that overall, attitudes, stigma, and exclusionary practices prevailed. Only one participant was forthcoming in talking about discrimination by mental health liaison professionals. The claim that some mental health nurses believed people diagnosed with a personality disorder were a waste of time appeared serious, with far reaching implications for how general hospitals respond to patients diagnosed with a personality disorder.

Although participants concluded that few patients with a formal diagnosis of personality disorder were referred to mental health liaison, the mandate on mental health liaison services was deemed to be substantial. Participants considered that mental health liaison services were essential to aiding communication regarding the mental health needs of some patients. Much of the clinical work, with patients diagnosed with a personality disorder, was typical of the mental health liaison role generally. Some participants suggested that inexperienced general hospital professionals might make ill informed decisions about mental capacity in relation to people diagnosed with a personality disorder.

The analysis indicated that more clarity between the services about the roles and expectations was needed

Participants described having to convince the general hospital professionals to use medicines with patients diagnosed with a personality disorder in a safe and timely manner. There was a sense that some mental health liaison nurse participants were perceived to be less credible than doctors and had difficulties convincing the general hospital to administer medicines. It was apparent from the data that participants from all disciplines had to be careful not to overstep their role. It appeared that participants used high level influencing skills, to persuade the general hospital to make referrals. Participants extensively referred to diplomacy and relationship building to promote the care and treatment of patients diagnosed with personality disorder. Participants appeared to hold little authority on the general hospital wards and they carefully managed their position to ensure that they could negotiate and influence effectively on behalf of patients. The alliances the participants created with their general hospital colleagues were used to subvert harm, and the impression was given that this interpersonal work was almost surreptitious. Measuring and reporting quality and demonstrating outcomes in this type of interpersonal work was identified to be challenging.

A key point, which was highlighted was that a service model, which prioritised accident and emergency over the inpatient wards, meant it was not feasible to wait for the mental health liaison team to arrive when patients diagnosed with a personality disorder were experiencing distress. Local policies on managing mental health crises in the general hospital setting were identified to be few, and the participants were under the impression that some general hospital professionals thought that not being mental health trained justified their unresponsiveness. Some general hospital professionals were perceived to be comfortable with being unaccommodating, as they believed mental illness was not their concern. Newly qualified health professionals were reported to be more educated about the need for parity of esteem. However, the participants deduced that the general hospital was generally unable to meet the needs of people

diagnosed with a personality disorder and there was little parity with other conditions.

Participants explained that general hospital professionals were anxious and afraid to work with people diagnosed with a personality disorder. It was considered that the general hospital workforce was easily overwhelmed due to a general lack of understanding. While no participants disputed that supporting anxious and fearful general hospital professionals was part of the liaison role, they reported it was not practical to respond to continuous phone calls or to provide one on one care to all distressed patients, which was sometimes the expectation. It appeared that mismatched expectations and unresolved anxiety and distress sometimes grew into interprofessional conflict. Front line mental health liaison nurses, in particular, reported they clashed with the general hospital over patient care. Participants considered that mental health liaison teams were under resourced and it was suggested that commissioners required a good understanding of mental health liaison services in order to fund mental health liaison services effectively.

## **Chapter 9 : Integration of the results and an explanatory framework of how general hospitals respond to patients diagnosed with personality disorder who are distressed**

This chapter reports the integrated results of study 1: the scoping review of the literature (n=10)<sup>17</sup>; studies 2a and 2b, QUAN<sup>18</sup> web based survey (n=65), and embedded [QUAL] telephone interviews (n=12) with patients; studies: 3a, QUAN web based survey of general hospital professionals (n=58); and 3b, QUAL telephone interviews with mental health liaison professionals (n=13). The sequencing of the studies is shown in Figure 17. In this chapter, the findings of this PhD research are integrated and interpreted, to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed. The checklists used to integrate the findings are available in Appendix 13.

The chapter begins in 9.1 by recapping the aims and objectives of this research. In 9.2 the themes from studies 1, 2a and 2b, 3a and 3b are assimilated to produce integrated themes and meta themes (Table 27). Figure 18 identifies the relationships between the integrated themes: Workforce; Service delivery; Service design; Organisational stress; and Adverse events, and the linkage with the identified meta-themes: Structures; Systems and logistics; and Outcomes. The explanatory framework is examined in detail in sections 9.3 to 9.5, exploring convergence, complementarity and dissonance, across all of the studies, drawing on systems thinking (World Health Organisation, 2009), and the wider literature to inform the discussion.

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<sup>17</sup> n refers to the number of studies included in the scoping review of the literature

<sup>18</sup> QUAN and [QUAL] refers to the notational system used in mixed methods research to denote the study design

Section 9.3 focuses on Structures: the personality disorder diagnosis and Service design. Section 9.4 moves on to discuss Systems and logistics: the Workforce and Service delivery. Section 9.5 explores the Outcomes: Organisational stress and Adverse events. The integrated findings underpinning each theme are reported after each discussion section, using tables, which display the scoping review findings, and the quantitative and qualitative results (Tables 28 to 33). The side by side display of mixed method data enables transparency, comparison, and interpretation of the data (Creswell, 2015). Chapter Nine concludes in 9.6 with a summary of the integrated findings.

## **9.1 Aims and objectives of the research**

This research aimed to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed. Study 1 aimed:

- **To conduct a scoping review of the literature**

The scoping review aimed to map and review the literature on personality disorder, violence, disruption, and the barriers and enablers of general hospital care. The review aimed to highlight methodological constraints in the current evidence base and to identify appropriate research designs to undertake the subsequent strands of the research. The findings of the scoping review were used to develop strand two. The aims of studies 2a and 2b were:

- **To conduct a QUAN web-based survey of patients diagnosed with a personality disorder and carers**
- **To conduct [QUAL] telephone interviews with patients diagnosed with a personality disorder**

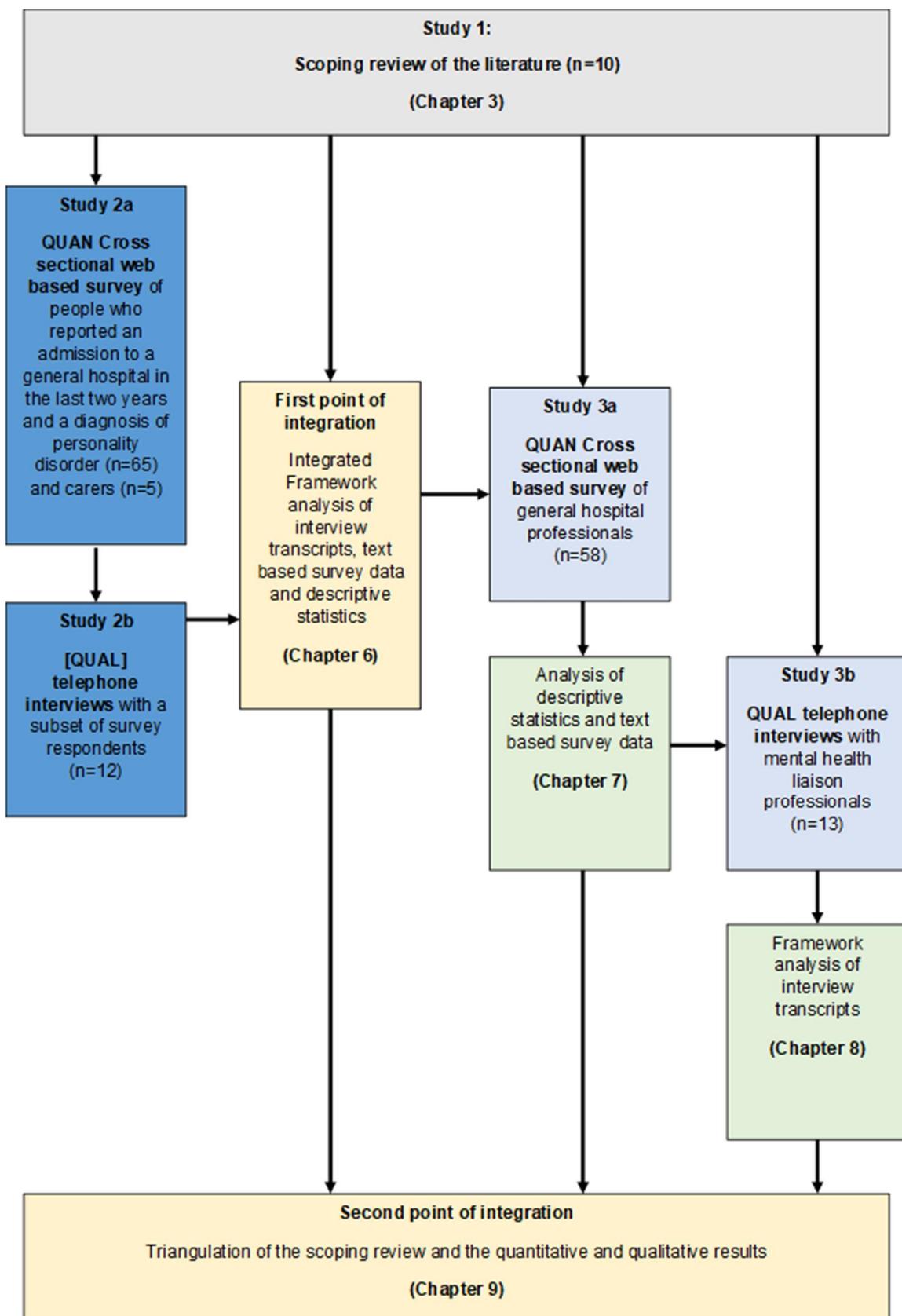
The objectives of the patient web based survey (study 2a) were to explore the views and perspectives of patients and carers on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. Telephone interviews were undertaken with a sub section of the survey sample (study 2b) to provide additional insight into the findings of the web based survey (study 2a). The integrated findings of studies 2a and 2b were used with the findings of study 1 to develop the subsequent work. The aims of studies 3a and 3b were:

- **To conduct a QUAN web-based survey of general hospital professionals**
- **To conduct QUAL telephone interviews with mental health liaison professionals**

The objectives of the general hospital web based survey (3a) were to explore the views and perspectives of general hospital professionals on how general hospitals respond to patients diagnosed with a personality disorder who are distressed. A final set of telephone interviews were undertaken with mental health liaison professionals (study 3b) to explore the findings of all of the previous studies 1, 2a and 2b, and 3a.

The results of all of the studies (1, 2a and 2b, 3a, and 3b) were integrated using mixed methods triangulation to connect, interpret and explain the results.

**Figure 17 The study design and structure of the thesis**



## **9.2 An explanatory framework of how general hospitals respond to patients diagnosed with personality disorder who are distressed**

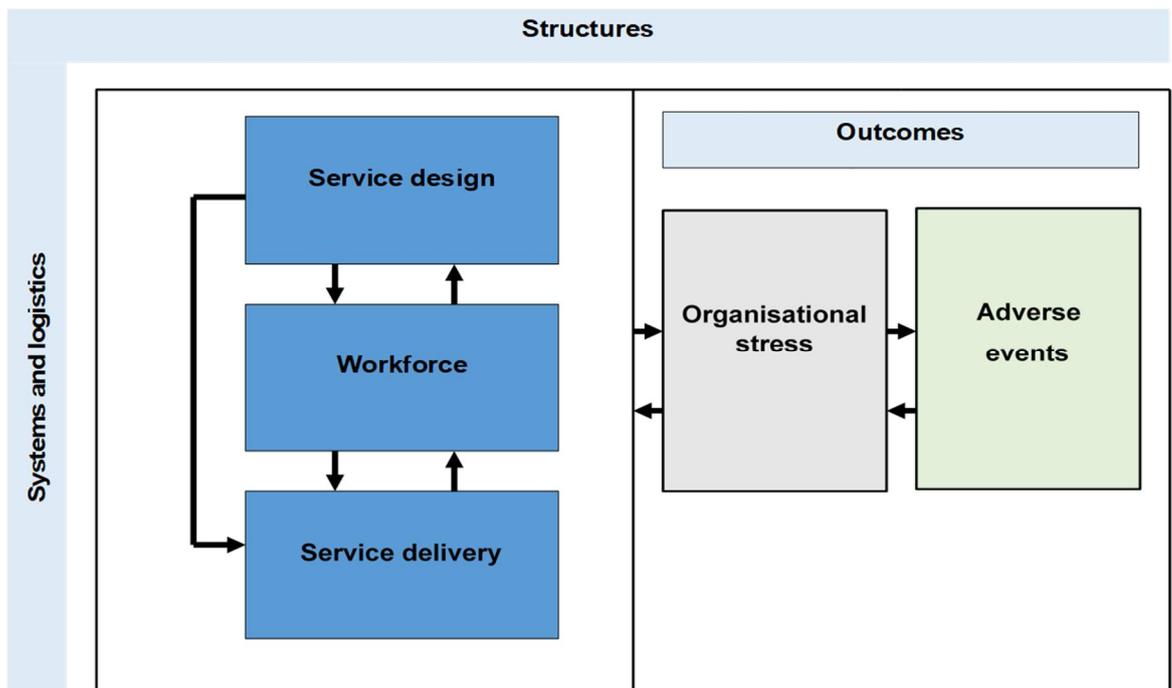
The themes from studies 1, 2a and 2b, 3a, and 3b were assimilated (Table 27) to produce the integrated themes and meta themes, which are discussed in this chapter. The integrated themes are aligned with the health system building blocks identified by the World Health Organisation (2009). Health system building blocks provide a useful mechanism for exploring health systems and understanding the interrelationships, between the components of healthcare systems (World Health Organisation, 2009). The use of these labels was a pragmatic decision, considered to enhance the application of the findings to the NHS. The identified themes: Workforce; Service delivery; Service design; Organisational stress; and Adverse patient events, and the overarching meta themes: Structures, Systems and logistics, and Outcomes are presented as an explanatory framework (Figure 18) of how general hospitals respond to patients diagnosed with personality disorder who are distressed.

The explanatory framework (Figure 18) maps the linkage between the themes, using arrows to show the interrelated components. The absence of an arrow means that no relationship could be determined from the integrated data and does not necessarily signify that no relationship exists. The systemic, logistical, and structural barriers which were identified, were pervasive across all of the components. The presence of systemic, logistical, and structural barriers was considered to confine and maintain a chain of circumstances, which produced adverse outcomes: organisational stress and adverse patient events. Each component of Figure 18 is discussed individually in sections 9.2 – 9.4, drawing on systems thinking and the wider literature to explain the dynamic interaction between the themes.

