

What are the experiences and perspectives of adults who are accessing secondary care psychological therapy for anxiety or depression?

A co-produced report of a qualitative analysis









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Cover image: 'Uncertain Reflections (reeds)' by Jessie Davies – winner of NCAAD art competition

"Where the reed stems enter the water, they disturb the calm reflections. Uncertainty grows as we look more closely, with multiple intrusions and distortions causing us to question our perceptions.

In the end, we seem to be viewing the scene as if we, ourselves, are under the water."

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REPORT SUMMARY

Background

This is the third report from the National Clinical Audit of Anxiety and Depression. The first report highlighted that most people who are admitted to hospital for anxiety and depression are not referred for psychological therapy.

The second report found that most adults who receive psychological therapy rated their therapist highly and felt helped by the treatment they received, but access was poor, there was often a lack of choice and outcome measures were not routinely being used.

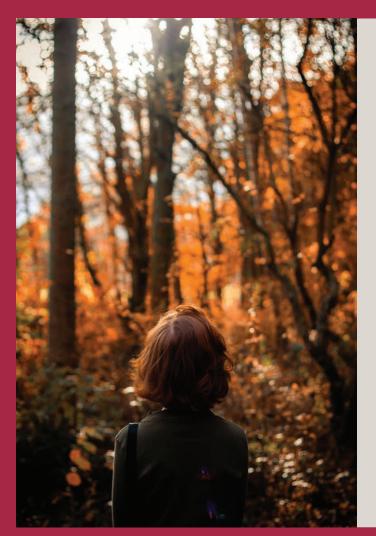
This report provides further insight into the experiences and perspectives of adults using psychological therapy services.

What we did

We examined written comments from 447 people who took part in a survey of their experience of secondary care psychological therapy services in England. We generated 'themes' from these and asked members of our Service User and Carer Reference Group to provide feedback.

We then used this feedback to make recommendations for people delivering psychological therapy services and for those conducting future audits.

See page 12 for further details of what we did and page 39 for the methodological limitations, which include potential inconsistencies in sampling between services.



What we found

Service users told us how hard it was to access therapy and asked for more information about the type of treatment being offered and how it could help them. They emphasised the importance of the personal attributes of the therapist and how important the physical environment was where their therapy was delivered.

While many people had positive experiences of therapy, others had negative experiences. Many reported having little choice or sense of involvement or control of their therapy. Service users described insufficient attention to what happened to them after therapy finished and to how they could seek help in the future if they needed it.

See pages 15-34 for further details of what we found and right, for our main recommendations for future service provision.

RECOMMENDATIONS FOR SERVICES

Recommendations to improve future secondary care service provision:

Steps should be taken by **NHS managers** to improve access to psychological therapy services, by:

- reducing waiting times
- offering greater flexibility with appointment times
- · making sure the venue is readily accessible.

Psychological therapy services and clinicians should provide better information before, during and after therapy.

This should include information about likely waiting times, managing difficulties that might arise during therapy, discharge planning and how to access support in the future.

Clinicians should work collaboratively with service users and support shared decision-making.

This should include the type of therapy that service users are offered and the likely number, frequency and times of their appointments.

Psychological therapy services should place a greater emphasis on monitoring the outcomes of therapy, including both positive and negative experiences.

THE PURPOSE OF THIS REPORT



This report presents an in-depth qualitative analysis of the service user survey feedback collected as part of the National Clinical Audit of Anxiety and Depression (NCAAD) of Psychological Therapies that ran in England between 2018 and 2019. Service users' responses to the free text query at the end of the survey, 'Do you have any other comments about your therapy?', were analysed. These answers and the resulting analysis provide additional insight into what matters to service users. We have used this feedback to develop recommendations for future audits of psychological therapy services.

This report is co-produced with input from service users and carers, clinical advisors, the NCAAD team and the McPin Foundation, an independent mental health research charity. It is designed to be accessible to anybody interested in mental health services and the provision of psychological therapy.

The main findings of the qualitative analysis are presented along with recommendations, jointly developed by the NCAAD team, service users and carers, and a steering group.



Jargon buster

McPin Foundation

They believe mental health research is done best when it involves people with relevant personal experience that relates to the research being carried out - in this case, people who have had psychological therapy or cared for those who have.

Qualitative data

These are data that come in the form of words as opposed to numbers (known as quantitative data). It could be freetext responses to questions in surveys, as is the case here, or it could be a transcript of what was said in a research interview or focus group.

HOW WERE SERVICE USERS AND CARERS INVOLVED IN THE AUDIT?

People with personal experience of accessing care for anxiety and depression have been involved from the start of the audit. A Service User and Carer Reference Group contributed to decisions about what data should be collected and helped develop tools to measure service performance.

Once the analysis of the qualitative data from the audit had been conducted, the Service User and Carer Reference Group was invited to discuss the results and offer thoughts on how the findings related to their own experiences. The audit team drafted recommendations based on this initial Service User and Carer Reference Group meeting, and these were further refined in an e-consultation sent to both the Service User and Carer Reference Group and the Steering Group.

These recommendations are detailed throughout the report and a full list can be found in the online appendices.

Jargon buster



Service user

For the purposes of clarity, we have used the term 'service user' to describe people who use services to receive support for their own anxiety and/ or depression. We acknowledge that people may have their own preferences or terms they identify with.

Carer

For the purposes of clarity, this describes family members, friends and other people who support or care for a loved one with anxiety and/ or depression. We acknowledge that people may have their own preferences or terms they identify with.



INTRODUCTION



Jargon buster

Royal College of Psychiatrists (RCPsych)

A professional body that is responsible for setting and improving standards in psychiatry. They manage a programme of National Clinical Audits, which are commissioned by a body called HQIP on behalf of NHS England.

