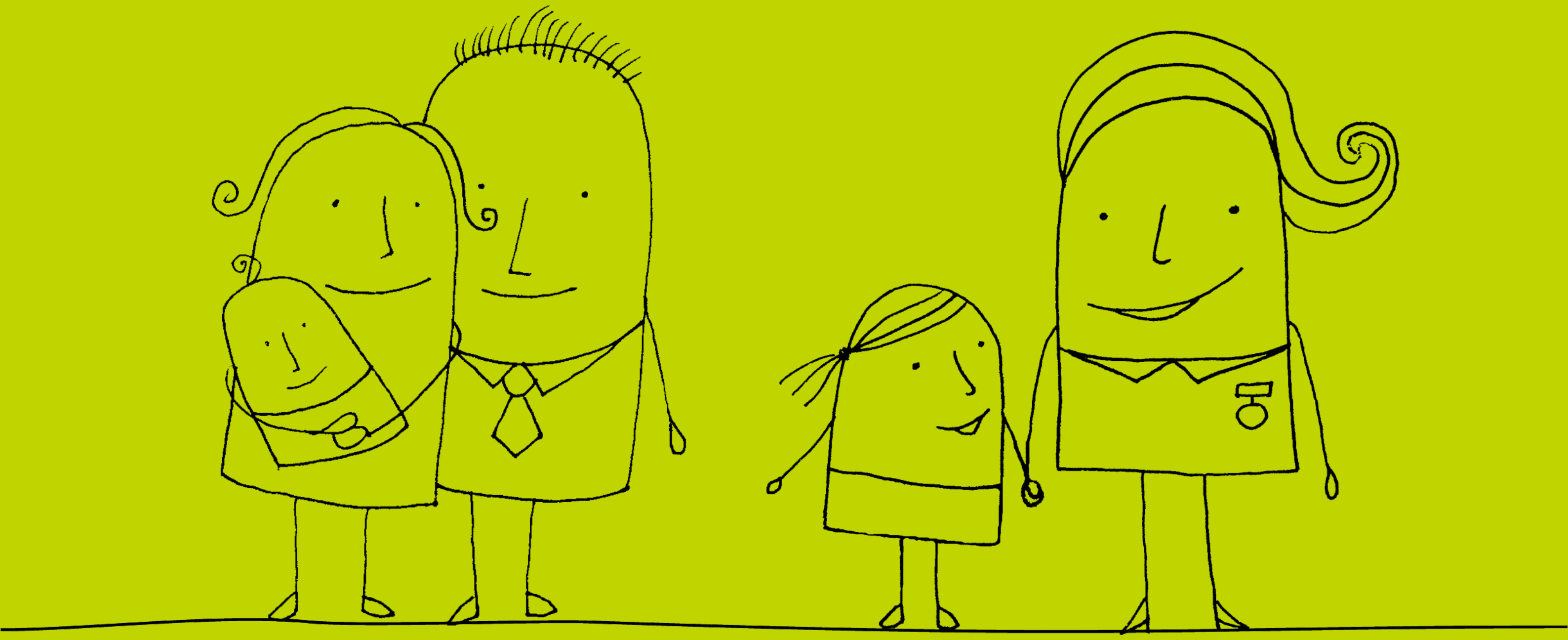
Patient and Client Council
**Your voice** in health and social care

# Borderline Personality Disorder Scoping Paper

## Service users discuss their experiences of living with Borderline Personality Disorder and using Adult Mental Health Services

## March 2019



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# 1.0 Introduction

## 1.1 Personality Disorders

Personality disorders are a type of mental health difficulty in which someone's way of thinking about the world, feelings and behaviours can cause longstanding emotional problems and difficulties in relationships with other people.

The word 'personality' refers to the way we think and feel and the things that we do that make each of us the individuals we are. We don't always think, feel and behave in exactly the same ways – it is often affected by the situation we are in, the people around us, the use of drugs or alcohol and many other things.

Someone with a Personality Disorder may think and feel in more extreme ways than other people. For example, the person's emotions may change from a happy state of mind to feeling down or sad very quickly or they may be particularly sensitive to criticism from other people and experience this as an attack. It is when these thoughts or feelings are intense enough to affect a person's daily life and their relationships that a mental health professional may consider Personality Disorder as a potential diagnosis.

The impact of all of this on someone's life is that a person with a Personality Disorder is more likely to experience adverse life events such as relationship difficulties, housing problems, long-term unemployment and also to suffer from alcohol and drug problems and offending behaviour[1].

People with Personality Disorders often have a complex range of problems and needs, and they may be involved with a number of different agencies. Without the right kind of treatment and support, these problems can continue, affecting their own wellbeing and the wellbeing of those close to them[2].

## 1.2 Borderline Personality Disorder

There are ten types of Personality Disorders, one of which is Borderline Personality Disorder[i] (BPD), also known as Emotionally Unstable Personality Disorder (EUPD) [3, 4]. It is present in just under 1% of the population[5] which would equate to approximately 19,000 people in Northern Ireland having BPD. It is estimated that around 1-5% of adolescents in the UK could meet the diagnostic criteria for BPD[6]. BPD is the most commonly seen Personality Disorder in women, though prevalence is thought to be roughly equal in men and women[7].