**Table 27 Assimilation of the themes from studies 1, 2a and 2b, 3a, and 3b**

<b>Study 1: Scoping review of the literature</b>	<b>Studies 2a and 2b: QUAN web based survey with patients and carers and embedded [QUAL] telephone interviews with patients</b>	<b>Study 3a: QUAN web based survey of general hospital professionals</b>	<b>Study 3b: QUAL telephone interviews with mental health liaison professionals</b>	<b>Integrated theme</b>	<b>Meta theme</b>
X	Integration of services	Barriers and facilitators to services	Parity of esteem	The diagnosis of personality disorder & <b>Service design</b>	<b>Structures</b>
X	Knowledge, understanding and skills, and discriminatory practice	How professionals respond to patients	Knowledge, understanding and skills, and discriminatory practice	<b>Workforce</b>	<b>Systems and logistics</b>
Working with patients considered to be violent or disruptive	Missed care and treatment	Understanding care and treatment needs	Alliances, diplomacy, and care	<b>Service delivery</b>	
Responses to patients considered to be violent or disruptive.	X	X	Mismatched expectations and decision making	<b>Organisational stress</b>	<b>Outcomes</b>
Scope of violence and disruption	Patient distress	How patients respond to the hospital	X	<b>Adverse patient events</b>	

**Figure 18 An explanatory framework of how general hospitals respond to patients diagnosed with a personality disorder who are distressed**



### **9.3 Structures: the diagnosis of personality disorder and the way hospitals are organised or set**

Structures regulate relationships between components of systems (Rowe and Hogarth, 2005) and in healthcare they include financial, administrative, responsibility, learning, environmental, and information structures (Langley et al., 2009). Participants across all studies identified the regulation and role of structures as a barrier to responding to the distress of patients.

### 9.3.1 The diagnosis of personality disorder

The integrated findings suggested that the diagnosis of personality disorder was problematic as an information structure. The diagnosis elicited anxiety and fear among general hospital professionals and appeared to produce an emotional contagion<sup>19</sup> effect among professionals in the general hospital. To circumvent discrimination, some patients (2a and 2b) and mental health liaison professionals (3b) avoided using the diagnosis of personality disorder when communicating needs. Although a recent meta-analysis calculated the prevalence of personality disorder in the general adult population of western countries to be 12.2% (Volkert et al., 2018), 62% (n=36) of general hospital professionals perceived that contact with patients diagnosed with a personality disorder was infrequent (3a). The diagnosis of personality disorder appeared to produce a double edged effect; use of the diagnosis resulted in discrimination but failing to recognise people diagnosed with a personality disorder in the general hospital may result in unmet needs because of insufficient evidence to justify improvements. As an information structure, the personality disorder diagnosis appeared to offer an impasse.

Intentional space

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<sup>19</sup> Emotional contagion is discussed further in section 9.5.1: Organisational stress

**Table 28 The integrated findings relating to the personality disorder diagnosis**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>Only ten studies of poor quality were located in the research literature. No studies investigated the prevalence of patients in general hospitals diagnosed with a personality disorder <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>55% of patient participants (n=36) believed professionals did not know about their personality disorder diagnosis <b>(2a)</b>.</li> <li>62% (n=36) of general hospital professionals reported contact with patients diagnosed with a personality disorder was infrequent <b>(3a)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>Patient participants stated they avoided telling professionals about their diagnosis <b>(2a and 2b)</b>.</li> <li>Personality disorder was considered to be a socially unacceptable term <b>(2a and 2b, 3b)</b>.</li> <li>Mental health liaison participants reported rarely receiving referrals that mentioned a personality disorder diagnosis <b>(3b)</b>.</li> <li>The mandate on services in supporting patients with the difficulties associated with personality disorder was believed to be substantial <b>(3b)</b>.</li> </ul>

### 9.3.2 Service design

Published in 2003, '*Personality disorder, no longer a diagnosis of exclusion*', highlighted that people diagnosed with a personality disorder were being treated at the periphery of healthcare (National Institute for Mental Health in England, 2003b). In the physical health context, little has changed, with several important reports dedicated to reducing health disparities in people with serious mental illnesses omitting to mention people diagnosed with a personality disorder (Dorning et al., 2015; RC Psych, 2016; World Health Organisation, 2018). The clinicians who took part in studies 3a and 3b identified few local directives to support patients diagnosed with a personality disorder in the general hospital

setting. Professional and patient participants reported that current service models were not conducive to integrated decision making and there was some suggestion that patients diagnosed with a personality disorder were denied access to mental health services because of local interpretations of national guidelines (3b). More recognition at the national level of the disparities faced by people diagnosed with a personality disorder was deemed necessary in order to raise the standard of care through service redesign (2a and 2b).

Patient and professional participants expressed concern about the funding and resources available to some mental health liaison services, and in some areas, the service levels were considered to be insufficient to deliver care and treatment to people diagnosed with a personality disorder in the general hospital. Participants described pressure on mental health liaison teams to respond to the emergency department, and some participants believed that the prioritisation of the emergency department detracted from care on wards (3b). More than half of the patient participants reported they were dissatisfied with their overall care (2a and 2b). A systematic review, which evaluated the general hospital care of people with severe mental illnesses, concluded that patients with psychiatric diagnoses generally received 'lower quality' health care (Reeves et al., 2018). Personality disorder was not included in the review by Reeves et al. (2018). However, the integrated findings of this PhD research suggested that the quality of general hospital care for patients diagnosed with a personality disorder was similarly concerning, and perhaps more so, because during a crisis the general hospital was often the only point of contact for people diagnosed with a personality disorder (2a and 2b, 3b).

A particularly salient issue that emerged was that patients diagnosed with a personality disorder believed they were unable to complain about their care (2a and 2b). The patient participants reported that complaints were not taken seriously and were dismissed based on unsubstantiated assumptions of mental disturbance. Patient complaints have been deemed vital to the identification of patient safety issues and improving hospital systems (Department of Health,

2000). The Francis inquiry reiterated that listening to patient complaints and concerns was essential to understanding systematic difficulties in hospitals (Francis, 2013). If complaints from patients diagnosed with a personality disorder have not been heard by hospital leaders, that may obstruct opportunities for organisational learning and reduce the impetus to design more responsive services.

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**Table 29 The integrated findings relating to service design**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>The literature conveyed patient dissatisfaction with services <b>(1)</b>.</li> <li>The literature advocated for increased resources, targeted interventions, and education <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>General hospital professionals provided 59 comments about managing risks to self or others. Only 4% (n=2) of the comments referred to a locally agreed risk protocol <b>(3a)</b>.</li> <li>39% (n=22) of general hospital professionals reported being less than satisfied with the physical healthcare available to patients diagnosed with a personality disorder. Whereas 82% (n=46) of professionals reported being less than satisfied with the mental healthcare available <b>(3a)</b>.</li> <li>58 % (n=36) of patient participants reported they were dissatisfied with their overall care (2a).</li> </ul>	<ul style="list-style-type: none"> <li>Local policies on managing mental health crises in the general hospital were believed to be few <b>(3b)</b>. General hospital professional participants reported a lack of integrated decision making with the mental health services <b>(3a)</b>. There was some suggestion that current service models, prioritising accident and emergency, over inpatient wards resulted in delays in mental health liaison teams attending the wards <b>(3b)</b>.</li> <li>Mental health liaison professional participants reported existing guidelines were used to exclude patients diagnosed with a personality disorder from services <b>(3b)</b>. Patient and mental health liaison participants believed improvements were needed to national policies and the expected standards of care <b>(2a and 2b, 3b)</b>.</li> <li>The dominant view among general hospital professionals was that the mental health liaison service levels were inadequate <b>(3a)</b> Patient participants believed that mental health liaison teams were in a challenging position as the broader mental health services were underfunded and resourced <b>(2a and 2b)</b>.</li> <li>General hospital professional participants believed that the general hospital needed more access to mental health professionals <b>(3a)</b>. Mental health liaison professional participants echoed the resourcing issues <b>(3b)</b>. Commissioners needed a good grasp of liaison to commission viable services <b>(3b)</b>.</li> <li>Mental healthcare was typically interrupted when patients were admitted to the general hospital. Patient participants suggested improvements to streamline care such as earlier and easier access to mental health liaison services and the option to self-refer. Patient participants wanted robust care pathways, not just signposting and assessment and wished there was more joined up thinking between providers <b>(2a and 2b)</b>.</li> <li>Patients participants perceived it was difficult to complain. Patient participants reported that complaints were dismissed on unsubstantiated assumptions of mental disturbance <b>(2a and 2b)</b>.</li> </ul>

## **9.4 Systems: the way hospitals work and logistics: the way services are implemented**

Mental health liaison services provide the interface between the general hospital and mental health services, but because they are typically commissioned as part of mental health services, they are unique in offering the most benefit to the general hospital system (Fossey and Parsonage, 2014). It is known that people working in different systems rarely share a common purpose (Langley et al., 2009) and across the studies, systems and logistics were repeatedly flagged by the participants. There is a considerable body of knowledge related to the way systems function in healthcare environments; they are characteristically non-linear, tightly linked, cause their behaviour, need to adapt quickly, are governed by feedback and are resistant to change (World Health Organisation, 2009).

### **9.4.1 The workforce**

The general hospital workforce, was generally, found to be negative and discriminative towards people diagnosed with a personality disorder (2a and 2b, 3a, and 3b). Study 3a suggested that general hospital professionals generally lacked the knowledge, understanding and skills to respond to patients diagnosed with a personality disorder who were distressed. They also seemed to lack the proficiency to identify and communicate the needs of patients diagnosed with a personality disorder to the mental health liaison service. General hospital professionals believed their professional education had not prepared them to work with people diagnosed with a personality disorder (3a). Patients and general hospital professionals believed in part that prejudices were driven by stereotyping.

Although there has been some suggestion that attitudes towards people diagnosed with a personality disorder have improved in the last fifteen years in the literature (Day et al., 2018). Discriminatory practice towards people diagnosed with a personality disorder has continued to be steadily reported in a range of healthcare settings including: the emergency department (Commons Treloar and Lewis, 2008; Clarke et al., 2014); the community (Newton-Howes et al., 2008; McGrath and Dowling, 2012); inpatient mental health settings (Bodner et al., 2015); and in general hospitals (Noble et al., 2015). The rational solution to discrimination has commonly been to propose education and training (Bodner et al., 2015; Clarke et al., 2014; Commons Treloar and Lewis, 2008; McGrath and Dowling, 2012), but, to date, evidence of brief education and training sessions changing practice and improving patient outcomes has been unsatisfactory (Dickens et al., 2016b).

Sporadic mental health training opportunities in general hospitals may not be exclusive to personality disorder. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD, 2017) reported that fifty four percent of NHS general hospitals (n=208) provided no mandatory training on any mental health condition (NCEPOD, 2017). However, while the case for improved education, training, and competence in responding to personality disorder, and possibly severe mental illness generally in general hospitals seems obvious, there are many unanswered questions about how that might be achieved. Brief training sessions may be most practicable in the general hospital setting, however, may not be the most effective and concerningly, this research suggested that some mental health liaison professionals did not always display positive attitudes towards people diagnosed with a personality disorder either (3a and 3b).

An interesting finding was that some of the mental health liaison participants, differentiated between conscious and unconscious types of discrimination. Unconscious stereotyping and prejudice has been explored extensively in the literature on race and gender discrimination (Schulman et al., 1999; Smedley et al., 2003; Holm et al., 2017; Hall et al., 2015; Hughes and Bernstein, 2018; Banaji

and Greenwald, 2016). The unconscious biases of healthcare professionals have garnered interest among authors exploring a range of disparities in healthcare (Blair et al., 2011; Waller et al., 2012; Peris et al., 2008; Ashford et al., 2018). A review using systematic methods concluded that there was a relationship between unconscious bias and healthcare quality (FitzGerald and Hurst, 2017). Unconscious bias might be a substantial factor, in driving prejudices. Education and training, to promote 'awareness' has been deemed insufficient to address unconscious types of discrimination (Byrne and Tanesini, 2015). There may be a strong case for increased emphasis on elevating the consciousness of the workforce through feedback and reflection (Byrne and Tanesini, 2015; Wright et al., 2007).

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**Table 30 The integrated findings relating to the workforce**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>The literature described a culture of discrimination in general hospitals <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>Only 20% of the patient participants (n=6) reported they were treated with empathy dignity and respect by mental health liaison teams during treatment of a mental health crisis <b>(2a)</b>. General hospital professional participants (n=39) were most likely to refer distress to mental health services <b>(3a)</b>.</li> <li>On a scale of 1-10, only 4 general hospital professionals rated their professional training to work with people diagnosed with a personality disorder above 5 <b>(3a)</b>.</li> <li>General hospital professionals (n=10) reported that access to formal education and training was less widely available to them <b>(3a)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>A small number of patient participants reported being treated with kindness and empathy by professionals working in the general hospital <b>(2a and 2b)</b>. Patients generally described a culture of discrimination in general hospitals <b>(2a and 2b)</b>.</li> <li>Most patient participants believed that professionals in the general hospital made assumptions about them <b>(2b)</b>.</li> <li>Among the survey 3a responses, there was evidence of compassion and self awareness, but overall general hospital professionals highlighted stigma amongst their immediate colleagues and a lack of understanding. There was a sense that some general hospital professionals were oblivious that their practice was condemnatory <b>(3b)</b>.</li> <li>Mental health liaison participants believed that the diagnosis of personality disorder was used pejoratively in the general hospital <b>(3b)</b>. There was some suggestion that mental health liaison professionals had negative attitudes <b>(3b)</b> and were reluctant to work with patients diagnosed with a personality disorder <b>(3a)</b>.</li> <li>Involvement of experts by experience was considered to be useful in improving attitudes <b>(2a and 2b)</b>. Personality disorder was considered to be less understood compared to common mental health problems such as depression and anxiety <b>(2a and 2b)</b>.</li> <li>Patient participants generally believed that the knowledge and skills needed to care for patients diagnosed with a personality disorder were absent <b>(2a and 2b)</b>. The General hospital professional participants agreed <b>(3a)</b>.</li> </ul>

		<ul style="list-style-type: none"><li>• The consultation liaison model of care relied on the general hospital electing to contact the mental health liaison service. However, mental health assessment skills were considered to be below the desired standard on many general hospital wards <b>(3b)</b>.</li><li>• Mental health liaison professionals believed that general hospital professionals were proficient in responding to distress and that working with people diagnosed with a personality disorder did not require sophisticated expertise <b>(3b)</b>. Patient participants agreed <b>(2a and 2b)</b>.</li><li>• Patient participants believed that general hospital professionals did not have access to high quality information about personality disorders <b>(2a and 2b)</b>.</li><li>• Mental health liaison professional participants suggested that newly qualified health professionals were more educated about the importance of achieving parity of esteem but were frustrated that training relating to mental health was commonly seen as an optional extra by many established general hospital professionals <b>(3b)</b>.</li><li>• Mental health liaison professional participants believed that general hospital professionals required more training if adverse outcomes were to be avoided <b>(3b)</b>. There were mixed views about whether it was important to develop knowledge, understanding and skills to work with people diagnosed with a personality disorder among the general hospital professionals, and whether this type of learning should be mandatory or not. Overall participants appeared to be in favour <b>(3a)</b>.</li><li>• Mental health liaison participants believed they were able to develop knowledge understanding and skills in the general hospital by forming good working relationships and offering peer support <b>(3b)</b>.</li></ul>
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### **9.4.2 Service delivery**

The majority of patients perceived their mental health was of comparable or greater importance than their physical health on admission to the general hospital. However, mental health liaison services were reported to be inaccessible (3a). In keeping with these results, case reviews undertaken by NCEPOD (2017) concluded that 96 patients (53%) not seen by liaison psychiatry should have received a review, in the clinical opinion of the reviewer. Although mental health liaison services vary by location (Joint Commissioning Panel for Mental Health, 2013; Aitken, 2014), in many areas, issues related to workload, underfunding, and insufficient staffing levels have compromised service delivery (NICE and NHS England, 2016). What was identified from study 3b, was that liaison teams were more impactful when mental health liaison professionals had high level interpersonal skills and were willing and able, to proactively engage with the general hospital to work with patients with mental health issues.

