

The Experience of a Peer Support Group for Carers of People with “Personality Difficulties”

Erica Milton

Commissioned by Sharon Prince, Consultant Clinical & Forensic Psychologist,
Supervised by Dr Jannine Dowling, Principal Clinical Psychologist, Pathway Development
Service & Leeds Personality Disorder Managed Clinical Network, Leeds and York
Partnership NHS Foundation Trust

Table of Contents

Introduction	3
Literature Review.....	4
Personality disorder.....	4
Carers of people with personality difficulties (CPPD).....	4
Impact on caring for people with personality difficulties.....	5
Carers needs	5
Interventions for CPPDs.....	6
Leeds Personality Disorder Managed Clinical Network (PDMCN).....	7
Aims	8
Method	8
Design.....	8
Recruitment.....	8
Data collection	9
Data analysis	9
Ethical considerations.....	10
Consent	10
Confidentiality	10
Sensitive material	11
Credibility checks.....	11
Researcher Bias	11
Results	12
Positive Participant Experiences.....	12
Support.....	13
Coping as a Carer	14
Challenging Participant Experiences	17
Changes due to Covid.....	17
Group Dynamics	17
Group Facilitation	18
Group Identity	18
Improvements to Carer Support.....	21
Improving Access.....	21
Group Practicalities	21
Group Structure.....	22

Further Learning.....	22
Discussion.....	25
Limitations.....	26
Recommendations.....	26
Conclusion.....	27
Dissemination of results.....	27
References.....	29
Appendix 1: Topic Guide.....	32
Appendix 2: Participant information sheet.....	33
Appendix 3: Consent form.....	36

Introduction

The following is a service evaluation project (SEP) that focuses on the experiences of carers of people with personality difficulties who have attended a peer-led support group called 'Andromeda'. This report will first review the current literature related to carers of people with personality difficulties followed by a description of the carers group and the aims of this SEP. It will then describe the qualitative methods and results, and finally a discussion of the findings, including limitations to the project and recommendations for the service.

Literature Review

Personality disorder

Personality disorder can be defined as “significant impairments in self...and interpersonal...personality functioning” (Volkert et al., 2018, p. 709) with persistent and pervasive difficulties causing distress to self and others (American Psychiatric Association, 2013). One way that personality disorder can be understood is as a reaction to trauma (Sutherland et al., 2020b). Prevalence rates of any type of personality disorder can range from 6% (Huang et al., 2009) to 12% (Volkert et al., 2018) in the general population.

This report will use the term “personality difficulties” to discuss the experiences of carers in order to be inclusive and reflect a more diverse perspective on diagnoses. Not all participants included in this project care for someone with a diagnosis of personality disorder and some may not wish to use this label. “Personality difficulties” can include traits or qualities that are related to or consistent with personality disorder. Using a diagnostic framework to categorise individuals difficulties can be stigmatising and create barriers to accessing services (Johnstone & Boyle, 2018). Using a non-diagnostic term also reflects and is consistent with the author’s personal view and professional way of working.

Carers of people with personality difficulties (CPPD)

Carers can include partners, parents or guardians, family members including children or siblings of people with personality difficulties (Bailey & Grenyer, 2014). They may also include friends, other relatives, or members of the community (Lawn & McMahon, 2015).

Impact on caring for people with personality difficulties

Caregiving can be rewarding and fulfilling (Ohaeri, 2003) but can also come with negative aspects such as carer burden, which may include financial difficulties, emotional impacts including guilt or embarrassment (Sutherland et al., 2020a) and disruption to family routines and relationships (Ohaeri, 2003).

Using quantitative measures and qualitative responses from CPPDs, Bailey and Grenyer (2014) found that carers reported a negative impact on their well-being, interpersonal relationships, noting feelings of anxiety and problems with emotion regulation. In an earlier study, Bailey and Grenyer (2013) conducted a systematic review of the needs of carers of people with borderline personality disorder (BPD) and found consistent results. Bailey and Grenyer (2014) reported that participants had higher levels of burden and grief compared to carers of people with other mental health difficulties, however they did not use a comparison group to measure this.

Carers needs

The needs of CPPDs fail to be recognised by health professionals (Bauer et al., 2012; Lawn & McMahon, 2015). Information from professionals is often lacking or contradictory (Giffin, 2008; Lohman et al., 2017). The National Institute for Health and Care Excellence recognise that people with personality disorder, specifically BPD, do not receive equal care within the healthcare system and that carers require more support and education around personality difficulties (NICE, 2009). This may be due to the stigma of their diagnosis (Lawn & McMahon, 2015; Lohman et al., 2017) and staff not feeling competent and confident to work with people with these difficulties (NICE, 2009). A diagnosis can lead to accessing support services. However, receiving a diagnosis of personality disorder can take a long time (Bauer et al., 2012). Therefore, those that have not received, or do not identify with, a diagnosis of personality disorder, may not receive the care they need or that their caregiver requires, leaving needs unmet.

Lawn and McMahon's (2015) Australian study of carers of people diagnosed with BPD, found that carers faced numerous barriers when they sought support, such as lack of communication with health professionals, lack of information about the diagnosis, stigma associated with BPD,

and lack of understanding of the impact of their caring role. Lawn and McMahon (2015) noted the importance of additional training for health staff on the needs and services available for carers, specifically for those who work in primary care settings, such as GPs. Further resources could be given to carers related to the personality difficulties themselves and to services available, which is consistent with other literature (Lohman et al., 2017; McFarlane et al., 2003).

It stands to reason that if carers are supported and their needs are met through available services, then this may ease the burden of their care and reduce negative outcomes for them and the person they care for, and improve the care they can provide (Bailey & Grenyer, 2014). Barr et al. (2020) found that CPPDs identified peer support as beneficial to managing their caring role. The research described above indicates that CPPDs needs continue to be unmet and an improvement in services and interventions for carers is needed (Bailey & Grenyer, 2014). Furthermore, research on CPPDs is minimal (Bailey & Grenyer, 2014; Sutherland et al., 2020a), often focusing on BPD (Bailey & Grenyer, 2013, 2014) or mental illnesses not specific to personality difficulties, and originating from countries outside of the UK (Atkinson, 2019). Therefore, research on how to meet carers needs for a range of personality difficulties (Bailey & Grenyer, 2013) and specific recommendations for UK services is required. Sutherland et al. (2020a) stated that a qualitative approach could be used to gain insight into carers needs and identify if there is an impact on the person for whom they care.

