Service User Satisfaction Survey
Personality Disorder Managed Clinical Network (PDMCN)

2018

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It has changed my life for the better, if it weren’t for the skills I learnt in DBT I’m unsure how things would have turned out

– DBT group member
Acknowledgements

Thank you to all the service users who took part in this survey. A particular thanks to the Personalities in Action (PiA) Involvement Group for their involvement and feedback.
Introduction

The Leeds Personality Disorder Managed Clinical Network (“the Network”) is a city-wide, multi-disciplinary and multi-agency service for people with a diagnosis of or presentation consistent with Personality Disorder in Leeds. There are a number of distinct elements of the service, which include:

- Care Co-ordination/case management, which includes access to psychotherapy, housing assessment and support, and an occupational and social inclusion service.
- Journey, an Occupationally Based Day Programme
- 3 Dialectical Behaviour Therapy Skills Groups across the Leeds area

In 2007, a qualitative research project was carried out examining service users’ experiences of the Network (Harrop & Prince, 2007). Consequently, and in line with Trust requirements, it was decided that service users’ feedback should be assessed regularly and a questionnaire based on the 2007 research was developed and piloted in September 2008. This current survey is based on a modified version of the 2008 questionnaire following feedback from staff and service users. This is the 11th year the survey has been undertaken.

Method

- **Measures**
  “Personality Disorder Clinical Network Service User Satisfaction Survey” was used (Appendix 1). The 2018 survey was similar to the 2017 survey however the complaints questions were reconfigured following recommendations made by service users and staff.

- **Participants**
  All service-users accessing the Network services at the end of March 2018 were eligible to participate in this survey, in addition to service users who had recently been discharged from the service. These included 26 care co-ordinated service users, 17 Journey and 30 DBT skills group members. A total of 73 service users were invited to participate.

- **Data Collection Procedure**
  Questionnaires were hand delivered to service users by the staff members who worked with them. Service users were requested to hand completed questionnaires to staff members in a sealed envelope. For those who were discharged the questionnaires were posted out to them and they were asked to post these back in the sealed envelope to the Assistant Psychologist. In addition service users were given the option to complete the survey over the telephone with the Assistant Psychologist.
The use of online methods was also introduced this year. Survey monkey (an online survey completion website) was used. Service users in DBT and Journey were texted a link to the survey by the Assistant Psychologist inviting them to take part. Care co-ordinated service users were texted a link by their care co-ordinators.

Individuals who were using more than one Network service were provided with a separate questionnaire for each service they used and were asked to complete the questionnaire with reference to one service only. Participants were assured of confidentiality and anonymity of their feedback, informed of their right to withdraw from the survey and how their data will be used.

- **Data Analysis**
  
  The quantitative data collected from questions 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 and 13 were collated and analysed using Microsoft Excel by the Assistant Psychologist, who also carried out content analysis on the qualitative data collected from questions 3a, 4a, 6a, 11a, 14, 15 and 16 using six-step method of thematic analysis (Braun & Clarke, 2006).

**Results**

**Response rates**

73 service users were eligible to take part in the survey. 43 responses in total were received (58.9% response rate overall). This was 2.1% lower than the response rate in 2017 of 61%.

41.9% (n=18) responses were received via online methods (survey monkey). Out of these 18 online responses, 6 were for Care Co-ordination, 1 was for Journey and 11 were for DBT. The graph below shows the overall response rates from each part of the service.

![Survey response rates (n=43)](chart.png)
Responses given to survey questions

The responses given by service users to the 16 questions in the survey are detailed below. For each question where service-users were invited to give a rating, there is one graph showing overall responses and another setting out responses from care co-ordination and group programmes separately. Question 1 was related to the service the feedback was for and is outlined above. Therefore the questions below start with question 2.

**Question 2:**

Approximately how long have you been involved with the service (n=43)?

The majority of the service users who completed the SUSS had been involved with the Network for a year or less.

Service users in group therapies were involved with the Network for a shorter period of time. People in Care co-co-ordination who completed the SUSS had generally been involved with the Network for longer.
**Question 3:**
Have you been clearly informed about what the service you receive can provide for you (n=43)?