Healthcare Quality Improvement Partnership (HQIP)

An independent organisation that aims to improve health outcomes by enabling those who commission, deliver and receive healthcare to measure and improve healthcare services.

The British Psychological Society (BPS)

The representative body for psychology and psychologists in the UK. It is made up of members from all walks of life whose primary interest is in the development and application of psychology for the greater public good. The society is responsible for the promotion of excellence and ethical practice in the science, education, and practical applications of psychology.

NHS England

NHS England leads the National Health Service in England and supports the NHS to deliver improved care for patients.

The aim of the National Clinical Audit of Anxiety and Depression (NCAAD) is to find out how inpatient and secondary care community services for adults with anxiety and depression are performing, so that the quality of care they offer can be improved. The NCAAD threeyear programme began in 2017 and is led by RCPsych. It is commissioned by HQIP on behalf of NHS England.

A core audit ran between 2017 and 2018 and assessed whether inpatient services for people with anxiety and depression in England were meeting 13 standards. The standards provide a framework of best practice - they give service users and carers an idea of the sort of care they should expect from a service and tell service providers what they need to do to provide high quality care.

The focus then turned to psychological therapies for anxiety and depression and a 'spotlight' audit was carried out between 2018 and 2019. This looked at the performance of secondary care psychological therapy services in England across 8 standards, and was carried out in partnership with the BPS. This audit, the Spotlight Audit of Psychological Therapies, consisted of analysing case note data from service users, survey data from therapists working in secondary care services, and survey data from service users who had been discharged from these services. A report of the findings is available here.

This report is solely concerned with the qualitative responses to the query, 'Do you have any other comments about your therapy?', in the service user survey, received as part of the Spotlight audit. The quantitative data gathered in the core audit and the Spotlight tell us what happened, but they do not convey what the experience was like for the service user.

Taken together, the quantitative and qualitative data offer a richer insight into how services are doing and how this is experienced by service users than either does alone.

The hope is that this report will provide a better understanding of the experience of service users, identifying issues that matter to them but are not covered in previous reports, and reinforcing the importance of certain standards services are currently measured against. It is also hoped that the findings will enable services to better understand the experience of service users.

In conclusion, this report outlines what service users think and feel about the therapy they have received, and makes recommendations in order to help Trusts to improve the services they provide and also shape and improve future audits.

"Reading the analysis, I felt that there were 447 service users in the room with me."

"I recognise every single point here. It is genuine... It could have been me writing."

Service User and Carer Reference **Group members**

Psychological therapies

There is strong evidence that psychological therapies are effective for a wide range of mental health problems, including anxiety and depression. Some types of psychological therapy are recommended by NICE.

Cognitive behavioural therapy (CBT) is recommended for all anxiety disorders and a wider range of therapies are recommended for depression, including interpersonal therapy, CBT, counselling, behavioural couples' therapy, behavioural activation and short-term psychodynamic therapy.



Jargon buster



The National Institute of Health and Care Excellence (NICE) This is a body that provides national guidance and advice to improve health and social care.

Improving Access to Psychological Therapies (IAPT)

This is an NHSE programme which began in 2008. It provides NICErecommended psychological therapies for adults with anxiety and depression. It is usually suitable for people whose needs can be managed safely and effectively in primary care services. IAPT services were not included in this audit, which only looks at services in secondary care.

Case notes

A written record of a service user's history, and which care providers update with the individual's care plan and any drug or psychological treatments prescribed.

Despite how common they are, anxiety and depression frequently go unrecognised and people can also have difficulty accessing psychological therapy services, which means that many adults who might benefit from treatment do not receive it.

The IAPT programme was initially developed in 2008 to improve access to evidence-based psychological therapies in the NHS. Most adults who ask for support with anxiety or depression will be seen in an IAPT service, which is closely linked to primary care. However, this provision is not suitable for everyone.

Some people have more complex and severe difficulties that require help from secondary care mental health services, such as community mental health teams, crisis and home treatment teams, secondary care psychology/psychotherapy services, specialist services, and inpatient services.



For more information on the development of the audit, please see page 8 of the Spotlight Audit of Psychological Therapies report.

Jargon buster

Primary care

Services that provide the first point of contact for healthcare. This will include general practice, community pharmacy, dental and optometry services.

Secondary care

Services where people are usually referred to when they have a health problem that cannot be managed in primary care. Secondary care healthcare is delivered by health professionals with specialist knowledge.

NHS Trust

For the purposes of this report, this is a body that provides secondary care health services.

Inpatient mental health services

A facility with hospital beds that provides 24-hour care for people experiencing severe mental illness. These units provide a range of treatment options that aim to help improve the mental wellbeing of patients, with a consultant psychiatrist or other professional acting as the responsible clinician. Inpatient mental health services also care for people detained under the Mental Health Act.

Community mental health services

Services within secondary care that use diverse teams of mental health professionals to provide specialist care outside of a hospital environment. Community services include crisis teams, early intervention teams and assertive outreach teams as well as generic community teams.



THE AUDIT

A total of 50 out of 54 NHS Mental Health Trusts in England registered to take part in the Spotlight Audit of Psychological Therapies. Trusts registered 232 services that provide psychological therapies in secondary care, including both inpatient and community services.

What happened in the audit?

Step 1

Trusts sent surveys to 30 randomly chosen eligible service users from each service



Step 2

Surveys were returned to the RCPsych

662 surveys were received, with **447 comments** responding to the final query.

ceeeeeeee

People were eligible to complete a survey if:



They were 18 years or over



They ended psychological therapy between 1 September 2017 and 31 August 2018



People were not eligible if they received a diagnosis of psychosis because this is covered in the National Clinical Audit of Psychosis

Do you have any other comments about your therapy?

