

Measuring access, appropriateness, acceptability and outcomes

Talking Treatment

-

Developing a service user satisfaction questionnaire for a national audit

A report by
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Executive Summary

In 2010, the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI) will be running the National Audit of Psychological Therapies for people with anxiety and depression in primary and secondary care. A key aspect of the audit is to collect data on people's satisfaction with the psychological service they have received.

A systematic literature review was conducted to identify an existing satisfaction measure that was sufficiently validated and reliable to meet the needs of the audit. However, none of the existing measures proved suitable for people receiving psychological interventions for common mental health problems in an outpatient setting. The project team therefore developed a draft service user satisfaction questionnaire which consisted of relevant items based on some of the most commonly used satisfaction tools that were identified in the literature review.

A number of focus groups with current and former users of mental health services were undertaken to discuss this first draft. The groups were asked to discuss the general content, layout, structure and wording of the questions.

The feedback obtained was analysed and categorised into two sets of themes. One set of themes related to people's experience with the mental health service. The second set of themes related directly to the content of the questionnaire. After consideration of both types of comments, the items in the questionnaire, the structure and layout were modified and a new service user satisfaction questionnaire, 'Talking Treatment', was developed.

Chapter 1

Introduction

1.1 Background

The Royal College of Psychiatrists' Centre for Quality Improvement (CCQI) has received three years of funding from the Healthcare Quality Improvement Partnership (HQIP) to conduct an audit of psychological therapies for anxiety and depression in primary and secondary care in England and Wales.

The audit's aim is to measure access, acceptability, appropriateness and outcomes of therapies received for common mental health problems across the majority of Primary Care Trusts (PCTs) and Local Health Boards (LHBs).

Drawing on relevant public documents and advice from the steering group members¹, a total of eleven standards were developed and a service's performance will be measured against these. Two of these standards relate to service users' experience and perceived quality of care.

Standard 11: People receiving psychological therapy experience and report a positive therapeutic relationship/helping alliance with their therapist (which is comparable to that reported by people receiving treatment from other therapists/services).

Standard 12: At least 80% of patients/clients who responded to the satisfaction survey for the treatment/service they have received reported a high level of satisfaction.

In order to measure the above standards as part of the national audit, it was necessary to develop 'Talking Treatment', a measure of service user satisfaction.

¹ Members of the steering group include representatives from the following organisations: British Psychological Society (BPS), the Royal College of General Practitioners (RCGP), the Royal College of Nursing (RCN), the New Savoy Partnership, Clinical Outcomes for Routine Evaluation (CORE), the British Association for Behavioural and Cognitive Psychotherapies (BABCP), the British Association for Counselling and Psychotherapy (BACP), United Kingdom Council for Psychotherapy (UKCP), the British Psychoanalytic Council (BPC), Mind, Rethink, Depression Alliance, No Panic, Anxiety UK and the Mental Health Providers Forum.

1.2 Who is this report for?

This report will be of interest to:

- The focus group participants who were involved in developing the new satisfaction measure
- Audit workers and managers involved in carrying out clinical audit and interested in using this satisfaction measure
- Researchers interested in developing new measures of service user satisfaction

1.3 Why did we need to develop a new measure of service user satisfaction?

In order to measure the audit's standards, service users' feedback on their experience with the psychological service in which they are engaged need to be obtained.

The first step was to conduct a systematic review of the literature. The aim was to identify all existing satisfaction measures that are suitable to be used in a mental health setting. All existing tools were reviewed to determine whether they were appropriate for use in the audit and whether they had been sufficiently validated (see **Chapter 2** for more detailed information).

The review did not identify an existing satisfaction measure available that was suitable for the purposes of the audit. It was therefore decided to develop a new measure of service user satisfaction.

Chapter 2

Development of the draft questionnaire

A systematic literature review was conducted to identify all existing satisfaction measures used in a mental health setting. The obtained tools were reviewed to determine whether they were appropriate for use in the audit and whether they had been sufficiently validated.

2.1 Search Strategy

The databases Pub-Med, CINAHL, EMBASE Psychiatry, PsycINFO and MEDLINE were searched in order to obtain any existing satisfaction questionnaires for people using the health service. The search resulted in a total of 12,347 articles (see **Appendix A** for search strategy log).

2.2 Sifting of search results

First sift: The first sift involved checking article titles and discarding those that did not have any relevance to satisfaction or feedback measures in the health service. After the first sift a total of 926 appeared to be of possible relevance.

Second sift: Abstracts for all 926 articles were checked to see whether the questionnaire was developed as part of a rigorous study and whether testing of reliability or validity had been carried out. A total of 190 articles appeared relevant.

Of the 190 articles, the project team was only able to retrieve 136. Only those articles that were available through the University College London (UCL) were included. Budget and time restrictions precluded ordering the other articles via interlibrary loan. After removing any duplicates the remaining number of relevant articles was 83.

Third sift: The 83 articles were checked for methodological quality and the satisfaction questionnaires discussed in the studies were obtained. The questionnaires were included if they were suitable or meaningful to a mental health setting. Measures were discarded if they focused exclusively on physical health needs, issues of medication or the environment and staff of an inpatient setting.

In summary, this systematic review of the literature resulted in 25 existing satisfaction questionnaires of relevance. These included generic satisfaction measures, such as the 'Client Satisfaction Questionnaire-8' (Attkisson & Zwick, 1982), as well as tools geared towards specific care services for physical or mental health, such as the 'Patient Experience Questionnaire' (Steine, Finset & Laerum, 2001).

In relation to measuring satisfaction with services, the audit's aim is to capture all aspects of the care pathway, from referral to discharge. This includes service users' experiences of accessing, and receiving psychological services, as well as their perceived outcomes of the treatment. In addition, it is considered essential that a service user satisfaction questionnaire elicits specific feedback on people's experiences in order to help services identify aspects that are working well and areas for improvement.

Some of the obtained measures were too narrowly focussed on particular aspects of care, such as administration of medication, which are not necessarily relevant for psychological services in primary or secondary care. Others centred on people's satisfaction in general, which lacked information for services on what aspects they need to improve in order to increase people's satisfaction.

After a careful review and discussion with three members of the project team, it was concluded that none of the existing tools fulfilled all of these criteria and provided a feedback measure that satisfied the needs of the audit.

2.3 Design of a first draft of a satisfaction measure

A first draft of a service user satisfaction questionnaire was designed by selecting relevant items from the existing validated measures identified in the literature review.

The questions from the tools were listed and divided in the categories relevant to a person's care pathway - access, acceptability and outcomes of treatment. Three staff members independently rated the list of questions and selected those that appeared to be most appropriate for the purpose of developing a satisfaction measure for people receiving psychological interventions for common mental health problems in primary and secondary care.

The project team agreed on a set of questions that would reflect a person's care pathway from referral to discharge in the mental health service based in the community. The questions were rephrased to be relevant for this project's purpose (e.g. the word doctor was replaced with therapist), the response scales were adjusted to provide a single response format and the structure and design was amended to form one coherent layout.

The team decided on the commonly used five-point Likert response scale with responses of an even interval (strongly agree, agree, neutral, disagree,

strongly disagree) (Likert, 1932). This provided respondents with an equal number of positive and negative answers towards a given questionnaire item.

The draft was presented to and discussed with participants of four focus groups (see **Appendix B** for draft questionnaire).

Chapter 3

Focus Groups with Service Users

In order to develop a satisfaction questionnaire that is meaningful and attractive to service users, it was essential to involve people with experience of psychological interventions in its development.

As suggested by Tait and Lester (2005), by involving service users, the project team would benefit and learn from their expertise, gain an understanding of their perspective of psychological services and their challenges when accessing and receiving services. In addition, the focus group meetings have often shown to be therapeutic for participants (Tait & Lester, 2005). It was therefore decided to run a number of focus groups with the help of different service user organisations.

Focus groups are known to be particularly helpful for generating ideas amongst vulnerable populations since they create a fairly 'naturalistic' setting (Green, 2007). Furthermore, the focus group setting provides an opportunity for people to participate who might be intimidated by a one-on-one interview or who are in doubt of the relevance of their experience (Kitzinger, 1994). Such group discussion has also been shown to produce a richer level of information than individual interviews alone, as participants are encouraged to share personal opinions and experiences (Kitzinger, 1994).

3.1 Aim of the focus groups

The aim of the focus groups was to obtain comments and feedback on the content, wording of questions, response scales, layout and structure of a draft questionnaire to inform the development of a suitable service user satisfaction questionnaire to be used for the National Audit of Psychological Therapies for Anxiety and Depression.

The voluntary organisations Mind, No Panic and Rethink were approached as they have a national network of people with experience of common mental health problems. Representatives of these groups are also members of the National Audit's Steering Group and offered to assist in the recruitment of participants.

The voluntary organisation Age Concern was approached as it was necessary to obtain the views and comments of older people since the final version of the satisfaction measure will be handed out to older people as well as working age adults.

Four focus groups were undertaken, one of which was a telephone discussion group.

3.2 Objectives

The objectives were

- To enquire whether all areas of relevance for people receiving psychological services are included when asking about their satisfaction with the service,
 - To explore the language used by people with experience of receiving psychological therapies for anxiety and depression,
 - To eliminate any wording that could cause offence to someone completing the questionnaire,
- and to modify the draft questionnaire accordingly.

3.3 Methods

In order to best meet the objectives above, it was decided to run focus groups with current or former service users.

This method has shown to be useful for research of health services (Green, 2007) and the development of questionnaire design (McKinley, Manku-Scott, Hastings, French & Baker, 1997; O'Brien, 1993).

A focus group design is particularly helpful when discussing sensitive issues and experiences, such as mental health difficulties as it enables people to discuss these topics in a peer-supported and 'naturalistic' environment (Green, 2007).

3.4 Design

Following Chandler-Oatts and Nelstrop (2005), all focus groups were recorded and transcribed.

The produced text was then analysed in two distinctive stages. For the first stage of the analysis, the content was coded and summarised by questionnaire item in order to identify specific comments to the individual questions of the satisfaction measure.

For the second stage a thematic content analysis was conducted identifying the key concept in each segment of the transcribed text (Green, 2007). After careful consideration of their content, the obtained concepts were merged into high and low order themes (Burnard, 1991).

3.5 Sampling

As discussed by Mays and Pope (1995), a 'systematic, non-probabilistic sampling' was applied, which is commonly used in qualitative research. Participants were recruited by deliberately selecting a sample of people sharing certain characteristics (Bowling, 2002).

Participants were expected to have experience of receiving psychological therapies and were therefore recruited through the networks of service user organisations, as explained below.

Mind: An advert was sent to members of MindLink, which is a network of people who have personally experienced mental distress. Interested participants were then referred to the project team.

No Panic: The chief executive invited members of the organisation to participate.

Rethink: A member of staff of a Rethink organisation informed users of their local psychology service about the project and recruited interested participants.

Age Concern: A member of staff, who specialises in psychological services for older people, asked one of their groups to participate.

3.6 Participants

The characteristics, such as age range and therapeutic experience, of the focus group participants from each service user organisation are presented in the following.

No Panic (telephone group)

Number of Participants: 5

Number of staff present: All participants are members of No Panic.

Age range: 60-65

Gender: 1 Male, 4 Females

Ethnicity: All White British

Therapy experience:

All participants have had psychological therapy experience provided by the NHS; four have also received privately funded interventions. All five participants have received counselling. Other experienced therapies were Cognitive Behaviour Therapy (2), Psychodynamic/Psychoanalytic Therapy (2), Guided Self-Help (1), Behaviour Therapy/Behavioural Activation (1) and Hypnosis (1).

The number of sessions received to date ranged from 13 to 130 (mean 58).

Mind

Number of participants: 10

Number of staff present: 1

Age range: 25-74

Gender: 3 Males, 7 Females

Ethnicity: 7 White British; 1 White Irish; 1 Indian; 1 White/Greek

Therapy Experience:

All participants have had psychological therapy experience provided by the NHS; four have also received privately funded interventions. Information on therapies received was completed by 7 participants.

The experienced therapies were Cognitive Behaviour Therapy (5), Counselling (5), Psychodynamic/Psychoanalytic Therapy (3), Interpersonal Therapy (1), Anger Management (1), Art Therapy (1), Couple Therapy (1),

Person-centred Therapy (1), Cognitive Analytic Therapy (1) and Psychoeducational Groups (1).

The number of sessions received to date ranged from 16 to approximately 239 (mean 88.5).

Age Concern

Number of Participants: 6

Number of staff present: 2

Age range: 75-93

Gender: All Female

Ethnicity: All White British

Therapy Experience:

It was difficult to gain a true picture of the experience with therapies by the group of older people. The project team did not ask the participants to complete the section on therapeutic experience on the monitoring forms as it became apparent during the focus group discussion that the majority of the participants were not aware that they had received talking therapies in the past. A staff member of Age Concern however assured that all participants had taken up psychological interventions in the past.

Rethink

Number of Participants: 7

Number of staff present: 5

Age range: 35-64

Gender: 3 Males, 4 Females

Ethnicity: All White British

Therapy Experience: Four participants filled in this section and indicated that they had experience with psychological therapies. Three of those were funded by the NHS and one was provided by a voluntary organisation. The experienced therapies were Cognitive Behaviour Therapy (3) and guided self-help (1).

Only two participants gave the number of sessions received to date. These ranged from 10 to 12 (mean 11).

3.7 Role of facilitator

The focus groups were facilitated by the project team Nici Gideon, Elizabeth Hancock and Louise Nelstrop. Two members of the project team were present at each focus group discussion. One person was leading the focus group and the other was taking notes about the discussion and any relevant behaviour, gestures or expressions. Representatives of the service user organisations were invited to co-facilitate the meetings.

The facilitator reminded the group of the purpose of the discussion and encouraged the participants to share their experiences and opinions. The facilitator's main role was to guide the discussion according to the focus group schedule (see 3.8), ask for clarification if needed, invite people to talk who had not had the opportunity to do so and enable a comfortable, safe and respectful environment for people to share their thoughts.

3.8 Focus Group Schedule

The focus group discussions lasted about three hours each with exception of the telephone discussion, which lasted about two hours.

The key points of the focus group schedule were to address:

- whether there are any general concerns about the questionnaire
- whether there are any questions/sections that participants consider problematic
- whether there are any issues that are not included
- whether there are any questions/sections that are redundant
- any wording that appears problematic
- specific questions that the project team found problematic
- participants' views about the general layout and structure of the questionnaire

3.9 Ethical considerations

This tool was developed as part of the National Audit of Psychological Therapies for Anxiety and Depression. Audits and the development of audit tools are exempt from ethical approval as clarified by the Central Office for Research and Ethics Committees (COREC). COREC's position is that *"Audit and Service Evaluation, however defined, were recognised to have no, or less than minimal (risk), and there was broad agreement that such work need not come before an NHS REC, unless specifically requested"* (COREC ethics consultation e-group: Audit, research or service evaluation, Oct 05).

Every effort was however made to ensure that due consideration was given to the ethical issues that arise from working with service users.

3.9.1 Information

An information leaflet (see **Appendix C**) explaining the background of the project and the purpose of the focus group discussion was sent out to participants. It also assured participants of the confidentiality and the anonymity of the information they would be sharing on the day.

After participants had agreed to participate, the first draft of the service user satisfaction questionnaire was emailed to them along with guidance on what to think about when reading through the questionnaire (see **Appendix D**).

In addition, a discussion schedule was included to provide an outline of what the team was hoping to talk about at the meeting (see **Appendix E**).

Participants were encouraged to contact the project team with any questions that they might have about the audit and/or the development of the service user satisfaction questionnaire.

Due to time constraints, the group organised through Age Concern received a copy of the documents on the day.

3.9.2 Informed consent

Before the focus group began participants were asked to sign a consent form² (see **Appendix F**). This was taken as a formal agreement that they were willing to take part in the development of this questionnaire. Prior to being asked to sign the consent form, they were given an opportunity to ask any questions they might have about the audit and the tool. They were under no obligation to participate in the discussion groups. Many participants were in fact extremely eager to take part in the groups as they saw the audit as a way of helping to improve practice. They expressed their frustration at being involved in research studies that did not have practical outcomes like that of the audit. It was repeatedly stressed that their participation was voluntary. It was also reiterated that they could withdraw their involvement at any time.

On the day of the focus group, participants were asked for permission to have the discussion recorded. All participants in all focus group verbally agreed.

3.9.3 Setting

The focus groups were conducted at facilities made available by the service user organisations so that the organisation would be able to offer support to any participants who felt the need to talk further after the discussions. A member of the service user organisation was present at all meetings to ensure appropriate support in the event of a distressing experience or feelings.

3.9.4 Payment

As recommended by relevant guidelines (Department of Health, 2006), participants were reimbursed for any expenses that they incurred travelling to the focus group. They were also given a one-off payment of £50 each as a reimbursement for their time. With the exception of Age Concern and the telephone focus group with No Panic, lunch was provided before or after the discussion.

² In the Age Concern group, participants gave verbal consent prior to the focus group. They were made aware that they did not have to take part in the study and that they could withdraw at any point. None chose to do so. The reason for this was that there was a time limit on the period in which the project team was able to set up the group discussion and to collect written consent. However time had been set aside by the facilitator after the meeting when the project team could talk carefully with individual participants and help them fill in the consent form and the demographic information forms. Many of the participants were visually impaired and one was unable to write for herself. It would have been too time consuming to have filled in the forms prior to beginning of the focus group. The project team ensured that informed written consent was attained prior to including the taped discussion in the report.

3.9.5 Confidentiality

Participants were assured that any information provided on the day would remain confidential. The recordings and all other documents relating to the focus groups were kept in a locked cupboard only accessible to the project team. Participants were assigned a number, which replaced their name to avoid identification in the transcripts. Any other identifying information within the transcripts was removed.

The recordings of the group discussions were destroyed after transcribing the data.

3.10 Data Analysis

Firstly, the content was coded and summarised by questionnaire item in order to identify specific comments to the individual questions of the satisfaction measure.

Secondly, the transcribed text was analysed according to a 'thematic content analysis' as described by Green (2007). The key concept of each segment of text was identified and coded with a heading.

The collated headings enabled two members of the project team to divide them into separate categories or themes to produce a coding framework (Green, 2007). During this qualitative analysis it emerged that participants commented on two distinctively different types of themes – their experience with the mental health service and comments directly linked to the questionnaire. The emerging themes identified in the four focus groups were therefore split into two sets of themes and within each further separated into general high and low order themes (Burnard, 1991). The themes were identified by two members of the project team (NG and LN) independently. Through discussions final terms of wording were agreed.

Some researchers suggest that the use of computer software in qualitative analysis adds rigour to the findings (Richards & Richards, 1991). The content of one focus group discussion was therefore inserted into the qualitative data management system NVivo. The text was re-analysed to examine whether the themes identified in the manual analysis would be confirmed. Welsh (2002) advises to apply the best features of the manual and the computer-assisted analysis in order to ensure 'that the data are thoroughly interrogated' (p.5, Welsh, 2002).

The project team identified the same set of high and low order themes when analysing the data with NVivo which further strengthens the presented results.

The findings were presented to the participants of the focus group discussions in a report. They were invited to comment on the findings by the project team and to add any thoughts or comments.

3.11 Results

During the focus group discussions it became apparent that there were two distinctive types of comments made. The first referred to the participants' experiences with mental health services, while the second referred to comments that had a direct relevance to the structure, format and content of the questionnaire.

The aim of the focus group was to obtain feedback on the questionnaire items. In order to explain and clarify their comments, participants shared their experiences with and opinions about psychological services. Many of these stories offered important insights, which influenced the questionnaire development, but also highlighted important gaps in service provision. To clarify the findings, the report will present and discuss the emerging themes from both types of comments separately (see Chapter 4).

In Chapter 5 changes made to structure, layout and timing, and the individual questions of the draft questionnaire will be explained and presented in more detail.

3.12 Limitations

A common drawback of group discussions is the occurrence of 'group think' (Janis, 1972); the phenomenon of a groups' readiness to come to a unanimous conclusion and the reduced willingness of generating alternative points of view.

As discussed by Moorhead, Ference and Neck (1991) 'group think' can be influenced by differences in leadership style. The facilitators therefore made every effort to reduce the risk of an occurring 'group think' by encouraging all participants to contribute to the discussion and by promoting an environment that was accepting of individual opinions. During the group discussions 'group think' might have however occurred at times despite the efforts to prevent it.

One of the conducted focus groups was run with older people. It has to be recognised that the focus group design did not appear to be the most appropriate method of obtaining feedback from older people in this instance. On reflection, it seemed likely that the older people would have benefitted more from a one-on-one interview design that would provide them with the undivided attention of the facilitator and the opportunity to share their stories without any interruptions. It proved difficult to engage the group in a joint discussion as there was a tendency to engage in one-on-one discussion between participants and a significant amount of time was spent on clarifying what was meant by the questions presented and the terminology used in the questionnaire. Many participants did not seem to have an opportunity to share their thoughts. It is therefore felt that the opinions expressed in this report are not necessarily representative of those by older people. The project team would conduct individual interviews with older people (75+ years) in any future work.

As a result of conducting this focus group the project team are undertaking further work during the pilot phase of the audit to ensure that the questionnaire is appropriate for this age group.

It is also recognised that this study is limited by the lack of service user researcher involvement. Trivedi and Wykes (2002) recommend the inclusion of user researchers as part of project teams, and Turner and Beresford (2005) promote a user-controlled research approach. A user researcher can change the focus of a project and influence the design and methodology used through the introduction of a user perspective.

The project team has attempted to address this issue by involving service user representatives from the audit's steering group. Still, it has to be acknowledged that this project could have further benefitted from a user researcher as a team member, which could have resulted in different approaches to designing the questionnaire for the audit.

The project group raised the lack of user research involvement with the senior management team and it is hoped to have a higher level of user researcher involvement during the main audit.

Chapter 4

Qualitative Evaluation of the Focus Group Discussions

In the following, the themes relating to participants experience with the mental health service and those referring to the questionnaire directly will be discussed separately.

Participants' experiences of the mental health service

The themes that emerged from participants' personal experiences of receiving psychological therapies are presented in Table 1. The themes have been categorised into high and low order themes (Burnard, 1991) to help identify the key issues that emerged from the analysis of the focus group discussions. High order themes represent the main topics that have been identified. The low order themes are more specific categories that relate to the relevant high order theme.

Table 1: High and low order themes of service users' experiences

High Order Themes	Low Order Themes
perceived barriers	access
	receiving treatment
	pressure to recover
choice	information vs. choice
	therapist vs. treatment
	decision making

4.1 Perceived Barriers

The first theme, 'perceived barriers', relates to people's experiences of accessing care, receiving treatment and a felt pressure to recover given that the number of therapeutic sessions is usually limited.

Participants in all groups described experiencing difficulties in different areas of their care pathways when trying to get help for their mental health problem. Problems caused by their anxiety or depression were often faced with unresponsiveness by the therapist or the service. Additionally, flaws in the NHS system sometimes exacerbated these difficulties.

4.1.1 Access

Some participants reported that they were seen very quickly by a therapist.

"My therapy started quite quick. I actually refused it at first, [laughs] I was that resistant to help...but within 2 or 3 weeks, I got the help I needed."
[Participant 18]

Many however explained that they had to overcome significant obstacles in order to access a talking treatment in the first place.

In some cases, their mental health problem made it difficult, if not even impossible, to arrive at the place of help. Participants reported that they did not have the confidence to leave their house or even answer the phone.

"You see that's the thing, they say go to the doctors, but if you're frightened literally of being out of the house, you know, you need a therapist actually to give you the confidence. So I think the doctor should understand that part of the problem is you haven't got the confidence to do simple things like that."
[Participant 24]

This difficulty often remained misunderstood by the General Practitioners and no further support was offered.

"...I went to my GP and he said, look, you can go to this hospital 4 miles away and I said to him, well, if I could get there I wouldn't need that help and he was absolutely livid with me and says well, you are just not taking the advantage of what's being offered, and I said well, I wish I could but there is an awful misconception that we can get anywhere." [Participant 1]

Some also revealed that flaws in the NHS system had contributed to perceived barriers of accessing treatment. One participant reported that she had waited for a long time to start her therapy, just to find out that she had slipped through the system and had lost her place on the waiting list.

"I was referred to the one at the local surgery and I waited, and I waited and I waited and nearly a year later my husband got on to them and to be told that I was accidentally dropped off the list." [Participant 2]

Additionally, others shared how they had been referred from one health professional to the other without being told the reasons for this. It was reported that the referral systems often did not work well. This resulted in long-lasting waiting times and feelings of confusion.

"Because seeing a therapist and starting treatment is not necessarily following on from the other. Because often, in our experience, you see one therapist who then, is the head of the team and then he or she allocates you to...You don't automatically see the therapist who's going to treat you."
[Participant 1]

As a result of these experiences, many reported that they turned to self-help resources, such as contacting charities for support to overcome their

problems as an insufficient amount of help was offered by psychological services.

"It's only when we went one day a week to the Centre [referring to charity] that we got the talking in then, not actually from the top people." [Participant 16]

It was the general consensus that participants acknowledged the need for psychological help when suffering from mental health problems but that many of them faced significant difficulties, which they had to overcome. Unfortunately, they often did not feel that the health professionals, including both GPs and therapists, were aware of these barriers and able to respond in a sensitive and helpful way. Furthermore, a complicated and non-transparent NHS referral system sometimes led to additional problems.

4.1.2 Receiving Treatment

All of the participating individuals had overcome their initial difficulties and had experiences of receiving psychological treatment. Some reported very positive experiences of having received the help they needed.

"My therapist, if I failed to do something, she was always so obliging, she never made me feel a failure, you know, it was always 'OK, let's try again'. That was what I needed to hear." [Participant 18]

Unfortunately, for some people, receiving treatment was associated with several difficulties. Many felt misunderstood by the therapist when talking about their problems, which resulted in a sense of having been left to cope alone.

"The experiences I had, was that they [the therapists] didn't understand about anxiety at all." [Participant 3]

The participants, however, acknowledged that some therapists might be more suitable for their needs than others depending on individual differences and preferences. The perceived barrier in receiving the treatment they needed was founded on the problems involved when wanting to change their therapist. People reported being afraid of enquiring whether it is possible to change their current therapist if their relationship did not seem to develop appropriately or if it was not of a positive kind. One of the questionnaire items asked if the participants would feel free to complain and another asked whether they often feel like complaining about their therapy. When participants were directed to these items they expressed fear of rejection, of losing their place and a sense of hopelessness. This fear was compounded by the belief that they would be abandoned and left alone if they shared their worry that they were not getting the right support.

"People won't often complain about the therapy in case they need help in the future." [Participant 5]

The majority of participants also believed that if someone was brave and well enough to make a complaint it would not be worth the struggle. It was argued that the complaints are not paid attention to or taken seriously.

"But I say, even if you make a complaint it goes nowhere, absolutely nowhere." [Participant 14]

4.1.3 Pressure to recover

They further expressed that they felt under immense pressure to recover in the allotted time, as the therapeutic sessions are limited from the very start of therapy. For them, this further stressed a barrier to recovery from their mental health problem.

"But there's also, right at the beginning, where the therapist says to you 'ok, what we can offer you is six weeks' and then you've got this awful feeling, right, I've got to get better in six weeks." [Participant 2]

It is felt that people receive the number of sessions according to a service's budget rather than according to the person's needs.

"...the budget that says you will treat so many patients, it doesn't say you are treating so many patients until they are better." [Participant 1]

"None is about people getting better, it's about targets..." [Participant 2]

The older people's experiences differed from those of the younger people with regards to their knowledge that there is help available if they needed to talk to someone about their anxiety and depression. The message that they are getting from the health professionals is that it is not possible to get a follow-up treatment or to start a new treatment if this was needed.

"Every time I go [to the psychiatrist] he says there is nothing else I can do with you." [Participant 16]

The focus group participants were well aware that the difficulties that have been caused by anxiety and depression might reappear. With exception of the Rethink group, who were reassured that they can access help without a lengthy referral process, participants felt that they had to rely on self-help to get through difficult times once they had finished their first course of treatment.

"Also people may get to a certain stage and then it's finished. And they still, they perhaps think, well, what was the point of me working so hard because I've got nothing to follow-up on that." [Participant 5]

It was surprising to listen to the wealth of perceived barriers to successful treatment – unfortunately it appeared to be the norm rather than the exception.

It needs to be said though, that the participants could have been a less representative sample of the population of service users caused by the self-selection bias of the recruitment process.

4.2 Choice

The second higher theme that emerged in the focus group discussion is presented in Table 1 (see pg. 20) and was summarised as the concept of choice.

The issues around choice were discussed in great detail by the focus group participants. One questionnaire item explored whether the participants were provided with information about their therapy options. This elicited a discussion about choice – as many believed that they are not given any options. The majority of service users were aware that the NHS would like to provide choice and that service users are entitled to make decisions about the healthcare they receive. It is, however, less clear in which areas people have the chance or the option to make these choices.

Further, often people are not supplied with sufficient information to practice their right of 'informed decision making'.

4.2.1 Information and Choice

A lot of discussion surrounded the relationship between information and choice. People wanted to be provided with a sufficient amount of information in order to be aware of their choices and to make decisions based on the information given to them. Some people reported that they are told very little by the healthcare professionals.

"People don't normally know what's what. There's no information about what's what." [Participant 14]

"My main problem with this is that, for example the first question 'I was adequately informed about the different therapies available' – how does somebody know what the different therapies are?" [Participant 10]

It was argued that some therapists not only neglect to tell their clients about different treatments available but more importantly they do not provide enough information about the specific treatment they are delivering.

"There are a lot of people who had a therapist who actually don't tell them what they are getting." [Participant 12]

However, other participants stated that they can receive too much information. One of the problems with the issue of choice was that people were sometimes unable, because of their illness, to take in lots of information pertaining to choice.

"Or 'Did you receive too much information?' [giving a possible alternative question] You know, you can receive too much information [...] You have piles, you'll have a pile of booklets." [Participant 24]

One participant received information leaflets about different types of therapies available and she felt overwhelmed by the amount of jargon that was used. It was difficult for her to understand the differences between the various approaches and what these would mean to the person receiving the therapy. When she asked for further explanation of the treatments, the healthcare professional stated that they were not able to do this.

"I've got a leaflet about psychological therapies and to be honest, I didn't have a bloody clue what it was on about. And I kept asking 'What is cognitive analytical therapy?' and even the people [delivering it] couldn't explain what it was to me. That wasn't very helpful." [Participant 7]

Another difficulty surrounding the issue of receiving information was that providing someone with information is part of an ongoing process.

"Well, I think that is going to make the difference, in the information sections, cause you don't just get given information all at once in the beginning and then that's it, out of the way, it's kinda one of those issues where you going to want to know a bit more about your therapy or about particular aspects later on in the stage of your therapy. Do you know what I mean? So it's like consent, you don't do it all at the beginning, it's a system of ongoing consent, with information it's going to be like that as well. So, for example, once it's getting near the end of therapy, you are going to want information then about different aspects as well, aren't you." [Participant 10]

An ongoing process of giving information to someone also means that the therapist or the service has to be flexible enough to provide the right kind of information at the right time, according to an individual's needs.

One participant explained that it helped him a lot to discuss the different options of therapies available with his support worker in order to make a decision.

"I was given that with 'Healthy Minds'. [The support worker] came round, do you remember [towards the support worker], when you discussed all the options and what was the best way to go." [Participant 23]

Even if a person has received sufficient information about different types of therapy or about a specific treatment, making an informed choice can be very difficult. As one participant explained, it might be difficult to see what a certain therapy entails before experiencing it first-hand.

"Other people, you know myself, I wouldn't have known what the therapy was until I was in it, even though I used to work in that field. I still had to be in there to know what it was and what I was going to get out of it or what I could get out of it before I committed a choice." [Participant 6]

Participants in one focus group explained that they had been offered telephone support instead of face-to-face therapy. Some participants initially

felt uncomfortable at the idea of telephone therapy but realised its advantages when they gave it a try.

"I thought it was very impersonal, and nobody was more set against it than me, I was adamant I wasn't going to speak to somebody on the other end of a phone. However, I'm the first to put my hand up and say that was wrong, because it has helped so so much. I can say things because I'm not sitting face to face with that person. I can have my heart out." [Participant 18]

For them, it would however been difficult to see the benefits of the telephone therapy before they had experienced it themselves.

4.2.2 Real Treatment Choice?

Even if people were provided with the right amount of information, it was argued that often there are not enough opportunities to actually make any choices.

When being referred for psychological therapy, a health professional, the GP for example, makes the referral to a particular service without consulting the client about their preferences.

"But it wouldn't be the service user that gets the choice. It would be the doctor saying 'I am referring you to a psychiatrist or GP counsellor or a psychotherapist'. It wouldn't be 'What would you like?'. The choice doesn't lay with the service user." [Participant 2]

At the psychological service, people are assessed and told that they will receive a certain therapy based on the assessment. The focus group participants explained that it was the experts who made the choices and decisions for them.

"The patient is usually told, we hope, that CBT is appropriate and I'll refer you to a CBT therapist. There isn't any choice, you know, different therapies available. Or, in my experience, I've never been given any options." [Participant 1]

(But also see quote in section 4.2.1, pg.23, with 'Healthy Minds')

It was also commented on that NICE guidance itself does not leave room to provide service users with the opportunity to have a choice of therapeutic interventions.

"Well, basically there's not really a choice, is there. I mean everyone is given CBT and that's it." [Participant 14]

"We're told it's CBT based – is that going to change? Because according to the NICE guidelines it isn't." [Participant 1]

Additionally, people felt that it was very important to be able to be seen by a therapist with certain characteristics. Some people, for example, prefer to be

seen by a woman or a man. They also felt that they should be able to change their therapist if their therapeutic relationship was not adequate. It was however felt, that being selective was not an option in the current mental health system, even where there was a definite need. People felt if they actively practiced their right of choice it would disadvantage them unfairly.

"And when you start seeing your therapist, and you have a personality clash, then that's it, that's the end of it. Then you have to wait for another year or two to get to another one. And another year or two to get to the right one." [Participant 13]

"This is one of the big national things, the idea is to increase choice for people and make it more available and more accessible, but for example, if you get given a therapist for psychotherapy that you don't want and you say 'no' and you then have to wait for another 2 years, that's hardly a choice, is it?" [Participant 10]

4.2.3 Decision Making

The participants have expressed regret that their involvement in the treatment was limited. Their comments ranged from making a decision about treatment modality to choosing an appropriate treatment time. Many felt that they should be involved in these decision-making processes and that the questionnaire should capture this.

"There are some bits missing in the section all about choice. There's lots of questions you could have about choice. And you kinda covered the therapist available at different times and I mean, you haven't covered location, whether you get a choice in that. I mean the therapist themselves can you change but the provider...[.] All these things about choice. If you don't want a certain type, can you get another type?" [Participant 10]

It is very difficult to capture the complexity of the issue surrounding choice in a short service user satisfaction measure that is being designed for the purpose of this project. It is appreciated that there is a need to make services aware of the limited opportunities for service users to make informed decisions. The tool that is being designed here will not however be able to capture this complex issue. Instead, in recognition of the complex nature of this issue questions relating to broad areas of choice that are supported by governmental guidance will be included in the satisfaction questionnaire. The Care Services Improvement Partnership (CSIP) (2006) emphasised the need for service users to express a preference for the timing and location of their treatment. Therefore, questionnaire items are included that reflect whether service users were given an opportunity to influence their treatment time and whether the treatment location is convenient. There will also be space for participants to comment further on the more complex nature of the issues.

Currently, there is no guideline or Department of Health publication that supports people's right to change their therapist in the NHS. A Department of Health (2001) leaflet recognises that people might want to choose or change their therapist if difficulties arise. It however also explains, that if a person decides to change their therapist, they would have to re-visit their GP, ask to be referred again and re-enter the waiting procedure, which ultimately does not provide real choice of therapist.

Having the choice of therapist was one of the key issues which participants felt very strongly about.

It is hoped that by highlighting service users' experiences and opinions in this way, practitioners will be made aware of the difficulties of people who receive talking therapies. It is further hoped that commissioners and other relevant professionals will realise that the concept of choice is still highly subjective and depends on the extent to which service-users are given relevant information in an appropriate and respectful manner.

The term 'choice' itself also appeared to be problematic. While participants recognised that their right to choice was important and needed to be safeguarded, they were also not clear that 'choice' was the right term to be using in a questionnaire of this nature. The wording of the questions reflects this by using the term 'option' rather than 'choice'.

Comments relevant to the questionnaire

The themes identified below are directly relevant to the design of the questionnaire. As before, they are categorised into high and low order themes and summarised in Table 2 below.

Table 2: High and low order themes regarding the questionnaire

High Order Themes	Low Order Themes
understanding the client's journey (affecting wording of questions)	accessing help
	assessment vs. treatment
	treatment end
client-focused (affecting type of questions)	appropriate involvement
	therapeutic alliance
	individual differences
effect of illness (layout & format)	simplifying
	need of support
	timing

4.3 Understanding the Client's Journey

The first high order theme that was identified related to the need to understand the client's journey.

The focus group participants impressed on the project team how imperative it is that the questionnaire reflects an understanding of the journey a client experiences when receiving psychological therapies. Several participants explained that they would not have continued filling in the questionnaire as it stood since they felt that some of the questions illustrated a lack of knowledge of the client's care journey in several aspects of the questionnaire.

"I think it would make any anxiety sufferer feel, this person hasn't got a clue, why are they asking me these dumb questions?" [Participant 2]

4.3.1 Accessing Help

When reading the questionnaire many participants felt that the questionnaire was not sufficiently sensitive to the problems faced by people suffering from anxiety and depression. The questions in the tool need to demonstrate an understanding of what they are going through, the challenges they face and concerns that are meaningful to them.

"When I read this questionnaire, what came through to me and I might be horribly wrong, and I'm really not trying to be rude, but what came through to me was the person who wrote this questionnaire doesn't understand anxiety. I'm sorry if that sounds rude. But that's what came across to me. Because somebody who understood it, it would not be written in this way." [Participant 2]

Participants stressed that it was important to have a question on waiting times as proposed by the draft questionnaire. However, it became apparent that many of the questions needed rewording to reflect a sensitivity for the person's emotional circumstances.

"See, the phrase 'too long', it doesn't tell you anything because tomorrow is too long if you're desperate. [...] 'I was happy' – none of us were happy when we were told it's going to be x-number of weeks or months!" [Participant 1]

Participants stressed that it can sometimes be very difficult to access help and that services should offer help to those who are elderly or suffering from agoraphobia and are unable to physically get to the service without any support.

Although all focus group participants eventually managed to reach a place of help, it was explained how this had involved a very long struggle for some. Part of this struggle was the fact that, even if the treatment centre were very near any journey might be problematic and challenging for someone suffering from anxiety or depression.

"And that brings me back to my initial point, when I read it I thought this person or persons does not know what it feels like to be an anxious person. They don't know! Because if they did know, they wouldn't have written the

question 'the appointment location is easy to get to', they'd know what that actually meant. They would know what it means, they would know what it feels like." [Participant 2]

Questions about location therefore need to be carefully worded to show awareness of the medical condition or the psychological difficulty some service users may have. Without this, the questionnaire is alienating and unlikely to be filled in by a large number of potential participants.

4.3.2 Assessment vs. Treatment

When being asked if participants were happy with their waiting time, they wanted to see a question that makes a clear distinction between the waiting time to assessment and the time to being actually treated. One participant said that after the assessment it took a long time for therapy to begin.

"The question I really, really wanted to ask and we've already covered it, is 'How quickly were you seen and when did your treatment start?' It's a big thing because it took me 10 weeks to be seen and three years to actually start my therapy. I'm not complaining about that. Just that you capture that." [Participant 12]

The wording of the waiting time question has to be changed to make it clear what it is asking for. The wording "when you first see a therapist" might be misleading, as participants described that they had been assessed by different people, who were therapists but did not subsequently treat them and referred them on to different places for further assessment or treatment.

4.3.3 Treatment End

Participants stated that often therapy was limited to a small number of sessions regardless of whether a patient had recovered. They wanted the questionnaire to be sensitive to this issue and reflect an awareness that treatment might end prematurely without the client having recovered completely.

Participant 2: "But nowadays [...] that question is laughable because it's, you know, you've had your six weeks and you know, if you want any other help – tough luck, because it just ain't there."

Participant 1: "You're on your own now."

Participant 2: "It just ain't there. So again, it's a laughable question. It would just make somebody feel really mad."

Some people might find that they do not feel 'recovered' after having received therapy.

"Like for some people that have therapy do not get better." [Participant 14]

It was suggested that the questions that related to treatment end, such as asking whether they have recovered, should be refocused on the client being able to cope better with their problems after therapy.

The participants of one service user organisation explained that they know they can go back to the organisation for further support. This was identified as a key element for having the confidence to move on and feeling supported even after the treatment had terminated.

It is therefore important for the questionnaire to establish whether the client knows who to contact if they needed further help or treatment.

The participants highlighted the need for the satisfaction questionnaire to be worded in a way meaningful to people who have experienced anxiety and depression. It is imperative that the questionnaire conveys an understanding of people's emotional and psychological difficulties in order for people to be prepared to share their experiences and to complete the form.

4.4 Client-Focused

The second high order theme that emerged related to the issue of increasing the focus of the questionnaire on the individual receiving a talking treatment. The focus group participants repeatedly commented that it is important for the questionnaire to capture the client's feelings, experiences and opinions. It was argued that the tool needs to include questions that are relevant to the individuals who it is aimed at and provide them with an opportunity to comment on their subjective experiences. Only in this way can they let the service know how they felt about different aspects of their treatment.

"...because I think a lot of this [the questionnaire] doesn't take into account the feelings of people, you know, how they feel in treatment." [Participant 4]

"It's not their therapy, it's YOUR therapy!" [Participant 6]

4.4.1 Appropriate Involvement

The participants stressed that they expect services and therapists to involve them as much as possible in their treatment, beginning with a discussion on treatment length to providing them with the information that will allow them the freedom of making decisions about their treatment. It was acknowledged that sometimes too much information can be disabling (see section 4.2.1).

They however stressed the importance of being told clearly what is going to happen to them during THEIR therapy.

Participant 2: "Because if on week one the therapist said 'right, we're gonna have, you know, x-number of sessions, and this is what we're gonna hope to

achieve and you know, so that at session one the person has some understanding about how many times they are going and what they are working towards."

Participant 1: "Yeah, cos it's almost fear of the unknown that is as threatening as the illness itself."

It is therefore important that the questionnaire includes a question that focuses on information given to the client about their specific treatment.

4.4.2 Therapeutic Alliance

A lot of the topics discussed surrounded the participants' experiences with their therapist. It was repeatedly reported that the service user's relationship with the therapist was a crucial element that influenced outcomes and satisfaction with the therapy received. The therapist determines whether someone feels comfortable to share their experiences, feels that they are being listened to, treated with respect, and also feels that they are working collaboratively towards a mutually agreed goal. Service users shared that they have had some wonderful experiences with therapists, who made them feel valued and understood.

Others however, had experience of being patronised, made to feel inferior and told what to do rather than a sense that they were working in co-operation. Participants therefore felt that a variety of questions should be asked concerning the therapeutic relationship with their therapist.

Participant 14: "I mean there are therapists who are keen and other ones they just do not, they are like machines, almost..."

Participant 7: "Like a robot!"

Participant 14: "A robot, yeah, they have too many problems themselves or whatever."

Participant 7: "They start talking about their own depression, thank you very much."

Participant 14: "All their body languages say they don't want to be there. You're just their work. This is for a therapy that you waited a year for. I mean, how do you sum this up?"

A number of participants referred to research evidence that suggests that therapeutic alliance is a fundamental aspect of therapy.

"Because research has shown, it makes no difference all those issues to whether your therapy is effective or not. The thing that makes the most differences [...] is the relationship you have with your therapist. It's not [...] or whether they are the same gender as you or the same age or their cultural background, none of that is particularly relevant to how effective your therapy is." [Participant 10]

The concept of therapeutic alliance was of great importance to the participants, and several studies have found a robust link between therapeutic alliance and outcomes of therapeutic interventions (Horvarth & Symonds, 1991; Horvarth & Luborsky, 1993; Martin, Garske & Davis, 2000).

The audit will therefore assess the therapeutic relationship separately by administering a standardised and validated tool, the five-dimensional Agnew Relationship Measure (ARM-5; Agenew-Davies, Stiles, Hardy, Barkham & Shapiro, 1998).

4.4.3 Individual Differences

Several times during the discussions, it was acknowledged that people have individual needs and preferences. One of the questions asked whether someone would recommend their treatment to a friend or family member. Participants reacted strongly to this question, emphasising the individuality as well as the privacy of their experience.

"Each person that goes to therapy is different, it's you know, it's just not this sort of thing you recommend to family and friends, and even if you did it mightn't be right for that person." [Participant 2]

It was suggested to remove this question and to ask instead whether an individual would take up this treatment again in similar circumstances rather than recommending it to someone else.

Participants felt that the questionnaire needs to acknowledge people's differences in needs and preferences by including more questions about choices (see Chapter 3, section 3.2). In this relation, it was suggested that people needed to be able to pick from a range of times when a therapist would be available, rather than being simply given an appointment which did not take their individual needs into account.

"I think also that I feel often worse in the mornings, so there should be a time morning, afternoon or something like that, if it's possible." [Participant 3]

It was further discussed that it is important for people to have a choice of changing their therapist if they needed to. One participant had past experiences such that she felt unable to confide in a male therapist. Others said that some people might be restricted to a certain gender of therapist for religious reasons. They felt that some question that covered this issue ought to be included in the questionnaire.

"You want to connect but then if you don't, then you want to be able to say that we don't connect at all, can I have someone else." [Participant 16]

"So somebody might think someone's great, but somebody else will think entirely different about that." [Participant 5]

The participants also stressed the need for questions to be made more specific to avoid subjective interpretations. For example, when discussing whether it is important to include a question on how people felt about the time they have had to wait to start therapy, participants explained that one needed to first establish exactly how long someone waited to be seen, before asking whether they were happy with the length of the wait; for some a few

days would be too long whereas others actually welcomed some time to prepare themselves mentally for the start of their treatment.

Participant 14: "And I think sometimes it's good to prepare for psychological services. Once you've started your decision, you know, you go away and read a book. You know, help to prepare for it. You are, it's in your hand..."

Participant 7: "If it is like counselling or something, if it's CBT...well, it depends on what kind of psychological therapy, how much is appropriate and severity, you know, what you're going through."

It was also acknowledged that it will be difficult for the satisfaction questionnaire to appeal to everybody who fills it in. Whether or not those who fill it in feel that it reflects their care journey, will be influenced by the severity of people's illness and by their individual preferences.

"This form is going to be used from the very mild right the way though to really sick patients, well, the more severe, long-term, so it's from everyone, isn't it? [...] So this form has got to do a hell of a job." [Participant 14]

"This is the thing. Everyone is so different and this is the right thing, your form. You are going to get some people like words, so they might like this [pointing at form], some people might like some kind of scales, some people like to work with pictures. You just can't do...you ideally, you would like to have something that appeals to everyone, but I don't know how you can do that, it's going to be hard." [Participant 9]

In conclusion, in order to focus on the client receiving the therapy, it is important to include questions that are relevant to service users. The broad range of experiences, reaching from accessing to ending treatment, confirmed the project team's belief that the service user feedback form needs to give service users a chance to comment on different aspects of their care. It is also essential to give people an opportunity to comment on how they feel about each question and to explain why they may not have been happy with the help or the service they have received. As a result the satisfaction questionnaire needs to be designed in such a way that takes individual differences into account and allows a range of people to provide their feedback on a range of experiences within the received care so that it can be of value to the audited service. The project team have carefully reflected on these considerations in the redesign of the form and the types of questions included.

4.5 Effect of Illness

Participants discussed in the focus groups how their anxiety or depression had changed their lives. They shared the effects that it had on them. Many felt that they were very debilitated by these illnesses but also showed a great deal of resilience when discussing their difficulties.

The participants stressed how difficult it can be to complete complex forms when suffering from anxiety or depression. Although it did not take them too long to fill in the questionnaire at the time of the focus group, they explained that it would be much harder for them to do this when they were feeling unwell.

"Well, when I was really ill I couldn't cope with a questionnaire, any paperwork I preferred to get rid of it, it stressed me out." [Participant 7]

"Well, it depends how ill you are. If you're very ill, you don't want anything too demanding." [Participant 9]

4.5.1 Simplifying

In connection to the above theme, it was recognised that the whole of the questionnaire needed to be simplified and shortened in order for it to be appropriate for people currently suffering with anxiety and depression.

"I mean, if I am sitting reading this now and I have to fill this in concerning the last therapist I saw with the way that my mind is working now, I could sit and I could analyse every question and I could give an answer to all these questions, but if this was put in front of me during any of the times that my anxiety was really, really bad, when I most needed the help, I think I would have thrown it in the bin, ripped it up or just sat in the corner and cried because I would have thought this person doesn't understand me." [Participant 2]

"I think it's simpler if there was a shorter form." [Participant 17]

It was further suggested to use simpler words and avoid any ambiguity in questions, as people would only get confused.

"It's just got to do with the word 'psychological therapist', and I don't think everybody is going to understand quite what that means. People are more likely to understand 'talking treatment', for example." [Participant 10]

"....you'd bypass the question, because you'd start it, you wouldn't understand it, and you'd think ahhh...where's this going [...] It needs to be in layman's terms, a common language for all, I think. Keep it simple!" [Participant 23]

The response scale was the centre of discussion in all groups. Some said the scale was too long and offered too many choices, whereas some did not want a scale at all. While others liked the scale, many participants disagreed about the meaning of the available responses.

"Do I strongly disagree or do I just disagree? What do you base it on?" [Participant 20]

"I thought the neutral response shows apathy, possibly that you don't even care about some of these things, like how can you have a neutral response to something that's yes or no? Like I don't know whether I have been told or not what I am going to have as a treatment. You can't really have a neutral response." [Participant 7]

However, in response to this comment another participant in the same focus group commented that they had ticked neutral because they felt that this indicated that they would have liked things to be different. In response to a question about whether they were happy with the treatment location, they stated that they were satisfied, but that they would, of course, have liked it to be closer, so they had ticked neutral. Such subjective understanding of the words was reflected across all the groups. Most participants in all groups suggested that it would be better to have simple 'yes' and 'no' answers, with tick boxes. This would be much easier to fill in when unwell.

"Just general about the format. Most of these questions are strongly agree, agree, neutral, disagree....I think there are a few questions where it might be useful to ask which has simple 'yes' or 'no' answer." [Participant 12]

"When I've been in that sort of state, to say 'strongly agree, disagree, strongly disagree'...I just want a 'yes' or 'no'. I'm not in that state now, but I have been." [Participant 20]

"'Yes' or 'no' would suffice, wouldn't it." [Participant 23]

Modifications to the questionnaire have therefore been made in accordance with these comments (see also **Chapter 5**).

4.5.2 Need of Support

It was suggested that it might be appropriate to have support available for those filling in the questionnaire. Many participants explained that they would have liked to fill in a form like this when they were receiving therapy but recognised that they might have been unable to do it without support. This issue was particularly relevant for the older people's focus group. Several participants commented that they had debilitating physical constraints which made writing of any kind extremely difficult.

"I can't do anything. [...] And I can't write and I've been trying to write postcards, uh, Christmas cards and I had to get somebody else to do them." [Participant 16]

Avenues will be explored to see whether service user organisations might be available to offer support to clients who want to take part in the audit but who are unable to fill in the form unassisted.

One participant mentioned that the font was too small for him to read, as he was having problems with his eyesight. The questionnaire therefore needs to be available in a larger font for people with impaired vision.

"I've got really bad eyes, I've got really poor eyes, but I tell you what, they're not this bad." [Participant 23]

4.5.3 Timing

As perceptions and experiences vary throughout the course of psychological difficulties, participants suggested that the questionnaire be split up and handed out at different stages in the therapeutic process. Some questions related to waiting times and were questions for early in the therapy. Participants reasoned that once people are feeling better, they would give very different responses than those that they might have given early on. They felt that it was important to capture the anguish that many sufferers may face when they have to wait for therapy to begin.

However, questions relating to the feedback on treatment would be best administered at a later stage in treatment or after the completion of treatment.

"It's got to be done retrospectively, probably 12 months down the road, where people can actually see what that treatment has actually given them - or not given them. There is a major timing problem as to when you ask these questions." [Participant 1]

If the questionnaire was split up in separate sections and administered at different points in time, participants noted that it would also make the questionnaire look less daunting.

Participant 1: " That's what I was going to say, Participant 5. Because this could be filled in one at stage one, so you do a short six questions, then two months later you do stage 2, three months later you do stage 3. I think it's too threatening to do all at one go."

Participant 5: "...too much for anxiety sufferers to do."

Participant 1: " Yeah, they're more likely to feel comfortable if they've only got to spend five minutes filling in questions 1 – 6 of one stage, then five minutes another six weeks later, rather than throwing it all at them once."

Participant 2: "Yes, and if they did section 1 in that way, then they could be told that there are other sections but we'll do it a bit at a time. So they'll know that there's more to come."

"Yeah, it could be ongoing with the treatment ...small parts through the course of the treatment." [23]

In order to acknowledge the difficulties people might face when filling in the form, the questionnaire needed to be changed to make it less confusing and ambiguous, so that it is a form that someone can easily fill in when unwell. It was further preferred if the form was split up in three sections and handed out at different points of the care pathway.

Chapter 5

Finalisation of the new measure

Firstly, changes to the structure and layout of the draft questionnaire will be illustrated. Issues and concerns about the timing of administration of the new questionnaire will also be discussed.

The subsequent section will demonstrate how the obtained feedback and comments informed changes to the individual questions of the draft questionnaire.

5.1 Changes to structure, layout and timing

As a result of the themes that arose out of the discussions, the questionnaire was simplified to account for the effects of people's illness. This involved reducing the number of questions, simplifying the wording of the questions and changing the response scale to 'yes' and 'no' answers. If any of the given answers are 'no', clients are asked to explain why they have selected this response. They are also invited to share anything else they would like to. In this way, it is hoped, that the questionnaire will be able to focus on the individual client and her or his needs and to capture any concerns they may have about different aspects of care, without the questionnaire being overly long. In addition, the questionnaire was given a simpler layout and was divided into three sections which focus on accessing treatment, therapeutic alliance and receiving treatment.

Focus group participants further suggested making the form more attractive for clients by, for example, giving it a "catchy title". The service user questionnaire was therefore renamed 'Talking Treatment'. The words 'psychological therapy' were replaced by 'talking treatment' throughout the questionnaire.

One aim of the pilot study of the National Audit of Psychological Therapies will be to determine whether the response rate is better if the questionnaire is split into sections and handed out at different points in therapy, or whether the response rate is better if the questionnaire is handed out once towards the end of treatment. Both methods will be tested during the pilot stage.

A revised information leaflet was produced. This leaflet provides information about the audit and the purpose of the 'Talking Treatment' questionnaire and will be handed out along with the measure (see **Appendix F**).

5.2 Changes to individual questions

The questions from the original questionnaire and the elicited discussion by the service users are presented below.

The comments and difficulties with the questionnaire items are summarised for each item individually.

Section 1: Getting help

1. How did you find out about psychological therapies for anxiety and depression?

- GP
- Voluntary Agency
- Friend/Family member
- Other

2. Who referred you for psychological therapy?

- GP
- Self-referral
- Voluntary Agency
- Job Centre
- Other

The participants highlighted that the list that followed these questions was not exhaustive enough and if included it was suggested that it be expanded. Further, the value for asking these questions was queried, as answers did not relate to information on how service users felt about the service.

These questions also elicited a lot of discussion and confusion as many people were surprised to learn that it is possible to self-refer or to be referred by the job centre, as initiated by the IAPT scheme.

These questions caused more confusion than expected and a decision was therefore taken to remove both from the satisfaction questionnaire.

3. I was happy with the waiting time to first see a therapist.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly disagree

4. I had to wait too long to start my therapy.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Questions 3 and 4 both focus on how people felt about their waiting time and are therefore discussed together. The difference between them is that question 3 is worded positively and question 4 negatively. Both questions were included in the draft questionnaire to find out which one participants would prefer and whether their responses varied depending on the wording.

All the focus groups felt very strongly about these two questions. Two issues were raised.

Firstly, many service users felt that the questions were “ambiguous”. If someone is suffering from anxiety or depression, people agreed that any length of time that one has to wait for psychological treatment will seem too long. Without further information, answers to such a question were thought to be of little value. Worse still, people explained that they felt very angry reading these questions as there is no acknowledgement of the possible desperation for treatment that the individual has to cope with. Participants said the feeling of being misunderstood that arose within them might influence a person’s attitude to the entire questionnaire. Focus group members stated that they would have been reluctant to fill in any more of this questionnaire after reading these two questions. The question therefore needs rewording in order to reflect an ‘understanding of the client’s journey’ (see section **4.3.1**).

“The person concerned is gonna think anytime is too long, because they’re desperate for their therapy, so, you know, it doesn’t sort of say, if you’ve waited more than 6 months or...It’s just a sort of ambiguous question. It doesn’t really give you any answers because the person by definition is bound to say Yes.” [Participant 2]

As discussed previously (see section **4.4.3**), participants pointed out that answers to these questions will also be highly subjective. Depending on individual situations, some people will have suffered a great deal while waiting for their treatment to start. Others however, may have even welcomed an opportunity to reflect on their feelings and prepare themselves for the therapy that lies ahead of them. Thus the analysability of people’s answers to these items was questioned.

The participants suggested instead asking how long the person has waited and then give them an opportunity to comment on how they feel about their waiting time.

"You need to define too long – how long is too long?" [Participant 13]

"But if it was a two part question, then you could see what the person understood the question to mean for themselves. If you said 'how long did you wait?', then 'how did you feel about that?', then you know how they're equating, well, I was quite happy really, I didn't mind waiting for 6 months. Or someone else 'Ah, I was going off my head waiting a month'."
[Participant 8]

It was further pointed out that the wording would need to be revised. Participants did not feel that using the word 'happy' with regards to waiting times would be appropriate.

"'I was happy' – none of us were happy when we were told it's going to be x-number of weeks or months!" [Participant 1]

It was suggested to ask whether the waiting time was 'reasonable' instead.

In the light of the comments from focus group participants question 3 and 4 were reworded as follows:

'How long did you have to wait for your talking treatment to start?'

'I feel the waiting time for my therapy to start was reasonable.'

The second issue mentioned was the fact that many people are seen by an assessor or a clinical lead, such as a psychiatrist, before they are referred for a specific treatment. Participants commented that people might get confused as to what counts as 'waiting time' and stressed that this needed to be made clearer (see section **4.3.2**)

"Because they assess people relatively quickly and now say: 'Right, now you've been seen.' [...] This is where the NHS really does cheat. If you want that information you've got to ask people 'When have you seen a therapist to start the regular treatment?'." [Participant 12]

Therefore, the following explanatory statement was added before the question that asks about people's waiting time:

'From the point of being referred by your GP to seeing your current therapist regularly'.

5. Therapy is available at times that are good for me.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

This question was of importance to the majority of participants as it highlights clients' 'individual differences' (see section 4.4.3). Some however suggested rewording it slightly as it currently prompts a very subjective response. Participants felt it would be more appropriate to ask if they have been given an option of different treatment times, rather than whether the therapy was available at times that were good for them.

This question was reworded to:

'I was given an option about different days/times available when scheduling my appointment.'

6. The appointment location is easy to get to.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

This question elicited a long discussion amongst participants who had experience of suffering from anxiety. For many anxiety sufferers this question was deeply problematic. Participants stated that people suffering from anxiety are often unable to access services because their anxiety prohibits travel of any kind. Even if the service is at a location nearby and well-connected to public transport it is often extremely difficult for those suffering with severe anxiety to access the services. This question in particular aroused feelings of anger in participants who felt misunderstood by what they perceived as the questionnaire's disregard of their illness since it asked whether it was 'easy' for them to get to a given location (see section 4.1.1 & 4.3.1).

"...if you've got acute agoraphobia and you can't virtually get past your front door, the treatment centre might only be 5 minutes away but it's still impossible at that time." [Participant 1]

Participants suggested including a question that asks whether there were any difficulties involved in getting to the location. They felt that it is necessary to be given some space to explain why they had difficulties getting to a given location. They felt that it was necessary to feed back this information to the service.

In response to these comments, the question was reworded to:

'I was able to get to my appointment location without too much difficulty.'

In order to capture the difficulty that many anxiety sufferers experience in accessing any location, a final question was added:

'If you have answered NO to any of the above or if you would like to add anything else, please comment below:'

This question was added to provide participants with an opportunity to give a more detailed explanation to their answers. It allows clients to comment on aspects of the service that they found difficult and give an indication to services of areas that they might be able to improve. It also allows service users with anxiety to comment on why they could not get to the appointment location.

Section 2: Information

8. I was adequately informed about the different therapies available to me.				
1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

9. I would have liked more information about my therapy options before therapy began.				
1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly

Questions 8 and 9 focus on the same issue: whether the information given on different therapy options was sufficient. The project team included a negative and a positive wording to see which one was preferred by the participants and whether they would respond differently to these questions.

Participants explained that people are often not informed about the different therapy types that are available. They reported that in the majority of cases the GP refers a person to a service without discussing the available options. The above items therefore do not reflect what is actually happening when being referred to psychological services. The value of this item was further questioned given that people often find themselves in a state where they are unable to take in the differences between the various therapeutic approaches and then make a decision accordingly (see section 4.4.1).

"I think it would be actually quite confusing for the person just starting off. Being bombarded with: you could have this or you could have that. Especially just the names of the therapies....." [Participant 9]

They suggested rewording the item to focus on receiving sufficient information about a specific treatment and what it involves.

"So yes, the more the people can explain to us what's gonna happen the easier we can deal with it. Rather than different therapies, I was informed

about THE therapy that was available to me or the type of therapy.”
[Participant 1]

After reflection on the range of comments the item was reworded to:

‘I received enough information about my talking treatment before it

10. I received information about the psychological therapies in a suitable format (e.g. large font, translated information sheet, via interpreters etc).					
1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

began.’

The only comments on this question were that it included too much jargon.

“‘I received information about the psychological therapies in a suitable format’. It’s quite a lot for somebody to take in...do you know what I mean?”
[Participant 23]

“Why use big words when your mind is already confused. Keep it simple.”
[Participant 2]

Although some participants recognised the importance of ensuring equity of information, for the most part this question was not considered a priority by participants. Most participants were more concerned that the form should not be overly long (see section 4.5.1.).

A decision was therefore taken to remove it from the form.

11. The therapist explained my treatment clearly to me.				
1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

It was felt that the newly added item **‘I have received enough information about my talking treatment before it began.’** covers this question. Question 11 was therefore removed from the questionnaire.

Section 3: Receiving treatment

13. I find it easy to talk to my therapist.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

14. It is a bit difficult to ask questions.

1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

15. My therapist and I agree the goals of treatment together.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

17. I wanted to be more involved in decisions made about my treatment.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Questions 13 & 14 & 15 & 17 all concern the therapeutic relationship.

The above questions elicited a passionate discussion about the importance of the therapeutic relationship (see section 4.4.2). All participants agreed that the therapeutic relationship is a central and crucial element of psychological treatment.

They stressed how important it is that therapists show an interest in the person receiving the treatment. Feeling valued, being treated with respect and being taken seriously were felt to be a necessity for a successful therapy.

A validated measure of therapeutic alliance was identified. The ARM-5 (Agnew-Davies et al., 1998) will be administered instead of using these questions (see **Appendix G**). Therefore, questions 13, 14, 15 and 17 have been removed from the questionnaire.

16. I am getting the kind of treatment that I want.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

This question was not discussed in much detail. It was however commented that the treatment someone 'wants' might not be the treatment a person actually 'needs'.

The question was therefore reworded into:

'I feel that I am getting the right kind of help.'

19. My therapist is sensitive to my specific needs (my gender, age and cultural/ethnic background etc.)

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Participants found this question difficult to talk about. Participants in all groups deviated into a discussion of the choice of therapist and felt that having a choice of therapist was more important than the therapist displaying a sensitivity to someone's specific needs.

They stated that sensitivity to specific needs would be sufficient if the therapist had a good therapeutic alliance with the client. This will be captured with the ARM-5. This question was therefore removed from the questionnaire.

18. I often feel like complaining about my therapy.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

20. I feel free to complain.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Questions 18 and 20 were included to gain a sense of whether service users would feel sufficiently comfortable to complain if necessary, and to capture whether they had felt a general level of dissatisfaction with the service. The focus group participants however read these statements extremely negatively. Fuelled by the perceived barriers in the care system (as discussed in section 4.1) long discussions were initiated about how participants felt too scared or worried to complain. They explained that very often people are too scared to talk to anybody about things they dislike in their therapy out of a fear that their treatment would be taken away from them.

Another participant stated that she would not even contemplate complaining about her therapist as she felt a huge amount of trust between them.

"Cos it's such a lot of trust you put in your therapist, it really goes against the grain to even think about, doesn't it, cos they're the person that's helping you aren't they." [Participant 19]

Rather than this question they suggested that a better question might be to ask whether people had been informed about the complaints procedure. As the main concern of most participants was to keep the questionnaire short, and since auditing complaint procedures falls outside the scope of the audit, a decision was taken to remove both questions.

As a result of the focus group discussions, the section was entirely removed from the questionnaire and replaced with the ARM-5

Section 4: Getting better – moving on

22. I believe the therapy helps me in achieving my treatment goals.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Participants entered into lengthy discussions about the language used in this section. They stated that a positive outcome of therapy often means that people are better able to cope with their problems rather than actually 'getting better' or 'recovering' (see section 4.3.3). They stated that this is often brought about as they come to better understand their problem and so find ways to deal with it. The idea of 'treatment goals' did not seem to convey this and it was suggested to reword it to 'goals' in general. One participant also mentioned that this question could be confusing as he had never been aware that any treatment goals had been set during his course of therapy.

This item was therefore rephrased to:

'I believe this talking treatment helps me to cope with my problem.'

Participants stressed that therapists need to help people understand their problems. They saw this as key to them 'getting better' and knowing how to cope with their problems. Participants stressed that it can be very frightening when one first suffers from anxiety or depression.

"These sensations they're so weird, you don't understand what's happening to you, so it's important that the therapist, as we do in our group, we help people to understand their illness and then tackle it, not assume that we understand it and that we can just go forward." [Participant 1]

In addition to the item above, the following item was added to the questionnaire:

'This talking treatment helps me to understand my problem.'

24. I would recommend this therapy to a friend or family member.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly

This question elicited a long discussion in all the groups.

Participants felt that it is impossible to recommend a therapy to someone else, since receiving therapy is a very personal experience. They stressed that every person has individual needs, opinions and feelings (see section **4.4.3**). They therefore felt that it would not be appropriate to ask whether a service user would recommend a treatment to someone else, regardless of how successful or beneficial it had been to that person.

"Each person that goes to therapy is different, it's you know, it's just not this sort of thing you recommend to family and friends, and even if you did it mightn't be right for that person. It's another question that's taking you nowhere." [Participant 2]

The project team were surprised by the strong response that this question aroused, as it was an extremely common item used in other satisfaction questionnaires. However, focus group participants stated that they did not like this question. They felt it was inappropriate.

One participant felt it was inappropriate to recommend a therapy to a friend or family member as psychological therapies should be offered to people who have actually experienced psychological problems – which might not be the case for a friend or family member. It was therefore felt that the statement did not acknowledge the difficulties that surround the need for a talking treatment.

"The question 24, I would recommend this therapy to a friend or family member. Well, would you? Because I would recommend a therapy to someone who had problems." [Participant 12]

Again they stressed that therapeutic alliance was deeply personal and there was no guarantee that a therapist would help someone else simply because they had been helped by them.

Others mentioned that having therapy is a private issue that they would not feel comfortable sharing with others.

They therefore suggested replacing the item with a statement that asked if the person would take up the same treatment if he or she found themselves in a similar situation again. The above item was removed and following item inserted:

'If I have similar difficulties in the future, I would take up this talking treatment again.'

25. My therapist has talked to me about what help is available if I need further treatment.

1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

Participants in all groups discussed the subject of follow-up treatments as the availability of further help was of great importance to everyone.

Some participants are reassured that further help is available if they needed it. Others however raised concerns about the limited number of treatment sessions often available (see section **4.3.3**). It led many participants to feel that they were misunderstood by the writers of the questionnaire. They explained that, for many, right from the beginning of treatment they have to deal with the pressure of recovery. They know that in many cases, despite long waiting times, their therapy will only operate within set limits.

Participants stated that this fear put them under tremendous pressure. It was a pressure which exacerbated their condition.

Some also expressed frustration about this statement and felt that it did not reflect reality. Many stated that there was no follow-up and that to suggest anything to the contrary again indicated that the authors of the questionnaire were unaware of the true state of psychological therapy services in the UK.

"But nowadays [...] that question is laughable because it's, you know, you've had your 6 weeks and you know, if you want any other help – tough luck because it just ain't there." [Participant 2]

Chapter 7

Conclusion

The aim of this project was to design a service user satisfaction questionnaire for the National Audit of Psychological Therapies for Anxiety and Depression in primary and secondary care. Four focus groups with current and former service users were conducted to obtain their comments and opinions about a proposed draft questionnaire.

The comments and experiences that were shared enabled the project team to modify the draft tool. By doing so, it is hoped that the new measure 'Talking Treatment' provides a meaningful way of asking people, who receive psychological therapies for anxiety and depression, in a sensitive and understanding manner about their experience.

During the analysis of the focus group discussions, it became apparent that two qualitatively different types of comments were presented, which influenced the development of 'Talking Treatment'.

One type of comments concerned the participants' experience with psychological services.

It was revealed that people reported 'perceived barriers' to the mental health system, the services and the therapists. Because of the reported barriers, it is important for 'Talking Treatment' to reflect an understanding of their potential distress, especially when accessing services. Some of the questions had to be reworded in a way that provides participants with an opportunity to express their difficulties in aspects of their care to inform the service provider about it.

It is further important to highlight people's feelings towards the health service as this might lead to further research that explores ways of breaking down the barriers.

It is further hoped that this report informs relevant people who are able to work towards mental health systems that convey accessibility, understanding towards the existing barriers and ongoing support.

Participants also expressed that the concept of 'choice' is difficult to apply in this context since it is highly dependent on the amount and type of information provided to the service user, as well as on their past experience of talking treatments.

Firstly, many barriers remain to there being an informed decision-making process. Mental health services still have to recognise that people need to receive a sufficient amount of information in order to make their choices. They need to receive this information in a jargon-free manner and delivered in a way sensitive to their difficulties. People should also be empowered to

make their own decisions as they are often unaware about the aspects of their care they can make choices about.

'Talking Treatment' attempted to capture aspects of decision-making in people's care by including questions on appointment time and location. Secondly, without prior experience of a particular therapy type, participants pointed out that being offered certain types of choice can be confusing. It is often not possible for new clients to know what the most acceptable treatment will be. They stated that trust is essential since they have to rely on the judgement of professions to offer therapy that is not only appropriate but also acceptable.

Being able to change a therapist if the relationship does not develop as hoped or if people prefer a therapist with certain characteristics (e.g. a woman) was of utmost important to the focus group participants. Currently, there is however no national recommendation on offering people a choice of therapist. It is hoped that this report highlights this shortcoming.

It is recognised that it is outside the scope of the 'Talking Treatment' questionnaire to address the issue of 'perceived barriers' and 'choice' at an adequate level.

The second type of comments that were captured related directly to the content and wording of questions, the structure and layout of the presented draft questionnaire.

It is important that 'Talking Treatment' reflects an 'understanding of the service user's journey' by using words that show empathy and do not make the person feel misunderstood.

It is further important that the new questionnaire 'focuses on the individual' as the experience of receiving a talking treatment is very personal and unique to each individual. Any ambiguities in the included questions have therefore been removed. The questionnaire also gives service users an opportunity to comment on every individual question.

Great consideration was also given to participants' explanations of the potentially disabling 'effects of illness'. It was recognised that the tool needs to reflect an understanding of this by being short and easy to complete. The questionnaire was therefore significantly reduced in length. In addition, the response scale was reduced to two items, 'yes' and 'no'. Participants stated that they preferred this approach to any form of Likert scale, which they felt would be confusing and add to their anxiety when they were unwell.

Participants' comments also had particular relevance to the timing of when to administer the questionnaire to service users participating in the national audit. The project team has been made aware that the feelings towards their waiting times might change after people have received the treatment they have been waiting for. This however does not deny the fact that some people might have had some very distressing experiences whilst waiting for months for their therapy to start and this should be fed back to the services if this was the case. Therefore, the pilot phase of the national audit will test out the feasibility of administering the three sections of the tool at different stages of the service users' care pathway.

It has been tremendously insightful to listen to the participants' experiences of psychological therapies and their opinions about the questionnaire, which has led to significant changes of the tool. It is hoped that the questionnaire was changed for the better and reflects the issues relevant to the people who will be completing the questionnaire as part of the National Audit of Psychological Therapies for Anxiety and Depression.

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Appendices

Appendix A – Search Log

Table 3: Search Log of Systematic Literature Review

Date	Database searched	Search Terms	Years	language	Initial hits	First Sift	Second Sift (checking abstracts)	able to retrieve	removing duplicates
30.09.2008	PubMed	1) service user or patient or client or outpatient 2)questionnaire or scale 3) satisfaction or feedback or opinion 4)psychological therapies or psychological service or psychological therapy 5) #1 AND #2 AND #3 AND #4	no limit	English	1917	126	11		
02.10.2008	CINAHL	1) service user or patient or client or outpatient (no subheadings) 2)questionnaire or scale or survey (no subheadings) 3) satisfaction or experience or feedback or opinion (no subheadings) 4) psych\$ (no subheadings) 5) 1 AND 2 AND 3 AND 4	no limit (1982-2008)	English	2631	170	41	31	
06.10.2008	EMBASE Psychiatry	As CINAHL	no limit (1997-2008)	English	3008	251	37	31	
30.09.2008	PsycINFO	As CINAHL	1985-2008	no limit	2524	224	49	30	
07.10.2008	MEDLINE	As CINAHL	1950-2008	English	4184	281	63	44	
	Totals				12347	926	190	136	83

Appendix B – First draft of service user satisfaction questionnaire

Service User Satisfaction Questionnaire

This questionnaire is part of a national audit of psychological therapy services. The audit is a national survey that is trying to improve psychological services for anxiety and depression in England and Wales.

The questionnaire is divided up into 4 sections:

- Getting help
- Information
- Receiving Treatment
- Getting Better and Moving On

There are **26** questions in total.

Filling in this questionnaire will help us to understand what you feel about the service now and help us plan with your service how it can improve it in the future.

No one will be able to identify you from the information that you give today.

Once you have completed the questionnaire please place it in the envelope provided, seal it and either hand it into the service or mail it freepost back to us.

Thank you for taking the time to fill in this questionnaire.

All questions relate to the therapy that you are **CURRENTLY** receiving. They do **NOT** relate to a therapy that you have received in the past.

SECTION 1: GETTING HELP

All the questions in this section are about how easy you found it to get psychological therapies for depression and anxiety.

1. How did you find out about psychological therapies for anxiety and depression?

- GP
- Voluntary Agency
- Friend/Family member
- Other

2. Who referred you for psychological therapy?

- GP
- Self-referral
- Voluntary Agency
- Job Centre
- Other

3. I was happy with the waiting time to first see a therapist.

- | | | | | |
|----------------|-------|---------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |

4. I had to wait too long to start my therapy.

- | | | | | |
|----------------|-------|---------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |

5. Therapy is available at times that are good for me.

- | | | | | |
|----------------|-------|---------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |

6. The appointment location is easy to get to.

- | | | | | |
|----------------|-------|---------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |

7. Please tell us anything else that you would like to about your experience of getting help.

SECTION 2: INFORMATION

All the questions in this section are about the information that you have been given about your therapy.

8. I was adequately informed about the different therapies available to me.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

9. I would have liked more information about my therapy options before therapy began.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

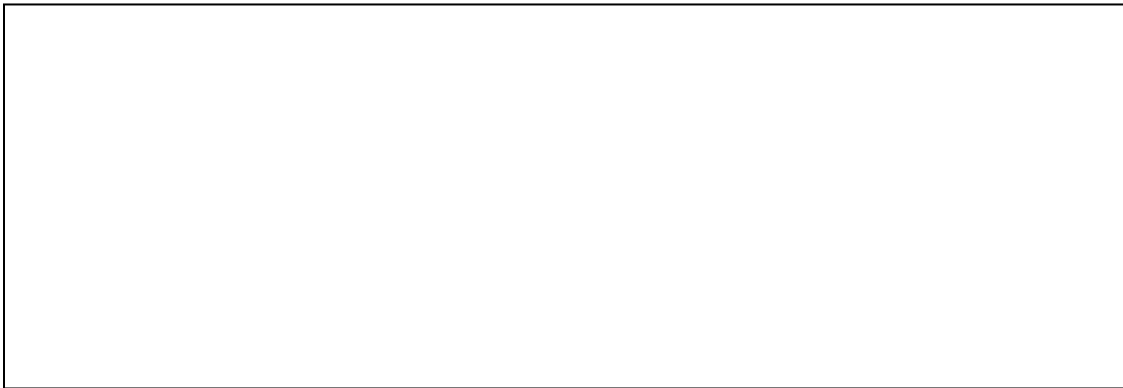
10. I received information about the psychological therapies in a suitable format (e.g. large font, translated information sheet, via interpreters etc).

1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

11. The therapist explained my treatment clearly to me.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

12. Please tell us anything else that you would like to about your experience of being given information about your therapy.



SECTION 3: RECEIVING TREATMENT

All the questions in this section are about your therapy and what it is like working with your therapist.

13. I find it easy to talk to my therapist.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

14. It is a bit difficult to ask questions.

1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

15. My therapist and I agree the goals of treatment together.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

16. I am getting the kind of treatment that I want.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

17. I wanted to be more involved in decisions made about my treatment.

1	2	3	4	5
Strongly agree	Agree	Neutral	Disagree	Strongly disagree

18. I often feel like complaining about my therapy.

1	2	3	4	5
---	---	---	---	---

Strongly agree Agree Neutral Disagree Strongly disagree

19. My therapist is sensitive to my specific needs (my gender, age and cultural/ethnic background etc.)

1 2 3 4 5
Strongly agree Agree Neutral Disagree Strongly disagree

20. I feel free to complain.

1 2 3 4 5
Strongly agree Agree Neutral Disagree Strongly disagree

21. Please tell us anything else that you would like to about your experience of receiving treatment.

SECTION 4: GETTING BETTER - MOVING ON

All the questions in this section are about whether you think your therapy is helping you to get better and what happens next.

22. I believe the therapy helps me in achieving my treatment goals.

1 2 3 4 5
Strongly agree Agree Neutral Disagree Strongly disagree

23. I feel that I am getting the right kind of help

1 2 3 4 5
Strongly agree Agree Neutral Disagree Strongly disagree

24. I would recommend this therapy to a friend or family member.

1 2 3 4 5
Strongly agree Agree Neutral Disagree Strongly disagree

25. My therapist has talked to me about what help is available if I need further treatment.

1	2	3	4	5	6
Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable

26. Please tell us anything else that you would like to about your experience of getting better/moving on.

Appendix C – Information Leaflet (prior to focus group discussion)



COLLEGE CENTRE FOR QUALITY IMPROVEMENT



Information Leaflet

Focus Group on ...

Thank you very much for your interest in joining our focus group. By taking part, you will be helping us to develop a 'service user satisfaction questionnaire' for our new national audit programme. This leaflet explains what the programme is about and what we will be asking you to do.

What is the National Audit of Psychological Therapies about?

The Royal College of Psychiatrists' Research and Training Unit (CRTU) in partnership with the British Psychological Society and the Royal College of General Practitioners has successfully secured three-years funding for a national audit of NHS-funded psychological therapy services for people with anxiety and depression. The programme will support services to compare the way they deliver psychological therapies against national 'good practice' standards and recommendations.

There are four key areas we want to focus on:

- ACCESS
- APPROPRIATENESS
- ACCEPTABILITY
- OUTCOMES

The data for this audit will be collected from the services themselves, from therapists and from service users.

What is the focus group about?

This is one of a number of focus groups that will be running between November and December 2008.

We want the focus group to help us develop a service user satisfaction questionnaire for people who are receiving psychological therapies in the NHS for anxiety and depression.

The questionnaire will be used in the national audit to gather information about people's experiences of receiving psychological therapies.

What will taking part involve?

We have invited members of ... to join in a focus group discussion, which will last for about 2 hours. Our discussion will focus around a draft questionnaire that we are currently developing. We will post you a copy of the draft questionnaire in early November. We hope this will give you enough time to read through the questions and to reflect on them.

On the day itself, we would like to hear your comments and thoughts on the draft questionnaire, particularly whether we have included all the things that you think are important and of value to people who are receiving psychological therapies.

Your personal details will remain confidential at all times. No one will be able to identify you from the information and comments that you have given.

What will happen after the focus group?

The discussions from your group and those gathered from other focus groups will be written up in a report that will summarise all the recommendations and feedback we receive.

To make sure that we have understood all the points you made, you will receive a copy of this draft report for your comments before we finalise it.

Once we have developed a final version of the questionnaire, we will email this to you. This way you can see the impact of your input on this audit tool.

Who are we?

The project team of the National Audit of Psychological Therapies are Louise Nelstrop (project manager), Elizabeth Hancock and Nici Gideon.

We have experience of working on national projects in cooperation with health professionals and service users, developing audit and research tools and collecting and analysing data.

We are based at the Royal College of Psychiatrists' Research and Training Unit (CRTU) in 4th Floor Standon House, 21 Mansell Street, London E1 8AA.

If you have any further questions please do not hesitate to contact us:

Louise: lnelstrop@cru.rcpsych.ac.uk
020 7977 4973

Elizabeth: ehancock@cru.rcpsych.ac.uk
020 7977 6641

Nici: ngideon@cru.rcpsych.ac.uk
020 7977 4974

Appendix D – Guidance Notes



College Research & Training Unit
4TH & 6TH Floors, Standon House
21 Mansell Street
London E1 8AA

Dear Focus Group Participant,

Re: Questionnaire for Focus Group

Thank you again for participating in this project.

Please find attached the draft questionnaire that we will be talking about during the focus group discussion. I have also attached a schedule that will guide us through the conversation.

We would be very grateful if you could take some time to read through the attached draft questionnaire.

The questions are divided into 4 sections.

- Getting Help
- Information
- Receiving Treatment
- Getting Better and Moving on

When reading through it please bear in mind that the questionnaire is aimed at people who are **currently** receiving a psychological therapy.

We have not included any questions that ask about the person's therapeutic relationship with their therapist as we will be collecting this particular information with a different questionnaire.

We would therefore be grateful if you could bear this in mind when reading through the questions.

One way to assess the usefulness of the questionnaire might simply be to fill it in before we meet. It might be helpful to see how long it takes you to complete it and to make notes about anything that crosses your mind when reading it. However, if you do not have time to do this, don't worry. Most important are the comments that you share with us during the focus group.

Here are some questions that you might want to think about when reading through each question:

- Do you find it easy to understand this question?

- Do you like the wording of the question?
- Do you find it easy to pick one of the possible responses?

We would also like you to think about a few more general things:

- Do you like the introduction to the questionnaire?
- Do you like the introductory sentence in each section?
- Do you feel that an important question is missing in the section 1) Getting Help, 2) Information, 3) Receiving Treatment and 4) Getting Better and Moving On?
- Do you think the questionnaire contains any questions that are NOT important to someone who receives psychological therapies?

Many thanks for taking the time to read through the draft.

I look forward to meeting you soon and am very interested what you have to say.

Best wishes,

Nici

Nici Gideon
Quality Improvement Worker

Appendix E – Discussion Schedule for Participants



COLLEGE CENTRE FOR QUALITY IMPROVEMENT



Focus Group Information on questionnaire

We would like to give you some information how we will be proceeding on the day.

My name is Nici and I have already been in touch with you via email. CO-FACILITATOR FROM ORGANISATION and I will be guiding the discussion about your views on the draft questionnaire.

My colleague Elizabeth/Louise from the Royal College of Psychiatrists will be present as well. She is mostly just there to listen and she might sometimes ask for points of clarification.

With your permission, we will also be recording the discussion so that it is easier to capture everyone's views.

Here is a brief outline of how we will go about talking about the questionnaire:

Introduction

I will introduce myself and my colleagues. I will then ask you to give your first name and why you chose to participate in this focus group.

I will briefly remind everyone about the purpose of the discussion and its value for improving the questionnaire.

I would like you to know that there are no right or wrong answers. We would like to encourage you to tell us anything that you would like to. This in particular is the value of a focus group discussion – stimulating new ideas and thoughts through a group conversation.

We would also like to ask you to keep anything that will be said during the discussion to yourself. You or others might share personal experiences or opinions and we would like everybody to respect each other's right of privacy.

I would like to reiterate at this point that the information that you give on the day will be kept confidential and anonymous.

Topic Guide

It would be useful if we could use the following topics as a guide. This does not mean however that we cannot discuss the questions on the questionnaire in a

different order or deviate from them if it fits into the natural flow of the conversation. These topics are meant only as a guide.

1. We will draw attention to a few questions which we had difficulty wording or which we weren't sure whether to include at all.
We would also like to know whether there are certain questions that you find particularly problematic.
2. Working through each of the sections, are there any issues which you feel need to be included that are not currently included.
3. Which section do you feel is most important and why? Do you think that any of the questions in this section need to be reworded?
4. Do you think that it is useful to have boxes for comments at the end of each section?
5. Do you think that this questionnaire will be overly time-consuming to fill in? Would it make a difference if the questionnaire was also available online?
6. Any other issues arising within the scope of the questionnaire.

Ending

Before we end our discussion we will briefly talk through the points that have come up. We would also like to remind you to take some time for yourself after having travelled home, as speaking or thinking about personal experiences can sometimes be upsetting. You might want to take this into account and ensure that you will have a friend to speak to afterwards.

If you have any questions about the questionnaire or the project that you would like to discuss before we meet, please get in touch with me via email:

Nici Gideon: ngideon@cru.rcpsych.ac.uk or via telephone on: 020 – 7977 4974

Appendix F – Consent Form



COLLEGE CENTRE FOR QUALITY IMPROVEMENT



Consent Form Participation in Focus Group

Title of Project: National Audit of Psychological Therapies

Project Lead: Nici Gideon

If you would like to take part in this focus group, please write **your initials** in each box and sign at the bottom to confirm the following:

1. I confirm that I have read and understand the information leaflet dated 30.10.08 (Version 2) on the development of a service user questionnaire.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.
4. I agree to take part in the focus group.

Please INITIAL
below

Your name _____

Date _____

Signature _____

Project Lead Nici Gideon

Date 24.11.2008

Signature _____

Please return one consent form along with your completed monitoring form in the enclosed pre-paid envelope. The consent form will be separated from the anonymous monitoring form on receipt and stored securely. Please keep one consent form for your records.

Appendix G - Revised Information Leaflet



COLLEGE CENTRE FOR QUALITY IMPROVEMENT

'Talking Treatment'



This questionnaire is part of a **national audit** of psychological therapy services run by the Royal College of Psychiatrists.

The audit is a national survey that collects information on service users' experience of talking treatments. We are doing this to try to improve psychological services for anxiety and depression in England and Wales (to find out more, go to www.rcpsych.ac.uk/napt).

There will be three sections to be filled in at different times.

Filling in the questionnaires will help us to understand about your experience of the service and how you feel about it. Please do **NOT** write your name on the form as the information you give today is **absolutely CONFIDENTIAL**. This way no one will be able to identify you. Please be assured that your treatment will **NOT** be affected by filling in the questionnaire.

We have carried out several group discussions with current and former users of TALKING TREATMENTS to make sure that the questions asked are meaningful to you. We have discovered that people would like to have an opportunity to comment on individual questions.

We have therefore left a space at the bottom of the questionnaire and would appreciate if you could tell us any comments you may have.

Your feedback is very important as it is a chance for you to **TALK** about your **TREATMENT** and to tell us what you really think. The information you give will highlight the things your service does well and those it does not. By telling us you might be able to change things for the better.

We will collect **ANONYMOUS** feedback from every person receiving talking treatment **between May and November 2010** and analyse the information. We will then inform the service about the outcome and work together to plan how the service can be improved in the future.

If you can, please take the time to fill in the questionnaire and give your honest opinion.

Once you have completed the questionnaire please place it in the envelope provided, seal it and either hand it into the service or mail it freepost back to us.

Thank you

The National Audit of Psychological Therapies for Anxiety and Depression
4th Floor Standon House
21 Mansell Street
E1 8AA
London

Appendix H - Agnew Relationship Measure-5 (ARM-5)

ARM-5 Client's Scale

Client ID:

Session:

Date:

Thinking about today's meeting, please indicate how strongly you agreed or disagreed with each statement by circling the appropriate number.

		strongly disagree	moderately disagree	slightly disagree	neutral	slightly agree	moderately agree	strongly agree
1	My therapist is supportive	1	2	3	4	5	6	7
2	My therapist and I agree about how to work together	1	2	3	4	5	6	7
3	My therapist and I have difficulty working jointly as a partnership	1	2	3	4	5	6	7
4	I have confidence in my therapist and his/her techniques	1	2	3	4	5	6	7
5	My therapist is confident in him/herself and his/her techniques	1	2	3	4	5	6	7

Appendix I – Talking Treatment (section 1 and 3)

TALKING TREATMENT



Service Code:
Your Talking Treatment:

- 1 Thinking about your current treatment, how long approximately did you have to wait for your talking treatment to start?**
(From the point of being referred by your GP to seeing your current therapist regularly)

Please circle your answer to each statement.

	yes	no
2 I feel the waiting time for my treatment to start was reasonable.	1	2
3 I was given an option about different days/times available when scheduling my appointment.	1	2
4 I was able to get to my appointment location without too much difficulty.	1	2
5 I received enough information about my talking treatment before it began.	1	2

If you have answered NO to any of the above, or if you would like to add anything else, please comment below:

TALKING TREATMENT



Service Code:

Your Talking Treatment:

Thinking about today's meeting, please circle your answer to each statement.

	yes	no
1 This talking treatment helps me to understand my problem.	1	2
2 I feel that I am getting the right kind of help.	1	2
3 If I have similar difficulties in the future, I would take up this talking treatment again.	1	2
4 I believe this talking treatment helps me to cope with my problem.	1	2

If you have answered NO to any of the above, or if you would like to add anything else, please comment below :