The majority of service users reported that they were clearly informed about what the service can provide for them. A small number (n=5), all from group therapies, stated that this was not clear.

Two people made additional comments, this included:
“I was told about dbt but not other support the service could offer. I was unaware care coordination was offered.”

**Question 4:**
Do you feel staff at the PD Network understand you (n=43)?

75% of the service users replied that they felt that PD network staff understood them a lot or a great deal, which is a 9% increase than the reported figure last year (66%).

10% of service users were not sure and a further 15% stated the Network staff understood them a little or not at all. The majority of these service users were either new to the service (0-6 months) or in group programmes.
**Question 4a:**

If you do not feel understood, please could you explain why?

Six service users responded to this question, all of whom were in group programmes and identified a similar theme relating to:

- **Difficulties in group setting:** “I think in DBT it's hard to discuss what your problems are because you don’t get to talk too deeply in the group sessions.” [DBT group member]

  “There are more extrovert / outgoing people in the group so I often feel overshadowed and then when I do share something my anxiety afterwards is so high I find it difficult.” [DBT group member]

**Question 5:**

How would you rate the level of support you have received from staff (n=43)?

86% (n=37) of service users who completed the SUSS reported that they found the level of support received from staff good or excellent. This is a 7% increase than the reported figure from year 2017 (79%). 11.6% (n=5) reported support was average and a small 2% (n=1) reported support was very poor.

**How would you rate the level of support you have received from staff?**
**Question 6:**
Is being in the PD Network making a positive difference to your life (n=43)?

The majority of service users (n=27, 63%) reported ‘a lot’ or ‘a great deal’ for this question. 28% (n=12) stated they were not sure if the Network was having a positive experience on their life and 9% (n=4) reported ‘not at all’.

**Question 6a:**
Please could you explain how, giving examples if possible?

26 service users responded to this question. One of the key reported explanations given was related to improved mental well-being and a greater understanding of their difficulties. In addition the value of new skills and coping strategies was reported:

- “Recognising signs and symptoms of self-harm and the steps to take to prevent harming myself.” [Care coordinated service user]
- “Given me the tools I’ve always needed to understand myself. I’m starting to make small but manageable changes to how I react to emotion”. [Journey group member]
- “I’m much more able to deal with myself in crisis and now have a plan of steps to keep myself safe.” [DBT group member]

Some service users also described the importance of regular groups, meetings and consistency which helped with routine and stability.

- “After Journey, I’m now able to have more structure at home - cleaning, making meals and taking care of myself.” [Journey group member]

Some service users described positive staff qualities and experiences:

- “I like talking to (staff member) and (staff member) because they understand me and listen and help me with practical things” [Care coordinated service user]
- “Staff very empathetic and understanding with discussions and general support.” [DBT group member]
Service users however also made comments in relation to worsening of their mental health / well-being:

- “The DBT I receive is not helping and is making it worse.” [DBT group member]
- “All the worms out of the tin, no coping strategies learned.” [Journey group member]  

**Question 7:**
Have you been informed about the Network’s complaints procedure (n=43)?

65% of service users reported that they were informed about the Network’s complaints procedure; this is a 19% increase than the figure reported in year 2017 (46%).

**Question 8:**
Have you made a complaint to the Network (n=43)?

Only one service user stated that they had made a made to the Network. This was a care co-ordinated service user.
Question 9:
If you have made a complaint were you supported to do so? (n=43)

The care co-ordinated service user who had made a complaint felt that they were only supported ‘a little’ to do this.

Question 10:
If you haven’t made a complaint but needed to, would you know what to do? (n=43)

Nearly half of the respondents suggested that they would know what to do if they needed to make a complaint, 31% reported that they would not and 24% reported not applicable.
**Question 11:**
How clear/easy to understand were the letters and/or reports you’ve received from the Network (n=43)?

The majority of service users responded good or excellent (n=34, 79%).

**Question 11a:**
Please could you explain what has or has not been clear for you, giving examples if possible?

Ten service users responded to this question.