Step 3

A thematic analysis of survey comments was conducted to identify recurring patterns or 'themes'

First researchers assigned 'codes' to chunks of text to make sense of it, then these were grouped together to form themes.



Step 4

Consistency checks were carried out to make sure that the researchers were coding the comments similarly





The themes and potential recommendations for future audits were discussed at the Service User and Carer Reference Group meeting



Step 5

8 themes were identified



Step 8

Final recommendations were drawn up for future audits

This was done using the feedback as well as looking back at the recommendations from the core and Spotlight audits to identify any gaps.

Step 7

Further feedback was given via an e-consultation that went to the **Steering Group and the Service User** and Carer Reference Group

WHAT DID WE FIND?

The next part of this report presents the findings from the audit. First the themes are introduced, then a summary of each theme is presented along with illustrative quotes from the survey respondents.

Extracts from the discussions had by the Service User and Carer Reference Group and in the e-consultation show how the themes resonate. We point out where recommendations and standards from the previous core and Spotlight audits are strengthened by this analysis.

Finally, recommendations on how to develop future audits are included, based on the service user feedback and any gaps identified in previous recommendations. This includes ideas for new standards for services to be measured against or new questions that can be added to the questionnaires for therapists, services and service users.



THEMES

Analysis of the responses to the free text query, 'Do you have any other comments about your therapy?', were categorised into the following themes:



THEME 1: **ACCESSIBILITY**

Therapy was not easily accessible for service users. They reported issues with how quickly they were able to access therapy and difficulties meeting service thresholds. Once they started sessions, service users reported issues with their frequency and physical access to the location, as well as with funding and resources.



THEME 2: **THERAPIST**

The personal attributes of a therapist and their behaviour and rapport with the service user were considered a key influence on the experience of therapy.



THEME 3: THERAPY CONTENT

Service users emphasised the importance of the content of the therapy sessions, including the type of therapy they received and the information they were provided about the therapeutic approach and journey.



THEME 4: CONTINUITY OF CARE

Service users reported experiencing a lack of onward care, which led to feelings of abandonment and loneliness.



THEME 5: COMMUNICATION

A lack of communication between services and between service and service user exacerbated many of the problems experienced, with service users feeling disenfranchised and not listened to.



THEME 6: PHYSICAL ENVIRONMENT

The physical environment in which therapy took place had an impact on the experience for service users, both positively and negatively.



THEME 7: IMPACT OF THERAPY

The impact of therapy for individuals was polarised across the sample, with some having an extremely positive experience and others an extremely negative experience.



THEME 8:

Control of the therapy experience, or a lack of it, was a key factor determining the extent to which outcomes of therapy were successful. Because of this lack of perceived control, service users felt lucky if they had had a good experience.

THEME 1 ACCESSIBILITY

A strongly held view was that the wait to begin therapy was too long, which could have detrimental effects. Time spent on waiting lists could be extremely stressful.

It took 17 years of being pushed from pillar to post to finally be offered therapy on the NHS.

■ I waited 4½ months for CBT therapy which I asked for. This was very helpful but came too late. The therapist agreed, I felt I would have recovered much earlier if I had received CBT at the beginning of my illness.

When therapy was scheduled, the time of day was not convenient for some as it clashed with work commitments.

My therapist offered me a weekly appointment which was not convenient. I told her of the difficulties. She offered me another. It was more convenient but not ideal... I am self-employed and it meant that I had to take that particular day off work.

In some instances, getting referred for therapy had been a struggle. The threshold for referral was perceived to be too high when people had been assessed as 'too well' to receive therapy.

■ I had stopped self-harming altogether and therapy was nearly stopped because of this (taken off waiting list).

■ I waited over a year for treatment that was not allocated until I was in crisis.

The geographical location of the therapy sessions could make them difficult for some to access, for example, if the journey was too long or complex.

For disabled service users, relying on transport services such as an ambulance or taxi could be stressful, and physical access to buildings could be difficult. People wrote of having to use steps or finding the lift broken.

Sometimes the lift in the place broke but always someone helped me. | |

Some days transport was on time and others it took ages to arrive adding to anxiety.

Under-resourced therapy services were considered by service users to be the main cause of difficulties with accessing therapy.

■ The whole experience is stressful, all that I think about is cut-backs and waiting lists. Only 1 therapist I was doing well with and my time was up. Makes me very nervous when the therapist are clock watching all the time. As patients, we understand about cut-backs and waiting times but don't need it drummed in to your head.



On inconvenient appointments



Appointments [during the working day] are really difficult to explain to your employer while keeping your mental health confidential.

I used to say I had a doctor's appointment, but that becomes more difficult week after week.





Mhen you're referred, it takes ages and you hear nothing, and then you get a letter saying it's next week with a fixed time and date. The onus is on you to try and sort it out if it's inconvenient.

Letters are problematic. Especially when I was at university. Sometimes it went to my house where I wasn't in but sometimes it went to the common post room. This is not as confidential as I would have liked. Email would have been more confidential.



This theme further supports the recommendations in the NCAAD psychological therapies audit to plan care collaboratively, consider access barriers, ensure therapy starts as soon as possible after referral and to keep people informed of their likely wait.

See previous recommendations 1b, 2a and c, 4b.

Recommendations for future audits

- a) Future audits should ask service users whether they were given a choice about the time of their appointment.
- b) Future audits should assess how easy service users found it to access the service.

THEME 2 **THERAPIST**

A therapist's manner and behaviour towards the service user was considered a key influence on outcomes of therapy. Personal attributes considered to support a positive experience included the therapist showing kindness, understanding, empathy, compassion, acceptance, sympathy, respect and a willingness to help.