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[i] While we acknowledge that there is disagreement over the term 'Borderline Personality Disorder', we have used the term in this paper because it is the most widely used and accepted one for this condition.

### 1.2.1 Traits or symptoms of Borderline Personality Disorder

Borderline Personality Disorder describes a specific set of personality traits or characteristics[8], but how these manifest will vary between individuals. These traits can be grouped into four main areas – those affecting Emotions, Behaviour, Relationships and Thinking:

**Emotions:** For someone with BPD, emotions are felt very intensely, and tend to be 'up and down' a lot, with mood changes over minutes, hours or days. Small, sometimes difficult to notice, triggers can cause these changes.

**Behaviours:** Behaviours can be impulsive, with a person making decisions very quickly to do things with little thought of the impact on themselves or others. This can be most obvious when someone acts destructively towards themselves. Many people with BPD self-harm and some also have suicidal thoughts.

**Relationships:** People with BPD often have relationships which are intense and which can be chaotic or unpredictable. Other people can be seen as very intensely positive or very intensely negative, even with the same person at different times. Within relationships, someone with BPD can have a strong fear of abandonment and can try to prevent people from leaving them.

**Thinking:** Patterns of thinking can become very negative, particularly in how someone with BPD sees other people, e.g. experiencing others as uncaring or even abusive.

Other symptoms of BPD include:

- Feeling empty;
- Having an uncertain sense of who they are as a person;
- Outbursts of anger; and/or
- Hearing voices or having distressing thoughts which are held very strongly (such as other people being 'out to get' or attack them). At times, these experiences can be symptoms of psychosis and will require medical help[8].

### 1.2.2 Causes

The factors that determine whether someone will develop BPD are complex. As with many mental health problems, BPD appears to result from a combination of environmental and genetic factors[9]. Environmental factors can include feeling stressed or unsupported growing up, family difficulties, the loss of a parent, parental neglect or physical, sexual or emotional abuse during their childhood. Those with a diagnosis of BPD are significantly more likely than people with other personality disorders to report having been emotionally and physically abused by a carer or sexually abused by a non-carer[10]. Many, but not all, people living with BPD will have experienced traumatic events in childhood[4].

### 1.2.3 Common co-morbidities

Those with Borderline Personality Disorder are more likely to have other mental health conditions alongside it. These comorbid mental health conditions can include:

- Depression;
- Anxiety;
- Eating disorder;
- Post-traumatic stress disorder;
- Alcohol and drug misuse[5].

### 1.2.4 Accessing treatment

The Regional Care Pathway for Personality Disorders sets out the associated services in Northern Ireland[11].

The main route to access mental health input is through seeing a GP who can, when appropriate, refer anyone to mental health services. While not intended as a route to access routine care, if someone has a mental health crisis, Emergency Departments can refer to emergency mental health services.

Mental health services will assess needs and determine the correct level of input. If appropriate, they will establish the diagnosis of BPD and offer suitable treatment interventions, which may include: treatment first of other mental health conditions (e.g. anxiety or depression), psychoeducational work, signposting for support with alcohol or drug misuse, referral to specialist Personality Disorder services for psychological interventions or transfer of care back to the GP.

The Regional Care Pathway outlines the following Principles of Recovery:

- Promoting Hope, and Self Determination;
- Personalised Whole Person-Centred Care;
- Encouraging Participation and Making Connections; and
- Focusing on Strengths.

These are the principles that should guide staff who work with those living with Personality Disorders (including BPD).

Services will also work with those close to the individual so that they are supported in the recovery process. In particular, the mental health charity, CAUSE works very closely with carers, family members and friends of people with Personality Disorders in Northern Ireland.

### 1.2.5 Stepped Care Model

The Regional Care Pathway describes the Stepped Care Model. When a person is referred, the stepped care approach is used to match their needs with the right level of support. The individual receives the level of treatment thought to be most appropriate to their needs. There can be 'steps up' to intensive/specialist services as their needs require and then 'steps down", when specialist intervention has been completed. The level of support offered is determined by the personal needs of the individual, matched to treatment and interventions that are known to help relieve their specific symptoms[11].

### 1.2.6 Treatment in Northern Ireland

A consensus statement, published in 2018, called for a wide variety of evidence based interventions and a collaborative, whole-system approach to treatment for 'people with complex mental health difficulties who are diagnosed with a Personality Disorder'[6]. It is widely accepted that treatment of BPD should maintain a focus on psychological treatment. Medications should be used largely to treat co-morbid mental health conditions or if medications are required they should preferably be used in the short term or kept under review.

There are a number of recognised, evidence-based psychological therapies to treat BPD[12,13] including Mentalisation Based Treatment (MBT), Dialectical Behaviour Therapy (DBT), Transference Focussed Therapy (TfP), Schema Therapy and Cognitive Analytic Therapy (CAT).

While these treatments are different, experts agree that all are efficacious and no one therapy is thought to be better than others. Some will focus more on managing the behaviours associated with BPD while others make attempts to consider the thoughts and feelings in more detail to help an individual try to readjust their experience of the world around them[12, 13].