Pharmacological treatments prescribed for patients diagnosed with a personality disorder were reported to be missed, interrupted, and omitted in the general hospital setting (2a and 2b). Patient participants believed that decision making regarding psychotropics and analgesics, was substantially influenced by the emotional state of the clinician. Although a UK study, which explored liaison psychiatry professionals views of general hospital care for patients with mental illness (Noblett et al., 2017) suggested that some hospital clinicians were adamant that supporting patients with psychotropic medicines was beyond their remit, the data from studies 2a and 2b, suggested that unconscious bias could be a major influence. In contrast, the psychiatrists interviewed as part of this research did not report any difficulties with the hospital providing pharmacological interventions. Nevertheless, the patient studies (2a and 2b) described great suffering and integrated with the findings of the general hospital professional survey (3a), systems for medicines management appeared to be lacking.

Some general hospital professionals expressed hesitancy about prescribing for people diagnosed with a personality disorder (3a). There has been some supporting evidence from mental health settings, which suggests that psychiatrists find prescribing for people diagnosed with a personality disorder to be challenging (Martean and Evans, 2014; Rogers and Acton, 2012). Although these studies appeared methodologically weak, the authors offered insight into prescribing as a carefully negotiated and individualised process. Moreover, an extensive cross sectional survey (n=2600 patients), which spanned 41 mental health service providers, found that among patients diagnosed with a personality disorder, psychotropic medicines were prolifically used off licence (Paton et al., 2015). Given the apparent complexity, it may not be surprising that some general hospital professionals were concerned about prescribing for patients diagnosed with a personality disorder. The majority of clinicians in mental health liaison teams are mental health nurses (Joint Commissioning Panel for Mental Health, 2013). The changing landscape of prescribing practice may offer opportunities for improvement in this area.

The general hospital professionals surveyed were frustrated by the lack of integrated working with their mental health liaison colleagues. General hospital professionals expressed concern about mental health liaison services refusing to review patients until they had been declared 'medically fit', a scenario similar to that reported by NCEPOD (2017). The general hospital professionals in this study reported that it was difficult to manage cooccurring physical and mental health problems without collaborating with the mental health liaison services, a finding which seemed to converge with patients experiences of diagnostic overshadowing (Studies 2a and 2b). Happell et al. (2016) linked diagnostic overshadowing to broader health disparities, explaining that diagnostic overshadowing can be a matter of 'life or death' for those affected.

Patients also reported an *inverse* treatment overshadowing in which their mental illness and the required treatment for that mental illness was completely ignored, while professionals focused on physical health issues. To date, inverse

diagnostic and treatment overshadowing has received little attention in the literature. Discussion of inverse, reverse, or opposite, diagnostic overshadowing has been mainly confined to the literature relating to primary care (Menchetti et al., 2009) and intellectual disabilities (Wodrich and Schmitt, 2006; Singh, 2016; Bouras and Holt, 2007). Complex physical presentations might mask psychiatric symptoms and clinicians may overlook the possibility of an underlying mental disorder (Noblett et al., 2017). Negative attitudes and prejudice among clinicians have been linked to diagnostic overshadowing and inverse diagnostic overshadowing (Noblett et al., 2015). The present study raises the possibility that patients diagnosed with a personality disorder have received substantially disadvantaged healthcare.

After contacting a mental health professional, general hospital professional participants were 'most likely' (n=20) to use one on one nursing care to support distressed patients diagnosed with a personality disorder (2a and 2b, 3a). There was no indication in the literature, or from the patient or general hospital participants that one on one observations were used therapeutically with patients diagnosed with a personality disorder in the general hospital. Instead, the data suggested that one on one care was used as a security measure, to provide containment, and to manage risk (2a and 2b, 3a). Inadequacies in the use of one on one nursing observations in the general hospital with people with mental disorders were also observed by NCEPOD (2017). NCEPOD (2017) found that one on one care was deficient in 68% (n=151) of the case notes they reviewed; however, no diagnosis specific data was reported. The term 'relational security' has been used in mental health settings to describe the link between professionals, patients, the setting, clinical knowledge, and how services respond (Allen, 2015). Adopting relational approaches may equip general hospitals to respond to more functionally to patient distress and risk.

Study 3a indicated that most general hospital professionals were not confident in assessing mental capacity in people diagnosed with a personality disorder. Although it was essential to bear in mind that legal frameworks for assessing

mental capacity differ across countries in the UK and the participants were predominantly in England, this study seemed to illustrate that mental capacity was a complex and contentious issue in the general hospital (3a and 3b). General hospital professionals lacked clarity about the overlap between the Mental Capacity and the Mental Health Act (3a), and there was discord about whether the general hospital or the mental health service was responsible for ensuring decisional capacity (Study 3b). Similarly, NCEPOD (2017) found room for improvement in 40% of mental capacity assessments (n=42). An issue that was not addressed was whether capacity assessments were missed on this basis. It appeared conceivable that the inability to assess mental capacity in the general hospital in people diagnosed with a personality disorder was contributory to adverse events.

Intentional space

**Table 31 The integrated findings relating to service delivery**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>The literature asserted that patients exploited hospital admissions to access pharmaceuticals <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>73% (n=47) of patient participants perceived their mental health was of comparable or greater importance than their physical health at the time of their admission to the general hospital <b>(2a)</b>.</li> <li>Only 21% of general hospital participants (n=12) reported it was easy or very easy to access mental health assessment and support for inpatients. Only 14% (n=8) reported it was easy to access advice and none reported it was very easy to access advice <b>(3a)</b>.</li> <li>55 % (n=36) of patients with a reported diagnosis of personality disorder stated that mental health liaison services did not see them during their general hospital admission <b>(2a)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>Mental health liaison participants considered the liaison role was important in aiding communication regarding the mental health needs of some patients. However, the liaison role extended beyond providing advice and psychosocial assessment. Diplomacy and relationship building with the general hospital was central to ensuring patient needs were met. Clinician and patient rated outcome measures (CROMs and PROMs), and patient reported experience measures (PREMs) might not capture the interpersonal work undertaken by liaison services <b>(3b)</b>.</li> <li>Patient participants believed they were overlooked for a referral to mental health liaison teams <b>(2a and 2b)</b>.</li> <li>Patients participants reported they were commonly admitted during periods of crisis and did not have their supply of medicines available. Patient participants perceived that medicines were routinely unavailable in the general hospital <b>(2a and 2b)</b>.</li> <li>Patient participants described considerable efforts to communicate their need for medicines but reported requests were usually overlooked <b>(2a and 2b)</b>. Some general hospital professionals expressed hesitancy in prescribing for people diagnosed with a personality disorder <b>(3a)</b>.</li> <li>Mental health liaison professionals reported that general hospitals commonly stopped psychotropic medicines. However, mental health liaison professionals also expressed concern about the excessive use of medicines, particularly hypnotics, anxiolytics and opioids (3b). There were mixed views about whether medicines were administered excessively or withheld in the general hospital <b>(3a)</b>.</li> </ul>

	<ul style="list-style-type: none"> <li>• Only 17% (n=5) of patient participants believed mental health liaison teams considered the support needs of family or carers <b>(2a)</b>.</li> <li>• 54% (n=35) of patient participants reported they were unable to access their usual treatment for their mental health <b>(2a)</b>.</li> <li>• General hospital professional participants were 'most likely' (n=20) to use one on one nursing care to support distressed patients diagnosed with a personality disorder after contacting a mental health professional <b>(3a)</b>.</li> <li>• General hospital professional participants (n=13) commented on the provision of one on one nursing care more than any other strategy to manage risk <b>(3a)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient participants suggested that unfair assumptions impacted on clinical decision making around medicines <b>(2a and 2b)</b>.</li> <li>• Although there were some good experiences of getting help to manage pain in the general hospital, the majority of the patient participants perceived pain was not taken seriously, and that pain relief was denied to reprimand them <b>(2a and 2b, 3a)</b>.</li> <li>• The consultation liaison role meant that mental health liaison services offered advice about prescribing but the general hospital undertook the decisions. The onus was on mental health clinicians to influence decision making <b>(3b)</b>.</li> <li>• Patient participants believed a diagnosis of personality disorder prevented diagnosis and treatment of physical health problems. However, patients also perceived that their mental health concerns were ignored while the general hospital focused entirely on their physical health <b>(2a and 2b)</b>.</li> <li>• General hospital professionals suggested mental health liaison services were reluctant to engage with patients diagnosed with a personality disorder. Patients were required to be 'medically fit' before their mental health needs could be addressed <b>(3a)</b>.</li> <li>• The personality disorder diagnosis was perceived to diminish referrals to other specialities and disciplines in both the mental and physical health services <b>(2a and 2b, 3b)</b>.</li> <li>• Patient participants expressed concern about the lack of consistency and continuity of one on one nursing care. One to one nursing care was not considered to be used for meaningful engagement <b>(2a and 2b)</b> and was conflated with the use of security guards <b>(3a)</b>.</li> <li>• There were mixed views on the assessment of capacity Some participants believed that the general hospital should assess decision making capacity as they would with any other patient. Others stated that determining decisional capacity could be more nuanced and complex with patients with psychological difficulties. Inexperienced professionals were believed by some to be at risk of making ill informed decisions <b>(3b)</b>.</li> </ul>
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	<ul style="list-style-type: none"><li>Forty participants (69%) stated they were not confident assessing mental capacity in people diagnosed with a personality disorder. Six participants said they were confident to some extent (10%). Only three nurses and two midwives reported confidence in assessing mental capacity <b>(3a)</b>.</li></ul>	<ul style="list-style-type: none"><li>The lack of assistance with complex capacity decisions was a source of frustration for some general hospital professionals <b>(3a)</b>.</li></ul>
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## **9.5 Outcomes**

The integrated findings of studies 1, 2a and 2b, 3a, and 3b suggested that general hospitals respond iatrogenically to patients diagnosed with a personality disorder. Section 9.4 explores the relationship identified between organisational stress, i.e., the stress originating from the interrelationship between the identified components, and the adverse patient events described in 9.4.2.

### **9.5.1 Organisational stress**

The mental health liaison participants perceived that general hospital professionals were anxious about working with patients diagnosed with a personality disorder (3b). The stress and strain was observed not only in individuals but also at ward level, with an emotional contagion effect described by participants (3b). The wider literature suggests that professionals commonly struggle to process strong emotional responses when there is no outlet, and their distress, often unconsciously, can produce an emotional ripple effect across teams (Campling, 2015; Moylan, 1994). Although the general hospital participants were responding to an online survey, there was a strong sense of emotional burden (3a). Only 15 (n=58) participants reported they were able to access clinical supervision to enhance knowledge and skills to work with people diagnosed with personality disorder (3a). Some of the clinician behaviours, which were described by the patient participants in studies 2a and 2b, e.g., dismissive and denigrating attitudes; obtrusive levels of observation; irrational decision making; and dehumanisation, might be construed as defence mechanisms, used to seek control over situations, perceived threatening (Moore, 2012). The mental health liaison participants believed that supporting general hospital professionals to undertake mental health work, which was emotionally challenging, was a vital function of the liaison role.

However, studies 3a and 3b suggested that there was a mismatch of expectations between the general hospital and the mental health liaison service. Mental health liaison professionals perceived that general hospital professionals should undertake the work, with their support, but the general hospital professionals perceived it was not their work to do (3b). There was some suggestion that unresolved anxiety and disagreements about service provision, the apparent unwillingness of mental health liaison to be involved with patients diagnosed with a personality disorder, and the assessment of mental capacity cultivated interprofessional conflict. The general hospital participants described particular challenges when comorbidity prevented clear care pathways. However, several general hospital professional participants highlighted issues with their immediate colleagues, rather than with the mental health professionals (3a). Unfortunately, the data was insufficient to understand the conflict between the general hospital professionals in any depth. A link between the psychological wellbeing of the workforce, the quality of patient experiences, and patient outcomes has increasingly been recognised (Taylor et al., 2018; Maben et al., 2012). Consistently, this PhD research appeared to suggest there was a connection between organisational and stress and adverse patient events (9.5.2).

Intentional space

**Table 32 The integrated findings relating to organisational stress**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>The literature suggested that general hospital professionals felt threatened by people diagnosed with a personality disorder, experienced professional invalidation and believed they were working beyond their capabilities. The literature also indicated that workers experienced strong feelings, high levels of distress, and were emotionally drained by working with people diagnosed with a personality disorder <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>Only 26% (n=15) of participants reported being able to access clinical supervision in the study context <b>(3a)</b>.</li> <li>33 comments (77% of responses) outlined experiences of interprofessional conflict in the general hospital <b>(3a)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>General hospital professionals were perceived to experience intense anxiety about working with patients diagnosed with a personality disorder. Professional anxiety was believed to evoke under and over reactions to the clinical needs of patients and impact on decision making. Anxiety was perceived to be experienced both by individual clinicians and by teams <b>(3b)</b>. The free text comments made by general hospital professionals in study 3a supported the idea that general hospital professionals experienced considerable emotional burden when undertaking this work <b>(3a)</b>.</li> <li>Mental health liaison professional participants believed there was an expectation grounded in anxiety that mental health liaison services should assume responsibility for patients diagnosed with a personality disorder <b>(3b)</b>.</li> <li>Patient participants believed that mental health liaison professionals were becoming 'burnt out' due to the lack of resources available to them <b>(2a and 2b)</b>.</li> <li>Participants indicated that mismatched expectations and unresolved anxiety sometimes grew into interprofessional conflict. For example, mental health liaison participants stated it was not practical to respond to constant phone calls or to provide one on one nursing care to all distressed patients. Mental health liaison nurses, in particular, reported they clashed with the general hospital over patient care <b>(3b)</b>.</li> <li>Participants described disputes about service provision, the apparent unwillingness of mental health liaison to be involved with patients diagnosed with a personality disorder, and the assessment of mental capacity. Participants described particular challenges when comorbidity prevented clear care pathways <b>(3a)</b>.</li> <li>General hospital professionals highlighted conflict with their immediate colleagues rather than the mental health liaison team. However, there was insufficient information to enable interprofessional conflict to be understood in any depth <b>(3a)</b>.</li> </ul>

### **9.5.2 Adverse events**

Patient participants described experiencing considerable distress in the general hospital setting. Forty two percent (n=27) of the patients surveyed reported needing emergency or crisis treatment during their admission to the general hospital. Patient distress was severe, and participants experienced anxiety attacks and dissociation. Patients highlighted that shouting, screaming and becoming withdrawn was indicative of intensifying distress. Participants described attempting suicide and self harming, including cutting, hitting, tying ligatures, vomiting, and not eating in the general hospital. However, consistent with the extant literature described in Chapter Two, this research found that patients diagnosed with a personality disorder were perceived by general hospital professionals to be difficult, rather than in a crisis. Although responding to a crisis can be difficult for services, failure to respond has resulted in patient deaths (Department of Health and Concordat Signatories, 2014).

