

Safer Care for Patients with Personality Disorder

National Confidential Inquiry
into Suicide and Homicide by People with Mental Illness

February 2018

CONTRIBUTORS

Lead contributors *

Louis Appleby	FRCPsych	Director
Jenny Shaw*	FRCPsych	Head of Homicide Research
Nav Kapur	FRCPsych	Head of Suicide Research
Sandra Flynn*	PhD	Research Fellow and Lecturer
Jane Graney*	MSc	Research Nurse
Thabiso Nyathi*	MRes	Research Nurse
Jessica Raphael*	MSc	Research Assistant
Seri Abraham	MRCPPsych	Higher Specialty Trainee in General Adult Psychiatry ST6
Sandeep Singh-Dernevik	MRCPPsych	Higher Specialty Trainee in Forensic Psychiatry ST6

Other contributors:

Louise Robinson	MRCPPsych	Consultant Forensic Psychiatrist
Alice Edwards		Medical student, University of East Anglia
Fahdia Abreem		Core Trainee, Psychiatry

Trust and Health Boards

Thanks to all Trusts and Health Boards for their continued participation in core NCISH data collection. Special thanks to the staff from Greater Manchester Mental Health NHS Foundation Trust (formerly Greater Manchester West NHS Trust), Betsi Cadwaladar University Health Board, NHS Lanarkshire and Belfast Health and Social Care Trust for their invaluable contribution to focus groups discussions.

Charities and service user representatives

Thanks to Sue Sibbald, Co-Chair of the National Personality Disorder Commission. Fiona Kuhn Thompson, Service Manager EmergencePlus. Marion Janner OBE, Founder of Star Wards. Marsha McAdam, Service User Representative.

FUNDERS

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. HQIP's aim is to promote quality improvement, and it hosts the contract to manage and develop the Clinical Outcome Review Programmes, one of which is the Mental Health Clinical Outcome Review Programme, funded by NHS England, NHS Wales, the Health and Social Care division of the Scottish Government, the Northern Ireland Department of Health and the States of Jersey and Guernsey. The programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers and policy makers to learn from adverse events and other relevant data. More details can be found at:

<http://www.hqip.org.uk/national-programmes/a-z-of-clinical-outcome-review-programmes/>

The interpretation and conclusions contained in this report are those of the authors alone. The study was approved by the Mental Health Clinical Outcome Review Programme Independent Advisory Group.

REPORT SUMMARY

What is personality disorder?

Personality disorder (PD) refers to a complex psychiatric condition characterised by emotional changeability and difficulty relating to other people. It is often linked to previous traumatic events. PD does not refer to a single diagnosis, the International Classification of Diseases; Tenth Revision (ICD-10)[†] classification system currently defines 10 types. In this study most patients were recorded as having borderline or antisocial PD. These are also the diagnoses for which National Institute for Health and Care Excellence (NICE) guidance has been published.[†]

Why did we carry out the study?

Individuals with PD are often frequent users of mental health care. However, management of PD patients is notoriously challenging and influenced by the type of PD, the degree of severity and the presence of comorbid psychiatric disorders. Problems in interpersonal functioning mean patients with PD have high levels of service disengagement and treatment refusal, and there are often difficulties in relationships between staff and patient.

Patients with PD, particularly borderline PD, are at high risk of suicide and commonly feel marginalised from mainstream mental health services. We wanted to analyse the characteristics of patients with PD prior to suicide and homicide to learn more about their treatment and pathways into care. We wanted to examine whether services followed NICE guidance for PD. Finally, we wanted to learn from patients and staff about their experiences and how they think services could be improved.

[†]NICE were formerly known as National Institute for Health and Clinical Excellence when the documents referred to in this report were published.

What did we do?

We used data from the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH) to identify patients across the UK with PD who died by suicide (in 2013) or were convicted of a homicide (between 2010 and 2013). There were 154 patients with PD who died by suicide and 41 who were convicted of homicide in these time periods.

We asked for medical records and Serious Incident (SI) reports from NHS Trusts and Health Boards to examine the antecedents to these events in more detail. We used the information from these sources to analyse patient deaths by suicide and patient homicide and derive key messages on risk and patient safety. Overall we obtained information on 169 of the 195 patients identified (87%).

We asked patients to share their experiences of services by completing an online survey and asked staff to participate in focus group discussions.

What were the main findings?

- We found gaps in care in patient suicide and homicide but these may not reflect the care of all patients with personality disorder
- The findings from the online survey and focus groups were based on comparatively small numbers and may not be representative of all care in patients with PD. This was a UK-wide study and we did not examine any differences between countries
- Many of the results echo findings from previous research and the recommendations published in NICE guidance on PD in 2009
- Patients who died by suicide were different from those who committed homicide. They were more commonly female and older. Fewer had a history of violence and alcohol and drug misuse but a higher proportion had a history of self-harm. Self-poisoning was the most common method of suicide

- Patients had commonly been diagnosed with PD for over 5 years and many patients had a comorbid mental health diagnosis. Where a diagnosis of PD was made, it was unclear what criteria were used. We found little evidence of discussion or explanation of how it was caused
- The qualitative findings presented in this report are the views of patients and staff of mental health services. In an area where there can be friction between staff and patients, we saw it as positive that there was considerable overlap in how both groups viewed care and treatment
- Staff and patients reported their experience that there was no clear care pathway to meet the needs of patients with PD. We heard of a lack of support and treatment for patients who did not meet the criteria for specialist PD services
- Patients often received care at a time of crisis due to a lack of earlier support and having no point of contact when feeling at risk
- Patients often found it hard to access the specialised psychological therapies recommended by NICE. Instead they might be prescribed medications, which we found could be used in overdose. When specialist services and therapies were accessed by patients they were viewed positively and appeared to lead to improved staff-patient relationships
- Staff felt they had a lack of understanding of patients' behaviour, little training in managing those at high risk and insufficient knowledge of appropriate treatments
- Patients reported continuing barriers in services, leading to short-term interventions rather than longer term therapeutic approaches. Patients often felt stigmatised and excluded from services

WHAT THIS STUDY CANNOT TELL US

1. We cannot draw direct causal links between the gaps we found in mental health services for people with personality disorder and patient suicide or homicide. We cannot conclude that gaps in care where a suicide or homicide has occurred reflect the care of all patients with PD.
2. The patient suicide and homicide cases consist of a complete national sample. However, the number of homicides by patients with PD is small (10 per year on average), even over 4 years. Adding previous years would have limited the applicability of the findings to current services.
3. In this UK-wide study, we did not examine the mental health services in individual countries separately. Therefore we cannot discuss potential differences between the devolved nations in the number of patient suicides or homicides or the provision of services.
4. The views of patients and staff from the online survey and focus groups are subjective and based on comparatively small numbers. They may not represent the views of all staff and patients, or the care of all patients with PD.

KEY MESSAGES

1. Patients with personality disorder who died by suicide or committed homicide were not receiving care consistent with NICE guidance. This recommends: patients are offered appropriate and timely psychological interventions; medication should only be prescribed short term; and admission to in-patient care should be avoided where possible.
2. Exploration with staff and patients about their experience suggests that problems in the care of patients with personality disorder are not limited to cases in which there is a tragic outcome, though these experiences may not be representative of services nationally.
3. Our findings therefore suggest the need for a more comprehensive examination of services for personality disorder, taking into account the safety concerns highlighted in this report.
4. Although personality disorder is part of international classification systems, in practice applying the diagnosis of personality disorder may be stigmatising and obscure individual needs. Working with patients to understand their traumatic experiences is likely to be more beneficial.
5. Psychotropic medication may be taken in fatal overdose, emphasising the importance of safe prescribing in mental health services and primary care.
6. Risk in personality disorder is linked to co-existing drug and alcohol misuse, showing the need for substance misuse services to be available.
7. Former patients are an under-used resource and they should have involvement in staff training, advocacy and peer support where possible.

BACKGROUND

What is personality disorder?

Personality disorder as a diagnostic label is considered to be pejorative by some, but remains in widespread use.² It is a type of mental health problem that can affect beliefs, attitudes and behaviour. The disorder can lead to a pattern of thinking and behaviour which can have a detrimental impact on lifestyle, behaviour and relationships.³

The main disorders referred to in NICE guidelines and in this study are borderline PD (BPD) which broadly equates to 'emotionally unstable PD' and antisocial PD (ASPD) also known as 'dissocial personality disorder'.^{4,5}

Box 1: ICD-10 definition of personality disorder¹

Emotionally unstable personality disorder (Borderline type)

"A liability to become involved in intense and unstable relationships may cause repeated emotional crises and may be associated with excessive efforts to avoid abandonment and a series of suicidal threats or acts of self-harm (although these can occur without obvious precipitants)."

Dissocial personality disorder

"Personality disorder, usually coming to attention because of a gross disparity between behaviour and the prevailing social norms... Includes amoral, antisocial, asocial, psychopathic and sociopathic personality disorder."

How common is suicide and homicide in patients with this diagnosis?

In a study examining mortality by suicide or undetermined cause, Baxter and Appleby (1999) examined suicide risk in mental disorders by gender, age and method. They found PD to be the diagnosis with the highest risk in women, increased more than twenty-fold.⁶ The Office for National Statistics (ONS) reported over 6,000 suicides by people aged 10 and above in the UK⁷ and

the ONS, Scottish Government and the Police Service of Northern Ireland recorded over 570 homicides in the UK in 2015.^{8, 9, 10} A previous NCISH report found 25% of deaths by suicide and 11% of homicides were by mental health patients in the UK. People with PD accounted for 9% of these patient suicides (2004-2014; a total of 1,630) and 13% of patient homicides (2004-2014; a total of 10) in the UK.¹¹

What are the known difficulties associated with this diagnosis and how are patients managed?