All Health and Social Care Trusts in Northern Ireland have a dedicated Personality Disorder service. Very rarely, if it is not possible to safely treat someone with a Personality Disorder psychologically while they live at home, and they may need to travel for specialist treatment outside Northern Ireland [14, 15, 16, 17, 18, 19].

Local services focus mainly on providing MBT or DBT as a treatment. These services were developed through the Bamford Review of Mental Health and Learning Disability Services, which involved service users and carers in the regional planning of services from the outset[20]. Local Personality Disorder services have always valued service user involvement and were among the first mental health services in Northern Ireland to employ peer support workers. Importantly for those working in the field, the original funding committed for developing services for people with Personality Disorders – in the Northern Ireland Personality Disorder Strategy[1] – has only ever been fulfilled to an estimated 50%.

### 1.2.7 Northern Ireland Personality Disorder Network

Northern Ireland has a Regional Personality Disorder Network which brings together:

- Specialists from NHS services;
- Representatives of Prison Services;
- Service users and experts by experience;
- Family members of people with personality disorder (including BPD);
- Health and Social Care Board staff; and
- Community & voluntary service providers.

The Network has grown from the previous Bamford Working Group on Personality Disorders. This Working Group involved both service users and carers and was influential in the development of the Northern Ireland Personality Disorder Strategy[1] and of local Personality Disorder services.

In recent years, the work of the Personality Disorder Network has included holding a conference in a local venue with nationally recognised speakers and a training day specifically planned for patients and their carers or love ones.

## 1.3 Our aim

As part of the PCC's 2018/2019 business plan, it was decided that a study should be undertaken with people with BPD and those close to them. The aim was to add to the knowledge and awareness of the needs of this group across the health and social care sector.

It is intended that this scoping paper will be shared with key decision makers to help inform the future of BPD services in Northern Ireland.

# 2.0 What we did

The Patient and Client Council (PCC) 2018/19 Business plan includes the following objective:

**Goal 1 - Representing the Interests of People**

**1.4 Personality Disorder**

As part of our role with Bamford Monitoring Group (BMG), we will work with people who have a borderline personality disorder to learn about services available to them.
Findings will be written up and shared with HSC bodies.

## 2.1 Overview of our approach

This topic was brought to us by a service user with BPD. They highlighted it as an issue we should look into.

During 2018/19, the Patient and Client Council spoke with seventeen service users and carers about their experience of BPD.

The topic guide was developed by a steering group consisting of Patient and Client Council staff and with service user involvement. This helped to shape the topic guide questions and discussion prompts which would be asked at the focus groups and interviews. A full topic guide with the question asked can be found in **Appendix 1**.

In order to gather views, an article was published on the PCC website, promoting the project. In addition, the following organisations, which work with BPD service users and carers, were contacted:

- Action Mental Health;
- Mindwise;
- CAUSE.

Service users and carers were asked to contact the PCC to register their interest in participating in the project.  A total of four panels and two one-to-one interviews were set up, and one email response was received. Panels and interviews were conducted at venues across Northern Ireland between July 2018 and January 2019. Seventeen people were interviewed, fifteen with BPD and two carers. Of those participants with BPD, five were in the criminal justice system.

**Table 1** gives an overview of the panels and people interviewed, the area they relate to, and the date of the visit.

**Table 1:** Overview of groups and interviews by area and date.

| Group/Interview | Area | Date visited |
|---|---|---|
| Focus group | Belfast | 18th July 2018 |
| One-to-one | Omagh | 20th July 2018 |
| Focus group | Ards | 24th July 2018 |
| Email response | Western Trust | 23rd August 2018 |
| One-to-one | HMP Hydebank Wood College and Women's Prison | 16th September 2018 |
| Focus group | HMP Maghaberry | 10th October 2018 |

Seventeen participants took part in the panels, one-to-one interviews and written responses. This included focus group participants, which consisted of two carers, and twelve people with BPD. Furthermore, two people with BPD took part in one-to-one interviews and one person submitted a written response. **Table 2** provides a breakdown of the number of people with BPD and carers by gender at each panel/interview.

**Table 2:** Overview of participants

| Group/Interview | BPD | | Carers | | Total |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | |
| Focus group, Belfast | 2 | 2 | - | - | 4 |
| One-to-one, Omagh | - | 1 | - | - | 1 |
| Focus groups, Ards | 1 | 3 | - | 2 | 6 |
| Focus group, HMP Maghaberry | 4 | - | - | - | 4 |
| One-to-one, HMP Hydebank Wood College & Women's Prison | - | 1 | - | - | 1 |
| Email response | - | 1 | - | - | 1 |
| **Total** | **7** | **8** | **0** | **2** | **17** |

There were at least two members of PCC staff at each panel, where we asked the participants a set of questions. These focused on the key Health and Social Care issues for people with BPD and their carers (**See Appendix 1**).

The panel members' discussion was recorded with their consent. The participants in the one-to-one interviews were asked the same questions and responses were also recorded. The prisoners we spoke to did not have their discussion recorded; rather, a member of the PCC staff wrote down key points from the discussion. The participant who sent an email response was sent the same set of questions asked at the panels. Content anaylsis was undertaken and key points identified.

