A Service User Evaluation of the IAPT for SMI Demonstration Sites

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Executive Summary

Background

This report presents findings from a user-focused evaluation of the six demonstration sites providing IAPT services for people with severe mental illness. The evaluation sought to put the views of people living with a severe mental illness at its heart, and the core evaluation team included three researchers with personal experience of mental health problems. The overarching aim of the project was to capture the range of experiences and perspectives of two distinct groups of people – those who engaged with the IAPT for SMI service, and those who were referred to the service, but did not go on to receive therapy – and to make recommendations where people identified room for improvement in the services.

The evaluation used a mixed method approach, consisting of:

- A survey of 305 respondents from across the six demonstration sites (241 IAPT service users, and 64 IAPT service non-users)
- Semi-structured interviews with 61 individuals strategically sampled from across the sites who completed the survey

Findings

The evaluation found that satisfaction with the IAPT for SMI services was generally very high. Overall, survey and interview participants were pleased with the way in which the therapy was provided, and their relationship with their therapist, and also felt that the service had impacted positively on their day-to-day lives. The less positive aspects of people’s experiences tended to be related to access issues and assessment processes – notably waiting times and the information and support offered during waiting times – as well as the structure, organisation and communication practices of the services. People who had not engaged with the IAPT for SMI service were more likely to report these negative experiences. Finally, the qualitative data in particular highlighted the challenges around receiving and accepting a diagnosis of Personality Disorder.

Based on our findings, we identified twelve recommendations for improving the IAPT for SMI service:

1. Simplification of the referral process.
2. Clear information about what to expect from therapy, including: commitment required from service user, types of therapy on offer and choices people have about their therapy; timings and number of sessions; and endings and planning ahead for completion.
3. Information around, and promotion of, ongoing peer support available locally.
4. Information and clarity around diagnosis; and Personality Disorders in particular.
5. Reduction in waiting times and the provision of clear information about waiting times at the outset.
6. Good communication, information and support from IAPT service, and other services, agencies and organisations, during the waiting period.
7. Flexibility and accommodation of individual needs regarding the delivery of the therapy.
8. Good organisation, communication and ‘customer service’ throughout.
9. Strong improvement of therapeutic relationship through providing a validating atmosphere and non-judgemental approach. Self-disclosure may sometimes help with this.
10. Strong boundaries on the part of the therapist during group sessions.
11. Ease of access regarding practical considerations such as work / childcare commitments and travel problems.
12. Increased follow-up support.
Background

Improving Access to Psychological Therapies (IAPT) started in 2006 to support the provision of talking therapies for people of working age with depression and anxiety. In 2011, the Government made a commitment to expand access to psychological therapies in England to include three new strands: children and young people; people with long-term physical conditions or medically unexplained symptoms, and people with a severe mental illness (SMI), specifically, with diagnoses of Psychotic Disorders, Bipolar Disorder and Personality Disorders (Department of Health, 2011).

In November 2012, six demonstration sites were selected and funded to deliver IAPT for people with SMI, and these pilots were operational until 31 March 2015. The sites were chosen for their ability to deliver NICE approved and evidence based psychological therapies to people with diagnoses of Psychotic Disorders, Bipolar Disorder and Personality Disorders as a frontline therapy. The sites are¹:

Providing psychological therapies for Psychosis:

• Lancashire Care NHS Foundation Trust²
• South London and Maudsley NHS Foundation Trust

Providing psychological therapies for Bipolar Disorder:

• Birmingham and Solihull Mental Health Foundation Trust and Spectrum Centre for Mental Health Research, Lancaster University (working in partnership)

Providing psychological therapies for Personality Disorders:

• Barnet, Enfield and Haringey Mental Health Trust
• North East London NHS Foundation Trust
• Somerset Partnership NHS Foundation Trust

These pilot sites are being evaluated to determine the benefits of IAPT for SMI to service-users, the staff working in services, the NHS and the economy as a whole.

This report forms part of the overarching IAPT for SMI evaluation by presenting the views and experiences of people who used the services in these six demonstration sites following a user focused evaluation design. It sought to capture views from people who completed and benefited from the therapy, and also those who did not engage, discontinued their therapy or did not benefit. The evaluation was commissioned and funded by NHS England, as the body responsible for making recommendations around the commissioning of these services. The specific aims of this service user evaluation are:

1. To capture the perspectives of those using the service in relation to the effectiveness of IAPT for SMI
2. To describe the experiences and levels of satisfaction of those using the IAPT for SMI services
3. To capture the views and rationale of those who chose not to use the IAPT for SMI services
4. To capture any recommendations for improvements in the IAPT for SMI services
5. To compare the views of those who completed therapy and those who did not complete therapy

¹ See Appendix 1 for more information about each of the sites and the services they provide.
² For brevity, throughout this report we refer to the sites as follows: Lancashire; SLaM; BSMHFT; BEH; NEL and Somerset.
Methodology

Collaborative Approach

This project proactively sought to put the views of people living with a severe mental illness at its heart through working collaboratively with researchers who had this personal experience themselves. The evaluation team consisted of three ‘peer’ or ‘service user’ researchers working alongside two researchers based at the McPin Foundation. The peer researchers were integral to all phases of the project – evaluation design, data collection, analysis and reporting – and conducted all of the qualitative interviews. There was also scope for them to provide some localised logistical support to the sites. In addition to the involvement of the peer researchers, the project consulted with a number of service user representatives from the sites, as well as the McPin Foundation’s own Peer Review Panel, which consists of service users and carers, on the design of the data collection tools.

This collaborative approach was felt to be important to providing a good understanding of the experiences of people using the service, to build rapport with those people being interviewed, and to ensure that the views of potential beneficiaries were kept as the central focus of the evaluation at all times. Towards the end of this report, our peer researchers offer some reflections on their experience of having been involved in this evaluation.

Evaluation Design

The study was designed in two stages:

- First, a survey co-designed with the peer researchers, the demonstration sites, and the McPin team to capture feedback from people using IAPT for SMI services, or those invited to use services
- Second, a strategically selected sample of survey respondents from across the sites were interviewed by peer researchers to explore views and experiences in greater detail

Survey

The key objective of the survey questionnaires was to capture as wide a range of views as possible. We developed two separate questionnaires (Survey 1 and Survey 2 – see Appendix 3) for distribution across service users who did, and those who did not, use the IAPT for SMI service. In doing so, we drew on the specific evaluation questions raised by the tender, the lived experience of the team members, and previously developed questionnaires on related topics. This included our own ‘Talking Back’ survey which was previously developed with service users for use in IAPT services in London, as well as the brief Patient Experience Questionnaire (PEQ) used by the IAPT for SMI sites. Both versions of the IAPT for SMI questionnaires were reviewed by our Peer Review Panel. Each of the questionnaires was modified to fit with the specificities of each service and make it as relevant as possible to potential respondents. In some cases, this involved adding extra questions or answer options, or removing questions that were not felt to be relevant. We also adapted the wording of questions to correspond to the wording used by the services. For example, some of the Personality Disorder services requested that we used the word ‘treatment’ instead of ‘therapy’.3

Survey 1 (IAPT service users)

- Those in the process of having therapy
- Those who had completed therapy

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3 For simplicity, throughout this report, we use the word ‘therapy’.
• Those who had started, but discontinued therapy

Survey 2 (IAPT service non-users)

• Those that were referred to the service but did not complete an assessment
• Those that completed an assessment with the service but did not go on to receive therapy

In-depth interviews

For the second phase of the evaluation, two interview schedules were developed by the team to address the questions outlined in the tender document in more depth and explore the range of experiences of the services (see Appendix 4). Both interview schedules were reviewed by service user representatives from the demonstration sites.

Data Collection

Survey

We worked closely with each of the six sites to ensure that the questionnaire was made available to all service users who had engaged with the service since it became a demonstration site in November 2012. It quickly transpired that given the time and budgetary constraints on the project, post, rather than email or distribution at the sites, would be the most appropriate mechanism for distribution, and ensured that only eligible respondents received a questionnaire. Some sites were provided with posters to help publicise the survey, and localised support, for example, help with filling out the survey at a service user event, was provided by the peer researchers where requested.

Questionnaires were addressed and posted out by the services themselves, with one service requesting that the McPin Foundation use their own franking facilities to send the envelopes once these had been addressed by the service. The approach taken was to provide flexibility to the sites to encourage maximum engagement in the process. Completed questionnaires were returned directly to the McPin Foundation offices using a supplied freepost envelope. Respondents could choose to remain anonymous; however, we invited all respondents to indicate whether they would be willing to take part in an interview, and to provide contact details if so. To encourage responses, we offered respondents entries into a prize draw to win prizes worth up to £100, with contact details for the prize draw filled in on a separate slip which was removed from the survey upon receipt. A small number of questionnaires were completed at service user events attended by peer researchers, who were able to offer respondents support with completion where this was needed.

In-depth Interviews

We selected a sample of participants to interview from those who indicated that they would be interested in this in their returned questionnaire. We sought to interview 10 service users from each site – a total sample size of 60 – and looked to sample strategically, rather than representatively, capturing a range of length of engagement (including people who chose not to engage), experiences and demographics. Our final sample was limited by the number and type of opt-ins to interview for each site, and was as follows:
Table 1 – Interviewees’ engagement with the IAPT for SMI service

<table>
<thead>
<tr>
<th></th>
<th>BEH</th>
<th>BSMHFT</th>
<th>Lancashire</th>
<th>NEL</th>
<th>SLaM</th>
<th>Somerset</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People who chose not to engage with the IAPT SMI service</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>People who started with the IAPT SMI service but did not complete</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>People who completed sessions and report broadly positive experiences</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>People who completed sessions and report broadly middling (or at least some negative) experiences</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>10</td>
<td>10</td>
<td>6</td>
<td>10</td>
<td>10</td>
<td>15</td>
<td>61</td>
</tr>
</tbody>
</table>

During the interview set-up, all participants were given clear information about the evaluation, including around consent, anonymity and confidentiality, and completed a Participant Preference Form with a member of the evaluation team. Participation in the interviews was incentivised with a £20 shopping voucher. The vast majority of the interviews were conducted over the phone at a time that was convenient for them, ensuring that there was evening and weekend availability of interviewers. One participant had a strong preference for a face-to-face interview, which we were able to arrange. All participants consented to their interviews being audio recorded and transcribed. All interviews were carried out by the peer researchers, who had a ‘Distress Flowchart’ they could refer to if they had any concerns about a participant’s wellbeing. They were also encouraged to remain aware of their own wellbeing throughout the duration of the project, and to seek support from the researchers at the McPin Foundation if needed.

**Analysis and Reporting**

Quantitative analysis was completed using Microsoft Excel software. Statistics were conducted descriptively, including where comparisons were made, as the small samples sizes generally meant that inferential analyses were unwarranted. The majority of the quantitative analysis was split across Survey 1 (people who used the IAPT service) and Survey 2 (people who were referred to, but did not use, the IAPT service) responses, as many of the questions were not transferrable across the two subpopulations of respondents. However, a small number of questions were included in both surveys, and for this reason demographic data and data on referral routes are presented across both groups of respondents. All analyses presented on ‘IAPT service users’ refer to those people who were eligible for Survey 1: those in the process of having therapy; those that had completed therapy; those that had discontinued therapy; and those that were about to begin therapy. All analyses that are presented on ‘IAPT service non-users’ refer to those people who were eligible for Survey 2: those that were referred but did not complete an assessment; and those that completed an assessment and did not go on to receive therapy. It is important to remember that the total numbers – even when aggregated across all sites – represent small numbers of individuals who chose to opt in to this evaluation, and should not be assumed to represent the experiences of IAPT for SMI service users and non-users as a whole.
Qualitative analysis was completed thematically. Part way through data collection, the team met and agreed on an initial set of themes based on the analysis of a small number of transcripts. Towards the end of the interviewing phase, a coding framework was finalised over the course of a two-day analysis session, with all transcripts analysed by at least one member of the evaluation team. This analysis process was also applied to all of the qualitative comments provided in the surveys. Throughout the report, the qualitative data is intended to illustrate in more detail the diversity of experiences reported, rather that proportionally represent the frequency of certain kinds of experiences, and quotes were selected for inclusion in this report on the basis that they communicate a range of experiences succinctly and engagingly. It is also important to note that the project timescales did not permit us to analyse the qualitative data in more depth, but there will be scope to do this in an addendum to this work due to take place from April – August 2015, on the basis of which the evaluation team hopes to produce a peer review publication.
Respondent Characteristics

The overall response rate for Surveys 1 and 2 combined was 12%, ranging from 5% to 21% across the different sites.\(^4\) The total number of surveys completed was 305, with 241 IAPT service users completing surveys, and 64 IAPT service non-users. Of those who completed the survey (\(n = 305\)), 60% (183 individuals), opted in to the interview phase. Table 2 below provides an overview of the response rates for both surveys broken down by site.

Table 2 – Response rates by site

<table>
<thead>
<tr>
<th></th>
<th>Total sample (n=305)</th>
<th>BEH (n=57)</th>
<th>BSMHF (n=31)</th>
<th>Lancashire (n=16)</th>
<th>NEL (n=57)</th>
<th>SLaM (n=79)</th>
<th>Somerset (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number sent</td>
<td>2515</td>
<td>475</td>
<td>270</td>
<td>156</td>
<td>600</td>
<td>182</td>
<td>300</td>
</tr>
<tr>
<td>Number received</td>
<td>305</td>
<td>57</td>
<td>31</td>
<td>16</td>
<td>57</td>
<td>11</td>
<td>52</td>
</tr>
<tr>
<td>Response rate</td>
<td>12%</td>
<td>12%</td>
<td>11%</td>
<td>10%</td>
<td>10%</td>
<td>6%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Table 3 on the following page provides an overview of the demographic characteristics of people taking part in the survey, broken down by site.\(^5\)

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\(^4\) A number of sites reported that they were aware that some surveys may have been returned undelivered due to having an outdated address on record. As one of the site’s surveys were posted from our office address, we were able to ascertain the delivery failure rate for this site, which was 1.8%. This was one of the London sites, in an area where people are arguably more likely to move addresses frequently, and we therefore estimate that the overall delivery failure rate would be no higher than this for the sample as a whole.