The management of patients with PD is determined by the type of PD, the severity of illness and the presence of comorbid psychiatric disorders. Patients with this diagnosis frequently have high levels of service disengagement and treatment refusal,¹² and there are often difficulties in the relationship between staff and patients.¹³ Many mental health services struggle in managing patients with PD, with clinicians often sceptical about the clinical treatability of the disorder.¹⁴ There has been limited research on recovery in patients with PD but some evidence that psychosocial interventions are effective.¹⁵

Hospitalisation has little value for patients with PD in crisis and may negatively influence suicidal behaviour in some. Patients admitted may become dependent on the locked hospital environment and be viewed as low risk by staff who sanction discharge when the patient is in fact still at high risk. For many patients, admission to in-patient care is likely to be ineffective and counterproductive.¹⁶

What do NICE guidelines recommend?

The guidance provided by NICE is officially for England and Wales. However, the devolved administrations in Scotland and Northern Ireland follow the principles set out by NICE on the management of patients with PD.

NICE guidelines on BPD⁴ suggest that hospitalisation should be brief, emphasising the importance of using specialist community PD services within trusts to co-ordinate care

and management and encourage patient autonomy. A recent study by Dale, Sethi, Stanton et al., (2017) has shown a five-fold increase in the provision of PD services in England. However, their findings show a variation in service availability with only 55% of organisations reporting that patients had equal access to these services. Specialist /dedicated PD services were more selective than generic services, using substance misuse and active risk to others as the most widely cited exclusion criteria.¹⁷

NICE guidance also recommends that assessing a patient's risk of harm to themselves or other people should take place as part of a full assessment of the patient's needs. A collaborative risk management plan should be developed with the patient, and be managed by the multidisciplinary team.

During a crisis, short term use of drug treatment may be helpful but polypharmacy should be avoided. Drug treatment should not be used in place of other more appropriate treatments such as psychological therapies.

Dialectical Behaviour Therapy (DBT) has been shown to be effective in reducing suicidal behaviour, with those receiving DBT being half as likely to attempt to take their own life and there being fewer episodes of hospitalisation for suicide ideation.¹⁸

The guidelines also recommend provision of staff training, and collaboration with other services such as housing, social services, and the criminal justice system. The guidance for ASPD encourages staff to actively engage patients in treatment and not exclude them from services.⁵ Box 2 shows the list of quality standards for the treatment and management of borderline and antisocial personality disorders.¹⁹

AIMS OF THE STUDY

- To describe the features of suicide and homicide in patients with PD
- To examine the care pathway
- To examine the extent to which care received adhered to NICE guidelines for PD
- To evaluate the quality of risk assessment, formulation and management in the 3 months prior to death or homicide

Box 2: NICE Quality Statements

Statement 1: Mental health professionals use a structured clinical assessment to diagnose borderline or antisocial personality disorder.

Statement 2: People with borderline personality disorders are offered psychological therapies and are involved in choosing the type, duration and intensity of therapy.

Statement 3: People with antisocial personality disorder are offered group-based cognitive and behavioural therapies and are involved in choosing the type, duration and intensity of the interventions.

Statement 4: People with borderline or antisocial personality disorders are prescribed antipsychotic or sedative medication only for short-term crisis management or treatment of comorbid conditions.

Statement 5: People with borderline or antisocial personality disorder agree a structured and phased plan with their care provider before their services change or are withdrawn.

Statement 6: People with borderline or antisocial personality disorder have their long-term goals for education and employment identified in their care plan.

Statement 7: Mental health professionals supporting people with borderline or antisocial personality disorder have an agreed level and frequency of supervision.

Study design and data sources

The study was a mixed-methods design combining quantitative and qualitative data collection methods and analysis.

There are many different types of personality disorder. The majority of patients in this study had emotionally unstable PD (also referred to as borderline PD) or antisocial PD. There are different associated treatment approaches; however, NICE guidance are specifically focused on borderline and anti-social PD and staff in focus groups indicated they were mainly talking about these 2 groups. Data were collected from 5 main sources described below and in Figure 1.

1. NCISH suicide and homicide databases

We used the NCISH databases to identify 195 patients with PD who died by suicide or were convicted of homicide. We included patients who died by suicide between 1st January 2013 and 31st December 2013 (154 cases) and patients convicted of homicide between January 2010 and December 2013 (41 cases). We included 3 additional years of homicide convictions to increase the sample size. A full description of NCISH data collection processes can be found in our Annual Report 2016.¹¹

We included patients with PD who died by suicide and people convicted of homicide from all 4 UK countries. Over the study period 113 (73%) patients died by suicide in England, 28 (18%) in Scotland, 8 (5%) in Wales and 5 (3%) in Northern Ireland. There were 25 (61%) patients convicted of homicide in England, 13 (32%) in Scotland. Due to the restriction on publishing small numbers, homicide figures for Wales and Northern Ireland cannot be provided.

The sample included patients with a primary diagnosis of PD or a secondary diagnosis of PD, where the primary diagnosis was alcohol misuse/dependence or drug misuse/dependence.

2. Online survey with patients

An online survey was launched on 1st April 2016 and closed on 31st December 2016. The survey was used to record the

experiences of patients with PD using mental health services and to understand their views of how these services could be improved. The responses were provided anonymously. The survey was advertised via the NCISH website, Facebook and Twitter. Charities such as EmergencePlus and patient user groups helped to promote the survey.

3. Interviews with service user representatives

For a more in-depth understanding and interpretation of the patients' views obtained via the online survey, we interviewed a selective group of service user representatives. We also specifically asked for their opinion on whether services needed to change and if so, how? Interviews were undertaken with a patient representative from Sheffield Health and Social Care Foundation Trust (who is also Co-Chair of the National Personality Disorder Commission); representatives from Emergenceplus and StarWards; and a service user with previous experience working with mental health services in Manchester.

4. Focus groups with staff

Six focus groups were conducted in all 4 UK countries. We sought the views from staff working on in-patient wards, in community teams, home based treatment teams and specialist PD services. The participants included:

- Service user consultant (1)
- Administrator (1)
- Team leader (2) / Ward managers (2)
- Nurse therapist/service manager (1)
- Student nurses (8) / Nursing assistants (4)
- Mental health nurses (21)
- ED liaison practitioners (2)
- Dual diagnosis practitioner (1)
- Social workers (2)

A topic guide was used to facilitate the discussion. The guide was used flexibly to ensure progression of the discussion on key areas of concern, whilst allowing for new topics to be raised. Informed consent was obtained from all of the participants before the focus groups commenced. The focus group discussions were digitally recorded and transcribed verbatim. Focus groups were undertaken with Greater Manchester Mental

Health NHS Foundation NHS Trust (formerly Greater Manchester West NHS Trust), Betsi Cadwaladar University Health Board, NHS Lanarkshire and Belfast Health and Social Care Trust.

5. Medical records and serious incident reports

Once we identified the 195 patients who died by suicide or were convicted of homicide from the NCISH database, we contacted 69 NHS Trusts and Health Boards across the UK to request a copy of the patient’s medical records and the Serious Incident/Critical Incident Reviews/Serious Adverse Incident reports (collectively referred to as SI for the remainder of this report). These reports presented the findings from the internal investigation in each case. Of the 195 patients with PD in our sample, additional information was available on 169 cases, as some Trusts were unable to provide the documents requested or did not participate in the study. Of the 169 cases where data were available we obtained medical records for 163 (96%) and SI reports for 125 (74%).

Statistical analysis

Information presented on patients who died by suicide or were convicted of homicide was derived from data in the NCISH database, medical records and SI reports. There was no separate analysis by UK country and the number of cases from countries apart from England are small. Data are presented as numbers and percentages. All proportions are provided as valid percentages. If an item of information was not known for a case (i.e. data were missing) the case was removed from the analysis of that item. The denominator in all estimates is the number of

valid cases. Pearson’s chi square tests were used to examine associations between subgroups. We have followed guidance from ONS on disclosure control to protect confidentiality within death statistics, and have suppressed cell counts under 3, including zero. We have applied this rule to all data in this report. Data were analysed using Stata 13.²⁰

Qualitative analysis

Thematic analysis was used to explore the responses from the online survey and focus groups.²¹ The findings were discussed among the research team to ensure the themes presented accurately represented the participants’ views. Data were analysed using NVivo 11.²²

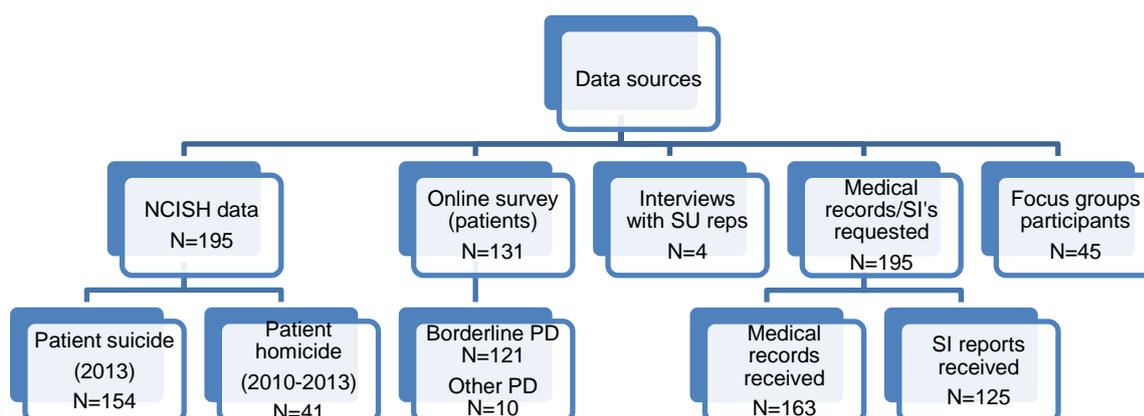
Definitions

Suicides were defined as deaths that received a conclusion of suicide or undetermined (open) at coroner’s inquest, as is conventional in suicide research.²³ Homicides are defined as convictions for murder, manslaughter and infanticide.