## 2.2 Reporting

This scoping paper aims to reflect the participants' views and opinions on their experiences of Personality Disorder (PD) service provision within Health and Social Care in Northern Ireland.

The findings are detailed in the following chapters, which focus on a number of areas discussed at the panels and interviews. They provide an outline of the views provided by people with BPD and carers.

## 2.3 Limitations

Whilst we only spoke to seventeen people, appointments had been scheduled to talk to more. However, on the day of the interviews some people did not attend as they were not feeling well enough. An option of sending an email response was presented as an alternative way for people to submit their views on services. PCC capacity was also a significant limitation as we did not have the time or staff to organise or carry out further interviews with service users. It must be acknowledged that those involved represent a very small proportion of the BPD population in Northern Ireland, and that the views expressed cannot therefore be generalised.

Furthermore, there was no engagement with HSC bodies or with relevant mental health professionals in the early stages of the project. On reflection, appropriate and timely involvement of relevant HSC staff should be a priority in future PCC projects, so that they can share their views, input to the research design and potentially support with recruiting service user/carer participants.

# 3.0 What people told us

We talked to seventeen people with BPD about their experiences of healthcare services in NI. The service users and carers we spoke to described the impact of having a Personality Disorder on their lives and shared their perspectives on the services and support available to them and their loved ones. The following sections detail these people's experiences and opinions of healthcare services in Northern Ireland and what their hopes are for future service provision.

## 3.1 Services accessed

Participants listed a range of services and support. These included, their GP, Therapists, and Counselling. Many stated that they had seen a Community Psychiatric Nurse (CPN), and/or a psychiatrist. Some participants had attended group therapy or accessed Dialectical Behavioural Therapy (DBT), but we did not speak to anyone who had accessed Mentalisation Based Treatment (MBT). A few mentioned they had been in a Mental Health Unit. Both sets of the prisoners we spoke to said they had access to the mental health team in prison. One person said that they had not accessed any services as their GP would not diagnose him with BPD.

## 3.2 What worked

When asked what support services worked well, participants listed a variety of things that helped them in their treatment and care and highlighted what worked in the current services that were available.

### 3.2.1 Continuity of Care

One person said he greatly benefited from sustained support with a specialist in Personality Disorder; this was a point on which many of our participants agreed. They said that, when their therapist or specialist was constantly changing, they would have to repeat their story and build up a new trusting relationship. When there was continuity, service users said they liked having the structure and consistency of care; this greatly helped them to have trust and confidence in their service provider.

***"What you need is a sustained support"***

*(Male, Service user)*

***"I suppose what really worked well was consistency"***

*(Female, Service user)*

### 3.2.2 Staff Awareness and Compassion

A few participants said that they had a positive experience with Health and Social Care staff. When staff had an awareness of Personality Disorders and treated them with care and respect it made them feel more comfortable when accessing Personality Disorder services.

***"My doctor and key worker … I find them to be generous and compassionate … seeing past the diagnosis and seeing me as a person"***

*(Female, Service user)*

### 3.2.3 Appropriate Therapies

A few participants spoke about the therapies they had undertaken such as Dialectical Behavioural Therapy (DBT) and Schema therapy. Of those who had received DBT, most said that it was beneficial as they learned coping tools for BPD. However, it took a long time to access this therapy.

***"I was very fortunate that last year I participated in Dialectical Behavioural Therapy but I wasn't able to get that place for three years. So during those three years it had an impact on every aspect of my life"***

*(Female, Service user)*

***"The therapy itself has been effective. Before that I would say I wasn't functioning very well but the therapy had been major in my recovery"***

*(Female, Service user)*

### 3.2.4 Support from Voluntary and Charity Organisations

Some said they received support from voluntary or charity organisations, such as group therapies. This helped to fill the gap in Trust services.

> ***"It's [only] for voluntary services that I've gotten more"***
>
> *(Female, Service user)*

### 3.2.5 Facilities and Support in Prison

Prisoners at Maghaberry had access to the Donard Centre, a health and wellbeing centre in the prison. Here they could avail of Stress Management and Anger Management courses. Furthermore, at the Donard Centre they could play a game of pool, and have a cup of coffee. They liked the centre as it meant they could leave their cell and avail of the facilities.

## 3.3 What didn't work

Participants were asked what did not work well for them in their treatment or care. Service Users, in particular, had a wide range of issues and concerns with the current service delivery.

### 3.3.1 Lack of Understanding and Compassion

Most people found that there were a lot of stereotypes and stigmas associated with BPD. There was a fear of being discriminated against in everyday life, hospitals and in the workplace. Furthermore, some participants stated that there were misconceptions that people with BPD were attention seekers and a burden to Health and Social Care Services.

> ***"I am really worried about the discrimination I might face wherever I go. You don't want to be different, you just want to be treated like anyone else who has diabetes or asthma or another health condition"***
>
> *(Female, Service user)*
>
> ***"I think the general consensus is that BPD is manipulative, and attention seeking, time waster … and that label then is put on every person. I don't think that we were taken seriously. I don't think people are listened to".***
>
> *(Female, Service user)*

A few participants said that the name of the condition was misleading and added to the stereotypes and false expectations about BPD.

