Leeds Personality Disorder Managed Clinical Network

Annual Review

April 2016 – March 2017

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“There really isn't a single area in my life that DBT hasn't somehow helped.”

- DBT Group Member
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Executive Summary

This Annual Review reports activity and performance for the Leeds Personality Disorder Managed Clinical Network (PDMCN) for the period 1st April 2016 to 31st March 2017. The main points are summarised below.

Referrals
The PDMCN received a total of 288 referrals this year, an increase of approximately 97% from last year’s total of 146. Community Mental Health Teams continue to provide the main source of referrals to the Network. Interestingly, the number of self-referrals has increased in the last financial year from 10.6% in 2013-2014, to 14% in 2014-2015, to 18% in 2015-2016 and to 22% in 2016-2017. The demographic profile of referrals has shifted slightly to that of previous years: the service users remain predominantly female (approximately 76% overall, an increase from 68% last year), the majority are White British and the average age has increased to the early thirties compared to the late twenties last year.

Service Users receiving support 2016-2017
During this Annual Review year, the total number of individuals who received support from each of the Network’s main services is as follows (totals include service users referred in previous years who continued to receive support):

- Care co-ordination: 28
- Citywide DBT skills groups: 39
- Journey: 30

Key Outcomes
During this year the service’s evaluation structure was reviewed and some changes have been implemented, which means that full sets of outcome measures were not available for all service users discharged this year. Routine evaluation however is now well established in the Network. A comparison of pre- and post-treatment mean scores showed some modest improvements in terms of psychological distress, interpersonal functioning and quality of life.

Care co-ordination
- Service-users accepted for care-coordination during the period 2016-2017 had a median age of 20.5 years ranging from 17 to 44 years. 80% were female and 20% were male.
- Due to the evaluation restructure and low discharge numbers in care coordination meaningful analysis was not possible. A case example discusses a service user who completed the programme however; measures showed improvement in scores of wellbeing, psychological distress, interpersonal functioning and risk to self and others.

Citywide DBT skills groups
- Due to the evaluation restructure and low discharge numbers in DBT this year, meaningful analysis was not possible.
- A pilot satisfaction survey for the Citywide DBT service revealed that service users feel positively about the groups and 100% stated that they would recommend the group.
Journey Day Service Programme

- There were improvements in the *Global Distress* score and improvements in scores across all individual domains of CORE; however these were not statistically significant.
- Service users made improvements in the OSA Competence and Values scale; these were not statistically significant however.
- Service users made improvements in physical, psychological and social domains of the WHOQOL; this improvement was only statistically significant for the Physical domain.
- 46.7% of service users who were involved in Journey during 2016-2017 and completed both pre and post CORE measures made a reliable change (CORE Global Distress scale).

Service User Involvement and Satisfaction

- Feedback from the Network’s annual Service User Satisfaction Survey, indicates that services are held in high regard. 82% of respondents rated their overall satisfaction with the service they received as “Excellent” or “Good”.
- Service user involvement has been led by the service’s Involvement Lead and a Service User Consultant (SUC) employed by the Network. The current SUC’s contract ended in March 2016; however the service is awaiting confirmation of funding for a new SUC post.
- A part-time SUC for the Citywide DBT service has been employed this year to provide peer support to one of the DBT skills groups.

Service User Safety

- Information from the Trust’s Datix system, used for reporting risk incidents, indicates that there has been a slight decrease in the number of risk incidents within the Network this year in comparison to the previous year. However there has been a slight increase in the reported severity of the incidents reported this year, suggesting that fewer but more severe incidents have occurred this year (e.g. people involved may have required treatment for injuries).

Supporting Carers

- Seven carers attended a six-week course in November-December 2016, facilitated by staff from the Network. The course provided information about Personality Disorder, how it develops and what can help people with Personality Disorder. The course also supported carers in thinking about their roles as carers and how to look after their own wellbeing.
- Feedback from the carers about the group was very positive. They reported high levels of satisfaction and improved understanding of Personality Disorder. Three new groups have been planned for 2017-2018, and a peer-support carers group is being planned in partnership with Carers Leeds.

Training, Conferences and Research

The Network continues to place a high priority on training, conferences and research. It has been a major contributor to leading conferences and also in providing consultation, teaching and training.
About Us

The Leeds Personality Disorder Managed Clinical Network (PDMCN) was established in 2004 as one of eleven community pilot projects working with people with Personality Disorder. The PDMCN is a city wide multiagency and multidisciplinary service, provided by a range of partnership organisations including Leeds Partnerships NHS Foundation Trust; Community Links (third sector provider); Leeds Survivor led Crisis Service and the Personality Disorder Institute (academic partners).

Managed Clinical Networks (MCN) have been described as linked groups of health professionals and organisations, working together in a co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality effective services. They are noted to be particularly effective when clients present with a range of complex needs and where a set of autonomous organisations come together to reach goals that no one organisation can reach separately.

Resources

- Clinical Service Manager / KUF Lead
- Consultant Clinical Psychologist (Clinical Lead)
- Clinical Team Manager
- Care Co-ordinators
- Health Care Support Worker
- Occupational Therapists
- Principal Clinical Psychologist / Involvement Lead
- Higher Assistant Psychologist
- Adult Psychotherapists
- Service User Consultants
- Housing and Resettlement Worker
- Administrative Support
Our Services

Care co-ordination

Care co-ordination comprises individual clinical case management for up to 100 weeks.

Care Coordination aims to develop collaborative relationships with service users under the framework of CPA care co-ordination as a means of identifying and meeting mental health and social care needs. PDMCN care co-ordination involves supporting service users to engage in a range of psycho-social interventions and activities aimed at developing self-management skills, improving quality of life and social integration. A care co-ordinator will look to develop and maintain a therapeutic relationship as a primary treatment goal and to support effective risk management and care planning. Care co-ordination can also include input from occupational therapy, psychology, psychotherapy, accommodation and health care support worker staff within the team in addition to the PDMCN’s therapeutic groups.

Over the last few years, the age of our service users have been getting younger and their representation within the service has been increasing. At the time of writing this report approximately over one third of the service user group were aged between 17 and 25. Service users transitioning from Community Adolescent Mental Health Teams (CAMHs) now access the "young person’s pathway", which revolves around early identification, reduces the need for multiple assessments and involves a time limited and focused service user led intervention.

Psychological Therapies

Assessment and formal therapy to service users receiving care-co-ordination in the Network.

A number of therapeutic approaches are offered, including Cognitive Behavioural Therapy (CBT); Schema-focused Therapy; DBT-Informed Therapy and Psychodynamic Psychotherapy. The length of the therapeutic contract varies depending upon service user need and model of therapy but can involve up to two years of regular therapy sessions.

In addition to direct clinical work, the therapy team plays a significant role in supporting psychological thinking across the Network. This occurs largely through consultation to care-coordinators regarding Network assessments, and supervision to care-coordinators and members of the housing team around ongoing clinical cases.

Occupational Therapy

Assessment and intervention for care co-ordinated service users.