Patients diagnosed with a personality disorder were found to be at risk of treatment non completion, with approximately one in four participants (2a) reporting leaving the general hospital against medical advice. Some of the general hospital professionals surveyed were frank about the relief they experienced when patients diagnosed with a personality disorder left the general hospital. Patient participants provided examples of premature discharge and readmission to the general hospital, which was to some extent contrary to the findings of the NCEPOD (2017) study, which found only 8.7% of patients with mental illnesses were readmitted to the general hospital within 30 days. Interestingly, NCEPOD (2017) identified that patients might have been readmitted to other hospitals and studies 2a and 2b suggested that some patients sought care and treatment in other hospitals following diagnostic overshadowing. Patients diagnosed with a personality disorder may be at substantial risk of treatment non completion in the general hospital setting.

**Table 33 The integrated findings relating to adverse events**

Scoping review of the literature	Quantitative results	Qualitative results
<ul style="list-style-type: none"> <li>• No data was found to support a relationship between violence and personality disorder in general hospitals. However, people diagnosed with a personality disorder were portrayed to be disruptive because of: refusal to maintain socially expected norms, hostility, impulsivity, rigidity, agitation, wandering, suicidality, disruption, and being so called problem patients <b>(1)</b>.</li> <li>• Behavioural management plans were used in the general hospital to address undesirable behaviour <b>(1)</b>.</li> <li>• ‘Personality problems’ were reported to be commonly seen among patients leaving hospital prematurely, against medical advice, or being frequently readmitted <b>(1)</b>.</li> </ul>	<ul style="list-style-type: none"> <li>• 94% (n=64) of patient participants reported experiencing distress during their admission to hospital <b>(2a)</b>.</li> <li>• 42% of patient participants (n=27) reported needing emergency or crisis treatment for mental ill health <b>(2a)</b>.</li> <li>• Patients believed support from professionals working in the general hospital was very important (n=31) during distress. The equivalent number of patients indicated support from mental health professionals was very important (n=31, <b>2a</b>).</li> <li>• 26% (n=16), approximately one in four participants, reported leaving the general hospital without waiting to be discharged by the general hospital team <b>(2a)</b>.</li> <li>• 18% (n=18) of general hospital professionals believed that patients</li> </ul>	<ul style="list-style-type: none"> <li>• Patient participants described experiencing a range of difficult emotions in the general hospital, most commonly expressed as being distressed or fearful. Participants described a range of manifestations of psychological distress, which included becoming withdrawn, experiencing anxiety attacks, dissociation, shouting and screaming. Participants described attempting suicide and self harming in the general hospital, including cutting, hitting, tying ligatures, vomiting and not eating in the context of considerable distress. Although self harm was in part attributed to mental health crisis, the qualitative data indicated that workforce, service delivery, and service design issues heightened psychological distress, and admission to the general hospital was not conducive to maintaining mental health <b>(2a and 2b)</b>.</li> <li>• The patient studies 2a and 2b, explained that concerns were dismissed, lived experience was not recognised, and there was conflict with professionals when patients tried to communicate individual needs. There were some circumstantial evidence of pain, and ‘lashing out’ <b>(2a and 2b)</b>.</li> <li>• There were some examples of behavioural management plans being used in NHS general hospitals <b>(2a and 2b)</b>.</li> <li>• The data indicated that leaving against medical advice was sometimes related to the mental state of participants. However, overwhelmingly participants reported they left because the hospital was unbearable, and basic needs were not met. Waiver or discharge against medical advice forms were commonly used in the general hospital but decision making was perceived to be disorganised and inconsistent in this area <b>(2a and 2b)</b>.</li> </ul>

	<p>diagnosed with a personality disorder frequently left the hospital without medical advice <b>(3a)</b>.</p> <ul style="list-style-type: none"><li>• 46% (n=30) of patient participants stated there was a strong possibility of readmission to the general hospital in the next 12 months, a further 34% (n=22) stated they were unsure <b>(2a)</b>.</li></ul>	<ul style="list-style-type: none"><li>• Participants reported they went to extreme lengths to avoid continued hospitalisation including spending the night in a police cell and feigning wellness <b>(2a and 2b)</b>.</li><li>• Some general hospital professionals expressed concern about patients diagnosed with a personality disorder leaving against medical advice. However, some professionals suggested that leaving against medical advice was the best outcome for the hospital <b>(3a)</b>.</li></ul>
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## **9.6 How do general hospitals respond to patients diagnosed with a personality disorder who are distressed: A summary of the integrated findings**

This chapter integrated the findings of three strands of research, a scoping review of the literature (Study 1); QUAN web based survey and [QUAL] telephone interviews with patients (studies 2a and 2b); QUAN web based survey of general hospital professionals (3a); and QUAL telephone interviews with mental health liaison professionals (3b). The findings of this research suggested that general hospitals respond to patients diagnosed with personality disorder iatrogenically. The systemic, logistical, and structural barriers identified, were pervasive and were considered to confine and maintain a chain of circumstances, which produced adverse outcomes: organisational stress and adverse patient events (Figure 18).

The integrated findings identified challenges in identifying the group of people who experience personality disorder in the general hospital setting and raised concern that this patient group was overlooked in the national policy. Local directives to support patients diagnosed with a personality disorder in general hospitals were believed to be few. More than half of the patient participants reported they were dissatisfied with their overall care. Patients diagnosed with a personality disorder were marginalised, and complaints were seemingly not upheld on account of the personality disorder diagnosis, which may have reduced opportunities for organisational learning. This research found that patients diagnosed with a personality disorder were perceived by general hospital professionals to be difficult, rather than in a crisis. The workforce was found to be discriminative of people diagnosed with a personality disorder and the diagnosis seemed to impact substantially on the professionals sense of responsibility.

The general hospital workforce appeared to lack the knowledge and skills required to respond to patients diagnosed with a personality disorder who were distressed. Professionals reported that the training and education available was ad-hoc and some mental health liaison professionals did not contribute positively. General hospital professionals appeared to require more support and supervision to manage the emotional burden of their work and to address unconscious biases. Mental health liaison services were more impactful when resourced, and skilled, to work collaboratively with the general hospital. However, this study suggested that resources to support patients diagnosed with a personality disorder may have been insufficient and integrated working was minimal. The lack of joined up thinking may have exposed patients diagnosed with a personality disorder to diagnostic overshadowing and inverse diagnostic and treatment overshadowing.

The systems to safeguard the use of psychotropic medicines appeared to be inadequate in the general hospital setting, and the systems to respond to risks such as self harm, suicide and violence in patients diagnosed with a personality disorder were undeveloped. The logistics of assessing mental capacity were poorly demarcated and general hospital professionals lacked the confidence to assess capacity in this clinical context. General hospital professionals were considered to be poorly supported, anxious and fearful, and engaged in defensive practices. There was some suggestion that unresolved anxiety and incompatible expectations of the interface between mental and physical health services cultivated interprofessional conflict.

These research findings appear to shed new light on the dynamic interaction between the workforce, service delivery, service design, organisational stress and adverse patient events, including distress, self harm, treatment non completion, premature discharge and readmissions.

## **Chapter 10 : Conclusion**

This thesis has presented a transparent and defensible account of PhD research to explain how general hospitals respond to patients diagnosed with a personality disorder who are distressed. The use of the mixed methods explanatory sequential design enabled rigorous integration of: the literature (Study 1, Chapter 3); a web based survey and telephone interviews with patients (Studies 2a and 2b, Chapter 6); a web based survey of general hospital professionals (Study 3a, Chapter 7); and telephone interviews with mental health liaison professionals (Study 3b, Chapter 8). This final chapter summarises the research objectives and results (10.1-10.4) and discusses the limitations of this PhD research (10.5). Section 10.6 provides recommendations for practice, commissioning, policy, and future research. This thesis concludes in section 10.7 with a summary of the integrated findings.

### **10.1 Scoping review of the literature (Study 1)**

Study one mapped and reviewed the literature on personality disorder, violence, disruption, and the barriers and enablers of general hospital care. The review located and appraised ten studies, which were identified to be methodologically weak. Thematic analysis generated three themes: The scope of violence and disruption, responses to patients considered to be violent or disruptive, and working with patients considered violent or disruptive. No linkage was found between violence in general hospitals and the diagnosis of personality disorder. The scoping review of the literature highlighted a gap in the knowledge of personality disorder, violence, and disturbed behaviour in the general hospital setting and explored the misperceptions reported in the literature.

## **10.2 QUAN web-based survey of patients diagnosed with a personality disorder and carers (Study 2a) and embedded [QUAL] telephone interviews with patients diagnosed with a personality disorder (Study 2b)**

Study 2a explored patients (n=65) and carers (n=5) views and perspectives of how general hospitals respond to patients diagnosed with a personality disorder who are distressed, using a web based survey. In study 2b, telephone interviews were undertaken with a sub section of the study 2a sample (n=12) to gain additional insight into the study 2a results. Framework analysis was used to produce an overarching thematic framework of the integrated qualitative and quantitative data. Four themes were identified: Workforce; Knowledge, understanding, skills and discriminatory practice in the general hospital; Service delivery; Missed care and treatment; Service design; Integration of services; and Distress. The studies 2a and 2b indicated that general hospitals respond adversely to patients diagnosed with a personality disorder.

## **10.3 QUAN web-based survey of general hospital professionals (Study 3a)**

Study 3a explored general hospital professionals (n=58) views and perspectives of how general hospitals respond to patients diagnosed with a personality disorder who are distressed, using a web based survey. Descriptive statistics and Framework analysis of the textual data provided insight into a struggling general hospital workforce, inadequately equipped with the skills and knowledge they believed they needed. General hospital professionals reported being dependant on unavailable and under resourced mental health liaison services. The systems and procedures in the general hospital to respond to risks to self or others were identified to be mostly unsupportive.

## **10.4 QUAL telephone interviews with mental health liaison professionals (Study 3b)**

Study 3b explored mental health liaison professionals (n=12) views and perspectives of how general hospitals respond to patients diagnosed with a personality disorder who are distressed, using qualitative telephone interviews. Framework analysis was used to produce a thematic framework. Four themes were identified: Workforce; Knowledge, understanding, skills, and discriminatory practice; Service delivery; Alliances, diplomacy, and the care and treatment of patients diagnosed with a personality disorder; Service design; Parity of esteem; and Organisational stress; Mismatched expectations, and decision making. Study 3b echoed previous findings that general hospitals respond adversely to patients diagnosed with a personality disorder, emphasising the role of organisational stress in producing adverse outcomes.

## **10.5 Limitations of this PhD research**

This PhD project was exploratory and sought an overarching view of the landscape: asking '*How do general hospitals respond to patients diagnosed with a personality disorder who are distressed*'. This research did not seek to draw definitive conclusions. The absence of any service user or carer involvement limited this study. The decision to undertake this particular PhD project has inherent researcher bias<sup>20</sup>. The involvement of experts by experience may have changed or enhanced the conceptualisation, analysis, and interpretation stages of this PhD thesis, particularly given the mental health nursing and mental health liaison background of the author. However, there was no budget to enable coproduction and the length of time taken to undertake this project prevented

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<sup>20</sup> Researcher bias, was discussed in more detail in section 4.9 in the section on reflexivity (Chapter 4).

asking experts by experience to offer time freely. Several visits were made to a third sector mental health project and staff and service users kindly provided feedback on the study design.

### **10.5.1 Recruitment**

The most critical limitation in the design of this research lay in the difficulties recruiting participants to a study about personality disorder and general hospitals. Although the need to access participants was pragmatically balanced against the methodological decisions taken, the research has been reported in accordance with the Good Reporting of a Mixed Methods Study guidelines (O'Cathain et al., 2008), and provides a transparent and defensible account of the decisions taken regarding recruitment, demonstrating quality and rigour. The integration of mixed methods data was a strength of this PhD research because it enabled the use of innovative methods and supported recruitment of hard to reach participants, in the time frame and budget, available.

A pragmatic approach to achieving a research sample of sufficient size and diversity had to be taken due to time, budgetary constraints, and the difficulties in recruiting (Sections 4.9 and 5.2). The recruitment on social media and the use of the emergent mixed methods study design enabled the research to progress. However, the use of a non-probability internet sample may have limited generalisability of the findings. The majority of people who elected to take part in studies 2a and 2b and 3a were women. In study 3b, interviews with mental health liaison professionals, there was an equivalent number of males and females that took part. Limited data were collected about the diversity of the sample to preserve the anonymity of the participants. Although supplementary understanding about the diversity of the sample may have provided additional context, the need to ensure that patients and professionals were sufficiently comfortable to participate was paramount. It was unknown if there were issues related to other protected characteristics, which overlapped the findings.

### **10.5.2 Web based surveys (2a and 3a)**

The decision to use a web based survey provided an economical means to access primary data covering a broad geographical area (De Leeuw, 2012). The privacy afforded online was considered to offer less risk of social desirability bias. However, self-reported data may be unreliable (Crutzen and Göritz, 2010). To counter recall bias, patient participants were eligible to take part if they were admitted to the general hospital in the two years before data collection. Participating clinicians were all employed in either a general hospital or in a mental health liaison service at the time of the study. The sample sizes in the quantitative strands were small, but the use of the mixed methods, explanatory sequential design, and the collection of data from several strands, was considered to offset some of the flaws in the individual data collection methods by producing a 'whole greater than the sum of the parts' (Barbour, 1999,p.40).

Although the literature review (study 1) did not contain any higher quality evidence, and the data analysis could not be finalised between the strands due to the length of the PhD candidature, every effort was taken to enhance the accuracy of the survey measurements. The survey questions were developed sequentially and to enhance face validity the question development was guided by the competencies set out in the UK personality disorder capabilities framework (National Institute for Mental Health in England, 2003). Patient study 2a also incorporated a nationally recognised and recommended patient experience measure, which was designed to assess the quality of care in general hospitals (NICE and NHS England, 2016).

A considerable amount of time was spent on social media during the data collection period to maximise the survey coverage. Twitter particularly, was labour intensive and it was necessary to tweet during the many hours of the day and night. While patterns of participant engagement started to emerge and were acted on, there may have been opinion leaders who were not reached during the

study period. It seemed probable that professionals who chose to take part in this research were more open to working with patients diagnosed with personality disorder, which may have positively skewed the findings.

Some of the service user and professional groups online were not receptive to sharing the recruitment message among members, which reduced the survey coverage. Suspension of the Facebook page may have impacted on engagement with the study. These issues might be attributable to: the decision not to add 'Facebook friends'; Facebook recognising the research activity to be spam, i.e., the same content being reposted; or the sole use of the account to search for groups related to mental illness.

There was little indication that surveys 2a or 3a were burdensome to the participants and that burden was a contributing factor to non response. In study 2a, which comprised 25 questions, all participants finished the survey except one participant who left the survey after question 22. In study 3a, which comprised 24 questions, all participants finished the survey, except for one participant who left the survey after question 23.