***"I think the diagnosis makes me sound like I am on the border of neurotic and psychotic and I hate it … it was even brought up at a conference that the name should be changed because it labels people in a way that is so derogatory".***

*(Female, Service user)*

Another issue raised was the lack of awareness about BPD amongst the general public and Health and Social Care staff. Many service users found that stereotypes about the condition were prevalent. Participants stated that there was very little understanding about BPD. Therefore, it was suggested that there should be more education about mental health and BPD within Health and Social Care.

***"I think education, awareness, [and] people talking to each other, more communication and education amongst other people that aren't in the system".***

*(Male, Service user)*

***"The training and the education I think is very important – the training of GPs, Social Workers, A&E staff, and anyone that is known to the community mental health team".***

*(Female, Service user)*

Furthermore some service users said that they needed to be listened to by healthcare staff as they were the experts in the condition, knowing what treatments and services work and what needs to be changed.

***"Nurses and doctors need retraining; services need to be provided that has been laid out … There needs to be a much more co-ordinated approach"***

*(Female, Service user)*

***"They need to listen, to take it on board and accept that we are the experts in it and that is where their learning will come from".***

*(Female, Service user)*

In addition, many said that they felt that it was a hidden condition. Participants felt that it was difficult for people outside of mental health to understand what was 'wrong' with them because unlike a physical injury, their condition is not obvious.

***"You are given a diagnosis and then you are isolated. There is no support … It is because nobody else sees – nobody knows what is going on".***

*(Female, Carer)*

*"It needs to be validated, because it is such a complex illness, it seems that the mental health teams don't want to help you because they know that they can't cure you and there is no certain treatment".*

*(Male, Service user)*

### 3.3.2 Lack of Continuity in Health Care Professionals

A major problem highlighted by all groups was a lack of continuity, namely that they did not always see the same psychiatrist. Having to explain their story again to a new person meant that the participants did not feel like they were making any progress within their treatment. Rather, they felt like they were wasting time and not moving onto new topics or tackling issues in depth. Some service users spoke of how hard it was to build a relationship with healthcare providers when they seemed to be constantly changing. They told us that it had a negative impact on them emotionally.

*"There isn't a while lot of quality there when it comes to the treatment itself like so you're telling your story all over again, and again until you get fed up like, you know".*

*(Female, Service user)*

*"I just find that there is no consistency… The services are trying their best but the services are broken".*

*(Female, Service user)*

*"There is a lot of locum psychiatrists because they couldn't recruit a full-time psychiatrist. So there was no consistency in care was the thing I found the most difficult thing".*

*(Female, Service user)*

*"There seems to be a real lack of co-ordination… and communication and it is because nurses are not trained that way. There also needs to be an obvious sense of feeling that the professional that you are speaking to actually cares. They're not good at that. You need to know that the person really empathises and really wants to do their best, will share all the information with you that is relevant, will be proactive".*

*(Female, Service user)*

### 3.3.3 Under Resourced Services

Another issue was the need for more funding and more staff, as the statutory Health and Social Care workforce was overworked and couldn't cope with the numbers of people who needed to use the service. There was a perception that this had created a reliance on voluntary services to provide counselling, therapy and helplines.

***"There should be a key worker so that if people are still struggling there is someone to contact – a year [long] support [is] not enough"***

*(Female, Service user)*

***"There's not enough money for services to run and the workforce is over worked"***

*(Female, Service user)*

Related to these perceptions of under-resourced services, most people noted that in Health and Social Care services, there were long gaps in the initial diagnosis and an appointment. There was an issue with appointments in general and the long waits placed a further strain on them emotionally.

***"You can't wait 18 months for somebody. [You] have to use voluntary or private".***

*(Female, Service user)*

***"Mental health resources in the West are underfunded and under resourced vastly. I know the community mental health team try their utmost best but they just don't have the resources. I think that is the major issue. Even to see a psychotherapist the average waiting time at the minute is eleven weeks. For someone who is distressed eleven weeks is a long time".***

*(Female, Service user)*

### 3.3.4 Equality and Consistency in Access to Services across Northern Ireland

As noted in Section 1.2.6, each of Northern Ireland's five Trusts has a dedicated Personality Disorder service and these all provide MBT and DBT. However, some participants perceived that there were different treatments available across the Trusts to deal with BPD, such as Dialectical Behavioural Therapy, Schema Therapy and Cognitive Behavioural Therapy. Specifically, some stated that they were unable to access DBT and one participant described service provision in Northern Ireland as a *"postcode lottery".* However, the lack of reference to Mentalisation Based Therapies suggests that our sample was not representative of the wider BPD population in Northern Ireland from a treatment perspective, given that MBT is one of the core treatment offerings for BPD across Northern Ireland.

Furthermore, conferences on Personality Disorder tended to be held in Belfast which made it difficult for people who lived further away to access them. This meant it could be a long journey for someone who has limited means of travel.