It uses a range of conceptual models of practice, with primary use of the Model of Human Occupation (MOHO) and the Sensory Integration Model (SI). Intervention with care co-ordinated service users focuses initially upon assisting people to more effectively and adaptively control and regulate their emotional state via engagement in purposeful activity, and then to assist people to engage in occupation which has the potential to move beyond the immediate experience of personality disorder. The Occupational Therapy Team directly facilitates the Journey day service.
City Wide Dialectical Behaviour Therapy (DBT) Skills Groups

The City Wide Dialectical Behaviour Therapy (DBT) programme is a partnership arrangement between the PDMCN and the Leeds Care Group. It came into being from 1st April 2016 in response to Clinical Commissioners requesting that DBT skills training groups be more widely available to people in Leeds. The service comprises a “hub and spoke” model of delivery with a DBT skills training group located in each of the three CMHT’s which are all supported by the DBT consultation meeting. Governance and clinical management arrangements are held by the PDMCN. The team comprises of Community Mental Health Nurses, Social Worker, Psychotherapists, Occupational Therapist and Service User Consultant.

DBT skills group training is a CBT adapted approach (Linehan, 1993) designed to teach people new skills to help them when they feel suicidal or want to use self-harming or life threatening behaviours to cope with traumatic experience. DBT recognises that people develop these methods of coping as a result of experiences in their lives that could be described as ‘invalidating’. This may include abuse, neglect or other kind of personal trauma. People who attend will often have a diagnosis of borderline personality disorder.

Groups are mixed gender and service users attend for 9 weekly two and a half hour groups called modules with a treatment offer of up to fifteen months. Groups cover four sets of skills:

1) Mindfulness
2) Interpersonal Effectiveness
3) Emotion Regulation
4) Distress Tolerance

Journey Day Programme

Journey meets weekly for the first eight weeks and then once a month in the second eight weeks. Group members also have five individual sessions over the course of the programme. The group consists of 10 members, 3 staff members and a service user consultant.

The aim of Journey is to provide group members with the skills and knowledge to actively engage in creating an individual balance of activity, which promotes health and wellbeing. It works with people on the understanding that what people do in their daily lives has a direct impact upon their health and how they experience themselves and others.

Journey works with group members using a variety of creative approaches to think about what they do, why they do it, and how that doing influences their lives. The programme assists group members to develop and implement individual action plans. The plans focus on enhancing what group members currently do, or focus on introducing new activity, which improves ability to manage distress more effectively and promotes quality of life.

Community Links Accommodation Service

The Community Links personality disorder accommodation support service is part of the PDMCN. The main aims of the service are to prevent homelessness by early intervention; work closely on trigger issues and with agencies that identify them; and offer short-term intervention or help for the service user to move or to sustain existing tenancies longer term. The service works collaboratively with service users and is guided by and responsive to their needs and preferences.
Activities and Care Pathways in 2016/17

Overview of total referrals and activity for the PDMCN

- In the period 1 April 2016 to 31 March 2017, the Network received a total of 288 referrals (see appendix 1). 279 referrals were external, and 9 were internal referrals.

- The total number of referrals this year was up by 97.2% on last year’s total of 146. The number of external referrals was also up by 95% from last year’s total of 143. The number of internal referrals was down by 30.8% on last year’s total of 13.

- A further 12 referrals were carried over from the previous financial year from the different parts of the service (2 assessments for care co-ordination and 10 assessments for Journey).

- 175 referrals were carried forward and either were to be allocated or were allocated into the various network services as shown in the table and pie chart below:

- 113 referrals did not meet criteria for a service within the Network. All referrers were provided with Care Pathway Management by Network staff.

Overview of services offered for PDMCN 1 April 2016 to 31 March 2017

<table>
<thead>
<tr>
<th>Service</th>
<th>Total number of referrals processed</th>
<th>Total number of external referrals</th>
<th>Total number of internal referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment for Care Co-ordination</td>
<td>19</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>Assessment for City Wide DBT Skills Groups</td>
<td>66</td>
<td>65</td>
<td>1</td>
</tr>
<tr>
<td>Assessment for Journey Occupational Day Service</td>
<td>67</td>
<td>62</td>
<td>5</td>
</tr>
<tr>
<td>Care Pathway Management</td>
<td>113</td>
<td>112</td>
<td>1</td>
</tr>
<tr>
<td>Ongoing – to be allocated</td>
<td>23</td>
<td>22</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>288</strong></td>
<td><strong>279</strong></td>
<td><strong>9</strong></td>
</tr>
</tbody>
</table>

Outcomes of referrals to PDMCN 1st April 2016 - 31st March 2017 (n=288)

- Assessment for Care Co-ordination
- Assessment for City Wide DBT Skills Group
- Assessment for Journey Occupational Day Service
- Care Pathway Management
- Ongoing – to be allocated
Care Pathway Management

- A large number of referrals did not meet the criteria for Network services. A smaller number were considered appropriate for the service but the service user declined to engage with the service or had already disengaged with the referrer. In some instances, service users stated they did not want group therapy, which is the nature of the DBT and Journey Day services.

- Over half of these referrals were for Journey or Care Co-ordination, with approximately a quarter being for DBT. A smaller number of referrers did not state which service was being requested.

- All referrers were provided with Care Pathway Management. This usually involves a telephone conversation to gain more information to confirm an understanding of the clinical issues. This is then followed up in a letter to the appropriate practitioner giving a sense of an initial formulation of need discussed. This formulation then determines the advice and support given, along with relevant signposting to services that might be more responsive and appropriate. A telephone conversation may also occur with a service user in respect of self-referrals we feel we are unable to help. This will also be followed up with a carefully worded letter to support service users to accessing the most helpful support for their needs.

Sources of referrals:
The chart below shows the sources of referrals to the PDMCN.
Demographics of referrals:

The table below sets out the demographic profile of referrals with a comparison to the previous year.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>2016-2017</th>
<th>2015-2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>n= 219 (76%)</td>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
<td>n=69 (24%)</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age range</td>
<td>17 to 67 years</td>
<td>Age range</td>
</tr>
<tr>
<td>Mean age</td>
<td>31.4 years, median age 28 years</td>
<td>Mean age</td>
</tr>
<tr>
<td>Males were on average older (mean 35.6, median 34) than females (mean 30.1, median 28).</td>
<td>Males were on average slightly older (mean 32, median 31) than females (mean 29, median 25).</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>n=234 (81.25%)</td>
<td>White British</td>
</tr>
<tr>
<td>White Irish</td>
<td>n = 1 (0.35%)</td>
<td>White Irish</td>
</tr>
<tr>
<td>White Other</td>
<td>n = 5 (1.74%)</td>
<td>White Other</td>
</tr>
<tr>
<td>Asian/Indian</td>
<td>n = 1 (0.35%)</td>
<td>Asian/Indian</td>
</tr>
<tr>
<td>Asian/Pakistani</td>
<td>n = 3 (1.04%)</td>
<td>Asian/ Pakistani</td>
</tr>
<tr>
<td>Asian/Bangladeshi</td>
<td>n = 2 (0.69%)</td>
<td>Mixed White/Black Caribbean</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>n = 1 (0.35%)</td>
<td>Mixed White/Asian</td>
</tr>
<tr>
<td>Asian/Chinese</td>
<td>n = 8 (2.78%)</td>
<td>Other Mixed Ethnic Background</td>
</tr>
<tr>
<td>Mixed White/Black Caribbean</td>
<td>n = 4 (1.39%)</td>
<td>Ethnicity not stated</td>
</tr>
<tr>
<td>Other Mixed Ethnic Background</td>
<td>n = 2 (0.69%)</td>
<td>Other Ethnic Background</td>
</tr>
<tr>
<td>Ethnicity not stated</td>
<td>n = 26 (9.03%)</td>
<td></td>
</tr>
</tbody>
</table>
Care Co-ordination
Profile of referrals