Comments were made on the simplicity and clarity of communication/ letters and/or reports:

- “It’s straight forward and simple to understand.” [DBT group member]
- “Everything is straight to the point. Still waiting on report but all letters are understandable” [Journey group member]
- “(staff member) goes through them with me which is helpful” [Care coordinated service user]

Some service users however reported that the reports/letters were complicated and did not always reflect their learning needs:

- “Too many complicated words” [Care coordinated service user]
- “Because British Sign Language is my first language I don’t always understand complex written English.” [Care coordinated service user]
- “The presentation of some group collected information can be difficult to understand.” [DBT group member]
**Question 12:**
Have you been informed about opportunities for service user involvement?  
(n=41) (2 skipped)

71% of service users reported that they were informed about the Network’s service user involvement opportunities. This is a 5% increase than the figure reported in year 2017 (66%).

**Question 13:**
Overall, how would you rate the service you have received from the Network?

84% (n=36) of service users rated the Network service as “Excellent” or “Good”; this is a 2% increase than the figure reported in 2017 (82%). 14% service users reported the Network service as “average”; this is a 4% decrease from year 2017 (18%). The majority of these responses were from group therapy service users (n=5) and 1 response was from a care co-ordinated service user. 2% (n=1) also reported that the Network service was overall “poor”. This response was from a Journey group member.
Question 14:
What has been good about the service you received?

38 service users responded to this question.

The key theme identified was the **non-judgemental, compassionate** and **understanding** approach from staff members:

- “Knowing I have someone who understands me to talk to when I’m struggling.” [Care coordinated service user]
- “(staff member) makes me feel hopeful for my recovery.” [Care coordinated service user]
- “The staff really listen and understand what I’m going through. They’re not afraid to talk about things.” [DBT group member]
- “Feel safe in the group and with the DBT trainers. They understand and don’t judge us. It’s helped in my daily life.” [DBT group member]
- “The support from staff and previous service user is amazing. They really care beyond it being their job and it’s built my confidence and enabled me to let my guard down and accept help.” [Journey group member]

Another theme was **learning of new coping skills** and **improved mental well-being/health**:

- “The therapists and assistance successfully teaches useful tools that can be used in daily life. I understand myself better and have found some level of peace. I’m beginning to accept myself.” [Journey group member]
- “Journey has helped me to cope with my illness and made me realise there is other things I can do instead of taking an overdose” [Journey group member]
- “It has changed my life for the better, if it weren’t for the skills I learnt in DBT I’m unsure how things would have turned out” [DBT group member]

A further theme was related to **content, structure** and **consistency** of care:

- “Good to break up days… activity really positively motivated me” [Journey group member]
- “The care co-ordinator who has worked with me has met me regularly.” [Care co-ordinated service user]
- “The skills I have learned and the continuity of care.” [DBT group member]

In addition service users commented on value of **connecting with peers**:

- “Meeting new people” [DBT group member]
- “Being around people with similar problems and seeing the variety of causes in group.” [DBT group member]
Question 15:
What could be improved?

35 service users responded to this question, with 12 service users stating that nothing required improvement.

A key theme identified was related to the level of staff support offered:
- “More individual support - checking in - just a text if a session seemed ‘tense, hard, okay’ - it would go a long way!” [DBT group member]
- “It would be helpful if you could speak to duty before 1.30 as sometimes you are struggling and need to speak to someone.” [Care co-ordinated service user]
- “I only get support from the DBT group and other support would be useful if I was told what was available that I could access.” [DBT group member]
- “Individual sessions to help compound DBT learning and to check individual progress.” [DBT group member]

Another key theme was related to the individual service structure and content:
- “Personalisation of content - sometimes information and sessions are very open and not explored enough in group.” [DBT group member]
- “1-2 months longer. The care and work you guys do is so good but I could have done with some more support after journey ends.” [Journey group member]
- “More examples and real life case studies. Maybe talking of people who have been through DBT…” [DBT group member]

Some service users outlined the importance of continuity of care:
- “Better continuity when external events affect group such as sickness / weather etc. be prepared, contingency plan!” [Journey group member]
- “…not to have staff team changes of staff.” [Journey group member]

Another theme was related to meeting individual needs:
- “Treat each person as an individual not by how they should be because of their diagnosis. We are all different and don’t all fit underneath the same umbrella.” [DBT group member]
- “To have a care coordinator who could communicate with BSL.” [Care co-ordinated service user]

Other comments made were related to communication and language:
- “Some of the communications outside of the group setting” [DBT group member]
- “Better forms… mindful of language – FEEDBACK” [DBT group member]
**Question 16:**

Do you have any other general comments relating to your experiences with the Network?