### **10.5.3 Qualitative telephone interviews (2b and 3b)**

Informational redundancy was achieved in both studies 2b and 3b. The patient data was particularly rich and some participants having established rapport made contact after their interview to offer information relating to subsequent hospital admissions. It was unfortunate that prospective data could not be used. All of the mental health liaison professionals who took part were relatively experienced clinicians, which benefitted the study. However, the views of less established liaison professionals, had they been accessible, may have offered a different perspective. A limitation of the qualitative strands was the absence of any interview data from the general hospital professionals and carers. Unfortunately, only one midwife was willing to take part in an interview and it was considered

unethical to interview a single general hospital professional participant. No carers were able to take part in an interview and data were collected from only five carers as part of the online survey, study 2a. The small number of carer participants prevented any meaningful analysis of the carer data.

Qualitative interviews with carers and general hospital professionals would have enhanced this PhD project. However, to some extent, the lack of interview data from general hospital professionals was mitigated by the explanatory sequential mixed methods design. This research design enabled the survey findings from study 3a to be explored in depth during the interviews with the mental health liaison professionals (study 3b), which provided a useful contrast.

#### **10.5.4 Analysis**

The use of framework analysis enabled a substantial amount of data to be managed systematically and transparently (Yin, 2014; Gale et al., 2013). However, the indexing, charting, mapping and interpretation of a large volume of data (Pope et al., 2006) and the reductive focus on how the hospital responded as a system, rather than on individual participants, may have resulted in the loss of some lived experience during the analytic process. While this was in keeping with the aims of the research and the pragmatic approach, this may be construed to be a limitation.

##### **10.5.4.1 Integration**

The integration of mixed methods data through mixed methods triangulation was considered to provide '*a whole greater than the sum of the parts*' (Barbour, 1999 ,p.40). However, the recommendations and guidance in the literature on the practicalities of undertaking mixed methods integration are sparse. In the absence of any recommended approach, a pragmatic decision was taken to

develop checklists, broadly based on the triangulation protocol developed by Farmer et al. (2006), informed by the discussion of mixed methods triangulation in O' Cathain et al. (2010). There are known limitations of triangulation. The value of triangulation is reliant on the question asked and the methods used (Redfern and Norman 1994). Triangulation does not mitigate researcher bias (Section 4.9), replication is difficult, and any sources of error may be compounded (Redfern and Norman 1994). This thesis provides a transparent and defensible account of the decisions taken, and the triangulation procedures used.

## **10.6 Recommendations**

This thesis indicated that considerable efforts are required to reduce organisational stress and to ensure that patients diagnosed with a personality disorder are not subject to adverse experiences in general hospitals. In this section, recommendations for clinical practice, commissioning, policy and future research are discussed. The recommendations may be of interest to patients, hospital managers, commissioners, policymakers, clinicians, and researchers.

### **10.6.1 Recommendations for practice**

- People working in the general hospital do not necessarily need specialist training to work well with people diagnosed with a personality disorder. Indeed, ad hoc training and education around 'personality disorder' may not address the gap in professional knowledge. Rather than pointing out communication deficits, it may be preferable to remind professionals that they have the skills to work with people, and that people diagnosed with a personality disorder need their compassion and humanity the same as any other patient. To work towards achieving parity of esteem in general hospitals, professionals appear to require practical training and

knowledge, e.g., to undertake observations with distressed patients, to assess mental capacity, and to understand psychopharmacology. General hospital professionals would also appear to benefit from understanding more about relational approaches to risk.

- This ability of liaison practitioners to establish relationships, negotiate, and influence their general hospital colleagues appeared essential. The findings suggested that liaison professionals required a high level of skill and cultural competence in this area. Competency frameworks, e.g. Eales et al. (2014), might place added emphasis on supporting liaison practitioners to develop negotiation and influencing skills.
- Medicines management was identified to be an area of deficiency. General hospitals seemed to require more input to use psychotropic medicines safely and therapeutically with patients diagnosed with a personality disorder. Mental health liaison services appear well placed to lead quality improvement work in this area. In the longer term, increasing the number of specialist mental health pharmacists and advanced practitioners in mental health liaison teams may support psychiatrists in providing the much needed medicines expertise.
- Complaints appear not to have been upheld in the general hospital setting because patients diagnosed with a personality disorder have been presumed unfit to complain because of their mental state. There may be a role for mental health liaison teams in advocating for patients who wish to complain about their care and treatment.

## **10.6.2 Recommendations for commissioning**

- The findings suggest that patients diagnosed with a personality disorder are experiencing adverse events in the general hospital setting. Patients diagnosed with a personality disorder appear to be at substantial risk of treatment non completion, premature discharge, discharge against medical advice, and of readmissions to the hospital. Strategic commissioners for general hospitals should engage with patients diagnosed with a personality disorder and their carers. A gap analysis may be indicated.
- The interpersonal work undertaken by mental health liaison professionals was considered fundamental to the liaison role. This research suggested that capacity in mental health liaison services for relationship building and peer support was linked to reducing organisational stress in the general hospital. This finding may have important implications for developing realistic clinical targets for mental health liaison services and raises questions about the over reliance on metrics to inform commissioning decisions.
- The training and education provided by mental health liaison teams was commonly identified as an optional extra. This thesis suggested that the education role of mental health liaison services was integral to the parity of esteem agenda and should be valued and resourced.

## **10.6.3 Recommendations for policy**

- Local and national policy and the literature has focused on managing mental health crises in the emergency department. The present study raises the possibility that from a patient safety perspective, this has been an oversight, with general hospital wards also providing de facto crisis care. This thesis indicates there is a requirement for policymakers to consider the care and

treatment in general hospital wards as part of the parity of esteem agenda. There may be a need for general hospital policies and guidance around the safe use of psychotropic medicines and the use of restrictive interventions.

- There may be a substantial risk of poor health outcomes among people diagnosed with a personality disorder as a result of diagnostic overshadowing and inverse diagnostic overshadowing. Strategies to improve the physical healthcare of people with severe mental illnesses should not overlook people diagnosed with a personality disorder. There appears to be an urgent need to lobby policymakers, to include people diagnosed with a personality disorder in policies, which seek to address parity of esteem.

#### **10.6.4 Recommendations for future research**

- More research may be needed to understand the prevalence of personality disorder in general hospitals. However, practically, that may not be achievable. Future quality research might include the lived experiences of patients diagnosed with a personality disorder and the experiences of carers or supporters, in the general hospital setting. An additional area for qualitative research might be patient and professionals experiences of interprofessional conflict in hospitals. Mixed methods research on the factors leading to treatment non-completion, and readmission in NHS general hospitals, among people with mental illnesses may also be a useful area for future research.
- There was a limited amount of data, which could not be analysed discretely, which related to patients diagnosed with a personality disorder in the ante and perinatal period. The experiences of having a personality disorder diagnosis or being a partner of somebody with a personality disorder diagnosis, and using maternity services may be a valuable area for future exploratory qualitative research.

- General hospital professionals may need more assistance to identify patients and carers who have enhanced needs related to psychological distress. The distress thermometer, initially developed for use with patients with cancer, has become a globally recognised tool to flag patient distress (Donovan et al., 2014). Future research to adapt and validate the distress thermometer for use with patients with a diagnosed mental illness and to explore the acceptability and feasibility of using the distress thermometer in the general hospital to facilitate referrals to mental health liaison services may be beneficial for patients and professionals.
- Unconscious biases were found to contribute to discriminatory practices. Further research to measure the extent of unconscious bias related to personality disorder in healthcare may be a fruitful area for further research. Healthcare professionals and patients may benefit from interventions to enhance self awareness. Building on the successful adoption of Schwartz rounds, aimed to enhance the emotional wellbeing of healthcare professionals (Robert et al., 2017), further research might explore the acceptability and feasibility of small group reflective practice on general hospital wards.

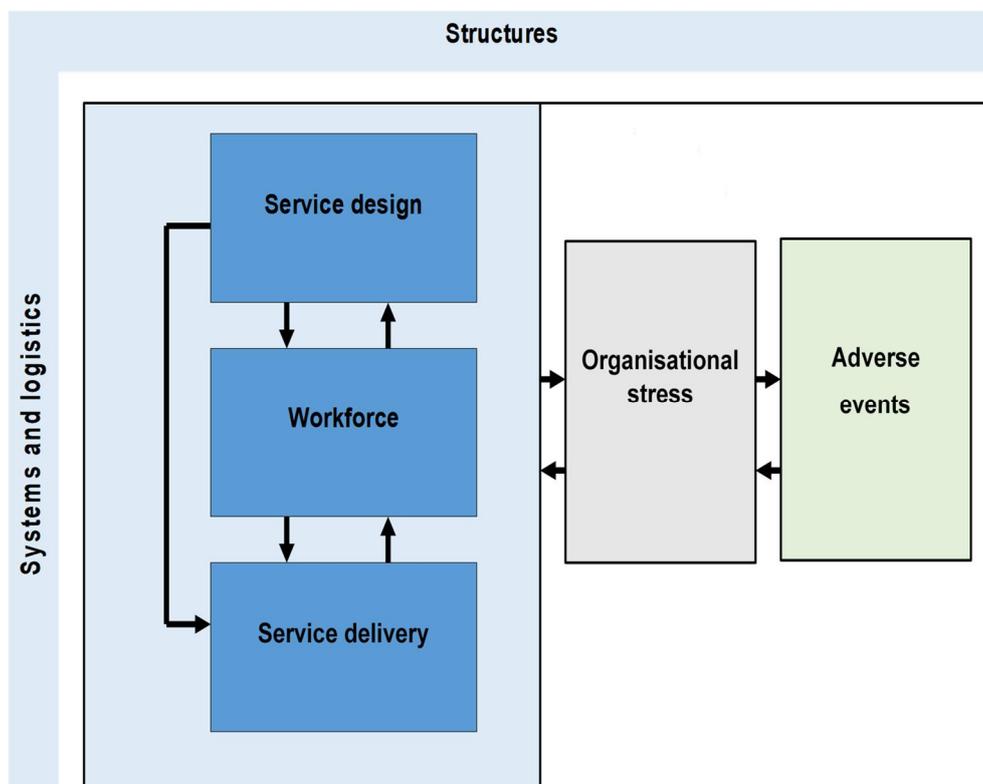
## **10.7 Dissemination strategy**

This work was presented at the Faculty of Liaison Psychiatry annual conference 2019. The oral presentation delivered was awarded joint first prize. Additional presentations have been given in Malmo and Lisbon as part of the European Academy of Nursing Science summer school programme and at two national 'personality disorder' conferences. This work will be incorporated into an NHS Health Education England online training package, specifically for people working in medicine. There is a plan to publish aspects of this work in the academic and professional literature, and on social media. Future opportunities for dissemination will be sought at conferences and in clinical practice.

## 10.8 A summary of the integrated findings

In accordance with the methodological approach used, the results of studies 1, 2a and 2b, 3a and 3b were integrated to connect, interpret and explain 'How do general hospitals respond to patients diagnosed with a personality disorder who are distressed'. The integrated themes: Workforce; Service delivery; Service design; Organisational stress; and Adverse patient events, and the overarching meta themes: Structures, Systems and logistics, and Outcomes were identified to be interrelated. This thesis contributes new knowledge by proposing an explanatory framework of how general hospitals respond to patients diagnosed with a personality disorder who are distressed (Figure 19).

**Figure 19 An explanatory framework of how general hospitals respond to patients diagnosed with a personality disorder who are distressed**



This research identified that general hospitals respond iatrogenically to patients diagnosed with a personality disorder. Systemic, logistical and structural barriers were identified to be pervasive and maintained a chain of circumstances, which produced organisational stress and adverse events. Considerable efforts appear to be required to reduce organisational stress and to ensure that patients with a diagnosis of personality disorder are not subject to adverse experiences in NHS general hospitals. The integrated findings of this PhD research underpin actionable recommendations for practice, commissioning, policy, and future research, pending further work in this neglected area of healthcare practice.

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# Appendices

Intentional space

**Appendix 1 Scoping review search strategy May 2019 (Study 1)**

297

<p><b>Personality disorder, violence and disruption and the barriers and enablers of general hospital care</b></p>	<p>Violence OR impulse control OR violence OR disrupt* OR behavio* OR conduct OR anger OR angry OR threat* OR aggress* OR disturb* OR impulsiv* OR hostil* OR violat* OR combative OR agitat* OR assault OR antagonis* OR rage OR attack OR danger OR intimidat* OR abuse OR distress AND personality ADJ disorder OR antisocial personality ADJ disorder OR borderline ADJ personality disorder OR compulsive ADJ personality disorder OR dependant ADJ personality disorder OR histrionic ADJ personality disorder OR paranoid ADJ personality disorder OR passive aggressive ADJ personality OR schizoid ADJ personality disorder OR schizotypal ADJ personality disorder OR antisocial OR asocial OR dissocial OR psychopath OR sociopath OR anankastic ADJ personality disorder OR hyster* OR disordered personality OR difficult AND hospital OR clinic OR ward OR district general OR inpatient OR general hospital OR infirmary</p>			
<p>Places to search for information:</p>	<p>Medline, PsycINFO, EMBASE, AMED, BNI, Cochrane library, Cinahl, Sociological abstracts, ASSIA. UKCRN and Opengrey.</p>			
<p>List of sources searched:</p>	<p>Date of search</p>			<p>Comments</p>

		Search strategy used, including any limits	Total number of results found	
Medline, AMED, EMBASE, PSYCHINFO via OVID	25/05/2019		0	Keyword search Limits: English language, humans, 2005 – current.
Medline, AMED, EMBASE, PSYCHINFO via OVID	25/05/2019	As above	11	Subject headings search. Limits: English language, humans, 2005 – current
Medline, AMED, EMBASE, PSYCHINFO via OVID	25/05/2019	As above	4	Title search. Limits: English language, humans, 2005 – current
EBM reviews via OVID	25/05/2019	As above	0	Keyword search No parameters
EBM reviews via OVID	25/05/2019	As above	0	Outline headings
EBM reviews via OVID	25/05/2019	As above	0	Title search

Sociological abstracts and ASSIA via Proquest	25/05/2019	As above	<b>19</b>	Main subject: English 2005 – current include only peer reviewed scholarly journals
Cinahl	25/05/2019	As above	MM exact major subheadings 0, Smart text searching 0 MW word in subject headings 0. Smart text searching 0. Title search 2.	Humans, English language 2005 – current
Cochrane	25/05/2019	As above		Keywords 2015 - current
Cochrane	25/05/2019	As above	<b>703</b>	2015 – current. Titles abstracts and keywords
BNI	No longer available	As above	NA	NA
UKCRN now UK clinical trials gateway		'personality disorder'	0 relevance	3 studies

Open Grey		'personality disorder and violence'	0 relevance	7 studies
Open Grey		'personality disorder and hospital'	0 relevance	13 studies
<b>TOTAL</b>			<b>739</b>	

- Articles exported into Endnote
- 34 duplicates removed
- **705 records screened**
- **Full texts obtained for 4 articles and read in full (+2 article trial protocol and no further info could be found)**
- Articles excluded: Trial protocol (2) Not relevant to an inpatient general hospital setting (1) Not specific to personality disorder (3)