19 referrals were directed to assessment for Network Care Co-ordination. The graph below shows the sources of these referrals. The main points and comparisons with last year are as follows:

- The overall number of referrals has decreased upon 2015/2016 figure of n=24
- Almost half of these referrals were from CMHT’s (n=9, 48%) however this was a decrease from last years 58% (n=14).
- Interestingly there has been an increase in referrals from inpatients wards of 28% (n=5) compared to last year’s 4% (n=1).

The table below sets out the demographic data for these referrals. The demographic profiles of those assessed for care co-ordination this year were similar to that of last years.
Compared to the previous year there has been an increase in the number of referrals who are male (+26.4%) and reduction in the number of referrals that are female (-36.4%).

<table>
<thead>
<tr>
<th></th>
<th>2016-2017</th>
<th>2015-2016 for comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>n=10 (52.6%)</td>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
<td>n=9 (47.4%)</td>
<td>Male</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=5 (21%)</td>
</tr>
<tr>
<td>Age</td>
<td>Age range 17 to 56 years</td>
<td></td>
</tr>
<tr>
<td>Mean age 26.8 yrs, median age 21 yrs</td>
<td>Age range 17 to 51 years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean age 26.6 yrs, median age 20.5 yrs</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>n=18 (94.7%)</td>
<td>White British</td>
</tr>
<tr>
<td>Ethnicity not stated</td>
<td>n=1 (5.3%)</td>
<td>Asian/Pakistani</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=1 (4.2%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ethnicity not stated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=1 (4.2%)</td>
</tr>
</tbody>
</table>
Assessments in the Care Co-ordination service

The care co-ordination service carried out a total of 21 assessments, of which 2 were referred in the financial year 2015-2016. The pie chart below shows the outcomes of these assessments.

Outcome at assessment stage (N=21)

- 38% Accepted for Care Co-ordination
- 29% Did not engage in assessment
- 14% Not suitable
- 14% Moved away from area
- 5% Ongoing assessments

In summary:
- 21 assessments were completed, with 8 clients being taken on for care co-ordination. Three clients were not offered the service due to care co-ordination not being suitable for them.
- Four assessments were begun but not completed, 3 because the client disengaged during the process and 1 due to moving out of area.
- A further 6 assessments begun however were still ongoing at the end of the financial year.

The demographic profile of the 8 clients taken on for care co-ordination in this Annual Review year was as follows:
- 6 (80%) were female and 2 (20%) were male.
- All 8 were White British
- Their ages ranged from 17 to 44 years, with a mean age of 25.9 years and median of 20.5 years.

Care co-ordination activity

A total of 28 service users received care co-ordination from the Network during this Annual Review year (compared with 38 in 2015/16). Activity during this period was as follows:
- 20 individuals completed their assessments and began care co-ordination prior to April 2016.
- Eight individuals completed their assessments and began care co-ordination in 2016-2017.
- Three service users were discharged. Of these, 1 had completed the full 2 year programme and 2 service users had planned discharges after a period of disengagement.

As at 31st March 2017 there were 28 service users in care co-ordination.
Journey Day Service

Profile of referrals

67 referrals were processed for assessment for the Annual Review year of 2016-2017. This is slightly higher to the 62 referrals that were directed to Journey in the last annual review year (2015-2016).

The graph below shows the sources of these referrals. The pattern of referrals was broadly similar to last year, with the majority of referrals coming from the CMHT, followed by Self referrals.

The table below sets out the demographic data for these referrals. The demographic profiles of those assessed for the Journey day group were slightly different from the previous financial year of 2015-2016. There has been an increase in female service users (2015-2016, n=46, 74%). The age group this year was slightly older compared to last year (mean = 30.5 years, median = 27 years). The ethnic background of service users was the similar to those in previous years; majority White British.

<table>
<thead>
<tr>
<th></th>
<th>2016-2017</th>
<th>2015-2016 for comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female n=57 (85.3%)</td>
<td>Female n=46 (74%)</td>
</tr>
<tr>
<td></td>
<td>Male n=10 (14.7%)</td>
<td>Male n=16 (26%)</td>
</tr>
<tr>
<td>Age</td>
<td>Age range 18 to 57 years Mean age 34.1 yrs, median age 32 yrs</td>
<td>Age range 18 to 57 years Mean age 30.5 yrs, median age 27 yrs</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White British n=55 (82%)</td>
<td>White British n=50 (80.6%)</td>
</tr>
<tr>
<td></td>
<td>Other White Background n=4 (6%)</td>
<td>White Irish n=2 (3.2%)</td>
</tr>
<tr>
<td></td>
<td>Asian/ Chinese n=1 (2%)</td>
<td>Ethnicity not stated n=6 (9.7%)</td>
</tr>
<tr>
<td></td>
<td>Mixed White &amp; Black Caribbean n=1 (1%)</td>
<td>One from each of the following ethnic groups (n=4 in total; 6.5%): Asian/Indian, Mixed White/Black Caribbean, Other White, Mixed Other.</td>
</tr>
<tr>
<td></td>
<td>Other Mixed Ethnic Background n=2 (3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ethnicity not stated n=4 (6%)</td>
<td></td>
</tr>
</tbody>
</table>
Activity in the Journey service

67 new referrals were offered assessment for Journey. A further 10 assessments which were on-going as at 31 March 2016 were also completed during this year. The pie chart below shows the outcomes of these 77 assessments:

![Outcome at assessment stage (N=77)](image)

Nearly half (n=32, 42%) of those assessed were offered a place on a Journey programme. Of those accepted, 24 (75%) were female and 8 (25%) were male. Those accepted for Journey ranged in age from 19 to 57 years, with an average age of 32.9 years. 25 (78%) were White British and 2 (7%) were from an Other White Background. There was one individual from each of the following ethnic groups: Asian/Indian, Asian/Chinese, Mixed White and Black Caribbean and Other Ethnic Background. One person’s ethnicity was not stated.

Journey group membership

A total of 3 Journey programmes (29, 30 and 31) continued or began during this Annual Review Year. These 3 programmes involved a total of 30 service users.