Positive professional attributes included being challenging, candid, setting clear boundaries and goals, and having emotional stability.

▲▲ My therapist was so kind and reassuring and I never felt like I was being judged or made to feel bad about my problems.

■ Did not wrap me in cotton wool, good, built resilience.



On choice of therapist

•• Quite often people have preferences for who they want their therapist to be, especially people with a history of trauma. It is sometimes useful to have perceptions challenged, but it could be retraumatising. I don't think I could have a male therapist. I would rather wait longer to see someone who I could build trust with quickly. Services have told me it will take longer to find a person with the right specialism plus my preference. But this is ok.

Having a therapist who did not show positive attributes and behaviours could damage trust and lead to the service user disengaging from services.

I nearly complained about one abusive psychologist and was very concerned about the behaviour of another staff member. My experience with [the service] was so negative that I will never contact mental health services again. "

▲▲ My therapist and I did not get along. At one session she made me cry because I missed an appointment... she made no effort to send me a reminder. When I asked to be discharged from her care and moved to another therapist, she ignored my request. I'm currently not able to get therapy because she won't discharge me and I don't want to attend her sessions.

Therapy was seen as less successful if the therapist lacked experience working with people with the issues the service user had, or lacked experience using the therapeutic approach they needed.

Continuity of therapist – having the same person throughout the course of therapy – was valued. A therapist's demographic, specifically their gender and ethnicity, was also important for some service users.



On the therapeutic relationship



fit's about a willingness to respect what you're saying. Therapists have to build up a picture of you, but they must also be willing to change that as otherwise they end up mushing every bit of you into that box they've created.

it's the chemistry between the therapist and service user. We all get on with some people better than others – that's a statement of fact.





📫 But there are some people I ask, 'What the hell you are in doing in this career?' 💵

📫 I had an interesting experience with a group therapy session, where there was friction between me and the facilitator. When I went back to get individual therapy, my therapist was the facilitator. I used the tension to get some interesting stuff onto the table. It was doubly hard because of our past interaction, but it was a good experience. My conclusion is that the therapeutic relationship and what works is really complicated.





My worst experience was with someone who was straight out of college. They delivered very mechanical CBT. It was worse for me than someone I couldn't build a rapport with.

[The person I care for] felt that her therapist was too 'offhand' and did not take her concerns seriously, leading to her becoming suicidal.



This theme further supports the recommendations in the NCAAD psychological therapies audit to ensure clinicians are accredited to deliver their therapy, that dissatisfaction is monitored and addressed, and that service users are provided with a separate named contact to approach if difficulties arise.

See previous recommendations 5a and b, and 8a.

Recommendations for future audits

- a) Future audits should ask therapists and services about what information is provided to service users who experience difficulties with their therapy.
- b) Future audits should ask service users about what help they received if they experienced difficulties with their therapy and how useful this was.



The number of sessions of therapy received was often seen as insufficient to meet respondents' needs. In some cases, sessions were not felt to be frequent enough, especially if they were less than weekly.

Perhaps it would be useful to base the length of the therapy on individual needs, not just cut off after 6 sessions!

L I did not feel my therapy lasted long enough, as I am aware I have cracked open the top of my emotional baggage and am now left with no support to manage it. "

Service users valued being given information about the therapeutic process and felt concerned when this was not provided. They felt it was important that the theory of the particular therapeutic approach and how it could work for them was explained, and that they were encouraged to ask questions about this.



I have found CBT to be extremely useful, my therapists have been excellent at helping me understand the concepts.

They also appreciated being taken through the stages of the therapy process ...

in I had three initial sessions with one therapist, then told they were 'assessment' and ultimately referred to another. This was a major shock. Fortunately, 2nd therapist was ideal but initial lack of information plus no checking that process had been understood led to extreme distress.

...and having this tailored to their needs, in terms of the appropriate type, format and pace, with topics of discussion decided on in conjunction with the service user rather than controlled by the therapist.

CBT therapist excellent calibre and adapted process to my needs rather than fit a person into a process – this impressed me.

it wasn't rushed, nicely paced she didn't push me to talk about things if I didn't want to. 🤫



On explaining the process



Im sure that therapists I've seen have told me what to expect in the first 10 minutes of the meeting. But this is a strange situation, so often you don't take in what you're being told. One thing that does stick is that you have X number of sessions, but if they say, 'I'm a psychodynamic psychotherapist' – whoosh, its over my head.

•• Some approaches drive me mad. I remember being in a group where there was always an empty chair. It took a few sessions for the group to realise this and the facilitator never explained it.



On the number of sessions



in the first session I am sussing out the therapist. I don't think clinicians realise this. I'm holding back in the first session as I'm working out whether you are any good. Therapeutic-wise, forget it. "

it's a two-way process – establishing the therapeutic relationship. Presumably they are also sussing you out – assessing your needs and how best to proceed. I find the first session very nerve-wracking. It's an unusual scenario, you don't usually speak to a stranger about problems you find hard to articulate.





1 I had an experience where my therapist was having to beg her manager for extra sessions so she could complete what she had in mind for me.

This theme further supports the recommendations in the NCAAD psychological therapies audit to ensure that the type and number of therapy sessions are tailored to the individual and that information about therapy type, venue, time, language and therapist gender is provided so that decisions can be made collaboratively. See previous recommendations 3b, 4a and b.

Recommendations for future audits

a) Future audits should ask therapists how service user needs and preferences are taken into account when planning the number and frequency of appointments.

THFMF 4

CONTINUITY OF CARE

The period after a course of therapy ended was considered to be a vulnerable time for service users. Sometimes the service user was able to put the tools they learnt in therapy into practice or the transition to other support was handled well.