## Appendix 2 A screenshot of the scoping review data charting spreadsheet (Study 1)

LS Lit Rev PhD, 19.9.15.xlsx - Excel

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Outcomes

G	H	I	J	K	L	M	N	O	P	Q	R	S
Study ID	Study type	Population/Participants	Purpose of the study?	Antecedent/Context	Data collection/Methods	Definition of conflict	How often?	What is the impact (harm)	Resolution?	Difficulties encountered	Outcomes	Long term
199	cross sectional	General hos 68 patients (M=42, F=26)	To describe disturbed beha disturbed be in the previous 7 days, how wards in 4 General ho and where they though the wards are be best.		Phase I collected num was used to assess in any physical force ad defined as 'pre alert s' to a worker and 'any maintained for 3 months however increased for the followu post intervention'. Bar which lasts a workes months. Not reported by diagnostic category. to believe that he or she is at risk of injury Phase II collated information about all patients who had been subject to an incident form coded for violence. Controls were matched by gender, month of admission and hospital unit. Exposure was defined as being in receipt of a risk flag. Chi squared tests were used to measure differences in study characteristics and conditional logistical regression was used to calculate odds ratios to investigate risk flag status. Adjustments were made for age, length of stay and diagnosis.							
1	Case Control	Hospital patients who report which was code had been assessed fo in a reported incident of violent/aggressive patients. Characteristics of the population are unreported. Authors state that the study took place in a large acute hospital unclear how typical this hospital is to other hospitals as no det was reported	high rates of To ascertain if the alert syst prompted this as a preventative measure. intervention strategies. Authors previous an 'alert system' as being effective in the of violent/aggressive patients.									
100	Case study	F, 38 year medical hist surgery. History of Del First husband for care 16 and 23. No family a visit although a good reported. No alcohol/s at the same hospital (2 other case studies excluded due to relevance)	To discuss the challenges of they are said Narcissistic personality disorder with administration. (Medical settings and discuss effective strategies to overcome these barriers. To understand for treatment/theoretical perspectives and how these may inform practice.									
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Papers 105-108 Papers 109-112 Papers 113-116 Papers 117-120 Papers 121-124 Papers 125-126 Included papers Exclusions

here to search

## Appendix 3 Confirmatory letter from the School Research Ethics Committee approving the study (Studies 2a and 2b)

Faculty of Medicine and Health  
Research Office

University of Leeds  
Worsley Building,  
Clarendon Way  
Leeds LS2 9NL  
United Kingdom  
31842  
Tel: +44 (0) 113 343  
25 April 2017



UNIVERSITY OF LEEDS

Ms Leila Sharda  
PhD student  
School of Healthcare  
University of Leeds  
Bairstow Wing  
LEEDS LS2 9JT

Dear Leila

Ref no: HREC16-033

Title: How do general hospitals respond to patients diagnosed with personality disorder who are distressed?

Thank you for submitting your documentation for the above project. Following review by the School of Healthcare Research Ethics Committee (SHREC), I can confirm a favourable ethical opinion based on the documentation received at date of this letter:

Document Received	Version	Date Submitted
Ethical_Review_Form_LS E Survey v2	2.0	31/03/2017
LS Doc1 V2 E- survey protocol	2.0	31/03/2017
LS Doc2 V2 E- survey data management plan	2.0	31/03/2017
LS Doc3 V2 E- survey respondent information	2.0	31/03/2017
LS Doc 4&5 V2 E-survey interviewee information and consent checklist x	2.0	31/03/2017
LS Doc 6 V2 E-survey distress protocol	2.0	31/03/2017
LS Doc 7 E-survey topic guide	1.0	31/03/2017
LS Survey protocol (Appendix 1) Recruitment emails	1.0	31/03/2017
LS Survey updated Mar 17	2.0	31/03/2017
Fieldwork_Assessment_Form_low_risk_final_protected_nov_15-1	1.0	31/03/2017

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics Administrator for further information [FMHUnEthics@leeds.ac.uk](mailto:FMHUnEthics@leeds.ac.uk)

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation,

including clinical areas. The SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, any risk assessments and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

## Appendix 4 Confirmatory letter from the School Research Ethics Committee approving the study (Studies 3a and 3b)

Faculty of Medicine and Health  
Research Office

University of Leeds  
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18 January 2018

Ms Leila Shanta  
PhD student  
School of Healthcare  
Faculty of Medicine and Health  
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University of Leeds  
LEEDS LS2 9JT



UNIVERSITY OF LEEDS

Dear Leila

**Ref no:** HREC17-007

**Title:** **How do general hospitals respond to patients diagnosed with personality disorder who are distressed? (Phase 2)**

Thank you for submitting your documentation for the above project. Following review by the School of Healthcare Research Ethics Committee (SHREC), I can confirm a favourable ethical opinion based on the documentation received at date of this letter.

Document Received	Version	Date Submitted
Ethical Review Form LS E Survey V2(3)	2.3	14/12/2017
Fieldwork Assessment Form_low_nsk_final_protected_nov_15-1(1)	1.0	10/11/2017
Gen HCP survey(1)	1.1	14/12/2017
Liaison survey(2)	2.0	14/12/2017
LS Doc1 V1 HCP E- survey protocol(1)	1.0	10/11/2017
LS Doc2 V1 HCP E- survey data management plan(1)	1.0	10/11/2017
LS Doc3 V1 HCP E- survey respondent information(1)	1.0	10/11/2017
LS Doc 4_5 V2 Hospital HCP E-survey interviewee information and consent checklist(1)	1.0	14/12/2017
LS Doc 6 V1 HCP E-survey distress protocol(1)	1.0	10/11/2017
LS Doc 7 V1 HCP E Survey topic guide(1)	1.0	10/11/2017
LS Doc 8_9 V2 Liaison HCP E-survey interviewee information and consent checklist(1)	1.0	14/12/2017

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics Administrator for further information [FMHUniEthics@leeds.ac.uk](mailto:FMHUniEthics@leeds.ac.uk)

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

## Appendix 5 Patient survey (Study 2a)



# How do general hospitals respond to patients diagnosed with personality disorder who are distressed?

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Thank you for your interest in this survey.

I am trying to find out about care for people with a diagnosis of personality disorder who have to stay in NHS (non mental health) hospitals. I want to know what happens when you need NHS (non mental health) hospital treatment but also have a mental health problem, and need help with that too.

Please help me by completing this short confidential survey. You will not be asked to give your name or say where you live.

---

**I really want to hear from people who have a diagnosis of personality disorder, who:**

- **were admitted to an NHS (non mental health) hospital in the last two years because of physical health problem**

**OR**

- **were admitted to an NHS (non mental health) hospital in the last two years to receive women's health services.**
- 

**I would also like to hear from you if you are a carer of somebody who has been in this position.**

---

**This survey is not about mental health or accident and emergency services and is only about people who are diagnosed with a personality disorder.** You will be asked about your experiences of being in hospital, and if you, or the person you care for, got the treatment required.

The survey will take around 15 minutes. You can do it in more than one visit. I will not get any of your responses or use your information until you press the finish button. This means you can change your mind about taking part in this survey at any point, until you press finish. A detailed information sheet about this study can be viewed and downloaded by clicking this link:

<https://www.dropbox.com/s/q2h2zl4nbap4tc4/Survey%20Respondent%20Information.pdf?dl=0>

Please don't hesitate to contact me at [hcls@leeds.ac.uk](mailto:hcls@leeds.ac.uk) with any questions. I will get back to you as soon as I am able.

---

I hope you find thinking about these issues interesting. However, sometimes thinking about your experiences can be upsetting. If you feel upset, there are some useful contact numbers at the end of this survey. I encourage you to seek support if you need to.

Welcome. I need some basic details about you.

Are you? \* *Required*

- Male
- Female
- Nonbinary
- Prefer not to say

Are you aged? \* *Required*

- 18 to 25
- 26 to 35
- 36 to 45
- 46 to 55
- 56 to 65

Are you completing this survey as? \* *Required*

- An individual who has a diagnosis of personality disorder, who has been admitted to an NHS hospital (non mental health) in the last two years.
- A carer of an individual who has a diagnosis of personality disorder, who has been admitted to an NHS hospital (non mental health) in the last two years.

## Your personal experiences

Thinking back to your admission(s) to an NHS (non mental health) hospital, can you tell me a little about your admission?

Do you think generally healthcare professionals were aware of your diagnosis of personality disorder? \* *Required*

- Yes.
- No.
- Not sure.

Thinking about your response to the last question, what made you think that?

When you were in the NHS (non mental health) hospital, what was most important to you at that time? \* *Required*

- Physical health (the reason I was admitted to the NHS, non mental health, hospital) was most important.
- Mental health was most important.
- Mental and physical health were equally important.
- Unsure.

Thinking about your response to the last question, can you say a little about what you thought was most important, and the care you actually received?

Was the specific treatment you needed for your mental health available while you were a patient in an NHS (non mental health) hospital? \* *Required*

- Yes. The treatment was available and I received it.
- Yes. The treatment was available but I refused it.
- Yes. The treatment was available but I was unable to get it.
- No. The treatment was not available.
- I didn't need any treatment for my mental health.

Would you like to say any more about the treatment you needed, how easy or difficult was it to get it?

If you needed treatment for your mental health, was this your usual treatment or an emergency/crisis treatment? \* *Required*

- Usual treatment.
- Emergency/crisis treatment.
- Both.
- I didn't need any treatment for my mental health.

Were you seen by anybody from the hospital mental health/liaison psychiatry service?

\* Required

- Yes.
- No.

**You will now see some statements which are just about your hospital mental health/liaison psychiatry service. The statements are taken from a document called 'Achieving better access 24/7 urgent and emergency mental health care' and were identified by service users as important, when receiving care and support from mental health services. Please say whether these statements reflect your experience of using your hospital mental health/ liaison psychiatry service. If I experience a mental health crisis again, I feel optimistic that care will be effective**

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

During the treatment for my crisis I was treated with empathy, dignity and respect

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

During the treatment for my crisis, I felt actively involved in shared decision making and supported in self management

- I strongly disagree with this statement.
- I disagree with this statement.

- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

I feel confident that my views are used to monitor and improve the performance of mental health care for crises

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

I can access mental health services when I need them

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

During the treatment for my crisis, I understood the assessment process, diagnosis and treatment options and received emotional support for any sensitive issues

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

During the treatment for my crisis, I jointly developed a care plan with mental health and social care professionals and was given a copy with an agreed date to review it.

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

When I accessed crisis support, I had a comprehensive assessment, undertaken by a professional competent in crisis working

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

The mental health team considered the support and care needs of my family or carers when I was in crisis. Where needs were identified, they ensured that they were met, when it was safe and practicable to do so.

- I strongly disagree with this statement.
- I disagree with this statement.
- I neither agree or disagree with this statement.
- I agree with this statement.
- I strongly agree with this statement.

### **Experiencing distress in an NHS (non mental health) hospital**

Many people experience distress when they have to stay in hospital. Were there any times you felt distressed? \* *Required*

- Yes.
- No.

When people become distressed they respond in different ways. People may cry, get angry, go quiet etc. What happened when you became distressed?

If you felt distressed, how important were the following:

Please don't select more than 1 answer(s) per row.

	Very important	Important	Quite important	Slightly important	Unimportant
Support from people who worked in the general hospital	<input type="checkbox"/>				
Support from a mental health professional	<input type="checkbox"/>				
Receiving medication	<input type="checkbox"/>				
Being able to use your own coping strategies	<input type="checkbox"/>				

Can you say a little about how well you were able to manage your distress in an NHS (non mental health) hospital, or if you were unable to manage your distress, can you say a little about that?

When you were discharged from an NHS (non mental health) hospital, was this? \*  
*Required*

- With medical advice.
- Against medical advice.

Is there anything else you would like to say about your discharge from hospital?

Overall, how satisfied were you with your experience(s) of being in an NHS (non mental health) hospital? \* *Required*

- Extremely satisfied.
- Quite satisfied.
- Somewhat satisfied.
- Quite dissatisfied.
- Extremley dissatisfied.

Thinking about your response to the last question, are you able to share the reason for answering like you did?

Do you think there is a strong possibility you will need to be admitted to an NHS (non mental health) hospital in the next 12 months? \* *Required*

- Yes.
- No.
- Not sure.

If you think there is a strong possibility you will need to be admitted to an NHS (non mental health) hospital again, can you say a little bit about your ongoing issues?

Overall, how do you feel about being admitted to an NHS (non mental health) hospital in the future?

## Your final thoughts

What could be done differently to support people who have a diagnosis of personality disorder, who are admitted to NHS (non mental health) hospitals?

Thinking about your responses overall, is there anything you would like to add?

There is an opportunity to be interviewed as part of this project. I will phone you, at a time and date convenient to you. Each interview will last around 30/40 minutes and will cover similar issues to this survey. The Interviews will be strictly confidential. Please indicate if you would be interested in participating in an interview.

- Yes, I would be interested in taking part in an interview.
- No, I would not be interested in taking part in an interview.

If you are interested in being contacted about giving an interview, please provide your email address. *Optional*

## Thank you for participating in this survey

Thank you for participating in this research. If you choose to exit this survey, your information will not be submitted. You are reminded that submitting your information provides consent for your information to be used as part of this research project.

Please do not hesitate to contact **Leila Sharda** at [hcls@leeds.ac.uk](mailto:hcls@leeds.ac.uk) if you have any further questions. Alternatively, if you have any concerns about this research, you may contact Professor John Baker at the University of Leeds, who is supervising this project, at [J.Baker@leeds.ac.uk](mailto:J.Baker@leeds.ac.uk)

## Appendix 6 Topic guide patient interviews (Study 2b)

### How do general hospitals respond to patients with a diagnosis of personality disorder who are distressed?

#### Introduction

Aim: To introduce the research and set the context for the proceeding discussion

- Introduce self
- Explain – nature and purpose of research
- What the research is for
- Talk through key points
  - Length of interview
  - Interview like a discussion, no right or wrong answers
  - Views are important
  - Participation is voluntary
  - Audio recorder is being used for accuracy
- Stress confidentiality
- Consent
- START RECORDING
- Ask for verbal confirmation that they have been given sufficient information about the study and are happy to proceed

#### 1. Background

Aim: To introduce the participant and highlight any background issues which might influence their overall care package.

2. The referral  
Aim: To explore the referral from the perspective of the participant, what happened, what treatment was received and the impact of that intervention.
  
3. Patient/carer outcomes  
Aim: To explore how current service provision fits with the needs of the patient/carer.
  
4. The hospital  
Aim: To find out what organisational factors support the patient to receive concurrent psychiatric interventions in the general hospital and/or involve carers.
  
5. Education and learning  
Aim: What do patients/carers perceive about the capacity and knowledge of healthcare professionals to work with people with a diagnosis of personality disorder in a general hospital setting?
  
6. Recommendations for the future  
Aim: to get the participants ideas about priorities to improve how general hospitals respond.