The drop-out rate across the Journey programme was 30%; this is 16% lower than last year’s drop-out rate of 46%. The main reasons for dropping out were non-attendance and the client feeling unable to tolerate group work at this time.

Due to the uncertainty of future funding for the Journey programme, Journey 32 had not begun at the end of this financial year. Funding has been agreed for the next Journey programme and this will commence in May 2017.
City Wide Dialectical Behaviour Therapy (DBT) Skills Groups

Profile of referrals

A total of 116 referrals were made for the City Wide DBT Skills Group. Out of these 23 were deactivated at the referral stage, 17 were deactivated after further information gathering and 66 were offered an assessment. There were 10 referrals which were ongoing at the end of the financial year. Out of these referrals 113 were external referrals and 3 were internal referrals.

Comparisons with the year of 2015-16 are not made due to referrals to DBT being closed for a significant portion of the year due to a shortfall in funding to the group-work programme. There has been a 205% increase in referrals compared to the year of 2014-2015 (n=38).

The table below sets out the demographic data for these referrals. The demographic profiles of those allocated to the City Wide DBT were not compared to last year due to the small number in last year’s referrals; however comparisons have been made with the year of 2014-2015. There was a small decrease in percentage of female service users (2014-2015, n=29, 91%) and a decrease in percentage of White British service users (2014-2015, n=29, 90.6%). The age group this year is younger (mean age= 34.1 years, median age 30 years).

<table>
<thead>
<tr>
<th>Sources of referrals allocated to City Wide DBT (n=116)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT</td>
</tr>
<tr>
<td>70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2016-2017</th>
<th>2014-2015 for comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female n=97 (84%)</td>
<td>Female n=29 (91%)</td>
</tr>
<tr>
<td>Male n=19 (16%)</td>
<td>Male n=3 (9%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Age range 18 to 57 years</td>
<td>Age range 19 to 62 years</td>
</tr>
<tr>
<td>Mean age 30 yrs, median age 28 yrs</td>
<td>Mean age 34.1 yrs, median age 30 yrs</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White British n=94 (81%)</td>
<td>White British n=29 (90.63%)</td>
</tr>
<tr>
<td>Other White Background n=1 (0.9%)</td>
<td>White Other n=2 (6.3%)</td>
</tr>
<tr>
<td>Asian/Bangladeshi n=2 (1.7%)</td>
<td>Mixed WB Caribbean n=1 (3.1%)</td>
</tr>
<tr>
<td>Asian/Pakistani n=1 (0.9%)</td>
<td></td>
</tr>
<tr>
<td>Black Caribbean n=1 (0.9%)</td>
<td></td>
</tr>
<tr>
<td>Mixed W/B Caribbean n=5 (4.3%)</td>
<td></td>
</tr>
<tr>
<td>Other Mixed n=2 (1.7%)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity not stated n=10 (8.6%)</td>
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Assessments in the Citywide DBT service

The DBT team were allocated a total of 66 referrals, the following pie chart shows the outcomes of these assessments:

![Outcome at assessment stage (N=66)](chart)

- **Offered DBT**: 47%
- **Waiting for assessment**: 26%
- **Did not meet criteria**: 11%
- **Group not suitable**: 10%
- **Did not engage in assessment**: 6%

Nearly half of people who were allocated for a DBT assessment were offered DBT (n=31). Over a quarter of the assessments service users either did not meet the criteria for the group, the group was not suitable or the service user did not engage in the assessment process. A number of service users were on the waiting list for assessment at the end of the financial year (n=17).

Activity in the DBT service

A total of 39 individuals were enrolled on the DBT Skills Group modules which ran in the period 1st April 2016 to 31st March 2017. Of this year’s attendees (including 9 enrolled pre April 2016):

- 11 service users were discharged from DBT during this financial year.
- 3 had a planned discharge after completing the full 14 month programme.
- 1 had a planned discharge but did not complete the full programme.
- 7 group members left treatment without completing the programme.
- 28 service users were still involved with the DBT Skills Group at the end of this period, 4 of whom had been accepted for treatment during the course of this year.

Since the DBT Skills Group operates a rolling membership with members starting and leaving in each module, it is not possible to calculate a definitive drop-out rate. The service users who left before completing the programme had generally attended intermittently during the earlier modules and were then discharged following a period of non-attendance.
**Occupational Therapy Team**

The Occupational Therapy service provides the Journey Day Service (see above) and also provides individual occupational assessments and interventions.

Seven service users in Network care co-ordination were referred for individual assessment the Occupational Therapy Team in the period 1 April 2016 to 31 March 2017. This is a 40% increase compared last year’s referrals (n=5). All 7 referrals were considered suitable and assessment was offered for all service users. One service user did not engage in the assessment process and one service user’s assessment was on hold due to other ongoing assessments taking priority. Five assessments led to an offer of individual OT interventions out of which 4 are currently ongoing. One service user recently disengaged from intervention.

**Psychological Therapies Team**

Twelve Network clients were referred for assessment/formulation over the past year. Ten of these were seen for assessment and 2 did not engage in the assessment process. Two assessments led to an offer of DBT group therapy, 5 were offered regular therapy or a series of sessions offering tailored support. For 1 service user therapy was not recommended. One assessment was still ongoing at the end of the financial year and 1 assessment was for psychometrics therefore therapy was not appropriate.

Three service users who were referred prior to 1st April 2016 were receiving ongoing therapy and one service user was receiving ongoing ’consultation’ support by the therapies team.

**Community Links Accommodation Service**

Fourteen PDMCN clients received support from the Community Links Accommodation Service, inclusive of long and short term housing intervention work. 10 were female, 4 were male and all were White British. The work undertaken has included providing support in obtaining appropriate accommodation (either due to homelessness or discharge from a secure environment) and support geared towards accommodation sustainment, benefit enquiries and respite applications.
In terms of outcome measurement, this section will consider:

- a) Clinical effectiveness
- b) Service user and other stakeholder satisfaction
- c) Service user safety

Clinical Effectiveness

This section will focus on the clinical effectiveness of each service area.

During this year the service’s evaluation structure was reviewed and some changes have been implemented, which means that full sets of outcome measures are not available for all service users discharged this year. The changes include ceasing use of the Inventory of Interpersonal Problems (IIP) and Brief Self-Harm Measure for service users in Care Coordination and DBT, as these were not considered to be providing useful information relating to outcome measures, and commencing use of the Borderline Evaluation of Severity over Time (BEST), a tool specifically developed for measuring outcomes for individuals with a diagnosis of Borderline Personality Disorder.

Clinical Outcomes for Care Co-ordination

In order to evaluate the impact of the care co-ordination service, as well as to provide guidance for care planning, the following outcome measures are routinely administered. The care co-ordination service introduced the CORE-OM in 2007 and the WHOQOL-BREF in 2011. The Borderline Evaluation of Severity over Time (BEST©) measure was introduced in 2016.

1. **The Clinical Outcomes in Routine Evaluation (CORE-OM)**, a 34-item self-report questionnaire assessing global distress. Four domains are measured: A. Wellbeing, referring to outlook for the future and self-perception; B. Symptoms, including anxiety, depression and intrusive thoughts; C. Life Functioning, referring to problem-solving abilities and interpersonal functioning; D. Risk to self and others. The higher the scores, the more difficulties the clients are experiencing, with a maximum mean score of 4.

2. **The World Health Organisation Quality of Life Scale (WHOQOL-BREF)** provides a measure of how a client perceives quality of life, which is represented in four domains: physical, psychological, social relationships and environment. The measure produces scores of 1 to 100 and the higher the score, the greater the perceived quality of life. Research is beginning to indicate that a score in the region of 70 for each of the four domains is the norm for the general non-clinical population.

3. **The Borderline Evaluation of Severity over Time (BEST©)** is a self-report measure developed to rate the thoughts, emotions and behaviours typical of Borderline Personality Disorder (BPD). This measure incorporates positive behaviours as well as negative behaviours and tracks change over time. Research hypothesises that negative behaviours (B) are likely to decrease more rapidly than thoughts and feelings (A). The composite score reflects the level of severity of difficulties with scores ranging from 12 at the best and 72 at the worst.

Service users are asked to complete a combination of the above outcome measures at entry and exit of the care co-ordination service, as well as mid-point of treatment.
CORE-OM, WHOQOL-BREF and BEST© data for care co-ordinated clients

Due to this years’ service evaluation restructure and low number of discharges in care co-ordination meaningful analysis of outcome measures has not been possible. However a case study is presented below of a service user who engaged in care co-ordination for a period of two years and was discharged in early 2017.

Case study – Client A

Client A’s referral was made following their release from prison which described they struggled to cope with their experiences and had made numerous suicide attempts. They engaged in dangerous self-harming behaviours and experienced challenging family relationships. A period of care co-ordination was offered and commenced in 2015.

Client A reported to experience a difficult childhood, experiencing emotional and physical abuse which likely also compromised formation of secure early attachments. These manifested in later life, avoiding closeness and intimate relationships due to fear of abandonment, or engaging in relationships that quickly became intense. In addition client A found it difficult to regulate their emotions, to think, contain or soothe and thus would take quick action, such as using alcohol/drugs in order to be rid of the feeling or state of anxiety.

During assessment client A described having aspirations and dreams about the future however that these were unachievable. This would result in them not caring for themselves as it would mean to lose more. However over a period of care co-ordination client A was able to develop an increased capacity to “stop and think”. By slowing things down in this way they were able to reduce their emotional arousal, think more clearly, tolerate their feelings, and take appropriate action.

Furthermore client A was able to build positive and trusting relationships. Client A themselves stated that this felt safer and more containing. Care-coordination appointments provided a safe space in which client A could converse openly and honestly and feel validated and contained whilst doing so.

This progress has been evident in client A’s scores on the CORE-OM which demonstrated an overall reduction in global distress and risk. In addition scores in the well-being domain which refer to the outlook for the future and self-perception showed significant improvements, reflecting client A moving closer towards their goals and having a more positive outlook on life. Scores on the CORE-OM showed clinically significant and reliable change from assessment to discharge. In addition client A’s scores on the WHOQOL- BREF showed an increased satisfaction of quality of life particularly in the psychological domain. This was evident in Client A’s reflections on their ability to tackle their difficulties in healthier and more productive ways.

Client A’s discharge from the PDMCN also represented their discharge from secondary mental health services. This reflected client A’s progress and the informal support structure they had developed around themselves was felt to be sufficient. This was however closely collaborated with client A and a crisis and contingency plan was created, which detailed how they can re-establish contact with mental health services in future should they need to.
Clinical Outcomes for the Citywide DBT Skills Groups

Three outcome measures are used routinely in the Citywide DBT service. The service introduced the CORE-OM in 2007 and the WHOQOL-BREF in 2011. The Borderline Evaluation of Severity over Time (BEST©) measure was introduced in 2016.

1. CORE-OM (see section above ‘Clinical Outcomes for Care Co-ordination’ for description)
2. The WHOQOL-BREF (see section above ordination’ for description).
3. BEST© (see section above description).
4. Service user satisfaction surveys and focus groups led by the Assistant Psychologist which focus on the group member’s experience of participating in the Citywide DBT skills groups.

Group members are required to complete the CORE, WHOQOL and the BEST© measures at different time points of their engagement in the programme.

CORE-OM, WHOQOL-BREF and BEST© data for City Wide DBT Groups

The City Wide DBT programme completed its first year in March 2017. There is a limited amount of completed clinical data sets available due to changes in the service evaluation structure this year, and a low number of discharges from DBT. This means meaningful analysis of the outcome measures has not possible at this stage. For the purposes of the 2016/17 Annual Review a narrative of setting up the programme is provided.

Setting up the programme

DBT skills groups have been part of the PDMCN group work programme for eight years. In 2015 Clinical Commissioners requested that DBT skills training groups be more widely available to people in Leeds and a series of meetings were held to establish how this might be provided. This involved the development of a DBT partnership group meeting with several initial meetings between the two Care Groups with representation from service managers and psychological practitioners. An option appraisal document provided focus for discussion. This provided evidence for DBT skills as stand-alone treatment, options for how skills groups might be provided across the city with a potential model for delivery.

Key to the development of provision was clinical accountability, governance and leadership of the programme. A “hub and spoke” model of delivery was agreed upon with a DBT skills training group to be located in each of the three CMHT’s, all supported by the DBT consultation meeting.

An operational framework document was drafted with agreement that the PDMCN lead the service within a partnership between the two Care Groups. This document detailed leadership roles to enable development. Financial commitments were agreed upon and parallel meetings were held between senior psychological practitioners to determine referral criteria, referral pathway, skills group provision and evaluation.

Visits to the CMHT localities were made by the DBT Team Lead to discuss recruitment to the new team. Job plans were developed and expressions of interest to the team invited. Informal interviews took place and new team members commenced DBT Intensive Training in April 2016 completing this in January 2017.

Meetings were also held with the Paris team to establish clinical record keeping. The team went “live” on 1 April 2016.
The programme is supported by the PDMCN Clinical Governance forum and the City Wide Partnership Group. The team is multi-disciplinary as follows:

- Sara Demaine - DBT Team Lead/Adult Psychotherapist Band 8a
- Debbie Thrush - Adult CBT Psychotherapist Band 8a
- Trish Cohen - CMHN Band 6
- Andy Small - CMHN Band 6
- Helen Feaviour - OT Band 6
- Zellany Neal - Social Worker Band 6
- Sue Ellis - Service User Consultant Band 3
- Higher Assistant Psychologist - Band 5

**Current group provision**

Three groups take place across the city as follows;

- East locality - St. Mary’s House
- West Locality – Southfield House
- South Locality – The Vale Circles Day Centre

There are two practitioners leading each group with a senior psychological therapist in all groups. Each group has capacity for 11 people and there are currently 28 people in skills training. Specific referral information is detailed on page 15.