■ I found CBT extremely beneficial to my long-term recovery process. He expertly provided me with a handful of tools which I now employ on a daily basis to cope with my neurological condition.

My therapist contacted social services to recommend 'help and care at home'. This is something we had tried to do at home without success. Her intervention successfully changed the situation, and we now have a little help.

At other times, a much-needed assessment of needs and ongoing care was not provided. This could be because of gaps in the referral process, for example: a service user being told they would be referred for further treatment but then receiving no further communication; a therapist leaving their post part-way through a course of therapy and no replacement being provided; or a service user registering with a new service, such as a GP surgery, part-way through therapy.

■ I received a copy of the letter sent to my GP saying I was being put back into the care of the GP - my GP had left the surgery so who was supposed to care? I then moved home and had to highlight at my new surgery I had had this therapy - no-one is interested because it is in the past - they don't read notes and I am left thinking that I am worth no further attention.

f Therapy stopped early because moving to different mental health authority and am still on waiting list to be resumed 6 months later, despite several overdoses in meantime.

Respondents felt it was important that the ending of therapy was managed well by the therapist and that they were provided with support for their onward journey. If this didn't happen, it caused distress and feelings of abandonment.

Avoided several times then discharged I feel extremely let down and abandoned left to try and cope alone.

■■ When it came to the end. I wasn't warned it was very sudden. And I was only told the day of my last session it had finished.

Well-managed endings were those where the therapist and service user discussed the upcoming ending during sessions and the therapist signposted to other sources of support. Suggestions were made that there should be a formal assessment of any further needs after therapy ends.

■ It would have been helpful to have been given the opportunity at the end of the treatment to discuss how to move forward and perhaps be given the option to either continue or discuss if any other long-term therapy might be required. I felt I was just completely dropped after finishing the therapy – who was to take responsibility? ""



On follow-up after therapy ends



Having someone check in afterwards is a brilliant idea.

📫 And not just about whether you need more therapy, but also what is going on in your life? I used to be sceptical about social prescribing, but I've since found non-medical things helpful. This could be a helpful point to signpost to recovery colleges, for example. Your therapy is over but your recovery isn't.





▲▲ It's a safety net – if you were referred elsewhere, did it happen? ■■

On continuity of care



I got kicked off an eating disorder service I'd waited 2 years for when my GP left. The GP system creates a mess of continuity of care. Now I see a dietician once a year. That level of follow-up is all I need as I am stable, but there is always a risk of relapse. But it is so reassuring to know that I am still in their system. If something bad does happen, I know I won't have to go to the back of the queue.

from CMHT Discharge is really tricky. I've fought against my discharge from CMHT [community mental health team]. Yes, I'm not too bad now so 6 months appointments are ok. But what if I'm bad in 6 months' time, I go back to the end of the waiting list?



There are no recommendations from previous audit reports that are relevant to this theme.

Recommendations for future audits

a) Future audits should include a standard on providing service users with information about how they can access further support after discharge.



A lack of communication between the service and the service user, or between services, exacerbated many of the problems service users experienced, with feelings of being disenfranchised and not listened to.

My treatment was stopped before I was well. I begged her not to stop. I was told I had been given my allocation... I live in a constant state of panic, distress and misery.

Various examples of poor communication were reported, most commonly before and after a course of therapy. These included service users left waiting to be told when therapy would begin or resume, and not being told what would happen after therapy ended or whether they had been discharged.

Therapist... agreed to write to my doctor. I have no idea what happens next. Please improve communication. These experiences gave service users the impression that therapy services lacked transparency and accountability, particularly when no explanation or apology was offered for issues such as long waiting times.

A lack of accountability and point of contact exacerbated the sense that the service lacked a human face, and that the service user was powerless against an impersonal bureaucracy. Sometimes this led to feelings of being unsupported and alone.

There's no compassion or sorry from anybody in regards to the amount of time you do actually have to wait.

I have nowhere to turn for mental health issues.





On long silences



It is very easy to get worried by services' lack of communication. Your GP might receive a 'confirmation of referral' letter but then nothing. Some idea of how long it will take to be assessed or begin therapy would be good.

for even an acknowledgement of your referral. Sometimes GPs don't even get that.





You feel forgotten. If you have no idea where you are in the system, it is very easy to feel abandoned.

•• You hear nothing until the week before, telling you you must come in at this time. No one checks with you that therapy is still right for you – even if it has been a long time since referral.





from referral right through to discharge. Good communication is essential for this.

This theme further supports the recommendations in the NCAAD psychological therapies audit to monitor waiting times and inform people of the expected wait, to provide details of how to access interim support and to ensure that therapy starts as soon as possible after referral.

See previous recommendations 2a and c.

Recommendations for future audits

- a) Future audits should develop a standard which looks at the means of communication between service users, services and therapists, including whether service users are asked how they would like to be contacted and updated about their therapy sessions.
- b) Future audits should explore whether service users are offered the opportunity to co-produce their discharge plan and letter, and whether they are offered a copy.



THEME 6

PHYSICAL ENVIRONMENT



The physical environment in which therapy sessions took place could influence a service user's experience of therapy.

For this reason, it was considered important that service users felt the venue where therapy took place was safe and physically secure, and was in an environment that made people feel comfortable.

■■ I had issues with the stability of the venue regarding security, noise and space. 🐬

Certain types of venue caused service users discomfort.

■ I felt very nervous about the location of the therapy in an old fashioned, secure, mental health detention centre.

On the positive side, certain venues for therapy were found to be particularly appealing. For example, one respondent liked the 'normality' of the art-room environment in which art therapy took place, while another appreciated being able to receive therapy at home.

