A user-focused evaluation of IAPT services in London


Prepared by

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We owe a huge thanks to: members of our panel, Carla Adem, Keith Mallinson, Laurie Bryant and others; all the staff at the IAPT services who supported us in recruiting participants to the evaluation; and everyone who took part in this study.
Executive summary

Background
This report presents findings from a user-focused evaluation of IAPT services in London. The study involved service users throughout the design, data collection and analysis. The project was steered by a panel of IAPT service users, and two mental health service users formed part of the project team. The user-focused approach to this study has allowed us to explore the experiences and perspectives of IAPT patients and investigate the key elements of an effective, person-centred IAPT service.

The evaluation used a mixture of data collection methods:

- four focus groups of patients from across IAPT services in London.
- A survey of 116 participants from 3 IAPT services
- Semi-structured telephone interviews with 20 participants who completed the survey

Findings
Satisfaction with the IAPT services was generally very high. Overall, participants sought a flexible service that responds to individual needs and goals. Based on responses from participants, we identified key principles for delivering a person-centred service.

Support during waiting times
Approximately a third of participants in the survey waited over two months to access the service. For some participants long waiting times were distressing and the immediate need for help had sometimes passed by the time support was available. People wanted more contact and information during long waits.

Person-centred therapy
Participants were most satisfied with therapy when they felt that therapists were able to respond to their individual needs and circumstances. In contrast, some participants felt that they received ‘text book’ therapy that did not adequately address their particular issues.

Creating a welcoming service
The atmosphere and facilities of services heavily influenced the way that participants experienced the therapy. Venue, location and reception staff are crucial in establishing a relaxed and welcoming setting. Services need to be sensitive to the potential for stigma when accessing mental health services.

Preparing for a positive end to therapy
Many participants were concerned about the limited number of sessions. The time-limited nature of the therapy needs to be communicated to patients carefully to avoid causing anxiety. Discussion and preparation for the end of therapy are important to avoid patients feeling abandoned after sessions are completed.
Offering opportunities for user involvement

Comments from participants suggest that there is a desire for more opportunities to get involved in the service or to provide feedback. In particular, people wanted opportunities to share learning with others, either through social and peer support events, or through patient recommended resources and coping strategies.

Recommendations
Based on our findings, we offer twelve recommendations for delivering a person-centred IAPT service.

1. Further promotion of the IAPT service to raise awareness among both public and GPs is needed to improve access
2. Provide more contact and information to provide support while waiting to access the service
3. Accessible resources should be made available to patients prior to, and during therapy
4. Provide flexible therapy within the IAPT model to address individual patient needs
5. Provide open communication for patients from the start, and as far as possible accommodate personal circumstances and preferences
6. More attention should be paid to training therapists on how to communicate with patients about the number of sessions available
7. More flexibility should be given when arranging appointments, and additional appointments outside standard working hours are needed to accommodate those patients who are in employment.
8. Procedures for re-accessing the service if needed should be made as simple as possible
9. Weekly measures should be discussed within the therapy and used for the immediate and ongoing benefit of patients
10. Recent plans to extend IAPT to younger and older patients, and to patients with diagnoses of severe mental illness are supported by our evaluation, but there is a need for further training
11. Stigma awareness training for all staff, including reception staff, would help to promote good practice and establish a welcoming environment
12. There is an appetite for more user involvement among patients, but creative approaches may be needed to make it possible for people to get involved
Background

Project aims
The aims of this evaluation were laid down in Commissioning Support for London’s tender document, specifically:

- to inform the future commissioning processes for IAPT provision across London
- to influence those who are delivering IAPT services as providers, as well as commissioning bodies, to ensure ‘user-friendly’ services
- to design or adopt a methodology that will assess the level of satisfaction with and effectiveness of the IAPT services, from the point of view of people who receive those services.

The evaluation aimed to address five key research questions with reference to the person’s journey from referral to follow up:

- How do service users experience IAPT services?
- What are the effective elements of IAPT services from the service user perspective?
- What do IAPT services do well?
- What improvements could be made to enhance the experience of service use?
- What individual and contextual factors influence the experience of service use?

These broad questions allowed scope to focus on those specific issues identified by the users involved in delivering the project and those identified through focus groups.

Due to the limited time and resource of the project, we were able to capture views only from service users, including those who were actively involved in the services, and who were accessing the service over the period of the evaluation.

Project design
This project aimed to place service user involvement at the centre of the design, conduct, data collection and analysis. Much has been written about how to conduct effective user involvement projects. There is general agreement that conducting effective involvement in research requires additional time and resource, particularly where the project involves hard-to-reach populations, or where there is not already a history of involvement in the subject group.

While influenced by User-Focused Monitoring, we were not able to follow this approach in this project. Many of the elements of user-focused monitoring and laid out by Kotecha et al, were present in this evaluation. Questions asked of participants were created by the panel and service user researchers alongside the project lead, service users formed more than half of the project team and the entirety of the expert advisory panel, and we encouraged and facilitated participants in the focus groups to input into later stages of the project
(Kotecha et al, 2007: 9-11). Nonetheless, service users did not ultimately initiate, control or lead the project which remained the responsibility of the research team at Rethink. Instead, we adapted a model of user involvement to meet the needs and constraints of this project, drawing on principles from User Focused Monitoring and co-production, and building on Rethink’s work in previous projects, particularly the Recovery Narratives project which led to publication of the *Back into the World* report, available online at [www.rethink.org/intotheworld](http://www.rethink.org/intotheworld) (Rethink, 2010).

This evaluation was constrained by both limited resource and time, with a short set-up time and fixed deadline. Conducting effective user involvement in this type of project posed a particular challenge. We developed a model of user involvement which was intended to address these challenges and to deliver the best possible involvement within the limits of the project brief.

When we discuss user involvement in this report, it refers specifically to the activity of service users who have a role in shaping and conducting the project, not to the input of study participants who contribute by completing a survey or being interviewed. This is an important distinction. Throughout the project, the information provided by participants helped to steer and inform further data collection and analysis as would be expected in any qualitative research. User involvement is distinct from this level of input, in that users take an active role in applying their experience and personal interpretation to shape the methods used and the data collected.

The involvement model we developed included 3 elements of service user involvement. These are demonstrated in Figure 1 below. Due to the short time available to get the project off the ground, it was not possible for us to recruit and train new Service User Researchers from the IAPT services. Instead, the Rethink Research team approached two people who had previously worked with the team and who had experience of mental health services but not of IAPT. People with experience of IAPT were involved through an Expert Advisory Panel recruited through the London Services.

**Figure 1**

<table>
<thead>
<tr>
<th>Independent user involvement consultant</th>
<th>Service user Researchers</th>
<th>Project lead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alison Faulkner (AF)</td>
<td>Alice Hicks (AH) &amp; Ruth Sayers (RS)</td>
<td>Sarah Hamilton (SH)</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Expert Advisory Panel</td>
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<tr>
<td></td>
<td></td>
<td>(IAPT service users)</td>
</tr>
</tbody>
</table>
User involvement roles

Service user researchers

The Service User Researcher role was intended to be involved in every stage of the project, including developing study tools, co-facilitating focus groups, carrying out all 20 semi-structured interviews, participation in analysis workshops, and writing the final report. The two service user researchers would form part of a small project team with the project lead, Sarah Hamilton (SH). The time available for this involvement was limited by resource, but as far as possible, it was intended that they would input into co-ordinating the study throughout, and be involved in decisions about the study design, problem solving and reflecting on the project progress.

Independent Service User involvement consultant

Following recommendations from service user researchers in previous projects, we introduced a role of independent consultant within the project (Bowyer et al, 2010: 31). This was intended to address previous experiences where service user researchers did not feel confident or comfortable to challenge the project team, or felt that they were not being supported or involved appropriately. The consultant recruited is Alison Faulkner, a highly experienced user involvement consultant and herself a service user. The purpose of this role was to provide an additional support to the Service User Researchers from outside the project team itself. This was not to replace the line management relationship between project lead and Service User Researchers, but to support them in raising issues themselves. This role was used throughout the project and was found to be extremely useful in improving communication where this was difficult. Further discussion of this role is given below.

Expert Advisory Panel

The Expert Advisory Panel brought expertise based on their experience of using the IAPT services. The role of the panel was to steer and inform the process and to bring the perspective of a service user to both the methods and the data.

The panel was paid, both for their time attending the meeting, and for preparation and reading time. This is considered essential, both to encourage participation, and to value their input. Efforts to demonstrate the value of this involvement were also made by producing an Agreement which members signed at the beginning of their involvement. This meant that their role was placed on an ‘official’ level and helped to give clarity about what was expected of them and what they could expect from Rethink.

The panel was expected to meet three times in total. The first meeting was to inform the approach of the study and the content of focus group schedule. The second meeting was to review the focus group data and inform the design of the survey. The final meeting was to review the project findings and inform the team’s interpretation of the data.

Further reflection on the effectiveness of the user involvement model used is given in a later section of this report.
**Evaluation design**

The project design was laid out in the initial protocol. We used a combination of qualitative data - collected through focus groups and semi-structured interviews – and quantitative survey data. Service users only had limited input to the development of the overall design of the project, which was drafted by the Rethink Research team and service user researchers invited to make comments and suggestions before finalising. In contrast, all the data collection instruments – focus group schedule, survey questionnaire and interview schedule – were developed alongside the service user researchers and the Expert Advisory Panel. The key steps in the project are summarised in the flow chart below (Figure 2).
Method

Recruitment to user involvement roles

The first step of implementing the project design outlined above was to recruit service users to the two separate involvement roles. This took place under considerable time pressure as they needed to be in place before data collection could begin. For this reason, we recruited wherever possible through existing contacts.

Service User Researchers
We approached two service user researchers (AH and RS) who had previously worked with Rethink on another research project exploring Recovery (Rethink, 2010). As part of this project both Service User Researchers had received training and had conducted a range of interviews. Both also had considerable research and other involvement experience from previous projects with other organisations. AH and RS both had experience of a wide range of service use, primarily in secondary mental health services, and both had some (though not necessarily extensive) experience of talking therapies. Neither, however, had used IAPT services, and neither were based in London.

Expert Advisory Panel
The Expert Advisory Panel was recruited early in the project. Initially, we approached the London services and asked them to promote the Panel to any service users and ex-service users they thought appropriate. A brief summary of what was involved was circulated to the services (See Appendix 1). Anyone interested was encouraged to contact the Project Lead directly to discuss it and get further information. Four services actively looked for potential panel members and 7 people approached the Project Lead. Of these, 3 attended the first meeting.

Membership of the panel fluctuated throughout the project, with only one person able to attend all three meetings. Two others attended two of the meetings, and two more attended just one meeting. Largely, this fluctuation was the result of difficulty scheduling meetings at a time that everyone was available. For the second meeting, we approached some of the participants from the focus groups to add numbers to the Panel and we successfully recruited one additional member this way.
Data collection

Focus groups

Schedule design
A focus group schedule with broad themes was developed following input from the Expert Advisory Panel at their first meeting. The meeting was facilitated by AH, RS and SH, using informal discussion with some structured elements, including asking people to draw a map of their own experience with talking therapies. Through this discussion we identified key points of the therapy process that we wanted to explore in the study. A summary of the issues raised in this first meeting was produced to inform the focus group guide (Figure 3).

Recruitment
We emailed all the London IAPT services and asked them to support recruitment for the focus groups through posters, flyers and email adverts (see Appendix 2). Six services distributed information about the focus groups. One service, Greenwich Time to Talk, mailed a letter and advert to a list of over 50 service users who had previously expressed an interest in feedback or research. This allowed us to have one focus group consisting only of users of this service. The remaining groups were made up of users from different services.

Anyone interested in taking part was asked to contact SH directly. This allowed SH to explain more about what was involved and for potential participants to ask questions. An information sheet/consent form was sent out prior to the focus group by post or email (see Appendix 3). At the start of each group, there was an opportunity to ask any further questions and written consent was collected from all participants.

Conduct
The focus groups were facilitated by AH and RS with support from SH. Discussions followed a broadly chronological approach rather than a thematic one. This allowed participants to raise issues important to them, rather than steering to topics of most interest to the Project Team. AH and RS used slightly different approaches to facilitation of the groups. Two of the groups used group discussion with light touch steering by the facilitator. In the other two groups, a more structured approach was used, and participants were encouraged to make notes at the start of the group under three headings: Referral to the IAPT service; Experience of using the service; Leaving the service or moving on. In all four groups, participants were also given post-it notes so that if there were issues they felt unable to raise in the discussion these could be written down and given to the researchers at the end. Focus Groups were audio recorded and notes were taken throughout.

Analysis
Data from the focus groups was reviewed and discussed together by AH, RS and SH. We drew key themes from the groups which were then presented to the Expert Advisory Panel and used to develop the survey.
Figure 3

Experiences of IAPT

Therapist

- Matching therapist to patient
- Choice about your therapist

Helpfulness of the homework

- Feeling in control of your therapy
- Appropriateness of therapy

Therapy

- Having enough information about different types of therapy
- Number of sessions
- Type of therapy

Getting involved?

- Opportunities to give feedback about the service

Process and structures

- Adequate support around exit from the service
- Knowing what to expect when the therapy comes to an end
- Having a clear goal for the therapy
- Tracking progress and integration into the therapy

Referral

- Length of time between referral and access to the service
- Expectations of IAPT

Family/support networks

- Service contact with family/support networks
- Appropriate information given to family/friends

Information received about IAPT

- Knowing what to expect when the therapy comes to an end

Number and type of opportunities to get involved in the service

Information received about IAPT
Survey

Questionnaire development and piloting

We took an iterative approach to the design of the survey. While the focus group themes provided a strong steer for the content of questions, we were also highly conscious of the need to keep the questions carefully within the limits of an evaluation. Keeping the questions strictly about the service and the participants’ experiences of the service proved very challenging. The often blurred line that distinguishes research from evaluation was difficult for everyone to agree on. Issues such as stigma – a feature of more than one focus group - were largely dropped from the questionnaire to avoid straying outside evaluation and into exploration of attitudes or personal experiences.

The type of questions, range of responses and structure of the questionnaire were debated within the project team. Ultimately, a range of options were presented to the Expert Advisory Panel to seek their input on preferred wording and structure. It was agreed that while quantitative data was necessary, there should be as much scope as possible for participants to give more detailed comment or clarification. Some areas of interest were dropped in order to keep the questionnaire simple and quick to complete. Demographic questions were informed by previously published research into equality assessments in IAPT (NHS, 2010).

Comments from the panel were used to develop a more complete draft. This was then reviewed by all members of the project team, the Expert Advisory Panel, and senior colleagues within Rethink.

We piloted the questionnaire by distributing it to people who had taken part in the focus groups. Due to the short time available, we were only able to collect pilot data from 5 participants. We reviewed their data to ensure that questions were clear and provided usable responses. We also asked participants for their feedback on how easy the questionnaire was to complete. Following the pilot, the questionnaire was amended and again reviewed by the Project Team.

Recruitment

We faced considerable challenge in recruiting to the survey. Early on in the project, it became clear that several services were concerned about the potential overlap between this survey and the National Audit for Psychological Therapies (NAPT) survey which was being distributed at roughly the same time. We approached all of the London services to gain support for this stage of the project. We received responses from ten of the IAPT services in London. All of these expressed concern about distributing another postal survey. Four services were prepared, however, to distribute the survey in another way. These four were Hammersmith & Fulham Back on Track, Lambeth Psychological Therapies, Wandsworth Psychological therapies, and Greenwich Time to Talk.

We worked with the four services to explore ways of distributing the questionnaires in place of posting them out. In two of the services, surveys were given to people in the waiting area of the main service locations. SH spent one day in each of these services handing surveys to each person who came in. The remainder of the surveys in these two sites were left at the reception along with freepost envelopes and a drop box so that people could return the
surveys securely. For the other two sites, it was felt that this would not work as most of the therapy was delivered in other locations. In these sites, it was agreed that therapists would take the questionnaires and hand them to the people they saw. In these sites, it was agreed that questionnaires would not be given back to the therapists but returned by the freepost address. All four services were given a brief explanation of the study for the therapists to enable them to answer any questions from their patients. We also advertised using posters in all of the services.

We explored the possibility of distributing by email with an online version of the questionnaire. However, at each of the services there was no easy access to email addresses en masse and the resource required to create a database of email addresses was not available.

While not ideal, these recruitment methods were selected as the best possible options given the limited time and resource available, particularly the concerns of the services around over-burdening service users following the NAPT survey. However, by recruiting through face-to-face contact with the service, we were unable to reach all of the groups as originally intended. In particular, we were unable to reach people using only computer or telephone therapies, and also those people who had dropped out of the service. This is a considerable limitation on the study given the original aims, however, the practical constraints made other methods impossible within this time and financial resource.

Two hundred surveys were printed for each service. We aimed for 75 completed questionnaires from each service. We offered participants a £10 gift voucher if they returned a questionnaire.

Analysis

The surveys were analysed using Excel and SPSS software. Analysis of the quantitative data is primarily descriptive due to the relatively small sample available. We also drew on the qualitative comments given in the survey to add detail and to supplement the quantitative data.
Interviews

Interview schedule

The aim of the interviews was to supplement the survey data with richer and more detailed responses. The interview schedule was developed by the project team (Project lead and service user researchers). As with the survey, this was an iterative process and paid particular attention to the need to remain within the limits of an evaluation. The questions also allowed us to address some questions which it was not possible to explore in quantitative data, for example around expectations and changing perceptions of the service. The interview schedule is included in Appendix 5.

Recruitment

On the distributed questionnaire, participants were invited to indicate whether they would be interested in taking part in a telephone interview to explore their experience of the service in more detail. Roughly half of those who returned questionnaires indicated that they would be interested in being interviewed and gave a telephone number that they could be contacted on.

We chose participants to interview to capture a variety of services, therapy types, gender, age, ethnicity and levels of satisfaction. Selected participants were called by the Project Lead and more information about the interviews was given, as well as an opportunity to ask questions. If following this information people were still happy to be interviewed, we sent them written information by email or post and arranged a time convenient for them to conduct the interview.

Participants were assigned to either AH or RS depending on availability. They contacted the participants at the date and time and confirmed consent on the telephone prior to the interview. Interviews were audio recorded and transcribed either by one of the research team or by a professional transcription company.

Analysis

We analysed the transcripts thematically. The first four interviews were analysed by the Project lead and two service user researchers together to agree an initial set of themes and approach. Subsequently, all interviews were analysed by at least two of the researchers, in most cases with the service user researchers analysing the interviews conducted by the other. We then came together to review and agree the analysis and interpretation.
Focus group findings

We held four focus groups, with a total of 19 participants. Focus groups were held in three locations – two in Rethink’s offices in Vauxhall, one in a community centre in Eltham, South London, and one in the IAPT offices in Hammersmith.