Ethical approval

Approvals were received from the University of Manchester Research Governance and Ethics; National Research Ethics Service (NRES) Committee North West (31/03/2016); Health Research Authority Confidential Advisory Group (HRA-CAG) (31/03/2016); Public Benefit and Privacy Panel for Health and Social Care (PBPP) (06/07/2016); and Research Management and Governance approvals from individual NHS Trusts and Health Boards.

Figure 1: Data sources



RESULTS

The results are presented in 3 parts. Firstly quantitative findings from the NCISH suicide and homicide databases are presented alongside data extracted from medical records and SI reports. Secondly, we have presented qualitative findings describing patients' experiences of mental health services. Thirdly, we have provided the clinical views of staff from the focus group discussions.

The quantitative findings refer to the care of patients who died by suicide or were convicted of homicide. They cannot be assumed to reflect care in all patients with PD where these tragic outcomes do not occur. The qualitative findings present a perspective on the general care of patients with PD but, as the number of participants is comparatively small, they cannot be assumed to be representative of all patient care in this clinical area.

WHAT WE KNOW FROM SERVICES

Suicide

More female patients died by suicide (85, 55%) compared to males (69, 45%). The average age of the patient was 42 at the time of death. One hundred and nineteen (78%) were unmarried and 82 (55%) lived alone. Most were unemployed or on long term sickness leave (121, 82%).

The most common method of suicide was self-poisoning (61, 40%) followed by hanging (58, 38%). This contrasted with patients in general who were more likely to die by hanging (43%) followed by self-poisoning (25%).¹¹ Of all the drugs used in self-poisoning deaths, opiates (heroin, methadone) were the most frequently used (19, 32%) followed by antipsychotics (12, 20%), tricyclic antidepressants (10, 17%), and SSRI/SNRI antidepressant/benzodiazepine/hypnotics (5, 8%). Of the 27 patients who used psychotropic drugs in the overdose, 13 used drugs prescribed to them.

For all drugs used in the fatal overdose (including analgesics), where known, 20 patients used drugs that had been prescribed for them, 4 used drugs prescribed for

someone else, 12 used non-prescribed drugs.

Homicide

The majority of patient homicides were male (35, 85%), with a median age of 31 years. Most were not married (32, 80%) and half lived alone at the time of the offence (22, 58%). Fifteen percent were from a Black, Asian and minority ethnic group. Using a sharp instrument was the most common method of homicide (17, 47%).

Table 1: Socio-demographic characteristics of patients

	Patient suicide N=154	Patient homicide N=41
Male	69 (45%)	35 (85%)*
Female	85 (55%)	6 (15%)*
Age: median/range	42 (17-82)	31 (18-55)*
Not currently married	119 (78%)	32 (80%)
Living alone	82 (55%)	22 (58%)
Unemployed/sickness leave	121 (82%)	38 (95%)**
Black, Asian & minority ethnic group	9 (6%)	6 (15%)
<i>Method of suicide</i>		
Self-poisoning	61 (40%)	-
Hanging	58 (38%)	-
Jumping	15 (10%)	-
<i>Method of homicide</i>		
Sharp instrument	-	17 (47%)
Strangulation	-	8 (22%)
Blunt instrument	-	5 (14%)

*P<0.01 **P<0.05

Primary and secondary diagnosis

Suicide

Of the 154 patient suicides, 132 (86%) had a primary diagnosis of PD. In 22 cases where PD was the secondary diagnosis, the primary diagnoses were recorded as alcohol dependence/misuse (14, 64%) or drug dependence/misuse (8, 36%). Information was available on the type of PD in 109 cases, of these 102 (94%) had a diagnosis of borderline/emotionally unstable PD, 7 (6%) antisocial PD.

Homicide

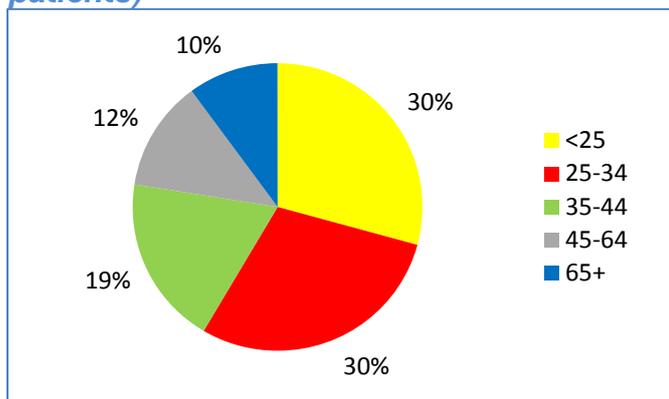
Of the 41 patient homicides, 28 (68%) had a primary diagnosis of PD. In the remaining cases where PD was the secondary diagnosis, the primary diagnoses were drug dependence/misuse (27%) and alcohol dependence/misuse (4%). Of the 21 cases where information on the type of PD was

available, 16 (76%) had a diagnosis of borderline/emotionally unstable PD and 5 (24%) had antisocial PD.

Clinical characteristics

The clinical characteristics of all cases are presented in Table 2. Overall, the number of in-patient suicides and homicides were small, 4% in total. Seventeen percent of patient deaths occurred within 3 months of discharge from in-patient care. Most patients had a recorded duration of illness for more than 5 years (153, 80%). The majority of patient suicides had a history of self-harm (146, 95%) and 36 (97%) of patients who committed homicide had a known history of violence. Substance misuse was common. The diagnosis of PD was most commonly made when the patient was aged under 25 or 25-34 (Figure 2).

Figure 2: Age first diagnosed with personality disorder (percentage of patients)



Note: the percentages do not tally due to rounding

Differences between patients with PD and other mental health patients

Suicide

The clinical characteristics for patients with PD described in Table 2 are different to other patients who died by suicide recorded by NCISH for the same year. The main differences in patients with PD who took their own life were; more patients with PD died within 3 months of discharge from in-patient care (21% v 13%); fewer had a history of illness of less than 12 months (3% v 22%); more had a duration of illness over 5 years (82% v 53%), self-harm was more common (95% v 63%), as was violence (41% v 21%), alcohol misuse (66% v 47%), drug misuse

(53% v 37%) and symptoms of emotional distress at the time of last contact (e.g. suicidal ideas, depressive illness, hopelessness, hostility, increased use of alcohol and drugs, and self-harm) (76% v 62%).

Homicide

For patients who were convicted of homicide in the same time period, the main differences compared to patients with other diagnoses were that it was more common for patients with PD to have had a history of mental illness for more than 5 years (74% v 50%); a history of self-harm (73% v 45%) and a history of violence (97% v 48%). It was unusual for patients with PD not to have comorbid substance misuse, i.e. a history of alcohol misuse (82% v 74%) or drug misuse (92% v 74%). More patients with PD had symptoms of mental distress at last contact (76% v 58%).

Table 2: Key clinical characteristics of patients

	Patient suicide N=154	Patient homicide N=41
In-patients	7 (5%)	<3
Recent (<3months) discharge	33 (21%)	<3*
Missed last contact	39 (25%)	10 (24%)
Non-adherence with medication in last month	16 (10%)	6 (15%)
Duration of illness		
Less than 12 months	4 (3%)	4 (11%)**
More than 5 years	125 (82%)	28 (74%)
Over 5 previous admissions	29 (19%)	<3**
First contact with services		
Less than 12 months	12 (8%)	3 (9%)
1-5 years ago	36 (24%)	7 (21%)
More than 5 years	104 (68%)	23 (70%)
Last admission was a readmission after 3mth	22 (14%)	<3
History of self-harm	146 (95%)	30 (73%)*
History of violence	62 (41%)	36 (97%)*
History of alcohol misuse	101 (66%)	32 (82%)
History of drug misuse	80 (53%)	36 (92%)*
Last contact within 7 days of death / offence	72 (47%)	11 (28%)*
Symptoms of mental distress at last contact	111 (76%)	29 (76%)

*P<0.01 **p<0.05

Contact with mental health services

History of contact

One hundred and fifty three (80%) patients had been in contact with mental health services for over 5 years, only 8 (4%) had

been ill for less than a year. However, this proportion was significantly higher in patient homicide compared to those who died by suicide (11% v 3%, Table 2). Of the patient suicides and homicides, 49 (25%) missed their final contact with services. Nearly half (83, 43%) had their last contact with services within 7 days of the incident. The last contact took place in the community/GP clinic in 41 (22%) cases, mental health unit (37, 20%), at the patients home (37, 20%) or by telephone (34, 19%). One hundred and forty (76%) had symptoms of mental illness at the last contact (emotional distress 83, 88%; depression 51, 73%). Evidence of recent self-harm at last contact was found in 48 of the 75 patients where information was known (64%).

Of the patients on whom additional information was received from medical records and/or SI reports (n=169), we found the average number of service contacts patients had over a 12 month period was 11 (range: 1-313). Twenty-two (16%) had over 50 contacts.

Referral to services

From the medical records and SI reports received (N=169) we found in the year before their death or before the offence, patients were most commonly referred to community mental health services (95, 57%),

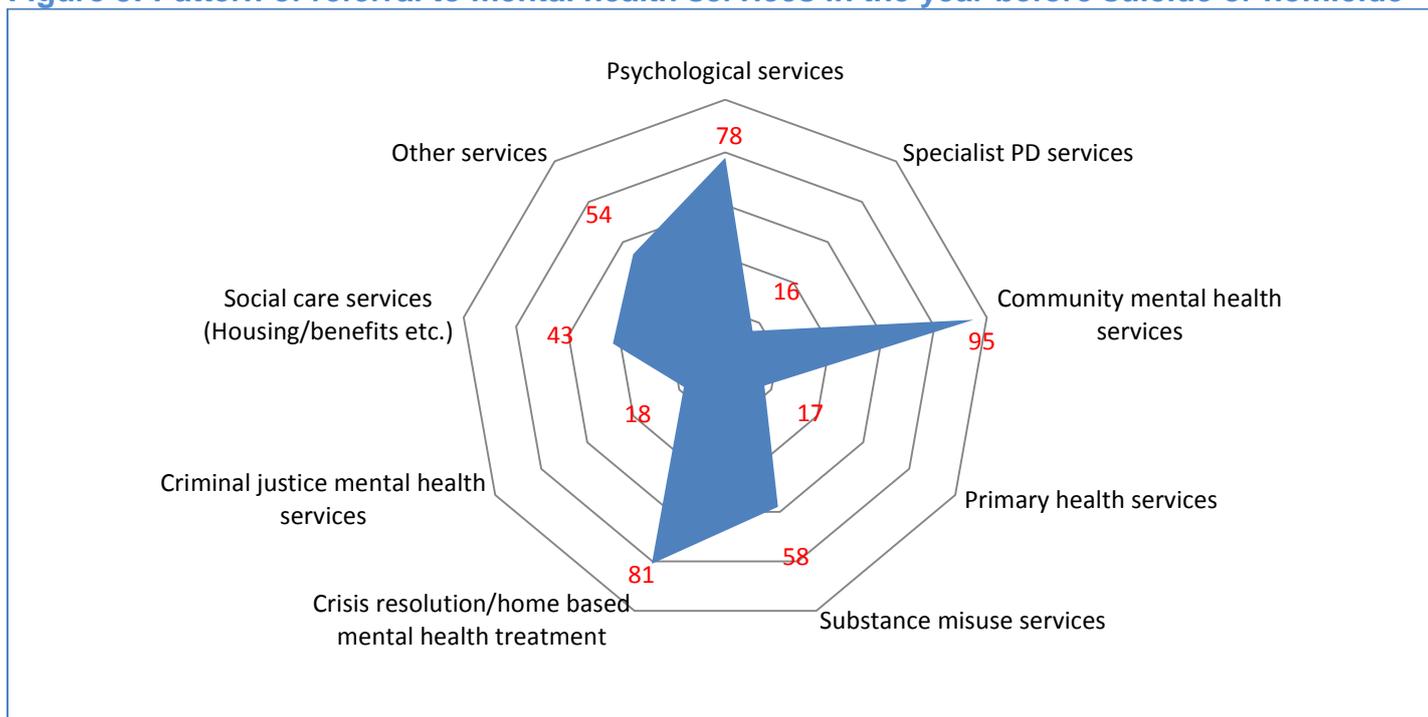
psychological services (78, 47%), crisis resolution home treatment (81, 49%) and drug and alcohol services (58, 35%).

In 16 cases a referral had been made to specialist PD services in the year before the incident, in 8 cases the patient had attended. Patients frequently had contact with a wide range of services (Figure 3). Box 3 provides an example of a patient with multiple different service contacts.

Box 3: Example of patient contact with multiple services

The patient was supported in the community by a care co-ordinator from the local Community Mental Health Team (CMHT) and a support worker from the community substance misuse service. Engagement with services was sporadic which led to multiple presentations to the Emergency Department (ED) in crisis. In the year before his death, the patient presented to ED four times following incidents of self-harm and suicidal ideation. This led to admission to a general psychiatric ward on one occasion and referral to the crisis team in the other three. Individual services focused on supporting different facets of his presentation, personality issues, drug use with lack of clarity around diagnosis and no shared treatment plan.

Figure 3: Pattern of referral to mental health services in the year before suicide or homicide



In-patient care

Eighty-one (51%) patients had been admitted to hospital in the year before death/offence. The number of previous in-patient admissions over the patients' lifetime is presented in Figure 4. It was common for those who died by suicide to have had multiple previous in-patient admissions.

The duration of the last in-patient admission is presented in Table 3. Fifty-one (45%) were short admissions for less than 1 week. This is higher in patients with PD compared with our total NCISH patient sample (21%). In 6 cases (5%) the admission lasted over 13 weeks. Forty-nine (38%) were referred for a hospital admission during the last episode.

Figure 4: Number of previous admissions to in-patient care

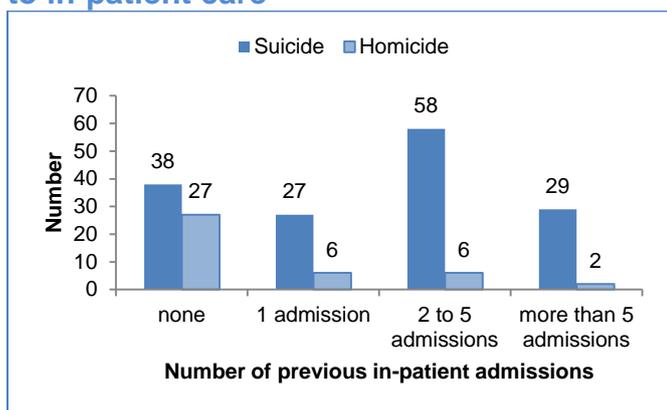


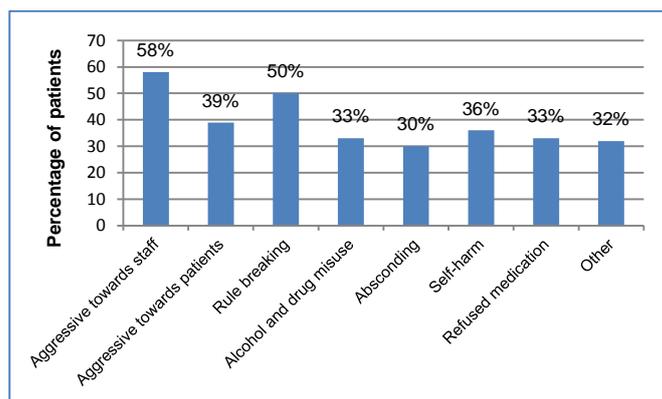
Table 3: Length of the last in-patient admission

Duration of last admission	N	%
< 7 days	51	45%
More than 1 week but < 4 weeks	42	37%
Between 4 weeks and 13 weeks	15	13%
More than 13 weeks	6	5%

Conflict and containment as an in-patient

It was not uncommon for conflict to have occurred during in-patient admissions. Figure 5 shows the type of incidents (where recorded) as a proportion of those admitted in the previous year. In 38 (58%), patients had been aggressive towards staff, 24 (39%) had been aggressive towards other patients. Half broke ward rules, nearly a third absconded and nearly a third self-harmed.

Figure 5: Percentage of conflict incidents occurring in in-patients



Staffing problems

In 13 (11%), direct reference in the SI report was made to staff training being insufficient when caring for patients with PD. The ward or mental health team were considered to be understaffed at the time of the suicide or homicide in 8 cases. In 47 (64%) it was reported that there was a good therapeutic relationship between staff and the patient. In 41 (48%) there were problems within the therapeutic relationship. An example is provided in Box 4.

Box 4: Example of a relationship problem between staff and patient

The patient had made verbally abusive and threatening telephone calls to the Consultant Psychiatrist responsible for his care. He made misogynistic remarks to staff, which were of such concern that as a protective factor, male staff were asked to see the patient. As a result of this behaviour, and subsequent death threats and threats to set fire to CMHT premises, the police were informed.

In the patients' case notes, there was evidence of staff having a negative attitude towards patients in 56 (of the 105 cases where information was known) (52%). Staff made reference to the patient behaviour as being uncooperative (66, 52%), hostile (50, 42%), manipulative (42, 39%), attention seeking (40, 37%) or complaining (30/81, 37%). There were complaints about the patient from other service users or staff in the

past year for 32 (30%). In 53 (42%) inappropriate demands were made or there was evidence of dependence on mental health services such as attending Community Mental Health Teams (CMHT) without an appointment and demanding to see staff involved in their care; threatening to harm themselves if their needs were not met; demanding benzodiazepine medication (sleeping tablets) or to be sectioned under the Mental Health Act (MHA).

In 75 (65%), a positive attitude towards patients was recorded, an example is provided in Box 5.

Box 5: Example of positive staff attitude towards a patient from SI report

The patient had a positive relationship with his support worker and was sustaining a steady level of progress with their help. He had recently gained access to his daughter. He had also been getting out more and sorting out his finances which had been causing him much stress and anxiety. (ID 112470)

Care pathway at last episode

We defined the last episode as a distinct event in the patient's treatment history, which can involve a single last contact or a sequence of unbroken care even if this was from a number of services, i.e. ED, in-patient, crisis resolution/home treatment (CRHT) teams, primary care. The last episode of care before the patient's suicide or the homicide was most commonly following a crisis (110, 65%) rather than a routine appointment. Of those in crisis, 89 (84%) were referred into mental health services, following an initial assessment. The main reason for the referral for those in crisis was due to the risk of harm to themselves (84, 76%). In nearly a third a referral was made to CRHT teams during the last episode (37, 30%) and to CMHT in 57 (47%) (Table 4).

Table 4: Community services referred to at last contact

Mental health service	N	%
CRHT / MH Home Treatment	37	30%
CMHT/ Assertive Outreach	57	47%
Primary health services	4	3%
Substance misuse services	21	17%
Psychological services	5	4%
Specialist PD services	4	3%
Other	17	14%

Forty-one (26%) had been discharged from mental health services at the time of their death/offence. Twelve were discharged following non-attendance, 15 were planned discharges. Other reasons for discharge included breach of rules and failure to opt into services.

Adverse life events before suicide

One hundred and thirteen patients had an adverse life event prior to suicide recorded in the case notes. Problems with intimate partner relationships immediately before suicide (16, 31%), problems with family members and friends (14, 35%), and alcohol and drug misuse (15, 41%) were found. Physical health and social problems including accommodation difficulties, employment and financial concerns were also common (Table 5).

Self-harm prior to patient suicide

The majority of patients who took their own life had a history of self-harm (146, 95%). The last episode of self-harm occurred within a week of death in 20 cases (16%), and 81 (70%) within 3 months. Repeated incidents of self-harm were common in the year before suicide (77, 66%). In most cases the triggers were known to services (106, 98%). These were:

- Alcohol intoxication
- Estrangement – isolation
- Relationship problems
- PTSD from past trauma/abuse

During the last episode, the most common methods of self-harm were self-poisoning with drugs (78, 62%) and cutting (36, 28%). The risk of the self-harm episode being lethal was considered to be high in 30 (28%).

Table 5: Adverse life events prior to suicide

Adverse life events relating to:	Within 24 hours		Within 3 months	
	N	%	N	%
Intimate partner problems	16	31%	52	62%
Friend/family problems	14	35%	54	68%
Substance misuse	15	41%	62	67%
Physical health	7	18%	56	67%
Accommodation	11	24%	51	59%
Employment	<3		41	55%
Financial problem	11	27%	45	58%
Problem with mental health care received	10	20%	34	44%

Violence

Suicide

Sixty-two (41%) patients who died by suicide had a history of violence.

Homicide

Most patients who committed homicide had a history of violence (36, 97%). It was recorded in the case notes that 4 were violent in the week before the offence. Fourteen (61%) had a history of repeated violence. The known triggers for violence included an increased use of substances in 4 cases.

NICE clinical guidance for personality disorder

In 2009, NICE issued guidance for the care and treatment of people with borderline and antisocial PD.^{4,5} One of the aims of the study was to examine whether these guidelines had been followed prior to the suicide and homicide.

Diagnosing PD

We found that the use of a standardised approach to diagnose PD was only evident in 7 cases (Table 6). This could partly be explained by our review of service contact 12 months prior to the suicide or homicide. It is likely that a diagnosis could have been recorded earlier on in the notes.

Care planning

Patients were involved in the planning of their transfer or discharge from care in 84 cases (78%). Long term education goals were recorded in the care plan in 46 (47%) and employment goals in 52 (51%). In a third of cases there had been a recent change in the patients care plan (34, 31%) and this caused distress for 16 patients particularly when being discharged from the service or having a change in the care team. An example is presented in Box 6.

Box 6: Distress following change to a care plan

The patient had been receiving weekly input from a support worker. This staff member's involvement in the patient's care was ending due to funding issues. The patient became anxious and distressed about the change in care. The patient began to have difficulty controlling their temper particularly towards friends and family members. The patient anticipated not having enough support from services, they became frustrated and stopped going out by themselves. This had a detrimental effect on their quality of life and mental state prior to them taking their own life.

Prescribing medication

NICE guidance recommends the short term prescribing of medication to manage crises. In 161 (99%) medication had been prescribed at some time during the patient's contact with services.

In the year before the suicide or homicide, 123 were prescribed antidepressant medication (73%), 86 antipsychotic medications (51%).

During the last episode of care, 75 (64%) were receiving antidepressants and 50 (43%) antipsychotic medication, overall 95 were prescribed some form of psychotropic medication during their last contact with services. In 42 cases (39%) the prescribing followed NICE guidance with short-term prescribing for comorbid conditions.

Risk ratings

During the last episode of care a risk assessment for suicide, self-harm and/or violence was undertaken in 121 (88%), a risk formulation undertaken in 91 (71%) and risk management plan developed in 85 (69% cases).

Access to psychological therapies

Figure 6 shows the recommended therapies proposed by NICE that should be provided to patients with borderline PD. There was a disparity in the number of patients offered therapy and the number who received it. This could be explained by patients not feeling ready to begin therapy when places became available, practical issues such as the time of appointments, distance to travel or dissatisfaction with the type of therapy offered. DBT (30, 25%) was the most common treatment received followed by Cognitive Behavioural Therapy (CBT, 25, 20%). The numbers receiving Mentalisation Based Therapy (MBT) were small (3, 3%). In 41 cases other therapies were offered. These are listed in Box 7.

Box 7: Other therapies received by patients

- Anxiety management
- Art therapy
- Cognitive remediation therapy
- Eye Movement Desensitisation and Reprocessing
- Group therapy
- Mentalisation Based Therapy
- Mindfulness
- Occupational therapy
- Schema Focused Therapy
- Sexual assault therapy
- Trauma services
- Transference Focused Psychotherapy

Figure 6: Therapies offered and received by patients with personality disorder prior to suicide and homicide

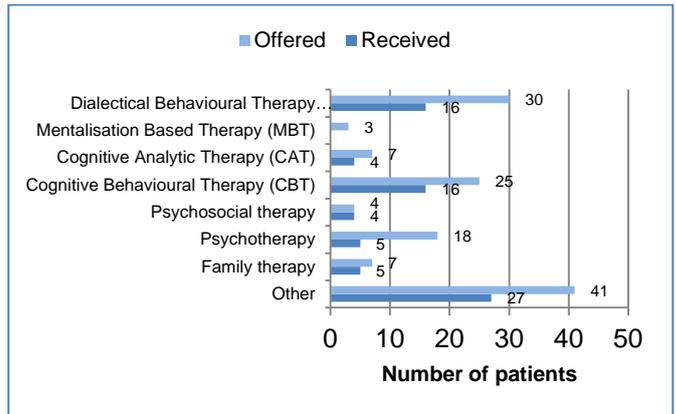


Table 6: Summary of findings relating to the 7 NICE quality statements for PD

	Action by services	N	%
1	Standardised approach to diagnosis ²	7	4%
2&3	Psychological treatment offered	90	74%
	Psychological treatment received	55	50%
4	Medication prescribed <12m		
	<i>antidepressants</i>	123	73%
	<i>antipsychotics</i>	86	51%
5	Patients involved in structured care planning	84	78%
6	Education needs assessed	46	47%
	Employment needs assessed	52	51%
7	Frequent supervision for staff ³	-	-

² As stated earlier, the proportion using a standardised approach to diagnosing PD could be explained by the methodology.

³ Information on procedures for staff supervision (NICE quality statement 7 in Box 2) were not recorded in the documents reviewed and therefore no information was available.

PATIENTS' VIEWS

Patients with personality disorder experiences of mental health services

One hundred and thirty one patients with a diagnosed PD participated in the online survey, 111 (85%) were female, 20 (15%) male. Most were current service users (107, 82%). Most described their diagnosis as borderline PD (122, 92%).

We asked patients who were using or had used mental health services to answer two important questions:

- Regarding their care: what worked well or less well?
- How could services change or do things differently to improve care quality?

In addition we interviewed four service user representatives. The answers to both of these open ended questions were analysed together. The comments were either critical or mixed. We have selected examples of both positive and negative to illustrate the themes.

1. Communicating with patients

Patients told us that there was poor communication between the services and patients. They specifically referred to communication around the diagnosis of PD, i.e. informing patients of their diagnosis, which many said had not been discussed with them or fully explained.

"I think an initial discussion at diagnosis to explain and illustrate which criteria I met and how such thoughts and behaviours come about in relation to past trauma and experiences. To have help to understand that it is not my fault, but that there are things to do that will help." (ID 115)

"It wasn't until two years post-diagnosis in a different unit that a MH professional explained to me that there were ways to recover, ways I could take back control of my life and have a positive contribution to society. This was incredibly helpful, before that all I saw for myself was a life in MH services, going in and out of hospital." (ID 112)

There were also good examples of communication between patients and staff.

"For me, a massive breakthrough in improving how professionals treat me, was by having just three of them take the time to sit down and talk with me, to really look into my actions and get down to the bottom of them; establish why I would do the things that I'd do. Once I had this knowledge and understanding, I could defend my actions to those who judged them and made assumptions about them. And so, I was supported, respected, and helped." (ID 52)

Some patients felt there was a lack of communication by staff to inform them of available treatments. There seemed to be confusion over what services were available to patients and a lack of consistency in care provision and standards across different, often neighbouring regions.

"Clarity would be great - knowing what is really there and being able to access this." (ID 33)

Communication between teams was also an area patients felt could be improved particularly when they were being referred between different mental health services. The patients reported feeling "batted" around, undergoing similar assessments with each new service contact.

*"...stop dissing people over budget issues no one wants to be a shuttlecock batted between CMT and PPU and police, don't give people lists of private providers unless you know that
a) they operate in your area and
b) the client can afford them
it's unprofessional." (ID 128)*

2. Lack of understanding of personality disorder by staff

Patients reported that having staff who understand the nuances of the disorder and factors driving behaviours was central to their experience and recovery. They felt that this was a particular area where mental health services could be improved. There was

particularly a perceived lack of compassion and empathy from staff which patients believed led to them not receiving the support and understanding they expected.

“Our voices are neglected and silenced by stigmas, stereotypes, and outdated theories.” (ID 30)

“Having someone really hear us can make the world of difference. We don't always need a solution, or a skill, sometimes we just need some understanding.” (ID 15)

A common theme was the lack of validation of their experiences and the underlying causes of their behaviours, which in many cases was considered to be untreated trauma. Patients felt this was not understood or recognised by mental health staff. Negative attitudes from staff were also raised, particularly labelling individuals as ‘attention seeking’ and not offering support in case they became dependent or too reliant on services.

“A BPD label is just a series of value judgements. A psychiatrist converts trauma symptoms into a personality disorder which MH staff holds you responsible and are punitive and blaming. The attitude of staff at all levels is one of prejudice and discrimination. I have never felt more stigmatised. The stigma is entrenched and seen as deserved.” (ID 22)

However, patients also reported positive experiences of staff and mental health services. Patients felt that services worked well when people across different disciplines treated them ‘holistically’ and provided individualised, person-centred treatment and were not solely focused on the ‘diagnosis’. Numerous patients commented on the value of staff with specialist skills who have a knowledge and understanding of the disorder. Also the availability of long-term therapy was considered by patients to be a positive approach to treatment.

“Now that I am outpatient I have an amazing team supporting me; a CPN, a support worker, a psychiatrist and DBT. I'm half way through my DBT programme and it is amazing. So helpful, the staff who run it are supportive and understanding and the skills I have learnt help a lot.” (ID 29)

“People believed and validated my experiences, including bad experiences within the health system. No one tried to put words into my mouth or make my experiences fit theories or books they had read. It was collaborative - I was an expert on myself and they had other expertise that could fit with that. Where I was, was accepted and I was allowed to be upset/angry/confused. I was referred to therapy that fit me, not just the label I have been given.” (ID 46)

3. Accessing appropriate and timely care

Perhaps one of the most common concerns for patients was the lack of available services and treatments. Patients described the impact that a lack of resources has had on mental health services in three main ways. Firstly, waiting times for psychological support were lengthy.

“I am getting the support I need but it has been a long hard slog getting there.” (ID 48)

Once received, the care was considered to be good. When asked what worked well, one patient replied:

“My therapy (however I waited five years to receive) has been life changing.” (ID 21)

Patients found it difficult to cope without support. They expressed frustration and felt they could only access and receive care from mental health services if they were in crisis. It was evident that they felt unsupported with no early intervention available. This could at times lead to patients taking drastic action including self-harm.

“Many PD patients usually don't actually want to die but don't have somewhere safe to go to deal with overwhelming distress... and hence suicide becomes the only option... only once a physical act of harm has taken place is it taken seriously.” (ID 2)

Secondly, patients felt there was a lack of services in the local area, requiring people to travel long distances to get care when they

were feeling vulnerable and unwell. Thirdly, access to staff was also a concern, with infrequent contact with CPN's and care co-ordinators making it difficult to get regular consistent support.

Overall, patients expressed a need for intermediate community based services, having activity and day centres available. Patients also felt that having a place to go when in distress, before reaching crisis or attempting suicide would reduce risk alongside the option to phone crisis therapists whenever they felt unwell.

4. Treatment offered to patients

When patients had accessed services, many reported that medication was the only treatment offered, largely because there were long waiting times for therapeutic alternatives. The lack of available long-term therapies such as DBT and MBT was a concern as patients felt these treatments were effective.

"DBT was amazing. My therapist was so warm and understanding, and I learned things I could put into practical use - like the mood diary I used for months afterwards. Unfortunately it lasted for a mere six sessions before I needed to be referred to a longer-term psychotherapy service and could no longer attend. This meant I didn't learn many skills which I believe could have helped me, and I went from weekly support to absolutely nothing for months while I waited for this referral. I was only referred to DBT once I got bad enough to be admitted to a secure psychiatric ward. This was after five or six serious suicide attempts, a lot of self-harm, and daily dissociation. Before that I was not offered any psychological help - just anti-depressants". (ID 101)

Patients said the following about the psychological therapies they received:

"I spent 6 years in services with a long list of diagnoses before I had any real meaningful engagement and direction in treatment. I had spent time under section and as informal and once discharge was eventually referred to the specialist psychotherapies services in our trust. I was part of a three day group therapy programme for 3 years. This changed my life". (ID 4)

There was criticism of the overall strategic approach to service delivery concerning a lack of investment in 'meaningful recovery' in favour of short term crisis management.

"Often PDs are caused by complex trauma and brief therapies and drugs alone (whilst useful in a crisis) are not the best way of treating a PD long term, it is like sticking a plaster on a severed limb." (ID 56)

Patients told us that treating people with compassion and empathy and investing in longer term therapies can be life changing and lead to real positive outcomes. However, there needs to be a network of support throughout the care pathway from GPs, CPNs, psychiatrists and psychotherapists. Support for families was also raised as they too have a lack of understanding of the diagnosis.

5. A diagnosis of exclusion

Patients expressed concerns that on the basis of their diagnosis, they were being 'excluded' from mainstream mental health services. Patients reported being discharged from services because their needs were often considered 'too complex' or 'too serious' for some services to manage. Patients perceived that the stigma attached to the condition marginalised them and perpetuated the notion that they cannot be helped in the same way as other patients with mental health problems.

"I am (understandably) labelled as 'treatment-resistant' when my experiences inform me that it is the system that remains 'treatment-averse'." (ID 68)

One patient suggested it was the very traits associated with a PD diagnosis that services do not have the time or resources to treat.

"These individuals are working in a system that is not joined up at all, under resourced, under trained, under-funded and understaffed, too often relying on volunteers and peers to support those in need." (ID 70)

MENTAL HEALTH PRACTITIONERS' VIEWS

Practitioners' experiences of working with patients with personality disorder

We sought the opinions of practitioners from a range of services across the UK. We were interested in understanding the experiences of staff working with patients with PD, the pathway into services, how the pathway worked in practice, whether NICE guidance was being followed and finally we asked how services for patients with PD could be improved.

1. Diagnosis

Mental health practitioners reported diagnosing patients with PD can be problematic. In some cases, staff actively avoided the diagnosis as they considered it unhelpful for the patient and an obstacle for accessing care. For example, patients were not formally diagnosed to avoid labelling them. One participant expressed the view that mental health services can cause more damage by:

"...giving people labels and telling them they're ill as opposed to being traumatised."
(ID R5.2)

In other cases practitioners reportedly did not want to have that difficult conversation with patients about diagnosis, particularly when they did not have a treatment to offer.

In contrast, other staff members stated that patients wanted and benefited from having a formal diagnosis in order to understand their condition and move towards recovery. Furthermore, there were examples provided where patients wanted the diagnosis to access Personal Independence Payment (PIP) benefits.

It was evident that having a formally recorded diagnosis of PD or not having the diagnosis can determine a patient's pathway into care.

2. Pathways into care

We were informed of a multitude of ways in which patients with PD access mental health care. Practitioners suggested that the route depends on a number of factors: service configuration within a particular trust or devolved nation; the complexity of the patients' needs; whether crisis or routine appointments are required; the availability of services and the accessibility of treatment provision.

Despite the complexities of the condition, two types of PD patients and pathways were described by most practitioners.

The first group of patients were described as having complex mental health needs with comorbid diagnoses including psychosis, affective disorder, schizoaffective disorder, acute anxiety disorder and substance dependence. These patients have commonly been under the care of mental health services for a long time and their mental health problems had become 'medicalised' resulting in frequent crises, in-patient admissions, regular contact with multiple agencies and prescription of psychotropic medications.

The second group of patients were described as having either a primary diagnosis of PD only; undiagnosed PD or identified 'personality traits'. The approach for these patients was to avoid 'medicalising' them by keeping them out of mainstream mental health services. This group therefore seemed to have only acute crisis care or treatment in a specialised PD service. Practitioners concluded that these treatment approaches were unhelpful. Staff concluded that PD is a complex diagnosis with a broad spectrum of presentations. Consequently, the diagnosis does not lend itself to a single pathway and an individual approach is more appropriate.

Specialist PD services

Where specialist PD services were available or teams had input from a staff member with expertise in treating PD, there was a more positive outlook for patient's recovery. Senior practitioners tended to have patients with the most complex needs on their caseload, however staff felt that colleagues at all levels

would benefit from shared expertise, advice and training on complex cases.

3. Staff experiences of working with patients with personality disorder

Managing expectations

Staff told us that because there are no clear pathways for patients with PD, managing patients' expectations can be difficult. Setting boundaries to achieve a positive therapeutic outcome can cause conflict when it does not match patients' expectations for treatment. Difficulties arise when patients have been told by other services (and often other patients) that they can access a range of therapies but in reality these treatments are not provided or not accessible within an 'acceptable' timeframe.

Problems commonly arose when patients expected admission to in-patient care and become extremely disappointed and upset when they were turned away. Staff stated that patients interpret this as a personal rejection. Families also become angry if a hospital admission is not arranged. One participant explained how a parent became extremely distressed, verbally abusive and threatening when her teenage daughter was not admitted to hospital. The reason for non-admission was because it was felt that she would not benefit from being on the ward as it would exacerbate her symptoms.

"Yeah, that's really difficult isn't it? They come out, what's in your bag? Clothes. Why have you brought your clothes? Oh, I'm coming in for a couple of weeks. And they've never been in before but just presumed by coming to A&E presenting this that they're going to be admitted, and then you've got the family putting pressure on to admit them. So it's quite hard saying no." (ID R1.2)

Staff told us that certain patients want to be admitted as they view hospital as a place of safety because they do not have family or therapeutic and social support in the community. Explaining that admissions are not helpful becomes even more difficult for the patients to understand and accept, particularly when they begin to consider staff members as their only social network.

4. The use of NICE guidance

Services across all four UK countries were familiar with NICE guidance on the management of patients with PD. We asked practitioners specifically whether they were familiar with the recommendations and the discussion focused on two main aspects, in-patient hospital admissions and prescribing psychotropic medication.

Short term admission – keeping patients out of hospital

The majority of staff were familiar with NICE guidance on this and agreed with the theory that in most circumstances hospital admissions were not helpful for patients with PD. If patients have to be admitted due to high risk suicidal behaviour, practitioners felt this should be a short admission, as it can become difficult to reduce the level of support if they are in hospital for prolonged periods of time. Staff members also commented on the difficulty created by admitting patients with PD on to wards with other patients with acute mental health needs, as this challenging environment may lead to escalation of harmful behaviour.

However, despite the NICE guidance staff said it can be difficult *not* to admit patients even though they recognised it was not in the patient's best interest. Some staff reported that patients seem to know all the right things to say when they get to ED to be admitted, recalling incidents where patients had deliberately overdosed in order to force an admission. In circumstances such as these, staff felt that not admitting the patient could be more of a risk and also there was not a viable alternative.

"...there comes a demand to be admitted to hospital... and it's not realistic to say, never, ever admit this person. But it's a difficult balance, because that person may do something to harm themselves, which is quite often the threat." (ID M2.1)

The use of psychotropic medication

Staff felt that prescribing psychotropic medication should only be done as a last resort, as these drugs can have adverse side

effects and be a hindrance to the patient's recovery. The risk in over-prescribing was recognised and practitioners also felt there were patients who probably should never have been prescribed medication to begin with.

Some participants suggested that their approach to treatment was not based on NICE guidance. Participants told us that some doctors medicalise PD and over prescribe medication. This can be consultant specific and therefore there is not a consistent clinical approach.

Other participants challenged the NICE guidance and said that they sometimes used antipsychotics to help patients manage stress as this was a safer alternative to benzodiazepines:

"They're not psychotic; it's kind of like depersonalisation experiences, because they're so distressed" (ID M1-1).

Risk assessment

Staff said that an individualised approach to risk assessment was recommended. Risk was continually assessed at each contact with the patient. A number of staff members said although they were aware that NICE guidance for PD was available, they were not familiar with the details and had not read the document.

"In all honesty, I've not read them, I've just looked at them, I ran out of time." (ID F2.1)

5. How could services be improved?

A gap in services for patients with PD

Staff reported that there are services for patients in crisis and there are Specialist PD services but there is a big gap in between with no consistent approach to managing care. It was evident that CMHTs were unsure how to treat patients with PD, particularly when they are told to avoid referring for hospital admission. Furthermore, staff informed us that if patients were not in crisis or did not meet criteria for specialist PD service or were on a waiting list for a psychological intervention, services did not know how to support them in the interim.

"...people with personality disorder consume so much time, so much time and resources from services and it's a huge gap ... there needs to be something a bit more specific around that for service provision." (ID R5.3)

Staff suggested services could be improved by health commissioners (CCG's) investing in psychological services. They emphasised that there has been an increase in young people coming into the service and felt that it would be more cost-effective to train staff in MBT and DBT now, which will be beneficial to patients and the service in the long run.

Practitioners described a fragmented service. Many participants voiced their frustration with regard to the levels of support from colleagues within their service and external agencies. They said there was no seamless pathway for referral and referrals were often not accepted due to:

- the patient not meeting the criteria for a particular service;
- the patients' needs being too complex;
- comorbidity issues such as substance misuse or anxiety which needed to be addressed first.

"Sometimes I think we're not sure if we're managing and accommodating or intervening and treating." (ID R1.3)

Staff also recalled encountering resistance from other mental health practitioners as they did not want to hold on to PD patients within their service (Primary Care or CMHT). The reason given was that they considered the patient better placed elsewhere, for example a specialised PD service. One mental health practitioner explained specialist input is not always required but that there is nothing else.

Staff described the need for good crisis care, including short term admission in hospital or a crisis house but that then the person needed to be supported with regular input and timely referral to primary care psychological therapies through Improving Access to Therapies (IAPT) programme or CMHT, with provision of CBT or other therapies. They indicated that people who were motivated to receive more intense long term interventions

should be referred into specialist PD services.

Multiagency working - collective responsibility

Having a joint multi-agency management plan was considered to be important so that whichever sector the patient comes into contact with; an agreed care plan has already been put in place. Staff felt that by maintaining a consistent approach across all mental health teams and other agencies, this would ensure boundaries are maintained and patients are not receiving contradictory advice or being admitted to hospital if the care plan clearly stated that this would not be beneficial.

In practice, staff recognised the difficulty in being consistent when there are numerous people involved in a patient's care. ED staff reported particular difficulty in accessing community plans, crisis plans, and notes on how to manage patients when they presented to emergency departments at high risk of suicide.

"There's huge, huge, difficulties within the service of these patients, and I think, we all agree that, and I know that, but typically they will split services, typically they will split staff, typically they will manipulate, they will cause chaos to services, is the best way to put it." (ID R8.3)

Support for staff

Staff said the view that there was a reluctance to work with patients with PD because they did not feel they had enough support. They emphasised that having team support and shared responsibility was important when faced with difficult decisions.

Staff would prefer to either refer patients to specialist services or work more closely with an experienced PD specialist to help them cope with the stress of setting boundaries with patients. Some patients can induce anxiety in newly qualified or inexperienced staff members and there is a need for additional support and supervision for them. By having specialist support available, staff felt reassured.

Staff also felt that the organisations have a responsibility to accept that there are going to be high risk patients and that there are

difficulties in managing them. Staff described a tendency towards risk aversion, with a fear of making decisions in case of adverse outcomes. The fear of recrimination from the trust and potentially appearing in a coroner's court was evident.

Staff acknowledged that they are sometimes complacent and can underestimate the risk to personal safety and wellbeing. It was felt to be important to deal with stress, potential burnout and transference issues (i.e. where the patient redirects their feelings or emotions toward the therapist).

Training needs

All the staff identified a need for training around the management and treatment of PD. Although practitioners learn from experienced colleagues, training is still considered important.

"A lot of this has been just learning on the job, learning from the multidisciplinary team, learning from your colleagues, and learning from doing referrals." (ID R1.4)

However, one participant felt that all newly qualified staff would benefit from Knowledge and Understanding Framework (KUF) training.²⁴ Furthermore, they added that it would be useful for all staff to undertake Structured Clinical Management Training.²⁵ The lack of formal training has an impact on both staff and patients. Training that includes service users was considered to be most effective as it helps to develop an understanding of behaviours.

"It's kind of nice to see it from his perspective to see how he pushed boundaries, how he was difficult, so to elicit the care he wanted at the time, and it was kind of nice hearing that, because straight away you question or doubt yourself, like oh really, I shouldn't be working for the NHS if I'm feeling this way and stuff. It was really good hearing that." (ID F1.1)

It was also felt that training should be made mandatory, as organisations do not always accommodate staff requests to attend training.

SUMMARY OF FINDINGS

Patient characteristics

There were 154 patients with PD who died by suicide (2013) and 41 who committed a homicide (2010-2013). Compared with patients with PD who committed homicide, those who died by suicide were more likely to be female and older. Being male, with a previous history of violence and substance misuse were more prevalent in patients who committed homicide.

Most patients had been diagnosed for more than five years (80%) and were frequent users of mental health services, 16% having over 50 contacts in a year. Comorbid diagnoses were common, most often alcohol and drug misuse/dependence. There was a high level of crisis care contact, including the last episode of care before the patient's suicide or the homicide (110, 65%). Nearly half had their last contact with services within 7 days of the suicide.

Compared to patients with diagnoses other than PD, those with PD were more likely to have had a diagnosis for longer than five years. Likewise for patients with PD who committed homicide, the main difference was a history of mental illness for more than 5 years, but also and a history of self-harm and substance misuse.

Diagnosis

We found there to be a lack of standardised structured approaches to diagnosing and assessing patients with PD in accordance with NICE guidance. It was often unclear how diagnoses were made and what criteria were used.

Patients were concerned that having a diagnosis of PD (being labelled) could affect access to care and lead them to being excluded from services. Overall, it was clear from both the patients and staff perspectives that diagnosing patients with PD was difficult and not communicated well.

The term 'personality disorder' is viewed as pejorative and both patients and staff are uncomfortable with it. However, it persists partly because the diagnosis is needed for administrative/legal purpose. Work with patients is needed for a new way of formulating the diagnosis, linked to understanding their traumatic experiences and a recovery approach to management.

NICE guidelines

Of the quality standards we measured, we found 3 were being met to an acceptable level: assessing education and employment needs; *offering* patients psychological treatment; and involving patients in structured care planning. However, services were not observing NICE guidance in relation to patients *receiving* therapeutic interventions, prescribing psychotropic medications and using a standardised approach to diagnosis. We were unable to measure the provision of supervision for staff.

We found patients were not receiving the specific psychological treatments recommended by NICE such as DBT and MBT, despite evidence of effectiveness. In the majority of cases patients had been prescribed psychotropic medication in the year before the suicide or homicide, either antidepressants (123, 73%) or antipsychotics (89, 51%). This figure is high and of particular concern because the most common method of suicide was self-poisoning, and antipsychotic medication was used in 20% of these self-poisoning deaths, antidepressants in 17%. NICE guidance states that drug treatment should not be used to manage the PD itself and antipsychotic drugs should not be used for the medium or long-term management of borderline PD.

Few of the staff reported being familiar with NICE guidance for the treatment and management of patients with PD. However, staff were in agreement that in-patient admissions were not generally helpful and should only be for short periods of time.

PD pathway

Patients described their experience of mental health services as disorganised and disjointed. There was no clear pathway or process by which patients commonly accessed care. Most did not meet the criteria for referral to specialist PD services and were therefore referred to a wide range of other services most commonly CMHT, crisis resolution and home treatment, psychological and substance misuse services.