21 service users responded with general comments relating to their experiences with the Network. The majority of the feedback reflected a positive experience with the Network:

- “The PD Network is the best service ever!” [Care coordinated service user]
- “Thank you!! 4 months ago all I could see was black, but today I can see tomorrow.” [Journey group member]
- “A life saver! Honestly made the most difference in my life that any service has ever offered, I think that everybody should be taught DBT from a young age” [DBT group member]

One comment was made in relation to communication:

- “I find that follow up calls tend to be quite quick and impersonal, aka if session is missed or I’ve been admitted etc.” [DBT group member]

One service user suggested that that the journey group was not useful to them:

- “Waste of time” [Journey group member]

Another group member noted some difficulties in relation to staff members:

- “It was important for us to be on time to sessions or at least call if running late, but when (staff members) picked me up they were always approx 5 mins late without some sort of notice.” [Journey group member]
Discussion

The numbers of service users who have been eligible to take part in this survey have changed over the last few years. This year 73 service users were eligible to take part compared with 64 last year (+14%), 45 in 2015 and 36 in 2014. A larger number of responses were received from care co-ordinated service users this year (n=12) compared to last year (n=5) (+140%). The number of DBT responses has decreased this year (n=20) compared to last year (n=24) (-16.7%). Journey responses have increased by 10% (n=11 this year in comparison to n=10 last year).

The findings from this year's survey indicate that a high proportion of service users feel very positively about the Network (84%); this is 2% increase from last years reported figure of 82%.

87% of service users felt they were clearly informed about what the service can provide, this is the same as the figure reported last year (87%). 86% of service users report feeling well supported; this is an increase of 7% from the reported figure of 79% in 2017. There has been an increase in the percentage of service users reporting that the PD network is having a positive impact on their life (63% this year in comparison to 56% last year, +7%). 28% of service users reported to be unsure (+2% on last year’s figure of 26%). A further 9% of service users have suggested that the Network is “not at all” having a positive impact on their lives.

A higher proportion of service users reported that they were informed about the Network’s complaints procedure (65%). This is a 19% increase from the reported figure of 46% last year. 45% of service users reported that they would know what to do if they needed to make a complaint, however 24% reported that they would not know what to do. One service user who had made a complaint to the Network stated that they were only supported “a little” in order to do this.

The percentage of service users who reported they have been informed about service user involvement opportunities has also increased this year (71%, +5% on the figure of 66% reported in year 2017).

The responses to the open questions revealed a number of positive qualities about the Network. These included the non-judgemental, compassionate and understanding approach of staff and service; opportunity to learn new coping skills and perceived improvement in mental well-being/health. Service users also commented on the value of the structure and consistency of care. In addition service users suggested valuing connecting with other peers. Overall the majority of open question responses were positive about the Network.

Service users also reported key criticisms and made suggestions for improvements. These included increased level of staff support within individual services’ and specific improvements within individual service structure and content. Service users also reported difficulties with understanding of individual needs and communication.
Reflection from the PiA Involvement Group

The *Personalities in Action* involvement group met to discuss the findings from the survey and provide recommendations. The group consisted of 4 members and the involvement lead.

The group reflected on the response rates and reflected on the generally positive nature of responses. They noted that there has been a significant increase in responses from care coordinated clients, which may be related to the offer of the online version of the questionnaire, but the group wondered if care coordinators had been working harder to encourage service users to engage with the survey. The group noted that a large proportion of service users still report no knowledge of the complaints procedure, although this has improved since last year. It was discussed that service users may be anxious about complaining and therefore may require more support, and perhaps this could be offered through the Dial House team? Some changes and additions to questions were suggested and this is outlined below.

**RECOMMENDATIONS AND ACTION PLAN**

The following recommendations were made in response to service user and staff feedback at the Service User Involvement Group and Clinical Governance meetings:

- All Network staff should be informed of the positive feedback and encouraged to continue their excellent work with service users
  - ACTION: Report to be circulated to all Network staff

- All Network staff to be made aware of some ongoing difficulties for service users in understanding letters and reports
  - ACTION: Report to be circulated and staff encouraged to use previously circulated information about use of complex language in reports

- We should continue to offer a range of methods for collecting feedback from service users:
  - ACTION: To continue to offer the questionnaire on both paper and online

- It will be helpful to know if the changes to the website and the new films make a difference to people’s knowledge about the service
  - ACTION: Feedback should be collected from service users about the films

- Whilst most responses were positive, there were a small number of responses from service users who reported feeling that their care was not good quality, feeling they are not understood, or even that their difficulties have gotten worse as a result of attending the service. The survey is anonymous, however it is vital that any dissatisfied service users receive information about who they can contact with any concerns or complaints.
- **ACTION:** On the summary SUSS report which is sent to service users, there should be information as to who they can speak to if they are concerned about their care or wish to make a complaint.

- To ensure questions are not ambiguous in order to get good quality information about service user experience:
  - **ACTION:** The 'not applicable' response should be removed from Q10 and the question changed slightly to "Would you know what to do if you needed to make a complaint?"

- To get a better understanding of the barriers to service users getting involved.
  - **ACTION:** In collaboration with Dial House team, to carry out work with current service users exploring the barriers to involvement.
  - **ACTION:** To consider a further film about involvement in the Network.

- To provide detailed feedback to service users regarding concerns raised in Q15 following discussion at Clinical Governance:
  - **ACTION:** To complete the ‘You Said, We Did’ table below.
<table>
<thead>
<tr>
<th>You said:</th>
<th>What we are doing:</th>
</tr>
</thead>
<tbody>
<tr>
<td>You said you did not have information about all services provided by</td>
<td>1. We have updated our website and are making some films about the services with Inkwell Arts, which</td>
</tr>
<tr>
<td>the Network</td>
<td>will be on our website shortly. These have been co-developed with service users and carers and we</td>
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<td>You said that reports/letters were too complicated, especially if</td>
<td>hope they will provide accessible and helpful information.</td>
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<tr>
<td>English is not their first language</td>
<td>2. The Network has developed some guidance for writing letters and reports for people whose first</td>
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<td></td>
<td>language is British Sign Language, with support from Deaf services.</td>
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<tr>
<td>You suggested that you would benefit from support after the Journey</td>
<td>1. Plans are being developed with Dial House for a peer support group for people leaving the Network.</td>
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<tr>
<td>group ends</td>
<td>If you are interested in being part of this development, please come along to “Personalities in Action”</td>
</tr>
<tr>
<td>You wanted better ‘contingency plans’ for when groups have been</td>
<td>(Please see ‘information for service users’ at: <a href="https://www.leedsandyorkpft.nhs.uk/our-services/personality-disorder-managed-clinical-network/">www.leedsandyorkpft.nhs.uk/our-services/personality-disorder-managed-clinical-network/</a></td>
</tr>
<tr>
<td>cancelled due to staff sickness or bad weather</td>
<td>2. We understand that this year there have been numerous disruptions to groups due to the bad weather</td>
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<tr>
<td>You asked that if staff are going to be late to meetings with service</td>
<td>over the winter period. The Journey team is discussing how they can improve contingency plans for</td>
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<tr>
<td>users can they give some notice or let them know (e.g. call)</td>
<td>next winter &amp; staff sickness when it occurs to avoid further disruption as far as is possible.</td>
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<td></td>
<td>A full time occupational therapist has also recently been recruited which will help in improving</td>
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<td></td>
<td>contingency plans.</td>
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<tr>
<td>You requested that a Duty worker could be available in the mornings</td>
<td>3. All staff have been reminded to contact service users if they are running late, we are sorry that</td>
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<td>You asked for a care coordinator who could communicate using British</td>
<td>this hasn’t always been the case.</td>
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<tr>
<td>Sign Language</td>
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<td>You suggested you wanted to engage in more activities</td>
<td>4. Despite being a group setting DBT tries to validate individual needs and ensures that this is</td>
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<td>understood at assessment, along with preparation for group attendance. The team recognises that we</td>
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<td>may not always ‘get it’; however we welcome hearing about when this happens and for this to be</td>
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<td></td>
<td>pointed out to us. The DBT team have also attended Equality &amp; Diversity training and we keen to</td>
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<td></td>
<td>ensure we meet the needs of the range of people who attend DBT groups.</td>
</tr>
<tr>
<td>You have concerns about the service you are receiving, you can contact</td>
<td></td>
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<tr>
<td>the Clinical Team Manager on 0113 8557951. Alternatively, you can</td>
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<tr>
<td>contact the Patient Advice and Liaison Team (PALS) on 0800 052 5790 or</td>
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<td>by email: <a href="mailto:pals.lypft@nhs.net">pals.lypft@nhs.net</a>. If you wish to make a complaint, please</td>
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<tr>
<td>see <a href="https://www.leedsandyorkpft.nhs.uk/advice-support/making-a-complaint/">https://www.leedsandyorkpft.nhs.uk/advice-support/making-a-complaint/</a></td>
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References