## Appendix 7 Nvivo Codebook (Studies 2a and 2b)

Name	Description
Distress	What happens when patients become distressed and what are the implications
Experiencing conflict	
Experiencing distress	
Leaving the hospital early or against medical advice	
Self harming in hospital	
Integration of services to provide mental and physical healthcare	How services meet the needs of patients that need physical and mental healthcare.
Ideas for improvement	What ideas are there for improvement?
Inefficient practice	Are services efficient?
Information sharing	How information is used to meet the needs of patients diagnosed with a personality disorder

Name	Description
Integration of mental health care in the general hospital	What are patients experiences of receiving this service?
Missed care and treatment	
Diagnostic overshadowing	
Medicines	How are medicines managed when patients are diagnosed with a personality disorder?
Pain management	
Professionalism	
How knowledge, understanding, skills and practice reflects the needs of patients diagnosed with a personality disorder	How knowledge, understanding, skills and practice reflects the needs of patients diagnosed with a personality disorder
Personality disorder and physical health	What are the issues and what is the relationship between personality disorder and physical (ill) health?
Responses to the personality disorder diagnosis	

Appendix 8 A screenshot of the framework used in the integrated analysis of the patient interviews and survey (Studies 2a and 2b)

Indexing framework patient study

Framework Matrix Tools

FRAMEWORK MATRIX

A: Inefficient practice	B: Distress	C: Information sharing	D: How knowledge, understanding, skills and practice reflects the needs of patient diagnosed with a personality disorder	E: Medicines	F: Pain management	G: Personality disorder and physical health	H: Ideas for improvement
	<p>The time I did not know about it until I was in a room with four psychiatrists I was so very angry about it.</p> <p>Then I was taken to a room and four psychiatrists asked me loads of questions for ages. I was made to feel like a liar and as if I was putting on these symptoms.</p> <p>I become very distressed, get defensive, go into sensory overload, can either have a meltdown or a shutdown, or become extremely upset, start sobbing, hitting myself</p>	<p>It is on my medical records, if asked what disabilities and mental illnesses I have I will say EUPD</p> <p>It has probably far more likely prevented treatment.</p>	<p>medical professionals to be more understanding, more aware, they are often so brutal and short with me. If I become distressed or have a meltdown, I am told to pull myself together. This only makes me feel worse and I want to go home. Often it is the medical professionals attitudes that are the worst thing.</p> <p>I have been told off for being on my phone, when I was on social media engaging with friends.</p> <p>Rarely, there have been some excellent understanding staff over the years, who have done amazing</p>	<p>usually my medication stops completely or for a few days</p> <p>The wards do not have my medication on them, so they must be ordered from pharmacy. One of my medications is a red drug, so take S along time to order. I often carry that days worth of medication if I am out, but if you suddenly go to A&amp;E you don't always think to take your medication, plus as I am only allowed a weeks supply of medication at a time, I often don't have enough anyway. So I will go several days without my medication, meaning not only am I</p>		<p>I was rushed to hospital with stroke like symptoms. The left side of my body drooped, went limp and I couldn't move it properly. The ward found out I have a rather long and complex history of mental illnesses and also were told that I had recently had a psychotic episode which had meant I had suddenly stopped all my psychiatric medication. So instead of doing any physical tests I lay in a hospital bed for a few days not knowing anything, except being constantly told I was stupid for stopping my tablets.</p> <p>Eventually after my partner kicked</p>	<p>Many more nurses on ward had, had extensive training in things like mental illnesses, etc., different ways people communicate (text to speech devices etc) this training was done by mentally ill people (mental illness) and autistic people (for autism) they after all are real experts. And any training other disabilities should again done by people with that disability.</p> <p>So listen to us, have training various disabilities and different things like communication and also LGBTQ+ people, actually have the training de</p>
<p>So, I was then discharged that night and then my symptoms got a lot worse and my parents who live in a different - they live in XXXXX (a different area) - came to pick me up and they took me to a hospital there and mental health didn't come up at all and I felt I was treated a lot better and they took me seriously and took my pain seriously. You know, even though they weren't that concerned about... that it was anything serious but that they listened and didn't make those sort of judgements or comments or... yeah.</p>		<p>I have a care co-ordinator and she was supposed to visit me that day and I'd contacted the CMH team to let them know I was in hospital and she later she told me she got to my house and I wasn't there [inaudible 09:27]. So, she must have got the message that I was in hospital, because she then rang the hospital and I have no idea how she, 'cause... I guess she rang A&amp;E and then they put her through, but then when I was bed, like, when I was in the bay, I overheard the conversation. And the doctor had given her loads of</p>			<p>I was being given pain relief before. I was on quite strong pain relief and when that, sort of... I was there for quite a long time. I was there for about 8 or 9 hours. So, that was when I first went in [inaudible 08:06] later I was still in a lot of pain, and I asked for some more pain relief and he was like, it could be [diagnosis 08:13] and not really... You know, I don't really want to give you that strong medication again, so here's some paracetamol, and I was, like...</p> <p>that is mental health [inaudible</p>	<p>my physical health has been, sort of, dodgy. Nothing really serious, but, sort of, enough to be under a couple of different consultants and various hospital appointments and several operations and stuff.</p> <p>when you know if they do a physical examination and they feel your reflexes and they feel your abdomen and stuff like that and I've got quite a lot of scars on my abdomen from self-harm and he was like, oh, what's this. And I, sort of, explained and I said, you know, [inaudible 06:51] BPD and he was like, oh, okay. And</p>	
	<p>if you're... in my experience, whenever I've been on a psychiatric ward, it's a question of go back to sleep, you're here to sleep, it's night time. And if I've asked to talk</p>	<p>I had a letter to bring home with me, it definitely didn't say anything about borderline. I don't think it said anything about bipolar either, to be honest. I think it mentioned</p>	<p>The nurses were really, really nice, really kind and empathetic, and very concentrated on like was I in pain.</p>	<p>You know, it seemed to be a really key focus to keep me out of pain, which quite surprised me because I've always sort of felt that I've had to fight to get a tablet if I need</p>	<p>I'm comparing it to being on a psychiatric ward and needing medication. There, I felt as though I really had to justify myself to the hit before I could get something, whereas if I</p>	<p>I didn't think that my stomach problems were related to the mood stabiliser, because I'd taken it and tolerated it so well before. And she said, well, yes, but you stopped taking it.</p>	

ve to search

## Appendix 9 General hospital professional survey (Study 3a)

### How do general hospitals respond to patients diagnosed with personality disorder who are distressed (HCP survey).

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Page 1: Thank you for your interest in this survey.

I am trying to find out about the care and treatment which is available to people with a diagnosis of personality disorder on general hospital wards.

I would like to hear from you if you work in an NHS general hospital (non mental health) in an inpatient area.

**This research is not about mental health or accident and emergency services and excludes people working in mental health liaison services.** There will be a separate survey for people working in mental health liaison teams, please contact me if you would like to be notified when it goes online.

The survey will take less than 15 minutes. You can do it in more than one visit. I will not get any of your responses or use your information until you press the finish button. This means you can change your mind about taking part in this survey at any point, until you press finish. A detailed information sheet about this study can be viewed and downloaded by clicking this link

<https://www.dropbox.com/s/vptbbrtb05qcwdf/LS%20Doc3%20V1%20HCP%20E-%20survey%20respondent%20information.docx?dl=0>

Please don't hesitate to contact me at [hcls@leeds.ac.uk](mailto:hcls@leeds.ac.uk) with any questions. I will get back to you as soon as I am able.

---

I hope you find thinking about these issues interesting. However, no matter who you are, there are times when thinking about your experiences can be upsetting. If you feel upset, I encourage you to speak to somebody. **Mind infoline** provide information on a range of topics, including where to get help. Their number is **0300 123 3393** or you can email them at [info@mind.org.uk](mailto:info@mind.org.uk).

Page 2: Welcome.

**Basic details about your clinical background.**

Are you?

- Male
- Female
- Nonbinary
- Prefer not to say

What is your professional background? \* *Required*

- Nurse
- Nursing assistant/support worker
- Midwife
- Psychologist
- Allied health professional/Therapist
- Doctor
- Student HCP or other (Please specify)

If you selected student HCP or other, please specify:

What is your general speciality/area of work? \* *Required*

- Anaesthesia/Theatres
- Oncology
- Radiology
- Sexual and reproductive health
- Obstetrics and gynaecology
- Medicine
- Surgery
- Pathology
- Intensive care
- Leadership/Management
- Other

If you selected Other, please specify:

How much direct contact do you have, in your current role, with people who have a diagnosis of personality disorder?

- Very frequently (More than 3 times per week)
- Frequently (1-2 times per week)
- Often (once per week)
- Occasionally (1-3 times per month)
- Rarely (Less than once per month)

**Promoting emotional wellbeing in your clinical area.**

How easy is it to access specialist mental health **assessment and support** for patients admitted to your clinical area, who have a comorbid diagnosis of personality disorder?

How easy is it to access **advice** from specialist mental health professionals to support you/your team to provide care and treatment to people with a diagnosis of personality disorder?

What happens in your clinical area when there are decisions to be made which cut across your clinical speciality into mental health services? What works well? What works less well?

Have you been involved in any situation, where there was conflict amongst professionals involved in the care and treatment of a patient with a diagnosis of personality disorder? What worked well? What didn't work well?

What are you most likely to do to support somebody, who has a diagnosis of personality disorder, who becomes distressed in your clinical area? (Please rate 1 most likely to offer and 5, least likely to offer)

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5
--	---	---	---	---	---

Encourage self help	<input type="checkbox"/>				
Provide/arrange 1-1 nursing time	<input type="checkbox"/>				
Provide/arrange 1-1 consultant time	<input type="checkbox"/>				
Offer a private room	<input type="checkbox"/>				
Offer medicines	<input type="checkbox"/>				
Refer to mental health services	<input type="checkbox"/>				
Discuss with a mental health professional	<input type="checkbox"/>				
Try to arrange a transfer to a mental health unit	<input type="checkbox"/>				

Are you able to say anything else about the strategies, which are available in your clinical area? Do you have any good practice examples to share? Have you learnt anything about working with this patient group? Are there additional strategies, which you have used, which have not been mentioned?

Please can you say a little about how the strategies in your area are decided upon? Who decides which patients get which types of clinical management?

Do you perceive there are any barriers to treating/caring for people who have a comorbid diagnosis of personality disorder in your clinical area?

Are you able to say why you answered the last question like you did?

Do you prescribe medicines?

Yes  
 No

What (if any) are the main issues around prescribing for this patient group in NHS (non mental health) hospitals?

**Assessing and managing risk in your clinical area**

If a patient is considered to present a risk, either to themselves or to other people, is there a formal process for identifying risks? Can you say a little about how risks are identified and how they are managed in your clinical area?

Do you feel confident in assessing mental capacity in people who have a comorbid diagnosis of personality disorder?

How often do people who are diagnosed with personality disorder leave your clinical area against medical advice?

Do you think leaving against medical advice is a particular issue amongst this patient group? Is this an issue which raises any particular concerns in your clinical area?

**Supporting professionals to work with patients diagnosed with personality disorder.**

How well do you think your professional training prepared you, to work with people who have a diagnosis of personality disorder? (1= least prepared, 10=most prepared).

Please don't select more than 1 answer(s) per row.

	N/A no professional training	1	2	3	4	5	6	7	8	9	10
Preparedness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, how satisfied are you with the **physical healthcare** which is provided to people with a diagnosis of personality disorder who have mental health needs in general hospitals?

- Not at all
- In part
- Satisfied
- Very satisfied
- Delighted

Is there anything you would like to add about the physical healthcare which is available to people diagnosed with a personality disorder, in NHS (non mental health) hospitals?

Overall, how satisfied are you with the **mental healthcare** which is provided to people with a diagnosis of personality disorder in general hospitals?

- Not at all
- In part
- Satisfied
- Very satisfied
- Delighted

Is there anything you would like to add about the mental healthcare which is available to people diagnosed with a personality disorder, in NHS (non mental health) hospitals?

If resources were no object, is there anything, which you think could be done differently, to support people who have a diagnosis of personality disorder, who are admitted to NHS (non mental health) hospitals?

Thinking about your responses overall, is there anything you would like to add?

There is an opportunity to be interviewed as part of this project. I will phone you, at a time and date convenient to you. Each interview will be confidential and will last around 30/40 minutes. The interviews will explore the same topic in more depth. Please indicate if you would be interested in taking part in a telephone interview in the future.

- Yes, I would be interested in taking part in an interview.
- No, I would not be interested in taking part in an interview.

If you are interested in being contacted about giving an interview, please provide your email address.

Thank you for participating in this research. If you choose to exit this survey, your information will not be submitted. You are reminded that submitting your information provides consent for your information to be used as part of this research project.

Please do not hesitate to contact **Leila Sharda** at [hcls@leeds.ac.uk](mailto:hcls@leeds.ac.uk) if you have any further questions. Alternatively, if you have any concerns about this research, you may contact Professor John Baker at the University of Leeds, who is supervising this project, at [J.Baker@leeds.ac.uk](mailto:J.Baker@leeds.ac.uk)

## Appendix 10 Interview topic guide (Study 3b)

### How do general hospitals respond to patients with a diagnosis of personality disorder who are distressed?

#### Introduction

Aim: To introduce the research and set the context for the proceeding discussion

- Introduce self
- Explain – nature and purpose of research
- What the research is for
- Talk through key points
  - Length of interview
  - Interview like a discussion, no right or wrong answers
  - Views are important
  - Participation is voluntary
  - Audio recorder is being used for accuracy
- Stress confidentiality
- Consent
- START RECORDING
- Ask for verbal confirmation that they have been given sufficient information about the study and are happy to proceed

#### 1. Background

Aim: To introduce the participant and highlight any background issues which might influence their practices.

2. The referral  
Aim: To explore issues around referrals for psychiatric interventions from the perspective of the participant, what their role is and what influences their practice.
  
3. Patient outcomes  
Aim: To explore how current service provision fits with the needs of the patient.
  
4. The hospital  
Aim: To find out what organisational factors support the health professional to undertake their role and do any make it more difficult?
  
5. Education and learning  
  
Aim: How do healthcare professionals learn how to work with people with a diagnosis of personality disorder and what are the principal sources of information?
  
6. Recommendations for the future  
Aim: to get the participants ideas about priorities to improve how general hospitals respond.

## Appendix 11 Nvivo codebook (Study 3b)

Name	Description
<b>Distressed professionals</b>	What happens when workers become distressed and what are the implications
Conflict amongst professionals	How anxiety and distress turns into conflict and the implications.
Responding to anxiety and fear amongst general hospital professionals	Perceptions of anxiety and fear amongst general hospital workers and the implications.
<b>Integrated services to provide mental and physical healthcare</b>	How front line services meet the needs of patients who need physical and mental healthcare.
Mental health liaison for people diagnosed with a personality disorder	What clinical work do liaison teams do with people diagnosed with personality disorders and why is it important?
Safe and timely use of medicines	How are medicines managed when patients are diagnosed with a personality disorder?
Working within legislation	Application of the Mental Health Act and the Mental Capacity Act in the general hospital setting.
<b>Organisational culture and practice</b>	How systems and structures support the care and treatment of patients diagnosed with a personality disorder
Ideas for improvement	What ideas are there for improvement?

Name	Description
Information sharing	How information is used and processed to meet the needs of patients diagnosed with a personality disorder
Parity with other conditions	How systems and structures impact on the care and treatment of people diagnosed with a personality disorder compared with other conditions
Resources and workforce effectiveness	Support and training to meet the needs of the general hospital workforce.
<b>Professionalism</b>	The competence and skills of general hospital workers to work with patients diagnosed with a personality disorder.
How professional knowledge, understanding, skills and practice reflects the needs of patients diagnosed with a personality disorder	How knowledge, understanding, skills and practice reflects the needs of patients diagnosed with a personality disorder
Responses to the personality disorder diagnosis	How professionals respond to the diagnosis, the language and terminology used and the implications.