Interventions for CPPDs

There remain questions about the best ways to meet carers needs and ease their burden. Research suggests that CPPDs need support and education specifically related to personality difficulties, and that general carers groups do not meet these requirements (Lawn & McMahon, 2015). A systematic review by Sutherland et al. (2020a) recognised that some interventions have been put in place for CPPDs however few have been robustly evaluated to determine if they are meeting carers needs.

Psychoeducational groups are the most common type of intervention for CPPDs (Ohaeri, 2003). They often include didactic information related to personality difficulties and coping strategies to help reduce carer burden (Ohaeri, 2003). In their systematic review, McFarlane et al. (2003) found that psychoeducational interventions, which have included empathy, support,

and social networks, have improved recovery and outcomes for the person with mental illness. In a UK randomised controlled trial, Bateman and Fonagy (2019) found that CPPDs who participated in a skills-based group resulted in a decrease in incidences reported by the carer, such as self harm, or verbal or physical aggression. However, these findings rely on the self-report of carers which may not be accurate. It also cannot be determined which aspect of the group helped to make this change (i.e., group content, peer support). Further research is needed to determine which aspects of interventions for carers are helpful.

The research on peer support groups for CPPDs is minimal, despite carers and the UK Department of Health recognising it as a valuable resource and encouraging its use (Barr et al., 2020; DOH, 2012). Research has been more focused on the effectiveness of support groups for carers of other mental health difficulties, such as psychosis (Chien et al., 2005), and it is difficult to separate the impact of peer support within psychoeducational groups (Pallaveshi et al., 2014).

In an American study of support groups for families of people with mental illness, Heller et al. (1997) found that members received helpful information from their peers about the illness and services available. They also felt an increased ability to cope with the person for whom they care. Also noted were an improvement in the relationships with the cared-for person and others within the family unit. There may be potential benefits for carers from peer support groups but there are few groups specifically for CPPDs.

Leeds Personality Disorder Managed Clinical Network (PDMCN)

The PDMCN is a community mental health service for people with personality difficulties. The PDMCN, in partnership with Carers Leeds, a charity focused on providing support, information and advice to carers, created a psychoeducational group for CPPDs in order to meet the needs of carers in the local area (Sutherland et al., 2020b). A SEP was conducted about participants experiences of this group. Results highlighted themes about valuing the connection with their peers and carers requested further peer support (Atkinson, 2019).

In response to this evaluation, the PDMCN developed a peer-led support group called 'Andromeda' for carers of people with traits consistent with a diagnosis of personality disorder. Prior to the pandemic, the Andromeda group was held bi-monthly and facilitated by professionals from the PDMCN. Carers would meet in person at a venue in Leeds. It is

estimated that 12-15 carers came to each meeting on a drop-in basis. During the pandemic, the structure of the Andromeda group changed. The frequency of the group increased to monthly meetings and the PDMCN and Carer Leeds began to alternate the facilitation of the group.

Aims

This evaluation aims to explore the experiences of group participants attending the peer support group Andromeda, specifically in terms of

- 1) The needs of carers of people with personality disorder
- 2) Carer experiences of the Andromeda Peer Support Group
- 3) The impact on the support they provide to the person for whom they care
- 4) Recommendations to improve the support offered to carers

Method

Design

Qualitative methodology was employed for this SEP as it “offers rich and compelling insights into the real worlds, experiences, and perspectives” of participants (Braun & Clarke, 2014, p. 1) that cannot necessarily be obtained from quantitative research. This evaluation used a topic guide (see Appendix 1) to explore the aims of the SEP.

Recruitment

Participants were recruited who were carers of people with difficulties associated with a diagnosis of personality disorder who have attended at least one session of Andromeda. Participants were identified through Carers Leeds and the PDMCN. Group members had consented for their details to be held on a mailing list for the purpose of receiving information, including research opportunities. All potential participants were sent a recruitment email by the PDMCN with an invitation to attend an online focus group for carers to discuss their experiences of attending the Andromeda group. Included in this email was a link to the forms

on an online surveys tool licensed by the University of Leeds, called Online Surveys, which included the participant information sheet (Appendix 2), the consent form (Appendix 3), and two background questions.

A focus group was the initial method for data collection. It is recommended to recruit between six to ten participants for interviews for a small research project (Braun & Clarke, 2013). Unfortunately, only three participants attended the focus group and so another recruitment email was sent by the PDMCN to offer other carers the opportunity of an individual interview. This included another link for Online Surveys which had an adapted version of the participant information sheet and consent form specifically for the interviews. Once the consent form was completed, a link invite for the focus group was emailed to participants. The Psychologist in Clinical Training (PICT) emailed those participants who consented to an interview to arrange a suitable time. Due to the level of interest for the interviews, one potential participant was added to a waiting list and was not subsequently included as a participant.

Data collection

Two background questions were asked of participants using Online Surveys to gain information about carer's attendance history of the Andromeda group. The following questions were asked: Please estimate how long you have been attending the Andromeda peer support group; How many Andromeda peer support groups have you attended?

Due to the pandemic, both the focus group and the interviews were conducted online. The focus group lasted 1.5 hours and the interviews took approximately 30 minutes. The assistant psychologist within the PDMCN service assisted by taking brief notes of the focus group discussions. Three participants attended the focus group and five people completed individual interviews for a total of eight participants. The data was collected from May to July 2021.

Data analysis

Thematic analysis was used to analyse the data and to explore themes within the data set. Thematic analysis is "a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). Using the process described by Braun and Clarke (2006), the PICT transcribed the data verbatim and then initial codes were created from the

transcripts. Those codes were combined into possible themes. Those themes were then reviewed and revised. Further refinement and clarification of the themes took place prior to the write-up of this report. Figure 1 provides an illustration of the six phases of thematic analysis, as described by Braun and Clarke (2006). The focus group and individual interview data were analysed together.

Figure 1

Phases of thematic analysis (Braun & Clarke, 2006)



Ethical considerations

Ethical approval was sought and gained from the University of Leeds Research Ethics Committee on 24th March 2021. An amendment to include an additional credibility check was granted on 10th September 2021. Approval for this evaluation was received from the Leeds and York Partnership NHS Foundation Trust Clinical Effectiveness team on 18th January 2021. The following ethical considerations were taken into account.

Consent

The participant information sheet and consent form were added to Online Surveys. The link to these forms was emailed to all potential participants during the recruitment phase. Participants were asked to type their name into the online system by way of their consent to take part in the SEP.

Confidentiality

Participants were asked to provide their name and email address for the PICT to contact them. This information was stored in a separate Microsoft Excel file on the University's secure network. The audio recorded focus group and interviews and their transcriptions were stored in line with the University of Leeds Data Protection Policy. Quotations of participant responses from the focus group and individual interviews are identifiable only by participant ID numbers. Any paper notes were destroyed. All data has been anonymised in this report.

Sensitive material

Discussing their experiences of attending the support group may highlight outstanding support needs. It is possible that these discussions could have evoked an emotional response. Participants were made aware in the participant information sheet that they can contact a member of the PDMCN team to share any difficulties which may have been raised during the interviews. The PICT was not aware of any distress or support required post-interview.

Credibility checks

The PICT discussed the emergent themes with their academic tutor and SEP commissioner prior to final write-up of the results. A fellow PICT reviewed 20% of the total sample of anonymised transcripts, initial codes, and themes to assess face validity. This PICT agreed with the current themes and no changes were made. Themes and subthemes were also sent to the participants via email to gain respondent validation. No feedback was received from the participants.

Researcher Bias

It is important in qualitative methodology that the researcher is aware of their own subjectivity and possible biases in qualitative research (Braun & Clarke, 2013). During the SEP, the PICT was mindful of how their own personal and professional experiences of personality difficulties may have influenced their interpretation of the data, and specifically the language used in association with personality difficulties. The credibility checks described above help to minimise any bias in the data.

Results

The following table, Table 1, shows the attendance of participants in the Andromeda group.

Table 1

Andromeda group attendance

	Response choices	Responses
Estimated attendance length	>1 year	1
	1-2 years	1
	3+ years	6
Number of support groups attended	1-2	1
	3-4	0
	5+	7

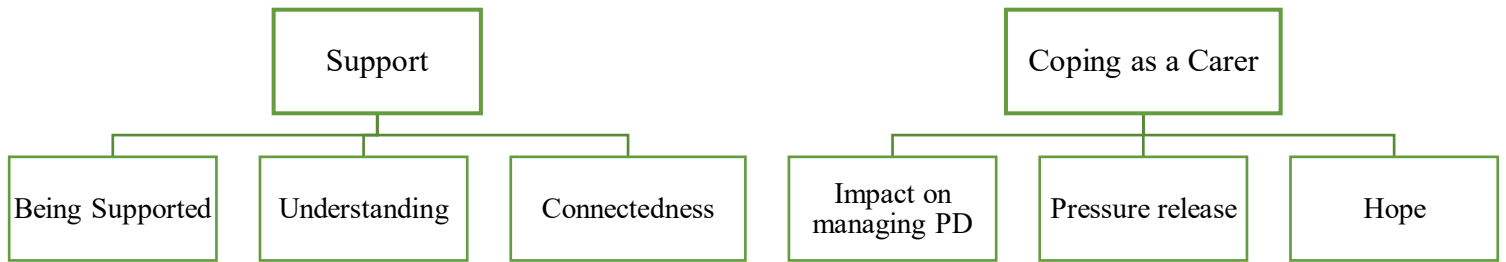
Three superordinate themes were identified from the data with themes and subthemes for each. These are ‘Positive Participant Experiences’, ‘Challenging Participant Experiences’, and ‘Improvements to Carer Support’. It is acknowledged that the themes mirrored the questions posed to participants. The results are divided into these sections and are described below. Direct quotations have been added into Tables to illustrate the themes.

Positive Participant Experiences

Two themes and six subthemes have been formed under Positive Participant Experiences. This is illustrated in Figure 2. Table 2 demonstrates quotations related to these themes and subthemes.

Figure 2

Themes and subthemes of Positive Participant Experiences of Andromeda



Support

The theme of support encompassed subthemes of ‘being supported’, ‘understanding’, and ‘connectedness’.

Being Supported

Carers identified a need for support from others. Participants described feeling supported and listened to in the group and felt able to share their experiences of caring for the person with personality difficulties. Carers also spoke about needing advice on how to manage difficult situations in their caring role and that they received this from the peer group.

Understanding

Carers described a need to share their experiences without feeling judged. They felt that the group met that need and they spoke about their experiences being validated by the other members. Additionally, carers felt that they gained a greater understanding of personality difficulties.

Connectedness

Carers felt they had made meaningful connections and friendships with other group members which extended beyond the group. Participants noted the importance of informal social activity outwith the group to maintain their connections during the pandemic.

Coping as a Carer

This theme included subthemes of ‘impact on managing PD’, ‘pressure release’, and ‘hope’.

Impact on managing PD

Carers described how they implemented understanding and learning gained from the group to manage difficult situations in their caring role. They felt this improved care, communication, and relationship with their cared-for person, other family, and themselves, and reported that it also reduced the frequency and length of adverse incidences.

Pressure Release

Some carers spoke about the release and relief they felt from sharing their experiences in the group.

Hope

Participants spoke about the hope they felt in attending the group and that this helped them to continue in their caring role.

Table 2

Themes and subthemes illustrated by participant quotations for Positive Participant Experiences

Theme	Subtheme	Quotation (Participant)
Support	Being Supported	<p><i>“My main needs are a sort of support system...to you know unburden yourself of all your worries and concerns.” (8)</i></p> <p><i>“people are very happy to listen and to sympathise and to offer support and offer guidance.” (6)</i></p>
	Understanding	<p><i>“Andromeda has been a very good support network, the people I’ve met are in the same circumstance as me, so it’s been lovely to talk openly and to realise that other people understand where you’re coming from.” (8)</i></p> <p><i>“you’re not having to explain yourself all the time to people, because they actually get what you’re going through and they’re having similar issues as yourself, secondly, to actually get to the bottom of why your loved one is like they are” (4)</i></p>
	Connectedness	<p><i>“a camaraderie developed between the people that participate, and you know they’ve met up recently...to, you know, just go and have a chat informally” (6)</i></p> <p><i>“it’s nice having someone care about you, when you spend so much time caring about someone else.” (1)</i></p>
Coping as a Carer	Impact on Managing PD	<p><i>“If I need to, I can handle more, I can take more of whenever anything’s being dished out, and from the things I’ve learned, and from the things people have said, it’s helped me know what I was doing wrong, what I, how I wasn’t handling things well when things were happening.” (3)</i></p> <p><i>“it’s only by talking to other people that you find out these things, and what works and what doesn’t so that’s made a terrific difference to how things have been at home.” (4)</i></p>
	Pressure Release	<p><i>“Group is my pressure cooker valve, even if I’m not saying anything coming in, umm hearing other people saying things that are almost identical to the things I’m thinking or have felt or whatever, um yea, it’s my release valve.” (3)</i></p> <p><i>“a big weight lifts, you know, when you’ve got somebody else to talk to, because they can cut through a lot of that emotion for you and make sense of a lot of the anxiety that you’re having, and that’s a big help. So, you just feel</i></p>

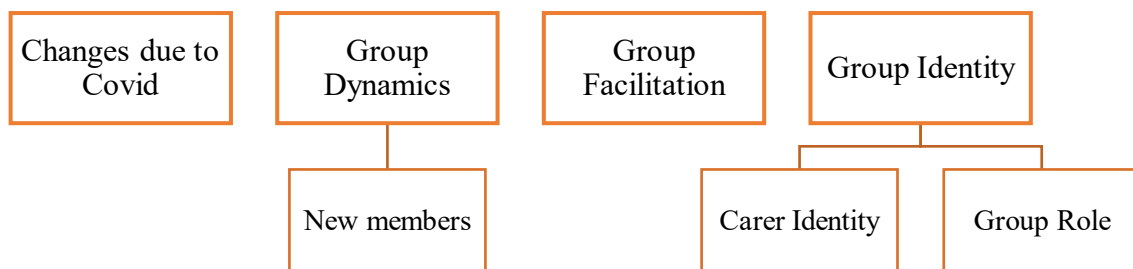
		<i>as though you've got another string to your bow really and you know you're not on your own cause they've got such a lot of experience.” (4)</i>
	Hope	<p><i>“I think it gives you hope as well. It's given me a lot of hope... I didn't know there was light at the end of the tunnel until I joined Andromeda and each month that I've come I've learnt a little bit more” (2)</i></p> <p><i>“Sometimes we're not seeing the light at the end of the tunnel, but the vast majority of us are in a place where we can see the light and it's lovely and we can tell the other people that it's coming...it might only be a speck at the minute, but in a minute it's going to be a huge thousand-Watt LED bulb shining right in your face, and it'll be there.” (3)</i></p>

Challenging Participant Experiences

Challenging Participant Experiences yielded four themes and three subthemes, as shown in Figure 3. Table 3 demonstrates quotations related to these themes and subthemes.

Figure 3

Themes and subthemes of Challenging Participant Experiences in Andromeda



Changes due to Covid

Participants felt that there had been a change in their experience of the group during the pandemic as the group had moved from face-to-face to online. Carers who had attended the group prior to this change felt it had detracted from their experience, mainly from their support post-group.

Group Dynamics

Participants found groups challenging when one person dominated the conversation and/or when the topic was heavily focused on negative aspects, such as the limitations of mental health services. It was felt that this was not the intended purpose or goal of the group. These situations appeared to be more prevalent in the online groups and negatively impacted on group members.

New members

This subtheme included responses from carers which highlighted that there may be different needs and challenges for new members integrating into an established group.

Group Facilitation

Overall, carers spoke about the many changes to the structure of the group and lack of consistency of facilitators throughout the pandemic. Carers felt that more support and structure was needed from the facilitators to help manage the group. Participants felt that the current structure of alternating group facilitation between Carers Leeds and the PDMCN was helpful, as the facilitators brought different perspectives.

Group Identity

Group identity incorporated subthemes of ‘carer identity’ and ‘group role’.

Carer identity

One participant spoke about the difference between group members’ caring roles and that these differences can influence their contributions and benefits from the group. Additionally, some participants did not like to identify themselves as a “carer” and felt that another term may describe their caring identity better.

Group role

Some members had been co-facilitators of the Andromeda group during the pandemic. This led to feelings of uncertainty about their role in the group and how other members perceived them.

Table 3

Themes and subthemes illustrated by participant quotations for Challenging Participant Experiences

Theme	Subtheme	Quotation (Participant)
Changes due to Covid		<p><i>“But you know the kind of less formal zoom meetings little bit less structured and I'm afraid to say I've kind of lost a little bit of interest in participating in that but that's no reflection on their value to other people.” (6)</i></p> <p><i>“on zoom it's just goodbye and there's no ‘we'll see you next week’, ‘if you need anything just give me a text’ or vice versa, we're unable to do that.” (2)</i></p>
Group Dynamics	Group Dynamics	<p><i>“Depending on how I'm feeling sometimes going to the group and hearing lots of negative experiences isn't always what I want to hear” (7)</i></p> <p><i>“The only thing I would say it's when people get very negative about mental health services and hold court, I guess, and yes they've had a bad journey and we all understand that...but that group is not about that issue that group it's about, in my opinion, helping each other and moving forward from there it's not about what's happened in the past” (4)</i></p>
	New Members	<p><i>“Whether it's in person or whether it's online, people when they're new to it, they have a lot to say and that it's like this relief for them to finally be able to say those things, to be heard, to understand, like have people who understand. And I think that's really important, but I think it's very difficult at the moment to manage the balance between that and people who have been going for a long time.” (1)</i></p> <p><i>“I think challenges is also about introducing new people and helping them embed themselves into the group and we do get a lot of people start coming for a bit and then leave. So, it'd be really interesting to understand why that happens.” (7)</i></p> <p><i>“I think that for people new to the group they probably don't quite understand what the group is about and that might be the fault, you know, we perhaps don't make it clear” (4)</i></p>
Group Facilitation		<p><i>“Sometimes, we are a wee bit rudderless in that we don't have an agenda, so we're not steered through conversations. So, I just wonder if maybe the person who's the facilitator might occasionally have an agenda.” (8)</i></p>

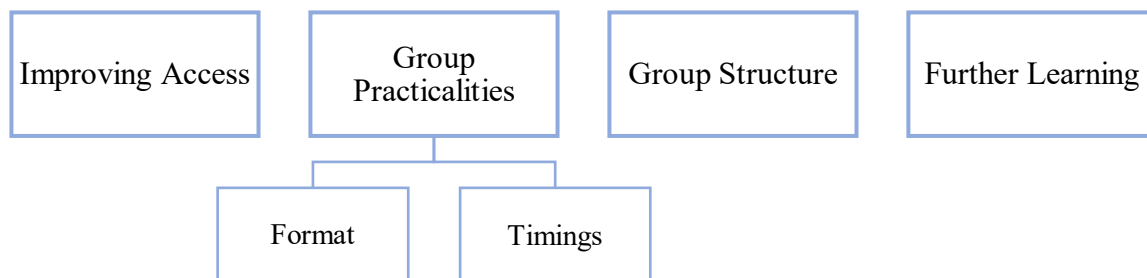
		<p><i>“Just someone to tug on the reins just a little bit to pull it pull the group back together towards conversation rather than... just letting it free roam off into somewhere...and I think zooms been part of the, a big part of the issue over that.” (3)</i></p> <p><i>“it's good to have those different perspectives of things, like Carers Leeds know different things to PD network and vice versa, so I think that's a positive.” (1)</i></p>
Group Identity	Carer Identity	<p><i>“Some of the discussion isn't as relevant for me. Equally, some of the things I need to say aren't as relevant to others...but I think sometimes I don't feel completely as though I can say what I want to say because it could sound a bit critical of people with PD and actually there's that that's their loved ones” (7)</i></p> <p><i>“I think, as well, if I was to say in front of my son, that I was his carer I don't think it'd go down very well with him. I support my son like I support all my children, like I support my husband and vice versa, so I think I'm a ‘supporter’ rather than a ‘carer’.” (2)</i></p> <p><i>“Made me step back from my caring role sometimes when I can because I don't like it, at the end of all this, I don't want to be carer, I want to be a partner. So, I think that's been really helpful. Um, obviously, you have to care like all partners have to care for each other, but I don't want to be seen as a carer, and so I think it's helped for that.” (1)</i></p>
	Group Role	<p><i>“Our role was questioned, you know, were we helping other people were we really getting anything out of it ourselves, and I think that was a difficult period... I don't know whether that group gives us what we need or it's, I don't know if it's as easy for us to open up anymore about things, and whether we need a little spin off group” (4)</i></p>

Improvements to Carer Support

Four themes and two subthemes have been generated under Improvements to Carer Support. These are demonstrated in Figure 4 below. Table 4 demonstrates quotations related to these themes and subthemes.

Figure 4

Themes and subthemes of Improvements to Carer Support



Improving Access

Some participants spoke about how the group needed to be advertised more widely to health services and to the public to benefit carers and the people they care for. Additionally, it was felt that further awareness of the need for support for CPPDs is required. Carers spoke about their need for resources to help explain the condition and their caring role to others. It was recommended that a co-produced resource would be helpful in that regard. Finally, it was noted that there is a lack of ethnic diversity within the group, and it was suggested this may be due to barriers accessing the group.

Group Practicalities

This theme included subthemes of ‘format’ and ‘timings’.

Format

Participants felt that the online group was more accessible to attend but had some technological issues. Participants preferred face-to-face groups but suggested a more easily accessible venue. One participant suggested that the group be in person at a venue with remote access, which may improve accessibility and connectedness with others. It was noted that carers may have difficulty finding a confidential space in their home to attend the group, as many of the carers live with the person for whom they care.

Timings

Participants felt that the increase in frequency of the group, from bi-monthly to monthly, was beneficial and keeping the timing to out of working hours accommodates more members availability.

Group Structure

Participants identified a need for further structure to the group to help guide conversations.

Further Learning

It was suggested that facilitators share information about personality difficulties through discussions in the group to further their learning. Additionally, it was recommended that CPPDs attend the psychoeducational group, facilitated by the PDMCN, to aid and consolidate learning and for new members to share their experiences.

Table 4

Themes and subthemes illustrated by participant quotations for Improvements to Carer Support

Theme	Subtheme	Quotation (Participant)
Improving Access		<p><i>“I didn't know that this group existed, and I think that is a bit of a failing really perhaps on the fact that it's, you kind of come in through the back door, if you like. It's not well advertised so that's another thing that probably we should as carers be aware of, that this support is there” (4)</i></p> <p><i>“Not all the NHS knows all the details about who we are caring for and the fact that we are carers, and a lot needs to be done in that respect” (8)</i></p> <p><i>“It takes a big toll on people, and I just think seeing carers as someone we need to support, because if we support them, they'll support the person with the personality disorder” (7)</i></p> <p><i>“Having something that explains what personality disorder is and you know what it means, in a sense, as a carer within that context would be really helpful. Um, I think it probably goes beyond this group, but it could be something that we co-produce...a little resource that you can just give out and just say just to educate people would really help I think support carers because people just don't understand, they don't get it and I think as a carer it's really hard to explain it all the time.” (7)</i></p> <p><i>“it's not a very diverse group and I do wonder why. Is it that people...who aren't white don't, you know, don't know how to deal with personality disorder or is it just that services aren't accessible? I think probably the latter. So, there is an issue there I think about access.” (7)</i></p>
Group Practicalities	Format	<p><i>“It is easier to attend by Zoom. But I would prefer to do face to face. I would probably suggest a venue that had good transport links and parking. I certainly sometimes struggled to get to Leeds, but I made the space to do that,” (7)</i></p> <p><i>“Could you do a hybrid course where it's available over zoom...and in person” (7)</i></p> <p><i>“it might be the only time they get to come out and actually speak to somebody who does get what they're saying and how exhausted they are and how tiring and everything else that comes into that...if they're having to do it on</i></p>

		<i>zoom they might not necessarily be able to find somewhere for the person they care for to be, so then they can't actually participate on zoom because of the confidentiality.” (2)</i>
	Timings	<i>“I think that's the only positive thing about zoom is we've been doing it every month and not every two months, because if we missed a meeting, you'd have to wait a long time, whereas on zoom because it's every four weeks it's not as long to wait. Because you miss it if you miss one.” (2)</i>
Group Structure		<i>“People can either email beforehand or put comments in the chat box, but to the facilitator of the group, and it can work quite well.” (1)</i> <i>“Maybe there's a nice way of checking in just to see how people are feeling at the start. Even if it's just a score out of 10.” (7)</i> <i>“we've done it a few times of actually going around the room and just talking about some of the positives that are happening.” (7)</i>
Further Learning		<i>“I think a bit of bringing it back to some of the material from the course, the key concepts, the kind of latest thinking about personality disorder is really helpful just to reinforce some of that learning that we had, but also and serve as a reminder, but I think it's also updating if things are developing, a little bit.” (7)</i> <i>“I'd recommend going on the six-week course first. But yeah, obviously if someone's struggling and that's not possible for a while, then yeah come straight to the group” (7)</i> <i>“There are often comments made that they would like to do the Cygnus course again that they would like a refresher of some type, so I think that would be something worth looking into. They would like to have something beyond that because, and the comment often is that they didn't want...that Cygnus course to end,” (4)</i>

Discussion

The aim of this SEP was to explore CPPD's experiences of the Andromeda peer support group, to identify their needs as carers, to understand the impact on the support they provide to their cared-for person, and provide recommendations to improve carer support services. The majority of participants in this evaluation had been long-standing members of the Andromeda group. Most had been a member for at least three years and attended five or more group sessions. All participants stated that they benefitted from the peer support group in some way and that they would recommend the group to other CPPDs. The superordinate themes derived from the data are positive participant experiences, challenging participant experiences, and improvements to carer support.

Participants highlighted numerous positive experiences from the Andromeda group. The themes centred on feeling supported and understood by their peers and this allowed for connections to develop between members, increasing their social support network out with the group. Their experiences in the group met carers' need for advice and was reported to have an increase in their understanding of personality difficulties and a significant impact on how they manage their caring role. Several participants highlighted that they felt better able to manage distress from the person whom they care for and a greater ability to manage their own distress. These benefits were consistent with Atkinson's (2019) SEP regarding the psychoeducation group with the PDMCN and Heller et al.'s (1997) and Chien et al.'s (2005) findings of peer support groups.

All participants found the change from the group being face to face to online challenging and expressed a strong interest to go back to in-person meetings. Participants identified difficulties with the group dynamics in terms of managing the discussion topic and how the group was facilitated. Overall, a lack of structure felt unhelpful. Participants asked for more educational materials or focusing the topic of conversation away from unhelpful topics. Lawn and McMahon (2015) had noted the importance of education around personality difficulties in their study for supporting CPPDs. Finally, there were comparisons made between group members (e.g., new members and regular attenders; carers with different relationships to the person whom they care for; facilitators and non-facilitators). Suggestions were made to split group members based on these categories to better suit their needs. This highlighted differences in group membership and may influence how carers interact with those

identified as different to themselves (Canales, 2000). Social support and a greater understanding of personality difficulties and how to cope with them may potentially reduce some of the barriers highlighted by Lawn and McMahon (2015). In turn, this may increase the likelihood of better outcomes for the person with personality difficulties (McFarlane et al., 2003).

Carers spoke about a range of improvements to carer support. Specifically, a need for increased awareness and resources to spread information about the needs of CPPDs with the hope of reducing carer burden and improving access to interventions and services. This need has been identified in the literature discussed above (Lawn & McMahon, 2015; Lohman et al., 2017). Carers also identified a need to continue to add to their own understanding. There were specific suggestions for improvements related to the practicalities of the group such as the location, frequency, and structure, which will be highlighted in the recommendations section of this report.

Limitations

Problems with recruitment meant that the focus group had minimal numbers and conducting individual interviews were necessary. Differing methods of data collection may have influenced the responses provided by participants. All participants recommended the Andromeda group and the majority of participants had been regular group members for a significant length of time. The responses, therefore, may not be representative of all group member's experiences and of the needs of CPPDs in general. This point was reflected by some of the participants during the interview. It would be helpful to capture the experiences and the needs of those carers that have attended the group only once or twice to help identify any differences and recommendations which could improve support for CPPDs.

Recommendations

The following are suggestions from participants responses which highlight specific ideas to improve the group to better meet the needs of CPPDs as well as recommendations for the wider service.

- Continue with monthly meetings and alternating facilitation between the PDMCN and Carers Leeds
- Consider re-introducing face to face group meetings, if possible, offer options of attending in-person or remotely
- Record demographic information from attendees to identify diversity issues
- Aim to understand group experiences of new members or those who have dropped out
- Group reminder of key expectations and boundaries within group
- Discuss agreeable discussion points and potential topics to avoid
- Increase structure to the group (e.g., create an agenda, use email/chat box for questions/agenda items, brief check-in with the group)
- Facilitators to continue to link psychoeducation with group discussions
- Consider using alternative terms for ‘carer’ (e.g., ‘supporter’)
- Co-produce resources that explain personality difficulties and carers needs
- Increase advertising of Andromeda in 3rd sector organisations and primary care settings
- Improve awareness of the needs of CPPDs to health services and the public
- Aim to address barriers to accessing services through systemic change

Conclusion

The aims of this SEP were to explore the needs of CPPDs, experiences of the Andromeda peer support group, the impact on the support carers provide, and improvements that could be made to increase support. These aims were met through qualitative interviews with participants. The results are consistent with the literature on CPPDs. Participants stated that the group met their needs as carers, however, further recommendations have been made to meet the needs of the group and increase support for CPPDs in the wider system.

Dissemination of results

Results from this project have been disseminated at the annual University of Leeds DClin SEP conference. A poster will be presented at the LYPFT Annual Research Forum. A condensed version of this report will be shared with the LYPFT clinical effectiveness team. This report may also be submitted for publication in a peer-reviewed academic journal.

References

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders. 5th Edition. In *Am Psychiatric Assoc.* Am Psychiatric Assoc.
- Atkinson, S. (2019). The experience of a psychoeducational course for carers of people with “personality difficulties .” *Service Evaluation Project for Doctorate in Clinical Psychology, University of Leeds. Commissioned by Ruth Sutherland, Leeds Personality Disorder Managed Clinical Network.*
- Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. *Harvard Review of Psychiatry, 21*(5), 248–258.
<https://doi.org/10.1097/HRP.0b013e3182a75c2c>
- Bailey, R. C., & Grenyer, B. F. S. (2014). Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders, 28*(6), 796–809. https://doi.org/10.1521/pedi_2014_28_136
- Barr, K. R., Jewell, M., Townsend, M. L., & Grenyer, B. F. S. (2020). Living with personality disorder and seeking mental health treatment: Patients and family members reflect on their experiences. *Borderline Personality Disorder and Emotion Dysregulation, 7*(1), 1–11. <https://doi.org/10.1186/s40479-020-00136-4>
- Bateman, A., & Fonagy, P. (2019). A randomized controlled trial of a mentalization-based intervention intervention (MBT-FACTS) for families of people with borderline personality disorder. *Personality Disorder, 10*, 70–79.
- Bauer, R., Döring, A., Schmidt, T., & Spießl, H. (2012). “Mad or bad?”: Burden on caregivers of patients with personality disorders. *Journal of Personality Disorders, 26*(6), 956–971. <https://doi.org/10.1521/pedi.2012.26.6.956>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.
<http://www.tandfonline.com/action/journalInformation?journalCode=uqrp20%5Cnhttp://www.tandfonline.com/action/journalInformation?journalCode=uqrp20>
- Braun, V., & Clarke, V. (2013). Successful Qualitative Research: A Practical Guide for Beginners. In *Los Angeles: Sage*. <https://doi.org/10.46743/2160-3715/2014.1206>
- Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being, 9*, 20–22. <https://doi.org/10.3402/qhw.v9.26152>

- Canales, M. K. (2000). Othering: Toward an understanding of difference. *Advances in Nursing Science*, 22(4), 16–31.
- Chien, W. T., Chan, S., Morrissey, J., & Thompson, D. (2005). Effectiveness of a mutual support group for families of patients with schizophrenia. *Journal of Advanced Nursing*, 51(6), 595–608. <https://doi.org/10.1111/j.1365-2648.2005.03545.x>
- DOH. (2012). *No health without mental health : implementation framework*. 54. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216870/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf
- Giffin, J. (2008). Family experience of borderline personality disorder. *Australian and New Zealand Journal of Family Therapy*, 29(3), 133–138. <https://doi.org/10.1375/anft.29.3.133>
- Heller, T., Roccoforte, J. A., Hsieh, K., Cook, J. A., & Pickett, S. (1997). Benefits of support groups for families of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67(2), 187–198.
- Huang, Y., Kotov, R., Giovanni de Girolamo, A. P., Matthias Angermeyer, C. B., Demyttenaere, K., Graaf, R. de, Gureje, O., Karam, A. N., Lee, S., Jean Pierre Lépine, H. M., Posada-Villa, J., Suliman, S., Vilagut, G., & Kessler, R. C. (2009). DSM-IV personality disorders in the WHO world mental health surveys. *The British Journal of Psychiatry*, 195, 46–53.
- Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework. In *British Psychological Society* (Vol. 3, Issue 3). www.bps.org.uk
- Lawn, S., & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, 22(4), 234–243. <https://doi.org/10.1111/jpm.12193>
- Lohman, M. C., Whiteman, K. L., Yeomans, F. E., Cherico, S. A., & Christ, W. R. (2017). Qualitative analysis of resources and barriers related to treatment of borderline personality disorder in the United States. *Psychiatric Services*, 68(2), 167–172. <https://doi.org/10.1176/appi.ps.201600108>
- McFarlane, W. R., Dixon, L., Lukens, E., & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy*, 29(2), 223–245. <https://doi.org/10.1111/j.1752-0606.2003.tb01202.x>
- NICE. (2009). *Borderline personality disorder: Recognition and management*. Cg78.

<https://www.nice.org.uk/guidance/CG78>

- Ohaeri, J. U. (2003). The burden of caregiving in families with a mental illness: a review of 2002. *Current Opinion in Psychiatry*, *16*(4), 457–465.
<https://doi.org/10.1097/01.yco.0000079212.36371.c0>
- Pallaveshi, L., Balachandra, K., Subramanian, P., & Rudnick, A. (2014). Peer-led and professional-led group interventions for people with co-occurring disorders: a qualitative study. *Community Mental Health Journal*, *50*(4), 388–394.
<https://doi.org/10.1007/s10597-013-9612-8>
- Sutherland, R., Baker, J., & Prince, S. (2020a). Support, interventions and outcomes for families/carers of people with borderline personality disorder: A systematic review. *Personality and Mental Health*, *14*(2), 199–214.
<https://doi.org/10.1002/pmh.1473>
- Sutherland, R., Holland, A., & Prince, S. (2020b). Cygnus: A psychoeducational group for carers of people with a personality disorder. *International Journal of Care and Caring*, *4*(2), 261–266.
<https://doi.org/10.1332/239788220X15785278215080>
- Volkert, J., Gablonski, T. C., & Rabung, S. (2018). Prevalence of personality disorders in the general adult population in Western countries: Systematic review and meta-analysis. *British Journal of Psychiatry*, *213*(6), 709–715.
<https://doi.org/10.1192/bjp.2018.202>

Appendix 1: Topic Guide

Carers Focus Group/Interview Topic Guide

Version 2

- 1) Introduction – aims and purpose of focus group. Structure of session, length, expectations, group rules. Data protection and confidentiality / recording of group.
- 2) Questions
 - What do you think are your main needs as a carer supporting someone with difficulties associated with a Personality Disorder?
 - How would you describe your experiences of attending the Andromeda Peer Support Group?
 - What aspects of the group have you found most helpful?
 - What aspects of the group have you found the most unhelpful?
 - Can you describe any challenges you have experienced whilst being in the group?
 - Do you feel you have been supported / or not supported by the group facilitators? Can you explain why?
 - How do you feel the support offered to carers could be improved?
 - What difference has the carers group made to your life? How?
 - Has attending the group helped you in your caring role? How?
 - What (if anything) gets in the way of or makes it easier to attend the group? (Ease of access).
 - Would you recommend the carers group? Why?
 - Do you have any other thoughts or comments you wish to share about your experience?
- 3) Reflections on focus group experience.
- 4) Close – questions / further information.

Appendix 2: Participant information sheet



Andromeda Carers Peer Support Group: Focus Group Personality Disorder Managed Clinical Network (PDMCN) Participant Information Sheet

Version 2

Information

You have been invited to take part in a focus group regarding the Andromeda Peer Support group for carers of people with a diagnosis of personality disorder. A focus group is a small meeting of people asked to discuss specific topics and issues. The discussions are normally facilitated by one researcher and another person attends to take notes. We wish to hear about your thoughts and experiences of attending the Andromeda group. This will help us to understand your experiences better and help us to improve the service we provide to carers now and in the future.

Before you decide to take part, it is important you understand what is being asked of you and how your information will be used. Please take time to read the following information and discuss it with others if you wish. You can change your mind at any time and withdraw your information without giving a reason. You are welcome to email me if you would like any further information.

Who is involved in the focus group?

The focus group will be led by Erica Milton (Psychologist in Clinical Training), who is carrying out this evaluation as part of their training at Leeds University. A member of the team from the PDMCN will also attend to take notes. All information will be stored securely and individual information will not be shared beyond the research team.

Ethical approval has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (DClinREC project number 20-007) and supervised by Jannine Dowling, Clinical Psychologist, in the PDMCN.

What will happen if I choose to take part?

You will be invited to attend an online focus group with other carers on **26th May 2021**. The focus group will be guided by Erica Milton who will introduce the topics and discussion points to the group. The focus group will last for approximately 1 ½ hours, starting promptly at **5:30pm** until approximately **7pm**.

The focus group will aim to explore:

- 1) The needs of Carers of people with personality disorder
- 2) Carer experiences of the Andromeda Peer Support Group
- 3) What aspects of the group may be helpful or unhelpful
- 4) How the PDMCN might improve the support they offer to Carers

It is possible that the discussions during the focus group could stir up an emotional response, particularly about how caring impacts you. If this happens and you wish to talk to someone you can contact a member of the PDMCN team to share any difficulties.

What will happen to the information that I give?

We would like to record the focus group using an audio recorder; this would allow us to capture all the information given by different members. The focus group will be audio recorded and then transcribed by the trainee clinical psychologist verbatim.

All recordings will be encrypted then transferred immediately after the focus group and stored onto a University of Leeds secure network. The original recording will then be deleted. The recording will be written up and any personal or identifying information will be removed or disguised.

Consent forms, recordings, notes, and any other confidential information will be stored securely according to the University Data Protection Policy. As per University guidelines, the data will be retained for 3 years from the completion of the project and will be disposed of securely after this time. Any data printed out, for example, during data analysis, will not include any personally identifiable data and will be stored in accordance with the University Data Protection Policy. Data storage and management is in compliance with GDPR regulations.

All the focus group materials will be stored securely on the University of Leeds network. Your feedback may be used for future evaluation, research, and audit purposes and to inform care planning. Information will be analysed and will be reported in service evaluation reports. Findings may be disseminated in the NHS Leeds and York Partnership Trust or submitted for publication in an appropriate academic journal. All information will be stored securely and individual data will not be shared beyond the research team.

Confidentiality/anonymity

The information we collect will not contain any personal information about you and any identifiable information will be omitted or changed to hide your identity e.g. your name, gender, specific-service information, and any service you reference. No one will link the information you provided to the identifying information you supplied.

What if I change my mind?

You can stop taking part in the focus group at any time. You can also refuse to answer or respond to any question that is asked of you without any consequences. Due to the nature of a focus group, you would not be able to withdraw your responses completely, however, if after taking part should you wish to remove a particular comment from your contributions then this can be done by contacting the lead facilitator until **one week** after the focus group takes place.

Further information / next steps

*Please note that although we value all of your views, the maximum number of required participants able to attend the group is 8. Once places have been filled, you will be placed on a waiting list and contacted about whether a place becomes available. If you have a place in the focus group but **no longer wish to attend**, please inform the focus group facilitator so that your place can be offered to someone else.*

If there are not enough participants to make up a focus group, you may be offered an individual interview instead.

Once the analysis has been conducted, you will be invited to comment on the themes from the discussions that took place.

We very much look forward to seeing you at the focus group if you decide to attend.

If you have any questions about the focus group or how your information might be used, you can direct these to the facilitator who will be happy answer these.

If after reading this information sheet you are happy to take part, **please complete the consent form on the next page.**

Contact

Focus group facilitator: Erica Milton (Psychologist in Clinical Training),
erica.milton@nhs.net

Research lead: Jannine Dowling (Clinical Psychologist, PDMCN),
jannine.dowling@nhs.net

Appendix 3: Consent form



FOCUS GROUP CONSENT FORM

Version 2

The 'Andromeda' Carers Peer Support group is a project by the Leeds PDMCN in partnership with Carers Leeds, which aims to provide on-going peer support for carers of people with a diagnosis of personality disorder.

The Leeds Personality Disorder Managed Clinical Network will be evaluating the project by asking you to take part in a focus group in order to help us to better understand your experience of the Andromeda group. This will help us plan how we support carers in the future.

The focus group facilitator will ask a range of questions about your experience as carers and in particular your experience of attending the group. We are asking for your permission to use the information collected from the focus group to be used in future service evaluation and audit. This may include submitting an article about the group for publication in an academic journal. When used for these purposes, all the information will be anonymous, that is, your name and any personal data which might identify you will be removed. The information is securely held and only people within the planning, delivery and evaluation team of the programme will see the information. We comply with Data Protection laws.

Please tick to confirm that you give consent to the following:

- I confirm that I have read and understood the information above.
- I have had the opportunity to ask questions and have had these answered satisfactorily.
- I give permission for audio recording of the focus group to take place.
- I give my permission for the anonymised data collected from the focus group to be used for future audits and service evaluations.
- I give my permission for the anonymised data to be submitted for publication, including direct (anonymised) quotes.
- I understand that my participation is voluntary.

I understand I can choose to not answer questions during the focus group and that I can withdraw specific comments within one week after the group by contacting the lead facilitator.

Name of Participant

Date

If you have any questions or concerns about this request, please do not hesitate to contact

Erica Milton (Psychologist in Clinical Training, Focus group facilitator) at erica.milton@nhs.net or Jannine Dowling at (Clinical Psychologist, PDMCN) jannine.dowling@nhs.net