\(^5\) In the creation of all the tables and graphs in this report, we have excluded data that was missing, ‘prefer not to answer’, or ‘not applicable’ unless otherwise specified.
Table 3 – Survey respondents’ demographics

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Total sample (n=305)</th>
<th>BEH (n=57)</th>
<th>BSMHFT (n=31)</th>
<th>Lancashire (n=16)</th>
<th>NEL (n=57)</th>
<th>SLaM (n=79)</th>
<th>Somerset (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Total</td>
<td>Survey 1</td>
<td>Survey 2</td>
<td>Total</td>
<td>Survey 1</td>
<td>Survey 2</td>
<td>Total</td>
</tr>
<tr>
<td>Female</td>
<td>220</td>
<td>177</td>
<td>43</td>
<td>48 (87%)</td>
<td>32 (89%)</td>
<td>16 (84%)</td>
<td>24 (89%)</td>
</tr>
<tr>
<td>Male</td>
<td>68</td>
<td>50</td>
<td>18</td>
<td>7 (13%)</td>
<td>4 (11%)</td>
<td>3 (16%)</td>
<td>3 (11%)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean</td>
<td>40</td>
<td>40</td>
<td>39</td>
<td>39</td>
<td>54</td>
<td>40</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White (British, Irish, Other White Background)</td>
<td>226 (79%)</td>
<td>181 (80%)</td>
<td>45 (85%)</td>
<td>47 (86%)</td>
<td>16 (84%)</td>
<td>21 (78%)</td>
</tr>
<tr>
<td></td>
<td>Black (African, Caribbean)</td>
<td>22 (8%)</td>
<td>17 (8%)</td>
<td>5 (8%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td></td>
<td>Asian (Indian, Pakistani, Bangladeshi, Chinese)</td>
<td>14 (5%)</td>
<td>11 (5%)</td>
<td>3 (5%)</td>
<td>2 (4%)</td>
<td>1 (3%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td></td>
<td>Mixed (White &amp; Black African / Caribbean, White &amp; Asian)</td>
<td>17 (6%)</td>
<td>13 (6%)</td>
<td>4 (5%)</td>
<td>3 (5%)</td>
<td>2 (6%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6 (2%)</td>
<td>3 (5%)</td>
<td>3 (5%)</td>
<td>2 (6%)</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
Figures provided by the NHS England IAPT for SMI programme indicate that across all users of, or those referred to, IAPT for SMI since its inception in November 2012, 70% were female and 30% male, which broadly corresponds to our overall survey sample. The survey included two transgender respondents. Eighty per cent of our sample identified as White British, which is also in line with the figures provided by NHS England. Despite this, there was some disparity between populations using, or referred to, the service, and those who responded to our survey, within individual services. For instance, Black respondents were particularly underrepresented in two of the London sites in relation to the numbers using, and referred to, the service. It is also important to note that for the third London site, SLaM, the split between BME and non-BME service users and respondents was roughly equal.

Four out of five survey respondents described their sexual orientation as heterosexual, 10% described themselves as bisexual, while 6% described themselves as either gay or lesbian.

Over half of the survey respondents self-identified as having a disability, which could be a physical, visual, hearing, learning, or ‘other’ disability. Some people who ticked ‘other’ stated that they considered their mental health problem to be a disability.

A third of the survey respondents declared that they had caring responsibilities of some nature.

Sixty per cent of survey respondents described themselves as having a religion, including Christian (49%), Muslim (6%) and Buddhist (4%), while 31% stated that they had no religion.

Table 4 below indicates the self-reported diagnoses of survey respondents, broken down by service.\(^6\) It is important to note that a diagnosis, or lack thereof, did not always correspond to the service specialism, and also that some people stated that they had multiple diagnoses.

### Table 4 – Survey respondents’ diagnoses

<table>
<thead>
<tr>
<th></th>
<th>Total sample (n=305)</th>
<th>BEH (n=57)</th>
<th>BSMHFT (n=31)</th>
<th>Lancashire (n=16)</th>
<th>NEL (n=57)</th>
<th>SLaM (n=79)</th>
<th>Somerset (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Psychotic Disorder</td>
<td>68</td>
<td>24%</td>
<td>5</td>
<td>9%</td>
<td>4</td>
<td>14%</td>
<td>12</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>66</td>
<td>23%</td>
<td>11</td>
<td>20%</td>
<td>27</td>
<td>93%</td>
<td>3</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>123</td>
<td>43%</td>
<td>44</td>
<td>81%</td>
<td>1</td>
<td>3%</td>
<td>2</td>
</tr>
<tr>
<td>Any other diagnosis</td>
<td>63</td>
<td>22%</td>
<td>12</td>
<td>22%</td>
<td>1</td>
<td>3%</td>
<td>4</td>
</tr>
<tr>
<td>Don’t know</td>
<td>24</td>
<td>8%</td>
<td>4</td>
<td>7%</td>
<td>1</td>
<td>3%</td>
<td>0</td>
</tr>
<tr>
<td>No diagnosis</td>
<td>9</td>
<td>6%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 5 below provides an overview of the demographic characteristics of people taking part in the interview, broken down by site. Where possible, we tried to interview those that were underrepresented in the survey demographics. This is why, for example, there is a slightly higher proportion of males in the interview sample than the survey sample, and the age range reflects the range found across the survey sample. For the same reasons, we prioritised respondents from BME backgrounds when setting up interviews. However, it is important to note that our ability to sample for interview was limited not only by who opted in to this stage of the evaluation, but also by whether or not they were contactable within a certain timeframe.

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\(^6\) Here and elsewhere in this report, all data on ‘diagnosis’ is self-reported.
interview was limited not only by who opted in to this stage of the evaluation, but also by whether or not they were contactable within a certain timeframe.

Table 5 – Interview participants’ demographics

<table>
<thead>
<tr>
<th></th>
<th>Total sample (n=61)</th>
<th>BEH (n=10)</th>
<th>BSMHFT (n=10)</th>
<th>Lancashire (n=6)</th>
<th>NEL (n=10)</th>
<th>SLaM (n=10)</th>
<th>Somerset (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>38 67%</td>
<td>8 80%</td>
<td>7 78%</td>
<td>4 67%</td>
<td>7 78%</td>
<td>5 50%</td>
<td>7 54%</td>
</tr>
<tr>
<td>Male</td>
<td>19 33%</td>
<td>2 20%</td>
<td>2 22%</td>
<td>2 33%</td>
<td>2 22%</td>
<td>5 50%</td>
<td>6 46%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>41 43</td>
<td>47</td>
<td>26</td>
<td>37</td>
<td>42</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>20-76</td>
<td>33-59</td>
<td>32-57</td>
<td>24-29</td>
<td>20-66</td>
<td>30-63</td>
<td>20-76</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (British, Irish, gypsy)</td>
<td>46 76%</td>
<td>7 70%</td>
<td>8 80%</td>
<td>5 83%</td>
<td>7 70%</td>
<td>7 70%</td>
<td>13 87%</td>
</tr>
<tr>
<td>Black (African, Caribbean)</td>
<td>1 2%</td>
<td>0 0%</td>
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<td>0 0%</td>
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<tr>
<td>Asian (Indian, Pakistani, Bangladeshi, Chinese)</td>
<td>4 6%</td>
<td>1 10%</td>
<td>1 10%</td>
<td>1 17%</td>
<td>0 0%</td>
<td>1 10%</td>
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<tr>
<td>Mixed (White &amp; Black African / Caribbean, White &amp; Asian)</td>
<td>4 6%</td>
<td>2 20%</td>
<td>0 0%</td>
<td>0 0%</td>
<td>1 10%</td>
<td>0 0%</td>
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<tr>
<td>PNA / Missing</td>
<td>6 10%</td>
<td>0 0%</td>
<td>1 10%</td>
<td>0 0%</td>
<td>2 20%</td>
<td>1 10%</td>
<td>2 13%</td>
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The diagnoses given for each service broadly reflect the diagnosis specific target groups (BEH, NEL & Somerset offered Personality Disorder services; BSMHFT offered a Bipolar Disorder service, and Lancashire and SLaM offered Psychosis services). Somerset had two services included in the survey, one for primary care users and one for secondary care users, which has resulted in a more diverse range of diagnoses being included. Almost half of our overall sample described themselves as having a diagnosis of Personality Disorder. Around a quarter of respondents indicated that they had a diagnosis of Psychotic Disorders, Bipolar Disorder or other diagnoses. Only 8% of the sample was unsure of their diagnosis.

Figure 1 below shows how far through therapy IAPT service user respondents were at the time of completing the survey. Over half had completed their therapy. A further quarter were part way through therapy at the time of survey completion, whilst just over 10% had started and stopped part way through. Around 60% of respondents had begun their therapy within the past year.
Figure 2 indicates how far along IAPT service non-user respondents were before deciding not to engage further with the service. Over half of these respondents had been assessed, but not continued to therapy, while around a fifth were referred to the service but did not complete an assessment. Just under half of IAPT service non-users had received their referral letter within the past year.
Findings: IAPT Service Users

Accessing the Services

Referral process

Figure 3 indicates how IAPT service users were referred to the service. Just under a third were referred by their GP, while over half were referred by either a psychiatrist or another mental health professional. The qualitative data highlighted many accounts of positive experiences with GPs in relation to the referral process.

![Figure 3 – Referral routes for IAPT service users](image)

Waiting times

Figure 4 overleaf shows IAPT service users’ satisfaction with waiting times, broken down by site. Fifty-five per cent of service users were either satisfied or very satisfied with the waiting times. Only 29% were either very dissatisfied or dissatisfied with the waiting times. IAPT service users were also asked about their satisfaction with the support offered during the waiting time. Fifty-six per cent of service users were either satisfied or very satisfied with the support that was provided during the waiting time. This varied between the sites with a range of 40% to 74%. Overall, 23% were very dissatisfied or dissatisfied with the support offered during waiting times.
The qualitative data revealed that some IAPT service users felt that the waiting times were reasonable, or even faster than expected, and good communication around the waiting time, for example being notified about how long it would last in advance, was experienced positively.

‘I was seen very quick, less than two weeks, very happy I was.’

Female, IAPT service user

‘My care co-ordinator pre-warned me of an approximately six to twelve [month] wait.’

Male, IAPT service user

Some participants were very understanding of the demands faced by services, and took this into account when assessing their satisfaction with the waiting times. Many acknowledged that funding issues were not the service’s fault:

‘Government cuts are affecting the service.’

Male, IAPT service user

Some made a link between a long waiting time and the nature or quality of the treatment they expected to receive:

‘[It was] long, over six months, however, I had to wait for a specialist trauma psychologist.’

Female, IAPT service user

Others explained that they found the waiting time useful, as it helped them build themselves up and get used to the idea of receiving therapy. This last point relates to a broader finding that emerged – in particular through the qualitative data – namely the significance of the timing of the therapy. If the therapy was offered at the wrong time, it was less likely to be experienced as helpful and valuable. In some cases, this was because the referral period or waiting time had been too long and the person’s condition had deteriorated, but in other cases it was because the person felt that they would have benefitted more from this kind of therapy had it been offered to them many years earlier.
Analysis of the qualitative comments and interview data also revealed some frustration with the waiting times. People were often surprised at the length of the waiting time, and this was often experienced negatively. Some participants explained that their hopes had been raised upon being referred to the service, and were left feeling disappointed when they realised how long they would have to wait:

‘I guess because I was so hopeful that finally something would start to change...and then it took quite a lot longer for me to actually see anyone or hear from anyone than I’d anticipated.’

Female, IAPT service user

There was also a sense that it was often left to the service user to ‘chase’ the service to find out how things were progressing and that they hadn’t been ‘forgotten’:

‘It’s ridiculous. And if you phoned up, it was always, you had to leave a message and they’d call you back and they didn’t – real evasive.’

Male, IAPT service user

Assessment process

Figure 5 below illustrates IAPT service users’ satisfaction with the assessment process. Seventy-one per cent of IAPT service users were either satisfied or very satisfied with the assessment process, and only 12% were dissatisfied or very dissatisfied with the process.

Figure 5 – IAPT service users’ satisfaction with the assessment process
The qualitative data revealed a range of experiences of the assessment process. Some people found the experience of meeting the therapist for the first time reassuring, or even empowering:

‘I was quite pleased that I was being taken notice of and that I was believed in what I was actually saying to people.’

Female, IAPT Service User

However, many others, especially IAPT service non-users, were daunted or frightened at the prospect of the assessment:

‘There’s a bit of nervousness, like all of a sudden it’s got very real...I’ve never had to talk about my mental health with anybody [before].’

Male, IAPT service user

‘Am I going to be locked up in a cage, key thrown away?’

Female, IAPT service user

‘How did you feel when you were finally getting that help? It was a combination of oh my God, I am challenged, I have got something wrong with me, but then it was a great relief. That was one of the best moments of my life actually, it really was.’

Male, IAPT service user

Some people viewed the assessment (and indeed the pre-assessment referral procedure) as a kind of test, whereby they had to work hard to ‘prove’ that they deserved treatment:

‘What am I going to have to do to prove I’m not well?’

Female, IAPT service user

For others who experienced the assessment process negatively, it was because they felt frustrated that they had to tell their story to someone yet again – often because they felt they had struggled with a convoluted referral process involving a number of different professionals.

Information

In the survey, we also asked about satisfaction with information provided about what would happen after assessment. Seventy per cent of IAPT service users reported they were either very satisfied or satisfied with this aspect of the process, compared with 16% who reported they were either dissatisfied or very dissatisfied.

The qualitative data also showed that some IAPT service users were satisfied with this aspect of the process, whilst others reported that the information provided about the service, both before and after assessment, was less than clear. This was sometimes linked to clarity around the meaning of the diagnosis they had been given, which is discussed further below.

‘[The information] was clearly given to me.’

Female, IAPT service user

\[7\] This is linked to issues around receiving and accepting a diagnosis, which are discussed below.
'I wasn’t given anything to read, no books, no leaflets, which I think would have been useful.'