## Appendix 12 A screenshot of the framework used in the analysis of the mental health liaison interviews (Study 3b)

Liaison Professionals study 3a

Framework Matrix Tools

REATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW

Framework Matrix

Coding Context  
 Coding Information  
 Coding Excerpt  
 New Summary Link  
 Delete Summary Link  
 Auto Summarize  
 Highlight Summary Links  
 Summary

lated View

A: Conflict amongst professionals	B: Responding to anxiety and fear amongst general hospital professionals	C: Mental health liaison for people diagnosed with a personality disorder	D: Safe and timely use of medicines	E: Working within legislation	F: Ideas for improvement	G: Information sharing	H: Parity with other conditions
<p>I mean there's sometimes conflict between ourselves and the treating team, because if someone's challenging, often the hope is that a mental health team will come in and take that patient away. But, you know, if an acute [inaudible 18:30] is indicated then the patient won't be taken away. So there's a bit of conflict about that sort of very basic [inaudible 18:39], should this patient be on our ward right now or could you please take them away.</p> <p>So if you think of a general</p> <p>I can think of a particular experience I had with somebody who was a very well known lady with diagnosis of personality disorder who was very good at splitting, very good at causing people to feel very anxious about her and I'd come back from days off and this lady hadn't been seen for a couple of days, I walked onto the ward and there was two doctors and the nurse in charge shouting at me up the corridor, that's the kind of thing that we have to avoid.</p> <p>so if we're able to keep things</p> <p>So I think the idea that... I think conflict comes from anxiety provoking situations, these are very stressful anxiety provoking situations. I think</p>	<p>A fair amount, it's the people who cause a lot of concern on the part of the general side of the hospital and we tend to give a lot of support with that really and as much of what we do is about supporting the staff and supporting the patient, I'd say.</p> <p>I think there's... people with personality disorder are generally very challenging in that they handle stress in a way differently to other people and that causes a lot of upset throughout the ward, we see a lot of splitting going on, we see a lot of general anxiety</p> <p>there's a bunch of extra risks and considerations we have to be concerned about, but interestingly, we do this training with the new nursing staff in liaison psychiatry, so they get a week's induction</p>	<p>They'll also see any cases of self-harm that have been admitted to the general hospital wards.</p> <p>in terms of referrals of patients who have got a definite personality disorder, probably are very low. However, they are very difficult to manage, you know, so they might consume a disproportionate amount of time in a way.</p> <p>so they'll have lots of kind of explicit rules and quite a lot of kind of un, kind of articulated rules as well. So patients who struggle with boundaries and</p> <p>I mean, thinking about particular cases, it's going to the ward fairly frequently, it's about clear notes and a clear idea of what's going on, I spend a lot of my time explaining what a personality disorder is and isn't, so what people on the wards can expect. How do deal with... they all get a full plan, which would detail how to deal with the fact that people can be very, very challenging, what the challenges are likely to be but all with the idea of trying to help people understand exactly what's going on behind the diagnosis, the</p> <p>it's usually around perhaps patients expressing a wish to no longer have medical treatment for their physical health difficulties that might be related to an overdose or an episode of self-harm... it might</p>	<p>Or let's put some boundaries in place about perhaps requests for analgesics which aren't, you know, necessarily going to help the patients.</p> <p>If someone's got a personality disorder they might present with high levels of distress, they might give the impression that they're not being helped and sort of the pressure for them to be given other helpful kind of interventions. So the net effect of that can be the patients end up on higher doses of medication than they would be perhaps if they didn't have a personality disorder.</p> <p>people understand that a personality disorder is a mental illness and can be medicated and that's not the case</p> <p>We tend to, sort of, avoid prescription of medication, I think benzos in particular so actually can make things worse, they can make people more likely to self-harm when they're taking the benzo, because it reduces their capacity to make a decision or it relaxes people into a situation where they feel able to self-harm, we have a lot of conversation about, well, can't</p> <p>I do specific training around rapid tranquilisation, but it's mainly to the emergency department, middle grade doctors and consultants, so there's a local session that we in twice a year. I do that with</p>	<p>We get into all kinds of arguments about capacity and what a personality disorder is, thinking about somebody who is physically very unwell and at the same time, we'd push boundaries and she was refusing to take medication which she desperately needed to stay alive and the question that was asked, how can we let her not take her medication? Where, you know, we'd have to sit down, and this is the same lady that had three people shouting at me, and we have to talk about well, has she got capacity?</p> <p>When my nursing colleagues are... perhaps have ongoing concerns about somebody's critical presentation, for example, if they feel their capacity is impaired or they feel that the... sort of. Mental</p>	<p>the glib thing to say is, yeah we could do more training and increase awareness and you know, perhaps get some people with personality disorders to be involved in that training as well, which I think would be really powerful</p> <p>there probably is more that can be done, but you know, you can go to XXXX where they've got, you know, 2,000 odd beds and [inaudible 12:00], you know, really big hospitals, it's just, you know, how do you do that sort of education in a way that's going to reach out to areas</p> <p>we can pick up on the idea of genuineness and sometimes genuineness isn't necessarily turning up exactly at the right times that you said you would turn up, so much as saying, sorry I didn't make it and explain it's really busy, but, yeah, it's difficult for the wards, but it's not a perfect situation and we have to work within those constraints, don't we?</p> <p>I think there should be a module where all psychiatric nurses sit down and spend a good month finding out what personality disorder is and to</p> <p>This is all about attitudes for me, it's about attitudes and values, so we've tried to do attitudes and values, I've researched it ad infinitum, tried to understand what kind of stuff works and we know</p>	<p>The other thing that's really helpful now is that we can view the drug charts electronically for most of the wards. So when we're discussing a patient we can actually get up, you know, on our screens, what the patient's taking. So we've got... you know, we can get a really good overview of what are the medications people are on.</p> <p>You know, I guess we can link in with the community mental health teams quite easily as well and the XXXX network. We're sufficiently sort of [inaudible 21:05] to the rest of</p> <p>We have all kinds of issues with different systems obviously, I work for one trust within two different other trusts, we have to record information so it's available to people so they're able to deal with the situation going on, so we tend to write things twice at least.</p> <p>A and E we have to see people within an hour on the ward, it's within 24 hours, in some wards that we have to see people within six hours, the recording of information we need to have something</p> <p>we turn them around quite quickly, because we've got good relationships with community colleagues, so we're able to discharge patients quite quickly if their physical health allows it</p>	<p>If a patient is distressed general hospital staff sh be able to deal with just, know, distressed, in the way they can, you know, with their kind of first aid resuscitation or whatever. They're just basic skills t general hospital staff sh have, which should inclu management of their kn minor mental health difficulties.</p> <p>the wards are so massn under resourced and so they have such a turnover people don't remain in hospital long enough to know a lot of the time, si doesn't happen and we to recognise that everyo has their limitations, but said, I think wards are v very good at making pe feel better, nurses and healthcare assistants, th their bread and butter, if what they do and it only becomes a problem wif personality disorders be they don't understand wf going on, they know ea</p>

to search

### Appendix 13 Triangulation checklists (Studies 1, 2a and 2b, 3a, and 3b)

Theme	Study 1: Literature review	Study 2a and 2b: Patient survey and interviews	Study 3a: General hospital survey	Study 3b: Mental health liaison interviews
<b>Service design</b>				
Personality disorder was perceived to be overlooked and excluded by local and national policy		6.4		8.3
Risk to self and others was not addressed by local policy			7.4.1  (Converges with workforce 2a and 2b, adverse events and service delivery 2a 2b)	8.3  (Converges with service delivery and medicines)
Priority given to accident and emergency means general hospital professionals need to be equipped to respond to distress			7.3.2	8.3
Education and training around mental health issues was not considered to be mandatory in the general hospital			7.3.4	8.3

Education and training around mental health issues was considered to be mandatory in the general hospital			7.3.4	8.3
The divide between mental and physical health services was believed to result in adverse outcomes			7.3.3	8.3  (converges with adverse events 2a 2b)
Participants unable to self refer to liaison teams and professionals 'prescribed' mental health liaison		6.4		
Mental health liaison offered assessment and no interventions		6.4		
Mental health services were under resourced		6.4		

Mental health liaison services were under resourced	3.5.3.2	6.4	7.6.3 7.6.4.	8.3
Limited support for carers		6.4		
Unsatisfactory information governance		6.4	7.3.5	
Dissatisfaction with services	3.5.3.2	6.4	7.6.1 7.6.2 7.6.3	
Inequitable complaints process		6.4		

Theme <b>Workforce</b>	Study 1: Literature review	Study 2a and 2b: Patient survey and interviews	Study 3a: General hospital survey	Study 3b: Mental health liaison interviews
General hospital workforce perceived they had infrequent contact with patients diagnosed with a personality disorder		6.2	7.2	
General hospital professionals rarely used the personality disorder diagnosis as a reason for referral				8.1
Patients believed they were treated with kindness empathy and respect by the general hospital workforce		6.2		

<p>The general hospital workforce was unresponsive to the needs of people diagnosed with a personality disorder</p>		<p>6.2</p>	<p>7.3.4 7.3.5 7.5.1  (Converges with service design)</p>	<p>8.1</p>
<p>General hospital workforce was pejorative and made assumptions about people diagnosed with a personality disorder e.g., neurotic, attention seeking angry</p>		<p>6.2  (Converges with service delivery 3a)</p>	<p>7.3.3  (Converges with adverse patient events 2a 2b)</p>	<p>8.1</p>
<p>Patients diagnosed with a personality disorder were treated differently to other patients in the general hospital</p>	<p>3.5.3.2  (Converges with service delivery)</p>	<p>6.2</p>		<p>8.1</p>

Patients preferred professionals not to know they had a diagnosis of personality disorder		6.2		8.2 (Converges with service delivery 3b)
Low level of knowledge and skills and compassion and limited self awareness in the general hospital		6.2	X low level knowledge and skills. Evidence of compassion and self awareness	8.1
Workforce receptive to developing knowledge and skills compassion and self awareness			Mixed views	8.1 dissonance with 8.2 influence and negotiation?
Belief that health professionals in the general hospital did not need sophisticated mental health skills (6 C's)		6.2		8.1

Personality disorder was less understood compared to common mental health problems such as depression and anxiety		6.2		
Personality disorder was considered to be a socially unacceptable term		6.2		8.1
General hospital professionals did not access high quality information about personality disorder		6.2	7.5.1.2	
Experts by experience could improve practice		6.2		

Patients believed they were not treated with kindness empathy and respect by the general hospital and the mental health liaison team		6.2		
The mental health liaison services were unresponsive to the needs of people diagnosed with a personality disorder		6.4	7.3.2	8.2 (Converges with service delivery 3b)
Mental health liaison professionals showed pejorative attitudes				8.1

<b>Theme</b>	Study 1: Literature review	Study 2a and 2b: Patient survey and interviews	Study 3a: General hospital survey	Study 3b: Mental health liaison interviews
<b>Service delivery</b>				
The mandate on mental health services was considered to be substantial				8.2

Evidence of mental health liaison teams using high level diplomacy and influencing skills				8.2
The mental health of patients was of comparable or greater importance than their physical health		6.3	7.3.1 ↔ Complementarity	8.2
Patients perceived they were unable to access their usual treatment for their mental health in the general hospital		6.3	7.3.2	
Missed, interrupted and omitted pharmacological treatments		6.3	7.3.6  (Converges with service design 2a 2b, concern about comorbid substance misuse 3a and workforce 2a 2b)	8.2
Excessive pharmacological treatments			7.3.5	8.2

Unable to persuade the general hospital of the clinical need for medicines		6.3		8.2
Personal expertise and lived experience not recognised in managing medicines		6.3		
Mental health concerns were perceived to be ignored while the general hospital focused on physical health (Inverse diagnostic overshadowing)		6.3	7.3.2	
Physical health concerns were perceived to be ignored while the general hospital focused on mental health (Diagnostic overshadowing)		6.3		

The general hospital was believed to manage pain better than psychiatric wards		6.3		
Patients diagnosed with a personality disorder reported pain was not taken seriously and they were denied pain relief to penalise them for wrong doing		6.3		
Concerns about comorbid substance misuse	3.5.3.2	6.3 (Converges with workforce)		8.2
Perception that there was minimal understanding of the interrelationship between mental and physical health		6.3		
The general hospital was able to undertake assessment of mental capacity			7.4.2 (Converges with organisational stress 3b)	8.2
A lack of clarity about the purpose of one to one nursing care	3.5.3.1	6.3	7.3.4	

Having a personality disorder attenuated referrals to other specialities (Physical and mental health services). Referrers had to pursue referrals and on occasions repeat them.		6.3		8.3
Measuring and reporting mental health liaison service outcomes was challenging in relation to people diagnosed with a personality disorder				8.2

<b>Theme</b>	Study 1: Literature review	Study 2a and 2b: Patient survey and interviews	Study 3a: General hospital survey	Study 3b: Mental health liaison interviews
<b>Organisational stress</b>				
General hospital professionals experienced intense anxiety about working with people diagnosed with a personality disorder	3.5.3.2			8.4

Anxiety and stress was described at ward level and experienced collectively	3.5.3.2			8.4
Anxious professionals underreacted				8.4
Anxious professionals overreacted				8.4
General hospitals wanted the mental health liaison service to reduce their anxieties by taking patients away				8.4
There was interprofessional conflict			7.3.3	8.4

Professional anxiety impacted on decision making				8.4
General hospital professionals described emotional burden			7.5.1.3	
Mental health liaison professionals were 'burnt out'		6.4  (Converges with service design)		

<b>Theme</b>	Study 1: Literature review	Study 2a and 2b: Patient survey and interviews	Study 3a: General hospital survey	Study 3b: Mental health liaison interviews
<b>Adverse events</b>				
Participants experienced distress/mental health crisis in the general hospital		6.5		
Patients believed being in hospital was detrimental to their mental health		6.5  (Converges with service delivery and workforce)		
Professionals working in the general hospital were considered to have an important role in reducing distress/avoiding adverse events		6.5		
Professionals working in the mental health services were considered to have an important role in reducing distress/avoiding adverse events		6.5		

Psychological distress in the general hospital manifested as adverse events e.g. cutting, tying ligatures, vomiting and not eating		6.5		
Participants attempted suicide in the general hospital		6.5		
Participants left the general hospital against medical advice (AMA)	3.5.3.1	6.5	7.4.3 (Converges with service delivery 3a)	
Conflict occurred between patients and professionals	3.5.3.1	6.3 (Converges with service delivery) and interprofessional conflict/organisational stress)		
Professionals used correctional strategies e.g., security guards or behaviour plans to respond to conflict	3.5.3.3	6.5  Complementarity with organisational stress		
Participants wanted to avoid being admitted to the general hospital		6.5  (Converges with workforce)		
Participants believed it was likely they would be readmitted	3.5.3.2	6.5		

## Appendix 14 Distress policy (Studies 2a and 3a)

### HOW DO GENERAL HOSPITALS RESPOND TO PATIENTS DIAGNOSED WITH PERSONALITY DISORDER WHO ARE DISTRESSED?

#### Distress Protocol