***"[DBT] is effective but the one issue we did find was that the group was initially in Omagh and a lot of people found that really difficult to get to because they relied on public transport. So it was moved to Enniskillen after 6 months. Even then the cost of getting to therapy was really difficult because a return bus fare was £20 and for people that is a lot of money".***

*(Female, Service user)*

> ***"Belfast is very different from what you would get from the Western Trust or to what you would get in the Southern Trust … Yes, there may be one [specialist] in each Trust but are they getting to everyone?"***
>
> *(Male, Service user)*

### 3.3.5 Poor Knowledge Amongst Professionals

Many of the participants found themselves having to do their own research into BPD, in order to find support groups and treatments available. Without this, they were reliant on finding out about them by word of mouth. This resulted in some people having to ask doctors if a certain therapy was available.

> ***"If I don't ask the things then nobody ever tell[s] me anything – but then again you don't know what to ask for because I don't know what is available".***
>
> *(Male, Service user)*
>
> ***"Until you actually badger them, you don't get anything done. You have to go and check everything out… You have to find out what the other Trusts are offering"***
>
> *(Female, Service user)*
>
> ***"After research I told [the] doctor that I wanted to be put on the list for DBT and he agreed. He hadn't suggested it – I told him that that is what I wanted"***
>
> *(Female, Service user)*

### 3.3.6 Lack of Consistency in Advice from Health Care Professionals

Many participants noted that there were inconsistencies in their Treatment or in the advice they were given by Health and Social Care staff.

> ***"Put three [specialists] in a room and they'll all disagree"***
>
> *(Male, Service user)*
>
> ***"Every doctor I have seen has not been consistent in what they have said. No two people the same. There needs to be consistency with who you see".***
>
> *(Female, Service user)*

### 3.3.7 Prisoners' Views

The prisoner participants stated that although they had access to the Mental Health Team in the prisons, they felt that there was no one trained there to deal with severe mental health disorders or Personality Disorder. One prisoner said that they did not think they were taken seriously by the Mental Health team and felt put off from approaching them again. Another prisoner said that in Northern Ireland prisoners are given a diagnosis but no treatment plan.

## 3.4 Suggestions for improvement

When asked what they hoped services for people with BPD would look like in the future, participants had a wide range of answers. Many responses reflected the findings set out in Section 3.3, including calls for:

- Greater consistency in BPD service provision and accessibility across Northern Ireland.
- More continuity when it came to seeing the same professionals, doctors and psychiatrists.
- More education and greater awareness about BPD among healthcare professionals and the wider public.

> ***"I think education, awareness, people talking to each other … more communication, [and more] education amongst other people that aren't in the system".***
>
> *(Male, Service user)*

### 3.4.1 Co-Production

Many participants also expressed a desire for more co-production within BPD services. They reiterated that there should be more recognition that service users are the experts in their condition through their experiences with BPD and with BPD services. Some service users said they should be a key part in the decision-making process with regards to BPD services, as they know what works in the services and what does not.

> ***"They need to listen, to take it on board and accept that we are the experts in it and that is where their learning will come from".***
>
> *(Female, Service user)*

### 3.4.2 More Funding

There was a call from participants for there to be more funding for BPD services. They wanted there to be more staff in order to reduce the long waits they had for accessing services, which often could be weeks or months. The resulting long breaks between therapies added more stress for the service users. Among those BPD patients and carers who participated, there was a heavy reliance on voluntary organisations' BPD services for help and support. They accepted that these organisations also required funding to carry out their work.

> ***"One thing that's going to help this [is] funding from everyone's point of view"***
>
> *(Female, Service user)*

*"From initial consultation to therapy, that the timescale is reduced. That there is more consistency in how patients are treated within departments by staff".*

*(Male Service user)*

*"When you come out of one therapy you might have to wait ten weeks to see somebody else. I think that is really hard for somebody that is going through a really difficult time in their life … That is a fault in the system, the fact that it had been underfunded for such a long period of time".*

*(Female, Service user)*

### 3.4.3 Supported Accommodation

In relation to resources, a few people stated that there should be more supported accommodation places available. They mentioned that in England there are more of these facilities, with some of the participants having spent time there. They felt that Northern Ireland was behind in their service provision and this needed to be rectified.

*"The vision hopefully is a single unit, you know like they do have in England … like [they have] for eating disorders or drinking".*

*(Female, Service user)*

### 3.4.4 Combined Approach to BPD and Co-Morbidities

Another service user said that there should be greater recognition of those co-morbid conditions with BPD, such as addictions, eating disorders and Post-Traumatic Stress Disorder (PTSD). The service user also stated that these co-morbid conditions should not be treated in isolation; rather, there should be a joint approach to the provision of treatment and care for those with multiple disorders.

### 3.4.5 Improved Support for Carers

When asked as a carer what they would need to support their loved one, carers had similar responses to the service users. However, a specific theme emerged around the lack of information, training and support for carers. One carer wished she had more advice and information, especially on what might trigger a person with BPD. One carer said that, like the service users, she had to research BPD herself as there was not enough information given to her.

*"You do it [research] because you are so frustrated that nobody's telling you what is going on"*

*(Female, Carer)*

> ***“As far as carers are concerned, I didn’t have anybody give me any advice at all”.***
>
> *(Female, Carer)*

We also asked service users what they thought would help carers of people with BPD. Many said that carers needed access to more support in their caring role such as counselling, education and training.

> ***“There is an awful lot of silence out there for loved ones as well …Maybe you want education of ‘How do I help my daughter? How do I help my son?’ You know, they’re self-harming or something ‘How do I help them?’ There’s no education in that regard really, other than self-education. And it’s the Wild West out there on the internet”.***
>
> *(Male, Service user)*

Specifically, it was reported that many families and carers were not given leaflets and that there was often little advice provided to them.

> ***“[What carers need is] proper, detailed information on what BPD is, how to help their loved one and how to help themselves. This should be provided at the point of diagnosis and should be available whenever it is needed from then on for the following years”.***
>
> *(Female, Service User)*
>
> ***“There is no information for them at all. My mother had to buy books online because there was no information. When [I] got the first diagnosis, I think that it was more traumatic for my family than it was for me because at least I got some information”.***
>
> *(Male, Service User)*

Several Service Users said that there should be more support available for families and carers. A few specifically mentioned that there should be more support for the partners of those with BPD.

> ***“I personally feel that because people with Borderline Personality Disorder do struggle within relationships … [you] can come across … erratic and you can come across narcissist… I think that there should be a course run for people that are in a relationship that don’t have Borderline Personality Disorder to actually have a course to see what their partner is going through … That is why we have so dramatic relationships because they don’t have the knowledge”.***
>
> *(Female, Service User)*

A few participants wanted training available for carers to help them understand and help their loved one with BPD. This could include learning about how to communicate and adapt their behaviours. It was also suggested that carers should be able to access therapies such as medication. One service user recognised the need for families to be involved in the healing process.

However, it was also acknowledged that for some people it may not be appropriate to involve family members as they could also be the cause of their condition.

> ***"Much of PD [Personality Disorder] derives from invalidation in families and some form of trauma … They are often broken and unhealthy communication is continuing ... Carers and siblings need massive help in understanding and henceforth adapting their behaviour around those with BPD to help communication improve".***
>
> *(Female, Service User)*

## 4.0 Conclusion

This paper highlights that there is work to be done to improve services for people living with BPD in Northern Ireland. The interviews and focus groups provided valuable insight into the sample's perception of current BPD service provision in Northern Ireland. Participants told us what services they accessed as part of their BPD care, what worked, what didn't work and the changes they would like to see to BPD services.

Overall, it should be noted that participants had much more to say regarding what did not work in their treatment than what did work. There were also some clear suggestions of how things could be improved. The key themes and aspirations running through the comments we received were largely around improving:

- ***Funding for services:*** those interviewed recognised the impact that underfunded Personality Disorder services had on their treatment. Participants wanted there to be more staff in the service to reduce the long waits they had in accessing services;
- ***Consistency and continuity of care:*** specifically, that people living with BPD should be able to access the same services and treatments regardless of Trust, and to see the same professional(s) throughout their care. This helped service users to have trust and confidence in their service provider. However, for several participants, this had not been their experience;
- ***Co-production:*** to ensure that the expertise of service users and carers is fed into the design and development of services, as they know what works in the services they use and what does not;
- ***Training for all healthcare staff:*** to address the perceived lack of understanding about BPD among the wider Health and Social care workforce and to encourage compassion for those living with BPD. When staff had an awareness of Personality Disorders and had treated participants with care and respect, it made them feel more comfortable when accessing Personality Disorder services;
- ***Support for carers:*** to include more and better advice, information, training and counselling for those caring for and supporting people living with BPD.

This scoping paper provides some preliminary insights into the issues faced by people with BPD in Northern Ireland and by the services they access. However, as discussed in Section 2.3, the views expressed by our sample cannot be generalised due to the relatively small number of people involved. The opinions reflected here are still valid and important but further research is needed in order to strengthen the evidence base around BPD in Northern Ireland and to build a case for change. On this basis, we recommend further engagement or research with service users and other stakeholders; the findings presented here can help to inform the design and focus of any such study.