Table 1: Themes from the focus groups

<table>
<thead>
<tr>
<th>Themes from the focus groups</th>
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</thead>
<tbody>
<tr>
<td><strong>Feeling informed</strong></td>
<td></td>
</tr>
<tr>
<td>At referral – knowing enough about what to expect from the therapy</td>
<td></td>
</tr>
<tr>
<td>Between referral and assessment – adequately supported/updated during this time</td>
<td></td>
</tr>
<tr>
<td>Therapy – having enough information about the types of therapy, different options, how it works</td>
<td></td>
</tr>
<tr>
<td>Ending therapy – knowing what the end point would be and how it would be agreed/managed</td>
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<tr>
<td><strong>Communication</strong></td>
<td></td>
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<tr>
<td>Being able to contact the therapist / service as required before, between and after sessions</td>
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<tr>
<td><strong>Decision-making</strong></td>
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<tr>
<td>Feeling a part of the decision making</td>
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<tr>
<td>Understanding why and how decisions are reached</td>
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<tr>
<td>Being informed of the constraints around decisions</td>
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<tr>
<td><strong>Being listened to</strong></td>
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<tr>
<td>Feeling that the therapy is individually focused, not formulaic</td>
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<tr>
<td>Using individual’s strengths in the therapy</td>
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<tr>
<td>Being asked about needs to inform therapy</td>
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<tr>
<td><strong>Relationship with the therapist</strong></td>
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<tr>
<td>Feeling safe talking with the therapist</td>
<td></td>
</tr>
<tr>
<td>Being confident in their skills</td>
<td></td>
</tr>
<tr>
<td>A sense of teamwork between therapist and individual</td>
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</tr>
<tr>
<td>Being focused on issues relevant to the individual</td>
<td></td>
</tr>
<tr>
<td>Being flexible/responsive to the individual’s needs</td>
<td></td>
</tr>
<tr>
<td>Therapist qualities – empathy, openness, (personal experience of similar issues)</td>
<td></td>
</tr>
<tr>
<td>Back up if therapist is away</td>
<td></td>
</tr>
<tr>
<td><strong>Therapy</strong></td>
<td></td>
</tr>
<tr>
<td>Responsive to individual needs</td>
<td></td>
</tr>
<tr>
<td>Number/frequency of sessions appropriate</td>
<td></td>
</tr>
<tr>
<td>Understanding and feeling able to complete homework</td>
<td></td>
</tr>
<tr>
<td>Being able to develop and use signposting/tips/suggestions</td>
<td></td>
</tr>
<tr>
<td>Feeling that monitoring and outcomes collection is meaningful rather than a burden</td>
<td></td>
</tr>
<tr>
<td>Receiving appropriate additional support materials where needed</td>
<td></td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td></td>
</tr>
<tr>
<td>Feeling comfortable attending therapy</td>
<td></td>
</tr>
<tr>
<td>Feeling able to tell other people</td>
<td></td>
</tr>
<tr>
<td>Feeling self-stigma</td>
<td></td>
</tr>
</tbody>
</table>
Survey findings

Demographics

Table 2 shows the demographics of people taking part in the survey, broken down by service.

<table>
<thead>
<tr>
<th>Table 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample N=116</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Data missing</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>White British</td>
</tr>
<tr>
<td>White Irish</td>
</tr>
<tr>
<td>White Other</td>
</tr>
<tr>
<td>Mixed - White &amp; Black Caribbean</td>
</tr>
<tr>
<td>Mixed - White &amp; Asian</td>
</tr>
<tr>
<td>Mixed - other</td>
</tr>
<tr>
<td>Black or Black British - Caribbean</td>
</tr>
<tr>
<td>Black or Black British - African</td>
</tr>
<tr>
<td>Black or Black British - Other</td>
</tr>
<tr>
<td>Asian - Indian</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Data missing</td>
</tr>
</tbody>
</table>

Figures from September 2009 to August 2010 show that users of these three services were 67% women and 33% men (London NHS Improving Access to Psychological Therapies (IAPT) activity, March 2011). Even given the higher numbers of women accessing the services, women were over-represented in this sample. Seventy-seven percent of our participants were of white ethnicity. This is broadly reflective of users of these services based on the published data for September 2009-August 2010.

Twenty-two percent of the participants said that they considered themselves to have a disability. These include mental health diagnoses, learning difficulties, mobility impairments, hearing impairments, and other physical health conditions.

Twenty-six percent of the participants said that they had caring responsibilities. Most of these were for young children, but also included dependant partners and parents.

Forty-five percent described themselves as belonging to a religion or otherwise spiritual, including Christian (36%) and Muslim (3%).
Use of IAPT services
Three London IAPT services took part in the survey. Figure 4 shows the breakdown of total participants by service. The findings reported here relate to the sample as a whole unless otherwise specified.

**Figure 4**

![Participants by IAPT service](image)

How participants heard about the service
Over three-quarters of the participants first heard about the service from their GP. A further eight percent were told about it by another health professional, including mental health services. Only nine percent became aware of the service for the first time through word of mouth or by seeing advertising – including leaflets and magazine adverts.

“I wouldn’t have known about the service at all if I wasn’t referred. Its too good a service to not be "SHOUTED" about!”

**Figure 5**

![How did you first hear about the service?](image)
How participants were first referred to the service
Seventy-five percent of participants were referred by their GP. Thirteen percent referred themselves and the remainder were referred by other health or social services.

Figure 6

Participants’ current use of the IAPT service
Since the majority of participants received a questionnaire when they attended the service, it is unsurprising that most (75%) were still currently using the service. Thirteen percent had not yet started using the service and presumably were attending either for their first appointment or for assessment. Eleven percent had completed their therapy, but the majority of these had plans to continue using the service in some form if possible.

Figure 7
We asked participants how many sessions of therapy they had had by the time they completed the survey. The median number of sessions was 6 and the mode was 3. Participants did not always give a precise number, making a mean impossible to calculate. Five participants had not yet received any sessions. One participant said she has received sessions every week for approximately 2 years.¹

**Type of therapy used**

Seventy-four percent of participants said that they had used only face-to-face therapy within the service. Again, we would expect this to be the bulk of participants based on the method of recruitment. A further sixteen percent had had a combination of individual, face-to-face therapy with other types of therapy, including groups, telephone and computer-based. Seven percent had had only group or telephone therapy or a combination of therapies not including face-to-face therapy.

<table>
<thead>
<tr>
<th>Therapy delivery</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>Telephone</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Face to face</td>
<td>86</td>
<td>74%</td>
</tr>
<tr>
<td>Computer</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Group &amp; telephone</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Group &amp; face to face</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Telephone &amp; face to face</td>
<td>14</td>
<td>12%</td>
</tr>
<tr>
<td>Telephone &amp; computer</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Face to face &amp; computer</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Group, telephone &amp; face to face</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>4%</td>
</tr>
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</table>

**Waiting to access therapy**

We asked participants how long they had waited between being referred to the service and being assessed, and then how long between assessment and receiving therapy. Nearly two-thirds of participants waited for less than a month between referral and assessment. The median wait was three weeks, and the mode was two weeks. However, a small proportion (6%) waited more than four months for assessment.

<table>
<thead>
<tr>
<th>Weeks to assessment</th>
<th>Total N=105</th>
<th>Back on Track N=37</th>
<th>Lambeth N=52</th>
<th>Time to Talk N=16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>5</td>
<td>7</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Median</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Mode</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Range</td>
<td>0-45</td>
<td>1-45</td>
<td>0-24</td>
<td>2-24</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weeks from assessment to therapy</th>
<th>Total N=98</th>
<th>Back on Track N=35</th>
<th>Lambeth N=46</th>
<th>Time to Talk N=17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Median</td>
<td>2</td>
<td>3</td>
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<td>2</td>
</tr>
<tr>
<td>Mode</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Range</td>
<td>0-24</td>
<td>1-15</td>
<td>0-24</td>
<td>1-10</td>
</tr>
</tbody>
</table>

¹ It is not clear whether all of this therapy was delivered through the IAPT programme as this appears to be longer than would normally be available through IAPT.
Sixty-three percent waited less than a month between receiving an assessment and accessing therapy. The longest wait after assessment was 24 weeks. Comments made in the surveys and interviews suggest that many people expected a long wait for access to the service. This expectation may be based on experience of accessing other services previously.

For those participants who waited a long time, this could be very unsettling. A particular criticism is that it was left for service users to chase the service, rather than being kept informed about progress with the referral.

In relation to this period between being initially referred to the service and actually receiving therapy, we asked participants about their satisfaction with three aspects: the information they received about the service; the support they received during the wait; and the assessment process itself.

Satisfaction with information received about the service was generally high. Among those people who were less satisfied, several people commented that they did not receive any information about the service, or that they received only basic information about accessing the service but little or nothing about what the service entailed in more detail.

“I was very satisfied with how long it took to be referred. I thought that the waiting list would be ages. Very happy.”

“I know of a friend, they had to wait 4 months to even start the process. I think that if I had had to wait I would have given up and not dealt with the problems I am experiencing now and they would have only got worse and taken longer to resolve.”

For those participants who waited a long time, this could be very unsettling. A particular criticism is that it was left for service users to chase the service, rather than being kept informed about progress with the referral.

“There was a mix up with the referral and I had to chase up the service myself. I was not called back when I was told I would be. This can be discouraging when it takes courage to ask for help and you are forced to ask again and again. Some people will be lost in this process.”

In relation to this period between being initially referred to the service and actually receiving therapy, we asked participants about their satisfaction with three aspects: the information they received about the service; the support they received during the wait; and the assessment process itself.

Satisfaction with information received about the service was generally high. Among those people who were less satisfied, several people commented that they did not receive any information about the service, or that they received only basic information about accessing the service but little or nothing about what the service entailed in more detail.

“Very little received about the service – could have made me better informed and prepared”

“I was told that I would be contacted to be assessed as to which particular type of therapy would be appropriate for me, but I wasn’t sure what each therapy would entail - I was in a pretty ropey state at the time, so this probably contributed to my confusion.”
While the majority of participants were satisfied with the support received during the waiting period, twenty percent had been dissatisfied or very dissatisfied with this. Participants’ comments suggest that support was interpreted in different ways. A number of people had support from other sources during this time, including a GP or other service. Others were given telephone numbers that they could contact if needed.

“At the time of my referral my anxiety was pretty bad and I didn’t know what to do. I would have appreciated some interim information regarding temporary services to help me get by until therapy could begin.”

To explore whether satisfaction with the support during the waiting period was associated with the length of the wait, we categorised the length of wait into short (0 – 4 weeks), medium (5 – 8 weeks) and long (9 weeks or more). These categories were based on review of the distribution of wait across the sample as well as drawing on comments to assess what length of wait was generally considered good or excessive. We hypothesised that those waiting shorter periods of time were more likely to be satisfied with the support during the wait, and those waiting longer would be less satisfied. This was based on the assumption that those waiting longer would expect or want more support than those who received the service more quickly. We tested the hypothesis using a Chi-squared test. We found a significant relationship between length of wait and satisfaction with support. Care should be taken with this finding as the numbers are small.

Table 5

<table>
<thead>
<tr>
<th>Length of wait</th>
<th>Very satisfied</th>
<th>Partly satisfied</th>
<th>Partly dissatisfied</th>
<th>Very dissatisfied</th>
<th>Not important to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 4 weeks</td>
<td>19 (55.9%)</td>
<td>8 (23.5%)</td>
<td>1 (2.9%)</td>
<td>3 (8.8%)</td>
<td>3 (8.8%)</td>
</tr>
<tr>
<td>N = 34</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 – 8 weeks</td>
<td>4 (18.2%)</td>
<td>11 (50%)</td>
<td>1 (4.5%)</td>
<td>1 (4.5%)</td>
<td>5 (22.7%)</td>
</tr>
<tr>
<td>N = 22</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 weeks +</td>
<td>8 (22.9%)</td>
<td>12 (34.3%)</td>
<td>3 (8.6%)</td>
<td>10 (28.6%)</td>
<td>2 (5.7%)</td>
</tr>
<tr>
<td>N = 35</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Satisfaction with the assessment process was very high. Among those who were dissatisfied with the assessment, comments suggest that they found assessment on the telephone difficult. Two people also felt that the assessment did not sufficiently identify specific needs.

“I saw someone who didn’t really have the knowledge to assess me fully. I needed a specific course of therapy and it took a while for people to realise this.”

“The lady I saw was friendly and very easy to talk to – she gave me two assessment sessions as she felt that was what was needed. She wrote me a detailed letter and I felt more positive about actually finally getting some help.”

“It is quite awkward to talk to a stranger over the phone about very personal issues. And I was not initially given a very adequate assessment and it had to be re-evaluated after my first session with a therapist. I then had to change therapists, which was better but it took more time and more assessments which are difficult.”

Expectations around number of sessions

We asked people whether they had been told at the start of the therapy how many sessions they should expect to receive. Seventy-one percent of participants said that they had been told how many to expect. Of these, the majority were told to expect up to 12 sessions (Figure 11). Commonly, people remarked that they had also been told that this number could be extended if needed.

In response to comments from the focus group participants, we wanted to know how people felt about being told how many sessions they would receive. We asked people how far they agreed with two statements: ‘In general, people should be told how many sessions they will receive at the start’ and ‘No limit should be placed on the number of sessions offered at the start’.
Two-thirds of participants agreed that people should be told how many sessions to expect, and nearly three-quarters agreed that no limit should be placed on the number of sessions offered. The comments given in relation to these remarks centre around whether being told an upper limit was helpful in giving a goal or placed extra anxiety on the therapy from the start. There was a general acceptance that therapy would be time limited but a strong feeling that there should be the possibility of extension where appropriate. The way in which the limit is communicated to the service user is clearly crucial as it can shape the way therapy is approached.

“It puts an unnecessary pressure and anxiety on the process I think (to be told X amount of sessions ONLY at the start)”

“People should be given clear info, it raised a lot of anxiety not knowing how long and when it will end”

“I understand why sessions are ‘rationed’ but also feel that one size does not fit all and I felt pressured by the restriction.”

“I feel that I have a lot on my plate and hearing that I might only have 6 weeks to sort it all was discouraging and frightening”

“I was told I would receive six sessions but there may be a possibility of extending it if necessary. I think this is a good way to approach the matter as it sets expectations but doesn’t feel too rigid.”

“Is good to have a goal and therefore be given an end date, however everyone is different and will respond to treatment differently.”

“It is good to know what is in store at the beginning, it helps to frame your goals in a time based manner. Progress seems achievable.”

“I don’t think that you can put a time limit on the sessions because people can work through their problems at different times, and at a different pace. And these things can’t be rushed.”
Satisfaction with the therapy

We asked participants about satisfaction with six areas of the therapy which had been raised in the focus groups as important aspects of users’ experience of the IAPT service: Choice of therapy offered; the number of sessions received; inclusion in decisions about therapy; the way that progress was measured in the service; planning for completion of the therapy; and follow-up arrangements. The last two of these were difficult for people to answer if they were early in their use of the service, and many participants indicated that they did not consider this applicable to them if they were not yet near the end of their sessions.

Choice of therapy offered

Over ninety percent were partly or very satisfied with the choice of therapy offered. The comments given suggest that not a great deal of choice was expected from the service. This may also indicate that although the options for different therapy were limited, they nonetheless suited the service users.

Others indicated that they were happy to follow the recommendations of the service or their GP. Some, however, would have liked further information about different types of therapy or additional options.

“I would have liked 1-to-1 therapy but the waiting list was longer than the group therapy sessions”

“I wasn’t offered a choice of therapies but I was happy to go with my GP’s/ the services recommendation. However I would have liked to have been given information about other options.”

“I was unsure what would suit me and I feel the decisions and advice given helped me make up my mind”

“There was no choice of therapy, it was CBT”
Number of sessions received
Three-quarters of participants said they were satisfied or very satisfied with the number of sessions received. Thirteen percent did not answer this question, often commenting that they did not yet know how many they would be receiving. A number of people echoed their views on the statements about limited numbers of sessions.

“In my case, I have had a lot of issues and feel I needed everyone of the 16 sessions I’ve had to work through. I would like to know I had some control when it would end, I am dreading the end.”

“At first I was given far fewer sessions considering my history and asked why that was, only then was my case reconsidered it was decided that I should have more.”

Inclusion in decisions about therapy
Around ninety percent were satisfied with how included they were in making decisions about their therapy. Some participants did say that they had not been included at all, but comments suggest that for those who are satisfied, decisions were made jointly with their therapist. Inclusion did not necessarily mean making all decisions themselves. Some participants highlighted that they preferred to follow therapists’ recommendations.

“I feel included but initially I felt I had to be quite bold and push to be involved.”

“I have been given various choices on my therapy and have gone along with what my therapist thinks is the best route”

“I was included in what I wanted to focus on. I could choose things to put on the agenda. Sometimes would be good if the therapist would choose perhaps.”

Figure 13
Number of sessions received

Figure 14
Inclusion in decisions about the therapy
Measuring progress
Over sixty percent of participants were very satisfied with how their progress was measured, and another twenty-seven percent were partly satisfied. Comments suggest that many participants like being able to see their progress in charts or reflected in the scores collected each week. In contrast, some participants felt that the forms were really more for the therapist than for them, and often weren’t used or discussed in the therapy.

“I could see my progress by filling in a form and get a number that I could compare to previous numbers”

Planning for completion
As mentioned above, there was a large proportion of missing data for this question. Where people did not answer, they often commented that it was too early for this as they were only part way into their therapy. This reflects service users’ expectations about planning for the end of therapy, that it is something to be discussed when closer to the end. For participants who had discussion the ending throughout the therapy, some found it helpful and others found it caused anxiety. One participant commented that they would like to discuss the ending because it worried her.

“I was told from the beginning and reminded all the way through about my therapy sessions ending. Not too happy about having to wait (an unknown amount of time) for next therapy.”

“we havent talked about it too much, perhaps because of the stage we are at. But I feel some anxiety around the completion and perhaps it should be helpful to discuss some of what happens early on.”
Arrangements for follow-up
As with planning for completion, a large proportion felt that arrangements for follow-up were not yet relevant to them. Where people were satisfied, very few indicated what arrangements had been made or why they were happy with them. The few comments made indicated that being able to come back to the service if they wanted, or being referred on to other services was helpful for them.

“Agreed I would be able to contact service immediately if I felt I needed them.”

“I was told if I feel like I wanted counselling I could have it.”

Satisfaction with therapist
We asked participants how far they agreed with the statement ‘I was satisfied with my therapist’. Ninety-three percent of those who answered this question said they agreed or strongly agreed with this statement (Figure 18). Even more (97%) agreed with the statement ‘my therapist listened to what I told them’.

“The therapist is pleasant, warm and makes me feel comfortable expressing myself.”

“I think my therapist is the perfect choice for me and I wouldn’t want to change therapist”
Where participants said they were not satisfied with their therapist, they often qualified this to be clear that dissatisfaction was to do with lack of expertise or limits of the therapy, not the therapist's own demeanour.

“I didn’t feel able to talk about everything with my therapist. A lot of my problems come from my relationship and I was told at the start that this therapy does not look at my relationship, so I feel unable to bring it up”

“My therapist herself was lovely & I felt comfortable with her, however she had never treated my condition before & was quite honest that she was learning too. I feel I should have been referred to someone who specialises in my condition, because I feel it has been a bit of a waste of time.”

“I know there needs to be training but felt uncomfortable talking to someone very young and felt not able to fully appreciate what I was having to deal with.”

Comments from the focus groups suggested that some felt they were not able to change therapist if they wanted to. We asked participants how far they agreed that they could change their therapist if they wanted to. A large proportion said that they didn’t know, which probably reflects the satisfaction they felt with their existing therapist, such that they didn’t feel the need to find out. This was also highlighted in the comments.

Figure 20
Working with the service

Responsive to needs
We asked participants how satisfied they were with how responsive the service was to their needs and circumstances. The question was left deliberately broad to allow participants to identify their own individual needs or issues. Seventy percent said they were very satisfied.

Comments suggest common areas of importance to participants: appointment times (particularly for those in work), specialist therapy for specific conditions and shorter waiting times to reflect urgent issues.

Ease of contact with the service
Over seventy percent were very satisfied with how easy it was to contact the service. Some negative comments, however, suggest that for people who have experienced problems contacting the service, this has caused real difficulties and frustrations.

"It has been hard to get appointments that do not clash with my 9-6 working hours but the centre have done their best to work with me on this"

"I've not been referred to someone who actually specialises in my condition. I felt like I was just a number that was thrown to the first available counsellor"

"If the person I wanted to speak to was unavailable there would always be an option to speak to someone else or for them to contact me."

"I could only email my therapist. I did have a phone number for the clinic at the beginning however it was changed and I was told by reception that they don’t give out the number. Made it very difficult to change appointments or to cancel"
Impact of the service

We asked participants whether they felt that the service had helped them, and to identify what they thought had been helpful or unhelpful about the service.

Forty-five percent of participants felt that the service had helped them a lot and a further twenty-six percent felt it helped quite a bit.

Participant comments identified several broad ways in which they felt the service helped them. For some, the service provided an empathetic listener, allowing them to talk without feeling judged. For others, the main benefit was what they learned about themselves and their experiences and the skills they developed. Several participants said they felt more positive following the therapy. Some identified practical outcomes, including getting back to work. A number of participants identified these as benefits they would have liked but didn’t feel they had.

“A lot of the therapy constitutes common sense. Maybe I am expecting too much but I want to learn how not to get depressed in the first place, not just how to cope.”

“I was quite bad when I first started and I felt like I was losing grip on my life. The first few sessions of CBT helped me to regain control and get my life back on track!”

“It has provided much needed support in my traumatic journey. It is the direct reason I have a job today which has done WONDERS for my mental health.”

“I have social phobia all my life and I did not know that I have it until I spoke to my therapist. It is a relief for me to know what my problem is”

“I feel supported. The group therapy has helped me feel that I am not alone in feeling the way I do. That feeling depressed with low self esteem and confidence is common. I don’t feel as isolated and relieved that I am not mad or bad. I am just going through a phase in my life like lots of other people.”
Suggestions for improvement

We asked participants whether they had any recommendations to improve the service. A range of suggestions were given and grouped into the broad categories below

Improving awareness and promotion of the service

“Although a 'young service' I think this provision is a breath of fresh air for the many, many low level mental health issues and clients around. I would like to see expansion into more partnership working with local public health, healthy living services like Health Trainers increasing capacity to refer and confer suitable clients to [the service] who don’t, won’t, can’t access services on their own.”

Increasing capacity to shorten waiting lists or reach more people

“Expand services that have huge waiting lists they are obviously in demand.”

“More resources should be given so more people could use it.”

“To make the waiting time from referral to assessment to treatment shorter. I've 'got through' each day - sometimes only just - for a long, long time so I just continued to do that whilst waiting. But for someone who was 'new' to struggling to 'stay on top' the wait I had could well have been just too long.”

Providing more sessions and simplifying re-referral to the service if required

“More sessions of follow up service”

“Re-referral should be streamlined- I was made to jump through exactly the same hoops with exactly the same time delays as when I first accessed IAPT”

“I would like to know whether I can refer myself if needed rather than having to go back to the GP which is quite degrading and referral is then based on how knowledgeable the GP is.”

More contact or support during the period between referral and access to therapy

“I think the period between referral and seeing a therapist is crucial! This is probably when patients are most in need and have the least support. I think the patient should be phoned by the service once the referral has been received (not the patient having to phone the service to ask) and perhaps there could be an option as to whether the evaluation should take place over the phone or in person. Perhaps some reading about different options for therapy.”

Providing more flexible hours and locations for therapy

“Increase the number of out-of-hours operated between 5.30pm for those who work.”

“More locations, so people can access the services close to their homes.”
Improvements to the venues

“Possibly better signing for the centre, without putting obvious sign about the fact that it is a mental health centre.”

“Relaxing on sofa or chairs. No desk. Nice cuppa”

“The environment where the therapy takes place is very clinical and not welcoming. Staff are not always sensitive re confidentiality. "Are you here for the depression group?" was something I overheard.”

Providing access to a wider variety of therapies

“It would also be good to offer someone who was skilled in both CBT and psychotherapy so they could deal with situations causing problems in the present as well as the past.”

“Offer therapies other than CBT, perhaps some group work as well”

“Combination therapy, directing clients to the correct specialists for their issue to get full benefit of the service”

Providing more opportunity for peer support

“Maybe we could once or twice in a week have a get together for all those suffering from anxiety or other similar disorders. This could give us a chance to meet other people going through the same condition and might be a sense of relief for most.”

“Within your time at the service, a joint class to see if problems you have us the same happening to others. How do they cope! Books they have read! Home life etc”

More opportunities for giving feedback

“Offer a feedback "suggestion box" mail or website so we can have time to think about it or make use of it when ideas or situations arise.”
Interview findings:

We selected a total of 22 participants for interview, two of which were unavailable at the time arranged. Six interviewed participants came from the Time to Talk service, seven from Back on Track and seven from Lambeth. Demographics of those interviewed are shown in

<table>
<thead>
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<th>Gender</th>
<th>Total N=20 (%)</th>
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<tbody>
<tr>
<td>Female</td>
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</tr>
<tr>
<td>Male</td>
<td>5 (25)</td>
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</table>

<table>
<thead>
<tr>
<th>Age</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
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<tr>
<td>Range</td>
<td>19-69</td>
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</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
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</tr>
</thead>
<tbody>
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</tr>
<tr>
<td>White Other</td>
<td>3 (15)</td>
</tr>
<tr>
<td>Mixed</td>
<td>3 (15)</td>
</tr>
<tr>
<td>Black or Black British</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (5)</td>
</tr>
</tbody>
</table>

These qualitative findings presented here are based on a small number of participants and are not intended to be representative. We have attempted to present a range of individual experiences and perspectives and to draw out common themes. The quotes given are used to illustrate these themes, but do not represent the responses of every participant.

The themes are grouped into four sections: experiences of service delivery; the therapist and therapy; impact of the service on participants’ day-to-day lives; and completing therapy or moving on.
1. Service Delivery

In this section, we present participants’ experiences with the IAPT service delivery. This included all elements of the service except what takes place within the content of the therapy sessions themselves. Communication and access to the service are two overarching elements of this feedback, from first finding out about IAPT and waiting to access therapy, to making appointments, communicating with the staff and attending the sessions.

Accessing the service

Finding out about IAPT

We asked participants in the interview how they had first found out about the IAPT service. The survey results had shown that the majority of people found out about the IAPT service through their GP or other health professionals. People were therefore largely dependent on their GPs knowing about the IAPT service and recommending it. Several participants were keen to see IAPT have a bigger profile with the public so that more people could access the service and could refer themselves directly. Some wanted targeted publicity to reach specific groups, for example new and expecting mothers.

“I think posters and leaflets. Posters and leaflets in libraries and free papers. That would mean you’re not just relying on people who’ve got a computer and could Google it […] even a notice in doctor’s, in baby clinics for probably post natal depression and that.”

“I had to look for it myself, to be honest. I needed to get some support, help, and I think I found it through a link through the Trust. I was looking on the website and I knew they were very good with dealing with things to do with therapies possibly. I just didn’t know where to look. I haven’t had a huge response from my doctor.”

The experiences of some participants show that some GPs are recommending talking therapies as a possible solution for a range of concerns brought by their patients, particularly for those who preferred not to take medication. Several participants talked about preferring talking therapies to medication, which for many was still the first offer from GPs.

“I went to my GP and I told him how I was feeling, and he offered me medication first. I said I didn’t want any medication, could I have this [IAPT] thing, and he referred me. […] He thoroughly agreed with me with what I said: I didn’t want medication.”

Comments from some participants suggest that some work is still needed to raise GP awareness of the IAPT services. GP’s lack of knowledge about IAPT acted as a barrier to referral. Not only were GPs not always suggesting IAPT to patients, it was some participants’ experience that even when they had themselves suggested the possibility of accessing IAPT not all GPs had heard of the service and that they did not know how to make a referral.

“I picked up the leaflet about IAPT service and it sounded interesting. Then I went to my doctor to see if I could get a referral, and she didn’t know nothing about it.”
“My GP didn’t know [...] she thought that the way in was via Centre for Anxiety Disorder and Trauma, so she referred me there. And it was the wrong place. So then I think it went back again and then I got the IAPT people to actually contact my doctor to explain the procedure, and they did.”

Concern about the attitudes of GPs towards mental health problems was also occasionally a barrier to accessing the service. GPs don’t always have a good understanding of depression or anxiety, and this may limit their ability to make effective recommendations. For one participant, the poor attitude of some GPs reinforced the need for more promotion and self referral.

“Can people refer themselves? Do they have to go through a GP, which can be very degrading because the GPs are not as sympathetic or I believe as well trained as the staff in depression and mental issues. Going to a GP can be degrading. You only need one kind of flippant locum doctor really to send you crashing.”

“GPs aren’t clued up, because when I went to see him a few years ago and told him about the sensations going through my body and he said to me ‘one morning you’ll wake up and it’ll all be gone’.”

Waiting to access therapy

Length of wait

The time between referral and therapy varied greatly across the participants interviewed. For some, it was only a couple of weeks and in general those people were hugely impressed to be seen so quickly. In contrast, several waited 2 to 3 months or even longer for access to the service. Although this wait was seen as a problem, it seems that many expected to have to wait for the service. Either they had been told to expect long waiting lists or had experience of having to wait for services in the past. It was common for people to qualify their concerns about the wait by highlighting their gratitude at getting this sort of free support at all. One participant did point out, however, that you would expect more from a physical health service.

“It was just too long, but then again, it was the only thing that I could get for free. I was offered other stuff, other counselling, that were up to £80 or £50 per hour, which I couldn’t afford, because I’m a Nurse. And that upset me even more, because I’m thinking, if I had a cancer everything would have been free for me. I could have seen a doctor right away. Instead there are all these delays. And the system is overbooked with people that need it.”

For some participants the delay in accessing the service meant that their need for support had changed. Among those interviewed in this study, participants still accessed the service though perhaps for other reasons. This problem could explain some of the drop out between referral and access to the service if potential patients find that immediate need for the service has gone.
“By which time the initial point of me being sent to them had gone. So I actually had to get through all of everything still on my own to do with [the original problem].”

“I mean it wasn’t an ideal length of time to have to wait. The whole reason why I’d been referred is because I needed to start the service straightaway.”

Some people had been offered alternative therapy that would be available more quickly. This could either be supportive or could place pressure on patients to choose a less suitable therapy.

“They said that if I wanted group therapy then it wouldn’t take so long, it wouldn’t be such a long waiting list. But because I wanted just one-to-one it would take longer, because a lot of people prefer the one-to-one.”

“[CBT]’s what the doctor put me in for, and I asked about some counselling as well and they said, well, no, you need to do this, or you need to go back to your doctor and ask for counselling, in which case we’ll go through the whole process again. And I said, well, do you know what, while I’m here let’s just do this – so I kind of felt like that was the option that I had to take otherwise they’d put me on the books for another three months before I got any kind of treatment.”

Support and contact while waiting

Although they were often understanding about the waiting time required, several of our participants would have liked more contact or support while waiting. Some wanted to be told how long the wait would be, or to be kept updated about their progress up the waiting list. A few of those who had waited a long time had come to assume that they had been forgotten or dropped from the list. In these cases some more regular contact, even just to ‘check in’ was felt to be helpful. Some participants did not even have a contact number for the service so that they could get in touch themselves to track progress.

“It would have been nice just to have a little, you know, you’re moving up the queue or we haven’t forgotten about you. It would have been nice to have a little bit of contact. [...] If there had been a number to ring, that would have been good.”

“Just the fact of being on a waiting list was enough, although some other people might want a little bit more promptly, to know they’re not forgotten. I think just knowing I was on a waiting list was useful and I received a letter saying so. That was nice as well to receive confirmation”

“I suppose I did at one stage, I did wonder if I just was never going to hear from [them] at all. It might have been helpful to at least have had some contact from somebody.”

Contact during the waiting time could also serve to be supportive in itself as it helps to show patients that they are valued and that the service was responding to urgent needs. In contrast, when participants had not heard anything from the service they felt abandoned. A number of participants had had to contact the service themselves during the wait to chase up on progress with their referral. This could be incredibly frustrating and gave participants the impression that they were not important to the service.
“I had to keep phoning, and eventually I did get hold of somebody who did call me back but it was after about two or three attempts of not being called back. It felt like they just didn’t care, that they were just too overworked, didn’t have the space”

“There was no phone calls from [the service] to see how I was feeling. There was no like intervention in between. It would have been very nice if somebody would have phoned up and said ‘how are you doing’.”

“Some situations may not require urgent treatment but I was probably in a category that did require urgent treatment, and to be left just like that made me feel like you’re just a number, when we get round to you, we’ll contact you kind of thing. It was really frustrating and it did actually make things a lot harder for me.”

To ensure appropriate contact during the wait, it may be necessary to ask participants about their preferences at referral. One participant believed that she had been forgotten by the service because she uses the answer machine to screen her calls but the service does not leave messages.

“That’s the only thing that frustrated me, the fact that I didn’t actually get told to start with that they weren’t allowed to leave messages. So for quite a while I think they managed to, they tried to get hold of me but they couldn’t get hold of me because my answering machine was on all the time, and finally they had to write to me to say that they’d been trying to get hold of me.”

We asked people whether there was additional support they would have liked during the wait, but apart from more contact and being kept updated about the wait, people generally did not expect or want interim support from the service. Some explicitly said that a stop-gap support would be more difficult than helpful.

“I didn’t ask for any support […] that would have been like an in-betweeny thing, and you’ve got to sort of explain to one and explain to another, and I thought, you know, I’ll wait and go straight for the [therapy]”

**Information about the therapy**

Some people suggested that the waiting period could be used for patients to learn more about the service or to prepare for it. People generally received very little information about what the service had to offer until the assessment. One participant suggested that books or other resources could be recommended prior to the start of therapy.

“I thought it would be nice in that process time to, I suppose, slip into your brain so you would be more prepared and realise what you’re suffering from. Although you know what you are going through, these books really help to the point that I’m reading them now for the second or third time, which I find is helping me.”
Assessment

Experience of assessment
Participants had had a mixture of face-to-face and telephone assessment. One participant mentioned that they had been offered a face-to-face assessment in response to their specific needs.

“They looked back in my previous record and said, that because of your background, we’re not going to do a telephone assessment, we’re going to give you a face-to-face assessment instead.”

On the whole, the assessment process was a positive experience for participants. This first point of contact was crucial for giving people information and hope about the therapy. A couple of people also mentioned that being assessed by the person who subsequently gave the therapy provided valuable consistency.

“I know certainly that the assessment lady was extremely good. And I did come away from her hopeful that CBT might be able to help me.”

“I didn’t expect as much as I got so that was quite amazing, so I thought I was just going to go along. I didn’t really know that even on the first meeting that it was actually the person I met would be the person I’d be seeing.”

Information and choice
Assessment was generally the first opportunity for people to learn about the different therapy options and discuss them with the therapist. Several participants pointed out that there was little or no choice about therapy types in reality. For some, more options about therapy would have been preferred, particularly to have a combination of therapy types.

Despite the lack of choice for some, the opportunity to learn what was involved was valuable to those we interviewed, and some did say that they were happy to be guided by their therapist about the type of therapy used.

“The initial interview, we talked about it then and I didn’t really want a long talking therapy, I wanted something to be an initial quick fix to get me out of this downward spiral and to initially fix it, but actually CBT was mainly the one that was on offer, as I understand it at that time.”

“There was ordinary counselling, but the woman at the assessment didn’t think that was what I needed. I didn’t need someone just to listen to me and all this. I needed something done more: done for me more than me talking. [...] In that literature they sent, I could have chosen from that, and everything was in that. You know it had a thing at the bottom: which do you think would be better for you, sort of thing.”
Communication with the service

Appropriate means of communication
Having easy contact with the service is important to the people we interviewed. Several participants had had to miss or change appointments and needed to let the service know. Most had no difficulty contacting the service when they wanted to. However, a few highlighted practical difficulties, including telephone opening hours being limited or, in one case, not being given a telephone number.

“I actually don’t have a number. I’ve got an email but I don’t always have a lot of internet access. They originally gave me a number and then I went to ring up one day to say, listen, I’ve had something happen at work, can I change my time, and their number was null and void [...] I think being able to get in contact with people – I mean I’m not asking for a therapist’s number; if you need to get in contact with the centre, if you need to change an appointment.”

Open communication was also important for participants if they experienced difficulties or required support. When communication with the service broke down, this could be very distressing to participants, making them feel abandoned, particularly during times of crisis.

“[the therapist] went away over Christmas and she said if you’re feeling bad, then you can ring, and she gave me a number to ring, which I did because I needed some help. The person I spoke to said, ‘okay, somebody will ring you back within 24 hours’ or whatever it was, and nobody did! Luckily nothing terribly bad happened.”

Reception staff
Reception staff at the services are the face of the service and often the primary means of communication with the therapist. People wanted reception staff to be friendly and helpful. Some participants mentioned finding the reception staff very good, but where participants’ impression of reception staff was poor it had a real impact on how they experienced the service. In particular, reception staff need to be sensitive to the potential for stigma associated with the use of mental health services, as highlighted by one participant’s experience of getting access to the IAPT offices.

“I think that just generally contacting the service. The reception staff, if you’re running late or caught in traffic, you can leave a message. You know, they’re just generally nice and they pass on messages.”

“I dreaded having to ring to tell them I’m late, I’m on the way. We laugh about it how rude they are, just listening to rude woman while you’re waiting, it doesn’t set the tone for the day does it? She’s rude to [the therapist] as well”

“You buzzed in [through an intercom], and you pressed a thing and say I’ve got an appointment and [the reception staff] would be like, pardon, why are you here? Why do you want to come in? And you’re standing outside on the road, people looking at you going, I’ve got an appointment. Who with? What for? I’m like I’m not going into all those details on the street, I’ve got an appointment”
Appointments

Choice and negotiation
Most of the participants in this study had individual face-to-face appointments. Arranging appointments that suited participants, particularly those in work, was not always easy, and could act as a barrier to using the service. In one case, a participant was told that she could not be accommodated because of her shift work which made it impossible for her to make a regular appointment.

“One of the problems for me is that I do shift work, and so they were saying, I need you to commit to it every Monday at, say, two o’clock because we can’t fit you in, but this week I might be off on a Monday but next week I might not. Basically I was told that because I did shift work they couldn’t put me in, that I really wasn’t entitled to treatment because I couldn’t commit to a regular day. [...] Eventually they found somebody that was prepared to take me on”

There was a real concern among participants about fitting therapy with work. For many it was not possible to arrange a regular time off work. Some participants were concerned about telling employers that they were accessing talking therapies which would make arranging appointments during normal working hours even harder.

“It was lucky that my work is structured like that, that I could actually change things around to do the appointments. So I don’t know what anybody would do in a normal nine to five situation because they’d have to take time off. With most employers obviously they start, you know, looking at you, if you’re unstable or whatever. They’re not going to be too happy about it.”

Some participants described services making an effort to accommodate their work and other life commitments. While in other cases they felt there was little discussion of this and no choice given. This occasionally meant that participants struggled to make appointments that were not easy for them to make.

“I’d actually told my counsellor I’d been having trouble sleeping and I couldn’t wake up early sometimes because I hadn’t slept, so my counsellor organised appointments that were later in the afternoon”

“I never choose. They choose for me. So every time at work I used to swap with people, if I’m doing a long shift. I have to be the one that’s, you know, make sure that I can go on that day.”

“The four times we have seen the couple’s therapist, we’ve both had to have time off work, which is not ideal. We have said that this isn’t something that we can continue with long-term, but unfortunately she doesn’t have any evening appointments”
Venue

Location
The location of the service was a big factor for participants, particularly in relation to accessibility. Mobility issues are not uncommon in this group and may affect whether people were able to attend appointments. In general, people found that the services had been flexible in providing a choice of locations, including local GP surgeries.

“I had to get two buses to get to [the service], and then I had to walk, which is a long way, and my mobility won’t let me do that. I’ve had the assessment interview, and I explained that I didn’t think I’d be able to come there every week, or every month. So they then said - we’ll choose a local GP surgery locally to me. So I agreed with that.”

“It was quite far, but I said to her I’ve got difficulty walking, like an hour at a time, because I’ve got Graves disease at the moment so I’m a lot slower, so she’s moved the appointments which is much easier for me to get to.”

The venue of the service also has to be appropriate. One participant described feeling uncomfortable about the therapy being delivered in a gender re-assignment clinic, highlighting to need for awareness of possible stigma and personal anxieties when choosing venues for therapy.

“It kind of made me feel like we’re just a side thought, stuck into a room somewhere It wasn’t a very nice environment, and it not because of fact that they had gender reassignment people there because that doesn’t bother me, but it was the fact that I was made to feel like I shouldn’t be here as well, or you know, I had trouble getting in the door because they’re questioning why I’m there. And I’m like, well, I’ve got an appointment as well.”

The atmosphere of the venue is also important in providing a welcoming environment for therapy. The set up of the venue helps to determine the relationship between patient and therapist and can help to make patients relaxed and comfortable. Suggestions for how services could improve their venues ranged from simply having water available to armchairs and ‘a cuppa’. There was also a recognition, however, that services sometimes had to use rooms in other premises and may not have scope to improve facilities.

“[My therapist] sits at the desk, with all her papers in front of her, and I sit in a chair at the side. And it’s like being in a doctor’s surgery. It’s patient and therapist. So it’d be nice for a more relaxed area with perhaps two armchairs and a cup of tea.”
Therapist and therapy

The following themes address what participants told us about their experiences of the therapy itself, including their relationships with their therapists. The most positive experiences of therapy occurred when participants felt that it responded to their individual needs and placed them at the centre of decision making.

Expectations

We asked the people we interviewed what they had expected from the service and from the therapy. Several participants had had previous experience of therapy. Those who hadn’t often didn’t know what to expect from the service. Others described general ideas they had about what the therapy would be like and what they could expect to get out of it. For many, the expectation was simply to have someone professional to talk to and who could help them to explore and understand their difficulties.

“I was expecting for another counsellor to understand a lot of my history and to ask me loads of questions and to get down to the root of why I was suffering from... because I was suffering from anxiety and depression, and I just wanted them to try and find perhaps the cause of it as well.”

“I mean, for my kind of treatment I didn’t really know quite what to expect apart from the fact that hopefully I’ll be seeing somebody regularly, getting treatment and getting help. I thought this is brilliant, I’m going to overcome this problem that I’ve got.”

Some people had very low expectations of the therapy, particularly for those who had lived a long time with problems. Several people talked about a long history of coping without help, having had poor levels of support or receiving only medication.

“You know, the awful thing of it is I actually don’t have any expectations of help from anybody. And I’ve learned very much not to have expectations because then, you know, I don’t get so disappointed if it’s just a disaster. So I sort of purposefully didn’t really think too much or have any huge expectations of it.”

“I suppose at the start I didn’t really expect to make an improvement, because I’d been the way I was so long, I thought how’s this actually gonna help me, you know.”

Some people had very specific goals that they wanted achieve, whether around recovery from symptoms, developing coping strategies or getting back into work. People talked about their hopes for changes in their work and relationships. Two people, for example, talked about wanting to learn skills and develop confidence and strength that could be passed on to their children.

“I had set goals, you know I wanted to be more confident and I had things I wanted to achieve and I think that helped to determine what sort of therapy was best for me”
“I was hoping it would help me cope with my anxiety and it would help with some of my problems. Also I was working so I needed to be okay so I could carry on working.”

“What I wanted was to cure myself, learn how to cope with depression, so I could learn skills and pass them on to my daughter if she has got it. If it’s genetic or she’s learnt from seeing my behaviour, possessing skills to pass on, that was a big key thing that I needed.”

Changing impressions of therapy

For many participants, their perceptions of the therapy changed over time and, with the exception of one participant, people’s experiences changed for the better. Key to this change was developing a relationship with the therapist. Participants talked about sussing out or coming to trust their therapist. Trust was both about the personal relationship and the professional skills and expertise of the therapist.

“The first meeting I was very scared, very nervous, anxious, I didn’t know what to expect. It took me about 3 sessions before I really opened up to the therapist. I had a lot of stuff that I needed to talk about and I’ll be honest I didn’t know whether I could trust her. I had to sit down and work her out to be honest, to see whether it was worth opening up and speaking to her about it.”

“At first I thought she was a little bit tough. I think in the first few sessions, you’re probably figuring each other out. As we got to know each other, she’s excellent. I know where she’s coming from. With hindsight, she needed to be tough with me”

Given the importance of building a relationship with the therapist, when there is disruption to the therapy it can be very distressing for participants and make it harder to engage with the service. Most of the people we interviewed had worked with the same therapist throughout their therapy, and some commented on how helpful this was. One participant had experienced severe disruption to their therapy but was later able to change to a therapist that they could work with more consistently.

“My first therapist, I saw her the first week and then she was going on holiday. And then she cancelled last minute, the morning of the day. And then I think I saw her one other time and in the space of about six, eight weeks, I think I saw her twice, because she just kept cancelling and cancelling. We hadn’t even built up a relationship. I just would rather have no treatment than thinking I’m getting treatment and then every week it being cancelled the morning of the day I’m going.”

As well as building a relationship with their therapists, people also talked about investing personally in the therapy and accepting the need to change. Participants stressed that therapy was done by the patient, not done to them. Often it took a few sessions for participants to identify and focus on the issues they would address in the therapy.

“It was just really at the start was the most difficult part. It was only when you accept that there’s something you want to change about yourself and you realise that other
people feel like that as well, that’s part of trying to accept it and trying to change it really.”

“I think the biggest change is focusing on what we want to discuss, because at first we weren’t too sure on what we needed to discuss or work on, but as the weeks went by we started, little by little, step by step, we started to concentrate on what we wanted to work on”

As therapy progressed, many people who had been sceptical about therapy became more optimistic about how it could help them. For people who didn’t know much about CBT and did not expect a short-term therapy of this sort to be effective, it took a few sessions to start to feel that it could help them.

“I think when I first went I was unsure and I started sort of listening, and things started to click into place. While at first it was really difficult, I just felt I could do it and I was taking on sort of everything I’d learned in theory and first put it into practice and to started to be a lot better and it slotted into place eventually. As time went on I got a lot more optimistic and confident and more relaxed as well.”

“At first I was sceptical as to whether it was going to work, and then, as I started to see results, I could tell that it was working. I just thought, well, it sounds a bit simple, I don’t know if it’s really going to. You know, is it as simple as that? I didn’t see how it was going to change much. But, you know, but obviously it did.”

“As the hour went on, you know I thought, you know, it might work.”

For some people, the therapy also got harder as they started to address issues. One person suggested that patients should be warned about this possibility early in the therapy.

“...Mostly for the better, but then also some for the worst because it was bringing up stuff that you’ve got to go through, to try and think about, so after the appointment I would come home and have a migraine or stuff like that.”
Therapist qualities and skills

“Patient, show interest, listen.”

Since the relationship between patient and therapist is so important to a positive experience of therapy, it is not surprising that participants identified a range of personal qualities that were important in their therapist. The most frequently talked about was feeling able to discuss things openly and to feel that the therapist was listening to what they had to say. Being patient and non-judgemental was especially important to reassure participants that they were improving and could make progress when they may feel themselves that they are struggling with it.

“I would suddenly start going off on one, and she would sort of just put her pen down, sit back, and listen to me. She will just listen, which is quite comforting actually, without commenting back.”

“The person I spoke to was really patient. I can remember at times being very tearful and I just thought they were lovely over the telephone and very patient. They helped steer me back when I veered off, they prompted me to keep to time, because I could talk for ages, and so could a lot of people with a lot of problems.”

“I never thought that she would give up on me and she always reassured me that she’d done this before and that it really could work and she could see the improvements in me and that I should just keep plugging away and I’d get there. There were times when I thought that she was going to be disappointed with me, but she wasn’t. So that acceptance was nice and the fact that she was aware that what I was trying to do was difficult.”

For the small number of participants who felt that their therapist had not listened to them or had not been sensitive to their individual response to the therapy, this was very distressing.

“There was one thing, which he said to me on 4 or 5 occasions: in the grand scheme of things does it really matter that you lost X amount of days. And that was a real bugbear to me, cause it does matter, you want to get out of this illness, condition as quickly as you can. And that was the thing that I used to go and see him and say, please don’t say that again. But he still wanted to put that point across.”

“The guy tried really hard and he was in training, but it was like, because he wasn’t listening as well as I’d hoped, he was giving me things to do which I found a bit too difficult really.”
Therapeutic skills and expertise
Participants wanted more than simply someone who was personable and who listened to them. They wanted someone professional, and someone who was knowledgeable about their conditions and skilled in relation to CBT or other therapies. There were a few participants who were not happy with the level of knowledge or skills of their therapist. This was particularly the case for people who presented with specific conditions that they felt needed specialist treatment.

“I want to work through stuff with somebody who’s a professional as opposed to talking to friends who don’t have an insight into stuff and can’t empathise or understand.”

“So I’ve found them positive and they are... I mean, skilled, really well trained at what they do.

“She really didn’t know anything about the condition; I felt more like a guinea pig, to be honest [...] I was just wishing that they’d actually put me in with somebody who knew about the condition and actually knew what to do. [...] I mean, she was a lovely person and for the right kind of therapy she’d probably be really good, but not

What makes a good therapist?
“She’s very professional, very boundary driven. You feel she knows what she’s doing.”

“Her persistence, I think. Her patience and acceptance.”

“I suppose it was really easy to talk to him.”

“Patient, show interest, listen.”

“Not condescending, down to earth, approachable. They made you feel at ease.”

“a very kind person”

“She was just there for me 100%.”

“I could have someone to say it to, and not to be judgemental”

“I feel very listened to and supported”

“So sort of the patience and the help is definitely the best aspect of it.”

“she makes me feel that I can trust her. She’s been just really lovely actually.”

“I feel like I can say what I want to say and what I need to say to her”

“she’s so professional, so accessible”

“a stable and very helpful influence to help me to do things that were difficult.”

“I want somebody’s who’s professional.”
knowing anything about the subject that she’s trying to do therapy on was really ineffective.”

“There were about eight sessions and then I needed somebody who’d been more highly trained. [...] He was in training and he felt that you know I could use more specialist help so then I moved on to somebody else.”

“When I just realised, you know what, all she is actually doing is photocopying pages out of a book and reading them out to me, I thought, geez, she really has no idea.”

As well as knowing a lot about the therapy and conditions, good therapists also need to be able to communicate that to patients. Therapists therefore need to be able to explain things clearly, give feedback and help patients when they are struggling to understand or use the techniques. Several participants praised their therapists particularly for their ability to explain things. One important way of helping patients to understand was to draw on personal experience. This could also help participants to feel that they were understood and that the therapist was able to empathise with them.

“If I sort of don’t understand something she’s really clear and concise and she’ll go through things with me, and I think one of the best things is if I want to plan something, using the CBT, she would help me do it and then I would go away and do it and she would sort of come back to it and help me if I get stuck.”

“She used a lot of examples of herself that I was able to relate to, and I think that helped a lot, the fact that she could give examples of what I felt, like I was experiencing. I think that really helped me to think about how much she did understand what was going on”

“She drew everything out on a whiteboard for me to see the technique clearly and I was just really impressed with how that helped.”

A few participants were dissatisfied with the therapy because they felt that their therapists delivered ‘text book’ CBT, but without always being as flexible or responsive in their approach as people would have liked. People wanted to know that the therapy was addressed to them as an individual, not simply a set process delivered a set way. Participants associated this approach with therapists’ lack of experience or confidence, particularly if they had a new or trainee therapist.

“It seemed like too much sticking to a set pattern, so whereas somebody maybe with more years of experience would be working on the basis of, okay, I take it from a textbook point of view but I then add some stuff I've learnt over the years. I think he was in a training situation. He had the experience of sort of referring too much to a textbook type situation.”

“He seemed to approach it too much on a textbook. I can understand where somebody would come from with that, if you've just sort of started in to it or you'd just passed your exams or whatever else: I know how to do it because the book told me to do it like this”

In contrast, where therapists could be flexible, and deliver a therapy that was tailored to the individual, people found this more helpful and felt more listened to.
“By the time I got to the second person I wanted to talk about depression. Then I had six sessions on depression and then six on social anxiety and she was very flexible. I could choose whatever I liked and as long as I liked, on an area. So she was very flexible.”

“I’m very, very happy with my therapist, because he’s completely taking a different approach, a different strategy to the normal CBT. He’s not doing that at all. He’s doing the sleep restriction therapy with me. And then we’re focusing on the panic attacks, and we’re going through the situations that I have with him, what I’m thinking, what I’m doing, and we’re working on those.”

As well as the therapist’s lack of experience delivering therapy, some participants found that the young age of some therapists did not inspire confidence, particularly for older patients. Life experience was felt to be important to allow therapists to empathise with patients, and for some patients to feel comfortable talking to them.

“My only thing was that my therapist was exceedingly young. As I got into it I had moments where I felt again that her inexperience didn’t fill me with confidence and just I sort of felt rather awkward because I am a middle aged woman coping with several classic signs of depression, life changes and all that sort of stuff and if you’re a young girl who’s 22 or 23 you have no huge understanding.”

“I find that life experiences can have a big impact on you and if somebody’s had - not necessarily the same life experiences - but just so that they can relate and have some empathy so it’s not just clinical.”

Working together as partners

Throughout the interviews, many participants talked about working together with their therapist. This sense of working as partners was found in the structure of therapy, whereby patients were able to steer the topics and content of the sessions, and in a ‘coaching’ approach to the therapist-patient relationship. This was also reflected in participants’ recognition that they were doing much of the work themselves, not having therapy done to them.

“She’s not dictating which way things are going. She’s always wanting my feedback about things as well, so I feel like a very good relationship.”

“I’ve felt that we were working together as a team during the sessions, because we’re feeding quite a lot off each other. I think that’s why I felt so comfortable because of the way we worked together to get to the bottom of my illness.”

“It was so much, you know, the two of us working together as opposed to being told that I sort of had to do something that actually I really wasn’t happy with. It was very much a two-way, you know, discussing things and that was really good.”

Participants were able to input into the topics addressed each session. One person described being able to email her therapist between sessions to say what she would like to
discuss at the next appointment. People also wanted input from the therapist, however, and at its best, there was a sense of genuine shared decision making. This approach also meant that participants were able to bring up ‘live’ issues or new problems that they wanted to address straightaway.

“I think that worked because we’d come up with a decision together and I felt that was the most helpful because obviously I know what I want to work on and as a professional she knows what we should be working on, and I think that’s what helped the most.”

“we come up with what we’re going to be talking about in the sessions together, and then we work on what we’re going to be talking about during the time that we meet.”

“Every time we meet, we sort of say, right, this week let’s concentrate on something, and we talk about that. So if I’ve had a bad couple of weeks I tell her, and she says right, let’s concentrate on that and what we can do about that. And it does seem to work.”

Being responsive
Participants wanted a service that was responsive to their individual needs and circumstances. As well as being flexible about the content of the therapy, this also involved being flexible in the way it was delivered. This also helps patients to feel less pressured if they struggled with something or if they found it hard to achieve things because of other things going on for them at the time.

“I had a bad week, I hadn’t been able to really go over the homework that week or hadn’t had time or something, she was flexible about that and we’d pick it up again.”

“We had a crisis and our relationship broke up and she couldn’t give any like immediate practical advice. I asked my therapist and she was like, well, no, that’s CBT and I don’t do CBT, and so my GP has actually been more helpful in a kind of pragmatic, hands-on, minute to minute approach.”

As well as being understanding of patient’s needs, in some cases services were able to make practical responses to help patients, for instance through changing the frequency of appointments.

“I don’t see her every week, so that’s my choice. I could see her every Wednesday if I wanted, but I can’t because of other commitments. So it’s usually every two weeks. Sometimes it’s three, or according to what’s happening.”

Some participants had specific needs related to patients’ health, mobility or current wellbeing that required flexibility from the service. Several participants pointed out that when they are very distressed, concentration and memory are affected, making it more difficult for them to engage with the therapy. Other participants had concurrent health needs that had to be accommodated by the service.

“It would have been helpful [to have things in writing] because it would have jogged my memory and when I got home I could look at it.”
Use of measures
As part of their therapy, participants all regularly completed measures. Some people found these to be very helpful, while others disliked completing them or even found they made them feel worse.

“The only thing that I found quite unhelpful was that every time you arrived they made you fill out a little questionnaire. I actually got to the point where I said to her can I not fill these out, please, because every week when I come in and I’m going to sit down to fill in this questionnaire about how I’m feeling, it only makes me feel worse. It would upset me, frustrate me.”

There was inconsistency in how these measures were used in the therapy. The main distinction was whether the measures were discussed together and used to inform the therapy and help the patient, or whether they were simply handed to the therapist for their own use or to be filed away. This had a real impact on people’s sense of ownership over the measures, and whether they considered them to be worthwhile. When used together with the therapist, the measures were seen as a valuable way for patients to see their own progress in the therapy.

“I did a questionnaire every week. Actually she didn’t talk much about that, because I did an output measure every week and that wasn’t really discussed. That would have been helpful.”

“She just took it and filed it. I don’t know if she was meant to go through it with you, but she’d just look at it and filed it.”

“She’s got what I’ve actually said in writing in a way, so I think that’s probably useful for her and it’s useful for me as well. I photocopy it myself.”

“Last week I was shown like a graph of my progress and it’s sort of marked out, it’s on the graph over the weeks so yeah I can actually see my progress. And I know it as well ‘cause I find myself changing my behaviours quite a lot, so there are a few things that sort of tell me that I’m definitely changing a lot.”

Learning through therapy

Many people talked about their experience of IAPT as a learning process, helping them to make sense of their condition and to cope with it better. People learned that what they experienced was a normal part of their condition, or in some cases found out for the first time what that condition was.

“My counsellor did explain to me the things that I should go through, the things I should expect. He explained to me all the things: what I’m thinking and the sensation that I’m going through.”

“More than anything at all was information for me to know sort of what linked into what. I had no idea at least four or five of the things that had got so bad with me were actually OCD symptoms.”
“we found out I was suffering from post traumatic stress disorder and so she gave me a booklet to read about that and I found out more about it on my own as well. So now I know what the feelings are and the illnesses that I was getting, if I get it again in the future, I refer back to this booklet and I can understand that it’s actually that I’m suffering from post traumatic stress or something that.”

As well as being able to make sense of the condition, people developed skills, techniques and coping strategies that allowed them to manage their symptoms. One person even explained that they were aiming to experience a panic attack in the therapy so that the therapist can help them with learning to manage it.

“We want to get to a point in the sessions of me having a panic attack while I’m with him, so that we can find out why they are prolonged.”

Many people mentioned a specific handout, book or technique that was of particular value to them. Participants also found the homework was a helpful way to apply this learning in their own lives.

“She did a model formulation of how it all fits together and that sort of thing.”

“The diagrams, and how things work, and what’s going on, all of that sort of thing was hugely helpful to me because if I at least know or can start to understand how things are going, even if I can’t get it right it does help me to actually understand what is actually going on.”

“Just by the things that [my therapist] introduces every week, you know, like the Worry Tree. It sounds simple, but it works. [...] It’s things like that. She’s done a couple of things like that.”

People also learned more about the therapy itself. Some made the distinction between understanding the theory behind CBT and being able to put it into practice, which was often harder.

“she manages to explain things to me, work through things with me, the theory and then she also helps me with the practical side of things as well, because although they’re related they can seem completely different at times. She recognises the fact that I might understand something but it doesn’t necessarily mean I could go out and do it right away.”

Not everyone found the materials helpful in learning about their condition, however. Some found that they were simply handed materials that may not be appropriate for them, or which caused them more worry.

“They gave you reading but usually find with the reading things, they all come at it from the same way and they all – when you’re debating it sometimes your problem gets worse, because you’re debating it and debating it and debating it.”

“I think that it could be simplified. I thought to myself several times if I wasn’t very well educated or I was in a worse state, I wouldn’t understand any of it.”
Groups

Benefits of groups
Several participants had experienced group therapy and others had been offered but declined groups. Engaging in groups brings its own anxieties and benefits. Those who were sceptical about groups raised concerns particularly around privacy and stigma, and were unconvinced that it could help them.

“They did take it up with me did I want to go to group therapy? But I’d been to group therapy before. It was easy for me to talk in a group, and I wouldn’t break down as much as I did when I was in a one to one.”

“The reason I didn’t want a group is that I’m a very private person, and you’re sitting there in a group, and you’re talking about yourself and your thoughts and these are strangers. I could be walking down the High Street with whoever, friends or family, and I see one of the people walking towards me, and I think, oh, my God! That person knows all about me. So I couldn’t do a group.”

The benefits for those who accessed the groups centred around meeting and learning from other people, and the distinct structure of group therapy. Being able to meet with other people helped in combating the isolation that many felt and recognising that others experienced similar problems which may help to tackle self-stigma.

“A lot of my problems are to do with isolation and not socialising, so the group sessions made me motivated to go and motivated to contribute and say that I’ve put things into practice.”

“I sit in a room with other people that I would pass in the street and not think they had any problem, some kind of working class people, some kind of upper class people, most kind of middle aged, but you wouldn’t think they had a problem, you know. Intelligent people, you know. And people say things and I say things and when I say things, I can see people going, oh, yes! And nodding heads and similarly when someone else says something. It’s helped me not be so isolated and it’s helped me not to be so paranoid perhaps, getting things really out of proportion, making things more dramatic than they are because I’m isolated and I think it’s only me that’s crazy and mad. And then I think, oh, no, perhaps we’re just a group of... perhaps people with just difficult situations. It’s helped me think that I’m not crazy or mad because there’s other people.”

People also found it helpful to learn from others, to share coping strategies and to have the chance to help and support other people in the group themselves. In this sense, these groups fulfil many of the roles of peer support groups in other health settings, including being able to compare your own situation with that of others.

“because you’re sharing experiences but also getting the involvement of the therapist, that by sharing you’re as much being helped by the therapist, you’re helping each other with the actual sharing of the experiences and the way you can see other people are handling similar experiences or sort of other situations that you
can sort of relate to. And also by the way that you see other people working and you can also think, oh yes, maybe that's not such a, you know, I shouldn't be doing it like that, I should think about doing it like this.”

“You feel you're still an individual within that group but at the end of the day, as I say, it's nice to be able to sort of talk to people and see that maybe, you know, you're not so badly off and you can actually help the other people”

**Telephone**

Our survey sampling methods meant that we had few people involved in the study who had experienced telephone therapy. Those who had were likely to have moved on to face-to-face therapy and had therefore most likely found telephone therapy less suitable or less effective for them. The main problems identified were a lack of depth permitted by short telephone appointments, and a sense of isolation for one participant.

“it’s very insular, it’s very... you could be sitting on the carpet, like I am now, next to the phone in my bedroom and you could be just isolated and you talk into a phone and it would make you feel more mad and crazy. You know, if you’ve got no one else... it’s a horrible term, but that’s sometimes how I’ve described myself and that’s how you probably feel if you don’t see other people.”

A couple of people did, however, find that being able to have occasional telephone appointments for practical reasons was very helpful. Again, this reflects the benefits of flexible delivery in response to individual needs and situations.
Impact

We asked participants in the interview whether they felt that the therapy had had an impact on their day-to-day lives. Most people had not yet completed their therapy, or were going on to do something additional. Nonetheless, many did feel that they had benefited, and talked about a wide range of ways that the therapy had helped them. Sometimes these benefits started to occur very quickly. These ranged from reduction of symptoms, developing coping strategies and making significant changes to their work or relationships. In a small number of cases, people felt that the therapy had not helped them and they were able to explain why.

Reduced symptoms
Several participants talked about the positive impact of the therapy on their symptoms, including anxiety, depression and physical symptoms like sleep. Improvements that came from attending the therapy itself did not always carry easily into people’s everyday lives, but several people talked about using techniques and ‘tools’ which did help them.

“Every time I leave the surgery I do feel positive, and I feel happier. I think, oh well, things are not that bad. It only lasts for a couple of days mind, but I do get that respite from the worry.”

“Instead of waking up and feeling really sad, miserable, lonely, I’m trying to get up and take a little bit of what I’ve learned, turn it round and be positive with it. Them little tools that I’m learning, I’m trying to use.”

“My sleep has improved. And I’m able to concentrate, I’m able to think, I’m able to remember, I’m able to focus, I’ve got more energy. My panic attacks have lessened. And I’m able to do some of the goals that I’ve written down.”

Other participants talked about learning to cope better with ongoing symptoms and not letting them affect their lives to the same extent.

“You still wake up in the morning, with your thoughts are going all the time, with the sensations, but now instead of laying there and dwelling on them, I get up now. It’s taught me that they’re not really going to hurt me. There’s nothing going to happen to you. You can get on with your life. I think I’ve learned with the counsellor how to cope with them and they’re not going to hurt me. No matter what my body’s going through, nothing’s going to hurt me, that’s the good thing, a coping mechanism definitely”

“Where [previously] an issue or an incident, the stress, it’ll go on an entire day, nightmares, go on for more than one day. Now I can have a bad moment, it’ll last maybe an hour, now I can STOP, I can move on.”
Activities and confidence: getting up, getting out, getting involved

People talked about the effect of the therapy on their ability to do more things. For some, symptoms had prevented them from being able to get out of bed most days. Techniques and confidence gained through the therapy changed this round for some participants and allowed them to start doing things that they hadn’t done in years.

“I’m not laying in bed so much. I went for about 7 months of Monday and Tuesday laying in bed trying to fight it. I called it my sticky mattress syndrome [...] I knew I could stay there all day, and fight the symptoms in bed. But, for the last 9 or 10 weeks I haven’t done that, I’ve been doing things.”

“I’m doing a lot more now than I was say six or seven months ago, I’m going out quite, still feel nervous, I’m meeting people, I’m playing tennis. I started to get back into conversations now, not looking away, and making eye contact.”

“With just everyday household activities and working activities and everything. Everything was an absolute nightmare. And now I’m, you know, lively and happy and outgoing and sociable and I’m back at work and I’m doing well. It’s just like chalk and cheese.”

Achieving goals

Some people specifically mentioned having fulfilled goals that they had set for themselves within the therapy. These individual achievements were important to participants and helped them to see that they were making progress. One participant pointed out the importance of recognising and rewarding yourself for these achievements.

“You can say to yourself ‘well done, you done well there, you did that, I wouldn’t have done that a couple of weeks ago’, so it’s taken me a long time, to have that experience ‘I did do well and I have achieved that’, so that’s another one that you think to yourself that can’t be right, this can’t be right, it’s so alien to you because you haven’t done it in so long “

“I felt so desperate to be honest. I’m really proud that we’ve accomplished so much in 5 weeks. That takes commitment.”

Not everyone we interviewed had achieved what they wanted to achieve in the therapy. There was a great deal of frustration for those who felt that the techniques and approach of the therapy did not work for them. Even where participants felt that they had achieved things, some were keen to have longer to be able to address more things or impact on other areas.

“In some ways I feel like it’s a waste of my time, but in other ways I think, well, you know, you’ve got to try everything because I want this to change, so I’m willing to try absolutely everything.”

“I did feel that he was doing some good but I think there’s still more that can be done”
Relationships
Several participants had identified the impact of their conditions on their relationships as a reason for wanting to undertake therapy, and the therapy often had a positive impact on their relationships with others. Sometimes these benefits came from lessening the pressure their difficulties had put on a relationship and symptoms being addressed. In one case, the therapy had helped them to change their perspective on their friends’ reactions to them.

“I thought that people were ignoring me, because they couldn’t handle what I was going through, they didn’t know what to say. [...] I’ve realised now that people want to speak to you but they don’t know how to approach you. And they can’t deal with it anyway, ‘cause they’re used to seeing you as you were, not as you are now.”

“I’ve been out a couple of times with my wife, which we haven’t been out that much for a three year period and I have actually been out with her staying concentrating all the time, and that’s how life should be”

In a few cases, others were explicitly included in the therapy, either in couples therapy or by bringing others into a session. This had been very positive for those who experienced it.

“He said, would your wife like to come along to one of the meetings, and we could discuss a few things that you’re experiencing which is affecting your life and not only your life, your wife’s life, so my wife came along to one of the meetings which I thought was really good.”

Work
Keeping people in work or getting them back to work is a key aim of the IAPT programme and several participants identified staying in work as a motivation for accessing therapy. For some, the therapy did help them to find or keep employment. People who were already working during their therapy had been able to discuss and address particular challenges in the workplace which could have a real impact on their ability to keep work, to cope with work, and even to enjoy and value their role in work more.

“I wasn’t able to work before because of the illness, but now I’m actively looking for work and I’ve actually been able to get a job now.”

“My biggest issue was going into work and there would be situations I wouldn’t feel comfortable in, like if I had to make a decision or I had to approach someone about something especially if I had to ask them to do something I found that difficult. I think now instead of dreading it and panicking, I think about what I’m going to do and I don’t make the same mistakes I used to do. I think about it and usually I’m quite successful and I’m actually getting what I want out at the end of it, I don’t feel bad about it, I actually feel quite good.”
Moving on

Time limited therapy

The IAPT service is time limited, and therapy is not open-ended. The number of sessions, and how this is communicated had an impact on the participants in this evaluation and how they engaged with the therapy. Several participants talked about feeling pressured by the time limit and some would have preferred something open-ended.

“I think that it’s better for it to be open-ended, because if you’re told that you have to have a finite number of sessions, then when you get towards the end, if you’re finding that you’re not making as much progress as you hoped you might, then you can start to feel a bit panicky. I’ve got to do all this work in one week. Whereas if it’s open ended then you feel a bit more comfortable about the fact that it will take as long as it takes and when it’s done, then you can stop.”

“The panic for me was when you have to think it might end in X number of sessions, when this is, for me, the first lifeline I've ever been given.”

On the whole, people were aware that realistically sessions had to be limited, and some identified advantages of knowing that there would be an ending. One person, expressed concern about the potential for becoming dependent on an open-ended therapy. Nonetheless, several people wanted more than they had or were expecting to receive.

“Then I’ve got a positive end to it. I’ve got to aim for that day, sort of thing. At the moment, it’s just rolling on.”

“One of my concerns was I would become reliant on it and dependent on it, and then once it’s over, I wouldn’t cope. I don’t want to be dependent on it, but what if it doesn’t work, what if I need more help, what if I’m not going to walk away cured.”

“It would definitely have been able to help me more had we had more time. And I suppose in my mind was always the knowledge that it should only be 13. So there was always that sort of issue over the time, if you see what I mean.”

Participants seemed most comfortable with the number of sessions when they knew that they would be extended if more were needed. Communication over the number of sessions is therefore very important, and may help to make the difference between those participants who feel ‘panicked’ and those who feel ‘comfortable’.

“So, her telling me that we were not going to have an end date, and that was it, and we would have seen later on how it goes, I felt a bit more comfortable”

“You’re told initially how many sessions you’re getting to start with but there doesn’t seem to be like a conclusion level as to how many you can have, which I think in itself is helpful because you’re not being told, well, that’s it, you’ve had your ten, you can’t do anything else.”
Planning for end of therapy

Discussing the end
We asked participants whether they had discussed completion of the therapy with their therapist. Some were still in the middle of the therapy and did not expect to have discussed this yet. These were generally confident that this would be discussed when appropriate. People did feel it was useful to have discussed the ending with their therapist, and those who hadn’t generally would like to. In one case, a participant had not been prepared for the end of therapy and when the end of the sessions came this was distressing.

“I know that once it’s finished I’m not left on my own, but I’m not aware of all the details yet, but like you say, it’s something that probably we’ll discuss pretty soon.”

“I guess like just to see like, yes, what’s next, you know, what am I going to do next after I see him,”

“There needs to be a conclusion otherwise I’m going to have the same problem I had last time. When I left I was really upset because I had no feedback, nothing.”

“I went in for my last session. [I was] a bit taken aback. I said to her, how can we stop, how come we’re stopping when I haven’t actually got on top of the situation?”

Discussing the end of therapy was important to participants, and allowed them to be involved in decisions about the end. When these discussions did take place, participants were given the opportunity to say how they felt about the ending and whether they were ready to move on. It also allowed participants to prepare for coping without the therapy. Discussion about the end has to be managed carefully, however. One participant described being distressed when told that the therapy would be ended. Reassurance and clarity about the possibility of extending is important in giving people a sense of security.

“She said to me that it was all in my hands and I was making the decisions, of how I felt, whether I needed to carry on talking”

“We discussed a future plan, I was quite keen to discuss with her ways of maintaining my health, so we spent a couple of sessions discussing those things before we ended the therapy. I felt as if I had a good plan in place, and a good strategy in case I needed it again in the future.”

“She went through what I’d felt had been helpful and how I might continue it forward. How I might continue without seeing her every week. And what sort of things I might envisage this time next year.”

“There were times to begin with, she talked about finishing and that just freaked me completely. When you’re very distressed and just starting to get the hang of it, I found it very distressing. So the next week I sort of said to her, oh it has to end and what will I do and she said no, it’s OK, there’s more available for you.”

Plans put in place for the end of therapy included giving participants information about coming back to the service if they needed to. The possibility of coming back to the service
was an important safety net for some. In one case, a participant had received a follow-up call which gave her the opportunity to come back to the service when she was not doing so well.

“A little while later, I became depressed again and it just so happened that the person that I had seen phoned me, just as a follow up. It was a few months after I’d seen her, and she rang to see how I was doing. So I said to her on the phone, and she said, well perhaps we’ll just start again then.”

The approach to this was inconsistent, however. Some were told that they would be able to come directly back to the service, while others were told they had to be re-referred through their GP. This was concerning for some as people wanted to avoid going through the referral process and wait again.

“They did say to me it’s possible that you might need some counselling or something to overcome it. […] They said to me you can’t have counselling and CBT at the same time, you have to choose one or the other. And then when you finish one you then go down the same process, go back to your doctor, apply for some counselling and then go, you know, down that road again, which to me seemed a little bit silly when you’re already in the system for starters. It’s just prolonging the situation really.”

“I’d have to do it through my GP again, and be recommended through my GP.”

“She did say, if at any other time you feel you need more you can always phone up and have somebody help you for 2 or 3 sessions”

“She did say something about that, that maybe in a year or so, if I felt I wanted to go back for more sessions, that that was always there.”

**Referral on**

Several participants had been able to access more than one course of therapy within the IAPT service. People receiving one-to-one sessions were referred to groups and classes, sometimes in response to specific points raised in the therapy. Participants were generally keen to get these different options as they gave people additional tools and approaches.

“I sort of, we had one session when I was talking about assertiveness and she said ‘maybe you could go to this group, try this out’, sort of group classes as well.”

“It was noted while I was doing assertiveness, perhaps you can do some self esteem, and I want to take anything that’s on offer. I’ve got so many little kinds of things that could do with a boost”

“They do other things, like relaxation workshop or yoga workshop. I just wanted to finish this one first, but I can consider those later on. Not for now. But the option is open if I want to.”
Several of the participants had been referred on to other services on completion of their therapy in the IAPT service. Some were referred on to specialist services to address particular needs, for example anorexia and panic disorder. This was helpful for people, particularly those who had not been entirely satisfied with the level of specialism available at the IAPT service. This was also an opportunity for people to build on the work at the service and to tackle issues that there had not been time to address.

“He said that he’s going to keep an eye on it and if he thinks I need it he will refer me to someone who specialises in panic disorder solving.”

“she knew there wasn’t enough time to really tackle that. That... but she did refer me back to the clinic for anorexia.”

Two participants were referred on to private therapy to give them a longer term intervention. Private services cost, however, and this was a problem. Participants’ circumstances need to be considered when referring to private services, and importantly, participants need to be told what to expect to pay for private therapy. In one case, the cost came as a surprise to the participant after they got in touch with the recommended service.

“she told me that I need something long-term, and she told me if I wanted to, how would I have felt if I put myself on the waiting list there? And I said I was fine. So I’ve called them up, and they called me back yesterday, and told me that I could be seen. Then they asked me for £50 on the phone. I didn’t expect them to be so expensive.”
Suggestions for improvement

We asked all of those interviewed whether they had ideas for how the service could be improved. Participants raised a range of suggestions. Some are ideas for additions to the service which would have given them extra support. Others are recommendations for improving the existing service or addressing perceived problems that exist currently.

More promotion of IAPT to GPs and directly to the public

People wanted more publicity about the service, and more work with GPs to break down some of the barriers to access. This could help with earlier use of therapy which people felt would be helpful to them.

“What would improve as well if more doctors’ surgery knew about the service, because a lot of them don’t know about it. […] In the actual practice, the doctors themselves knowing about it, because not enough is being done about promoting the service.”

More capacity in the service

People wanted additional resource for the services to allow them to reach more people, to reduce waiting lists and to offer more sessions where needed.

“More staff, so the waiting lists perhaps aren’t so [long]. Are there enough qualified people coming out and doing this job? And will the budget allow it?”

More access to specialist therapies

A few participants felt that the standard CBT did not adequately address their needs. They wanted people who understood the condition they had better and who had experience of helping people in a similar situation.

Recomending additional materials and handouts

People found resources they had been given helpful, but some wanted more recommendations about books, tapes and other materials that they could use on their own. One suggestion was to keep track of recommendation made by other service users, as well as by therapists.

“I would like to have had some influencing books or something because now that I’ve realised what my problem is, through my therapy and things like that, I’ve been to the library and there’s so many books there that are helpful to the people that are going through this.”
Giving suggestions for coping with the therapy

One participant found that the therapy itself could be distressing and would have liked more recognition of this, as well as tips for how to cope with the therapy.

“Maybe perhaps saying to you, like maybe you might feel worse after a session. Something positive like a suggestion maybe to go home and relax or have a bath or relax to music or just take it easy and don’t rush around too hectically or just sit down when you get home if you need to.”

Improved contact with reception staff

A few participants felt that reception staff were not always sensitive toward patients, particularly when under pressure. Some also wanted better arrangements for contacting the service and passing on messages to therapists. There was also a desire for staff to be more sensitive to the potential for stigma and a need for greater privacy when accessing the service.

“I think maybe getting a bigger reception staff, like people that aren’t quite so short tempered. Or maybe people who are maybe a little more friendly or understanding, especially towards other people.”

“I think being able to get in contact with people – I mean I’m not asking for a therapist’s number; if you need to get in contact with the centre, if you need to change an appointment, because otherwise they’ll simply go, well, are they, why haven’t they turned up? You know, because I’ve been caught because a flight has been delayed or something like that”

Evening appointments

Several people wanted access to more appointments outside working hours. While there was a recognition of the difficulty in providing this, it was nonetheless a major barrier for people in work or with other life commitments. People also wanted to feel that they had more choice around appointment times.

Appropriate premises

People wanted premises that were appropriate for them. This was a particular challenge when therapy was held in buildings that were used for other services. People also wanted locations close to home, especially for those with reduced mobility.
More contact with other service users

Aside from group therapies, some people felt that more opportunities to meet and socialise with other service users, to learn from them and to share experiences, would be a valuable addition to the service.

“Maybe within that time people are seeing individuals, maybe sometimes it would be better on occasion, something like every 5 to 6 weeks to have sort of like an open forum to say, what have you experienced? What are you experiencing now? You might be able to see another light from somebody looking at it from a different angle.”

“I suppose that is, because sometimes you do feel a bit isolated when you’re off of a chair into a room when you know there’s things going on. It would be nice that [...] Maybe there would be somebody, like two doors away from me, who’s going through it, who’s going through it by themselves, you just have to say to him, where do you live? Then you can do things together.”
Discussion

Our findings show very high levels of satisfaction with the IAPT services. Most people were very happy with the therapy and with their therapist and were able to point to a direct, positive impact of the service on their day-to-day lives. The issues identified by participants as contributing to this positive experience have also been those that were inadequately addressed for participants whose experience of therapy was less satisfactory. A number of these themes have been dominant throughout every stage of the data collection, applying a range of different methods (expert consultation, focus groups, survey and individual interviews). Recognition of these issues should help services successfully engage with patients. Although the methods used in this evaluation have not allowed us to explore reasons for drop out from the services, there is nonetheless indication of the types of barrier that may lead other patients to leave the service or not to engage at all.

Waiting times
Our survey data shows that large numbers of people are now being assessed within two weeks of referral, and are accessing therapy within two weeks of assessment. This is extremely positive, and exceeds the expectations of many of the people we spoke with. However, a considerable number still had to wait long periods of time. Where people had to wait a long time, it severely impacted on their experience of the service. The difficulties people faced that led them to seek help in the first place had sometimes passed or changed. Several people expressed concern for patients who might have been more vulnerable than themselves and who couldn’t cope without support during this period.

While long waits might be unavoidable, our evaluation suggests that relatively simple processes could be put in place that would alleviate patient distress during this time, and which might also lessen drop out at this point. Most important of these was regular contact. By keeping people updated while they are waiting for assessment services will allow people to see progress, and they will know that they are not forgotten and feel valued. This first point of contact with the service gave people hope that they would be getting help.

While waiting, additional resources and information could help patients to prepare for therapy and to be more informed about options. For many participants, the first information they had about what to expect from the service came at assessment.

Finally, for participants who were struggling during the wait, recommendations for urgent support would be helpful. Some participants did get support from elsewhere during this period, particularly from a GP, but others had nothing to fall back on. Contact information for the IAPT service or for other forms of support would be valuable for people who were reaching a crisis point while waiting for therapy.
**Person-centred therapy**

Most people found the therapy and their therapist extremely helpful. At its best, therapy was delivered in a responsive and flexible way to meet the individual needs of patients. It was often a failure to be flexible that characterised unsatisfactory experiences of the service. Person-centredness has been a buzzword for mental health services for over twenty years. A key benefit of user-focused evaluations is the opportunity to explore what person-centred practice might mean for the individuals involved in the service. This evaluation has highlighted a number of areas where services could address the needs of individuals, despite the highly manualised approach of IAPT.

A number of the participants in this evaluation felt strongly that specific diagnoses and higher level difficulties were not adequately addressed by the standard course of therapy offered. People’s responses seemed to have been aimed less at the therapy itself or techniques used, and more about the level of understanding that individual therapists had about their condition. For our participants, so much of the benefit of CBT came from the opportunity to learn about their experiences and condition, but for this to happen they had to feel comfortable that their therapist understood and could adequately explain things to them, and could reassure them that this approach could help people in their situation. Addressing this may require additional training and support for new therapists around specific diagnoses, or it may require a more careful matching of therapists to patients with less common conditions.

The phrase ‘textbook’ therapy was used many times by our interview participants. There is a danger that a standardised therapy can appear unresponsive, or make participants feel that they have to adapt to the therapy rather than the other way around. When participants were able to steer the therapy to address issues of importance to them, this gave them a sense of ownership over the therapy and of a genuine partnership with their therapist. It was also more effective because it allowed them to work at their pace and to address issues in their lives as they occurred. Being flexible in delivering the therapy requires high levels of confidence and skill among therapists, and it might be especially difficult for therapists just starting out. Therapists need to have clear boundaries around what is appropriate in therapy and be given authority to be as flexible as needed within these boundaries.

On a more practical level, there was a wide variation in how flexible services were about when and where they delivered therapy. Many examples of positive practice were cited, in which access to the appointments was made easier by the flexibility provided by the service. Appointments were offered closer to home for those with impaired mobility. Some were able to negotiate appointments less frequently to accommodate other demands on their time. In some cases, appointments were offered by telephone if people were away from home. In contrast, however, some participants found that services were unable to accommodate often very basic needs. The starkest example of this may be one participant who was told that she would not be able to access the service because she was unable to commit to the same time every week due to shift working. Flexibility does place additional demands on services and often participants explicitly recognised the difficulty of accommodating individual needs. However, every effort should be made to recognise the barriers to access and to remove them.
Creating a welcoming service

The experience of IAPT services was also strongly affected by the atmosphere and facilities in which therapy was delivered. Services were delivered in a wide range of locations which may be more or less within the services ability to control. In choosing and setting up locations, attention needs to be given to creating a comfortable and relaxed environment. At a simple level, more could be done in some locations to help people feel comfortable: having tea, coffee and water available, and avoiding therapy rooms that place physical barriers between patient and therapist.

For some services and staff there needs to be a greater awareness of the potential for stigma when accessing a mental health service. People often do not wish others to know that they are suffering from mental health problems or that they are accessing talking therapies. This was a factor for those in work when arranging appointments. It was also a problem for some people when arriving at services. Locations should be discrete and appropriate and staff need to respect people’s concerns about privacy even within the service. Some staff were felt to be insensitive to this, when speaking to people in public areas.

Reception staff are vital to creating a positive atmosphere in the service. We had reports of friendly, helpful and efficient staff, but we also heard about staff who were snappy and unfriendly. People talked about the courage involved in coming to the IAPT service. What might seem like a small gesture on the part of individual staff members may have a huge impact on whether patients feel relaxed in attending the service.

Preparing a positive end to therapy

Preparing people for a constructive end to the therapy begins right at the start of engagement with the service. It is important to explain to patients that the therapy is not open-ended, but the way that this is done can influence how patients feel throughout the therapy. Some people are very distressed and find it hard to take things in at the beginning of therapy. Many of those involved in this evaluation could not recall clearly what they were told about the limited number of sessions. There was, however, a clear distinction between people who understood that their sessions would run out after a set number, and those who understood that their situation would be reviewed and more sessions given as required.

Those who thought their sessions would simply run out often felt anxious and rushed. It placed a lot of pressure on patients to deal with things as quickly as possible. This is a particular problem as our findings suggest that some people can take two or three weeks before they start to feel comfortable opening up to a therapist. It also made some people pessimistic about what could be achieved, especially if they had lived with these problems for a long time and not been able to address them. In contrast, people who understood that their sessions would be extended if necessary did not seem to experience this same pressure. There was a degree of security in knowing that they would not be dropped by the service until they were ready.

Discussing the end of therapy early on in sessions could provoke anxiety for some people. For others, it helped to give them a goal to aim for and reassurance that they would not become dependent on the service. Participants often benefited from knowing what to expect
and how far they would be involved in decisions about when sessions would stop. Early conversations also helped people to put strategies in place for after therapy ended. Examples of positive practice highlighted that discussions about the end could support patients to set their own goals. Other participants demonstrated how distressing it could be to feel unexpectedly ‘dropped’ from the service if they hadn’t been aware it was coming.

Preparing for the end of the immediate therapy might also involve referring people on to other types of support or leaving a door open for them to come back. Many participants were adamant that return to the service should be streamlined. Going back through the referral and waiting process could be very daunting. Brief ‘top-up’ sessions if required later on were thought to be more cost-effective as well as preferable for the patient.

It may not always be possible to address all the needs of an individual patient, particularly where more specialist help is needed. For a small number of participants, the perceived response of the service was simply to end the therapy without having helped. For others, a more positive response was to refer people on to other services. IAPT services are able to be a valuable conduit into a range of other therapies or types of support, both those delivered by the service and those delivered by other organisations. It is important that these referrals take into account patients’ circumstances (including financial constraints if referring to private or charging therapies). Involving patients in decisions about referrals, as in other decisions, should help to ensure that suggestions are appropriate.

Service User involvement

The evaluation raised awareness of a number of ways that patients could become more involved in the service. It also suggested some appetite for more opportunities to influence the service and to support other users. At the simplest level, people wanted more opportunities to give feedback to the service. This may reflect the kind of people who choose to take part in this type of evaluation study, however it is important that people do have these opportunities. Many of the comments made in this project could easily have been picked up and addressed by services directly if patients were more easily able to feed back to the service.

There is also desire among some participants to have opportunities to meet with and learn from other patients. This was also reflected in our experience of the focus groups and panel where people were very keen to exchange learning and support. Group therapy provides an opportunity to do this in a more formal setting, but consideration should be given to other ways of facilitating peer support. One very simple suggestion was the collation of patients’ recommendations of books and other resources that could be picked up by people when they are first referred.

A lot of work is still needed to build a culture of user involvement in IAPT services. The nature of this group may make it impossible to use the standard approaches to service user involvement seen in secondary mental health services. People’s involvement may fluctuate more, and their availability may be limited. Creative approaches should be used to encourage and facilitate involvement. The approach taken by Greenwich Time to Talk service is an example that may be successful in other services. People were encouraged to express an interest in involvement or feedback opportunities and were then approached with
specific opportunities. The response for our focus group from this group was very positive and demonstrated that this can be an effective way to get people involved.

**Limitations**

Our findings come from a very specific group of patients within IAPT, and they will not reflect the experiences of everyone using these services. A number of perspectives have been excluded because of the methods we used. In particular we have not captured the experiences of people who used only computer-based or telephone therapy. We have also not reached people who dropped out of the service.

This limitation needs to be considered when interpreting what we have found. The fact that this group has engaged with the service sufficiently to pick up a questionnaire indicates that the barriers they have identified have not prevented them from accessing the therapy. Nonetheless, many of their experiences are likely to be shared by others who may have responded to them differently. Many of the issues identified in the report could have caused other patients to drop out.

Levels of satisfaction might also be exaggerated by this evaluation, both because they have stuck with the service and because many indicated that they were keen to feedback because they felt grateful to the service. People who had had less positive experiences may have been less inclined to complete a questionnaire.

The number of questionnaires completed is comparatively small, and this makes it difficult to draw firm conclusions from the survey findings, particularly at a service level. Across the sample as a whole, however, there are some strong trends which would lead to a fair degree of confidence in headline findings.

**Strengths**

While we have a comparatively small quantitative data set, this is supplemented by rich qualitative data from both survey and interview participants. This has allowed us to explore a variety of individual experiences in some depth. We used three different data collection methods in this project – focus groups, survey and interviews – and the themes identified at each stage have helped to verify our findings and to go explore them in a variety of ways. The consistency of the messages from across different services, individuals and research methods lends them considerable weight.

The role of the panel and the service user researchers in this study has helped to ground our findings in the service user perspective and lends credibility to the observations made. This has also helped to ensure that the focus of the evaluation has been ‘user-focused’ rather focusing on the perspective of those delivering services. This may lead to additional challenges for services in implementing changes. This report has not attempted to engage with the difficulties for services in delivering a quality service under budgetary, staff and other constraints. Instead, it has aimed to give an honest reflection of the views and experiences of those who have taken part. By presenting this perspective on its own terms, we believe services can better understand how they can improve the service for those using it.
Recommendations for a person-centred IAPT service

Overall, satisfaction with the service was very high. There were a great many suggestions made by participants and these are presented within the report. Here we make twelve key recommendations based on common areas of concern for patients, and on examples of good practice that could be replicated elsewhere. We believe these recommendations would help to make the service more centred around individual patient needs.

1. Further promotion of the IAPT service is needed to improve access

There is a need for further advertising of the IAPT service and the possibility of self-referral. Some patients will find going through a GP to be an additional barrier to accessing therapy. Findings from this evaluation provide strong support for the view that additional, targeted promotion would help to reach more people earlier.

Although we didn’t obtain data directly from GPs, findings from IAPT patients suggest that there is still a lack of awareness about IAPT services among many GPs. Continued work needs to be done to work with practices, particularly those who may be unwilling to engage or lack interest in referring to IAPT services. In a broader sense, there may still be a need for further training to address a lack of knowledge and poor attitudes around mental health.

2. Provide more contact and information to offer support while waiting to access the service

Long waiting times can be highly distressing for patients. Regular contact during the waiting period can help patients to feel that they have not been forgotten. Patients should be contacted and kept up-dated about expected waiting times.

More information about CBT or other therapies can help participants to understand better what they can expect to achieve and what it will involve for them, which may also help them to engage more effectively with the service early on. Recommendations for books and other resources should be made available for patients during the waiting period. Services could link with schemes such as ‘Books on Prescription’ to make resources available in local libraries. Possible recommendations could also be gathered from patients to share with others. This could help support patients, give them a sense of progress and hope, and prepare them for therapy.

3. Additional, accessible resources should be offered to patients

Many of the evaluation participants would have liked more resources in writing and on tape to help them between therapy sessions. When distressed, patients may find it particularly difficult to concentrate or retain the information given to them in sessions. Some patients will also have other health needs which should be accommodated in making resources accessible. Written or audio materials would be helpful for some patients to refer back to, to support in doing homework and to practice between appointments.
4. Provide flexible therapy within the IAPT model to address individual patient needs

Therapy needs to respond to patients’ individual needs. Therapist training should provide trainees with tools and confidence to provide flexible therapy, led by the patients’ specific needs. Where possible, flexibility in delivery can also make engagement with therapy easier for patients, including arranging appointments more or less frequently, offering telephone appointments and providing alternative locations where possible.

Therapists should consider patients’ own goals in therapy and address these where possible. For example, a number of patients wanted to improve relationships with their families or pass on learning to their children. Examples given in this evaluation demonstrate that where therapists respond directly to these issues, this can be particularly supportive. The effect of continued distress on relationships should also be considered when assessing needs. Early access to therapy may help to prevent further breakdown in relationships, providing better support for the patient and their family.

5. Provide open communication for patients from the start and accommodate personal circumstances and preferences

Preferred means of communication should be established early in the patient’s contact with the service, ideally from the point of referral. Patients should have a contact number for the service. This is important to facilitate re-arranging or cancelling appointments. Patients also benefit from having a number they can call if they are struggling between appointments. Simply having a contact number can offer reassurance to patients who are distressed.

It would be valuable to explore possibilities for extended telephone hours, perhaps by sharing a point of contact outside office hours across several London services.

6. More attention should be paid to training therapists on how to communicate with patients about the number of sessions available

Clear and reassuring communication about the limits to therapy sessions available through IAPT help to establish the expectations and groundwork for the therapy. Therapists need to be aware of the potential anxiety caused by telling patients that they may only receive a set number of sessions. We recommend that therapists present the number of sessions to be provided as involving regular review of therapy needed, rather than upper limits or standard numbers offered.

Therapists also need to be skilled in preparing patients for when therapy has ended. Patients should be encouraged to plan for when they no longer need appointments. Patients should know in advance when the number of sessions is to be reviewed or is coming to an end. If discussions about this are left to the penultimate – or even the last – session, patients can feel abandoned and unprepared.
7. More flexibility should be given when arranging appointments, and additional appointments outside standard working hours are needed to accommodate those patients who are in employment.

Difficulty getting appointments outside working hours was a particular barrier for many the participants in our evaluation. High demand for out of hours appointments may make it difficult to accommodate everyone, but additional appointments at evenings and weekends where possible make access easier for some. Working with patients to offer the best possible appointments is important. It may be that a mixture of day time and evening appointments would make it easier for people to arrange time off work when needed. Certainly, there needs to be flexibility to accommodate shift work.

8. Procedures for re-accessing the service if needed should be made as simple as possible

There was a lack of consistency and clarity about how patients might reaccess the service if required after the therapy is completed. Where this was available, knowing that they could come back was an important safety net for people moving on from the service, and was a key part of preparing for the end of therapy. Providing simple and quick access to the service for brief refreshers would provide valuable support for patients who are self-managing. It is also likely to be more cost-effective to provide this kind of rapid ‘top-up’ intervention rather than to wait for patients to become more distressed or unwell before they re-access therapy.

There may be other, creative ways to provide refreshers for people who have left the service, perhaps through group sessions and peer support that are available to people after ending therapy.

9. Weekly measures should be discussed within the therapy and used for the immediate benefit of patients

Patients complete measures every week, and these are not always easy for people. These measures can be used to demonstrate progress and to open discussions about patient needs and concerns. When measures are simply handed in to the therapist without feedback, it is difficult for patients to see the point of them. Training for therapists must address how measures can be used directly with the client.

10. Recent plans to extend IAPT to younger and older patients, and to patients with diagnoses of severe mental illness are supported by our evaluation, but there is a need for further training

Previous restrictions on age had acted as a barrier for some of those we worked with, including one person waiting extra months to turn 18 before she could start therapy. Diagnoses of severe mental illness had also prevented access on initial referral. In these and other cases, however, the participants had benefitted from the service when they accessed it.

Additional training and skills are needed, however, for therapists working with patients who have more severe mental health problems. Even where the therapy model is
unchanged, therapists need to be aware of different diagnoses and symptoms in order to support patients’ understanding. Confidence in their therapist’s skills is a key element to effective therapeutic relationships. In this evaluation, some participants felt that their therapists were out of their depth and did not feel confident that they could work effectively with their specific needs. Where possible, patients presenting with more severe or complex problems should be matched to therapists with relevant expertise and experience.

11. Stigma awareness training for all staff, including reception staff, would help to promote good practice and establish a welcoming environment

Patients may feel anxious and stigmatised when accessing an IAPT service. Services need to be sensitive to these concerns when communicating and working with patients. This should also include more awareness of the potential for stigma when choosing locations for the therapy. A friendly, welcoming and non-stigmatising attitude and environment is essential to a good quality service.

12. There is an appetite for more user involvement among patients, and creative approaches may be needed to make it possible for people to get involved

Options for extending service user involvement range from providing more opportunities for feedback, to offering opportunities for social networking, peer support and shared learning. Standard approaches to user involvement may need to be adapted to accommodate IAPT service users. Many patients have contact with the service over only a short time, and many are in work or looking for work.

New approaches should be tried to find what involvement opportunities are most suitable. We recommend asking patients when they attend the service whether they would be interested in getting involved in different ways. This would help to establish what types of involvement would appeal to patients, and provide an opportunity to target invitations to involvement opportunities, as has been the case at the Greenwich Time to Talk service.
Reflections on conducting a user-focused evaluation

In this section, we report our own reflections of the user involvement in this project. The model developed for this project and presented above, has presented both challenges and advantages. We present some learning from this work which may be of use to others commissioning or conducting user-focused evaluations.

In keeping with the user involvement aim of providing different perspectives, the project team have each provided a personal reflection on the project experience. These personal accounts represent our own views, not those of the team. As a result, they may give complementary or contradict ory perspectives. The rest of this section is based on team discussions of the learning from this project.

The user involvement model

The project remained largely consistent with the original model established and outlined in the project design, however the different roles evolved over the course of the project. The main differences were with the extent of AH and RS’s involvement, which over time grew in depth and scope.

Service user researchers

The role of the two service user researchers was specified early in the project by SH, in conjunction with colleagues at Rethink. The intention was to provide AH and RS with a clear outline of what they could expect from the project, and particularly what sort of time commitment was required. This was presented to AH and RS for comment, but was not fully discussed. This led to some confusion about their role.

The role was complicated by the fact that neither AH nor RS brought experience of using IAPT services. Instead they brought experience of using other mental health (including talking therapy) services, and of previous involvement in user-focused monitoring and other research projects. Initially, we approached the role as facilitating the involvement of the panel and of research participants through conducting data collection. Their expertise was in making access to the study easier and ensuring that the project faithfully reflected the input of IAPT service users.

As the project progressed, and as the role of AH and RS in the project expanded, this distinction became more problematic. The lack of experience of IAPT services was at times worrying for AH and RS because it was not clear what experiences they should be drawing on, or what perspective they were putting forward. It also became increasingly clear that there was no natural distinction between the views of SH (as a non-service user researcher) and AH and RS (as service user researchers). Rather, three separate perspectives were represented. Part way through the project, this understanding of three standpoints, based not only on experience of service use, but on a range of personal and research experience, was made more explicit. This helped to establish a clearer team structure and approach.
My experiences of working on the IAPT project by Alice Hicks

Being involved with this project has been an interesting and stimulating time for me and it has been a great pleasure to work with Ruth and Sarah and Alison.

Having worked for Rethink before, as an involvement researcher on the Recovery Narratives, I was invited to be part of the Evaluation of London IAPT services. Personally, I had not used IAPT services myself but was aware that some of my friends had and had found them very helpful. I thought the project looked interesting and worthwhile, so I signed up.

As I started to work on the project, I began to wonder about my role within the project. I had obviously read the IAPT evaluation project proposal but the exact nature of what my involvement with the Expert Advisory Panel would involve was not entirely clear to me. Also the fact that this was an evaluation and not research was something I realised I needed to understand.

However, I was able to talk over my concerns with Sarah and Alison and became much clearer about how I would be working in the team. I realised that my many years of experience, working and listening to people with lived experience, would be of value. As the project was about reflecting the perspectives of how people experienced the IAPT services, it was important that we were able to really listen and capture their views.

Facilitating the focus groups went well and people talked openly and interestingly about their experiences. The fact that Ruth and I were service users definitely made the atmosphere relaxed and lively. The participants were able to connect with us and after the focus groups, some people carried on conversations with me about their experiences.

During this whole project, I have been struck by how keen the IAPT service users have been to contribute their views in the survey questionnaires, focus groups and telephone interviews. The impression was that they really wanted to be involved and make a difference to how their service was run. Working with the Advisory panel has proved most enjoyable and productive too, with its members giving us much insightful information. It felt as if we really gelled as a group. Many of the participants of the evaluation expressed an interest in seeing the final report. In my view, the whole project has been a really good example of “meaningful user involvement”

Having worked with the Recovery Narratives project, when we investigated what helped promote recovery for people, I was interested to note how, in the IAPT project, people were also talking about how they were in fact “recovering”. They spoke of having the hope that something at last could be done to help. Many talked of how they realised that it was “up to them” and that they were actually responsible for change and that they could start learning self help techniques (personal empowerment). Others told of how helpful it was that the therapist was non judgemental and really listened to them. And of how they were able to get back to their lives and enjoy things again. It sounded like many of the participants were “recovering” to me.

...
As we have been working to a very short time scale, I have found doing the analysis a bit challenging. It would have been easier for me if things had gone more at my pace. I certainly felt the pressure when we were doing the final analysis phase and was not able to contribute as much as I would have liked. Perhaps in future a project such as this it would be best to employ someone who has more experience of working in this way. However, in this project, I think, it was a question of employing someone who had already worked for and was known by Rethink, to save time.

Throughout our project, Sarah has been a really great boss. She has kept us well informed of progress at all stages and has responded quickly to any queries I made. For me personally, I found her to be friendly, patient and reassuring and I felt able to honest and open with her about any of my concerns. As a team, we have all got on well and we have enjoyed some great meals together! Meeting up occasionally with Alison during the project and being able to talk things through with her, was most helpful for me too.

It would be good if we have the chance to disseminate the results of our Evaluation widely, as many people have expressed an interest in seeing what we have found. I think our project is particularly valuable because it has been driven throughout by IAPT service user’s opinions and experiences. The participants have also made some good recommendations for improvements, which will be of great interest to the providers. Let’s hope our report will influence IAPT services for the better in London and hopefully England.

All in all, this has been an exciting experience for me. I really enjoy working for Rethink and coming up to head quarters, experience the “Buzz” and see all the interesting work that is going on. I always pick up a handful of leaflets to take home!
The initial information I received about the project was an email asking for comments on the completed funding application. Shortly afterwards I was invited to join the project team, which laid out a fairly limited role for the User Researchers, but included additional input from users via the EAP and the User Researcher Mentor, Alison Faulkner. I was interested in trying out a new approach to focusing on user experience via three different user inputs, but unsure about how it would work in practice. I had lots of initial questions about the extent of involvement and of user input into the project design, but I was reassured by Alison’s involvement, as I had known her for 10 years and worked with her previously. Alice and I already knew each other from a previous Rethink research study, so we talked about some of our initial reactions to what we were expected to do over the phone, before meeting the project team for the first time. Ideally we would also have talked to the Project Mentor before our first meeting, and / or she would have been present at it.

At first the three different aspects of User Involvement were somewhat confusing, and potentially contradictory. After a while it became clear to me that the EAP was there to provide input on the product of our evaluation, while the Mentor’s role was to ease the process of carrying it out. However, there were times when this distinction was not absolute.

The Expert Advisory Panel (EAP)
The EAP acted, in practice, like a three- stage Focus Group: initially to draw up issues for the study; part way through to comment on emerging issues and our survey methods; and finally to hear and reflect on our findings.

There were a number of challenges to making full use of the potential of the EAP. Firstly, the composition was smaller than would have been ideal, especially as not everyone could attend every meeting. One person came to all three meetings, two to two meetings and two to only one meeting. We began the first session with a discussion about the members’ personal experience of using IAPT, following a time line, and panel members seemed to welcome the opportunity to review their own experiences. This also enabled the group to bond very quickly, and later discussions included personal elements quite naturally.

Another challenge was the pressure of time – panel members was asked to prepare for meetings beforehand. But in practice, we did not always get the documents we wanted to discuss to them in advance of the meeting - particularly at the end - due to the tight deadlines, and the need to plan EAP meetings in advance.

This meant it was a demanding task for Panel members to both absorb what we had come up with, and make constructive, reflective and critical commentary on it. Ideally they would have had time to prepare for meetings and give more detailed responses, as the payment system had anticipated.

However, given these constraints, the panel meetings were both helpful and encouraging. They added validity to the study by re-grounding our findings, confirming the validity of the User focussed approach, and adding their own examples of similar or different situations to the ones we were discovering.
We were particularly lucky to have Laurie as a panel member, who as the NSUN User Representative brought with him a wealth of experience, not only of using psychological therapy, but of developing and promoting the IAPT model nationally and internationally. Other members had all used, and benefited from, London IAPT services. It was heartening to see their commitment to improving and developing the services, and observe the relationships that developed between those who attended more than one meeting. For me it was another positive experience of the power of group solidarity and debate within the mental health service user movement.

I felt the Panel added value and authenticity to the project by providing a fixed reference point, and enabling us to check our findings against people using the local service.

**Project mentor**

The role of the mentor was suggested following a previous project – Recovery Narratives – at Rethink, which Alice and I had both worked on as user researchers. It was very open-ended at the start, merely being a contract for five days work during the project, to be used as required. In practice this meant she sometimes attended meetings, spoke to us individually on the phone a lot and was always available via email. It was sometimes difficult to know how much to update her on the progress of the research itself.

In practice, the absence of time set aside, or other mechanisms, for team building at the start of the project meant the first half of our work together as evaluators was quite difficult, and led me to question my involvement in the project. In this potentially critical situation, the support of the mentor was invaluable. I managed to write down some issues and talk and meet with her to clarify which issues needed resolution. She then attended a meeting with me and two managers, which talked through my agenda. This led to some beneficial changes in the management and conduct of the work, which made things much easier for the whole project team. The process of getting myself, and my involvement with the project, back to where I could make a useful contribution was much smoother because I had the support of a Mentor. In her absence, I would have found it difficult to contribute effectively. There would have then been fewer resources for the project, and report would not have been so extensive in its coverage of the user perspective of IAPT services.

Following this meeting, we worked more effectively as a team; this was essential, especially in the later stages where time pressure was building up.

**The User Researcher role**

I have enjoyed working on this topic, as a researcher. I was able to bring my own mental health experiences to the work: of using therapy within secondary mental health services and privately in the past; of being trained and working as a counsellor (in student support); and of having been (unsuccessfully) referred to my local IAPT services. Having used questionnaires extensively to gather qualitative data in past User-led research also helped me to contribute to the design of a survey which was, in the event, less significant statistically than valuable for the comments written in by many respondents. During the second half of the project, pressure to get the work done in time were easier to live with because we had forged an effective way of working as a team. This was essential as both Alice and myself had many other commitments in addition to our part-time contribution to this study.

The model of having user input via a number of different routes working simultaneously gave me a feeling of security within this time pressured project; knowing that where problems and issues arose, there were a variety of ways of moving forward without losing the essential focus of the project.
The inclusion of an independent consultant to support the service user researchers was in response to a recommendation coming from a previous Rethink project. The purpose of this role was to supplement the support given to AH and RS by SH, not to replace it. External support was felt to be valuable, however, particularly if difficulties arose within the project team.

No-one in the team had previous experience of working with this type of role. Early discussions were helpful in trying to clarify how this position would work. However, once again this evolved as the project progressed. This is not a straightforward role, and was made possible by the considerable skills and experience of Alison Faulkner (AF), as well as the fact that AH and RS had worked with AF previously.

Key to this role was open communication. AH and RS were given explicit permission to telephone or email AF whenever they wanted. AF provided advice and reassurance to support AH and RS to raise difficulties with SH where required. AH, RS and AF met on a number of occasions throughout the project.

This role was most valuable at the start of the project as the team was getting to know each other. In the second half of the work, AF was called upon less, which was a reflection of improved working relations between AH, RS and SH. The most direct input from AF came in supporting a meeting to resolve a number of difficulties that arose about half way through the project. Having an independent consultant at that meeting was helpful in diffusing tensions around the project work, supporting open and honest airing of views, and seeking greater clarity. Without this input, it is likely that these issues would have been much harder to resolve and may have made it difficult for all members of the team to continue working on the project.
Expert Advisory Panel

The role of the panel was also set out in writing from the start of the project. In this case, however, role was much more stable and having a clear remit from the start was helpful, both to the project team and to the panel members.

It was difficult to recruit to the panel. Services were encouraged to approach people they thought would be interested. In total, six people expressed an interest in being part of the panel. Three of these were able to attend the first meeting, and four attended at least one of the three meetings. After the first meeting, we approached some of those who took part in the focus groups to see if any would like to be on the panel. One of these was able to attend the second meeting. Overall, five people attended at least one meeting, two people attended two of the three meetings, and only one person was able to attend all three.

The fluctuating membership of the panel was not ideal in some sense. It meant that people were not involved in every stage. However, the meetings were extremely productive and people were very generous in sharing their experiences. Among those who attended two or more meetings, an excellent rapport was established which contributed to a relaxed, open and enjoyable atmosphere.

The fast pace of the project made it difficult to keep panel members updated between meetings, and often we could not get papers out to people far in advance. This does not appear to have limited the usefulness of the discussion however. At each meeting, we presented progress and data, and the panel was able to question the team and provide comment and suggestion.

At the last session, we asked the panel members for their own reflections on the project and on their role in it. Responses were extremely positive. In particular, people valued the opportunity to give something back and to help ensure high quality care for others.

“The only negative thing I’ve had out of this is having to sit down for three hours. It is so hard for me. But in terms of actually being a part of it, I’ve really enjoyed being part of it. It really makes you feel like you’re actually doing something for others as well to try and help. I have really enjoyed it. It’s that purpose, I think, yeah I have done some good myself, and actually if I can show that to other people and I can help other people to come out of, whether it’s the same hole or a different hole, I can only learn from them and I hope vice versa.”

“I was a bit pessimistic at the first meeting. It’s a hard to engage group, in primary care, a fairly new service, with stigma and discrimination, and I just wondered how it would go. But credit to you, you’ve proved that engagement with this group is possible.

I’ve got to ask how you’re going to complete the circle and go back to those people you’ve actually seen and sent a questionnaire to, to say ‘look, this is what we’ve found.’”

Enjoyable. Feeling that one has contributed by suggesting how best practice can be expanded. Feeling that the user’s voice is being listened to and one has ownership of the procedure, rather than something imposed.
Challenges and learning points

Input into the project design
AH and RS were given only limited opportunity to feed into the design of the study, after a draft had been produced by the Rethink Research Team. This was due to the short time frame in which the proposal was developed and submitted. Had they had greater opportunity to shape the first ideas and initial draft it is likely that the study proposal would have been significantly different, and possibly better. Certainly greater involvement in the design phase would have helped to give greater clarity and ownership over the project.

Team-building
At the start of the project, AH and RS had not met SH. With this in mind it would have been useful to spend more time at the start of the project getting to know each other better. As the project progressed, we spent more time socialising which helped us to build positive working relationships and to understand each other better. Sharing meals together as a team was key to this.

Management heavy team structure
The project initially included involvement from two senior colleagues at Rethink. Despite the value of this input, the result was a management heavy team structure. This also meant that the project was negotiated across five people. Decision-making processes were complicated by additional levels of management. Towards the end of this project, the management structures became clearer and this helped everyone in the decision to understand how and where decisions were taken.

Skills and training
While AH and RS both had considerable experience of involvement in various research projects, both would have benefited, in different ways, to additional training and skills development. At the start of the project, we would have benefited from a review of the skills required for the project so that any gaps could be addressed. For example, additional IT and quantitative analysis skills would have helped to make greater involvement possible at key stages, particularly when time was tight.

Time pressures
The biggest challenge throughout the project was the limited time available. The project attempted to achieve a lot over a six-month period. The tight time-scales limited possibility for discussion, negotiation and feedback. This was particularly true in the last 6 weeks of the project when we were working on data analysis and writing up. When done as a team, these ideally require face-to-face discussion and reiteration. The extent to which this was possible was very limited and it placed too much pressure on all members of the team to turn things round very quickly.

The tight timescales also made it difficult for SH to provide adequate feedback and support for learning throughout the project. There were a number of elements in this project that were difficult to manage effectively, and ideally more time should have been taken to ensure that everyone on the team was happy and confident their own tasks.
The pressure over time was aggravated by the fact that the team were geographically spread across London, Oxford and Bristol. This made meetings more difficult and required a great deal of travel for AH and RS as meetings were mostly held in London.

**Evaluation vs research**
Neither AH nor RS had previous experience of working on evaluation projects of this kind. The distinction between evaluation and research is not always a clear one, but it is an important distinction as ethics governance requirements for research are different. Navigating this distinction was a challenge for every member of the team. The restrictions placed on the project by this distinction also limited the extent to which the service user researchers were able to shape the project, or to explore areas of interest.

**Sarah’s perspective**

**Expert Advisory Panel**
Recruiting to the Expert Advisory Panel was more difficult than I had expected. With hindsight, perhaps it shouldn’t be surprising. There was comparatively little background of user involvement among these services, and the nature of this group is that people often move on very quickly.

Those people who were part of the panel brought both a wealth of expertise – both through using the services and through their other work – and an incredible generosity in sharing that expertise and applying it to the project. For those members who were able to attend more than one meeting, there was an amazing sense of bonding that resulted from this sharing and which made the panel very enjoyable as well as valuable to the study.

**Service user researchers**
This project involved service user researchers more closely than any I had been involved in before. Beyond the administration and budgeting, Alice and Ruth inputted at virtually every stage of the project, from planning to data collection to analysis and writing. To a large extent, this level of involvement was driven by the interest and motivation of the Service User Researchers. Certainly, the level of involvement they had was considerably more than that envisaged in the initial project plan. This has been of huge value to the project. I have no doubt that their involvement forced us to consider and justify our research assumptions and habits and helped us to build better relationships with our participants. At the same time, this greater level of involvement has at times placed huge pressure on project resource and time and has been stressful for the whole team.

At the start of the project we made a considered effort to lay out the role and expectations of the Service User Researchers. This was of limited usefulness, however. I wrote the initial outline prior to discussion with the Service User Researchers. Although I expected it to be amended and agreed, without this face-to-face discussion in advance, questions and issues were not properly resolved until much further into the project. Having an outline in writing perhaps led to false assumptions about what had been agreed. In addition, as with so many research projects, it was not possible to predict at the start what problems would arise and what flexibility would be required. While many researchers have highlighted the importance of being clear about exactly what is involved in a project, I would argue that real clarity can only be given when the involvement is limited. In order to genuinely steer a project, the service user researchers have to be a part of the problem solving and management of the research.

...
The role of the two service user researchers for this project was complicated because neither had used IAPT services. The experience they brought was broad in relation to both use of mental health services and involvement in research projects, but without having used the service being studied, it raised questions about how far they were expected to draw on their personal experience. The Expert Advisory Panel did bring experience of IAPT services and a level of expertise into how they are run and used. The relationship between the panel and the service user researchers, while extremely productive did not always feel clear.

The increased depth of involvement in the project put additional pressure on all three researchers. Alice and Ruth both had considerable commitments beyond this project. Working a fast-paced project like this around those other commitments was often a challenge for them, and for me. The project could only move as fast as we could move as a team. This was further complicated by physical distance. Being dispersed between Bristol, Oxford and London meant that meetings involved a great deal of travel for the Service User researchers. Often our meetings started later in the morning and continued into the early evening which could be exhausting, particularly for those having to travel there and back. This also limited the amount we could achieve in meetings and at times made progress slower. Towards the end of the project, the increased pace required to meet the deadline placed a great deal of pressure on the involvement process and did limit the depth of input that was possible on the write up of the project.

For me, the hardest aspect of user involvement in this project was the balancing act required to manage this project. Having three different researchers on a project meant three different perspectives, not all of which could be followed all the time. Three is a difficult number because the dissenter can feel isolated or sidelined. Decision making was made more challenging because we were not, as a team, free to make any decisions we wanted. We were constrained by the demands of the project resources and time frame, by the expectations of funders and IAPT services, by research governance and regulations, by the views of my senior colleagues and Rethink policies. At times this could be incredibly frustrating: for me because I often felt torn in several directions, for Alice and Ruth because it was not always clear why decisions could not be taken. As the project progressed, I felt more able to be explicit about these constraints which, I hope, made them easier to navigate.

Managing the challenges within this project was made much easier by having an independent consultant. This is something I would strongly recommend for future projects. As well as the support that Alison offered to Ruth and Alice, Alison helped to resolve issues by bringing a fresh and neutral perspective. It was also only possible because of the incredible level of commitment to the work shown by both Alice and Ruth, and their willingness to work hard at making the involvement process productive.

I would be lying if I said there were not times when this project was frustrating and high pressured. However, it has also been extremely constructive. Alice and Ruth demanded more of the project, and of me, than would otherwise have been the case. In my view, this has led to a better piece of work throughout, and I hope that is reflected in this report.
References


Appendices

Appendix 1: Information on Expert Advisory Panel for potential members

A user-focused evaluation of IAPT services in London

We are looking for 6 people who have experience of using IAPT services in London to sit on the Expert Advisory Panel for a user-focused evaluation of IAPT in London.

Panel members may be using IAPT services currently or have used them in the past. People would need to be available to meet in London on three occasions, lasting between half a day and a full day. No other skills or experience of evaluation or research is required.

We would like the panel to reflect the diversity of London IAPT patients and users, so we are looking for men and women of all ages and cultural backgrounds.

The first meeting of the panel will take place in Vauxhall on 14th October, from 10am until 2pm. Please contact Sarah Hamilton on 020 7840 3075 if you are interested or for further details.

About the project

We have been asked to carry out a user-focused evaluation of IAPT services in London. We will be working with 15 IAPT services across London to find out about the experiences of people who use them. The evaluation will take place between September 2010 and March 2011.

The evaluation will use different methods to capture the views and experiences of people who use IAPT services, or people who have been referred but chosen not to use them:

1. We will carry out 5 focus groups to get an understanding of the types of issues of interest to IAPT users and to inform the rest of the evaluation.

2. We will carry out a short and simple survey to gather the views of larger numbers of IAPT users.

3. We will conduct interviews with a smaller number of people to get a more in-depth understanding of their experiences.
What is a user-focused evaluation?

The aim of this evaluation is to find out about the experiences and priorities of people who use IAPT services. A user-focused approach places service users in the driving seat at all stages of the evaluation, from deciding what questions the evaluation should address to designing the data collection tools and analysing the data.

About the evaluation team

Rethink is the leading national mental health membership charity. It works to help people affected by mental illness recover a better quality of life. The team working on this project consists of four researchers; Sarah Hamilton, Sue Patterson, Alice Hicks and Ruth Sayers. Two of the researchers have personal experience of using mental health services and have a great deal of experience doing user-focused research.

Expert Advisory Panel

The evaluation will be steered throughout by an Expert Advisory Panel. This panel will be made up of people who have used London IAPT services. They will meet three times in the project:

- The first meeting (14<sup>th</sup> October, 2010) will get everybody familiar with the project and what it aims to do. At this meeting, the panel will work with the evaluation team to decide the focus of the evaluation, and the questions to ask at the focus groups.

- At the second meeting (November, 2010), the Panel will review the data collected so far and help the team to interpret it. The Panel will also steer the next phase of data collection and contribute to the design of the survey and interviews.

- At the final meeting (March, 2011), the Panel will review the data collected and analysed by the evaluation team. They will inform the conclusions drawn from this, and help to make sure that they address the priorities and perspectives of people who use IAPT services.

Payment

Members of the Panel will be paid £13 per hour for attending the meetings. For every hour of meeting time, we also pay for an hour of preparation time. So for a meeting that lasts 3 hours, the Panel members would be paid for 6 hours in total (coming to £78).

We also cover all travel expenses and will provide refreshments at the meetings.

If you are interested...

If you would like to know more about the evaluation or are interested in being part of the Expert Advisory Panel, you can contact Sarah Hamilton on 020 7840 3075 or sarah.hamilton@rethink.org. The first meeting of the Panel is on 14th October, so please do get in touch as soon as possible.
Appendix 2: Focus Group advert

How is IAPT for you?
Come to a focus group and tell us about your experience of therapy

What has worked for you? What would you change?
Tell us about your experiences of using this service and help to shape IAPT services for the future.

We are a group of researchers who have experience of mental distress. We have been asked to look at how well IAPT (Increasing Access to Psychological Therapy) services in London are doing. First we need to know what is important to people who are using these services.

We would like you to attend a focus group in London at one of these times:

26th November, 11.30 am – 1 pm
26th November, 3pm – 4.30 pm

At the Focus Group we will ask you to talk about your experience of using IAPT services. Whatever you say is confidential.

We will provide refreshments and give you £20 as a thank you for taking part.

If you are interested in being part of these focus groups, or if you would like to know more, please contact Sarah Hamilton on 020 7840 3075 or sarah.hamilton@rethink.org.

Take part and we will give you £20
Appendix 3: Focus Group Information and Consent form

Your experience of the Increased Access to Psychological Therapies programme

Further Information and Agreement about what taking part in our Focus Group will involve

Thank you for your interest in the focus group. This page gives you some key information about the groups. Please ask Sarah Hamilton if you have any other questions, either at the focus group or on 020 78403075, or sarah.hamilton@rethink.org

What we are doing:
We are carrying out an evaluation of London IAPT services. The evaluation aims to focus on what’s really important for people who use these services. That’s where you come in. We will use these focus groups to find out what are the right questions to ask in the evaluation. We hope the information we collect will help to improve services in future.

Privacy:
There will be about 5 – 10 people at the focus groups and we would like you to talk about your experiences and views. The conversation is private, and we ask everyone who takes part not to tell anyone else what you say. Your IAPT service will not know you have taken part unless you choose to tell them yourself. The only exception is if you mention something that indicates a serious risk to yourself or others. In that case we may have a responsibility to inform appropriate authorities.

We would like to tape record this so that we don’t miss anything. Only the three researchers working on the project will be allowed to listen to the recording. We might like to quote something you say when we write up the key points, but we will not use your name, or tell anyone you have taken part.

Money:
As a thank you for taking part, we will give you £20. We will also pay the cost of any bus or train tickets. Please keep your receipts or tickets so that we can take a copy and give you the money.

If you have read this page and you would still like to take part, please sign below.

Signature

Print your name ___________________________ Date ____________
Appendix 4: Survey used, Hammersmith & Fulham Back on Track service.

"Talking Back" Survey

Thank you for picking up this questionnaire. We understand that you might have been asked to complete another survey recently as part of a national review of all talking therapy services. This questionnaire is part of a local project looking at London services. The results of this study will be ready in the spring and fed back to your service.

With your help, services can find out what they do well and what they can do better. We really appreciate your help. As an extra thank you, when you return this to us we will send you a £10 gift voucher. Please complete this front page so we know where to send the voucher. We will separate this page from your answers so that no-one knows who said what.

Your name: ________________________________

Your address: ________________________________

______________________________________________________________________________

Your telephone number or email address: ________________________________

If you would like to receive a summary of our findings, please tick this box: ☐

Please return your completed questionnaire as soon as possible and by 5th March at the latest to the Freepost address below:

Rethink London IAPT Evaluation
FREEPPOST RRYH-TZ3Z-GEHU
15th Floor, 89 Albert Embankment, London, SE1 7TP

(This page will be removed when returned to Rethink)
Talking Back

Please tell us about your experience of the Back on Track service

About this questionnaire

We want to find out about people’s experiences of using talking therapy services in London. The information you give us will be used to help see how well services are performing, and to help influence future services.

To thank you for taking the time to complete this questionnaire, we will send you a £10 gift voucher once we have received your response. Please put your name and address on the slip attached so we can send this to you. We will remove this slip from the questionnaire as soon as we receive it.

Please do not write your name on this questionnaire. You should feel free to answer honestly as the service will not know who has given this feedback.

Please answer as fully as possible and use the space after each question if you would like to give more detail or suggestions for how the service can improve.

Thank you for taking the time to fill in this questionnaire and helping to inform future services

Tell us more!

We would like to interview a small number of people who have completed the survey to find out more about your experience in your own words. Interviews will take place on the phone and last about 20 – 30 minutes. People who are interviewed will receive an extra £20 voucher. If you are happy to be interviewed please tick here.

If you are chosen to be interviewed we will telephone to arrange a convenient time. Please give us your telephone number: ____________________
Referral and access to the service

1. How did you first find out about the Back on Track service?

2. How were you referred to the Back on Track service? (Please mark one option)
   - Referred myself
   - GP
   - Other medical professional
   - Social services
   - Job centre
   - Voluntary organisation

3. Roughly how many weeks did you wait:
   a. between being referred and having an assessment?
   b. between having an assessment and receiving talking therapy?

Thinking about the time between being referred to the service and accessing talking therapy, how satisfied were you with...

4. information you received about the service?
   - Very satisfied
   - Partly satisfied
   - Partly dissatisfied
   - Very dissatisfied
   - This is not important to me

Your comments

5. support offered to you during the waiting period?
   - Very satisfied
   - Partly satisfied
   - Partly dissatisfied
   - Very dissatisfied
   - This is not important to me

Your comments

6. the assessment process?
   - Very satisfied
   - Partly satisfied
   - Partly dissatisfied
   - Very dissatisfied
   - This is not important to me

Your comments
Your experience of talking therapy

7. Which of the following best describes your current use of the service?

<table>
<thead>
<tr>
<th>Option</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have not yet started my therapy</td>
</tr>
<tr>
<td>I am part way through my therapy</td>
</tr>
<tr>
<td>I have completed my therapy sessions and no longer use the service</td>
</tr>
<tr>
<td>I have completed my therapy sessions but am planning to use the service further</td>
</tr>
</tbody>
</table>

8. How was your therapy delivered? (Please mark as many options as appropriate)

<table>
<thead>
<tr>
<th>Option</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group therapy</td>
</tr>
<tr>
<td>Individual, face-to-face therapy</td>
</tr>
<tr>
<td>Telephone-based therapy</td>
</tr>
<tr>
<td>Computer-based therapy</td>
</tr>
</tbody>
</table>

9. How many sessions of therapy have you had with this service?


10. At the beginning of your therapy, were you told how many sessions you would be able to receive? (please mark one option)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>If yes, how many?</th>
</tr>
</thead>
</table>

11. Please rate your agreement with the following statements: (please mark one option for each statement)

a. In general, people should be told how many sessions they will receive at the start

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
</table>

b. No limit should be placed on the number of sessions offered at the start

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
</table>

Your comments
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Your comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. the choice of therapy you were offered?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. the number of sessions you received?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. how included you were in decisions about your therapy?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. the way your progress was measured during therapy?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. the planning for completion of your therapy?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. arrangements made for follow-up?</td>
<td>Very satisfied</td>
<td>Partly satisfied</td>
</tr>
<tr>
<td>Your comments</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Working with your therapist

If you have not worked with a therapist, please mark here and skip to question 21

<table>
<thead>
<tr>
<th>Please rate your agreement with the following statements:</th>
<th>(please mark one option)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. I was satisfied with my therapist</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>19. My therapist listened to what I told them</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>20. I could change to another therapist if I wanted to</td>
<td>Strongly agree</td>
</tr>
</tbody>
</table>

Your comments

### Your experience of the *Back on Track* service

Thinking about your experience of *Back on Track*, how satisfied were you with...

<table>
<thead>
<tr>
<th>(please mark one option)</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. how responsive the service was to your own needs and circumstances?</td>
</tr>
</tbody>
</table>

Your comments

| 22. how easy it was to contact someone at the service when you wanted to? | Very satisfied | Partly satisfied | Partly dissatisfied | Very dissatisfied | This is not important to me |

Your comments
## Overall

23. Do you feel that the service has helped you?  
(Please mark one option)

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
<th>Don't know</th>
</tr>
</thead>
</table>

Please tell us more about what helpful or unhelpful for you.

24. Do you have any other suggestions for how the Back on Track service could be improved?

Thank you for giving your feedback on the service.
About you

We would like to know more about you, to help us to understand how well the service is meeting people’s different needs. All the information you give is confidential. If you do not want to answer a question, please mark the box labelled “I would prefer not to answer”.

Your age: __________________________ I would prefer not to answer

Your gender:  Male  Female  Transgender
I would prefer not to answer

Your ethnicity:  
| White – British | White – Irish | White – Other |
| Mixed – white and Black Caribbean | Mixed – White and Black African |
| Mixed – white and Asian | Mixed – Other |
| Black or Black British - Caribbean | Black or Black British - African | Black or Black British - Other |
| Asian – Indian | Asian – Pakistani | Asian – Bangladeshi |
| Asian – Chinese | Asian – Other | Any other ethnicity |
I would prefer not to answer

Your religion or belief:  
None  I would prefer not to answer

Do you consider yourself to have a disability?  
Yes  No
If yes, please tell us what condition or impairment you have

I would prefer not to answer

Do you have caring responsibilities for children, dependant relatives or other adults?  
Yes  No
If yes, please tell us who you have caring responsibilities for

I would prefer not to answer

Please return your completed questionnaire as soon as possible and by 5th March at the latest to the Freepost address below:

Rethink London IAPT Evaluation, FREEPOST RRYH-TZBZ-GEHU
15th Floor, 89 Albert Embankment, London, SE1 7TP
Appendix 5: Interview schedule

Preamble

1. Confirm you have the right person (don’t say you’re from Rethink until you have the right person.)
2. Introduce yourself and remind them about the survey and volunteering for interview. Confirm if they received further information in the post about it.
3. Remind them that: a) It is confidential; b) we are independent of 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 service specifically. As it’s quite focused we won’t be able to talk more generally about your experiences. From time to time I might prompt you to come back to talking about the service if we wander a little. It isn’t because I’m not interested in other things you might have to say, but just because we have to focus on what the service can do. Is that OK?”
5. After we have done the interview, we will send you a £20 shopping voucher in the post.
6. “We would really like to record the interview so that we can listen to it again and make sure we represent your views accurately. We’d also like to use some quotes but without saying who they are from. Only the research 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. Is it OK if I record the interview? Are you happy to do the interview now? (Must answer yes before going further)

1. How were you first put in touch the service?

1a. When was that?

1b. How long did you wait to use the service?

1c. Is there anything you would have liked to have during the waiting period?

Yes

No (go to next page Q2.)

1c. i) Did you get it?
2. What were you expecting from the service when you were first referred?

2a. Did it turn out to be what you expected?

2b. Were there things that surprised you?

2c. Did you have particular things you hoped to achieve?

   Yes  No

   2c. i) Has the service helped you to achieve these?

      Yes  No

      How?  Why not?

3. Do you know what type(s) of therapy you’ve had?

3a. Were you able to talk to the service about the type of therapy before starting?

4. Was it easy to make appointments that suited you?
5. What were your first impressions of the therapy?

5a. Did that change over time?

Yes

No

5a. i) How did it change?

6. How did you get on with your therapist?

6a. Did you feel able to speak freely with your therapist?

6b. What did you find most helpful about your therapist?

6c. Was there anything you found unhelpful?
7. Are you still using the service?

7a. Have you talked/did you talk to your therapist about how your therapy will come to an end?

Yes

What sort of things have you discussed?

No

Would you find this helpful?

8. Do you think the therapy has had an impact on your day-to-day life?

9. Was there anything else about the therapy you found particularly helpful?

10. Was there anything else about the therapy you found difficult?

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