**The year ahead**

Groups are predicted to reach capacity in the autumn of 2017. The programme is therefore considering how those waiting for treatment will be supported and a waiting list group is being developed. Newly trained practitioners continue to consolidate their experience and develop confidence in their practice. Consideration to the development of a network of LYPFT DBT trained practitioners is ongoing to assist with maintaining capacity of the team and to attend to successor planning.

**Citywide DBT Satisfaction Survey**

The DBT satisfaction survey was piloted this financial year to learn about service users’ experiences of engaging in the DBT programme (a copy of the completed report is available from the PDMCN). Of the 26 people who were invited to take part in this a total of 16 (61.5%) responses were received. The survey explored service users’ experience of staff support, impact of DBT on their lives, accessibility of groups, challenges, helpfulness/unhelpfulness and general feedback on the DBT service. Service users were given the opportunity to explain their responses.

100% of the service users stated that they would recommend the DBT group. Service users’ responses across the three groups were positive, whilst some difficulties and challenges were recognised. The following are the key points from the feedback:

- Positive qualities of the staff team; understanding and sensitive approach, warmth, positivity and clarity of teaching.
- Feeling connected to peers with similar experiences.
- Difficulties opening up in a group. This increased anxiety.
- Practical learning from the modules was helpful to service users, helping to reduce distress, emotional
arousal and to cope in difficult situations.
   - Limited time for one to one support was acknowledged. Alongside some **uncertainty** about what staff support is offered,
   - Barriers to attending group included work / childcare commitments.

Overall the findings from the DBT satisfaction survey indicate that service users are finding DBT helpful. In response to the feedback, the service is considering how to overcome barriers and challenges that have been described by service users.

**Clinical outcomes for the Journey Day Service**

Four outcome measures are used routinely in the Journey Day Service. These include:

1. Service user consultant-led group interviews, which focus on the group members’ **experience** of participating in the Journey programme;
2. The Occupational Self-Assessment (OSA) (Baron et al, 2006), which provides a measure of service users’ perception of their own **competence** in fulfilling a number of occupational areas, and their perception of how much **value** (importance) they attribute to fulfilling those occupational areas.
3. The WHOQOL-BREF (see section above ‘Clinical Outcomes for Care Co-ordination’ for description).
4. CORE (see above for description).

The OSA and WHOQOL are conducted pre- and post-programme. CORE is administered at the beginning, mid-point and end of the programme.

**OSA data for clients completing Journey programmes 29-31 during 2016-2017**

The graph below sets out pre- and post-programme OSA **Competence** and **Values** scores for service users (n=16) who completed Journey programmes 29-31 in the year 2016-2017, and who completed pre and post measures. The post Journey scores showed a slight improvement in both competence and values domains however these were not statistically significant:
WHOQOL data for clients completing Journey programmes 29-31

The graph below sets out pre- and post-programme WHOQOL scores for 16 service users who completed Journey programmes 29 to 31, who completed pre- and post-measures.

The post measure scores across the physical, psychological and social domain showed improvements in perceived quality of life. The scores in the physical domain were statistically significant ($T$-test, $p=0.0324$). There was a slight decrease in post measure scores in the environmental domain; but this was not statistically significant.

It is interesting to note that statistically significant effects in the physical domain are consistent with last year’s outcomes. Journey incorporates an active action plan and routine, in addition the group energy and the lasting effects may help to understand these consistent statistically significant effects in the physical domain of the WHOQOL.

CORE data for clients completing Journey programmes 29-31

Pre- and post-programme CORE data was collected for a total of 15 service users. There were improvements in the Global Distress score and across all individual domains however none of these scores were statistically significant.
The scatterplot below compares pre- and post-treatment CORE *Global Distress* scores for the sample of 15 service users during 2016-2017, to determine reliable and clinically significant change. 7 (46.67%) service users demonstrated statistically reliable improvement.

Service user consultant-led group interviews

Data was available for a total of 15 service users who participated in the group interviews for Journey 29, 30 and 31. Findings revealed that service users had a positive experience of the service. Service users commented that staff were “understanding, knowledgeable, and supportive”. They also stated that the group helped them to feel like they were “not alone” and that they valued meeting people who had similar experiences to them. In addition a positive impact of the service user consultant role was noted where people felt “hopeful” for the future. Challenges were also identified such as difficulties with endings and lunchtimes. However, service users reported that lunch time became easier as weeks went on. Some service users also commented on some of the content feeling “rushed” and the ice breakers being “awkward”. However service users’ overall comments about their experience of the group were positive.
Service User Involvement

The Network offers a range of opportunities for all current and previous service users to become involved with service development, delivery and improvement. These reflect different points on the continuum of involvement and ways in which services can involve service users, as set out in Real Involvement – Working with people to improve health services (Department of Health, 2008).

Re-imagining Service User Involvement Event – November 2016

Following last year’s review and strategy development for involvement in the Network, a conference event was held in November 2016 at the Thackray Medical Museum. The day was co-developed and co-delivered by members of the Service User Involvement Group and Network staff, and included a range of presentations and small-group discussions.

The day was attended by about 40 people; about 25% of attendees were service users and carers, including service users from both local community and local specialist hospital settings. Attendees also included staff from across LYPFT and a number of other services and organisations such as Carer’s Leeds, Community Links and Leeds Involving People. Feedback from this event has led to a co-developed strategy for structured, meaningful and sustainable involvement across all aspects and levels of its services. A new Involvement Steering Group has been convened and will start meeting regularly in June 2017.

Involvement roles

Service user involvement has been led by the service’s Involvement Lead and a Service User Consultant (SUC) employed by the Network. The SUC has had a number of roles, including facilitating the Service User Involvement Group (SUIG), sitting on interview panels for staff recruitment. The current SUC’s contract ended in March 2016; however the service is awaiting confirmation of funding for a new SUC post.

A part-time SUC for the City-Wide DBT service has been employed this year to provide peer support to one of the DBT skills groups. This worker has lived experience of Personality Disorder and has attended DBT groups herself in the past, and uses this to help current group participants. This post is part of the City-Wide DBT group pilot scheme which is co-funded between Leeds Care Group and the Network. The post will be reviewed next year with a view to providing future support across all three skills groups.

Two volunteer SUCs works as part of the staff team in the Journey service. They have completed Journey themselves and use this and their life experiences to help current participants. They attend group supervision with Journey staff and are involved with evaluation of the Journey groups.
The Service User Involvement Group

The SUIG meets every two weeks. It is a work focussed group and typical tasks are reviewing policies, looking at changes the service is planning and using service user experiences to influence this. Some of the work is for the Network and some of it is Trust-wide. The Annual Service User Satisfaction Survey is an example of the group’s involvement. The group considers the content and wording of the questionnaire before it is distributed to clients and reviews the draft report to make recommendations for inclusion in the report. The group also produces and edits the Validate Newsletter, which is produced 3-4 times a year and offers service users a chance to explore their creative side. The newsletter is filled with information about the Network and beyond and is distributed to all current and some previous clients of the Network. Members of the group are also invited to attend Clinical Governance meetings.

Membership of the group has been small and following the event in November, it was agreed that the scope of the group should be extended to involve any LYPFT service users with lived experience of Personality Disorder, rather than only those who have used the Network. A re-launch of the group is planned for June 2017.

Involving Young People

The Network has particularly struggled to engage younger service users (18-25) in Involvement. Following feedback from the event in November, plans are in development for a future event to meet with younger service users in order to gain their views and feedback on how they would like to be involved in service development and delivery.

Project work

Social Media Survey: A questionnaire on the use of social media has been co-designed by the SUIG and the Network’s Assistant Psychologist. This is to explore the current use of social media by our service users and how they might want the Network to engage and use social media in the future. The questionnaire has been sent to all current service users and the results will inform the development of the service’s future social media strategy.

Conferences

British and Irish Group for the Study of Personality Disorder Conference 2017. Leeds Personality Disorder Services led a Symposium on ‘Reimagining Service User Involvement’ at this conference, which consisted of a series of three presentations from the PD Network, the Pathway Development Service, and the Offender Pathway Development Service. The Service User Consultant and Network Clinical Team Manager co-developed and co-presented for the Network. Staff from the service also attended a number of other presentations on Involvement during the conference.
Service User Satisfaction Survey

A Service User Satisfaction Survey was conducted in April 2017 (a copy of the completed report is available from PDMCN). Of the 64 service users invited to participate in the survey, 39 responses were received. This year’s response rate of 61% was 17% higher than last year’s rate of 44%. These responses included 5 from care coordinated service users, 10 from Journey group members, and 24 from DBT group members.

The survey examines service users’ feedback on various areas of the Network’s service, these include; service expectations, staff support for and understanding of service users, the impact of service on service user’s lives, complaints procedures, clarity of correspondence, service user involvement and general feedback on the service individuals received. The survey also offers the opportunity for service-users to give some explanations for their responses and general feedback on the service.

82% of respondents chose ‘Excellent’ or ‘Good’ as their response to the question ‘Overall, how would you rate the service you receive from the network?’

Overall, how would you rate the service you have received from the Network? (n=39)

The findings from this year’s survey indicate that the majority of service users feel very positively about the Network and they rate the services they receive highly. However this is 18% lower to the responses reported in 2016 of 100% and 8% lower than responses reported in 2015 (90%).

Feedback from the survey included the following:

- **Service expectations and staff support**: Overall, ratings in this area were positive. 87% of service users felt they were clearly informed about what the service can provide and 79% felt well supported by the service and staff.
‘What has been good about the service you have received?’ The responses to the open questions revealed a number of positive qualities about the Network. These included the supportive, understanding and consistent approach of the staff/service; the development of self-understanding and opportunities to meet service users with similar experiences. Overall the majority of open question responses were positive about the PD Network.

‘What could be improved?’ Key criticisms were also reported, these included some service users feeling less individually understood by staff, limited amount of time and one to one support, services’ socio-political awareness, difficulties in communication, group content and environment.
Service User Safety

A total of 62 Datix incidents were reported to the PDCMN between 1st April 2016 and 31st March 2017. This is a 6% decrease compared to last year’s 66 reports.

It is notable that there were more service users accessing Network services during 2017 (n=97) than in 2016 (n=91). This being the case, there was an average of 0.64 incidents per service user in 2017 compared to 0.73 incidents per service user in 2016. This suggests a small ‘real term’ decrease in serious incidents this year in comparison to last year.

The graph below breaks down the category of the incidents for each year (2015-2016 and 2016-2017).

The majority of incidents this year were related to self-harm (n=36), however this is a 21% decrease from last year’s reported figure of 46. Compared to 2015-2016 there has been a slight reduction in substance abuse, verbal abuse, clinical patient care, medication and security incidents and there has been a slight increase in fire/smoking, public violence, staff violence, violence (assault) incidents. There has also been one serious death incident reported in 2016-2017 compared to last year (n=0).
Compared to the year of 2015-2016 there has been a 55% decrease in incidents where no harm was caused. There has been a 6% increase in 'low' and 23% increase in 'moderate' severity incidents and one death incident reported in 2016-2017.

Similar to the year of 2015-2016 the demographics of people affected by the incident are predominantly White British and female.

**Summary**

In summary, there appears to have been a slight decrease in the number of risk incidents this year in comparison to the previous year; however the severity of the incidents reported appears to have increased.
Working with Carers

Six-week Psychoeducational Course for Carers of People with Personality Disorder

A carers’ group was facilitated by Leeds PD Services in November-December 2016. The group aimed to provide education about personality disorder, to support carers in thinking about what caring for someone with a personality disorder might entail, and to consider self-care as an essential part of caring. The group was facilitated by a Clinical Psychologist, a Care Coordinator and a Service User Consultant and was held at a local social services day centre. The group met weekly on a Thursday evening for six weeks. Each group session lasted for two hours.

Attendees

Eight carers attended the first group, one of whom decided not to attend further.

Of the remaining seven carers, five attended all six sessions, and two attended five sessions. Six carers were female and one was male. Five were in the age group 56-65, one was 46-55, and one was 26-35. All described themselves as White British. They cared for a range of relatives including children, parents, siblings and grandchildren. Some of these individuals had received a diagnosis of Personality Disorder, others had not received a diagnosis but their difficulties seemed consistent with such a diagnosis. Four carers had previous contact with Leeds Carers services and two had previous contact with Leeds PD services.

The majority of attendees heard about the group via an advert in the “Carer’s Leeds” newsletter. A number of current PD Network Service Users and carers had been given invitations directly by staff but only one attendee was a carer for someone currently involved with the Network.

Evaluation

Outcomes of the group were measured using three short measures.

1. The Personality Disorder: Knowledge and Skills Questionnaire (PD-KASQ), adapted for Carers specifically for this group. The PD-KASQ measures understanding, capability and emotional responses regarding working with people with personality disorder.

The scores for the PD-KASQ indicate a significant positive change (p= 0.00045) in carers’ knowledge and skills regarding Personality Disorder. It should be noted however that this adapted version of the PD-KASQ has not been validated.

2. The Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS) which is a brief self-reported measure of wellbeing. This measure is well-validated and is used extensively across NHS settings.

The scores for the SWEMWBS suggest some improvement in carer wellbeing following the course, although this was not a statistically significant change (p=0.43).

3. The Carer Satisfaction Questionnaire which contains eight statements relating to satisfaction with the group scored on a 4-point Likert scale. Statements relate to the overall quality, supportiveness and helpfulness of the group. The questionnaire also contains 3 open questions for further comments.
Overall, satisfaction scores regarding the group were high, with the majority of responses falling into the 'very satisfied' or 'mostly satisfied' categories, with only one response being 'somewhat satisfied' and no responses falling into the 'not satisfied' category. A brief thematic analysis identified a small number of themes from the open questions:

What was most helpful about the group?
- Opportunity to share and hear stories and experiences with other carers
- Feeling validated and hopeful
- Opportunity to learn and receive information about personality disorder
- Facilitators seen as interested, helpful, professional, knowledgeable and experienced

What could be changed or added to the group?
- More time to discuss topics and issues in-depth
- Opportunities for discussions in pairs/small groups rather than always in the large group
- The group should lead on to further ongoing support
- A need for balance between discussion of specific topics and provision of more 'open space' for support and general discussions

Reflections

Some reflections from the facilitators:
- The challenge of balancing psychoeducation, peer support and developing carer wellbeing
- The value of involving Experts-by-Experience
- The importance of being realistic about group expectations

Some reflections from a carer:
- “We gained an insight into Personality Disorders, learned how to provide support to those with the condition and had the opportunity to meet with other carers... We learnt about one another’s stories slowly and gradually and as the weeks went by we grew in trust. Our experiences varied [but] each of us joined this carers’ group because we were concerned about our family member and also because we needed support ourselves”.
- “Having the support of other carers in the group was invaluable. It can be difficult to find the words to explain the impact of another person’s Personality Disorder, especially when they are the people we care for. In the group I found I didn’t need to over explain as I felt that there was a lot of understanding and empathy amongst us”.
- “There is a need for more face-to-face peer support groups for carers of someone with a Personality Disorder [to] provide a safe space in which we can share, learn from and support each other”.

Future plans for working with Carers
- Plans are in place to run the psychoeducational group three times during the 2017-2018 financial year, with the aim of recruiting a Carer Expert-by-Experience to co-facilitate the groups with a member of Network staff. A second staff member will be available to cover sickness absence, etc. The groups have been planned to run at different times of day and in different venues in order to improve accessibility.
- Work is ongoing with Network staff to consider how we can best connect with and support carers of current users of Leeds PD services, who were not well represented in this pilot group. This will involve ensuring information is provided to all new service users of the Network regarding support available for carers.
- Discussions are continuing with the group members and Carers Leeds to develop an ongoing peer support group for carers of people with Personality Disorder. A bi-monthly peer-led support group is being planned in partnership with Carers Leeds, with the aim of being co-facilitated by a Carer Expert-by-Experience and staff from the Network/Carers Leeds.
Training, Conferences and Consultancy

The Network provides Personality Disorder specific training regionally to statutory and voluntary sector services and probation and criminal justice services.

Training Provision

Staff deliver the accredited National Personality Disorder Knowledge and Understanding Framework (KUF) – Awareness Level training, and have also contributed to teaching on the KUF BSc course. This training is a combination of e-learning and facilitated learning days.

In addition, staff regularly participate in the training and development of students, including nursing, occupational therapy and psychology.

Other training provided by staff during this Annual Review period included the following:

- Personality Disorder teaching to Leeds IAPT Team, Sign Health and Graduates in LYPFT
- Teaching on Personality Disorder at Specialist Section Conference
- Teaching on D Clin Psychol course ‘Introduction to working with Personality Disorder’
- Teaching on ‘Working with Personality Disorder’ to Children’s Social Work Therapy Team
- Workshops at BIGSPD on service user involvement

Staff Development and Training

All staff are supported in developing their own therapeutic and technical skills with a mixture of individual courses and team development days. Team Development Days have included learning on ‘Working with young adults – Understanding how adolescence is affected by early emotional deprivation and trauma’, ‘Support After Rape and Sexual Violence (SARSV)’, ‘Compassion Focussed Therapy’.

All staff make a commitment to finding a way of bringing some of the learning back into the team. We have funded and supported staff in a range of training and development this year, including KUF BSc and MSc modules, KUF “Train the Trainer”, Sensory Integration, LYPFT Appraisal, Qualitative Research Methods, Writing for Publication, Cochrane library and PREVENT.
Conferences

PDMCN staff have attended the following conferences and workshops:

- **BIGSPD 2017 including presentations (Service User Involvement in Leeds PD Services, PDS poster)**
- **BABCP Workshop on CBT Supervision**
- **DCP Conference on Personality Disorder and Involvement**
- **Reimagining SU Involvement in Leeds PD Services (coproduced and co-facilitated with service users)**
- **DBT North ‘Endings and Transitions in DBT’**
- **Society of DBT Annual Conference**
- **DBT North - Completing Chain Analysis**
- **BABCP event ‘Using DBT to treat young people with suicidal & self-harming behaviours’**
- **LYPFT Specialist & LD Conference including presentations ‘How a model & multi-agency working seemed to get it right’**
- **Clinical Psychology Pre-qualification Group Annual Conference**
- **‘Funding changes for healthcare students’ conference**
- **Rapid Improvement Event (Risk and Safety)**

Consultancy, Reference and Networking Groups

Network staff have been involved with the following:

- A number of staff are part of the BIGSPD Community of Practice
- Sara Demaine co-ordinates DBT North, quarterly CPD meetings to promote adherence and best practice in the delivery of DBT
- Helen Easton is part of the MBT national network and the network of Psychoanalytic practitioners working with service users with complex needs (including tutors from the Portman Clinic’s).
- Tom Mullen is the co-President of the British and Irish Group for the Study of Personality Disorder (BIGSPD).
- Sharon Prince is a committee member of BIGSPD and also offers consultancy to the BME Workers’ Group within Community Links.
- Paul Butler is a member of the Educational Lead Forum

Research, Development and Publication

The Network is committed to producing service evaluation projects and research of a high standard.
Research and Evaluation activity is discussed and promoted within the PDMCN clinical governance meetings.

**Social media project** – an ongoing project which commenced this financial year aims to investigate the different types and communication, internet and media use of service users in the PDMCN. This is to understand how and if as a service we can use media to support our service users.

**Self-help project** – an ongoing project which commenced this financial year aims to assess the quality of self-help materials which may be recommended by staff to service users and/or carers.


**Young Person’s Model** - The PDMCN model for working with young adults with personality disorder continues to be piloted. At the end of the financial year there were two young people accessing this model.
References


- Department of Health (DoH, 2008). *Real Involvement – Working with people to improve health services*


Appendices

- Appendix 1- Consort Diagram of referrals through the Network
Appendix 1. Consort Diagram of referrals through the Network

Total Referrals to PDMCN 2016-2017
N=288 (279 external, 9 internal)

Referred within PDMCN
N=152 (plus 23 to be allocated)

Care Co-ordination N=19
(plus additional N=2 referred end of 2015-2016)

DBT N=66

Care pathway management
N=113

Total Assessed 2016-2017 N=66
31 = accepted for DBT
7 = did not meet criteria
4 = group not appropriate
7 = did not engage in assessment
17 referrals received at the end of the financial year have been carried over for assessment 2017-2018

Total Assessed 2016-2017 N=77
32 = accepted for Journey
10 = clients disengaged
4 = group not appropriate
6 = no longer interested in group
25 = assessments ongoing

Journey N=67
(plus addition N=10 referred end of 2015-2016)

Total Assessed 2016-2017 N=21
8 = accepted for CC
3 = clients disengaged
3 = not offered CC
1 = moved OOA

6 referrals received at the end of the financial year have been carried over for assessment 2017-2018