Female, IAPT service user

‘At no point was it told to me or explained to me that what that first twelve, eighteen weeks, whatever it was, was the introduction. No, I thought that was the treatment. And I want you to know I got a PhD and a First Class degree from Oxford, so I’m no fool, I might be mentally challenged but I’m not an idiot. I honestly want you to know, that’s how vague the whole process was.’

Male, IAPT service user

Expectations of the Service

Initial expectations and motivations

The qualitative interviews and comments revealed a range of motivations of IAPT service users for accessing the service, and found that people’s expectations regarding outcomes were connected to a number of factors, including their previous experience of therapy. An important factor was people’s personal attitudes towards therapy at the start of the process, which were highly variable:

‘I’m the type of person that I think that any help that’s offered, you should take it really.’

Female, IAPT service user

‘Up until a certain point, you think you can run your life, so you’re sort of giving up a slight amount of dignity [by receiving therapy].’

Female, IAPT service user

Some participants were sceptical about whether it would do any good – often because they had already gone through therapy elsewhere, but sometimes because they didn’t know enough about it. Others were more optimistic, and expected, or at least hoped, that the service could ‘change your life’. Some had very specific outcomes in mind: one participant explained that she believed that receiving therapy would increase the likelihood of being able to keep her young child, while another hoped that it would enable her to come off her medication.

There could be feelings of disappointment when people realised that achieving goals could be hard work. Some participants explained how they had come to this realisation retrospectively:

‘[I thought it would be like] waving a little magic wand over things. And then you realise no, that’s not what’s going to happen.’

Female, IAPT service user

‘If you’re not quite open to the process, and engaging willingly, then it will be hard work. You’ve got to want it because it’s difficult.’

Male, IAPT service user

Other reasons for seeking therapy included looking for some additional support, someone to talk things through with, a way to identify some underlying issues, a way to help improve their relationships with others, or a way to become better at coping. There was often a sense that the therapy might help with some things, but not necessarily with others.

‘I was hoping to find a root to what was causing this psychotic behaviour.’

Male, IAPT service user
In the survey, we asked respondents how confident they felt that the therapy would be helpful. Figure 6 below shows how confident IAPT service users were before beginning therapy that it would be helpful. Before beginning therapy, 37% were either very or somewhat confident that therapy would be helpful, whilst 29% were either not at all or not very confident that the service would help them. This differed between sites with a range of 6% to 21% reporting that they were very confident the therapy would be helpful.

Figure 6 – IAPT service users’ confidence that treatment would be helpful

![Bar chart showing confidence levels before treatment](chart)

Before beginning treatment, how confident were you that it would be helpful? (n=237)

- Very confident
- Somewhat confident
- Not sure
- Not very confident
- Not at all confident

BEH (n=36)
Birmingham (n=28)
Lancashire (n=14)
NEL (n=42)
SLaM (n=64)
Somerset (n=53)

Figure 7 shows IAPT service users’ responses to whether or not they felt the service had met their expectations. Just under three quarters (n=161) of IAPT service users felt that the service had met their expectations either somewhat or a lot. Only 9% (n=21) felt that the service had not met their expectations at all.

The qualitative data suggested that people’s expectations of the service often changed once they had had the assessment process or at the very beginning of therapy, based on their initial impressions of the service. There were a number of accounts of people’s expectations improving following a positively experienced assessment, for example, but also accounts of expectations being dashed due to a long waiting time or a problematic assessment.

‘I went from being so sceptical to being really really pleased. I guess, it’s just fear of the unknown, being sceptical as well.’

Female, IAPT service user
Of those that felt very confident that the therapy would be helpful, over three quarters agreed that the service had helped them a lot. Within those that did not feel at all confident that the therapy would help them, half agreed that the service had helped them a lot.

**Experiences of the Service**

**Provision of therapy**

The vast majority of IAPT service users had received individual, face-to-face therapy (81%, n=186), whilst nearly half (n=102) had received group therapy. Only 10% (n=24) received telephone therapy and 2% (n=4) computer therapy. Within SLaM, the only service for which this question was asked, 11% (n=7) had received family or partner therapy. Respondents could select multiple forms of therapy.

Eighty-three per cent of those IAPT service users reported that they were either satisfied or very satisfied with the way in which their therapy was provided. Figure 8 below shows that there was a fair amount of variation between the sites, with those feeling very dissatisfied or dissatisfied ranging from between 0% and 32%.

**Figure 8 – IAPT service users’ satisfaction with how therapy was provided**
Figure 9 below illustrates IAPT service users’ satisfaction with the number of sessions offered, broken down by service. Seventy-seven per cent were satisfied with the number of sessions that were offered. Again, this varied between services with a range of between 50% and 96% feeling satisfied or very satisfied with the number of sessions that were offered to them.

Figure 9 – IAPT service users’ satisfaction with number of sessions offered

The qualitative material revealed that the issue of choice around the way in which therapy was provided, or lack thereof, first arose during the early stages of the process. The evaluation found that there was limited choice around the type of therapy on offer, or the way in which it was provided. However, people often acknowledged that they didn’t know enough about different kinds of therapy at that point to make an informed choice:

‘To be honest with you, I don’t know what other therapies are out there so I wouldn’t know if any would benefit me.’

Female, IAPT service user

‘They said, “Do you want to do mindfulness or do you want to do mentalising?”’, and I said, “Well which do you think, as professionals, would be the best for me?” and they gave me no answer.’

Male, IAPT service user

Some people were consequently happy that the decision was made for them, while others reported that they felt there were ‘too many rules’ and a lack of flexibility around the way in which therapy was delivered. For example, some people were initially not keen to have group therapy, and explained that they had been told there was no alternative.

Participants’ views on choice may have been formed in hindsight. Those who had had a positive experience tended to claim they would not have wished to have a choice, and those with a less satisfactory experience tended to express that they would have preferred to be able to choose an alternative. The latter scenario was sometimes connected to the experience of being given a diagnosis that they did not feel was accurate or helpful (notably of a Personality Disorder), and feeling as though the therapy on offer was therefore not appropriate to their needs. Some people’s
views on whether they would have preferred to have a choice were clearly linked to their previous experience and associated knowledge of various therapies.

‘I felt a bit like you’re trying to fob me off onto something else so that you don’t have to deal with the difficult things of my past or whatever it is that’s making life more difficult. I felt like reducing my risk was going to be difficult without dealing with the things that were causing my risk.’

Female, IAPT service user

Related to the issue of choice in the way that therapy was delivered, but also to access issues (see below), was the presence or absence of a flexible approach towards the way in which therapy was delivered. One participant explained that the service was able to be flexible around timing, but at the expense of a much later start to the therapy:

‘When they contacted me they asked me about timing and they told me this time was available. And then I asked whether I could have a later slot, and they said that would be possible, but I would have to wait, maybe for another month or so. And I wasn’t really prepared to do that.’

Male, IAPT service user

Information, communication and clarity

Closely related to the question of choice and flexibility are issues around the provision of information, and communication and clarity. Sometimes, this was in relation to the actual content of the therapy:

‘I still don’t know what the therapist based her therapy on, which method that she employed – I’ve no clue as to that.’

Male, IAPT service user

However, many of the other issues around clarity and communication related to the service as a whole, including its ‘customer service’. The qualitative data suggest some variation between services here, with some being described as highly organised, and others badly structured with poor communication standards. Some participants recognised that they were feeling particularly confused due to their mental health issues, and felt they could have benefitted from more clarity in the way the service communicated with them, for example, letters confirming appointments rather than just being told verbally. This was often related to an overriding sense of feeling overwhelmed by the ‘system’ as a whole and the range of professionals and services they had been in contact with.

‘The structure of the CBT and DBT wasn’t very organised, in a sense of, they’d keep changing the co-facilitators…’

Female, IAPT service user

Figure 10 below shows the satisfaction with communication between services. Eighty-four per cent of IAPT service users were either satisfied or very satisfied with the way that the service communicated with them. This varied between sites with a range of 59% to 95%.
Practicalities of access

In the survey, we asked about ease of accessibility of the service. This could refer to, but was not limited to, issues around therapy timing or location. Figure 11 below shows satisfaction levels with access, broken down by service. Eighty per cent of IAPT service users were either satisfied or very satisfied with the accessibility of the service. This varied between the sites with a range between 68% and 93%. This level of satisfaction did not differ much between those who identified as having a disability and those who didn’t, nor did it differ between those who had caring responsibilities and those who didn’t.

In the qualitative interviews, distance and travel were frequently cited as challenges, or barriers to access, as was the timing of the sessions, which were not always compatible with work or childcare. However, we also heard a few accounts of services going the extra mile to accommodate personal circumstances, such as childcare.
'There's no tube, it's in the back of beyond. It's easier to get to Scotland or to get to Paris. I can get to Paris quicker than I can get to [Hospital] from here.'

Male, IAPT service user

There were also a number of reports of unsuitable or inappropriate premises, which made the service feel less accessible to people. This ranged from descriptions of a ‘crusty old room’ to a case where the person’s anonymity had been compromised, because she had realised that the door to the therapy room was not soundproof and she could be overheard by a family member who was waiting for her outside.

‘And then obviously after getting the job and then with the shift work and that, she said because where I’d missed a couple of sessions, they had to take me off their services… obviously working, that’s a good thing for me. But then obviously I got the impression that she didn’t like me missing the appointments because of working so I couldn’t really win.’

Female, IAPT service user

**Therapeutic relationships**

The evaluation found that the therapeutic relationship was at the heart of the experience of the service for the vast majority of those who had engaged with the service. Many people reported very positive relationships with their therapists, and highlighted that they had good rapport, that the therapist was empathetic, kind, and a good listener – in one person’s words, ‘we spoke the same language’. Others explained that they felt that the therapist had the right personal qualities, but that it still took a while to build up the rapport and trust due to their own nervousness. Most people emphasised that they appreciated being able to direct the conversation, and didn’t feel pressured to focus on certain things:

‘Yes, well let me tell you, [Therapist] read my recipe.’

Male, IAPT service user

‘She was friendly, patient, she was sensitive to how I was feeling. She didn’t push me or anything.’

Female, IAPT service user

However, others appreciated having the therapist take more of a lead:

‘She used to give me the option of what we wanted to talk about that day, it was very much led by me. Sometimes I would have preferred it if she could lead onto a particular subject and sort of know the boundaries of when to stop, because I feel like it was so open and up to me that I just didn’t know what to talk about or what to do.’

Female, IAPT service user

Alongside kindness and empathy, honest advice was also valued in a therapist:

‘It’s the sort of information or advice you’d want from a friend that can’t give it to you because they don’t want to hurt your feelings.’

Female, IAPT service user

It also emerged that a positive experience could be linked to having a therapist who focused on, or brought out, the positive, as well as the negative:
‘I tell you something the consultant psychiatrist said to me, because I said, “can I get some alleviation of this pain, can I get something, a better life?” She said, “I’ll tell you straight away, the thing that you tell me that makes me say ‘yes’ is that you are very keen on your garden, you grow things”.

Male, IAPT service user

Finally, several people emphasised the importance of having a therapist who was ‘non-judgemental’ of the person’s situation:

‘I just thought that everybody was really professional and it was really important to me that they were non-judgmental, that’s what I was afraid of. But they didn’t judge me at all and they knew like where I was coming from so I’d recommend it to anybody else that was wanting to use it.’

Female, IAPT service user

Some people who did not have such a satisfactory relationship with their therapist explained that it was because the therapist focused excessively on matters that they did not themselves feel were helpful. Mostly, this was because the therapist was focused on addressing behaviours in the present, rather than the perceived ‘root’ of the problems in the past, which the person felt were what needed addressing – or the other way around, where the therapy was focused too much on the past rather than the present. This links back to issues of communication and understanding the different kinds of therapy available, and being able to make an informed choice at the outset.

Some of the more negative therapist experiences related to situations where the therapist was not perceived to be listening to the participant and valuing their perspective, and there were some accounts where people said that they had felt blamed or judged by the therapist.

‘And another thing that she has a big standing on that, an opinion, is the fact that I’m a practicing Christian.’

Male, IAPT service user

‘I said “I’m not going to talk about murdering someone and burying them in the garden, what the hell do you think I’m going to say”…. I think she’s a patronising ***** actually, the therapist.’

Male, IAPT service user

In the context of group therapy, some people experienced this in relation to other people in the group:

‘It was the other patients that upset me…They put their expressions outwardly. I didn’t, and I found that very threatening.’

Female, IAPT service user

Overall, there was a strong sense that a positive experience with a therapist was closely linked to them behaving in a ‘human’ way, rather than being overly ‘professional’. This included friendly behaviour outside of the therapy sessions (e.g. when bumping into each other elsewhere on the premises), within the sessions (e.g. providing cups of tea and biscuits) but above all therapist drawing on their own life experience in the therapy sessions:

‘It’s almost if you like, sitting in your living room, with a cup of tea, sort of thing, talking to you, as a friend, rather than being really kind of, I don’t know, clinical, and what’s the word? Like, just kind of robotic, and sitting there, and firing questions at you. So there’s this, immediately, there’s this kind of friendly rapport, that we kind of built up.’

Male, IAPT service user
'So they could say, well, this is how I coped with it, because I think that makes the therapists seem more human if they can show how they use these sorts of skills rather than some therapists who don’t mention anything about themselves at all.'

Male, IAPT service user

‘It was, let’s all have a cup of coffee together and they have a great range of chocolate biscuits. You’ll think I’m food obsessed, but it does make a difference.’

Female, IAPT service user

Sometimes, this human relationship was perceived to be lacking, or ‘false’ – one participant recalled ‘that moment where you remember the therapist isn’t your friend.’ Where this human, personal relationship was perceived to be lacking, participants expressed that they felt it was important to be able to find a different therapist who was better suited to meet the person’s needs:

‘I think it’s down to the therapist and the client, the patient, to work out whether they’ve got that rapport or not. And if they haven’t, there should be an avenue where they could change therapists if they felt they needed to.’

Female, IAPT service user

Similarly, where the relationship was experienced as positive, being required to change therapist part-way through was often experienced very negatively.

The table below shows the extent to which IAPT service users agreed with the statement that they did not feel judged by their therapist. Eighty-five per cent agreed that they did not feel judged by their therapist. This differed from site to site with a range of 63% to 96% agreeing or strongly agreeing that they did not feel judged.
Figure 13 shows the extent to which IAPT service users agreed with the statement that their therapist understood them. Similarly to the previous statement, 83% of participants agreed or strongly agreed that their therapist understood them. This again varied between the services, with a range of 60% to 97%.

Eighty-five per cent of participants either agreed or strongly agreed that their therapist took their individual circumstances into account (see Figure 14 below). This varied between the services with a range of 72% to 93% agreeing or strongly agreeing. When looking at this question in relation to participant demographics such as ethnicity, age, gender, sexual orientation, religion, disability and caring responsibilities, we found very little difference in participant’s propensity to agree with this statement depending on their personal circumstances. The qualitative data revealed a small number of instances where a participant felt that their personal characteristics, e.g. gender or religion, were not adequately taken into account by the therapist or the service.

‘I have nothing against him, he’s not a bad person, or anything like that, but I wanted a female therapist, and for me, that’s really important.’

Female, IAPT service user

‘I think it’s more of a wider spread issue among the services, that there aren’t any, there aren’t any programmes for people my age [under 25] so there’s kind of, this middle ground where you’re not really an adult but you want to kind of mix with people your own age.’

Male, IAPT service user

‘I can relate to certain people better than others. So maybe someone who was a bit younger, or has dealt with people who are doubting their sexuality.’

Male, IAPT service user

‘I just thought, why are there more women, why am I the only man all the time?’

Male, IAPT service user
Figure 14 – IAPT service users’ agreement with ‘I feel my therapist takes my individual circumstances into account’

![Bar chart](image)

Figure 15 below shows to what extent participants agreed that their therapist helped them to develop new skills and approaches to manage their mental health. Seventy-seven per cent of participants either agreed or strongly agreed that their therapist had helped them to develop these skills. Again, there was variation between the services, with a range of 52% to 96% agreeing with this statement.

‘I was asked if a trainee could sit in. I thought no, I need time for me now, after waiting all this time. I don’t want to have people bloody practising on me. To be honest with you, I’m actually quite outraged by that. I didn’t feel confident, I didn’t feel at all confident.’

*Male, IAPT service user*
Use of regular measures and forms

We asked IAPT service users the experience of completing regular measures and forms, and this was also something that was probed in more depth in the interviews. This related both to measures of progress, but also the ability to provide feedback about the helpfulness of the service. Figure 16 shows the satisfaction with the way participant’s therapy was monitored, broken down by service. Seventy-two per cent of IAPT service users felt either very satisfied or satisfied with the way in which their therapy was monitored. This varied between the services with a range of 44% to 90%.

The qualitative comments and interviews revealed that although there was a tendency to find the completion of forms ‘monotonous’ and lengthy, most people were understanding of the need for this kind of monitoring. Some people reported that they enjoyed being able to think about the questions, while others found it hard to decide how to...
answer. Overall, the experience was found to be most rewarding when people were able to view their progress and feel that they were directly benefiting from the provision of this information.

‘It helped on a weekly basis to have that...you know, you reflect on the past week and how you’ve felt about things? And that was quite helpful actually.’

Male, IAPT service user

‘When [Therapist] sat down with me and was able to make interesting comments purely on the basis of me having filled in these forms for all that time, relevant comments to my condition, it was good...I gained a lot of confidence from a professional telling me that actually, I’m doing a good job.’

Female, IAPT service user

Endings and follow-up

Ending therapy is often challenging, and the qualitative interviews revealed that those who were part-way through therapy were nervous about what would happen at the end.

‘I’m a bit worried about leaving because after a year, it’s quite embedded in your routine and I’m going to miss the people and that opportunity to talk and to learn.’

Female, IAPT service user

Figure 17 below shows IAPT service users’ satisfaction with the planning for completion of therapy broken down by service. Sixty-seven per cent of IAPT service users felt satisfied or very satisfied with the planning for the completion of therapy. This varied largely between services, with a range of 31% - 82%. In one site (BEH) more people were dissatisfied with this aspect of the service than were satisfied.

Figure 17 – IAPT service users’ satisfaction with planning for the completion of therapy

![Chart showing satisfaction with planning for the completion of therapy](chart)

Figure 18 shows the satisfaction with the arrangements made for continued support, broken down by service. Fifty-nine per cent of participants felt satisfied or very satisfied with the arrangements made for follow up and / or continued support. Again, this varied significantly between the services, with a range of 28% to 78% and in one service, more people reported being dissatisfied than satisfied about this. In general, the two questions around the ending of treatment revealed less satisfaction with this aspect the service than most of the other areas asked about.
The qualitative interviews and comments highlighted the importance of a satisfactory ending and follow-up support to a longer-term positive impact of the therapy. Those who had the most positive experiences described how they had been given a lot of information around being able to re-contact the service, or other sources of support. What seemed to be perceived as particularly helpful was the provision of a ‘safety net’ by the service itself – for example, having the therapist’s number to call in case of a crisis. However people emphasised that they knew that they could not rely on this on a regular basis, suggesting that a big part of the benefit would be the knowledge that they could get help in this way, rather than actually accessing it.

‘The last session, we did a whole relapse pack, and it was made very clear to us that if we were unwell, and we wanted to talk to somebody, that we could speak to them.’

*Female, IAPT service user*

‘My most important thing is, I’ve got my contact number for [Therapist] and [Therapist] and I know that I can phone them even if I’m feeling unwell.’

*Female, IAPT service user*

Not surprisingly perhaps, those who reported a negative experience of the ending of the therapy or follow-up support offered were often those whose therapy had ended prematurely, and, from their perspective, not by choice.

‘And then [Therapist] had to have a week off, and then he came back, and then he said, “One more session and that’s it”. And that was it. I thought, well, you know, I thought we were in mid-flow and it cut off.’

*Male, IAPT service user*

‘Well, that was the problem you see, because I was speaking to my counsellor and he was saying, “You’re doing really well, we might just get you to the six months”. I went to one therapy session and then the counsellor suddenly said, “Oh by the way, I’ve just realised it’s [Participant’s] last day, and my ears pricked up, thinking, oh right, so it’s stopping now.’

*Male, IAPT service user*

Among IAPT service users, 11% (n=27) had begun therapy and stopped part way through. Figure 19 below shows that those who stopped therapy part way through were generally more dissatisfied with the planning for the completion
of therapy. Similarly, Figure 20 shows that those who stopped therapy part way through were generally more dissatisfied with the arrangements for follow up support.

The range of reasons for discontinuing therapy ranged from changing personal circumstances, to service-driven issues – including some reports of therapists leaving, and no replacement being provided. Sometimes, there was a fine line between these two sets of reasons: one person explained how she felt the therapy was just a little helpful, and that because it was difficult for her to get to for personal reasons, she decided that the benefits were outweighed by the access issues. In other cases, the reasons appeared to be more clear-cut: one person explained how she had had to miss some sessions due to a bereavement, at which point she was informed that her therapy was to be discontinued.

‘I think [stopping] was mainly just [because] you don’t get many options yourself of what you feel like you want to do and stuff.’

*Female, IAPT service user*

**Figure 19 – Comparison of IAPT service users’ who completed or did not complete therapy levels of satisfaction with planning for completion of treatment**

![Satisfaction with planning for completion of treatment](image1)

**Figure 20 – Comparison of IAPT service users’ who completed or did not complete therapy levels of satisfaction with arrangements for continued support**

![Satisfaction with arrangements for continued support](image2)
Figure 21 below shows that those who stopped therapy part way through generally felt much more negatively about how much the service had helped them, with 78% believing the service had helped them only a little or not at all.

Figure 21 – Comparison of how helpful IAPT service users who completed, and those who dropped out, found the service

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Somewhat</th>
<th>Don’t know</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part way through</td>
<td>60%</td>
<td>20%</td>
<td>10%</td>
<td>10%</td>
<td>0%</td>
</tr>
<tr>
<td>Completed</td>
<td>70%</td>
<td>20%</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Started and stopped</td>
<td>80%</td>
<td>20%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Impact for Service Users

Overall reflections

Our findings suggest that most people who had engaged with therapy felt that the IAPT for SMI service they had accessed had impacted positively on their day-to-day lives. Many people reported feeling broadly happier and more positive, and were confident that the therapy had led to an improvement in their mental health and general wellbeing. Those interviewed were able to identify a range of ways in which this positive impact was experienced.

‘Before, I was looking around for ways to kill myself, but now I’m looking around for ways to improve my flat.’

Male, IAPT service user

Overall, 52% of participants felt the service had helped them a lot. Only 8% felt that it had not helped them at all. Again, this varied largely between services as can be seen in Figure 22 below.
Developing positive coping mechanisms

Many of those interviewed described how they were able to deploy the skills and tools they had learnt in the therapy in their everyday lives, reflecting on their feelings and behaviour, for example, ‘coming to terms with the past’, or ‘watching what I say’. For some, these coping mechanisms ultimately prevented relapse – with a number of people explicitly stating that the service had saved their lives.

*I’ve become a lot more in tune with those early warning signs.*

Male, IAPT service user

Some alluded to the fact that developing these positive coping mechanisms was an ongoing process that did not finish with therapy, and still needed to be worked at – and the provision of follow-up support was central to this. A couple of people explained that they had found that their learnings in therapy had not translated into longer-term day-to-day impacts.

‘Normality’, social relationships and engaging in new activities

One of the overarching impacts of the therapy for those that successfully developed and implemented these positive coping mechanisms was a feeling of a gradual return to ‘normality’ and ‘managing’. In practice, this often meant that they were ‘getting out’ more, or ‘participating in society’. People described themselves as less fearful, and more able to make social connections. They were also more likely to engage in new activities or pastimes, or to pick up ones they had discontinued.

*I started eating, started going to a boxing club, something to get back in, I’m getting back into that.*

Male, IAPT service user

Some people reported that they experienced the act of going to therapy as an ‘enabler’, in the sense that it made them get out of the house, while others found that group therapy provided a helpful avenue into starting to socialise again.

People also reported that therapy had improved, or helped them re-build, their closest social relationships, with partners, family and friends.
‘And, I’m getting my relationship back on track as well with my girlfriend.’

Male, IAPT service user

Other impacts

The qualitative interviews revealed a number of other impacts that were not necessarily to be expected at the outset. One person explained how they felt that a positive therapeutic relationship had led to greater tolerance of people from different ethnic or cultural backgrounds. Another described how they were more comfortable talking openly about mental health problems:

‘I feel more confident now talking about it to other people.’

Female, IAPT service user

Negative impacts

The qualitative data indicated that some people perceived that their experience of therapy had had a negative impact. The reasons for this included struggling with the ending of the therapy, feeling that the therapy prevented progress and ‘kept me in the same place for years’, and feelings of disappointment or guilt when hopes and expectations were not fulfilled or met.
Findings: IAPT Service Non-Users

Referral process

Figure 23 below shows how IAPT service non-users were referred to the service. Almost half of IAPT service non-users were referred by their GP whilst just over a third were referred by a psychiatrist or a mental health professional. These routes were also the three most common routes for IAPT service users, although a slightly higher proportion of IAPT service non-users were referred by their GP.

The qualitative data indicated that some people found the referral process frustrating, and felt that it wasn’t as quick or straightforward as it could have been:

‘It took very long for me to get referred to the service…and it was a bit annoying because I had to tell my story again.’

Female, IAPT service non-user

Figure 23 – Referral routes IAPT service non-users

Waiting times

In the survey, we asked IAPT service non-users how long they had waited (or how long they expected to wait) between being referred to the service and being assessed, and we also asked about levels of satisfaction with the waiting times.

The average waiting time for IAPT service non-users was 10 weeks. Within this group, the average waiting time for those who were very satisfied with the waiting time was 4 weeks, in contrast with the average waiting time for those who were very dissatisfied with the waiting time, which was 17 weeks.

Figure 24 below illustrates the satisfaction with waiting times among IAPT service non-users, while Figure 25 compares IAPT service users’ and non-users’ satisfaction with waiting times. As can be seen from the column chart,

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Referral routes (n=63)

- GP, 44%
- Psychiatrist, 19%
- Other MHP, 17%
- Social worker, 5%
- Not sure, 5%
- Referred myself, 6%
- Other, 3%

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8 Due to the very small sample sizes, analysis of IAPT service non-users is not presented broken down by site.
non-users were generally less likely to express satisfaction with the waiting times, and were three times more likely than service users to say that they were very dissatisfied with the waiting times.

**Figure 24 – IAPT service non-users’ satisfaction with waiting times**

![Satisfaction with waiting times - IAPT service non-users (n=51)](image)

**Figure 25 – Comparison of IAPT service users’ and IAPT service non-users’ satisfaction with waiting times**

![Satisfaction with waiting times - IAPT service users and non-users (n=278)](image)

Analysis of the qualitative comments and interview data also revealed that one of the main reasons that IAPT service non-users did not continue to therapy related to the length of the waiting time between referral and assessment. As with IAPT service users, a long waiting time was generally experienced negatively, with people indicating that they had been in distress and had needed help urgently. Several IAPT service non-users reported that they had been left reliant on medication during this time, a situation which they did not wish to be in. Others explained that their hopes had been raised upon being referred to the service, and were left feeling distressed when they realised how long they would have to wait.
We also asked IAPT service non-users about how they felt about the support that was offered to them from the service, GP, or other professional, during the waiting time. We found that this group were more than three times more likely than IAPT service users to state that they were very dissatisfied with the support offered during this waiting time, with over a quarter of IAPT service non-users selecting this option.

Information

In Survey 2, we asked about the different sources of information provided to people before they were assessed. Over half of IAPT service non-users received information from a mental health professional, whilst a further 44% received a leaflet about the service. Seventeen percent received information from their GP and 6% sought information through a website description. Nearly a quarter of non-users did not receive any information at all. Of those that had received information, 80% said they found it useful, and 72% claimed that the information given to them helped them to make a decision about whether the therapy would be right for them.

The qualitative data revealed that some services provided people with thorough information about the service, in the form of a folder or pack, which was generally found to be helpful.

‘There was a nice pack actually that came through, to do with things like that. I did have a good look through it.’

Female, IAPT service non-user

Assessment process

Figure 26 below illustrates IAPT service non-users’ satisfaction with the assessment process. 53% of non-users were either satisfied or very satisfied with the assessment process, and 25% were dissatisfied or very dissatisfied. Figure 27 shows how these figures compare to IAPT service users’ experiences of the assessment process, and again, we can see that non-users’ experience this less positively than people who engaged with the service.

Figure 26 –IAPT service non-users’ satisfaction with assessment process
Some non-users had a positive assessment process; however, other IAPT service non-users were daunted or frightened at the prospect of the assessment, and did not always feel that this was adequately taken into account.

‘[Therapist] who was assessing me was kind, explained everything in a comforting way.’

*Female, IAPT service non-user*

‘The interviewer kept insisting that I answer the questions even though I clearly said I felt uncomfortable about answering them.’

*Female, IAPT service non-user*

Figure 27 - Comparison of IAPT service users’ and IAPT service non-users’ satisfaction with assessment process

In the survey, we also asked about satisfaction with information provided about what would happen after assessment. Fifty-five per cent of IAPT service non-users were either satisfied or very satisfied with this, whilst 22% were either dissatisfied or very dissatisfied with this. Compared to IAPT service users, these figures show slightly fewer participants were satisfied and slightly more were dissatisfied.

**Reasons for not engaging in the therapy**

We asked IAPT service non-users about why they did not engage with therapy, and provided a number of answers they could select from – they could tick more than one option if they liked (see Appendix 3).

Figure 28 below provides an overview of these responses. The most frequently cited reason was that respondents did not feel it was helpful (n=11). Respondents who ticked ‘other’ provided a range of both personal and service-related reasons for not engaging with therapy. Personal reasons included things such as ‘sudden troubles caused me to quit everything’, and were often linked to difficult or changing personal circumstances. Service-related reasons included issues such as no female therapists being available. Some people who did not engage did not feel that this was down to their choosing, but due to the limitations of the service, and 16% reported that following assessment, a decision was made not to offer therapy. However, others did not continue because the assessment process had led them to
believe that the treatment on offer did not meet their needs. The qualitative data showed that some of those who ‘dropped out’ prior to therapy had said that they found the waiting time too long, even where they cited other reasons for not engaging.

‘I have been fighting to get treatment for nearly two years now, and am still being shuffled through assessments. The waiting is ridiculous and dangerous considering the nature of mental health issues. Better communication is needed between services.’

Female, IAPT service non-user

Figure 28 – IAPT service non-users’ reasons for not engaging in therapy
The Significance of Diagnosis

In the surveys, we asked both IAPT service users and non-users to let us know which diagnosis, or diagnoses, they had been given, with the possibility of selecting more than one option. Recognising that the experience of receiving a diagnosis can be challenging in itself, we also asked whether or not they found the diagnosis helpful. In analysing the quantitative data, we found little difference across the different diagnoses regarding how helpful (or otherwise) respondents found receiving a diagnosis. Eighty per cent of those who described themselves as having a diagnosis of Personality Disorder found the diagnosis to be helpful, while 88% of those with Bipolar Disorder found the diagnosis helpful and 85% of those with Psychotic Disorders found the diagnosis helpful. The qualitative data indicated that, for many, receiving a diagnosis was the first step towards getting help they felt they needed.

‘It was a relief to know that I did have a diagnosis, that there’s something wrong and therefore it’s treatable.’

Male, IAPT service user

‘It’s only when I got ill that everything has gone right; it’s bloody silly.’

Male, IAPT service user

However, the qualitative data also raised some interesting issues around receiving a diagnosis, particularly, though not exclusively, in relation to Personality Disorder. The first was that people sometimes felt that by receiving a diagnosis and proceeding with treatment, they were, in a sense, pretending to be something they were not. This links back to the point made earlier in this report about how people sometimes viewed the assessment process as a ‘test’ to see if they were ill enough to qualify for help:

‘I felt like I had to be ‘crazy’ enough to be allowed help from EIS but I didn’t mind this.’

Female, IAPT service user

Others, however – especially those with a Personality Disorder diagnosis – felt that they were pigeonholed and subject to negative stereotyping as a result of their diagnosis, and were not happy that they had to ‘accept’ this diagnosis in order to proceed to treatment. Most people in this situation did feel that the treatment might be helpful, and were eager to access it, but resented some of the assumptions that were made about them on the basis of their diagnosis as part of that treatment, and the stigma and lack of clarity amongst professionals and the public. Others felt that a treatment based on a diagnosis they did not agree with would not be helpful, and withdrew from the service.

Closely linked to the problem of assumptions and stereotyping was a perceived lack of information about what ‘Personality Disorders’ are. Participants described how they self-stigmatised as they struggled with the loaded wording of this diagnosis – in one person’s words, one that she associated with ‘psychopaths and killers’. The evaluation findings around the experience of receiving a diagnosis of Personality Disorder suggest that there is still a need for further work in this area. It is also worth noting that the three sites with a Personality Disorder specialism had lower service user satisfaction in a number of areas than the other three sites. Again, there is a need for further work to understand how this is shaped by the diagnosis of Personality Disorder per se, the service provided by the sites, and the characteristics of the client groups.

‘When I got to the complex care team, I think the first thing they should have said, this is what, you’ve been given this diagnosis, let me explain to you what this diagnosis means.’

Male, IAPT service user

‘I received a diagnosis but had to wait a long time to start to understand what this is…’

Female, IAPT service user
Suggestions for Improvement

The following is a summary of the recommendations and suggestions for improvement articulated by the evaluation participants:

Referral and access

- Reduction in waiting times, and more monitoring and support during waiting times, e.g. from a charity, or peer support.
- More cohesive system that enables a straightforward referral process; not having to tell your story again and again.
- More localised access, e.g. in GP surgery.
- Extending availability to a greater number of people.
- Better preparation for what’s going to happen at the start – e.g. that it will be hard work.

‘Some of the waiting times to see the doctor was a bit long so I think that could have been improved.’

Female, IAPT service user

‘I think the key thing was also trying to gain a bit more involvement from GP level. They are the general practitioners but I think they could be just a bit more... I don’t know whether it’s a bit more informed or a bit more aware, I don’t know.’

Male, IAPT service user

Service structures

- Clarity and transparency around what is happening and why.
- Improved communication and information provision.
- Reduction in bureaucracy.
- Having access to a nutritionist via the service.

‘When you’re in a peculiar state of mind, things that are supposed to be clear... everything is really unclear. I was confused.’

Female, IAPT service non-user

‘I think it’s brilliant that it’s there, I think it’s not being implemented properly. I think it’s chaotic, the communication is pathetic, I think there is a general feeling that everybody is making it up as they go along. I don’t think enough is being done to hold patients and inform them and keep them sage and make them aware of what it is.’

Male, IAPT service user

‘I mean, I think it would be very useful if... because there seems to be a lot of things going on in the hospital, and also, like charities and things. But I think it would be very useful if there was this, sort of, pack at the beginning by your team telling you all the opportunities which are out there.’

Male, IAPT service user
Flexibility and choice

- Fewer rules and limitations around length and delivery of therapy.
- Better arrangements for follow-up, such as ‘maintenance’ therapy (e.g. quick catch-up calls with therapist or other team members that know the individual) that can flex to changing circumstances.
- Better tailoring of the therapy to individual needs.

‘Because he knows me so well, and knows my thinking styles, actually speaking to someone, even someone for ten minutes who’s 140 miles away, has been so much more helpful than any of the support... the sort of, official support that I’d tried to seek out at the university here... I don’t know, he can talk to me for ten minutes and really make a massive difference.’

Female, IAPT service user

‘I’d like to have seen an extra group during the week, because I think, if somebody thinks they’re going to be going to therapy for a year, it seems quite daunting. A lot of people who are sort of working or have got families would have found that hard to commit to. Whereas if you had a sort of shorter period of therapy, maybe for three or four months, with two groups a week, that might be more practical for some people.’

Male, IAPT service user

Measures and forms

- Focus on the most important measures, as it can become time-consuming.
- Allow people to comment freely with open text answers.
- Ensure that people see the benefit of filling out the forms, e.g. that they can revisit and / or receive feedback on them.

‘I think it would have been helpful if we could see what we’d previously...on previous weeks so you could compare and see if your mood had improved or if it stayed the same or worse. But just to do them and not get any feedback on them....’

Male, IAPT service user

Influencing the service

- More opportunities to get involved in how the service is run, and ‘have a voice’, including more evaluation / feedback forms.
- Clarity around how to get involved.

‘I’d like to [get involved]. I don’t know who is in charge of what, and who are the powers that be.’

Female, IAPT service non-user

Stigma and education

- Better communication with people around implications of diagnosis.
- More public education around different diagnoses.
- More public information about the support that’s available
- More opportunities to share experiences with others and meet people who have already been through therapy – e.g. in the form of peer support during the waiting time.
- Need for more information that can be shared with family, e.g. children.

‘I mean, when you have a physical disability, the first thing that the doctor does is sit you down and explain what it is and give you leaflets, and I just feel with mental health I never had that.’

Female, IAPT service user
Conclusions and Recommendations

Our findings suggest that satisfaction levels with the IAPT for SMI service are very high overall, with some variation across the sites. Most people were very happy with the way in which the therapy was provided, and their relationship with their therapist, and were able to identify a range of ways in which the service had impacted positively on their day-to-day lives. The reasons identified by respondents as contributing to a positive experience were often those that were inadequately addressed for those who had a less satisfactory experience. However, our inclusion of people in the evaluation who had either not engaged with therapy despite having been referred to the service, or who had started therapy and stopped part-way through, highlighted that a negative experience could also be related to more ‘peripheral’ features of the service, such as access and assessment process (notably waiting times), and structure, clarity and communication. Moreover, the qualitative data in particular highlighted the challenges around receiving and accepting a diagnosis of Personality Disorder, which was the specialism of three of the six sites evaluated, and where there may be scope for future work.

Authors’ recommendations

The project participants offered many suggestions for improving the IAPT for SMI service, and these are presented above. Here, we make 12 key recommendations based on what we found to be common areas of concern for service users across the sites, and on examples of good practice that could be replicated elsewhere.

1. Simplification of the referral process.
2. Clear information about what to expect from therapy, including: commitment required from service user, types of therapy on offer and choices people have about their therapy; timings and number of sessions; and endings and planning ahead for completion.
3. Information around, and promotion of, ongoing peer support available locally.
4. Information and clarity around diagnosis; and Personality Disorders in particular.
5. Reduction in waiting times and the provision of clear information about waiting times at the outset.
6. Good communication, information and support from service, and other services, agencies and organisations, during the waiting period.
7. Flexibility and accommodation of individual needs regarding the delivery of the therapy.
8. Good organisation, communication and ‘customer service’ throughout.
9. Strong improvement of therapeutic relationship through providing a validating atmosphere and non-judgemental approach. Self-disclosure may sometimes help with this.
10. Strong boundaries on the part of the therapist during group sessions.
11. Ease of access regarding practical considerations such as work / childcare commitments and travel problems.
12. Increased ‘maintenance’ or follow-up support.
Reflections on the Evaluation

Julie Billsborough

As I interviewed participants for this project, I often found myself thinking about my own use of mental health services and how it compared with other people’s experiences. It has also made me view my own personal experiences in a different light; sometimes for the better and sometimes for the worse. Sometimes, I felt able to share my own experiences of service use in the interviews, and one participant told me how being interviewed by a Peer Researcher made her feel more comfortable about being interviewed.

Having this shared experience was an important part of my role as a Peer Researcher on this evaluation, but the evaluation has given me insight into how varied people’s experiences are of different mental health services, and how hard it is to generalise about them.

Throughout the evaluation, and in this report, we’ve tried hard to balance representing this diversity of experiences of the service that was found with identifying some common themes and recommendations that we hope will help improve the IAPT for SMI service for a wide range of people.

Lisa Couperthwaite

What has stood out for me while interviewing people for this evaluation is just how enriching and life changing psychological therapy can be for those who have experienced it, when delivered effectively. The emphasis on the word ‘effective’ is key here as the impact can be detrimental when effective delivery of therapy isn’t carried out.

As somebody who suffers from mental health problems I have found the actual process of carrying out the evaluation challenging at times. By nature I will avoid exposing myself to anything that takes me out of my comfort zones. Consequently, I found myself utilising the skills I learned from my own experience of psychological therapy several years ago in order to be able to approach becoming involved in the evaluation - an experience that I would have sorely missed had I not been taught these valuable life skills during therapy. However, had I been asked at the time, what the impact of having DBT has been on my life, I don’t believe I would have been able to accurately assess this, not having had the time and experience to really see how helpful it had been.

It took many years for me to develop a mental health problem and it seems that this is often the case for many people. It would, therefore, appear to be unrealistic to assume that these problems will immediately disappear when a prescribed course of therapy has been completed. Because of this, I feel that it is not only important to evaluate the effects of therapy shortly after completion, but to continue to evaluate it for many years. It is vital to be aware of the need for further evaluation with respect to assessing the long-term impacts of IAPT for SMI.

Elaine Hewis

Working on this project has proved to be a real contrast to the work I do as a trainee mental health nurse. I have lived experience of using the services over many years, and am also a carer of somebody who has used the services. I have previously worked on a three year research project that involved looking at professional and patient involvement on an online forum, which proved to be fraught with all sorts of conflicting issues for the professionals as to whether they should be acting in their professional role or as people – like the two should never meet. This is also something that I have been told on my nursing degree – that I need to have firmer boundaries between who I am as a person and my professional role. All of these experiences have given me a variety of interesting perspectives in which to view my working on this project.
I felt conflict over who I should be while conducting the interviews – coming from a place where I was supposed to be ‘professional’ and was subject to daily assessment as to my professional development, to a place which is so familiar to me: encouraging and listening to people’s stories, and their experiences, in this case, of a particular service, as they saw it. There was nobody to judge me as to whether I was conducting the interview in a professional way. Ironically, I was asking people if they had felt judged by their therapist and here I was, interviewing and at the same time judging myself as to which role or professional stance I was being loyal to. I decided that to be true to myself, and it is the value of the lived experience and indeed the qualitative data I was gathering that I deem as the most valuable above all else. Throughout my years as a psychiatric patient it has always been the strengths and commitments of the patients which has most struck me, especially when paired with a trusting relationship, be it with the lady who does the cleaning of the ward, the cook, the nurse who can talk in a way that makes you feel truly valued and respected. I can ‘feel’ the value in the interviews when people talk of experiencing honesty from a worker.

I believe that my intuitions about how to approach this evaluation have been validated, to an extent, by our findings, which show how important the ‘humanity’ of the therapist is for people receiving therapy.
### Appendix 1: The IAPT for SMI Demonstration Sites

**Barnet, Enfield and Haringey Mental Health Trust**

Barnet, Enfield and Haringey Personality Disorder Services are a sub-team of a Complex Care Mental Health Community Team. The service offers specialist treatment for all personality disorders in each of the London Boroughs. Each borough team operates to a defined framework but works as a stand-alone team. Staff of each team not only offer specialist mentalization based treatment and supportive clinical management but also act as care co-ordinators for all patients, managing their overall psychiatric and social care including child protection proceedings, court and probation requirements, and financial and housing needs. The Personality Disorder Service is commissioned separately in each Borough and has varied referral rates and waiting times to treatment. In Enfield and Haringey, services are commissioned for all personality disorders, including antisocial personality disorder. In Barnet, limited access to specialist psychological treatment has been commissioned for 12 patients to access mentalization based treatment every two years, leaving the remaining population with access to supportive clinical management.

**Birmingham and Solihull Mental Health Foundation Trust and Spectrum Centre for Mental Health Research, Lancaster University**

The ‘Mood On Track’ programme is the name of the psychological intervention delivered by the Bipolar disorder service (MDS) which is a service based in Birmingham & Solihull Mental Health NHS Foundation Trust (BSMHFT). The Bipolar service is part of BSMHFT’s secondary care services and receives referrals from all of the community teams across the trust.

The aims of the Mood On Track intervention are:

- To improve people’s understanding of their problem mood changes
- To improve awareness of personal triggers and early signs of a problem mood change
- To help people to enhance the coping strategies they utilise to manage early signs of a problem mood change
- To increase people’s knowledge of factors that may improve inter-episode well being
- To signpost those attending the group to family focussed approaches they are able to access and to facilitate that access as appropriate
- To reduce feelings of isolation by offering opportunities to meet others with a diagnosis of bipolar disorder in the group programme

The approach was developed drawing from the evidence base for psychological therapy for people with a diagnosis of bipolar disorder; and includes:

- Assessment of individuals referred and initial formulation of presenting problems identified during the assessment process
- CBT to highlight the role of thoughts feelings behaviours and biology in problem elevated and low moods
- Providing tools to monitor mood and highlight triggers and protective factors
- Social Rhythm therapy, giving people information on circadian rhythms and their regulation, and providing tools to enable group members to track their own social rhythms and information on adapting problem schedules to enhance mood regulation
• Introduction to mindfulness and the rationale for mindfulness approaches

• Relaxation techniques as part of stress management

• Relapse management to address triggers, early signs and coping strategies; (this is done both in the group sessions and as part of the individual sessions and/or family focussed sessions)

Lancashire Care NHS Foundation Trust

The Lancashire Early Intervention Service (LCFT EIS) aims to provide NICE (2009, 2014) concordant care, in order to intervene as early as possible after a person has their first experience of psychosis, with the aim of maximising their chances of recovery and of living a meaningful and fulfilling life. The Service also has an At Risk Mental State (ARMS) clinic which aims to intervene early to prevent transition to psychosis.

The Improving Access to Psychological Therapies (IAPT) Serious Mental Illness (SMI) Demonstration Site related specifically to the work of the therapy team, which provides service users of the EIS with psychological care, including Cognitive Behavioural Therapy (CBT) and Family Interventions. At the time of the Demonstration site project, the therapy team had a workforce of 5.2 FTE, consisting of staff trained to deliver psychological therapies, including NICE concordant Cognitive Behavioural Therapy for psychosis (CBTp) and family interventions.

This team receives referrals for therapy input from 3 Multi-Disciplinary Teams, covering North, Central and East Lancashire, which serves approximately 825 service users, across a large geographical area with a population of approximately 1.5 million people.

LCFT EIS developed a specific service model to maximise the provision of psychological informed care, by training all clinical staff in Psychosocial Interventions (PSI), through delivering a bespoke 3 day, in-house training course in PSI to all care coordinators and support time and recovery workers. This course was based on the cognitive behavioural competencies outlined by Roth & Pilling (2007). This training was designed to both support and sustain a psychological culture across the whole service and enabled a ‘matching of care’, from tier 1 cognitive behavioural informed care coordination, tier 2 cognitive behavioural interventions for anxiety, depression and related difficulties to tier 3 cognitive behavioural therapy for psychosis.

North East London NHS Foundation Trust

IMPART is a psychological therapies service providing evidence based and NICE guideline recommended treatments for individuals with a personality disorder and who present a high risk to self in North East London. The service is comprised of psychological therapists from a range of backgrounds (including nursing, social work, psychology, and occupational therapy) and provides both out-patient based treatment, and in-reaches to the local in-patient facility to work with the ward staff providing care for individuals with a personality disorder.

Referrals are accepted from primary care, secondary care, probation, and social services. Individuals initially receive a screening assessment during which the presence of a personality disorder and evidence of risk are assessed. If the individual does not meet criteria for the service a referral is made to appropriate services, primarily the psychology department. If the individual meets criteria for IMPART, they are provided with a self-help pack and offered a place in one of the skills groups on offer (Dialectical Behavioural skills (DBT), Cognitive Behavioural Skills (CBT), or Acceptance and Commitment skills (ACT)). Within 16 weeks they will be allocated to an individual therapist and enter a course of Motivational Interviewing followed by either fully programmatic DBT or CBT.

With respect to families and friends, IMPART offers an information Q&A evening quarterly, a one day DBT skills training sessions for families, and a Family Connections programme.

In addition to the provision of direct therapy for service users IMPART offers consultation to staff working with individuals with a personality disorder, and training in the recognition of personality disorders.
Somerset Partnership NHS Foundation Trust

The Somerset Partnership NHS Foundation Trust provides a wide range of integrated community health, mental health, learning disability and social care services to people of all ages across a rural county with a population of approximately 550,000.

The demonstration site involves four key areas that provide psychological therapies and psychological interventions for people with personality disorder including:

- **Primary Care Talking Therapies** an IAPT Plus service that includes psychological therapies and specific interventions for people with significant personality disorder traits
- **Secondary Care Psychological Therapies** a service that includes Cognitive Analytic Therapy, Art Therapy, Cognitive Behavioral Therapy and Family Therapy
- **Personality Disorder Service** providing a whole system psychological approach to the treatment and management of personality disorder to all frontline mental health staff
- **Emerging Personality Disorder Service**, a small innovative service providing an attachment based approach to the treatment and management of 16 – 25 year olds

South London and Maudsley NHS Foundation Trust

The South London and Maudsley NHS Foundation Trust (SLaM) serves four London boroughs, each with high rates of diversity, socio-economic deprivation, and psychosis incidence. SLaM services are provided within Clinical Academic Groups (CAGs), and the Psychosis CAG provides care for about 7,000 people with psychosis, across four Care Pathways: Early Intervention (EI), Promoting Recovery (PR), Complex Care, and Acute Inpatient Care. The SLaM IAPT-SMI demonstration site comprises three clinical teams in the EI and PR pathways: an Early Intervention team (STEP), a specialist recovery service (SHARP), and a psychological therapy team (PICuP). It operates alongside existing psychological therapy provision and the multidisciplinary Community Mental Health Teams (CMHTs). The EI pathway sees people with a first presentation of psychotic symptoms, which may reach the criteria for a range of diagnoses. The PR pathway serves people with established schizophrenia spectrum diagnoses, or with psychotic symptoms in the context of bipolar affective disorder. Service users and carers hold consultancy positions in key steering groups for psychological therapy provision within SLaM, including the IAPT-SMI steering group.

The SLaM IAPT-SMI service offers NICE-recommended, evidence-based interventions for people with psychosis (Cognitive Behavioural Therapy; Family Intervention). Cognitive behaviour therapy for psychosis (CBTp) is an adaptation of CBT for emotional disorders tailored to the needs of people with psychosis, and Family Intervention for psychosis (FiP) is a talking therapy involving both the person with psychosis and their caregiver. The service offers regular planned sessions over six to nine months, and the therapists are trained to competence and receive regular clinical supervision. Therapy is individualised and formulation based, but adheres to published manuals and the CORE competence framework in terms of core principles, structure, and techniques employed. Progress is measured by trained assessors (assistant psychologists) using a range of questionnaire measures before, during, and after completion of therapy.
Appendix 2: Word Cloud

The following word cloud – created by asking each of our interviewees, both IAPT service users and non-users, to provide us with their top ‘three words to describe the service’ – provides a visual overview of people’s experiences with the service:9

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9 This word cloud has been generated by a freely available software whereby the size of the words reflects the percentage of responses. Where words were very similar, or where phrases were used, we decided on using just one of the terms – such as ‘slow’ and ‘took too long’. The location of the words is generated randomly.
Appendix 3: Example of Survey Questionnaires

Your Views On Talking Therapy Services

About this questionnaire

This questionnaire is asking about your experiences of receiving therapy from the IMPART Service at North East London NHS Foundation Trust. It is part of an evaluation to find out whether this type of service is useful. Your feedback is crucial in helping to improve this service by telling us what worked for you and what did not.

We are researchers at The McPin Foundation, an independent specialist mental health research charity. We are carrying out this evaluation on behalf of NHS England who make recommendations about the usefulness of these and similar types of support.

You have been given this survey because you:

- Are in the process of having therapy
- Have completed, or discontinued therapy
- Are about to start therapy

You do not need to write your name on this questionnaire unless you would like to take part in our follow-up work and/or enter our prize draw. Everything you say will be kept private and anonymous. We are interested in what you think and how you found the experience. There are no right and wrong answers. Some of the questions have a space afterwards where you can give us more details or suggestions for how to improve things.

Thank you for taking the time to help improve services by sharing your views. As a thank you, we are offering you the chance to win a gift voucher, one for £100 and four for £25. If you would like to be entered into the prize draw, please fill out your contact details on the slip attached to this questionnaire. We will remove this slip from the questionnaire as soon as we receive it.

Tell us more

We would like to interview a small number of people with a range of experiences who have completed the questionnaire. This will be a chance for you to explain your experience to us in more detail. Interviews can take place over the phone or face-to-face, and will last around 30-45 minutes. The interviewers will be people who have personal experience of using mental health services. People who are interviewed will receive a £20 voucher for their time. If you are interested in being interviewed, please tick here: ☐

We will only be able to interview a small number of people due to the tight timescale of this project. Please do not be offended if you are not called, it is not because we don’t want to hear about your experiences. If we are able to interview you, we will phone you to tell you more about what the interview will be like, and, if you are happy, arrange a date and time. Please provide your name and telephone number so we can contact you:

www.mcpin.org
Introduction

1. How were you referred to the IMPART service? (Please mark one option)
   - Referred myself
   - GP
   - Psychiatrist
   - Other mental health professional
   - Social Worker
   - Other please give details
   - Not sure please give details

2. I... (Please mark one option)
   - Am part way through my therapy
   - None of these please give details
   - Started my therapy and stopped part way through
   - Have completed my therapy
   - Am about to start my therapy

3. Approximately when did you begin your therapy with the IMPART service? (Please mark one option)
   - Less than 1 month ago
   - Not sure / can’t remember please give details
   - 1-6 months ago
   - 7-12 months ago
   - 1-2 years ago
   - More than 2 years ago
   - Has not started yet
### Starting the process

4. Thinking about the time between first being referred and starting therapy, how satisfied were you with... (Please mark one option for each statement and provide comments)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The waiting time?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Comments:</strong></td>
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</tr>
<tr>
<td>b. The support that was offered from mental health services or your GP in the waiting time, if any?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Comments:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c. The assessment process before beginning therapy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Comments:</strong></td>
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<tr>
<td>d. The information provided about what would happen after the assessment process?</td>
<td></td>
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</tr>
<tr>
<td><strong>Comments:</strong></td>
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<td></td>
</tr>
</tbody>
</table>

5. At the start of therapy, how confident were you that it would be helpful? (Please mark one option and provide comments)

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>Very confident</th>
<th>Somewhat confident</th>
<th>Not sure</th>
<th>Not very confident</th>
<th>Not confident at all</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Comments:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please send us your completed surveys by **Friday 13th February 2015**. Freepost envelope enclosed, or send to: Freepost RTEE-RCZ2-RCTR, The McPin Foundation, 32-36 Loman Street, London, SE1 0EH
**Your experience of the therapy**

6. **How was your therapy provided?** (Please mark all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>In a group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual, face-to-face with therapist</td>
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<tr>
<td>By telephone</td>
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<td></td>
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<tr>
<td>By computer</td>
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</tbody>
</table>

7. **Thinking about your experience of the therapy provided by the IMPART service, how satisfied were you with...** (Please mark one option for each statement and provide comments)

a. The way in which it was provided (group sessions, individual therapy etc.)?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:

b. The number of sessions offered?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Comments:

c. How easy it was for you to access (e.g. timing, flexibility, location etc.)?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:

d. How the service communicated with you?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
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<td></td>
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</table>

Comments:

e. The way your progress was monitored (e.g. completing IAPT measures)?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
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</thead>
<tbody>
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</table>

Comments:
**Working with your therapist**

If you have not worked with a therapist, please mark here and go to Q. 10

8. Thinking about your experience of working with your therapist, please rate your agreement with the following statements: (Please mark one option for each statement and provide comments)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I don’t feel judged by my therapist.</td>
<td></td>
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<tr>
<td>Comments:</td>
<td></td>
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<tr>
<td>b. I feel that my therapist understands me.</td>
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<tr>
<td>Comments:</td>
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<tr>
<td>c. My therapist takes my individual circumstances into account (e.g., age; ethnic background; religion; gender; sexual orientation; disability etc.).</td>
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<tr>
<td>Comments:</td>
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<tr>
<td>d. I feel that my therapist helped me develop new skills and approaches to manage my mental health.</td>
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<tr>
<td>Comments:</td>
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</tbody>
</table>
## Completing the therapy

9. Thinking about the therapy you received, how satisfied were you with... (Please mark one option for each statement and provide comments)

<table>
<thead>
<tr>
<th></th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The planning for the completion of the therapy?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Comments:</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>b. Arrangements made for follow-up and / or continued support?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>Comments:</td>
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</tbody>
</table>
Overall reflections

10. Thinking about your overall experience with the IMPART service ... (Please mark one option for each statement and provide comments)

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Do you feel that the service has helped you?</td>
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<tr>
<td>Please tell us more about what you found helpful or unhelpful:</td>
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<td></td>
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<tr>
<td>b. Did the service meet your expectations?</td>
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<tr>
<td>Comments:</td>
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</tbody>
</table>

11. How would you rate the support the service provided to family / carers? (Please mark one option and provide comments)

<table>
<thead>
<tr>
<th></th>
<th>Very good</th>
<th>Good</th>
<th>Okay</th>
<th>Poor</th>
<th>Very poor</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments:</td>
<td></td>
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</tbody>
</table>

12. Do you have any other comments, or suggestions for how to improve the service?

Please send us your completed surveys by Friday 13th February 2015. Freepost envelope enclosed. or send to: Freepost RTFEE-RC2Z-RCTR, The McPin Foundation, 32-36 Loman Street, London, SE1 OEH

MCPin Foundation
About you

We would like to know more about you to help us understand how well the IMPART service at North East London NHS Foundation Trust is meeting people’s different needs. This information is optional, but can help make the service better for people from a range of different backgrounds and circumstances. It won’t be used to select you in any way.

**Your age:**
- [ ] □ 13
- [ ] □ Prefer not to answer

**What is your gender? (Please mark one option)**
- [ ] □ Female
- [ ] □ Male
- [ ] □ Prefer not to answer
- [ ] □ Other

**How would you describe your sexual orientation? (Please mark one option)**
- [ ] □ Heterosexual
- [ ] □ Bisexual
- [ ] □ Gay
- [ ] □ Prefer not to answer

**How would you describe your ethnic background? (Please mark one option)**
- [ ] □ White - English / Welsh / Scottish / Northern Irish
- [ ] □ Other - Mixed background
- [ ] □ Black - Caribbean
- [ ] □ White - Irish
- [ ] □ Asian - Indian
- [ ] □ Other Black background
- [ ] □ White - Gypsy or Irish Traveller
- [ ] □ Asian - Pakistani
- [ ] □ Arab
- [ ] □ Other White background
- [ ] □ Asian - Bangladeshi
- [ ] □ Any other background
- [ ] □ White & Black Caribbean
- [ ] □ Asian - Chinese
- [ ] □ Prefer not to answer
- [ ] □ White & Black African
- [ ] □ Other Asian background
- [ ] □ Black - African
- [ ] □ White & Asian
- [ ] □

**How would you describe your religion, even if you are not practicing it? (Please mark one option)**
- [ ] □ Buddhist
- [ ] □ Sikh
- [ ] □ Christian
- [ ] □ No religion
- [ ] □ Hindu
- [ ] □ Other
- [ ] □ Jewish
- [ ] □ Prefer not to answer
- [ ] □ Muslim

**Would you describe yourself as someone with a disability? (Please mark all that apply)**
- [ ] □ Physical
- [ ] □ Other
- [ ] □ Visual
- [ ] □ No disability
- [ ] □ Hearing
- [ ] □ Prefer not to answer
- [ ] □ Learning

**Do you have caring responsibilities for children, dependent relatives, or other adults?**
- [ ] □ Yes (Please give more details below)
- [ ] □ No
- [ ] □ Prefer not to answer

**Have you been diagnosed with...? (Please mark all that apply)**
- [ ] □ Psychosis
- [ ] □ Bipolar disorder
- [ ] □ Personality disorder
- [ ] □ Any other diagnoses, please give more details below
- [ ] □ Don’t know
- [ ] □ No diagnosis
- [ ] □ Prefer not to say

**Do you feel that this diagnosis has been helpful?**
- [ ] □ Yes
- [ ] □ No
- [ ] □ Don’t know
- [ ] □ Prefer not to answer

Comments:
Your Views On Talking Therapy Services

About this questionnaire

This questionnaire is asking about your experiences of accessing therapy from the IMPART Service at North East London NHS Foundation Trust. It is part of an evaluation to find out whether this type of service is useful. Your feedback is crucial in helping to improve this service by telling us what worked for you and what did not.

We are researchers at The McPin Foundation, an independent specialist mental health research charity. We are carrying out this evaluation on behalf of NHS England who make recommendations about the usefulness of these and similar types of support.

You have been given this survey because you:

* Were referred to the IMPART Service and did not have an assessment
* Completed part or all of the assessment process and did not go on to receive therapy

We know that it may seem strange being asked to provide a view on therapy you did not receive. However, in order to improve the IMPART Service, it is important to understand why people choose not to use it at the point in time it is offered to them. We know there might be lots of reasons for this and would be most grateful if you could share some of these with us.

You do not need to write your name on this questionnaire unless you would like to take part in our follow-up work and/or enter our prize draw. Everything you say will be kept private and anonymous. We are interested in what you think and how you found the experience. There are no right and wrong answers. Some of the questions have a space afterwards where you can give us more details or suggestions for how to improve things.

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We will only be able to interview a small number of people due to the tight timescale of this project. Please do not be offended if you are not called, it is not because we don’t want to hear about your experiences. If we are able to interview you, we will phone you to tell you more about what the interview will be like, and, if you are happy, arrange a date and time. Please provide your name and telephone number so we can contact you:

__________________________________________________________________________
Introduction

1. How were you referred to the IMPART Service? (Please mark one option)

<table>
<thead>
<tr>
<th>Option</th>
<th>Yes</th>
<th>No</th>
<th>Other please give details</th>
<th>Not sure please give details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred myself</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>GP</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>Other mental health professional</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Social Worker</td>
<td>☐</td>
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</tbody>
</table>

2. 1. (Please mark one option)

- Was referred to the IMPART Service and did not complete an assessment
- Completed all or part of an assessment at the IMPART Service but did not go on to receive therapy
- Not sure / can’t remember please give details

3. Approximately when did you receive your referral letter or information from the IMPART Service explaining about the service and next steps towards having an assessment? (Please mark one option)

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Yes</th>
<th>No</th>
<th>Other please give details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 month ago</td>
<td>☐</td>
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<tr>
<td>1-6 months ago</td>
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<td>7-12 months ago</td>
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<tr>
<td>More than 2 years ago</td>
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Please send us your completed surveys by **Friday 13th February 2015**, Freepost envelope enclosed, or send to: Freepost RTEE-REZZ-RETR, The McPin Foundation, 13-36 Leman Street, London, SE1 6EH
### Previous experience of psychological therapy

#### 4. Had you ever been offered psychological therapy before being referred to the IMPART Service? (Please mark one option)
- Yes
- No please go to Q.7
- Not sure

#### 5. If yes, was this...? (Please mark all that apply)
- In a group
- Individual, face-to-face with therapist
- By telephone
- By computer
- Other please give details
- Not sure please give details

#### 6. Thinking back, how satisfied were you that this had met your needs? (Please mark one option and provide comments)

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
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</table>

Comments:
Your experience of the IMPART Service at North East London NHS Foundation Trust

7. Thinking about when you were contacted by the IMPART Service, what information did you have about the therapy before the assessment process? (Please mark all that apply)

<table>
<thead>
<tr>
<th>Information</th>
<th>Yes</th>
<th>No</th>
<th>Comments:</th>
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</thead>
<tbody>
<tr>
<td>No information <em>please go to Q.10</em></td>
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<tr>
<td>Leaflet</td>
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<tr>
<td>Found description on website</td>
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<td>Information from GP</td>
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<tr>
<td>Information from mental health professional</td>
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<tr>
<td>Other <em>please give details</em></td>
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</table>

8. Was this information helpful?

<table>
<thead>
<tr>
<th>Response</th>
<th>Yes</th>
<th>No</th>
<th>Comments:</th>
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<tbody>
<tr>
<td>Yes</td>
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<td>No</td>
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<tr>
<td>Not sure</td>
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</table>

9. Did this information help you make a decision about whether the therapy would be right for you?

<table>
<thead>
<tr>
<th>Response</th>
<th>Yes</th>
<th>No</th>
<th>Comments:</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>Not sure</td>
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</table>

10. Thinking back, roughly how many weeks did you wait between getting your referral letter or information about therapy and beginning your assessment?

*If you did not have an assessment, please go to Q.12*
11. Thinking about the time between first being referred and beginning your assessment, how satisfied were you with... (Please mark one option for each statement and provide comments)

<table>
<thead>
<tr>
<th></th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The waiting time?</td>
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<td>Comments:</td>
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<td>b. The support that was offered from mental health services or your GP in the waiting time, if any?</td>
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<td>c. The assessment process?</td>
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<tr>
<td>d. The information provided about what would happen after the assessment process?</td>
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</tbody>
</table>
12. What were your reasons for not continuing to the assessment process, or to therapy: (Please mark all that apply)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Mark</th>
</tr>
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<tbody>
<tr>
<td>Did not feel it was necessary</td>
<td></td>
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<tr>
<td>Did not feel it would be helpful</td>
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<tr>
<td>Did not feel it was the right time</td>
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<tr>
<td>Did not have the time to attend</td>
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<tr>
<td>Worried about what would happen</td>
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<tr>
<td>Not given enough information to decide whether the service was right for me</td>
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<tr>
<td>Was not practical for me to attend</td>
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<tr>
<td>Was only seeking assessment</td>
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<tr>
<td>Had to wait too long</td>
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<tr>
<td>Sought alternative treatment</td>
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</tr>
<tr>
<td>Decision influenced by previous experiences of therapy</td>
<td></td>
</tr>
<tr>
<td>Not offered therapy following assessment</td>
<td></td>
</tr>
<tr>
<td>Other: please give details below</td>
<td></td>
</tr>
<tr>
<td>None of the above</td>
<td></td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
</tbody>
</table>

13. If you were referred to the IMPART Service again, what might make you more likely to receive therapy?

14. Do you have any other comments, or suggestions for how the service could be improved?

THANK YOU VERY MUCH FOR GIVING FEEDBACK ON THE SERVICE
### About you

We would like to know more about you to help us understand how well the IMPART service at North East London NHS Foundation Trust is meeting people’s different needs. This information is optional, but can help make the service better for people from a range of different backgrounds and circumstances. It won’t be used to select you in any way.

#### Your age:
- [ ] Prefer not to answer

#### What is your gender? (Please mark one option)
- [ ] Female
- [ ] Male
- [ ] Prefer not to answer
- [ ] Other

#### How would you describe your sexual orientation? (Please mark one option)
- [ ] Heterosexual
- [ ] Bisexual
- [ ] Gay
- [ ] Prefer not to answer
- [ ] Lesbian

#### How would you describe your ethnic background? (Please mark one option)
- [ ] White - English / Welsh / Scottish / Northern Irish
- [ ] White - Irish
- [ ] White - Gypsy or Irish Traveller
- [ ] Other White background
- [ ] White & Black Caribbean
- [ ] White & Black African
- [ ] White & Asian
- [ ] Other Mixed background
- [ ] Asian - Indian
- [ ] Asian - Pakistani
- [ ] Asian - Bangladeshi
- [ ] Asian - Chinese
- [ ] Other Asian background
- [ ] Black - Caribbean
- [ ] Other Black background
- [ ] Arab
- [ ] Any other background
- [ ] Prefer not to answer

#### How would you describe your religion, even if you are not practicing it? (Please mark one option)
- [ ] Buddhist
- [ ] Sikh
- [ ] Christian
- [ ] No religion
- [ ] Hindu
- [ ] Other
- [ ] Jewish
- [ ] Prefer not to answer
- [ ] Muslim

#### Would you describe yourself as someone with a disability? (Please mark all that apply)
- [ ] Physical
- [ ] Visual
- [ ] Hearing
- [ ] Learning
- [ ] Other
- [ ] No disability
- [ ] Prefer not to answer

#### Do you have caring responsibilities for children, dependent relatives, or other adults?
- [ ] Yes (Please give more details below)
- [ ] No
- [ ] Prefer not to answer

#### Have you been diagnosed with...? (Please mark all that apply)
- [ ] Psychosis
- [ ] Bipolar disorder
- [ ] Personality disorder
- [ ] Any other diagnoses, please give more details below
- [ ] Don’t know
- [ ] No diagnosis
- [ ] Prefer not to say

#### Do you feel that this diagnosis has been helpful?
- [ ] Yes
- [ ] No
- [ ] Don’t know
- [ ] Prefer not to answer

Comments:

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Please send us your completed surveys by **Friday 13th February 2015**, Freepost envelope enclosed, or send to: Freepost RTTE-RC22-RCTR, The McPin Foundation, 32-36 Loman Street, London, SE1 0EH
Appendix 4: Interview Schedules

Interview Schedule for Survey 1 (‘did engage’)

About this Interview Schedule

- The interview schedule is structured with ‘lead questions’ and ‘follow-up questions’. The lead questions indicate the key areas to be covered. You may or may not want to ask follow-up questions – this will depend on how much is raised spontaneously in response to the lead question.

- This document is intended to be used flexibly. It might be helpful to think of it more as a ‘discussion guide’ than an ‘interview schedule’. This means that:
  - Building rapport is essential. Ideally, the participant will be able to speak freely and spontaneously about their experience in a way that covers what we want to know. We want to avoid receiving short answers to rigid interview questions.
  - It is not essential to go through the questions in order. It may not even be necessary to ask some questions at all as the relevant issues may be raised spontaneously by interviewees.
  - Prompts should only be used if necessary. We would like the interview to be led by the participant. Sometimes prompts can be helpful, but give the interviewee a chance to raise an issue first, and only prompt if you think it’s likely there are other important issues that they have forgotten to mention.

Pre-Interview

- Have the Information Sheet and Consent Form to hand.

1. Confirm you have the right person (don’t say you’re from the McPin Foundation or phoning about mental health until you have the right person).
2. Introduce yourself and remind them about the survey and volunteering for interview.
3. Remind them that: a) it is confidential; b) we are independent of the service; c) it will be written up without names; d) they can stop any time they like; e) any questions?
4. “The interview is to find out about your expectations and experience of the XXX [service] at XXX [site]. We’re interested in hearing about your views and experiences in more detail, but because of time, sometimes I might say that we have to move on to the next question. This isn’t because I’m not interested in other things you might have to say. For this interview the focus is purely on your experiences of the XXX [service] rather than any other services you may have used. Does this sound okay?”
5. Once the interview is over we will end the conversation and you will be sent a £20 shopping voucher in the post that can be spent at various retail outlets on the High Street.
6. “We would like to record the interview so that we can listen to it again and make sure we represent your views accurately. We might like to quote some of what you say because we think it will be valuable for other people to read, when we report on our findings. You will not be identifiable. Only the evaluation team will listen to the recordings, and we might send it to a specialist company to type out what is said. We’ll keep them secure and delete them at the end of the project.”
7. IF CONSENT FORM HASN’T BEEN RETURNED TO MCPIN AT TIME OF INTERVIEW (CHECK WITH MCPIN). You should have been sent a Consent Form in the post, alongside your Information Sheet. I’m not sure if you’ve had a chance to post it back yet – perhaps you have and it hasn’t arrived yet. Could I just ask you to confirm that you have read and signed the consent form? I need to record you saying this so that we know you are happy for us to interview you.

8. Are you happy for me to start the recorder and begin the interview now? (Must answer yes before going further)

**Interview Schedule**

**Exercise: Just before we start, I wanted to ask you – if you had to pick three words to describe the XXX [service], what would these be?** If they can’t think of three, say that we can return to this question at the end of the interview if they prefer.

1. Thinking back to when you were first told about the XXX [service], can you tell me what was going on in your life at that time?
   - Who referred you and why?
   - What would you say were your reasons for being offered / wanting therapy?
   - How did you feel about being referred?
   - How did you find the process of referral?

2. What were you hoping to get out of the therapy?
   - If necessary, prompt with:
     - Emotional support
     - Practical support
     - Socialising

3. What were your expectations of what would happen during therapy?
   - **Probe around prior knowledge of therapy**
   - Did you know what to expect from therapy?
   - Were you able to get all the information you needed? Why / why not?
   - Were there things the service offered that you thought would be helpful? Why / why not?
   - Anything you thought would be unhelpful? Why / why not?

4. Can you tell me a bit more about what happened after you were referred?
   - If necessary, probe around:
     - Communication with the service about what would happen next
     - The assessment process
     - What were your first impressions?
     - Did your impressions change over time? If so, how / why?

5. How long did you wait before the assessment / before you started therapy?
6. Is there anything that made it difficult for you to access therapy?

If necessary, prompt with:

- Getting a referral (being taken seriously)
- Travel
- Childcare
- Work commitments
- Did not have time to attend
- Stigma
- No choice in therapist
- Previous poor experience of therapy
- Fear of the unknown
- General anxieties

NB: We want to look at barriers to engaging with the service – both personal and service-based barriers

7. Were you given any choice in the type of therapy you received?

- If no, would you have liked a choice?
- If yes, how did you find that?
- If yes, were the different options explained to you?

8. Can you tell me a bit more about how the therapy was delivered?

- Can you describe how the sessions worked?
- How many sessions did you have / how many are you expecting to have?
- Was there any flexibility in the amount of sessions – could more be added on for example?
- Is it enough / too much?
- Did you stop the therapy part way through? If so, why?

9. Can you tell me a bit more about your therapist?

- What kind of personal qualities did they have?
- Did you feel able to speak freely with your therapist?
- Did you see the same person throughout your therapy?
- Did you get on well with your therapist?
- Did you feel they had the right skills to help you?
- Were you given a choice of therapist?
- Would you have liked a choice?

10. Do you feel that you have been able to make decisions about your therapy for yourself?

- How did you feel about the level of decision-making you had in your therapy / treatment?
  - Any examples?
- How did you feel about the level of decision making you had in the way in which it was delivered:
  - How many sessions?
  - Changing therapist?
  - Moving from group to individual?
• How did you feel about the level of decision making you had in the content of therapy sessions?
  o Any examples?

11. I understand there were various feedback forms you were asked to fill in. How did you find filling out these forms?

• Did you know why you were asked to fill them out?
• How easy / difficult did you find completing these forms?
• Were they helpful for you? Unhelpful? Why / why not?
• Is there anything about the forms you would change?

12. Overall, how helpful do you feel the therapy has been?

• In what ways has it been helpful / unhelpful?
• Have you noticed any changes in your mental health?
• What kind of impact do you think receiving this therapy has had / has had / will have?
• Do you have a sense of what the longer term impact of this therapy will / might be?
• Did your family / friends notice any changes in you while you were waiting for therapy / after your therapy? (positive or negative)
• Why do you think these changes happened?
• How helpful have your family / carers found it?
• Have you noticed any changes in other areas of your life?
  If necessary, prompt with:
  o Feeling more empowered or confident
  o Being able to socialise more
  o Better engagement with other services
  o Coping day-to-day
  o Relationships with friends and family
• Overall, would you recommend the service to anyone else? Why / why not?

13. Was there anything you found unhelpful, or feel could be improved?

• Were there any downsides?
• What would you change to make the service/therapy more helpful?

14. Have you had any opportunities to influence the way the service is run or to get involved?

• In which ways?
• Is this something that is important to you?
• Would you have liked more opportunities to do this?
• How can service users have more of a voice in the way that organisations provide psychological therapies for people?

15. [Summary question, may already have been covered:]. Has the service helped you to achieve what you wanted?

Yes No
↓ ↓

How? Why not? What got in the way? Probe here to understand why and…

NB: We want to look at the impact of engagement with the service on their:
• Mental health
• Engagement with other services
• Daily activities
• Coping strategies
• Families and wider networks
If necessary prompt with:

- Physical
- Practical
- Emotional
- Other personal circumstances
- And what else helped (or didn’t help) – it won’t just be IAPT

16. [Summary question, may already have been covered]: Did the treatment / therapy turn out to be what you expected?
   - In what ways?

17. Thank you – I think we’re coming towards the end of the interview now. Is there anything else that you’d like to add?

18. How have you found the interview? Has it been alright?

If they haven’t already done this at the start: Exercise: Can we come back to the ‘three words’ exercise – if you had to pick three words to describe the XXX [service], what would these be?

At the end of the interview:

1. Thank participant for their time.
2. Check how participant is feeling.
3. Any questions?
4. Would you like to receive a summary of what we found? If yes, we will send this in the post in the early summer after the project is complete. Can you make sure to keep track of who would like this please.
5. Your voucher will be sent in the post in the next couple of days to the address they’ve given in the set-up interview.

After the interview

- Take a break! Interviewing is exhausting.
- If it has been emotionally hard, you can call Agnes, Laura or Sarah to talk it through. You can also call each other to debrief if you like. Remember to take care of yourself.
- Please send an email to Laura to confirm that the interview is completed so she can send out the voucher.
- Remember to contact the team **immediately** if you have any concerns about the person's safety. Consult the 'Distress Flow-chart' for guidance.
Interview Schedule for Survey 2 (‘did not engage’)

About this Interview Schedule

- The interview schedule is structured with ‘lead questions’ and ‘follow-up questions’. The lead questions indicate the key areas to be covered. You may or may not want to ask follow-up questions – this will depend on how much is raised spontaneously in response to the lead question.

- This document is intended to be used flexibly. It might be helpful to think of it more as a ‘discussion guide’ than an ‘interview schedule’. This means that:
  - Building rapport is essential. Ideally, the participant will be able to speak freely and spontaneously about their experience in a way that covers what we want to know. We want to avoid receiving short answers to rigid interview questions.
  - It is not essential to go through the questions in order. It may not even be necessary to ask some questions at all as the relevant issues may be raised spontaneously by interviewees.
  - Prompts should only be used if necessary. We would like the interview to be led by the participant. Sometimes prompts can be helpful, but give the interviewee a chance to raise an issue first, and only prompt if you think it’s likely there are other important issues that they have forgotten to mention.

Pre-Interview

- Have the Information Sheet and Consent Form to hand.
- Make sure you have the following information about the participant:
  - Whether or not they had an assessment (i.e. at what point did they ‘drop out’)?
  - Some of their reasons for not continuing to therapy / assessment (should be in the summary document).

9. Confirm you have the right person (don’t say you’re from the McPin Foundation or phoning about mental health until you have the right person).

10. Introduce yourself and remind them about the survey and volunteering for interview.

11. Remind them that: a) it is confidential; b) we are independent of the service; c) it will be written up without names; d) they can stop any time they like; e) any questions?

12. “The interview is to find out about your expectations and experiences of being referred to the XXX [service] at XXX [site]. We’re interested in hearing about your views and experiences in more detail, but because of time, sometimes I might say that we have to move on to the next question. This isn’t because I’m not interested in other things you might have to say. For this interview the focus is purely on your experiences of the XXX [service] rather than any other services you may have used. Does this sound okay?”

13. Once the interview is over we will end the conversation and you will be sent a £20 shopping voucher in the post that can be spent at various retail outlets on the High Street.

14. “We would like to record the interview so that we can listen to it again and make sure we represent your views accurately. We might like to quote some of what you say because we think it will be valuable for other people to read, when we report on our findings. You will not be identifiable. Only the evaluation
team will listen to the recordings, and we might send it to a specialist company to type out what is said. We'll keep them secure and delete them at the end of the project."

15. **IF CONSENT FORM HASN’T BEEN RETURNED TO MCPIN AT TIME OF INTERVIEW (CHECK WITH MCPIN).** You should have been sent a Consent Form in the post, alongside your Information Sheet. I'm not sure if you've had a chance to post it back yet – perhaps you have and it hasn't arrived yet. Could I just ask you to confirm that you have read and signed the consent form? I need to record you saying this so that we know you are happy for us to interview you.

16. Are you happy for me to start the recorder and begin the interview now? (Must answer yes before going further)

**Interview Schedule**

1. What was going on in your life when you were first referred to therapy from the XXX [service]?
   - Who referred you and why?
   - What would you say were your reasons for being offered / wanting therapy?
   - How did you feel about being referred?
   - How did you find the process of referral?

2. What were you hoping to get out of the therapy?
   - If necessary, prompt with:
     - Emotional support
     - Practical support
     - Socialising

3. What were your expectations of what would happen during therapy?
   - Did you know what to expect from therapy?
   - Were you able to get all the information you needed? Why / why not?
   - What aspects of the service did you think would be helpful? Why?
   - Anything you thought would be unhelpful? Why / why not?

4. Can you tell me a bit more about what happened after you were referred?
   *If necessary, probe around:*
   - Communication with the service about what would happen next
   - What were your first impressions?
   - Did your impressions change over time? If so, how / why?

5. **[If applicable – check notes]** How long did you wait before the assessment?
   - How did you feel about the waiting time?
• Were you kept informed about what was happening while you were waiting?
• Would you have liked any other help while you were waiting? If yes, what?
• Were you offered any?

6. How did you find the assessment?
• What was your general impression of the staff and service?
• How helpful did you find it?
• What was the outcome of your assessment? Next steps?
• How do you think the assessment process could have been improved?

7. You mentioned in the questionnaire that one of the reasons for not going ahead with the assessment / therapy was XXX. Could you tell me a bit more about that?

8. Did anyone from the service ask about your reasons for not using the therapy?
• If no, would you have liked them to ask?
• If yes, how was this? Did you feel heard and understood?

9. Is there anything that would have made you more likely to use the therapy?
• Prompts: process of referral, travel, child care, work commitments, stigma, the service they offered, the situation they were in, the assessment process, the diagnosis etc.

10. How do you feel now about your decision not to take up the therapy?
• Do you still think it was the right choice not to take it up?

11. Since your referral, have your circumstances changed in any way?
• Have you managed to get the help you need from a different source?
• Have things got better or worse?
• Do you feel that you would benefit from some support now?

12. Thank you – I think we’re coming towards the end of the interview now. Is there anything else that you’d like to add?
13. How have you found the interview? Has it been alright?

**At the end of the interview:**

6. Thank participant for their time.

7. Check how participant is feeling.

8. Any questions?

9. Would you like to receive a summary of what we found? If yes, we will send this in the post in the early summer after the project is complete. Can you make sure to keep track of who would like this please.

10. Your voucher will be sent in the post in the next couple of days to the address they’ve given in the set-up interview.

**After the interview**

- Take a break! Interviewing is exhausting.

- If it has been emotionally hard, you can call Agnes, Laura or Sarah to talk it through. You can also call each other to debrief if you like. Remember to take care of yourself.

- Please send an email to Laura to confirm that the interview is completed so she can send out the voucher.

- Remember to contact the team immediately if you have any concerns about the person’s safety. Consult the ‘Distress Flow-chart’ for guidance.
NHS England commissioned the McPin Foundation to undertake this work. The McPin Foundation is a specialist mental health research charity based in London but working across England. It exists to transform mental health research by placing lived experience at the heart of research activities and the research agenda.

Its work includes:

• Guidance and expert support on public and patient involvement in mental health research
• Collaborative research studies in partnership with organisations interested in user focused mental health research
• Campaign and policy work to raise the profile of mental health

Promoting equality and addressing health inequalities are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have:

• Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
• Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities