

Maintaining therapeutic gains questionnaire – Summary to date (v4 4.6.18)

1. Introduction

Following previous work, which indicated that up to 40% of clients who finish treatment within an IAPT service seek additional help for their problems within the first 6 months of discharge, a survey was designed, with significant input from our patient forum, to determine:

- (i) what is already being done *in service* before treatment finishes to help keep people well after discharge?
- (ii) what additional help or support might clients want or find helpful *post discharge*?

Clients who had used IAPT services and been discharged for at least 3 months, and who had indicated that they were willing to be contacted to help with service improvement (i.e. were on the 'patient bank' within Berkshire, Buckinghamshire Oxfordshire and Milton Keynes) were sent an electronic version of the survey via Qualtrics (or were sent a hard copy of the survey if no email address was available). To date we have had 44 responses (17 from Berks, 11 from Bucks, 15 from Oxford and one from Milton Keynes). The following report provides an overview of findings from this survey.

2. Treatment information about clients completing the survey

Thirty-five percent of respondents had completed treatment within the past six months, 26% had completed treatment between six and 12 months previously, 20% had completed treatment between one and two years previously, and the remainder of respondents (20%) had completed treatment more than two years prior to completing the survey (please note because of rounding up/down percentages for each category, the total percentage here equals 101%).

Respondents were asked to indicate which difficulties they had received treatment for. Please note that because many respondents had treatment for more than one difficulty, the following percentages do not add up to 100%. Most respondents (60%) had received treatment for depression. Around half (51%) had received treatment for Generalised Anxiety Disorder. Around a quarter had been treated for health anxiety (23%). Other presenting disorders in clients responding to the survey included social phobia (14%), OCD (11%), panic disorder (9%), PTSD (6%), simple phobia (3%), and agoraphobia (3%). Nine percent had a long term physical health condition.

The majority of clients were unsure as to what 'step' treatment they had received. Patient forum highlighted that this was a likely possibility, so respondents were also asked to indicate how many *sessions* of treatment they had received (with eight or fewer sessions being indicative of treatment

at step 2). Around half of the sample (51%) reporting having eight sessions or less at their local IAPT service.

Clients were also asked to indicate treatment type (*how* treatment had been delivered). Many respondents had received more than one type of treatment (for example, they may have started treatment with a PWP via the phone, and then been 'stepped-up' to one to one work with a CBT therapist), and for this reason, the percentages reported here around treatment delivery do not add to 100%. Around half of clients (49%) had received face to face therapy, around half (51%) had done group-work, around one quarter of clients (23%) had worked with a PWP on the phone and 14% had completed online help via a computer programme or similar.

Around a third of clients (34%) had received further help for their difficulties since finishing treatment. Further treatment included help (and medication) from a GP, mindfulness, private therapy, additional group-work, online therapy, referral to a clinical psychologist and input from Mind.

3. Perceived benefits of treatment

Most respondents (97%) felt like they had benefited from treatment at their local IAPT service. Responses relating to *how* and *why* treatment had been useful could be broadly grouped into three categories:

Treatment helped to connect with others

Clients spoke about the importance of connecting with others, be that their therapist or other members of a group. This was particularly helpful in normalising difficulties, reducing stigma and feeling less isolated.

Treatment helped clients to understand their difficulties better

Clients spoke about treatment helping them to better understand factors contributing to the development and maintenance of their symptoms, including triggers and situational factors

Treatment helped clients to learn new techniques and skills in order to help themselves

Clients spoke about techniques and skills such as mindfulness, recognising negative or distorted thoughts, behavioural experiments, relaxation and breathing, sleep hygiene, problem solving, 'worry time' and various other CBT-based techniques which had contributed to their recovery.

4. Scheduling of FU appointments

Around two-thirds of clients (63%) were offered a FU appointment (scheduled to occur after treatment had finished), before finishing treatment. Of those offered an appointment, the clear majority (91%) took up this offer. Many participants felt that even though they had made good gains during treatment, having this additional session schedule 3 or 6 months down the line provided a safety net:

'I wanted to be prompted to review how I was doing after a certain time and have the possibility to ask for more help if I needed it' (HM002)

'I felt great, but knew this might slip so felt it would be good to check in' (TS024)

Those who did take up the offer indicated that it was a useful exercise – helping to remind them that they were on the right track, or if not, helping to remind them of pointers which could help them to get back on track:

'Very useful. Helped to know that I was still on track.' (TT005)

'I was able to refresh and check out the methods I had learnt in therapy. I also found that some new issues had arisen during that six months, and although a single session was not enough to tackle them totally, I was able to get some sense of direction from my therapist.' (HM003)

Those who didn't take up the offer indicated that this was because they didn't feel they would need it at the time:

'I feel I am ok and I felt ready to let go at the time. It was made clear to me at the time that if things didn't work out for me there was plenty of ways to go back in, from online tools to a re-referral. I didn't feel I was left on my own' (TT015)

5. Strategies offered/discussed with client *before* finishing treatment

Patient forum identified key strategies which were often used with clients prior to discharge. Clients completing the survey were asked to indicate whether these had featured within their own treatment.

Strategy 1: Receiving information about continued support for your difficulties, either from this service or from other services (such as online help or support groups)?

83% of the sample said this had occurred before end of treatment, and of these clients, 79% had used this information after discharge. Examples of information/resources given included:

- SHARON in Berkshire
- Talking Therapies café in Maidenhead and Bracknell
- Books and written resources
- Websites
- CDs with Mindfulness exercises
- Details of a local drop in centre
- Evening sessions at High Wycombe Mind
- Peer group meetings

I regularly look at the initial weekly questionnaire to help me think about my moods, feelings, thoughts etc. I take the info away on holiday with me so that I can have access to it. (TT011)

I have attended the Café and also a group follow-up session on Mindfulness (I was disappointed that there was quite a delay before any dates were offered). (TT018)

I often think back to all the things that I have been taught during my time with healthy minds it just helps keep me a little bit more level. I also take a look at the booklet I was kindly given for health anxiety (HM024)

I've attended the peer group meetings (HM035)

I kept a folder of all the useful information I was given and refer back to it from time to time. (MK003)

Strategy 2: Identifying the specific tools/skills learnt in therapy which helped you to get better?

64% of the sample said this had occurred before the end of treatment, and of those who did identify skills/tools learnt in therapy, 92% had referred to this information post-discharge. The following skills/tools were identified:

- Worry time
- Me time
- Writing things down
- Mindfulness
- Being kind to yourself
- Behavioural activation
- Not avoiding things

Worry time, me time, were both helpful. The idea that your life is like a boat, and if it only has one compartment, and the boat crashes, it will fill up with water and sink. But if it has two or more compartments, if it crashes, only one will flood, but the other compartments will keep the ship afloat. I keep the info to hand, and regularly complete a well-being questionnaire, to see how I'm doing, (for my own purposes) I take it on holiday, so I can have it at hand if needed. I have the booklets stores as emails for easy access. I have given friends, colleagues, etc the leaflet for talking Therapies and signposted them. (TT011)

We talked about the value of writing things down, so you can refer to them when you are not feeling ok and would otherwise find it difficult to reach those ideas. I use a table where I have a problem and I write the pros and cons of every solution I can think of is still being used and helps me out in many situations. (TT015)

We did talk about making a blue print and it was explained to me how to do it, but we ran out of time to do it in therapy. I was fine with that, as I thought the additional information I received which touched on other problems I had that influenced my anxiety was much more important to me. And I appreciated the effort to provide me with as many tools as possible. (HM035)

I completed a written account of the skills I had learnt and kept a copy. For example, the behavioural activation chart, unhelpful thinking styles (which I found particularly useful) and the worry tree and thought record sheet. (MK003)

I have put up a list of the most important/useful tools in my room, so I can look at it whenever I feel I struggle more again. I have continued to keep up the challenging myself exercise and I refer back to the worry time/tree when I feel the need to. (HM035)

Strategy 3: Discussing how you might try and keep yourself well after discharge?

71% of the sample said this had occurred before the end of treatment, and of those who had discussed this, 77% had used the information after discharge. Examples of how to keep well included:

- Having goals about the future
- Keeping physically well through exercise and healthy eating
- Referring to course material
- Becoming your own therapist

We also talked about the Bracknell Parkrun, and what a buzz I got from attending, and how exercise like this was so good for mental well-being. I think everyone should be told about the Parkrun, as talking Therapies and Parkrun work so well together (TT011)

Referring to course notes, listening to the CDs and doing the recommended meditations (TS018)

As a group we discussed the need for exposure and to keep applying the rules learnt (TS019)

Yes in the group we went through the various ways we could help keep ourselves well, focusing on self-care, and activity scheduling in things to make sure we are staying varied. (TS022)

We discussed techniques and strategies that would be 1) useful to incorporate into my day-to-day life and 2) things that would be useful to fall back on in particularly stressful times. (HM022)

Checking in monthly, my wife & I sit down & chat about how I'm doing & any changes I / we might make (TS024)

Strategy 4: Putting together a written summary about triggers for relapse and overcoming obstacles (this may have been referred to as a relapse prevention plan or blueprint)

46% of the sample said this had occurred before the end of treatment (although it may have been higher in reality as people may not have used or been familiar with this terminology, even though it had been outlined in the survey). Of those who did put together a relapse prevention plan, 67% had used it since being discharged:

I believe we were given a sheet to help with relapses which we could fill in as and when necessary to help us get through it (TS014)

We were asked to identify & write down triggers, and to think about what to do to improve our ability to cope with them (TS024)

We put a relapse prevent plan together (HM007)

We did put together a blueprint about triggers and relapses. I rarely ever look at the blueprint paper because I think that the sessions were so good that all the information was ground into my mind. (HM024)

I enjoyed writing a written summary about possible lessons triggers. It forced me to think about how to cope in the future. (MK003)

I quite often think about the time I went through during counselling so remembering the blueprint has been easier for me e.g. keeping myself busy, fit, Useful thinking styles, mindfulness, and not being afraid to talk to people. Healthy minds made this all possible (HM024)

I haven't looked at my written account since but probably should do. (MK003)

Strategy 5: Being given access to materials/tools that you could use to help keep yourself well (e.g. printed worksheets/online resources etc).

69% of the sample said this had occurred before the end of treatment, and of those who were given resources, 68% had made use of them after discharge. Examples included:

- Online resources and the course workbooks (TT009)
- Memory stick with relaxation material on it. Workbooks, Leaflets, info about Sharon. (TT011)
- Mindfulness workbook and memory stick with practices. Also details of where to access other practices. (TT018)
- Handouts each week and recommendations for reading and videos etc (TS014)
- Course notes, online websites and CDs (TS018)
- Group session notes (TS022)
- Worksheets, exercises, and we discussed a few online resources (TS024)
- Various online resources (HM022)
- A folder with all the printed materials on that we worked through. (HM024)
- Yes - printed worksheets (HM035)

The most helpful ones are up on my wall as a reminder. Sometimes I look through them if I forgot about something and would like to remind myself. (HM035)

Additional strategies

38% of clients mentioned additional strategies which were put into place with clients prior to finishing treatment to try and help them stay well after treatment. Some examples are included below:

- Importance of thinking positively and being told I could do more, and was worth more than I thought (TS012)
- Some of us in the group opened a WhatsApp group chat in order to keep in touch and encourage each of us to continue with what we'd learnt (TS018)

- A solid plan of exercises to do that have been useful, making a list together of things that help me stay well so i have a list of things to refer to. (TS022)
- It was extremely helpful to be told that, were I to feel in need of help again, I could contact them at any time. I have been fortunate enough not to have to do this, but the knowledge that such a safety net was there was extremely helpful. (HM022)
- I seem to remember a support group being offered to me which was a good comfort at the time, knowing that healthy minds were always still slightly there in the background (HM024)
- I was asked if I'd like to join a new ex-service users group. (MK003)

6. Client experience since finishing treatment

83% of clients felt they were able to maintain the gains achieved during treatment.

What helped participants to maintain (or make additional or new) gains since finishing/leaving treatment?

A number of themes emerged here, including:

- having a variety of relevant and appropriate resources to work with post-discharge
- identifying specific skills or techniques which were learnt in therapy and were helpful in bringing about change (and having the means/will/motivation to continue practicing these post-discharge)
- regularly checking in with other people (family or friends)
- playing an active role in keeping well, and keeping physically healthy

I'm getting out far more, to feel needed. I also go to the Talking Therapies My Space Cafe at St Marks once a month which I find invaluable and love meeting up with everyone (T008)

I keep using some of the tools, especially problem solving and some exposure, which helps, especially in difficult times. That said, I've also explored CBT on my own (via books) and I've also done hypnotherapy and other therapy, so it's unclear how much each therapy contributes, but in all I do think the problem solving and exposure and challenging of negative beliefs that we were taught is very helpful. (TS005)

Leaving job. Reducing stress. Avoiding things I don't enjoy. Walking. Taking time out to appreciate positive things. (TS009)

Definitely meeting other people in similar situations to myself. We have a WhatsApp group which is nice as we can support each other as and when needs be. We often meet up as well. This has been a huge help to me as before I felt very lonely having OCD as I didn't know anyone else with it (TS014)

It has been up and down, I feel I am able to control the thoughts a lot better and process the feelings and emotions a lot better. Using tools such as activity scheduling, worry time and my

anxiety diary I am able to notice patterns and also I have become aware of my habits and triggers. Medication has also helped. (TS022)

My wife's support, a conscious switch to an easier work/life balance, regularly checking in with my mental health & using the techniques I learned (TS024)

I had the benefit of further therapy, but the Healthy Minds experience helped me out of a particularly deep hole. They put me on the right track to learning the skills and techniques which I now use on a day-to-day basis. (HM022)

Trying to be mindful about what I learnt and not wasting the valuable skills I developed. (MK003)

Barriers to maintaining gains after discharge

Those who were not able to maintain their gains spoke about

- Not feeling the need to use the techniques unless they were facing a crisis (by which point it was too late)
- Not having the time to use resources provided
- Not knowing how to play an active role in keeping themselves well
- Not being sufficiently familiar with how to keep well
- Difficulties associated with actually practicing the techniques

Yes, I kept revising the tools we were taught, and used as many as I could comprehend well. However, it's absolutely worth noting that some CBT tools are tricky to understand (eg what constitutes avoidance behaviour vs. coping mechanisms) and I had to Google a lot and research on my own (TT018)

I believe that it's the practice of the skills that leads to real change, and that practice not only benefits from active coaching, but I'd say requires active coaching. (TS005)

7. Thoughts about how services could better support clients post-discharge

Although people were very positive about the support they had received ('I think the service does everything it can' HM003; 'I was very pleased with the support I received. And it got me over a very challenging period in my life.' TS009), most clients (59%) still thought it would have been helpful for their service to offer *more* in the way of support after finishing treatment. Ideas included:

- Systematic FU calls for everyone
- 6 monthly check ups over the phone
- More help to practice skills that are needed after discharge
- Drop in evenings and/or refresher days
- Specific services available in local area

- More signposting
- Peer support group meetings

On a personal basis, I feel that going to the My Space Cafe once a month keeps me going in the right direction. I also feel that this makes me feel that I have not just been abandoned (T008)

*As already mentioned, I think it's the practise that makes CBT useful. And, given that CBT tools can be tricky to understand and certainly so to master, I'm convinced that a practise period *followed by* (more sparing) follow up sessions would have been very helpful. (TS005)*

Sometimes a 'touch base' session is helpful to remind people of certain tools they can use and give them the nudge they need if perhaps they have gone back to some old ways (TS014)

Maybe a refresher day, to help underline the lessons learned and to learn from others experience (TS019)

Maybe a 6-monthly online questionnaire to check I'm still doing well, with a follow up phone call if the results indicated I was struggling. I don't want to take up resources if I'm fine, but know that relapse is very common with depression & anxiety (TS024)

The peer group helped, but it would be nice if there was something else that supports you in keeping up with your progress and not just falling back into old habits once daily life takes over again. Maybe an app or online thing that sends reminders to keep well or do certain exercises or that you can engage with. Especially on the go. I always have my phone with me, but not my stack of papers and worksheets. Some mindfulness classes could also be helpful (HM035)