A suggestion was made that some therapy sessions located 'off site' would be helpful, suggesting that the location and physical surroundings of a therapy session influenced the overall experience.



On the right space



I know people who have refused to attend therapy in the psychiatric unit in the middle of town. This is known to be a psychiatric unit so people don't want to be seen to go there.

📫 This will be a particular problem in small towns. 💵





1 I'd request a building with doors that don't bang. For people with trauma or who are hypervigilant, doors banging are stressful. It's also good to have a choice about where to sit. Little things like this make people feel more comfortable.

•• You want a calm, quiet room. You shouldn't be distracted by external noise, such as hearing voices in another room or in the corridor as this means they can hear you. Building work or busy roads can also drive you mad.





■ I once walked into a room with a CCTV [closed-circuit television] camera. I refused to have the session and the therapist was able to find an alternative.

1 I agree that good environments are those outside of the hospital setting. The waiting space is also important. I had therapy in an outpatient hospital ward where there were screaming children. It made me feel worse.



There are no recommendations from previous audit reports that are relevant to this theme.

Recommendations for future audits

a) Future audits should ask service users how satisfied they were with the physical environment where they received their therapy.



THEME 7

IMPACT OF THERAPY

Respondents had generally been affected either very negatively or very positively by their experience of therapy.

Extremely positive impacts included therapy having saved the lives of some respondents.

■ I don't believe I would have survived without them. **99**

■■ When I started therapy I was suicidal. When I finished I was looking forward to life.

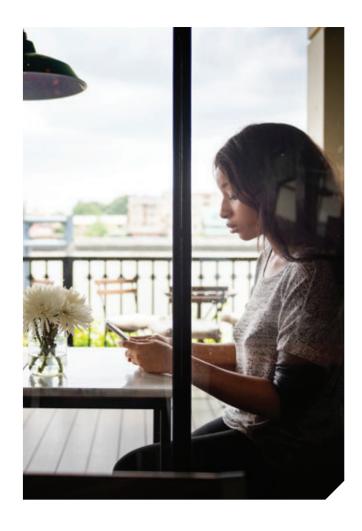
Ways in which therapy had effected positive change included increasing a person's selfconfidence, independence, understanding of themselves, ability to manage everyday activities and relationships, and enabling them to 'move forward' with their lives.

This therapy was brilliant and I would recommend it to anyone who has felt rejected growing up, this helps you to feel listened to and to be able to exercise your voice and feel understood is vital for growth and development.

However, negative experiences of therapy had made some feel more unwell and less willing to engage with therapy services in the future. The disappointment of the negative experience of therapy left people feeling abandoned and let down.

▲▲ I stopped having talking treatment after 5 or 6 sessions because it was making me more unwell.

▲▲ My health conditions have not got any better and I have less confidence in the NHS mental health services or telling my story to anyone as I feel that nobody really wants to help.





On impact



■■ When I first went through therapy, I assumed when I had been through it I'd be better. But it doesn't work like that. It is very hard for service users to evaluate the impact on them.

it is so hard to quantify. You need time to experience a less awful life – one day you'll wake up and you'll realise you don't want to die anymore.





Therapy sends ripples through your life. When things have got better, you might put two and two together and realise the therapy helped. Often impact is more an absence of important symptoms rather than something tangible.

but there are so many factors. How do you know whether any change is down to therapy, a change in medication or something else in your life?





figure EMDR was my most pure moment of realising that something had worked. I could feel that my memories of what happened to me were more slippery, less clear and less distressing.

it's about expectation management. Recovery takes a lot of time, it proceeds in fits and starts, and is different for everyone.





The most helpful thing said to me about my eating disorder was that, 'It is like diabetes. You can learn how to manage it and you will be able to do everything, but it will be with you all your life'. This is expectation management. You learn how to manage your mental health as well as manage your physical health. For me, that was the most helpful thing that therapy can enable you to do.



On impact on carers



There is no support for carers while their loved one is in therapy. It will have an impact on them. They need support and information, and to know what impact it might have on the person.

Selection Before EMDR, my therapist gave me an idea of what would happen in between sessions, how hard it would be, and the things that my partner could do to help if I became distressed. It was great to have my partner involved.





This theme further supports the recommendations in the NCAAD psychological therapies audit for therapists to work with service users to complete validated outcome measures at least twice over the course of therapy, and review progress against service user defined goals. See previous recommendations 6b and c.

Recommendations for future audits

- a) Future audits should ask about the information provided to carers, including whether sufficient information was provided.
- b) Future audits should ask service users about the information they were provided about the potential impact of therapy (including possible negative effects) and how prepared they felt for therapy, and whether they were provided with enough information.
- c) Future audits should ask service users about how prepared they felt for ending therapy.





The words 'lucky' and 'fortunate' were frequently used by service users to describe their experiences of therapy. This was in part due to the scale of positive impact it had had on their lives...

■ I found the help from a really professional man who saved my life... thank you. 💵

You could say it saved my life, literally, and I'm so very grateful that this treatment was available.

... and in part due to the sense that a successful outcome depended on various factors that were largely outside the control of the service user.



Knowing that many others did not receive therapy that met their needs (as a result of long waiting lists, for example), led service users to feel disempowered. They did not see themselves as active agents who could exercise choice and control over the process. This meant that when people did experience positive outcomes, they felt it was due to luck rather than any deliberate exercise of power.

▲▲ Mental health care is very underfunded. It needs more psychiatrists, CPNs [community psychiatric nurses], therapists and hospital beds. I was fortunate in that in my area there is a service for over 65s and I saw a psychiatrist in about 10 days.

▲▲ I was incredibly lucky to be able to see the same therapist as I had seen previously, which enabled the therapy to go forward from the beginning rather than me having to go over old ground again.

Not feeling in control of so many varying factors could also lead to feelings of disenfranchisement and disconnection from the experience of therapy, where service users felt like passive rather than active agents in the process.

■ [The appointment time my therapist offered] was not ideal. Frankly, I was so grateful to be getting the therapy in the first place that I simply accepted it... I acknowledge that commitment is an important aspect of therapy.

The importance of agency

Looking at the themes collectively, control of the therapy experience or a lack of it was a key factor determining the extent to which respondents felt their therapy was successful. Dissatisfaction with therapy services stemmed from an overall sense of a lack of choice. personalisation and opportunity to be involved in and influence the design of therapy.

This included a lack of control by the service user over how quickly they could begin a course of therapy, the type received, the content of therapy, the individual therapist they were allocated to, how many sessions they had, how frequently and in what format (whether individual or group), their understanding of how therapy works, and how to communicate with services to gain information or try to influence the process in any way.

A lack of control of these factors led to feelings of disenfranchisement and disconnection from the experience of therapy, which in some cases led to service users' disengagement from psychological therapy services altogether.

Although there were some very positive experiences of therapy, those who had found therapy helpful were inclined to consider their experience to have been due at least in part to good luck, rather than any deliberate action or choice exercised by the service user. It was perceived as being a lucky 'one-off' rather than something that was extended systematically.

In conversation with the Service User and Carer Reference Group



On luck



1 I can really relate to this. You never know what you're going to get. It's like spinning a coin.

1 It is sad that people feel lucky if they have a good experience. If I broke my arm or got tonsillitis and was treated appropriately, it's not luck, it's the system working as it should.





■ I felt like I was being passed around and around, but as soon as I was sitting in a room with the right person, something clicked. The system seemed to work.

How many people never get to that point? They never find the right room. That's when we lose people.





On control



- **1** 'Control' is a funny word. For me, feeling not in control is axiomatic to mental health problems. I feel out of control because of my mental health.
- f you're in a car accident, you're in the ambulance and then A&E. You're not in control, but you are trusting that the team know what they are doing. You want the same thing when you go into therapy.





- I think this theme reflects people's mistrust of the system. Sometimes you don't want to be in control, you want to trust people or services and that's difficult when you don't.
- 4 Yes, sometimes you want to be able to feel you can relinquish control and put your trust in services to do the best for you, but other times, feeling like you are in control and able to direct the process to some extent is so important. Service users need to be able to exercise choice. If something goes wrong, we also need to be able to negotiate the complaints system in a way that feels safe. You need to be quite resilient to do that.





1 Yes, I am not sure if the service user I care for would be happy to complain as they might feel it would influence their care in future.

This theme further supports the recommendations in the NCAAD psychological therapies audit to ensure choice and shared decision-making are supported, monitor and address dissatisfaction and provide service users with a named contact separate to the therapist to approach if difficulties arise. See previous recommendations 4a and b, 5a and b.

Recommendations for future audits

a) Future audits should ask service users about whether they felt they had influence over their therapy, including their level of involvement in decisions made about the type, number and frequency of therapy sessions and the times of their appointments.



RECOMMENDATIONS FOR SERVICES

Recommendations to improve future secondary care service provision:

Steps should be taken by **NHS managers** to improve access to psychological therapy services, by:

- reducing waiting times
- · offering greater flexibility with appointment times
- making sure the venue is readily accessible.

Psychological therapy services and clinicians should provide better information before, during and after therapy.

This should include information about likely waiting times, managing difficulties that might arise during therapy, discharge planning and how to access support in the future.

Clinicians should work collaboratively with service users and support shared decision-making.

This should include the type of therapy that service users are offered and the likely number, frequency and times of their appointments.

Psychological therapy services should place a greater emphasis on monitoring the outcomes of therapy, including both positive and negative experiences.



WHAT HAPPENS NEXT?

For service users and carers

There are several ways for people to voice their opinions about their local mental health services. They may also wish to get involved in how services are run, in order to help improve them.

Concerns and complaints

- People who want to report concerns about performance should initially approach their local Patient Advice and Liaison Service (PALS). You can find your local PALS by visiting https:// www.nhs.uk/Service-Search/Patient-advice-andliaison-services-(PALS)/LocationSearch/363
- **Healthwatch** is an independent 'national champion' for people who use health and social care services in England. They focus on "ensuring that people's worries and concerns about current services are addressed". You can find your local Healthwatch by visiting https://www.healthwatch.co.uk/your-localhealthwatch/list

Shaping services locally and nationally

Local involvement

Opportunities to get involved locally vary between areas.

- To shape how services are run from the ground up, consider getting involved with your local Clinical Commissioning **Group**. These are the bodies that plan and buy healthcare services for people in their area. More information about how to get involved is available at https://www.england. nhs.uk/participation/get-involved/local/
- Some other suggestions to discover what is available in your area include contacting your mental health Trust to find out if they have an active service user and carer involvement group or a disability forum, speaking to someone involved in your care, and

- contacting any local mental health charities or patient organisations.
- You may also find that PALS or your local **Healthwatch** may be able to provide further information.