APPENDIX 1:

Personality Disorder Clinical Network Service User Satisfaction Survey 2018

Please answer each of the questions by circling the appropriate option. The blank lines at the end of the questions can be used to tell us where you think our service is performing well or how it could be better. Please write comments so they are clearly readable. If you need any assistance in completing this survey please ask Network staff for support

1) First of all, please tell us which part of the service your feedback is about. If you use more than one service, we will give you a separate form for each service.

   Journey □  Care co-ordination □  DBT □

2) Approximately how long have you been involved with the service?

   0-6months □  7-12months □  13-18months □  19-24months □

3) Have you been given an opportunity to discuss what the service you receive can provide for you?

   ☹ No  ☺ Yes

3a) If no, please can you tell us more about your experience?

4) Do you feel staff at the PD Network understand you?

   ☹ Not at all  ☺ A little  ☹ Not sure  ☺ A lot  ☺ A great deal

4a) If you did not feel understood, please can you explain why?

5) How would you rate the level of support you have received from staff?

   ☹ Very Poor  ☺ Poor  ☹ Average  ☺ Good  ☺ Excellent

6) Is being in the PD Network making a positive difference to your life?

   ☹ Not at All  ☺ A little  ☹ Not sure  ☺ A lot  ☺ A great deal

6(a) Please could you explain how, giving examples if possible?
7) Have you been informed about the Network’s complaints procedure? ☒ No ☑ Yes

8) Have you made a complaint to the Network? No Yes

9) If you have made a complaint, were you supported to do so? N/A Not at all A little Not sure Mostly A great deal

10) If you haven’t made a complaint, but needed to, would you know what to do? N/A No Yes

11) How clear/easy to understand were the letters and/or reports you’ve received from the Network? ☒ Very Poor ☑ Poor ☘️ Average ☑ Good ☘️ Excellent

11(a) Please could you explain what has or has not been clear for you, giving examples if possible?

12) Have you been informed about opportunities for service user involvement? ☒ No ☑ Yes

13) Overall, how would you rate the service you have received from the Network?

○ Very Poor ☐ Poor ☐ Average ☐ Good ☐ Excellent

14) What has been good about the service you received?

15) What could be improved?

16) Do you have any other general comments related to your experience with the Network?

Thank you for taking the time to complete this questionnaire, your opinions are very important to us. Once completed, please insert it in the envelope provided and return it to your team member.

If you have any queries or would like to go through the questionnaire over the telephone please call Aliya Zamir or Ruth Sutherland at the PD Network on: 0113 8557951