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# 6.0 Resources

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- Mind, Information on BPD: https://www.mind.org.uk/media/2198702/understanding-bpd-2015-online-version.pdf [Accessed 4th December 2019].
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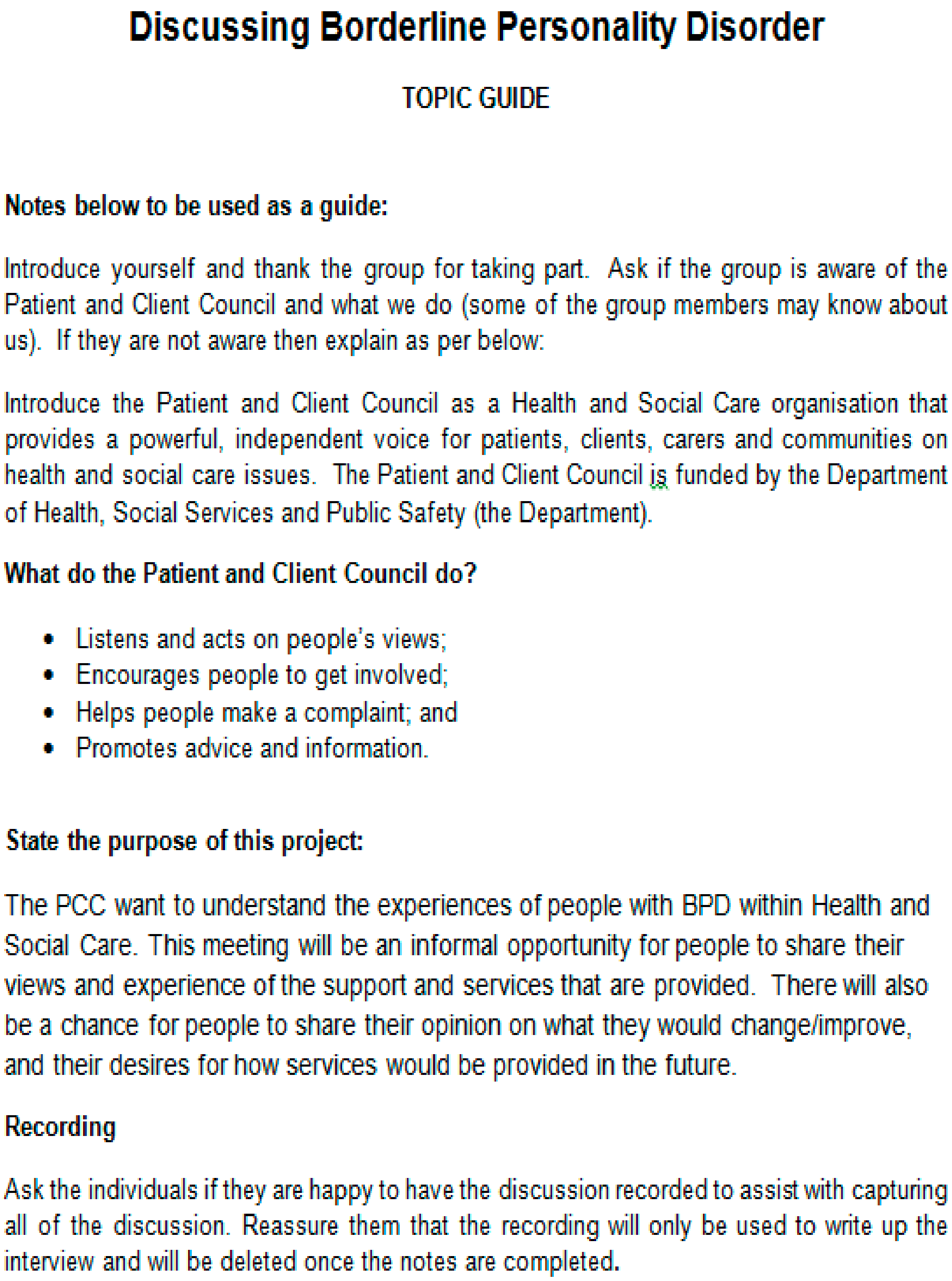
# 7.0 Appendix 1 - Topic Guide



## Discussing Borderline Personality Disorder

TOPIC GUIDE

**Notes below to be used as a guide:**

Introduce yourself and thank the group for taking part. Ask if the group is aware of the Patient and Client Council and what we do (some of the group members may know about us). If they are not aware then explain as per below:

Introduce the Patient and Client Council as a Health and Social Care organisation that provides a powerful, independent voice for patients, clients, carers and communities on health and social care issues. The Patient and Client Council is funded by the Department of Health, Social Services and Public Safety (the Department).

**What do the Patient and Client Council do?**

- Listens and acts on people's views;
- Encourages people to get involved;
- Helps people make a complaint; and
- Promotes advice and information.

**State the purpose of this project:**

The PCC want to understand the experiences of people with BPD within Health and Social Care. This meeting will be an informal opportunity for people to share their views and experience of the support and services that are provided. There will also be a chance for people to share their opinion on what they would change/improve, and their desires for how services would be provided in the future.

**Recording**

Ask the individuals if they are happy to have the discussion recorded to assist with capturing all of the discussion. Reassure them that the recording will only be used to write up the interview and will be deleted once the notes are completed.

Group Discussion Questions:

| Section | Question | Time (indicative) |
|---|---|---|
| | | |
| Introduction | Give people an opportunity to introduce themselves and share if they are a service user/carer or supporter. | |
| | Q: What services or support do you use to help you with your personality disorder?<br>• When/how were you diagnosed?<br>• Do you get support from your GP<br>• Do you get help from psychology or a psychiatric professional?<br>• Do you a have key worker?<br>• Have you had an inpatient stay?<br>Q: What has worked well for you in the support services you have received?<br>Q: What has not worked well within your treatment or care?<br>Q: What would be the No. 1 thing you would change to improve your support and recovery?<br>Q: What do you hope services for people with BPD would look like in the future?<br>Q: As a service user, what do you think would help Carers of people with personality disorders?<br>Q: As a carer, how would you best be supported to help your loved one? | |
| Close | Q: Have we missed anything or is there anything anyone would like to add? | |
| | | |
| Conclusion | Sum up and next steps. | |

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