A common concern raised by patients was that they were being passed around between different services, with no team wanting to manage their care longer term as they feared patients would become “too dependent”. However, by not retaining continued contact with patients, patients felt ignored, excluded and unable to cope resulting in frequent episodes of crisis. Some believed that the way to get back into mainstream care was to self-harm.

Specialist PD services were considered to be good and effective for patient recovery where available, but the majority of patients do not get help from a specialist service. Following a crisis patients are either referred to short-term crisis resolution home treatment teams, put on a waiting list for psychological interventions (where available) or prescribed medication. Patients found difficulty coping without ongoing support and commonly disengaged, missed appointments, which often result in them going back to the beginning of the waiting list and needing to be reassessed. Therefore patients were not accessing appropriate and timely care.

When specialist services and therapies such as DBT were accessed by patients they were found to be good. Patients valued treatment from staff with expertise and understanding of their individual needs.

Within the criminal justice system, the Offender Personality Disorder pathway is a jointly developed strategy with HM Prison service and the probation service for offender who commit serious violent or sexual offences. Preliminary findings have shown some positive outcomes.

Risk, fear, knowledge and supervision

Patients

The main concern from patients was that there was nowhere to go consistently for support, resulting in frequent crisis episodes, self-harming, attempting suicide and presentations to ED.

Both patients and staff reported that routine service contact for patients with PD would be beneficial to prevent them going from crisis to crisis. The care provided to patients after crises was considered to be too short term and failed to address underlying issues, including trauma. Patients felt services were failing to invest in the resource intensive therapeutic interventions which are required to achieve meaningful recovery.

Former patients are an under-used resource. Work is needed to development their role in areas such as staff training, advocacy, and peer support where possible.

Staff

Staff also confirmed that there was a gap in service provision between crisis management and specialist PD services. There was also a gap in the treatments offered and actually received by patients.

There was a clear knowledge gap for both newly qualified and more experienced staff, all of whom called for training to be provided to improve services and patient care. Staff felt that their role had become one of ‘*managing and accommodating*’ patients rather than ‘*intervening and treating*’ and there was a lack of communication which patients found to be frustrating.

More support was requested in terms of mandatory training provision, clearer guidance on referral pathways and the availability of treatment and support. In the event of an adverse incident such as a death by suicide or homicide, staff wanted reassurance that organisations would be supportive of their decision making.

Risk was strongly linked to comorbid substance misuse, suggesting that availability

of substance misuse and dual diagnosis services is an important component of care.

KEY MESSAGES

1. Patients with personality disorder who died by suicide or committed homicide were not receiving care consistent with NICE guidance. This recommends: patients are offered appropriate and timely psychological interventions; medication should only be prescribed short term; and admission to in-patient care should be avoided where possible.
2. Exploration with staff and patients about their experience suggests that problems in the care of patients with personality disorder are not limited to cases in which there is a tragic outcome, though these experiences may not be representative of services nationally.
3. Our findings therefore suggest the need for a more comprehensive examination of services for personality disorder, taking into account the safety concerns highlighted in this report.
4. Although personality disorder is part of international classification systems, in practice applying the diagnosis of personality disorder may be stigmatising and obscure individual needs. Working with patients to understand their traumatic experiences is likely to be more beneficial.
5. Psychotropic medication may be taken in fatal overdose, emphasising the importance of safe prescribing in mental health services and primary care.
6. Risk in personality disorder is linked to co-existing drug and alcohol misuse, showing the need for substance misuse services to be available.
7. Former patients are an under-used resource and should have involvement in staff training, advocacy and peer support where possible.

INDEPENDENT ADVISORY GROUP MEMBERS

Ben Thomas (Chair)	Department of Health, England
Richard Bunn	Shannon Clinic Regional Forensic Unit, Belfast Health and Social Care Trust, Northern Ireland
Jonathan Campion	Director for Public Mental Health, England
Carolyn Chew-Graham	Keele University
Caroline Dollery	East of England Strategic Clinical Network for Mental Health Neurology and Learning Disability
Frances Healey	NHS Improvement
Ann John	Public Health Wales
Tim Kendall	NHS England
Sarah Markham	Lay representative, Healthcare Quality Improvement Programme (HQIP)
Ian McMaster	Department of Health, Northern Ireland (DoH-NI)
John Mitchell	Mental Health and Protection of Rights Division, Scottish Government
Sian Rees	University of Oxford Health Experiences Institute, Department of Primary Care Health Sciences
Tina Strack	Healthcare Quality Improvement Programme (HQIP)
Sarah Watkins	Department for Health and Social Services and Children (DHSSC) and Department of Public Health and Health Professions (DPHHP), Welsh Government

REFERENCES

1. World Health Organization. (1992). The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organisation.
2. Lewis, G., & Appleby, L. (1988). Personality disorder: the patients psychiatrists dislike. *The British Journal of Psychiatry*, 153(1), 44-49.
3. MIND. What is a personality disorder?
<http://www.mind.org.uk/information-support/types-of-mental-health-problems/personality-disorders/#.WOuFVfkrLIU>
4. National Institute for Health and Clinical Excellence. (2009). Borderline Personality Disorder: recognition and management. NICE clinical guidance 78. January 2009.
5. National Institute for Health and Clinical Excellence. (2009). Antisocial personality disorder: Treatment, management and prevention. NICE clinical guidance 77. January 2009.
6. Baxter, D., & Appleby, L. (1999). Case register of suicide risk in mental disorders. *The British Journal of Psychiatry*, 175(4), 322-326.
7. Office for National Statistics. Statistical bulletin: Suicides in the UK: 2015 registrations. <https://www.ons.gov.uk/peoplepopulationsandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicideintheunitedkingdom/2015registration>
8. Office for National Statistics. (2017). Focus on violent crime and sexual offences, England and Wales: year ending Mar 2016. <https://ons.gov.uk/peoplepopulationsandcommunity/crimeandjustice/compendium/focusonviolentcrimeandsexualoffences/yearendingmarch2016/homicide>
9. Scottish Government. (2016). Homicide in Scotland 2015-2016. www.gov.scot/Publications/2016/10/1834/downloads~res-1
10. Police Service of Northern Ireland. (2016). Police Recorded Crime in Northern Ireland: Monthly Update to February 2016. <https://www.psni.police.uk/globalassets/inside-the-psni/our-statistics/police-recorded-crime-statistics/2016/february/monthly-crime-bulletin-period-ending-feb-16.pdf>
11. The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness *Making Mental Health Care Safer: Annual Report and 20-year review*. Manchester: University of Manchester, 2016. <http://research.bmh.manchester.ac.uk/cmhs/research/centreforsuicideprevention/nci/reports/2016-report.pdf>
12. Percudani, M., Belloni, G., Contini, A., et al. (2002). Monitoring community psychiatric services in Italy: differences between patients who leave care and those who stay in treatment. *British Journal of Psychiatry*, 180, 254-259.
13. Norton, K. (1996). Management of difficult personality disorder patients. *Advances in Psychiatric Treatment*, 2, 202-210.
14. National Institute for Mental Health in England. (2003). Personality disorder: No longer a diagnosis of exclusion. Policy implementation guidance for the development of services for people with personality disorder. Department of Health.
15. Bateman, A.W., & Gunderson, J. (2015). Treatment of personality disorder. *The Lancet*. 385(9969), 735-743.
16. Paris, J. (2004). Is hospitalization useful for suicidal patients with borderline personality disorder? *Journal of Personality Disorders*. 18, 240-247.
17. Dale, O., Sethi, F., Stanton, C., et al. (2017). Personality disorder services in England: findings from a national survey. *BJPsych Bulletin* 1-7, doi: 10.1192/pb.bp.116.055251
18. Linehan, M. M., Comtois, K.A., Murray, A.M., et al. (2006). Two-year randomized controlled trial and follow-up of dialectical behavior therapy vs therapy by experts for suicidal behaviors and borderline personality disorder. *Archives of general psychiatry*, 63, 757-766.
19. National Institute for Health and Clinical Excellence. Personality disorders: borderline and antisocial. List of quality statements. <https://www.nice.org.uk/guidance/qs88/chapter/List-of-quality-statements>
20. StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP.
21. Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative research in psychology*. 3, 77-101.
22. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 11. 2015.
23. Linsley, K.R., Schapira, K., Kelly, TP. (2001). Open verdict v. suicide - importance to research. *British Journal of Psychiatry*. 178, 465-48.
24. Knowledge and Understanding Framework. (2007). <http://www.institutemh.org.uk/-education-the-knowledge-and-understanding-framework/268-personality-disorder-and-the-kuf> Accessed 15 March 2017
25. Bateman, A.W. and Krawitz, R., 2013. *Borderline personality disorder: an evidence-based guide for generalist mental health professionals*. Oxford University Press.

CONTACT US:

National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH),
Centre for Mental Health and Safety, Centre for Suicide Prevention, Jean McFarlane Building,
University of Manchester, Oxford Road, Manchester, M13 9PL.

Telephone: 0161 275 0700

Email: nci@manchester.ac.uk

Visit us on our website:

<http://research.bmh.manchester.ac.uk/cmhs/research/centreforsuicideprevention/nci>



Follow us on Twitter: @NCISH_UK



Like us on Facebook to get our latest research findings: Centre-for-Mental-Health-and-Safety

CITE THIS REPORT AS:

National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH).
Safer Care for Patients with Personality Disorder. Manchester: University of Manchester 2018.

Copyright All rights reserved. © Healthcare Quality Improvement Partnership. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any other means, electronic, mechanical, photocopying, recording, or otherwise, without prior permission, in writing, of the copyright holders.