National involvement

- To get involved specifically with mental health services, consider becoming a 'participating stakeholder' for a mental health Clinical Reference Group (CRG). CRGs are groups of clinicians, commissioners, public health experts, service users and carers who use their knowledge and expertise (including that gained through lived experience) to advise NHS England on the best ways that specialised services, such as mental health services, should be provided.
- You can read more about CRGs and how to register as a stakeholder at https://www.england.nhs.uk/commissioning/ spec-services/npc-crq/
- For more information about getting involved in NHS England mental health services generally, visit https://www.england.nhs.uk/ commissioning/spec-services/get-involved/

National policy developments

The NHS Long Term Plan was published in 2019 to set out plans to address funding, staffing and pressures from a growing and ageing population over the next 10 years. This includes NHS England's ongoing commitment to mental health and outlines ambitions to increase access to psychological therapies for adults and older adults both with common mental health problems (depression and anxiety), and more severe mental health problems (e.g. psychosis, bipolar disorder), through investment and workforce development. This is set out in more detail in the NHS Mental Health Implementation Plan 2019/20 - 2023/24. https://www.longtermplan.nhs.uk/wpcontent/uploads/2019/07/nhs-mental-healthimplementation-plan-2019-20-2023-24.pdf.

LIMITATIONS OF THE AUDIT

Inconsistent sampling between services

The NCAAD service user survey invited individuals who had been discharged from psychological therapy services to give feedback on their experience. Services were responsible for sending a template letter to a group of service users randomly selected by the NCAAD team, inviting them to take part and explaining the purpose of the survey in the context of the audit. It is not possible to know whether surveys were sent exclusively to the randomly selected service users, or whether all registered service users were sent the survey instead. Therefore, there may have been inconsistencies in sampling between services.

The survey data are not representative of all service users

Several services opted out of participating in the service user survey component of the audit altogether, due to information governance reasons and/or staffing issues. The survey data is therefore not representative of all the randomly selected service users who have accessed psychological therapy. In addition, not all eligible service users who were contacted decided to take part, and not all the service users who completed the survey filled in the free text query that was analysed in this report. The survey was unavailable in languages others than English and Welsh and was not available in an easy to read format. Consequently, the sample was restricted to a smaller number of service user than were originally selected by the NCAAD team to participate.

Furthermore, the Service User and Carer Reference Group, who offered thoughts on the findings and took part in the e-consultation, comprised of 7 people.

While the group members felt that the comments resonated with their personal experience, this might not reflect the view or experience of every eligible service user in the NCAAD sample. One should exercise caution when generalising the views of this small group of service users to the whole sample and, indeed, service users across the country who have accessed psychological therapy services.

There is also a risk that adults who have had very good, or very bad, experiences might be more likely to complete a feedback survey, perhaps impacting on the representativeness of the sample.

The question was not originally designed for qualitative analysis

The free text query that the service users responded to was not originally designed to be used to capture data for a standalone qualitative analysis and report. The richness of the data that was collected prompted the team to perform the analysis, but the question itself was not designed for this purpose and was general and open-ended in nature. While this allowed for a range of responses and did not restrict service user opinion, there was no opportunity for the team to follow up people's comments with queries to gain further context because the surveys were submitted anonymously. Furthermore, there were a small number of comments that were illegible, and it was not possible to contact these service users to gain clarification.

While the survey data might not be representative of all eligible service users who have accessed psychological therapy services, it did give us a good indication of what service users think without restricting them to predefined response options.

WHO WAS INVOLVED?

- Nick Barber, NCAAD Service User Representative
- Professor David S. Baldwin, NCAAD Clinical Lead, RCPsych
- Jessica Bond, Communications Manager, McPin Foundation
- Emily Coll, Project Officer, RCPsych
- Professor Mike Crawford, Director of the Centre for Quality Improvement (CCQI), RCPsych
- Dr Mary Dang, NCAAD Programme Manager, RCPsych
- Dr Lorna Farquharson, Clinical Advisor to the Psychological Therapies Spotlight Audit, RCPsych
- Naomi FitzPatrick, NCAAD Project Officer, RCPsych
- Stephanie Learmonth, Programme Manager, RCPsych
- Natasha Lindsay, NCAAD Project Officer, RCPsych
- Dr Keith Miller, Division of Clinical Psychology London Committee, BPS
- C. Newton, NCAAD Carer Representative
- Rachael Owen, Qualitative Consultant
- A.H.P. NCAAD Service User Advisor
- Dr Alan Quirk, CCQI Head of Clinical Audit and Research, RCPsych
- Dr Roman Raczka, Chair of the Division of Clinical Psychology England, BPS
- Ellen Rhodes, NCAAD Deputy Programme Manager, RCPsych
- Prisha Shah, NCAAD Service User Advisor, RCPsych
- Imogen Voysey, NCAAD Young Person Representative
- Chris Wright, NCAAD Service User Advisor

Thank you to all the service users and carers who contributed to the audit, and to those who gave their time and insight to co-create this report.

Steering Group

- Alison Brabban, Clinical Advisor to Adult Mental Health Programme, NHS England and NHS Improvement
- James Campbell, Associate Director, HQIP
- Linda Chadburn, Clinical Effectiveness & Quality Improvement Lead, Pennine Care NHS Foundation Trust
- David Clark, National Clinical & Informatics Advisor for IAPT, NHS England and NHS Improvement
- Jeremy Clarke, Chair and Research & Practice Lead, Association for Psychoanalytic Psychotherapy in the NHS
- Esther Cohen-Tovee, Chair of the British Psychological Society's Division of Clinical Psychology, BPS
- Wendy Harlow, Head of Clinical Audit, Sussex Partnership NHS Foundation Trust
- Sam Harper, Project Manager, HQIP
- Geoff Heyes, Head of Policy and Campaigns, Mind
- Tim Kendall, National Clinical Director for Mental Health, NHS England and NHS Improvement
- Lorraine Knibbs, President Elect, EMDR UK & Ireland
- Gary Lamph, Senior Research Fellow, Royal College of Nursing
- Roslyn Law, Chair, Interpersonal Psychotherapy UK Network
- Del Loewenthal, Chair, Universities Psychotherapy & