

**NAPT**  
NATIONAL AUDIT OF  
PSYCHOLOGICAL THERAPIES



**Service User Views on Psychological Therapy Services:  
A report on qualitative responses**

**November 2011**

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# Executive Summary

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“Waiting time was too long – 5 months from when I saw my Doctor and 4 months from when I was assessed. It would have been longer (maybe another 6 months!) had I not got upset about the wait, at which point they put me at the top of the list”.

“It was a great comfort for me being able to open up and discuss very private feelings. My therapist certainly put me at ease and I felt relaxed and able to talk about everything that was affecting my life”.

“If I knew from the beginning I was just going to get occasional phone calls with a bit of CBT and a few suggestions, like 'join some clubs', I probably wouldn't have bothered”.

## Background to the overall audit

The National Audit of Psychological Therapies for Anxiety and Depression (NAPT) was established in 2008 with funding from the Healthcare Quality Improvement Partnership (HQIP, see <http://www.hqip.org.uk>). The aim of this three-year project was to evaluate and improve the quality of treatment and care provided to people who suffer from anxiety and depression in England and Wales. The audit aimed to investigate: what kind of therapy was being provided to people with anxiety and depression, how useful the therapy was, how long people had to wait and what service users thought about the service being provided.

## Methods of the audit

To measure the quality of psychological therapy services, a manual of standards and audit tools were developed. The audit tools included questionnaires for therapists, managers and service users.

The service user questionnaire (named 'Talking Treatment') was designed to find out what service users think of psychological therapy services. The questionnaire was developed and tested with input from service users and researchers.

**The following report focuses on the qualitative data arising from the open-ended questions asked to service users about their therapy, using the Talking Treatment questionnaires.**

For more information on the audit methodology and tools, and the development of the 'Talking Treatment' questionnaire, please see [www.rcpsych.ac.uk/napt](http://www.rcpsych.ac.uk/napt)

## Analysing the data from the Talking Treatment questionnaire

Qualitative data from approximately 3500 Talking Treatment questionnaires were analysed using a thematic approach. There were two main sections of the questionnaire: Access to Talking Treatment and Outcomes of Talking Treatment and the report is laid out under these two main headings.

### Key Findings

Six main themes were identified in **Access to Talking Treatment**:

- Waiting Time
- Convenience
- Information
- Choice
- Difficulties
- Initiative

The predominant theme was waiting time, with most respondents commenting on what they felt was an unreasonable and too lengthy waiting period at all stages of the process – to receive a referral, an assessment and the talking treatment itself.

Often respondents were offered no choice regarding therapist, talking treatment, appointment time or venue. If they were then it usually resulted in a longer waiting time. Many received little information about the talking treatment until they received their first appointment and in addition, they sometimes experienced difficulties associated with administration or communication. These effects combined to cause additional distress to respondents, who were obviously referred in the first place because of their already existing mental health difficulties. Some chased up referrals themselves or tried to resolve other difficulties; however, many were unable to take the initiative in this manner due to their mental health.

Within the theme **Outcomes of Talking Treatment**, seven main themes were identified:

- Sessions
- Therapist
- Talking Treatment Approach
- Structure and Format of Talking Treatment
- Personal Factors
- Talking Treatment Outcomes
- Alternative Services

Issues related to sessions were highlighted, with the majority of respondents feeling they hadn't received enough talking treatment sessions.

Most respondents valued the skills, experience and personal qualities of their therapist and felt comfortable talking.

The majority of comments received on talking treatment approach related to low intensity treatment and were received via the telephone. Most respondents were

critical of this approach, including disliking the questionnaires, although some appreciated the accessibility of the approach.

The majority of respondents felt the talking treatment had helped them to understand their difficulties better; however, they expressed mixed views about whether it had helped them to cope better. They appreciated the strategies and skills they had learnt but sometimes found them difficult to put into practice. Often respondents felt that their talking treatment hadn't covered everything that they wanted to talk about. Some were hopeful about the future, others concerned about relapsing.

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# 1. Methods

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For this part of the NAPT a total of 10,970 completed Talking Treatment questionnaires were returned and approximately 3,500 of these were used for this analysis and report.

The questionnaire and other related information can be found here:

<http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/psychologicaltherapies1.aspx>

## 1.1. Data Management

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Qualitative data from three sections of the Talking Treatment questionnaire were analysed:

- *Access*
- *Outcomes*
- *Additional comments about your experience of treatment*

All comments, regardless of where they had been made in the questionnaire were organised under two sub-headings: 'Access to Talking Treatment' and 'Outcomes of Talking Treatment'. Some comments were disregarded due to their irrelevance to the NAPT, for example comments concerning other services such as hospital admissions. Several users stated they hadn't received any talking treatment and these comments were also disregarded unless they provided additional relevant data.

## 1.2. Data Analysis

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A full thematic analysis was carried out using methods as described by Braun and Clarke (2006), chosen because it is both rigorous and flexible in approach. Six phases were undertaken, based mainly on Braun and Clarke's description of the process (2006, p. 87), described in detail in **Table 1**.

<b>Phase</b>	<b>Description of the process</b>
1. Familiarising yourself with the data	Data management, reading and re-reading the data, noting down initial comments
2. Generating initial codes	Coding data in a systematic manner
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each theme
4. Reviewing themes	Checking if the themes work in relation to the coded extracts and the dataset, generating a thematic map of the analysis
5. Defining and naming themes	Ongoing analysis refining the specifics of each theme, generating clear definitions and names for each theme
6. Producing the report	Final opportunity for analysis, selection of extract examples, producing report

**Table 1. Phases of thematic analysis**

Braun and Clarke (2006) state that it is not uncommon to find authors describing themes “emerging” from the data. However, they describe this as being a “passive account of the process of analysis...that denies the active role the researcher always plays in identifying patterns/themes, selecting which are of interest, and reporting them” (p. 80). To address this issue, the researcher has explored their own perspectives while carrying out the analysis and these are discussed in the section on reflexivity. In addition, an audit trail was kept of the different phases.

Several decisions were made throughout the process, including what was identified as a theme, in both the amount of data and its significance. This is discussed in more detail in the reflexivity section. Similarly, a decision was made to use an inductive approach to the analysis. Therefore, although the two main sections of Access to Talking Treatment and Outcomes of Talking Treatment were taken from the format of the questionnaire, the themes were derived independently.

### **1.3. Validity and Reliability**

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A small sample of qualitative comments from both the Access and Outcomes sections were independently coded by two other members of the research team. Any differences were discussed and used to inform the final themes. This served to increase the validity and reliability of the analysis.



## 1.4 Consent and Confidentiality

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Eligible service users – those in therapy between October and December 2010 – were invited by their local service to complete a questionnaire for NAPT. Local services contacted users through the post, providing a questionnaire, a letter and an information sheet. The contact details of service users were not shared with the central NAPT team. Although they were not asked to, some service users provided names of their therapist and/or the service where they received therapy. All details that could identify a person and/or service were removed during the analysis process.

It was made clear to participants that completing the questionnaire was entirely optional and that their decision to complete it, or the content of their response, would not affect the care that they received. It was also made clear that all feedback would be anonymous – the questionnaires were returned in Freepost envelopes directly to the central NAPT team. None of the items in the questionnaire ask for information that could be used to identify individual service users.

## 2. Results

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A number of main themes, all with sub-themes, were identified for both sections on Access to Talking Treatment and Outcomes of Talking Treatment. These are discussed in detail below and thematic maps are used to illustrate both sections.

Quotes are used extensively to illustrate the vast amount of comments in the data received. All quotes are given verbatim unless otherwise indicated and any highlighting is the respondent's own emphasis.

For ease, the terms talking treatment or therapy, therapist and respondent or user are used throughout.

### 2.1. Access to Talking Treatment

Six main themes were identified in the responses to questions about Access:

- Waiting Time
- Convenience
- Information
- Choice
- Difficulties Experienced
- Initiative

The themes were collated and ordered to provide an understanding of the experiences of access to talking treatment from the initial referral onwards. All themes and sub-themes are shown in **Diagram 1**.

#### 2.1.1. Waiting Time

This was the predominant theme throughout the section on Access and included comments about the waiting time at both the referral and assessment stages in addition to the waiting time for talking treatment itself. Within this theme issues were raised concerning reasons for the wait, use of other services in the waiting period and other impacts of waiting on users.

## **Presentation**

Many respondents said it had taken them some time to first approach a professional and ask for help – often people waited for several months and a few mentioned periods of 10 to 20 years. A range of reasons were given for this. Some were unsure what could be done to help them or even if anything could help at all. Others said it had taken them some time to realise that they needed help and they recognised that their own lack of awareness about mental health contributed to their late presentation:

“I didn’t realise this was a major depressive bout setting in. It took two months I think to get the first appointment and even then it was more assessment. I need earlier and quicker intervention. I left it too late via my GP but I really did not understand the recurrent nature of my depression”.

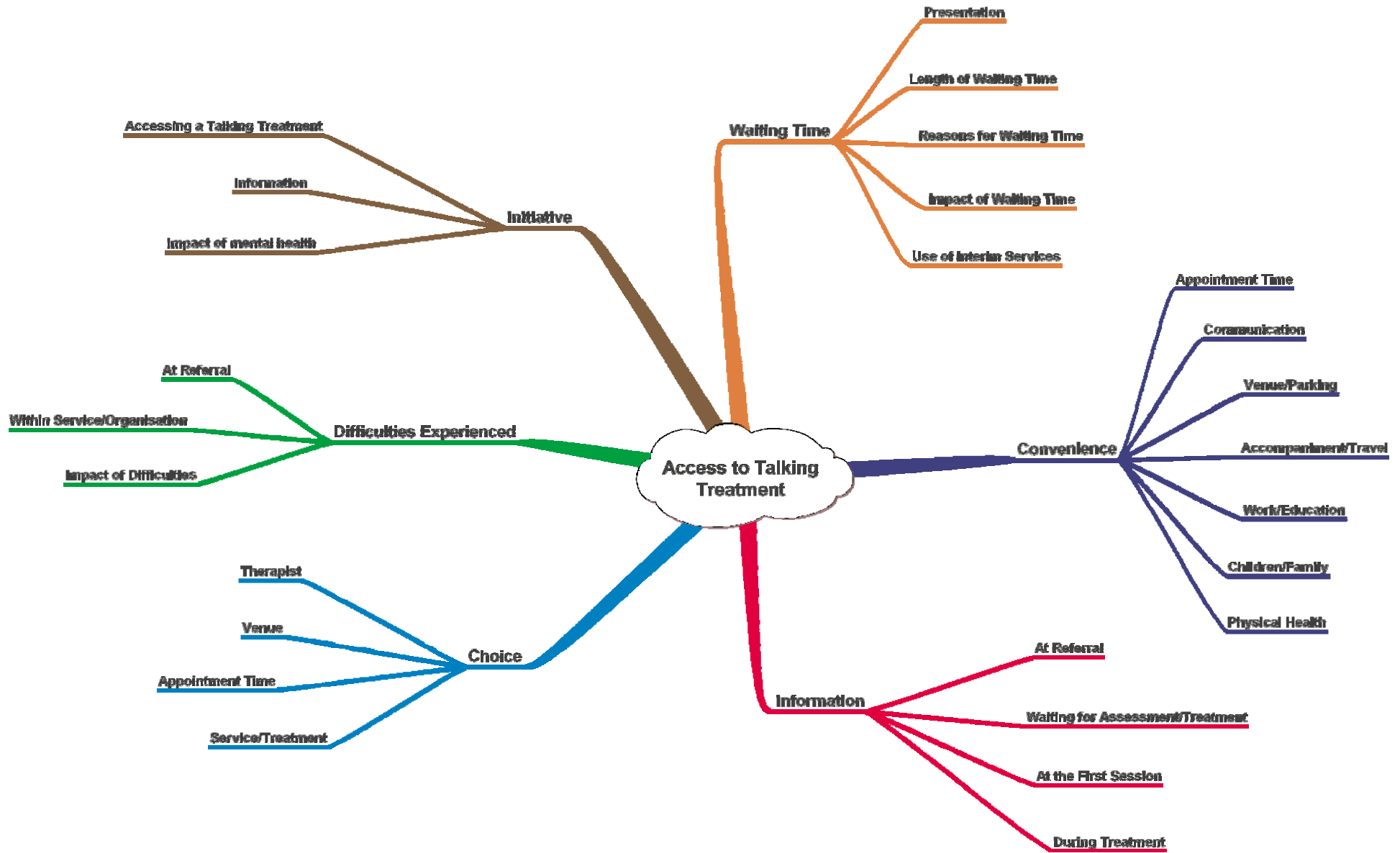


Diagram 1. Final thematic map of Access to Talking Treatment

"The difficulty was that I wasn't aware myself what my symptoms could mean, and therefore did not go to my GP soon enough. I had made my own 'diagnosis' and was thus reluctant to go to the Doctor - for fear of looking stupid, I suppose".

Some respondents said they felt fearful or lacked courage to speak about it. The stigma associated with mental health was specifically mentioned with several feeling embarrassed to admit that they needed help:

"In retrospect I should have asked for help earlier (but due to the "stigma" attached to mental health issues I was not comfortable requesting help)".

Others said they had felt too confused or depressed and had therefore not had the wherewithal to do anything. As a result, many were at a crisis point or "had hit rock bottom" by the time they spoke to someone:

"I suspect that I am not unusual in people who go to their GP with anxiety problems in that I did not go until my anxiety was severely impacting on my life and I was at a very low ebb".

Some blamed themselves for this:

"The understanding of my suffering from depression became noted at a point in my life which was really too late. Not sure this is anyone's fault but my own?"

"I had been suffering with depression for approx 6 months before I attended the doctor. Therefore, I was rather desperate for treatment once I admitted to myself that I couldn't cope without help. Once this was established, I wanted to get started asap. In hindsight I feel this was an error on my part, in ignoring my situation for so long and then expecting a 'quick fix' once I had".

The delay in seeking help often had an impact on people, with some later regretting they hadn't spoken up earlier. The late presentation then sometimes made the subsequent waiting time seem worse:

"It took me quite a while to find the courage to admit I needed help but then to find out that I would have to wait a minimum of 3 to 4 months before my first appointment was quite a blow".

## **Length of Waiting Time**

Most respondents commented on the length of time they had to wait to receive a talking treatment, with the overwhelming majority stating they felt they had to wait too long. Only a very few said they found the waiting time to be reasonable. Long waiting times were described at all three stages of the process – referral, assessment and talking treatment itself. Many users provided detailed information on the length of time they had to wait at all these stages. However, in some cases it was unclear whether they were referring to the length of time it took to be referred and/or the actual time on the waiting list after the referral to receive either an assessment or the talking treatment itself.

The waiting times to receive a talking treatment after referral were described as between two weeks and over five years. Most felt they should have been referred sooner, although there were mixed experiences. Some respondents received a

referral immediately whereas others waited for many years. One user poignantly stated:

"I am now 74, I should have been referred when I was 17".

Some participants received an appointment for assessment promptly but others said they waited for up to 13 months. A few confused the assessment appointment with treatment because they had waited so long. Other difficulties associated with assessment were mentioned, including having more than one assessment or having to wait for the assessment in order to then find out what treatment would be appropriate or beneficial:

"I had two assessment interviews before my sessions began; I was told that the second one was a further assessment which was frustrating. The wait before the first one was about 2 months then 9 weeks until my second assessment and a further 14 weeks until I began treatment".

"My first appointment I waited a month. It should be a lot sooner for your first appointment, as no-one knows how bad a patient is".

Several users expressed concern that although they were referred as "urgent" this was seemingly disregarded:

"It was months before I could be seen. I was desperate and feeling very low and so more vulnerable when I was referred as urgent and high impact, but nothing happened".

Respondents then described waiting a further period of time for the talking treatment itself, of between 14 weeks and 18 months:

"I was screened for Cognitive Behavioural psychotherapy treatment on April 2009. I then waited another 18 months for my first talking treatment session which was October 2010".

"I first sought help in January 2010 when I was referred. I then had an assessment interview in May 2010...and then my first appointment with a therapist was Oct 2010 some 10 months after being referred. For a 'fast-track' service this seems an awfully long time, an unbelievably long time".

There were differences in the length of time that users felt it was reasonable to wait. One thought a three week wait for their appointment was unreasonable whereas another thought a three month wait was reasonable. Only a few users made positive comments about the length of the waiting time:

"I self-referred from my GP. The wait for an initial assessment and the treatment was shorter than predicted".

"I was told about the IAPT service and self-referred. A manager rang me the following week. I was extremely impressed and very happy at this level of service".

However, many showed an understanding of the resource limitations, and seemed prepared to wait longer as a result:

“The waiting time was reasonable given that this sort of talking treatment is not a priority in the NHS”.

“Access is all about Mohammed coming to the mountain (institution). The institution does not have enough therapists and everything flows from that”.

Some were aware of differences in waiting times in different localities and others made comparisons with other services:

“Reference waiting time, I was told I was ‘lucky’ that I lived in an area where funding and access was fairly readily available within a few weeks as other areas of the country had to wait 8 weeks or more for an appointment”.

“If a patient is suffering from severe depression you need help when you need it, not when it is available; imagine the outcry from the public if they were to turn up to A&E and told to come back in six months time!”

Sometimes participants described getting appointments more quickly because they expressed concern about having to wait so long or there was a cancellation:

“Waiting time was too long – 5 months from when I saw my Doctor and 4 months from when I was assessed. It would have been longer (maybe another 6 months!) had I not got upset about the wait, at which point they put me at the top of the list”.

On other occasions professionals or family and friends advocated on behalf of the user:

“It took quite a lot of pestering my doctor to actually get a referral, it was a very long time until I had an appointment”.

“It was family who pushed the hospital for psychotherapy treatment. The psychiatrists were not very helpful and did not suggest I could use CBT. This came from my family”.

## **Reasons for Waiting Time**

A diverse range of reasons were given for the long waiting times. Referrals were usually made by the GP and prominent reasons for delays at this stage included “not being taken seriously”, a lack of awareness or recognition of mental health issues and/or available services, and a preference for prescribing medication over talking treatment:

“I had previously seen another GP at my practice at the beginning of this year – I am afraid he wasn’t very sympathetic to my situation and I was basically turned away and told to re-evaluate my lifestyle”.

“I was requesting talking treatment prior to treatment for 20 years. I have been on and off anti-depressants during those years and always felt that tablets were an ‘easy option’ for the Doctors to just get rid of me instead of dealing with the problem”.

Sometimes users self-referred and also a variety of other professionals made referrals, including Health Visitors, Psychiatrists, Psychologists and Community Psychiatric Nurses. These referrals highlighted additional reasons including waiting

lists being too long, inaccurate assessments of needs and misunderstandings about referrals:

“My GP said the waiting list was too long and would not refer me. I got referred by the Clinical Psychologist who was helping me diagnose my children's autism because I kept breaking down in our meetings”.

“Tried to call and register but was told to call back in two weeks as they'd had too many referrals! My waiting time got longer and longer. Initially it was to be 16 weeks, whereas finally, it was over 6 months”.

Often delays were due to practical matters such as not being able to attend the appointments at the times provided or the venue being too far away. This was particularly relevant for those who worked or who had mobility difficulties, who were forced into making a choice between a shorter waiting time or a convenient appointment time/venue:

“Appointment was very hard to get outside of work hours/within a good distance from my office. I had to go back on the waiting list twice when I couldn't accept the times given to me (one would have taken an hour from my flat and even further from my work!)”.

“Initial appointment was offered on a day that I had said wasn't possible. As I can only attend with assistance available to me on a particular day each week this delayed the initial appointment which was rescheduled”.

Often users cancelled other appointments, took time off work or travelled some distance in order to avoid having to wait for even longer periods of time:

“I waited a total of ten months for treatment. It takes me a total of 3 hours to travel to my session and another 3 hours back but transferring would have meant even longer to wait”.

Sometimes respondents asked specifically to see a certain therapist because they wanted someone of a particular gender or they had previously seen a therapist and wanted the same one again:

“Unfortunately because I had asked for a male psychologist I had a long trip to the [organisation]...if I had asked for a female she could have seen me in my downstairs clinic”.

“I asked to see the therapist who did my assessment as I felt comfortable with her. I waited a couple of months longer until she could see me”.

The level of experience of the therapist also had an impact on the waiting times, with users again faced with making a decision between a shorter waiting time or a more experienced therapist, if the choice was available to them at all:

“After waiting for an appointment for a long time, when I was in a desperate state of mind, I was offered an appointment to see a trainee therapist. I was told that the wait for a fully trained therapist would take months, so I took the appointment to see the trainee”.

"I waited 18 months for my CBT. I understand this is because in my psychiatric history I had an episode of psychosis and not all therapists feel able to work with this (in fact all my CBT concentrated on anxiety). I think it is wrong to have to wait this amount of time when others are waiting a standard 8 months, because of a certain condition you have/had. It is almost discriminatory".

The type of talking treatment affected the waiting time in a number of ways. If users were waiting for a group or course, there was often a delay while waiting for the next one to start and if cancelled an even longer wait. At other times respondents were again forced to choose between a shorter waiting time or a talking treatment of their choice and/or were constrained by when information on approaches was available to them:

"I am currently in group talking treatment only because it was the best option due to current restrictions on the service provided, which consisted of a limited number of 'one to one' talking treatment sessions. The waiting time for 'one to one' was quite considerable with no guarantees as to where, with whom or when".

"Information on what model of counselling is preferred by the client is not really available until assessment, which can lead to longer waiting times to get the particular type of talking treatment best suited to client".

Sometimes respondents were referred to a therapist or type of talking treatment only to find out that it was unsuitable and they then had to wait again for a new one:

"I could have been referred earlier but instead I was persuaded to do on-line CBT which I found no help. Once referred I had to wait months. It was well worth the wait".

"Referral from another counsellor to a new counsellor took ages to be sorted out".

Users also described delays caused by appointments being cancelled by the organisation or when workers left the service or trainees finished their placements:

"I was seeing a trainee when her placement finished. I had to wait 6 months for another appointment to carry on my treatment".

"I was unlucky as my therapist was leaving and I had to wait for a new one to be appointed".

Finally, a few respondents described having to go through the whole waiting process again after receiving a time-limited talking treatment that was too short for them or due to the talking treatment ending too soon:

"Both myself and my counsellor realised I needed much more but in order to receive it I would have to get another referral from my GP and join the bottom of a 10 week waiting list".

"I experienced a 5 month wait to see the first therapist. After 1 meeting it was assumed that as certain symptoms had eased, I was fine. Within 1 month I had to arrange another appointment. This was subject to a further 2 month wait".



## Impact of Waiting Time

Many participants explained the impact on them of having to wait to receive a talking treatment. They described feeling alone and isolated, distressed, frightened and desperate. One said they had felt abandoned and another that they had to put their life "on hold". Many described the waiting period vividly, explaining that it "felt like forever"; some said their mental health had worsened during this time:

"I think most people can't say how long the appointment is going to take and I feel we were clock watching all the time and I felt like throwing the clock at the wall".

"I feel that after 14 years of building up enough courage to talk about the abuse, having to wait almost 1 year for treatment left me feeling worse and I went into the treatment in a worse place than what I was when I initially went to the doctors".

Particular impacts were portrayed that included a worsening of both physical and emotional symptoms, becoming "entrenched" in the condition, a poor quality of life and the additional stress and anxiety caused by having to wait. Others described more profound impacts:

"Referral was initially in March. Appointment came through in August. In June I took an overdose and was hospitalised, therefore my appointment was not given at the right time. The waiting time was unreasonable. It may have been that if I had had immediate counselling, I would not have tried to commit suicide!"

"The treatment took so long to arrange that as a result I lost my life partner because she could no longer cope with the affect that my OCD was having on our relationship...and now I'm devastated".

"In order to get referred to mental health services from my GP I had to wait 9 months during which time I was so desperate I went to a charity-run [name of organisation] depression group. I was 'groomed' by the leader who then abused me".

Some described having to wait so long that their mental health had improved by the time they received treatment. A few even stated that their symptoms had improved and then worsened again by the time they received a talking treatment:

"I had to wait 14 months for my appointment and by then I was through one crisis but in another".

The waiting time caused a few participants additional difficulties with the talking treatment:

"By the time I was able to access the service my condition had temporarily improved, meaning that the way I presented at my appointment was not very representative of the reason I had sought a referral".

"I had to wait a long time for the whole process to get moving by which time I had started to get through the worst. When the appointment came through I had to rake the whole thing up again not what I necessarily wanted to do".

Most felt that earlier access to talking treatment would have been more beneficial – it would have enabled a quicker recovery and return to their daily lives, including getting back to work. However, a few expressed an advantage to the waiting time:

“Although it has been difficult to wait so long I feel that I am perhaps in a better position to benefit from the talking treatment as I am not experiencing an episode of depression at this current time and am more able to be proactive and try and work through things. In the middle of a phase of depression this can be too painful to do and I have difficulty focusing/concentrating”.

“I don’t know if I had been seen any sooner whether I would have been able to completely understand the course”.

### **Use of Interim Services**

Participants described using other services whilst waiting for their talking treatment. These included both services they were already receiving and new services they had specifically sought whilst waiting. Services from all sectors were cited – statutory, voluntary and private sectors. Voluntary organisations included Mind, Cruse and the Samaritans; NHS services included ongoing support from their GP and counselling from their GP practice. Users were appreciative of such services, sometimes feeling that they couldn’t have coped without them, although they felt they shouldn’t have been put in the position of having to use them in the first place:

“It took nearly six months from referral to getting treatment, during this time my condition deteriorated and I went into 'crisis'. Should I have not been in the fortunate position to gain treatment through Occupational Health at my work I feel I may well have ended my life”.

“I had to wait for over 18 months for my treatment to start. This is totally UNACCEPTABLE. Through my work I was put in touch with a private therapist who saw me every week for 3 months. Only this kept me in work and good through major crises in my life since I contacted my GP for help with depression as a result of traumatic experiences. I was let down by [place name] IAPT”.

Some participants found medication to be beneficial in the interim period, however, many were reluctant to use medication or raised difficulties associated with it:

“I waited about 4 months before getting sessions, so I had to start on a course of anti-depressants to cope, which I had **not** wanted to do. I am now having to deal with a terrible withdrawal from them, which is adding to my difficulties”.

“The right treatment took too long in coming! I was put on a strong anti-depressant!”

A few respondents explained how they were able to receive a short-term “holding” service from the same organisation they were on the waiting list with, but this appeared to be unusual:

“I felt extremely disappointed, frustrated and upset that I had to wait so long. I rang [name of organisation] several times over the months I was waiting for treatment and finally in August I was offered an intermediate ‘Step 2’ form of

treatment which I readily accepted. This was to help until my place on the waiting list for 'Step 3' came up".

"Support was given by the service during the waiting time, which I really needed".

However, often participants were unable to access any interim support because organisations were unable to provide the appropriate type of treatment for them or because of financial constraints:

"I tried Victim Support but was told I needed specialist help or to contact a Doctor or therapist".

"Due to the long wait for talking treatment I was forced to go to a charity, not being in the position to pay for a private therapist".

Private services in particular were discussed, with some participants expressing surprise at having to use such services:

"I waited 15 months on the NHS for my appointment. I had to go privately at first to see someone!"

"I had to wait 6-7 months for the treatment. As an anxiety sufferer this is completely unacceptable. I had to resort to private treatment in the meantime. There is no way I would have been able to wait that long. With anxiety every hour suffering is like days".

Usually no alternatives to services were offered by organisations but occasionally other suggestions were made:

"I initially requested referral to the psychological talking treatment service via CPN...told 'not to bother because the waiting list is too long'...advised to 'look elsewhere' in the meantime, ie. pay for it myself".

Informal support such as friends and family was also mentioned as helping during this time, although not everyone has access to this:

"The waiting time was about 7 months which was a long time. If I had not had some altruistic friends prepared to give me time, it could have meant I'd become very ill before I got to see the counsellor".

A few participants made suggestions as to what type of services would have been helpful to them whilst waiting. Ideas included an initial session "to make you feel help is on its way", a group or a drop-in service.

## 2.1.2. Convenience

This theme concerns the factors that effect how convenient the talking treatment was for respondents. It includes general issues such as the appointment time, venue and communication as well as additional matters such as work or physical health that can also influence convenience.

### Appointment Time

Mixed views were expressed about the convenience of appointment times. Some users experienced no difficulties with making and attending appointments, however many described a range of difficulties, notably available appointment times being limited:

“I would have preferred an appointment for earlier in the day. Mine was for late afternoon but was able to attend without difficulty”.

“My therapist was only available on one day in the afternoon”.

Respondents valued therapists being more flexible:

“The therapist has always been very helpful when I have had to change dates/times”.

“Therapist not always understanding about times of appointment. She would be very forceful regarding times and dates and this made me late for appointments, which she would make a comment about this change times without letting me know as well”.

### Communication

Respondents mentioned communication in a number of contexts. Some described receiving communication from the service while waiting, which included asking them if they still wanted to be on the waiting list. Sometimes this was described as helpful, sometimes not:

“From the date of referral, I had to wait approx 6 weeks for talking treatment to begin. However, I did receive numerous telephone calls prior to my treatment commencing to assess my situation which was beneficial”.

“During the wait I was called every 6 months or so if I still wanted to be on the list and to reply if I want to be left on the list. I felt they were trying to whittle down the numbers waiting on the list”.

However, usually no correspondence was received at all, leaving users not knowing what was happening, where they were in the waiting list or even if they had been forgotten about:

“I had given up about hearing from [name of organisation]. So it came as a pleasant surprise when I received the phone call to arrange the sessions”.

“The wait was long with no communication during the waiting period, so I thought I was no longer on the waiting list”.

Some respondents described receiving a letter or telephone call in advance of their first appointment. However, this sometimes was received with very little notice – in some cases only 1-3 days prior to the appointment and it was unclear to some whether the appointment was for an assessment or for the talking treatment itself.

There were other difficulties concerning communication during this period, as one user relayed:

“I waited 21 months from the initial referral to beginning regular treatment...what made this time particularly hopeless was that I was told, at the beginning of my second assessment session, that I would not be offered a place. Only after 15 months was I told that I could have a place. At the time, I was extremely ill, and possibly did not hold on to information I was told during assessment sessions. Therefore, it would have been useful to have had explanations in writing or to have had the therapist check carefully whether I understood”.

Some commented on the communication with their therapist, which was experienced as both positive and negative. Participants clearly valued a more “human approach” with the therapist themselves arranging the appointments:

“It is very difficult to arrange appointments when I don’t see my therapist – I have to leave a message at his office and then it takes a while to make an appointment”.

“What was very good though, was that I was telephoned to discuss what appointment time would work for me – not just for the first one but also on an ongoing basis”.

## **Venue/Parking**

Many respondents felt the venue for their talking treatment was too far away or difficult to get to, particularly if they had to rely on public transport:

“I wanted the appointments to be at my local clinic, this was not possible so had to go to different location which was not convenient”.

“I had to turn the first appointment down, as it was 43 miles away, I told them I wouldn’t be able to attend, and they did get me one nearer my home”.

Others stated they used a more local venue, such as their GP surgery, which was more convenient for them. Some mentioned additional difficulties such as anxiety or agoraphobia that meant a local venue was more convenient:

“I found the venue of the sessions convenient as they were at my GP surgery, so no travelling was needed. I think this is a really good idea to have at your local surgery as sometimes people find it difficult to travel and also going to a strange place for sessions can be off putting”.

“The venue is approx 1 hour from my house, I have difficulty being further than 10 minutes away from my house”.

However, having sessions at their GPs didn’t suit everyone and one user said they would have preferred the treatment in a different room from where they usually saw

their GP. Several users who were unable to leave their house had their talking treatment sessions in their own homes, sometimes by telephone only, which they found convenient:

“I had my appointment over the phone which suited me as I have a baby and travelling is hard, as I don’t drive”.

“I opted for telephone counselling sessions which was easier because I live in a very rural location and these have worked well for me”.

Some described difficulties finding the venue due to receiving poor instructions or unclear maps; others had difficulty getting inside the venue:

“Directions to centre needed to be clearer for people unfamiliar with venue and inside labelling – some couldn’t find it and staff didn’t know”.

“The location was okay to get to but it was quite stressful trying to get into the building as it was normally locked when I got there”.

Others raised issues connected with confidentiality or entrances being conspicuous:

“The clinic doors are quite thin and, as I can hear people's conversations outside, I don’t feel entirely happy that what I’m saying is private”.

“I don’t like the location of [organisation]. Standing in the middle of the High Street and having to wait to gain access to the building was a massive challenge for me the first time I arrived, I still don’t like it”.

Several users raised difficulties they had experienced connected with parking at the venue, either a lack of parking spaces or the cost involved to park somewhere close to the venue:

“Parking was a problem – as I thought I could park on-site. However not enough spaces for building and I had no money at this point in the week – so on the 1<sup>st</sup> session I was 20 minutes late as I didn’t know what to do! Embarrassingly, I had to borrow the £1.50 from total strangers! Very awkward position to be in!”

“Car parking is terrible. Either £2 to park for 1 hour on the street or £1.50 to park in the market car park and walk back. If these are busy there is little choice to park anywhere else”.

Respondents described feeling anxious about being on time and some went early for their appointments in order to find somewhere convenient to park.

### **Accompaniment/Travel**

Many users said it was inconvenient for them to travel to the venue. This was for a variety of reasons, including lack of available public transport, the cost of transport and reliance on others to take them:

“Difficult to get to location on public transport so until could drive again had to ask a friend to take me”.

"I was unable to get my appointments every week due to an hours bus journey there and back and it costs me £8.60 a week out of my benefits which is nearly £40 a month which is a lot of money as I only get £168 per fortnight and I have all my bills to pay which doesn't leave me enough money to attend the appointments I feel I need".

Some mentioned the traffic or outside noise caused them difficulties with travelling. Others had to walk or cycle to the venue:

"I have to walk for about 20 minutes to get the hospital at the time of my appointment – there are no buses. If it's raining I get wet! A real incentive to drag myself out of the house – NOT!"

"I live immediately opposite one of the surgery buildings in my local practice group, yet I have had to cycle between 8 and 10 miles to attend appointments at other surgery buildings in the practice then make the journey back. This is apparently due to there being no rooms/times available at the surgery 'on my doorstep'. As a result, I have been unable to attend some appointments, resulting in a sporadic, discontinuous service".

Some respondents explained that they experienced difficulties travelling because of their mental health, including agoraphobia, social anxiety disorder, general anxiety and other phobias:

"I have difficulty getting to my appointment because I cannot use public transport or taxis, because of my phobias, and I have to use my ex-wife or my support worker who are not always available to take me".

"In spite of my suffering from anxiety I am forced to travel to [town name]. This increases my anxiety therefore why can't home visits be arranged for counselling? It doesn't make sense".

Only a few mentioned that transport had been provided for them, including one describing her counsellor had driven them to and from the first session. One thought that perhaps "coping with travel there and back is perhaps part of the healing process".

## **Work/Education**

Many respondents described difficulties associated with their work, voluntary work or education. Of these, most were unable to get appointments at convenient times, ie. outside of the usual working hours of 9am to 5pm. They explained that as a result they were sometimes late for appointments or tired due to coming straight from work. Sometimes users had to return to work after their appointment, thereby making it hard for them to concentrate during the appointment or causing difficulties as they felt upset afterwards at work. One explained how their shift work made it impossible to keep an appointment at a regular time.

A few worked from home so were able to accommodate the appointments into their working days. However, most had no choice but to take time off work. They explained how this caused them to lose money or to have to make up the hours in their job at other times:

"The only time available to me was Monday afternoons which has made it quite difficult for me to take time out of work to attend. I am having to make up the time in lunchtimes throughout the week".

"The appointments were never early in the morning or in the late afternoon/evening, so I had to take some hours off from work. I work on a contract base and that caused me a little loss of money".

Some were unable to accommodate appointments at all and therefore either didn't receive an appropriate talking treatment or even made a choice to end their employment:

"Unfortunately due to my shift work and the fact that my therapist has been ill, I have not had as many sessions as I would have liked".

"The company I work for will not allow me to take anytime off. So I handed my notice in on [date] as I feel my treatment is more important than employment at the moment".

Only a few were able to obtain an appointment outside of working hours, and they had to wait longer with detrimental effects:

"My initial appointment was inconvenient because I was working full time and the appointment offered was during working hours. I had to wait until mid-June by which time I had become unable to work due to anxiety and depression".

"The date I was originally given for my first appt was at 10.30am. As I work during the day, I asked for the date to be changed. I did not get a warm response but instead was made to feel uncomfortable as is 'why would I be working'. After some persuasion, I was given an alternative time for later in the day which fitted better around my work".

The majority of respondents described additional problems related to stigma or simply not wanting to disclose their mental health difficulty to either their employer or work colleagues:

"I have to take time off work to get to my sessions which is uncomfortable as I have to either explain why to colleagues or lie. It would be good to have access to services out of work hours".

"I work a 9-5 and am very reluctant to expose myself to mental health stigma by informing my employer that I need to take 2 hours leave from a working day to see a CBT therapist".

Only a very few specifically mentioned that their employer had been helpful:

"It would have assisted if there has been later appointments as it was necessary to take time off work – although my workplace was helpful in this respect other people may not have been so lucky".

"Although it wasn't too difficult for me to attend sessions through the day, as the Company I work for are very supportive and have flexible working, this could be harder if an employer was not as flexible".



It was suggested that the majority of services made the assumption that users weren't working:

"It appears that it is assumed that anyone in need of IAPT services will not be working, but some of us do try to continue working...Saturday morning appointments or appointments outside of 'office hours' would be much more helpful and eliminate the need to have to advise employers who may not be very understanding".

## Children/Family

Several respondents described having family commitments which meant they faced greater obstacles to access. Sometimes they mentioned additional details such as family members with disabilities, difficulties travelling with children or lack of childcare/being unable to afford childcare:

"Despite filling in travel expenses forms, I never received any help or funding for this. Found it difficult getting a babysitter for my daughter while attending the CBT sessions again, I had no help or funding for this".

"I care for two disabled children my appointments **have** to work around them. My world revolves round my children. **The appointments will as well. No exceptions**".

## Physical Health

Some respondents raised additional issues connected with their physical health or a disability. These were related to travelling to the venue, the venue itself and the time of the appointment:

"Just the fact that I'm physically disabled and O.A.P. and there is no transport available. Public transport is out of the question and so my weekly appointments cost me £10.00 minimum. I don't mean to sound ungrateful but that does amount to £40.00 per month".

"I have been in group sessions in the large room and the acoustics are not good for someone hard of hearing like me. Noise of traffic and the air conditioning make hearing aids ineffective. Small rooms for one-to-one very good".

A few respondents specifically mentioned being wheelchair users and relayed mixed experiences. Some found the venue to be very accessible, others had a different experience:

"The facility is not fully wheelchair accessible The entrance is on a steep, downhill slope The main door is very narrow, as are the corridors and inside doors".

"The parking at the venue is **awful!** I am a wheelchair user and need access to a space where I can get my chair out too which makes it even harder, especially as staff from the building have a tendency to park in the one disabled space and almost all other spaces all day".

### 2.1.3. Information

This theme discusses issues connected with information, from the point of referral onwards. The majority of users stated they had received little or no information at the earlier stages of the process, in particular prior to starting their talking treatment.

#### At Referral

At the referral stage, users were given minimal information about the types of talking treatment available, what approach they were being referred for or how it might help them:

“When I finally went to the GP all he said that perhaps a course of CBT might help me – I had no idea at the time what CBT could do for me”.

“I was told it would be counselling but didn’t know what it was”.

Some acknowledged the lack of information was because their GP was aware that they already knew what was involved. However, most commented that they would have appreciated much more information at this stage, including written information in the form of leaflets or similar.

Some users were unsure why they were being referred or what they were to expect and in one case, the user said it had not even been made clear that a referral had actually been made. Sometimes the referrer had provided information about how long the waiting time was, which was much appreciated by users. However, this often turned out to be incorrect:

“I was told it would be **12 weeks** to start treatment but it was about 9 months”.

“My waiting time got longer and longer. Initially it was to be 16 weeks, whereas finally, it was over 6 months”.

#### Waiting for Assessment/Treatment

Several respondents specifically said they would have liked to have received information in advance of the assessment so they would have had a better idea of what to expect in that first session:

“I had no idea what to expect when I went to my initial appointment. Therefore I was extremely apprehensive. What I did not know was the way that it works. Am I going to be asked lots of questions? Do I have to answer? A short talk explaining, to take away the fear would be very helpful”.

“I did not totally understand what talking therapies was all about and I had a panic attack when first contact was made”.

While waiting, users sometimes received more information about the therapeutic approach and structure of sessions but most said that it was still insufficient:

“I received a very basic info pamphlet outlining what IPT is. Looking back I think having a more detailed outline of how the 16 week talking treatment would take shape may have been very helpful in order for me to be more

reflective on how the talking treatment would evolve and what structure it would take on a more personal level”.

“I didn’t receive enough information about my treatment. The information provided was not detailed enough regarding the sessions and what was involved in the process”.

Some explained that when they were told the date and time of the first session, they had also been given further information about the more practical aspects of the treatment. This included the venue, name of the therapist and how long sessions would last for. However, such practical information was also fairly limited:

“I would have liked it have been told how many sessions I could potentially have as I was worrying that I would only be given 6-8 when in fact I have now been told I could have up to 18-20”.

“I received no information about my treatment other than details of my first appointment (date, time, location etc). It would also have been useful to receive information on how to contact or who, should I need to cancel an appointment. I would have welcomed as much information as possible prior to starting my treatment”.

This waiting time after the referral and before the first session was a particularly difficult time and many respondents highlighted the importance of information during this period:

“The letter that I received after my telephone assessment and prior to my first talking treatment session was very useful, reassuring and informative”.

“Would have liked a leaflet, perhaps with related information and maybe a follow up letter saying ‘we know your there and the wait time is’”.

However, only a few actually received information during this stage. One had found a taster session prior to starting a course very useful. Others suggested that leaflets, information sheets or letters before the first appointment would be beneficial.

### **At the First Session**

It wasn’t usually until the assessment or first session of talking treatment when respondents received much more information regarding the therapeutic approach, the number of sessions, etc. Most found the initial sessions to be valuable in providing information and positive experiences were relayed:

“The literature for the talking treatment was very good, and I spoke to a therapist from [name of organisation] who talked me through the therapies I was to undertake”.

Usually information-giving was done verbally and a few users explained they would have also liked written information to take away. Some welcomed the opportunity to be able to ask questions:

“I didn’t have any information about my group talking treatment prior to it starting but when I went for my assessment, the assessor told me all about what to expect and she answered my relevant questions too”.

"I had no real idea who I was going to have the treatment with – was it a psychiatrist, a psychotherapist, a nurse? Or what their qualifications or background were? I did however ask these questions at my first appointment and these were answered in full".

However, a few described difficulties they had experienced at this stage, including a lack of information about how the sessions would run:

"During the first session I was dissuaded from asking any questions about the therapist or what the treatment would involve. At the same time it was made clear to me I would have to commit to a full year's talking treatment".

"I had a lengthy telephone assessment first which I found difficult but no information about how the talking treatment would follow".

## **During Treatment**

Several respondents identified a need for information to be provided on an ongoing basis during treatment. They explained how it was difficult to take everything in at one go and described how their mental health contributed to them feeling confused or not being able to think clearly:

"Not sure what information I was given – nothing in writing. Due to the condition I was in I don't feel it appropriate to give info once and verbally. Need to check back with service users about what they think they need to know. As time goes on these needs may change and need new info".

"At the time, I was extremely ill, and possibly did not hold on to information I was told during assessment sessions. Therefore, it would have been useful to have had it in writing, or to have had the therapist check carefully whether I understood".

Other information needs were identified and included the importance of information being jargon-free and understandable. The importance of providing information on what the options were after the planned treatment ended was also mentioned. One respondent raised the issue of information about claiming travelling expenses:

"I was only told at the end of my treatment that I could reclaim my bus fare. This would have been very helpful if mentioned at the start or if some sort of notice was in the notice board. I'm on benefits at the mo, so this would have helped".

It was acknowledged by several users that information needs would vary according to the individual. Some respondents already had some knowledge of talking treatments and what was entailed due to prior service use or working in mental health.

Unfortunately, it seemed that for some users information difficulties continued throughout their talking treatment:

"I still don't know after completing 12 sessions this time what I was suppose to take to the sessions or get from them".

"When I asked about the process of group talking treatment, I wasn't told anything about it, rather my therapist felt that it should be an organic process. The problem is that over 2 yrs into my group talking treatment and it's still an area of contention in the group on how group talking treatment should work/run. I am still unsure".

#### **2.1.4. Choice**

Choice impacted significantly on the waiting time as previously shown. A choice of anything connected with receiving a talking treatment, if a choice was offered at all, often resulted in a longer waiting time for the user.

##### **Therapist**

Several respondents said they would have liked a choice about which therapist they saw, in particular they would have liked to have seen a female therapist. However, often they weren't offered any choice and were also sometimes reluctant to raise the issue themselves:

"I am a woman and I think I would have responded better to a female therapist. I should have said so at the time".

"Was not asked if I minded a male therapist when my problems are hormone related and I feel it's pointless and I feel uncomfortable discussing in detail my issues. Would not have chosen a male!"

Others specifically requested to see a therapist of their choice for other reasons, including having already established a relationship with a therapist previously or when they had concerns over the therapist's training or experience:

"I was initially told there was an eight week waiting list however, I requested to see the therapist I'd had last year and was told this was not possible. I explained I was prepared to wait. Shortly after this telephone conversation I was contacted by the same person to say it would be possible to see the same therapist providing I didn't mind waiting longer than eight weeks, which I agreed to".

"The wait was months, and when I asked about the therapists training and approach, I found out that another one might have suited better. After such a long wait for the first appointment I would have been too scared to change and wait all over again, so there was no choice really by that point".

##### **Venue**

Several respondents described how they were offered no choice with regard to the venue or location:

"The first appointment could have been made at a more convenient location: no choice was offered, although the therapist visits different locations".

"Was not asked or offered any other sites to go. Found out that others were available after being told there no other site that my therapist went to".

Sometimes receiving a therapist of their choice meant that respondents had to travel further to see them:

"I felt I had no choice with the location because I wanted a female therapist and therefore I had to travel a very long distance to get there which I didn't think was fair".

Only one relayed a more positive experience:

"The venue was chosen by myself from a selection available on the basis of the venue being accessible to get to".

## **Appointment Time**

Several respondents described having no choice whatsoever over the day or time of their appointment. Some were told that if they didn't accept the appointment time then they would have to go back on the waiting list or could not see anyone else:

"I wasn't given a choice of day/time so I had to cancel other things as they said if I didn't take this appointment I would have to go back onto the waiting list".

"There was no choice in date or time just Wednesdays 9.30am".

Some were offered an appointment time which they were unable to make. This meant that they had to either ask for a different time, take time off work or cancel other appointments in order to accommodate it:

"I turned the first offer down because the offer was in working hours and I had previously been counselled at a time convenient to me. Was I being unreasonable? Should I have been thankful for my offer? I could have avoided some stress by accepting that offer".

"I wasn't given a choice of appointment, and it wasn't possible to have an afternoon appointment which would have been more beneficial for me because I don't like to go out so early in the day as I need to stay in bed longer and am very slow in the morning. I had to cancel some appointments because I couldn't get there in the morning".

## **Service/Treatment**

Many respondents stated that initially they had no choice but to take medication as a talking treatment wasn't offered to them. After a period of time or due to taking the initiative themselves, they were then offered a talking treatment:

"I kept being told the service was very over-subscribed and that I would need to be on anti-depressants for longer despite taking them on and off for 5+ years".

"I was only referred to this service after asking for help in dealing with my problems as in the past I had been only given tablets as an option. I feel that for someone of my age (23) who is struggling with anxiety, not depression, a talking treatment is a much more useful tool to avoid future problems in life".

Furthermore, often there was no choice in the type of talking treatment, whether that was between group and one-to-one talking treatment or a choice between different approaches:

“I don’t think the CBT was for me at all. I think I was given this because nothing else was available at the time”.

“9 month process – quite appalling! For me, better to have begun one-to-one immediately. Would have been good to have had the discussion myself about whether I felt group/one-to-one appropriate”.

This sometimes resulted in referrals to inappropriate services. In some cases, users were not provided with information to enable them to make informed choices at the referral stage and were therefore unable to identify other more suitable treatments until some time afterwards:

“I was only offered one form of talking treatment, other treatments may have been more useful (stress management, relaxation) but not offered or discussed as option”.

“I was only told I could have phone appointments. After 5 or 6 weeks of pointless phone conversations I was finally told there were other options”.

### **2.1.5. Difficulties Experienced**

Various difficulties, including some serious errors, were described by respondents at all stages of the process and are discussed in this section.

#### **At Referral**

At the referral stage various difficulties were described by users. These included referrals not being made properly initially or professionals “forgetting” to make the referral:

“The psychiatrist I saw failed 3 times to refer me: he forgot to refer me when I saw him, he forgot to refer me when I phoned up several weeks after seeing him to see what was happening, he failed to refer me after I hand delivered a letter asking what was happening”.

“My main difficulty was with the GP who really had no idea where to refer me to initially. He was clearly very uncomfortable when I outlined I need help with dealing with sexual abuse that was triggered by a case at work”.

Administration errors were cited, such as problems with computers and referrals getting lost or being sent to the wrong place. This necessitated referrals having to be made again:

“I was originally referred to the service in Feb 2010 but did not get to see a counsellor until Oct 2010. This delay was due to a computer failure at the GP surgery”.

"I didn't hear a word about the treatment for weeks and when I spoke to my doctor about it she said I'd obviously slipped through the net and went about getting me a quick appointment".

Problems with communication between different agencies were mentioned:

"Miscommunication between GP and service".

"The transfer of information was poor from [one service] to [another service], which made the process more distressing than it needed to be".

Respondents were given incorrect information regarding the length of time they would have to wait to receive a talking treatment:

"I was told that my 'urgent' referral would be in 3-4 weeks (I was having regular suicidal thoughts). It was 14 months before I started treatment".

"I waited 18 months to see a therapist. Initially I was told it would be 8 months".

Several respondents experienced the referral process as time-consuming and were passed from "pillar to post":

"I found the process of accessing the treatment long-winded and unnecessary. I wanted to use 'Beating the Blues' but needed to have a referral. I rang up [name of organisation] who said I couldn't self-refer and had to go the GP. I went to GP who didn't even know about the [name of organisation]. Got the referral".

"I was asked by Early Intervention Service to self-refer. This was firstly a mistake from this service. I was then referred back to them after seeing the [another service]. Then referred back again. Took a long time before I was properly assessed".

### **Within Service/Organisation**

Once a referral was received by the service or organisation, further delays were sometimes experienced before the user received an appointment:

"There was an administrative hiccup at [name of organisation]. Consequently a substantial amount of time passed between the first telephone interview and the actual referral for a first meeting...service later apologised saying my paperwork got stuck in an in-tray".

"Due to clerical errors (wrong address **and** telephone number) I was nearly discharged before I knew I had been given an appointment!"

A wide range of problems were experienced with appointments themselves. These included appointments being cancelled or offered at short notice, being double-booked or provided at different times than originally agreed or correspondence going astray:

"I turned up for my second appointment to be told my counsellor had changed it to the following day without informing me. They said they didn't have my telephone number, despite the fact I am in the phone book!"



"I had to wait 5-7 months for my talking treatment and got sent a letter to cancel appointments I hadn't even been offered".

Several respondents described other communication difficulties such as not being able to get hold of workers or telephone calls not being returned. This resulted in users having to contact organisations several times:

"They state they were unable to get hold of me, so sent me a letter instead. The letter was the first contact I had actually received from them. When I contacted them and left messages, they never got back to me. I ended up being passed from pillar to post (I cannot remember exactly all the details, however I do recall calling one number, being told to speak to another office to reach a certain individual, so calling that new number, only to be told that I had been misinformed as that individual was not based there at all)".

"Received a letter informing me to make contact within three weeks. First call I made I was informed the person(s) I needed to speak to were not available that day. So I rang again 3 days later, was told the person to speak to was on the phone and they would ring me later that day. I am still waiting for the call".

Sometimes respondents were actively refused treatment by organisations, often because they were regarded as "too severe to treat or not poorly enough" or they were already being seen by one particular service and therefore couldn't also be seen by a different service:

"I was referred to [name of mental health NHS Trust]. They concluded there was nothing wrong with me purely on the basis of a GP letter of referral. I complained and it ended up with the Ombudsman...Ombudsman concluded that this wasn't right but outcome was I was denied treatment. I referred myself to GP again requesting IAPT/Beating the Blues, was referred and assessed and accepted with mild/moderate depression".

"The people who carried out the initial telephone screening had obviously been instructed to 'filter out' anyone who did not appear to have 'sufficient' mental health problems. The first time I was referred, they managed to persuade me that I did not need talking treatment, but I really did. It was only when I returned to my GP for the second time that I eventually got a successful referral".

Only a few users spoke positively about the way errors were handled:

"My information was misplaced and I had not received any holding letters. When I did contact the Manager I was very impressed with the way it was dealt with. He was quick, understanding and resolved the problems within days".

"I waited over 6 weeks to be seen. When I contacted the doctors they said they had referred me and gave me the IAPT number. When I rang them they said I had not been referred but they would sort it out, I was contacted the next day with an appointment".

## **Impact of Difficulties**

Users explained the impact that these difficulties had on them. They described the additional distress caused and sometimes referred to their mental health becoming worse as a result:

“I was recommended for counselling talking treatment as an urgent case from my GP. She gave me a basic leaflet on [name of organisation]. [name of organisation] lost her first request and I had to chase it up myself...I turned up for my 2<sup>nd</sup> appointment to be told my counsellor had changed it to the following day without informing me...I have left [name of organisation] further stressed than when I started”.

“I had to follow this up several times and ask my doctors surgery to re-send the referral. Finally someone at [name of service] finally took ownership of the problem and established that they had received the original referral. I even got a letter telling me I had failed to send information. I found this very stressful and frustrating at a time when I was already distressed. Some of the admin staff were very uncaring”.

Others felt that the difficulties and errors reduced their level of confidence in the service to be received.

### **2.1.6. Initiative**

Many respondents described having to take the initiative themselves in order to deal with any delays or difficulties when accessing a talking treatment or when seeking information.

#### **Accessing a Talking Treatment**

At the referral stage many users described not being offered a talking treatment and having to ask for it themselves. Sometimes they had to ask several times over a period of time before a referral was made:

“Although I had been through a traumatic experience and my GP was aware of this, I was not offered counselling on returning home from hospital and had to ask for it”.

“I had to keep pushing to be referred for the appropriate treatment...the psychiatrist I saw failed 3 times to refer me”.

Others referred themselves or found they had to follow up referrals after having been waiting for some time:

“I referred myself to the mental service after reading an article in a magazine published by my local council”.

“In the end it took a lot of chasing and implementing by me to ensure the referral”.

Respondents explained that they had to sometimes be quite forceful in order to gain a referral. They used words such as having to “push” for talking treatment or “demand” it:

“I also had to convince doctors and staff that I was worthy of treatment”.

“At crisis point so I kept RINGING”.

At the later stages of waiting or dealing with appointments respondents described similar experiences:

“The wait for treatment was too long. The wait for initial assessment was ok but I had to call to nag for both. I don’t know how long I would have waited if I hadn’t kept calling”.

“I just got told counsellor will call you for your next appointment. I had to call them 5 times to find out the woman was ill”.

## **Information**

Sometimes users took the initiative in order to get information about talking treatments. This often involved going to libraries or using the internet:

“Didn’t receive any information at all, but I had done a lot of my own research so I know what the treatment was about”.

“I was on the NHS website and found information on the talking treatment”.

## **Impact of Mental Health**

It was often difficult for users to take the initiative in the ways described because of their already existing mental health difficulties:

“I made the brave step of asking for help and then obstacles put upfront of me. When you suffer with severe depression you do not and are not in a responsive frame of mind to keep asking for help”.

“I am not sure how [name of organisation] expect people with depression to cope with these kinds of obstacles. I could barely get out of bed, let alone call various phone numbers, only to be told I had to call somewhere else, over and over again”.

Some felt there must be others worse off than them so considered themselves not as deserving. Others were unable to ask for a referral or information because they lacked confidence or motivation, or felt this may be them in the future:

“Many people with depression would not have the energy to go back after denial of service and would deteriorate. The process of being denied service was itself very hard to deal with. An anti-service”.

“I felt so low when the GP would not refer me that I put up no objection/resistance, I just accepted that nobody was going to help me”.

Others believed that as a result:

“a considerable number of people fall through the net – give up”.

## 2.2. Outcomes of Talking Treatment

Seven main themes were identified in this section:

- Sessions
- Therapist
- Talking Treatment Approach
- Structure and Format of Talking Treatment
- Personal Factors
- Talking Treatment Outcomes
- Alternative Services

Respondents commented on a wide range of issues related to their talking treatment in general and therefore this section is not restricted to discussing outcomes but takes a broader approach. It therefore includes any comments related to the talking treatment received from the start of the treatment onwards. The themes are illustrated in **Diagram 2**.

Many respondents had difficulty answering some of the questions on Outcome in this part of the questionnaire as they felt they hadn't received enough sessions in order to be able to make an adequate judgement. These comments have been disregarded.

### 2.2.1. Sessions

This was a prominent theme in the Outcomes section and included comments on the number, frequency and length of talking treatment sessions as well as other related issues.

#### Number

The predominant issue was the majority of respondents feeling they hadn't received enough sessions of talking treatment. Many received only a small number of sessions, typically 6 or 8:

"I cant believe that 6 (or 12) sessions turn around depression (assuming many clients must be depressed, if not more so than me). Right number of treatments? I cannot believe anyone will even begin to resolve depression and life long patterns in this period".

"I have been told I've had my 'quota' of sessions. I'm probably experiencing the most difficult period of my life so far. Since I've had my 'quota' then I've been signed off...what is the point of the service if you are kicked off the list when you have had a number of sessions and not when you are deemed to be able to cope with issues/life etc?"

Some described in detail how they needed more sessions to allow them time to develop a relationship with their therapist or to deal with the complexity of the issues that took them to the treatment in the first place, often described as "opening a can of worms":



Diagram 2. Final thematic map of Outcomes of Talking Treatment

"I believe I am only entitled to 8 sessions (of 50 minutes each). I do not believe that this is sufficient. It's taken at least 4 sessions for my therapist to get a proper picture of what I am like, and my current situation. My issues are very intricate. I have been on anti-depressants for 10 years. I cannot be 'fixed' in the next 4 sessions. I believe it will take far longer than this. I will most probably get onto the right path, but by this time it will be the 8th session".

"My NO's are all about the duration of the treatment, which I think is completely inappropriate. I had 8 sessions, which means I am no longer in treatment. I feel I did not have the opportunity to make a strong and trustworthy bond with my therapist, which would have enabled me to feel safe enough in order to share and explore my issues in a more profound and effective way. I would like to say, as a professional of this area (I am a Psychologist myself) I find that to offer 8 sessions is not worthy for this kind of treatment, where a strong bond between therapist and client is essential. **I am aware that the main concern of the service is to reach the most possible number of people, however I think the people in charge of the service should ask themselves what goal they really would like to achieve: the most great number of people or the effective help and heal of that very same people**".

Others received a greater number of sessions, but still felt it wasn't sufficient. Some specifically mentioned the NHS services they had received and felt the emphasis was on finances not need:

"6 half hour sessions is all I can access on the NHS. The first 5-10 minutes is taken up with answering PHQ9 questions and audit questions every session (if you refuse you don't get another appointment). It isn't remotely long enough to form a good therapeutic relationship never mind deal with complex longstanding issues".

"Given a) limited number of sessions and b) narrow focus of therapy; I sought further support from a therapist privately despite the financial struggle this entails as I felt I needed longer term more in-depth support to fully deal with my issues. This was not possible through the NHS".

Some respondents felt they were unable to say at the beginning of their talking treatment how many sessions they might need.

"I would say that most people would have no idea of the time they need to work through their problems. So to state at the beginning that you will receive 12 sessions does not mean anything until you get to 12 and realise you need more".

"I would prefer a bit longer. When you are asked at the beginning what you would like to achieve, you don't actually know the process and so unable to identify what is possible to achieve".

Several commented that they felt there should not be a time limit to the number of sessions but that the number should be based on the individual and their particular needs and some users had in fact received extra sessions on this basis:

"I feel this treatment should not have a time limit. I do understand this treatment cannot go on forever, but feel putting a year limit on it is very

restrictive especially when some appointments cannot be attended through various reasons, such as therapist's holidays and childcare difficulties. I think it would be better for the individual therapist to set the limit along with the service user as some may need longer but some may well need less time".

"My therapist has extended the number of treatments I can have as it has taken me a lot of weeks to reach my now 'workable' state".

Some felt embarrassed to ask for more session or said they would feel guilty for "taking up too many sessions". Others could understand the lack of resources and constraints that affected services and organisations:

"I feel I would like more sessions for longer but appreciate the service is under pressure to reduce its waiting time for new patients".

Some users described particular situations regarding the number of sessions they received that they felt were unfair. One raised the issue of concurrent medication and said that while taking anti-depressants it appeared that they didn't have depression and therefore was only allocated a limited number of sessions. However, if they were to stop taking the medication then they would become more unwell. Another made the point that if they were unable to attend a session then this still counted towards their total number or sessions from previous therapies also counted:

"I had to miss a session as my child was ill but you but you LOSE that session rather than have it at another time. I am a carer for my daughter so this could have eaten substantially in to my sessions".

"First session of therapy, the sort I was having didn't work. Now having CBT, but they counted number of sessions as started with first therapy. I would have liked to be told at the start that I was having so many sessions and it would be less as this was the second therapy".

Sometimes users commented on the viewpoint of their therapist or the negative impact on their therapist of a limited number of sessions:

"I get the impression that our therapist is frustrated by the imposition of time limited therapy and she does not believe it helpful".

"Sessions were stopped (because I had the max number of sessions allowed) when I and the therapist thought I still needed help".

Only a very few respondents said they had received enough sessions:

"My counsellor was extremely supportive and never made me feel that I only had a certain number of sessions available to me and when they were completed I would be left to manage as best I could. I genuinely felt that my treatment was centred around me and not a pre-prescribed number of sessions. This in itself has been a great help".



## Frequency

Some users described receiving sessions once a week and felt this was most suitable for them. However, many received less and would have preferred them both more frequently and more regularly:

“Once a week would make it much easier to keep continuity but the therapist is fully booked”.

“I received treatment very occasionally once every 5 weeks. Sometimes once every 3 weeks. It's not enough and very irregular treatment”.

Users felt that irregular or infrequent sessions impacted on the treatment they received, mainly disrupting the continuity of sessions:

“The one-to-one NHS therapy was not on a regular basis and therefore didn't ‘flow’”.

“I feel that once every couple of weeks is not quite enough. I **wish** it could be ongoing as I emotionally have continuous up and downs”.

Sometimes respondents wanted sessions more than once a week, particularly in the early stages of treatment:

“Once a week is at times not enough. I would prefer some flexibility – perhaps twice a week for the first three months (from a year's treatment). Maybe there should have been more dialogue over frequency and intensity”.

“Ideally I would prefer more intensive treatment, ie. twice a week, but this was refused”.

A few users described their therapist as being flexible with the frequency of sessions and/or phasing the sessions out towards the end:

“The person I see is very flexible and does accommodate to organising the right interval between sessions”.

“A phased reduction of sessions from weekly, to monthly and then to quarterly, although not the standard practice, this really helped me. I think it should be considered for others”.

## Length

Several respondents described receiving sessions that they felt were too short. A few of these were an hour in length but others described sessions that were shorter:

“The time allocated was ½ hr which I found quite rushed as there was a lot of paperwork to go through and little time for discussing difficulties which have arose whilst using these techniques”.

“As its only telephone for 30 minutes, it doesn't feel enough is covered. I'd prefer face-to-face 1 hour sessions”.

One recounted sessions that were only 15 minutes in length:

"I have found at the moment that I have been worse since starting the treatment. I find the therapist is rushing through my treatment and I have had appointments that only last 15 minutes".

Group sessions or courses were also mentioned. One user explained how her course had been shortened to 1½ hours from the more preferable 2 hours. Another mentioned specific health difficulties that made shorter sessions more inappropriate:

"I feel the session length is too short at 50 minutes. I suffer from severe chronic anxiety and would benefit from longer sessions so I can take more time to focus on trying to help myself during my session. It may take 20 minutes just to lower my anxiety levels to a point whereby I can concentrate".

One described how difficulties getting into the venue caused appointments to be delayed. Another felt the short sessions were the fault of her therapist:

"At times I feel my session is rushed due to my therapist's poor time keeping. 1 hour is not long enough".

## **Venue**

A variety of comments were made concerning venues. Some made positive comments – they felt the venue was comfortable, safe, peaceful, quiet and clean:

"I do feel from when I enter the centre it has a calming affect, I feel relaxed I find the people friendly but not over-friendly, very professional".

"The venue is a very lovely place to attend. Very welcoming and discreet. Staff are excellent and really love their job which filters through in the atmosphere".

The waiting area or reception was described, with suggestions made for a drinks machine and friendly welcoming reception staff:

"Would have been nice if there was someone to greet you. Waiting in an area which is unfamiliar with strangers can be very daunting and exceedingly stressful. When stress levels are already really high".

"I have seen people come into reception, who are treated with disdain and disinterest. The staff here are just 'ticking boxes' to justify their jobs. No interest at all. Disgusting!!!"

Negative aspects to the venue were described, with some users stating it was depressing, uncomfortable, the rooms were too small, the environment was too medical or clinical and they often used different rooms. Some respondents disliked using their GP surgery or an office:

"I would have preferred more relaxing surroundings, instead of a hot "grotty" office with bits and bobs and files and shelves on display. The ambiance is pretty poor".

"The rooms used are very cold, I don't mean in temperature but decoration. I feel the rooms could be made more comfortable. When we are escorted to the rooms it's almost as if we are being taken to the broom cupboard".

Several participants made particular reference to the GP surgery where their sessions were held:

“The room allocated at my Doctors surgery was very hot and stuffy, I think I was getting very hot and bothered talking about myself”.

“I do feel that a **busy** Doctors surgery isn't the place to hold sessions like these. My therapist and I were quite often put in a side room which was tiny and very unprofessional especially sat amongst blood files and leaning on a couch reading!”

Some experienced particular difficulties related to their physical health:

“The acoustics are not good for someone hard of hearing like me – noise of traffic and the air conditioning make hearing aids ineffective”.

“I have arthritis and have difficulty getting out of low chairs. I explained and was given a computer chair which had wheels. In the following appointments I was still given the same chair which made me sat upright whilst the therapist sat low on the easy chair. This didn't give me much faith in the therapist if she couldn't see the situation”.

Particular aspects to the rooms were mentioned. One suggested they should have a box of tissues available. Another disliked the ticking clock in their room. Someone else commented on how hard it was talking to their therapist with their back to a bright window so it was “like talking to a silhouette!” Confidentiality was a consideration for some:

“The venue was a tiny room off the main waiting room so I was very conscious that people may be able to hear what I was saying. It was not a very comfortable environment in which to talk”.

“Each time I arrive I have to check in on a computer screen, which than shows that I am receiving mental-health counselling. This screen can be seen by any other patients in the waiting room. I find this a breach of my privacy”.

Several respondents made suggestions for improving venues:

“Some thought should be given to the environment where we have the session, ie. brighter, more uplifting, perhaps even the nature of them, ie. not necessarily sitting in a room; perhaps a private/secluded garden outside in the fresh air. Refreshments offered so the mood is more relaxed than clinical”.

## **Follow-up Sessions**

Several respondents stated they would have appreciated receiving follow-up/top-up sessions or a review after their main talking treatment sessions finished:

“I think it may have been useful to have had a couple of consolidatory sessions about 2 to 3 months apart just to check I was progressing well and not slipping back into my old ways”.

"I would have liked to be able to go back once after treatment had ended for review and if I had any questions I needed to ask or advice but I realise that this is not always possible".

Only a few mentioned being able to receive such sessions or had a therapist who was flexible in this respect:

"Although my block of sessions have finished, my therapist still sees me every three months for a review. I am very grateful for this".

"I have also been given the opportunity to link back into the service should I be unable to manage any flare ups – this is an important lifeline and I don't feel that I have just been discharged and left it 'get on with it'".

## **Continuity**

Continuity was important for users and many described difficulties caused by holidays, sickness, work commitments or members of staff leaving:

"Lack of continuity between session (therapist ill, bank holiday, therapists holiday, group cancelled because of little number of participants, therapists training days) if on top of this you add your own difficulties and self doubts to attend, I understand why I felt a lot of doubt about the benefit of the therapy – was supposed to be once a week, but too many times was on average twice a month".

"After 2 sessions I was passed to another staff member & had to start again from scratch. Frustrating and fairly depressing".

There were occasions when organisations said they would contact users but didn't and some respondents felt that more could be done by the service to deal with lack of continuity issues:

"If a therapist is on annual leave, I have not been offered an alternative contact point".

"There were also gaps when my counsellor had to cancel in order to attend training sessions. I think that if a counsellor has an appointment then it should be honoured. I feel that counsellors should be given longer notice about training sessions and could make their appointments accordingly".

Also, it seemed that if users were able to access additional sessions, they usually had to start again with a new therapist:

"I believe that I require additional sessions and this has been recommended. I would have preferred to continue with the same therapist without interruption but understand that's not possible and so have been referred to begin a new program".

"My only concern is that, despite the talking therapy working well, it cannot continue because it has a time limit so I have to change to a new therapist. It took months to build up a relationship with this one and I'm very apprehensive about repeating this".

## Impact

The constraints on sessions, in particular the limited number of sessions, had clear impacts on users, including anxiety about what would happen after the talking treatment had finished and an increased pressure while still receiving it:

“You feel under real pressure! Only 12-20 sessions per person after waiting 6 months. The pressure is on!”

“The limited number of sessions (10) puts pressure on me to 'get well'/'improve' in a short space of time – which leads to anxiety! Bit counter-productive that!”

### 2.2.2. Therapist

Many respondents commented on their therapist, including their personal qualities, skills and experience. Some acknowledged that the talking treatment was “dependant on the quality of the therapist” hence this was an important theme with regard to Outcome.

#### Experience/Skills

Mixed views were provided on therapists' experience and skills, with both positive and negative comments received. Some respondents were able to compare therapists if they had seen more than one:

“I have a very good therapist and I believe that one's experience relies on the ability and approach of the therapist. My first therapist (for CBT) was, quite frankly, awful – she was unsupportive and appeared to find my issues quite amusing or even, pathetic. I am glad that my therapist was changed to someone more experienced and who understood the complexities and my traumas and am very happy with the service now”.

“The first I felt was undertrained, relied heavily on paperwork/questionnaires, was not competent at summarising/analyzing results and allowed me to facilitate sessions...she was not comfortable in her work and it showed. The second therapist was a specialist in her field, highly competent and a person for whom I have the greatest respect”.

Many respondents relayed particular examples of where they felt their therapist's skills were lacking. These included working with particular groups of users, such as those with eating disorders or anxiety or ex-military personnel. Other more general examples were provided:

“It was very clear that my therapist was very busy and the work load was huge. I felt that she was at times unorganised for the sessions. Agreed that we would work on things on the next appointment but this was quite often forgotten”.

“I may be wrong but I feel that my therapist is not experienced enough to know what to say or do. Everything is read from a script and if I ask anything that isn't she doesn't know. I feel that she doesn't know what to do with me and has actually said this. It is unfair on her and me”.

Some users relayed examples where their therapist had forgotten information about them:

“My therapist familiarises himself with my case while I am there which makes me feel like just a number. He keeps checking his watch - not discreetly - which makes me feel like I am holding him up”.

“I did feel like a number, as my therapist didn't remember details about me. Only the basics”.

Others identified that their therapist was simply inexperienced or needed further training:

“He gives the impression of not being very experienced in the role, trying to fit all of my experiences into a preconceived CBT ‘model’ to explain my difficulties”.

“I initially saw a trainee psychologist who I struggled to work with as I found her patronising and lacking confidence in her job. When I mentioned these difficulties I was transferred to a more experienced psychologist and I am very happy with the level of care”.

## **Personal Qualities**

A very wide range of personal qualities were mentioned and the most frequently cited are discussed below. However, respondents appreciated other qualities such as thoughtfulness, sensitivity, kindness, helpfulness and confidence. Others relayed negative attributes of their therapists:

“My mentor is a little timid and wishy-washy and an ‘oh, there there’ type. I need a more confident, assertive personality type but dare not say as fear of not getting help”.

“I did not find she helped me. I found her artificial in her listening skills which were 'overstated' and a bit silly/childish. She spent a lot of time telling me she understood and telling me about the problems she had experienced in life. I found her treatment of me irritating and unintentionally patronising”.

## **Caring/Supportive**

Respondents described their therapist with words such as friendly, caring, supportive and sympathetic. The majority spoke positively about their therapist in this respect and found the treatment helpful:

“The therapist, [name of therapist], extended enormous patience, kindness and care towards me”.

“I am seeing an excellent psychologist who is very sympathetic to my issues and is of great help”.

Several felt that although their therapist was kind and sympathetic, they hadn't really helped them that much and a few experienced their therapist as unsympathetic, unkind or lacking in empathy:

"The counsellor was very nice and kind but I did not find she helped me".

"Sometimes the therapist can be too harsh, for example, in my first session I was told to stop eating chocolate and stop eating as much, to walk straight after university or work, and many other things. The therapist was very blunt in saying all these things, seemed to have no sort of sympathy and I felt **worse** after the session than when I'd gone in".

### **Trust/Feeling at Ease**

Feeling comfortable or at ease was mentioned as being important to many users but they expressed mixed views as to how much they trusted their therapist or were able to open up to them. Some were positive:

"The lady I did see, made me feel at ease, her voice was calming".

"It was a great comfort for me being able to open up and discuss very private feelings. My therapist certainly put me at ease and I felt relaxed and able to talk about everything that was affecting my life".

Others described situations where they felt unable to trust their therapist or to talk to them openly, the number or length of sessions often being cited as a reason why:

"The things we never talked about were probably the most important ones because it took time to build up the trust to begin talking about them but then my sessions were over".

"It's less the number of sessions and more an issue with their length. Forty minutes is not enough and it's too abrupt to just stop at this point, when I feel as though I'm just starting to feel at ease and open up to the therapist".

Some specifically explained that they kept things hidden from their therapist or had put on a "front":

"I can't open up to her. I just give her my usual 'I'm fine, University is great' spiel – similar to that which I give the grandparents!"

"I am sometimes not myself and put a veneer on, so that my therapist only gets what I want to show".

Some mentioned the difficulties of trusting someone when they only had telephone contact and one person described feeling uncomfortable as there was someone else in the room assessing the therapist. Others described how they had to start again building trust when they started seeing a new therapist.

### **Listening/Talking**

Some users described how they appreciated having the opportunity to simply talk to someone who would listen. They explained how talking helped them face, explore and deal with their difficulties, and how it was often useful to have someone outside of their family and friends to talk to:

"Did not realise just talking has helped greatly to understand my emotions are only natural due to the circumstances. Good to talk to someone out of immediate friends/family circle".

Others held the opposite view:

"No amount of talk will be enough to change things".

"Talking about what makes me depressed doesn't stop it making me depressed".

Several respondents commented positively on the listening skills of their therapist and how easy they found them to talk to:

"She was a good listener and I found her a very useful 'sounding board' for my anxiety problems".

"I am talking about issues I thought I would never talk about to anyone until I met my therapist".

Others relayed unhelpful experiences with their therapists, often when their treatment was carried out by telephone:

"His conversation didn't really make sense. I didn't understand why he was talking to me. Third time I spoke to him I was opening up but then he never called again. I didn't get anything from it".

"I was originally referred for therapy over the phone. Although the therapist was very nice I found it very difficult to talk especially when I would get upset".

A few felt that their therapist talked too much and didn't allow them to talk:

"I find that sometimes the counsellor talks too much about things in general (re everyday stuff) sometimes not allowing me to talk – but maybe this is normal and part of the treatment?"

"I wanted a treatment more where I could discuss problems and try to resolve why past traumatic experiences were affecting me now...instead I was given irrelevant advice and was often 'talked at' for 90% of the time".

### **Non-judgemental/Valuing**

Some respondents felt valued by their therapist and some specifically mentioned the importance of their therapist being non-judgemental:

"I'm beginning to have considerable comfort in having someone who listens in a non-judgemental way. Sessions pass quickly, without awkward pauses. I respect the therapist's impartiality – and discreet presence".

"It's nice to be able to speak to someone about how you are feeling that is not a friend or a family member. I can open up more about how I feel knowing that I am not being judged".



A few relayed unsatisfactory experiences:

"After the in depth personal history she'd taken in the first session, by the end of the second session I had the feeling of being humiliated and judged by someone who was cold and aloof".

"A therapist has a lot of power! On a few occasions in our talk session my anxiety and self doubt has been made much worse by comments made by my therapist. I understand that the journey out of the cycle is a hard one and that things get worse before they get better but I think personal judgements should be avoided as it heightens anxiety".

### **Availability/Flexibility**

Mixed views were expressed regarding the availability and flexibility of therapists. Some respondents appreciated their therapists being available between sessions and trying to provide extra sessions:

"Being able to call and speak to my therapist between appointments was also really helpful".

"The therapist has been really good at fitting in appointments around my work hours".

Others did not experience the same level of flexibility and had difficulties trying to get hold of their therapist outside of sessions and concerns regarding their availability in general.

### **Understanding**

Some respondents described their therapist as understanding. However, this wasn't always the case:

"I just didn't feel that my therapist really understood what I was going through".

"If as a patient you do not feel that the counsellor really knows and understand your emotions and depth of the emotion then you can't progress".

One user in particular had concerns:

"I often feel during sessions that the therapist does not know what to do, misunderstands what I am saying and I am often left feeling I have not said things in the right way to be understood. There are also some things I am finding it hard to say and do not feel supported or helped with this in anyway in that important things I say are understood".

Another user explained how they felt it would be beneficial to have therapists who had actually experienced depression themselves as they would have a greater understanding:

"I feel there need to be more therapists on the team that have first hand experience of what I am talking about and going through, ie. have suffered first

hand and the way I am thinking and knowing how to recover from there experiences...very tricky to understand it you have not been through it".

## **Working Together**

This was a theme that ran throughout the section on *Sessions*, as several factors including number of sessions and continuity affected how well the user and therapist were able to work together. Respondents stressed the importance of forming a good rapport and some appreciated the positive relationship and "real sense of working together" they had developed.

Several commented on the difficulties of developing a good relationship when they only received a limited number of sessions or if they received a service over the telephone:

"Driving was very difficult for me so I opted for telephone therapy. I was pleased to have been offered this option but as it transpired this option was not ideal to form a successful working relationship".

"The person I speak to once a week, seems very kind, although I don't know her and she doesn't know me or anything about my problems".

A few users described how their particular treatment had particularly emphasised working together:

"I feel also that by participating via homework that I shared the responsibility in working towards recovery".

"The therapist is excellent and has a good manner and rapport with me. We go at my pace and his warmth in the therapeutic relationship has enabled me to make progress in my recovery".

### **2.2.3. Talking Treatment Approach**

Respondents discussed different approaches of talking treatment, including one-to-one, group and telephone, as well as different modalities. The majority of comments related to Low Intensity Treatment and was criticised by most respondents.

## **Counselling**

Sometimes it was unclear whether respondents were using the words counselling or counsellor when they were actually referring to other types of talking treatment, therefore this sub-theme only uses data where there is no doubt of the intended meaning.

Several users said they had already tried other types of therapy and were now waiting for or having counselling, or vice versa. Some compared the two types in relation to themselves, in particular regarding effectiveness:

"I was more suited to Person-Centred than CBT. I have however been referred. Maybe a client with personal insight may be referred to Person-Centred?"

"Counselling great and what I needed, wanted and what the GP recommended. Guided self-help was okay, it was nice to talk to somebody, but there was nothing I had not already looked up and tried myself really".

A few respondents explained that it had been recommended to them that they also have counselling. Some advocated having counselling concurrently with another treatment:

"I think CBT would work better with counselling at the same time. I had counselling at the same time as CAT and found it enormously helpful. I know this is not supposed to be good. But counselling gave me an outlet to talk about all the little day to day things/explained thoughts and feelings while therapy got to the root of the reason of it all. I think this would work well with CBT as CBT is about solving problems rather than 'talking about it'".

### **Cognitive Analytic Therapy (CAT)**

Several respondents described having to wait for some time to receive CAT. One thought it was too much focussed on what was going wrong rather than looking at the positives. Some compared CAT to Cognitive Behavioural Therapy (CBT) and felt that they had benefitted more from CAT. Another stated:

"CAT appears to be excellent if you have no understanding of your own problems. As I have been like this for twelve years I am understanding quite well".

Another explained her experiences from an older person's perspective:

"At 63 I feel that I'm considered too old. It was suggested I get out and make friends instead of relying on psychiatric therapy. This is despite the fact that the CAT had an enormous positive effect on controlling my depression/anxiety".

### **Group Therapy**

Several respondents had started group therapy after having received a one-to-one talking treatment previously. Some groups were focussed on specific diagnoses or issues, such as OCD, bi-polar, post natal depression or bereavement, which was appreciated by users:

"It really does help to be amongst people who have similar problems".

"I am the only person in the group with Bi-Polar everyone else has just depression would be helpful to have group specific for Bi-Polar or at least a mixed group so I can relate and others can relate more to my conditions more complex to understand and learn coping techniques".

Mixed views were expressed. Some found the group therapy beneficial but difficult and others felt the group was unsuitable for them. Many said they would have preferred a one-to-one treatment instead or had only started group therapy because there was a shorter waiting list than for one-to-one treatment:

"Group therapy is useful but one-to-one therapy is most effective for me. Unless I take up the entire group every week I am not getting enough support. Also, group of 8 far too large".

"I have never had this kind of treatment before (group therapy). It was very difficult in the beginning even turning up was initially a problem. However after some effort and commitment on my part I pressed on with it".

Some respondents commented on the benefits and/or difficulties of a group setting, often made worse if the groups were too large. Comments included difficulties with communication or getting support, sessions being too short for everyone to be able to fully participate, individual group members taking over and making unhelpful comparisons with others:

"You do not always get a chance to say what you want to in a group therapy – should have more sessions on a one to one basis. There are some things that I get embarrassed about talking about in a group".

"I felt I had failed as I had not got to the root of my problem and felt I needed more time I felt inadequate as others had shown a great improvement".

Several users commented that they spent time listening to and being supportive to others in the group but often didn't receive the same in return:

"My role in the group has evolved as being very nurturing and supportive but its very difficult for me to get attention and feedback for my difficulties".

"My group is really supportive and encouraging and help me to feel more confident. I seem to spend a lot of time listening to the others talk these days and trying to make helpful suggestions. That's fine, but sometimes the awful things they speak of make me quite sad!"

Several respondents described particularly difficult experiences they had in groups:

"I was referred for group therapy with no form of support. Not ideal and I became worse. Anxious, violent and dangerous".

"Ironically my current problems were triggered by an Autism/Asperger group set up by [name of organisation]...[they] did not have the foresight to establish what support is in place for when things inevitably go badly wrong and people with these communication and imagination impairments are not equipped to resolves these issues without support".

The time limits for attending the group were raised by several users:

"I've been told that ill probably attend for 18-24 months, which should be fine for me. One of my group has just been told to think about leaving (she's been coming for 2 ½ years) but she still has a lot of problems and doesn't seem ready to go, so it's a shame that it's time-limited and not related to the person's 'progress' or well-being".

## Cognitive Behavioural Therapy (CBT)

This approach was used by many respondents, although it was unclear in some cases whether respondents were referring to Low Intensity Treatment or to CBT therapy. This section refers to CBT therapy only.

Some were very positive about the therapy or their therapist:

“The CBT therapist was outstanding. Her dedication, knowledge and insight were superb to say the least. As was her ability to see cultural reasons for sense of my issues, her approach also matched the circumstances”.

“CBT has helped me to understand that there are certain things I cannot change and helped me to move forward in accepting this and in some cases have been able to completely let go. I use this in my every day life and it has empowered me and helped me to realise that I was wasting so much effort on problems that I could not solve. This does not mean I have not had any problems, but my therapist has allowed me the time and freedom to discuss these issues and to see things in a different light – for which I would very much like to say thank you”.

A few described not fully understanding CBT initially and also suggested that other professionals, including GPs, needed to be more aware of it. Several explained how CBT had helped to change their thinking and behaviour, and described how they would continue to use the tools learnt in the future:

“It is better because you work together to develop the skills to solve your problems. It is action orientated; change behaviour, change feelings and thoughts”.

“The learning tools are brilliant in CBT however I felt sometimes it lacks a bit of the human approach in therapy and can be quite clinical at times”.

Several had realised that CBT wasn't suitable for them because of their particular mental health issues or because they felt CBT didn't address more severe or long-standing difficulties:

“I have been referred for CBT which does not allow exploration of deep rooted issues, in my case as a survivor of violence and abuse. My therapist understands the limitations of CBT and has referred me for different therapy”.

“The CBT therapist I saw was **extremely** kind, thoughtful & understanding. However, I think that perhaps my 'issues' may have been better addressed/resolved by a different type of talking treatment, not necessarily through the CBT approach”.

Others disliked it as an approach and highlighted certain aspects of it, including the need for self-motivation and the view that it was often seen as a “cure-all solution”:

“CBT can seem a little formulaic and one-dimensional. I imagine it is not for everyone”.

"I don't think 8 sessions of CBT can remedy a life gone completely astray. The idea is somehow to enable a person 'to become their own therapist'. But my problems are too deep rooted for one to be able to do this. It is too late for me to be 'cured' but to allow the remainder of my life to be bearable, or to have some semblance of meaning I need much more intensive long lasting treatment looking beyond the surface. To exaggerate a little: CBT is a little akin to a sophisticated, elaborate version of 'pull yourself together' with little account taken of the organic, genetic, and experiential elements of the disease. If you are unable to respond in the way hoped, there seems the suggestion that you are not trying hard enough. I appreciate the treatment I am receiving in so far as it involves meeting someone for a few weeks and the therapist is kind and helpful, but it is insufficient".

## **Low Intensity Treatment**

This section includes any general comments regarding Low Intensity Treatment that are not covered in the following sections on *Attending a Course*, *Telephone Support* and *cCBT*.

Most respondents described the service they received as being too basic and raised a variety of issues including there being not enough to the sessions beyond doing exercises or questionnaires or being given information:

"If I knew from the beginning I was just going to get occasional phone calls with a bit of CBT and a few suggestions, like 'join some clubs', I probably wouldn't have bothered".

"The nature of the therapy I didn't feel was suitable for me...I felt it was quite patronising (not the therapist) and tokenistic – filling in effectively activity sheets. Moreover it wasn't so much low intensity CBT itself, that was the problem, I just know it wasn't appropriate for me. I was already very aware of my problems & origins of my feelings/delusions & agreed with the therapist (who was more of a bi-weekly supervisor) that that was a big component of how that therapy could've helped had I needed it".

Some felt they hadn't received enough time:

"I felt the treatment was patronising and limited both time-wise and in its scope. The mental health worker seemed only capable of operating within her brief and pitched her engagement with me at an extremely low level".

"I think when I had a student therapist who worked with me on CBT methods, the time allocated was ½ hr which I found quite rushed as there was a lot of paperwork to go through, and little time for discussing difficulties which have arose whilst using these techniques. I would take up talking therapy but with an hour of time allocated, so that the treatment is not rushed".

Only a few stated they felt it had been beneficial:

"Helpful. Has begun a process of rebuilding my life, in manageable steps. Having someone planning every 2 weeks helps focus and implementation of material".

"I had one 'face to face' session and several follow-up phone calls. Although I found the initial 'face to face' session very helpful – and I would have liked to have benefitted from this much earlier on, I did not find the follow-up 'phone calls' as useful".

## **Attending a Course**

Many respondents had been on a course in a group setting; including for depression, anxiety, stress, self-esteem, "wellness" or to learn CBT techniques. One was offered an "art course" but declined this as they felt it wasn't suitable. Several respondents were disappointed that there was no opportunity for group discussions or one-to-one sessions in the courses they attended:

"My treatment was a stress and anxiety course and was led by the therapists without any real interaction with the group. I think that combining this with a few opportunities to have a group discussion may have been helpful – although I can appreciate not everyone would have felt comfortable with it".

Several said they would have preferred a one-to-one talking treatment where it would have been possible to provide a more individualised approach – "it was a case of 'one course fits all'". However, it was acknowledged that it was useful to meet others in the same situation.

There were several difficulties associated with practicalities that respondents raised. One user said they hadn't been told when a session had been cancelled and another thought they had received too many handouts. Some felt the group sizes were too big or they wanted the sessions or courses to be longer:

"Smaller classes (eg 6 people) would allow us each to have some time with a therapist individually, each week. Because of this, I have requested one-to-one, therefore costing the Government more".

"I think a lot was covered in the sessions, the courses were condensed. I felt some of the sessions were rushed because of a time limit of 2 hours and other attendees tended to 'take over' trying to use the course for their personal counselling time. Also when we had to talk in pairs/groups, this was often rushed because of the time limit, so perhaps the sessions needed to be longer or extended".

A few spoke positively about their experience:

"The venue where the sessions were held was light and comfortable with refreshments available. The therapists were very knowledgeable and kept a degree of humour which was good for the class, making it easier for the group to open up, to talk about their problems. I found it a relaxed atmosphere which helped me a lot".

"I participated in group CBT which I found really helpful in giving me practical tools to use in managing anxiety and depression. I feel more able to manage these difficulties now although I am hoping to do a Mindfulness course to increase my ability to manage".

## Telephone Support

Many users described receiving their treatment by telephone only and several felt what they received could not be described as a “talking treatment”:

“Was done over phone so no 'venue'. I wouldn't have said I received a 'talking treatment' till you used the term on this questionnaire”.

The majority commented that they didn't like it, for a variety of reasons, including finding it difficult to talk with someone “with no face”:

“At times you could hear other people in the background so it was like talking to a call centre”.

“Most of my sessions have been by telephone. Whilst I appreciate that this makes it easier for the therapist to fit in appointments I personally would find it useful to talk face to face. I would get more from talking face to face. The telephone can be limiting and de-personal”.

Some didn't like the manner of the person at the other end of the telephone who they found to be impersonal or impatient:

“The 'therapist' who phones me is more like a call-centre employee than a professional. We once had a scheduled conversation and he obviously hadn't read any of my replies from last time. Rang me back shortly after 'oh my God, I just noticed you feel suicidal'. Not very confidence-inspiring; you're just a number to them, they never talk about you, just what the course says. It would be money well spent to scrap the phone-call side of it”.

“Initially I had low impact, telephone appointments. They were terrible. I was left crying, lonely and very distressed. I couldn't return to work. I feel Person-Centered treatment, face to face is so much better – leaving the session calm and composed. (The counsellor previously seemed impatient and not experienced)”.

Several users specifically mentioned that it sounded as though their worker was reading from a script:

“The follow up calls I've found of little benefit apart from the 1<sup>st</sup> one introducing me to Beating the Blues. The follow up calls I've found unhelpful as the person just talks and almost sounds like they have a script which they are reading from. Perhaps it's just me!

“I did the treatment through [name of organisation]. The therapist sounded at times like she was reading off a script on the telephone sessions. Sometimes the time was too short and it was evident from the therapist's tone that she wanted to move on or close the call down even though there was an issue which I wished to discuss”.

Many made comparisons to, and would have preferred, a face-to-face treatment:

“Although the therapist was very nice I found it very difficult to talk especially when I would get upset. The therapy was just upsetting and felt very



impersonal and did not do any good. I am now seeing a therapist in person which is much better".

"All of my treatments happen on the telephone, I find this difficult as I feel I express myself better to people when face to face. Not everyone is comfortable talking on the phone and I think this needs to be taken into account and alternative options made possible".

Some mentioned issues such as having a baby or living in a rural area and how they therefore appreciated the accessibility of a telephone approach:

"I opted for telephone counselling sessions which was easier because I live in a very rural location and these have worked well for me".

"Driving was very difficult for me so I opted for telephone therapy. I was pleased to have been offered this option but as it transpired this option was not ideal to form a successful working relationship".

A few had found it difficult to obtain enough privacy or time in the day for their telephone sessions:

"The phone appointment are not always easy as they are usually during my babies nap-time so easily interrupted by her. It's also easy not to put my full attention into them when it's not a face to face meeting".

"It's an over the phone service, which so far has failed to impress! It's not private or sociably easy to do with 3 kids and a disabled partner!"

Only a few said they found it helpful:

"It was very convenient to have a telephone conversation with my therapist once a week. I was surprised when this was offered to me but very happy with it".

"This method of CBT via the telephone has been very helpful. I had reservations at first about having no visual contact but the system has worked well and saves time and energy by being able to be home for the sessions".

### **Computerised CBT (cCBT)**

Several users commented on having cCBT and stated they didn't find it helpful. For some cCBT wasn't their first choice of treatment:

"I could have been referred earlier but instead I was persuaded to do on-line CBT which I found no help".

"I tried the computer CBT programme before my one-to-one sessions and found it very unhelpful and alienating".

Some participants didn't regard cCBT as a "talking treatment":

"Could have done with the talking treatment initially when I thought I was having a breakdown, yet it was months later after Beating the Blues and phone call treatment".

"Not receiving 'Talking Treatment'. This was not available although it would have been the preferred method of treatment. I was offered information sheets and a computer course".

Only a few users found cCBT to be beneficial and/or appreciated its accessibility:

"The information on the program was a bit vague, but it appealed to me as I could access the program from home. Having young children and being unable to drive, I would have been rather restricted otherwise".

"I chose to do my treatment through the computer, as part of my problem was meeting and facing people. So this was an ideal solution for me".

Several respondents relayed difficulties using the program because they were too tired, couldn't find the time or had a particular health condition:

"I found that being a stay at home Mother with three young children it is very easy to miss doing a 'Beating the Blues'. As it is just down to me to find the right time at home".

"Because of chronic back pain, I cannot sit up for very long, therefore it has proved difficult to sit at the computer long enough to do the session well. Even when I break them into parts, it is difficult. Because my back has worsened and has had periods, I have had to leave more than a week between some sessions".

Some described technical difficulties with using the program:

"Only have computer based CBT which I feel is no help at all as you can not stop and start the programme half way through which is needed when you cannot dedicate a long period of time in one go. Not very user friendly".

"Few blips on the computer where I had to go back and re-do entire session!"

One described an unpleasant experience when using cCBT but had no support available at the time:

"I undertook the on-line CBT option. During one session I had a very uncomfortable experience, like a huge revelation, as a result of the 'downward arrow' activity. Having this happen during an on-line session made it very difficult to deal with. I really needed to talk to someone about it, and was referred to a counsellor, with a 16 week wait. I have become more depressed as a result, and I'm still waiting to see the counsellor. I don't know if this means the CBT has worked well or not, but access to someone to talk to immediately should be built in".

## Other types of treatment

Several other types of talking treatment were mentioned. One user had received Eye Movement Desensitization and Reprocessing (EMDR):

“I have had treatment for depression since 1979 and this treatment (EMDR) is the first time I have felt a difference. I hope in the future this is more available to everyone”.

A few mentioned Psychodynamic therapy. One respondent had received this in the past but had found that it “aggravated” their condition, another wanted Psychodynamic therapy but thought it was unavailable on the NHS. A third user spoke positively of their experience of it and made suggestions for raising awareness about the therapy:

“Most importantly, I was highly dismissive and critical of the idea of Psychodynamic long-term therapy. After a few months, I felt it was the best step I had taken to recover. Is there anything that can be done to demystify the process?”

Some users had received Mindfulness therapy and found it effective. However, a few had been unable to obtain it:

“I didn’t know they did Mindfulness CBT or CBT for sleep and really feel I need help in those areas too, but am unable to get them”.

“The idea of 'Mindfulness' is excellent but is not universally applicable and it seems that there are no viable alternatives”.

One user described using a variety of techniques:

“To progress to a useful state of mind I employed NLP strategies to interrupt current modes of thinking and limiting beliefs. I also used mentoring strategies, life counselling and hydrotherapy”.

### 2.2.4. Structure and Format of Talking Treatment

Respondents commented on different aspects of their talking treatment, including the materials used, questionnaires and the focus of the treatment. A prominent sub-theme in this section was the errors/difficulties experienced by users.

#### Assessment

A number of respondents specifically raised issues connected with their assessment, including having too many assessments (four in one case), concerns over the accuracy of the assessments, having their assessment carried out over the telephone and finding it upsetting having to complete an initial questionnaire by post:

“My assessment appointment before I started with my actual therapist wasn't helpful and neither was the assessment report that was written. It is too much to expect to get a snapshot of someone which turns into a detailed report when you have only seen the patient for a one hour assessment”.

"I was not happy about being assessed over the phone on a score system".

Some mentioned concerns regarding the worker carrying out the assessment:

"The person I spoke to for my initial consultation HAD NOT READ MY LETTER OF REFERRAL and made untrue assumptions about my past treatment".

"My initial assessment was not very well done, with the therapist leaving the room to answer the phone/queries five times in half hour, and did not cover the key points of my reason for being sent for assessment in the first place".

Only a few were positive about their assessment, praising the therapist:

"Initially I had an interview with a therapist to determine my issues and she was brilliant".

"I had my initial assessment today. The therapist was excellent, I really felt both heard and understood".

### **Focus of Talking Treatment**

Several respondents commented that there wasn't enough structure to their treatment and as a result they were unsure what they were meant to be talking about, it seemed irrelevant to them or they simply sat in silence:

"The treatment veered off in the wrong direction for half the sessions. Sometimes feels a bit vague, maybe that's part of process".

"I think the sessions could have been more structured because of my many problems. It would have been much better for me if we talked about one problem for each session but ended up talking about several, therefore not really concluding any or only a few of my problems".

Sometimes users felt they were asked to address other areas of their life rather than the areas they themselves had wanted to look at.

"I feel I've been asked to question other parts of my life, not what I went for".

"Whenever I tried to talk about how I was feeling or what was bothering me, I would 'quickly get bought' back to what I felt was the agenda of our phone conversation. This was never set by me".

A few users referred to the sessions being too structured:

"The only part I don't like is having such a rigid schedule to fill out at the start of each session re what will be covered and how long each issue will take".

"Initially it didn't start well because I felt the therapist was trying to force a prescribed format on the sessions that didn't fit my needs. I had to point this out and ask her to work differently, which she did".

## Questionnaires/Paperwork

Many respondents disliked the questionnaires that they were obliged to complete. Some felt that continual assessment did not help them deal with their difficulties and in fact actually detracted from them being able to use the sessions most effectively:

“Repetitive filling in of questionnaires pre-session worked to undermine this and I seriously objected to the therapist having to verbally and formally ask me each session whether I was suicidal – I might as well have been interacting with a machine”.

“I also get the impression that my phone call appointments are more about filling in the questionnaire to monitor how I'm feeling rather than actually dealing with anything”.

The predominant issue was the amount of time the forms took in each session, thereby leaving less time in which to talk:

“6 half hour sessions is all I can access on the NHS. The first 5-10 minutes is taken up with answering PHQ9 questions and audit questions every session (if you refuse you don't get another appointment)”.

“By the time I had finished filling all the paperwork there wasn't enough talking time”.

Some felt that the questionnaires did not measure their treatment accurately or sensitively enough:

“Too many questionnaires are used in PTSD evaluate and assessment. Questionnaires do not get to the complexity and subtle nature of change in oneself. One size does not fit all – and questionnaires are a blunt instrument for a measurement of success. I believe I am having fantastic treatment however, this is not reflected in my questionnaire scoring because change is slow”.

“I do think the feedback forms, although are helpful, are ambiguous as they are purely tick box answers and does not really reflect where I'm at so have always had to add notes although there is no room on the feedback forms each week to add notes”.

One was concerned about having to complete the questionnaires in public where others could see. Another described receiving questionnaires through the post:

“I have only had one talking treatment which resulted in answering a questionnaire over the phone. I was then sent a further six questionnaires (all the same) which I had to complete before my next appointment which was cancelled”.

## Homework/Exercises

Respondents explained how they were given exercises or homework to complete, sometimes as part of a course or group:

“Joined a stress management course at [place name] and followed a 7 week programme – handouts and explanations were given and were recapped upon following on the next course date. Given exercises to complete and practice to control my stress/panic/depression”.

Several described how the exercises took up time, both in sessions and out, and this had implications for the number, frequency and length of sessions, thereby reducing the time they had to simply talk:

“With all the practice of exercises I feel I would like to have had longer course”.

“Feel very constricted by our sessions as sometimes it takes 30 minutes to talk about homework and what’s been happening, so only get about 20-30 minutes of actual therapy”.

Some users described feeling overwhelmed or daunted at first by the tasks, found the workbooks too general or not appropriate for them or felt that “homework tasks were not consistently given”:

“I was frequently told to do ‘homework’ which would be followed up the following week, but it never was. Was also frequently told I would have a ‘mood’ form to fill out every visit, to assess changes in mood over the course of the treatment – this was actually only done a couple of times”.

“I may try elsewhere for help in the future, because it was a bit too regimental with homework (written) and writing things down”.

Others were concerned that they hadn’t been informed of the exercises at the outset or experienced other difficulties, which sometimes even caused them to end the treatment:

“Most significant was the lack of prior info about the work which I would need to put in at home between one session and the next. Hand writing and form filling were difficult for me before the course, and still are. These are both physical and emotional difficulties”.

“I have now discontinued my talking treatment without finishing the course. I...wasn’t focussed enough to complete the required tasks at home”.

Some found the exercises too basic:

“I felt it was quite patronising (not the therapist) and tokenistic – filling in effectively activity sheets”.

“I was given an exercise to complete about anxiety and it caused me a lot more stress! At the moment I have 6 forms to fill out...so I didn’t need more questions to be answered! Also thought the exercise was childish – so she has given me a CBT self help course to do at home and we will meet up to discuss. I’m beginning to think that is not for me”.

Only a few respondents said they found the exercises and homework useful:

"I...discipline myself to do my 'homework' which does help as it makes me think deeply about some of the issues I have, which has made a very positive difference to the way I am feeling".

"Found that the exercises helped me to 'identify' my stress then problem solve to improve/control it".

## **Materials**

Mixed views were expressed on the other self-help materials that were given to respondents, which included CDs, handouts, booklets, workbooks and other literature. Some were disappointed with the nature and quality of the materials:

"Guides were all second-hand bits of photocopies that did not relate together".

"The handouts used at my treatment centre were fully of typos and inaccuracies. Seeing that they come from [name of organisation]...I was quite horrified. They confused some of the patients and created unnecessary worry. These forms should be updated and improved. They are plenty of clinicians at the [name of organisation] who I am sure would be more than happy to oblige".

Some felt there was an over-reliance on these materials or that they were given too many:

"On the course I went on we were given too many handouts and it was information overload. This is not good when you have memory and concentration problems".

"All she gave me was pieces of paper to read when I get angry – it did not work".

Others found them useful, including for future use:

"Reading materials suggested to me eg. books and information via internet really helped as well, eg. 'Overcoming ...' series and CBT for dummies were actually very useful and very readable".

"Good accompanying literature and CDs".

A few respondents commented on the use of the materials and/or compared this self-help approach to other interventions:

"When it was literature suggesting that I could improve with self-help I was devastated. I was too ill to even read a few pages of the booklet. My husband made a couple of phone calls to explain this".

"Books have a small part to play but they cannot replace one-to-one support. I am disappointed with the 'treatment' I have received".

## Information

Respondents appreciated receiving information on what their treatment entailed, why they were having this particular type of talking treatment, its benefits and so on. However, they didn't always receive this:

"I found this treatment confusing. It isn't really counselling and I don't really understand its benefits".

"My psychologist has already illustrated very clearly and concisely how my 'head' is not processing historical events etc. so I'm fully aware of the reasons, problems and how this treatment can help reduce the damaging results I've been and still suffering".

Several respondents explained they had wanted information on other services and the different roles workers had:

"I have never received any information about other support available, as what to do in a crisis. I have picked all of the leaflets up myself".

"It is not clear to me as a service user what the different roles and treatments are! Not enough is explained! And who does what role!"

Sometimes users hadn't been provided with practical information such as how many sessions they would be having, whether there was any flexibility around this or what would happen after their treatment ended:

"I do not know exactly how many sessions have been allocated to me or whether they might be extended if I feel it to be necessary".

"I am not aware that I could be referred for other treatment, for example CBT. It would be helpful if signposts for other therapies could be made available".

Some showed an even greater lack of understanding:

"I still don't know what treatment I will be receiving!!!! I have discussed and confirmed this with my IAPT worker".

"Please explain what is "talking treatment"!"

## Errors/Difficulties

Many respondents described errors on the part of the service they were using or other associated difficulties they experienced during their talking treatment. Often these were related to administration and included information not being sent or inappropriate letters received from the service:

"The treatment I have received is scandalous as is some of the letters I have received from them, including ones which have a go at me!"

"The therapist said he'd send me some information through the post and a recommended reading list, he didn't send either. Then the therapist helper I was assigned to didn't answer my emails and was hard to reach by phone, she also said she'd send me info through the post and never did. When I chased it up, I was informed she had left the service without informing me".



The errors sometimes involved telephone calls not being made as agreed:

"My course 'contact' arranged a phone call with me to see how I was getting on with worksheets. She did not phone, and now, several weeks on, I have still not heard from her".

"I was sent letters telling me when I would be called but twice I failed to get calls".

Some of the difficulties were specifically connected with appointments cancelled at the last minute with no notice given or new appointments not being made:

"Had first appointment, arrived for second appointment after it being stressed to me I must attend all appointments otherwise I would lose my place. Therapist sick on second appointment, no notice given, hard place to get to. Then I was told she was ill we will be in touch – no word. Most unprofessional service ever!"

"I had to chase the service twice because no-one contacted me after the last one was cancelled".

A variety of issues were described related to confidentiality, including letters being sent to the wrong people, wrong telephone numbers being used or people walking into rooms in the middle of sessions:

"I was also repeatedly called re another patient and I had to phone [name of organisation] on 3 separate occasions before the calls stopped for another client and began for me!!"

"Letters from the assessing therapist have been cc'd to individuals not involved in my care (thus breaching confidentiality)".

Sometimes the errors/difficulties resulted in the user not receiving a service:

"My experience of [name of organisation] was that it was totally useless. I never got to talk to a therapist in the first place, because of administration and bureaucratic failures. I went back to my GP and told him [name of organisation] was useless".

"They were unhelpful and unorganised. After 5 phone calls and voice messages I had nothing back and gave up!"

Several respondents felt the difficulties or errors on the part of the services had a greater impact because of people's mental health:

"The third time she never turned up. I rang the office and they promised she would ring me later. She never did, so I rang again and they said she would ring me the next day at 8.30am. Once again she never did. I feel that I have been totally let down when I most needed help and understanding".

"Letters from IAPT (therapy team) abrupt in tone re consequences of not attending an appointment – unhelpful when already feeling anxious/depressed. No choice apparent in first appointment given just consequences for not

attending!! Could have got same message across with a more positive use of language”.

One user stated they would have made a formal complaint if it hadn't been for the quality of their current therapist. Another said very strongly:

“No amount of skill in psychotherapeutic techniques will ever compensate for this distinct lack of respect and display of utter contempt”.

### **2.2.5. Personal Factors**

Respondents identified a number of personal factors that could affect the outcome of their talking treatment. These included demographic characteristics such as age or ethnicity, the level of individualisation of treatment and how much choice or control they felt they had.

#### **Age**

Several users mentioned the age difference between themselves and their therapist as being important:

“I am a retired person with a wide experience of life, and I found a person in the twenties not an ideal person for me. She was cold and I didn't gel with her at all. Maybe a person a little older with more life experience, more able to help me”.

“I first saw a very young therapist & had problems talking my thoughts through as she was younger than both my children. I rang talking therapies & explained this & they made an appointment for me with an older lady”.

Only one specifically stated that the age difference was not a problem:

“In spite of our wide age difference (me over 70 and therapist under 30) our relationship was very positive”.

Another respondent described a positive experience:

“I'd also like to thank our local 'older people' mental health review in continuing to help me at the age of 94. It is an excellent example on non-discriminatory practice!”

#### **Gender**

Some respondents explained how they felt more comfortable with a therapist of a certain gender:

“I think if I'd been able to talk with a female it would have been easier for me. I stopped going because I felt uncomfortable talking to a male”.

“I have found being able to talk to a therapist, of the same sex, very helpful and encouraging”.

## Physical Health

Some respondents experienced a lack of understanding from therapists regarding their physical health condition. One found the acoustics in the room to be poor and made their hearing aid ineffective. Another explained how they were unable to use a low chair due to their arthritis but instead of replacing both chairs the therapist only replaced one, leaving the user sitting upright on a computer chair and the therapist on a comfy low chair: "This didn't give me much faith in the therapist if she couldn't see the situation". Others experienced staff being rude or thought nothing had been done to accommodate their health condition:

"An initial appointment with a nurse who was worse than useless and **very rude** to me when I had to cancel two appointments due to illness related to my physical disability".

"I struggled to get to the appointments which I explained and I also turned up on the wrong day due to confused 'foggy' state I was in. I got a letter stating if I did not turn up I would no longer be treated. I felt very distressed and I asked for a reminder text message if I had an appointment coming up. They didn't do this for whatever reason".

Several believed that their depression was due in part to a physical health problem and that this hadn't always been taken into account by their therapist:

"I personally thought that my first session was a complete waste of my time and that this sort of treatment is not suited to 'chronic pain conditions' at all. My therapist didn't really listen or explain how this was supposed to help and I felt as if I was being dismissed as having 'other' issues rather than the reason I thought I had been referred for".

"Too many of my problems cannot be stopped – a lot of my depression is caused by my inability to leave the house following a nasty stroke, leaving me unable to use my left side".

A few users relayed positive experiences:

"My counsellor already had some knowledge of autism and is open to learning which makes communication so much better. It would be wonderful if there were more therapists like this".

"As a profoundly deaf person, I required sign language interpreters for my appointments. The clinic were very good at arranging this for me".

## Ethnicity

A few respondents described positive experiences in connection with their ethnicity:

"I felt that the therapist made a sensitive effort to understand and connect with me as a personal individual and with a cultural context".

However, most had experienced difficulties, mainly related to communication and understanding. Some users experienced additional delays to receiving their talking treatment when services failed to provide interpreters:

"I was anxious and did not understand as it was only in English and I cannot speak English, I did put recommendation for Punjabi interpreter but was not accompanied with one on the day. I could not speak up in front of all the group, my head was blank".

Some respondents expressed a wish to have a talking treatment with someone of the same ethnic background or who spoke the same language and others had experienced communication difficulties when this hadn't been realised:

"He is of a different cultural/ethnic background to myself and there have been various misunderstandings over the use of the English language and interpretation that have caused difficulties in understanding my problems".

"The cultural knowledge, background and nuances between therapist and I – massive. I prattle on and on reflection realise that has probably 'got wrong end of stick'. When I say things with passion and anger he probably takes me literally rather than from the cultural peculiarities and expressions for effect rather than actuality".

One had to discontinue having a talking treatment because of difficulties experienced due to being an asylum seeker:

"There is no one to leave my two year old daughter with so I had to take her with me for my counselling and this made it difficult for me to concentrate because she's always disturbing, so my counsellor decided my session should be postponed till I get a nursery space for her and being an asylum seeker, there is no funding for her nursery. So I couldn't continue with the talking treatment".

### **Personal Commitment**

A few users commented that the outcome of their talking treatment was partly dependant on the personal commitment they gave to it. Most were unaware of this when first starting:

"A lot of the CBT is down to you and what you'd like to get out of life, I later discovered, which wasn't much good as I did not know".

"I think that treatments should be explained that this will only help if you are willing to help yourself. In my experience most people hear 'therapist' and expect to be given all the answers and as we know that is not the case".

One described ending the talking treatment as a result:

"I have now discontinued my talking treatment without finishing the course. I was having difficulty keeping the appointments and wasn't focussed enough to complete the required tasks at home".

### **Initiative**

Respondents described having to take the initiative at several points throughout the talking treatment, in a similar manner to how they had to take the initiative at the access stage. Sometimes this concerned practical matters such as having to chase up

appointments when their therapist didn't contact them as arranged or asking for extra sessions when their talking treatment came to an end:

"I had to talk my psychologist into keeping me on, as she was under pressure to discharge me".

Others had found out information for themselves, including researching on the internet:

"I looked up the majority of the problems for myself and as such understand my thought processes and the majority of why I do what I do".

Some users said they felt unable to raise issues with the service or the therapist and this therefore influenced the service they received.

## **Individuality**

Many users expressed a wish for their talking treatment to be more individualised. They highlighted this in two particular respects – the number of sessions and the treatment approach used. They felt the number and frequency of sessions should be based on individual needs rather than being a prescribed amount for everyone:

"I think everyone is different, some people may need more, without going through their GP for another appointment it should flow".

"I do not think there can be a 'right' number of sessions. It depends on how an individual progresses through the sessions. I appreciate there has to be limitations due to the number of clients on waiting lists, but it needs to be on an individual basis with consultation between counsellor and client".

Respondents were also critical of therapists not taking a personalised approach with users or groups/courses not taking individual needs into account:

"The service would benefit from being more individually tailored to each patient/client. It seems to ignore the fact that the relationship between therapist and patient is key".

"Too impersonal – felt like questions were being read from a computer screen".

Only a few recounted situations where an individual approach was taken:

"Counsellor's having the autonomy to make decisions about the type of support one needs and treating people as individuals is much less disruptive than having to seek consent from a senior – I am so pleased that [name of organisation] respect their staff and listen to them regarding individual client needs".

"I have been delighted by the 'flexibility' of the treatment...I genuinely felt that my treatment was centred around me".

## **Faith/Hope**

Some respondents mentioned that having hope or faith, in the treatment or therapist, was important and kept them going:

"I hope to feel much better when I have completed the planned for sessions. I am told that I am 'in recovery' but I still have very bad days. My therapist seems confident that I will recover. I trust her judgment".

"It is early days in my current treatment, as such the most positive aspect is an intuition that this will help me progress. By that I mean I have a sense that this will help me address difficult situation which are both deep seated and very self-limiting".

Conversely some described having no hope, including somewhat despairingly at the end of their talking treatment:

"I had no faith that this counselling would work. My therapist [name] was so kind and helpful. I didn't want to let her or my family down. The first few treatments I found very painful and hard to face, strangely it had a very positive impact on me. I am amazed at how much better I am now".

"In the long run I don't think it has made much difference. I am pretty much a hopeless case, I think! I don't blame my therapist".

## **Choice/Control**

In addition to the lack of choice often experienced when accessing a talking treatment, respondents wanted greater choice and control in various respects throughout their treatment. This concerned practicalities such as the number and frequency of sessions, the type of talking treatment and choice of therapist:

"I think that if there had been an option to change a previous counsellor/therapist then I would have done so, since back then I was already in a crisis and discontinued due to the therapy, being another burden rather than a help".

"I would like to see a greater choice of therapy ie. psychodynamic, dialectic behavioural, cognitive analytic therapy".

Some users specifically wanted to have a review of their treatment with their therapist and some choice and control over their future options:

"More discussion from the therapist about how they feel you have progressed/ or not by the end of the course of treatment. More discussions about other options e.g. medication, long term therapy. Links with private therapists in my area, for example, how to find a therapist, who is good in the local area".

"I was given absolutely no choice as to who I would be seeing next and it all went horribly wrong for me. I ended up in a psychiatric hospital".

A few provided examples of where they felt they were able to exercise choice or control and found this beneficial:

"My treatment is very much dependant on me and I can decide how many sessions I need and how frequent".

"My first appointment was meeting my therapist, talking about my problems, then deciding which treatment I would feel happy with. At that point I chose to do my treatment through the computer".

### 2.2.6. Talking Treatment Outcomes

Respondents described a range of outcomes that they had experienced from their talking treatment, including understanding, coping, and learning new skills. Some explained the treatment had other impacts on them and they also discussed what the future may hold.

#### Understanding/Exploring

Most respondents described how the talking treatment had helped them to understand, explore and/or work through their difficulties:

"I have felt very happy with my therapist and feel she has helped me to talk and explore my feelings and reactions and helped me to see the light at the end of a very long tunnel and given me the confidence to work towards it".

"I have a much better understanding of myself and my thoughts and processes than I used to have. It has made me much more self aware".

Some felt that they already had an understanding of their difficulties before they started the talking treatment:

"I fully understand my difficulties, that is why I went to my GP in the first place. Coping with them is a different matter".

"I understood my difficulties before I came to therapy, so in that respect I did not require any help from therapy".

Some said they still did not understand their difficulties after the talking treatment ended or the treatment was not what they wanted in this respect:

"I feel as though, I am not any closer to getting any better as I feel as tho I don't understand why I'm feeling this way. I feel like I need more feedback and someone that can help me get a better understanding of what's wrong with me or not".

"Don't really understand why I have my difficulties. Not sure what help I need. Unsure if I really need to go back".

One felt strongly that talking treatment does not help those who already have a good understanding:

"Talking treatment works if the patient knows they feel bad, have difficulties coping etc but don't understand **why/what is** causing them. Talking treatment

does not help patients **who know** what causes their problems and know what they should do to help themselves but can not put advice/their own solutions into action. Talking treatment does **not** solve problems with **self discipline**".

## **Coping**

Respondents expressed mixed views about how well their talking treatment had helped them to cope. Some felt they were better able to cope now, with their difficulties or symptoms or more generally in their daily lives:

"The treatment helps me to cope with my difficulties but not to understand them necessarily".

"Without this treatment I think my coping mechanisms and strategies to cope daily would not exist".

Many were less positive:

"It doesn't really help me cope, because my sessions are fortnightly but I never know when I'm going to get a major setback which will knock me for six. I haven't been taught any coping mechanisms for when things get difficult".

"Sometimes talking helps but some times you lay everything out and then think...now what? I don't know how to cope when everything's out. This is the hard bit".

## **Skills/Strategies**

Respondents described learning skills and strategies from their talking treatment and mainly felt they had been beneficial:

"Since this treatment for my anxiety, I now have the tools to come and understand more if it happens again".

"It is really helpful to have someone explain strategies to help me combat my difficulties".

Some users expressed difficulties in translating what they had learnt into "a workable tool":

"Because there is a lack of practical application (as a result of my type of phobia) it is hard to put what I can into practise".

"Just doesn't work for me – can understand completely the theory but can't DO it".

## **Solution/A Cure**

Several respondents talked in terms of finding a solution or cure for their difficulties. Some felt this was unrealistic but felt instead that the talking treatment increased their understanding or ability to live with their difficulties:

"It did not 'solve' my problem though but maybe I am more accepting of my problem".



"I'm not "cured" but I'm living/coping with my condition much better now. I still get down from time to time but what I learnt helps me get through the bad times".

A few acknowledged that their goals had changed in this respect:

"Hoped for a magic cure for my depression. Did not realize just talking has helped greatly to understand my emotions are only natural due to the circumstances".

Some couldn't identify any solutions at all:

"Can not see yet how this treatment is helping. Problems have not reduced at all yet. Talking is only going round in circles, is not helping me find solutions yet".

### **Missing from Talking Treatment**

Many users felt that their talking treatment hadn't covered areas that they wanted to explore. Sometimes this was because there weren't enough sessions and they simply ran out of time:

"I am approaching the end of my schedule of sessions and yet I feel I am only beginning to "scratch the surface" of my difficulties. Consequently I am extremely worried that the service will not be enough to allow me to cope".

"It would have been nice to have more sessions because I don't feel we covered everything that I feel was relevant".

On other occasions it was because of the limitations of the approach of the talking treatment, which was often viewed as "not in depth enough" and not reaching the root of people's difficulties:

"It's how one understands 'talking treatment'. I know there is so much in my past that I have put right to the back of my mind and that hasn't been explored but, which has an immense bearing on my present predicament. I touch on this while 'talking', however, we seem to gloss over this".

"I feel my problems are more deep-rooted and long running than a bit of positive thinking, or joining some clubs or dating websites will solve".

### **Impact of Talking Treatment**

Some respondents described the difficulties they had personally encountered with undertaking a talking treatment, including finding it very upsetting, particularly initially:

"I found the treatment very, very, upsetting to start with I did not know I should end up in floods of **TEAR'S** to start with".

Some felt that the talking treatment hadn't helped at all, but had left them feeling worse than before they started:

"I leave more stressed and upset than when I went so if anything its making things worse despite me trying to discuss this problem with the Psychologist".

"I understand the reasoning behind talking treatment but it isn't helping me. My anxiety has got worse since taking this treatment".

## **The Future**

Several respondents mentioned the future and what they would do after their talking treatment ended. Some said they would continue using techniques or materials they had learnt, others described how what their therapist had said would remain with them:

"I feel the talking treatment will remain with me forever. The things I have discussed, the books I have read and the notes I have made would all be referred to again in the future should I need them and I don't think I would CBT again".

"Now that I have finished my sessions with her I still try to keep in mind the 'reasons' to what she told me were about my behaviour and resist the compulsion to not do the things I do".

Some were hopeful but unsure what benefits the talking treatment would have for them in the long term and believed "only time will tell". A few mentioned specific events coming up that may prove particularly testing, such as coming off medication or gaining employment:

"I believe it helps me to cope to an extent and hopefully in the long term much better – it is very difficult to change habits of a lifetime. It is difficult to realise that it will take time".

"I believe with these tools and what I have read will help me to take charge and hopefully use the techniques when problems occur. I will be looking for employment soon so that will be the test, challenging my thoughts when I am there!"

Others were less optimistic and mentioned relapses:

"I am unsure as I keep slipping back into old patterns of thinking. I haven't seen any permanent changes yet".

"Continuing to experience periods of depression and difficulty coping with very stressful situation (ongoing and will be for some time to come, likely to get more stressful yet)".

A few felt that the treatment may help to lessen the intensity of relapses:

"It doesn't happen overnight and I'll have to keep working at it. And I'll probably relapse, but maybe not so badly this time".

Some specifically said that they had stopped finding the talking treatment helpful when it stopped:

“Treatment helped only whilst able to discuss my problems and feelings afterwards I could not seem to think positively”.

“Bit like a sticking plaster makes it feel better for a while but take it off and the wound has yet to heal”.

A few respondents said they would try a talking treatment again in the future, usually a different one, if they felt they needed it but some were concerned about having to wait for a long period of time again or whether they would be entitled to it. Some had already looked into related matters:

“Since finishing my treatment I have continued utilising the tools and skills that I learnt and tried to find out more about how CBT could enhance my life”.

“The progress I made seems now more to do with being off work and on medication than by the 'talking treatment'. Now having been back at work for some weeks I am again feeling anxious and don't feel able to use much of the CBT toolkit to help my situation. I have approached my GP again for advice”.

Several expressed an understanding of the scarcity of services and weren't sure if they would be able to receive another service as a result:

“I worry that if I have similar difficulties in the future it may not be possible to get this treatment again as mental health seems to be considered a Cinderella service that would be high on the list for cuts, and access to it feels like a lottery”.

“I would seek help again if I felt I needed it but it has been made clear to me that the counselling help is 'rationed' because of over-demand so I'm not confident that I'd receive it”.

Only a few respondents had been told that they could contact the same service again in the future if needed:

“I am concerned that once the sessions cease I will relapse. The advisor tells me that although the service isn't a day-to-day 'safety net', in real difficulties I could contact them and in the future if the need exists I could have further support/sessions”.

### **2.2.7. Alternative Services**

Many respondents described using alternative services or support, either concurrently with their talking treatment or afterwards.

#### **Referral Elsewhere**

Users were referred elsewhere after they had started or when they had finished their talking treatment. Sometimes the first talking treatment was too limited in dealing with their particular mental health issues and a referral was made to a more specialist service, including to Secondary care, such as for eating disorders or abuse. At other

times the referral was for a different type of talking treatment, such as a group treatment:

“I have been referred for EMDR since the therapist believes it will help my problem”.

“Attendance at the talking treatment helped to identify that my illness would be better served by referral to a Psychiatrist”.

Respondents explained that sometimes they would have preferred to have been referred directly to the second talking treatment. In these cases often their first service was a telephone treatment or sometimes cCBT:

“Could have done with the talking treatment initially when I thought I was having a breakdown, yet it was months later after beating the blues and phone call treatment”.

“Had to do guided self-help before being allowed to have counselling”.

In a few cases, respondents were referred several times to a range of services and experienced difficulties with the referral or sometimes still didn't receive a service:

“I was referred to A, who referred me to B, who referred me to C, who referred me to D, who referred me back to A. So much time has been wasted waiting for the next appointment. Repeating myself and never seeing the same person twice. All this time trying to manage my mental health. Very frustrating and frightening at times”.

“I had treatment with the IAPT team. My IAPT therapist referred me to CMHT but this referral got 'stuck'. I eventually made an appointment with my GP who informed me the IAPT referral got 'bounced' back and he said he would have to make the referral instead due to a rule about money. The delay from IAPT to CMHT to GP to CMHT was lengthy and frustrating”.

## **Other Talking Treatment**

Many respondents entered into talking treatment having received it in the past and/or having a good idea of what they wanted now. However, they often experienced great difficulties in the NHS in particular, and described having to undergo long-winded and time-consuming processes in order to be referred to the type of treatment they wanted:

“I already knew that CBT isn't the right therapy for me but this was all that was offered. I did try to talk about my concerns of CBT. It was only after 6 very difficult phone calls that I managed to get put on another waiting list. I also said that I wasn't happy with phone calls but was never offered face to face therapy”.

“I had previously paid for private psychodynamic counselling which aggravated my condition too much. On referral and assessment this was recognized. But I was initially given 6 sessions of CBT and in first session therapist said she couldn't help me with CBT – I needed longer help. After CBT and another long wait, I was referred to a psychodynamic therapist, which was incredibly disappointing and upsetting. My assessment for treatment had advised against

this! So another long wait ensued. And of course this 'waiting' was in a desperate and deteriorating state of mental health. So it took a lot of extra suffering + trauma, not to mention delay, which was very damaging and unnecessary. My third therapist has been great, but should ideally have been my first".

Some described paying for private treatment as an alternative:

"Therapist was booked up constantly I went to private CBT in the end. That service was excellent and I will use the private therapist in future even if it makes me broke!"

"The private CBT I went to was excellent and helped me back from a dark place. It cost me a fortune which is unnecessary if NHS service was any good".

Some respondents described wanting a "cocktail of therapy":

"I think CBT would work better with counselling at the same time. I had counselling at the same time as CAT and found it enormously helpful. I know this is not supposed to be good. But counselling gave me an outlet to talk about all the little day to day things/explained thoughts and feelings while therapy got to the root of the reason of it all".

"A combination of some psychoanalytic with some CBT and some Mindfulness/NLP might have been good although appreciate therapy types don't usually work in combination".

Some acknowledged that sometimes the provided treatment wasn't sufficient but had been helpful in leading to them seeking other types of talking treatments, often in the Private sector:

"I am now looking into private psychoanalysis therapy but this service was a good starting point".

"The service was a step in the right direction. It helped me identify the issues and gave me the impetus to explore further avenues and long term projects".

Several mentioned the financial impacts of this, with some unable to afford such treatment:

"I have since turned to private therapy and in future I would probably opt for this even at great expense to myself as this seems to be more beneficial and I don't get the same feelings I do with the NHS therapists".

"I and my counsellor felt I needed more, but the thought of having to start again with someone new and affording to pay for treatment made it not possible".

A few users were unaware of what would be the most appropriate talking treatment and wanted advice and information on treatments available and how to access them:

"I would like more help with identifying other psychological treatments in the future. When I was told that I would probably need further treatment after this

current treatment I was asked to research it myself, and I'd probably prefer more guidance with the different types".

"Although IPT therapy has been of great help to me, it has also highlighted many other issues for which I feel different therapies would be of great help, and am not sure how to access them, or even if they are available without going private".

## Medication

Several users described their use of medication. Sometimes they were reluctant to use it and had only started taking it while waiting for their talking treatment to start, as described earlier. At other times, they took medication concurrently and appreciated it:

"Medication is still a great friend for me and I have learned to use it wisely after many years of trial and error".

"It is only early days but I am sure therapy will help me along with medication".

Several respondents explained that they had found the talking treatment more helpful than the medication and had therefore discontinued their medication or had plans to:

"I have found talking therapy significantly more helpful than the prescription drugs I have also tried".

"I'm hoping that I won't need [talking treatment] again and that it will help me when I decide to discontinue taking medication".

Others were unable to identify whether the medication or talking treatment were most helpful. Some of these still had difficulties and were continuing with the medication:

"Am currently on medication and don't feel the talking treatment was of great benefit on top of this".

A few explained that the only choice available to them was medication or talking treatment and some had purposefully opted for a talking treatment:

"I would recommend talking treatment first before going down the medication route. If you can sort out your mind set, you don't need to pop a pill every morning, is what I think".

"I feel my local GP and the psychiatric doctor who reviewed my case were too eager to prescribe anti-depressant drugs as a panacea to all problems. Mind altering drugs do not resolve problems and can be a hindrance rather than a help. I wanted to be in charge of my own brain. Consequently I started feeling better (assuming I was ill in the first place) very quickly after I stopped taking the anti-depressant drugs".

One respondent commented on the differences between medication and talking treatments:

"Psychiatric treatment (use of antidepressants) and psychological treatment ('talking treatment') often seem to me to come from differing viewpoints on

how to treat anxiety disorders. This can be confusing and a little conflicting from the patient's point of view. It would seem that more dialogue between the two would be a good thing".

## **Other Services**

Respondents described a range of other services they were receiving at the same time as their talking treatment, including support workers, CMHT workers and GPs:

"I started to pick up when I was given a regular support worker every week. Up until then my depression was getting worse! She encouraged me to leave the house, drive again, and gradually resume most of the things I had stopped doing...now I am taking an anxiety course in the new year and have had several sessions with a clinical psychologist, which I am continuing! I will also be able to contact my support worker whenever I need her".

"I needed to also be supported by my local CMHT [place name] whilst undergoing therapy initially".

A few specifically mentioned a need for crisis services:

"I asked for phone numbers etc in case of emergency or if I need to just talk to someone, but there doesn't seem to be anything available in my areas. I was finally given The Samaritans and Saneline numbers, but it has taken months for this to happen".

"Treatment helps understand, not cope, particularly in 'crisis' moments. If anything these times feel worse now because other avenues of support are closed now that treatment has begun".

Some explained they needed more support concurrently with their talking treatment but were unable to access it:

"Not enough support while doing this and was left feeling down at times".

"Too few sessions and no external help".

## **Informal Support**

Users were appreciative of the informal support they received from family, friends and other places such as their church. They described how such support helped:

"I felt often lucky that I had other support (friends) to help me through the difficulty I was on and to encourage me into the benefit of group therapy".

"I have had huge support from my family and friends who also listen to me".

One compared their formal talking treatment to the support they received from their Mother:

"Sitting and talking to my Mum has more positive effect than this kind of 'therapy'".

## Self-help

A few respondents explained they carried out self-help activities at the same time as or prior to starting their talking treatment and felt that this had greatly contributed to their recovery:

“Things have improved dramatically but this is in part to CBT, my own efforts & research and a very long time span”.

“I think I would have just used some self help books and be disciplined on completing the tasks such as ‘exposure’ to over-come my anxieties. I have previously read and followed self help books so during my phone calls from talking space I could relate to the advice given”.

Some respondents felt that they hadn’t learnt anything new from their talking treatment:

“I feel I have already come, through my own logic and reason, to manage my conditions in the way our group is being brought the skills to do, so am a little disappointed”.

“I haven't been told or learnt anything I didn't know already through self help books etc...tapes for relaxation”.



## 2.3. Reflexivity

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The author of the report is a user of mental health services and has experienced a variety of talking treatments herself. She therefore brings her own perspectives into the process, as is true with all researchers of course. At certain points in the analysis specific decisions were made.

For example, during the phase of reviewing the themes, it could be argued that there were not sufficient data to support a number of sub-themes. This includes some of the sub-themes that related to demographic characteristics in the main theme *Personal Factors*. However, coming from a user perspective, the author believed it important to include these as distinct sub-themes as the issues involved are often thought to be important to service users.

Conversely, the opposite was carried out in some cases. For example, a sub-theme entitled *Learning* was removed from Outcomes of Talking Treatment, because it was felt that the issues were adequately covered in other sub-themes in that main theme.

## 2.4. Limitations

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Users were sent the Talking Treatment questionnaire by services if they had received at least one session of talking treatment, however this was sometimes not a sufficient number of sessions for users to be able to make a judgement regarding many of the questions. In fact, many users stated they were unable to answer some questions even if they had received several sessions of talking treatment.

In addition, some users commented on the format of the Talking Treatment questionnaire and stated that they were unable to give a simple yes or no answer to some of the questions and would have appreciated being able to give an “unsure” answer. These comments will be taken into account when the questionnaire is used again in future audit work.

Due to resource limitations, qualitative comments from only approximately one third of questionnaires were able to be analysed. In addition, the questionnaires used were mainly those that were returned at an early date.

As has been described in several sections of the results (see sub-themes Telephone and cCBT in the main theme of Talking Treatment Approach), some respondents felt that the intervention they received was not a “talking treatment”. Some of these therefore didn’t comment on some of the sections because they felt it was irrelevant to them.

It is not known how significant all of these limitations are.

### 3. Conclusion

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This report highlights some important themes regarding people's experience of psychological therapy services. The findings from this report will be shared with therapists, service managers, service user groups, the voluntary sector, commissioners of services and policy makers. It is hoped that this report, along with other data from NAPT can be used to help improve the quality of future services.

## 4. References

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## Glossary

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**Cognitive Behavioural Therapy (CBT)**- a type of therapy which aims to help a person understand how thoughts and feelings influence behaviours.

**Computerised Cognitive Behavioural Therapy (cCBT)**- is CBT delivered by an interactive computer programme which guides a person through the principles of CBT.

**Cognitive Analytical Therapy (CAT)**- a form of psychological therapy that looks at the way a person thinks, feels and acts, and the events and relationships that underlie these experiences (often from childhood or earlier in life).

**Community Psychiatric Nurse (CPN)**-A CPN is a mental health nurse who works in the community.

**Eye movement desensitization and reprocessing (EMDR)**- a type of therapy used for trauma and using bilateral stimulation of the client/ service user.

**High intensity therapy/treatment**- therapy that is offered to those with more complex needs, it allows for a greater number of sessions and includes CBT, DBT, IPT, and Couples Therapy (see below).

**IAPT and non-IAPT services**- Improving Access to Psychological Therapies (IAPT) is a primary care service, developed over the last three years to improve patients access to evidence based treatments and reduce waiting times.

**Interpersonal therapy (IPT)**- is a time-limited psychotherapy that focuses on the interpersonal context and on building interpersonal skills.

**Low intensity treatment**- therapy that is offered to individuals with mild-moderate mental health disorders and includes cCBT, psychoeducation (see below) and CBT based self help techniques.

**Obsessive Compulsive Disorder (OCD)**- an anxiety disorder characterized by obsessive thoughts and compulsive actions such as cleaning, counting and checking.

**Outcomes**- What happens on the basis of treatment, could include e.g. recovery, improvement.

**PHQ-9**- a nine item depression scale of the Patient Health Questionnaire to help clinicians in diagnosing depression as well as selecting and monitoring treatment.

**Post Traumatic Stress Disorder (PTSD)**- is a severe anxiety disorder that can develop after exposure to any event that results in psychological trauma.

**Primary and secondary care**- Primary care is centred around a GP and usually refers to initial or first contact/ treatment. Secondary care is provided by specialists who are not usually the initial point of contact.

**Qualitative research-** Qualitative research explores people's beliefs, experiences, attitudes, behaviour and interactions. It asks questions about how and why. It generates non-numerical data. Qualitative research techniques include focus groups and in depth interviews.

**Quantitative data-** Data that is taken from surveys and is usually numerical.

**Thematic Analysis-** a commonly used method of qualitative analysis which involves searching through data to identify any meaningful themes.



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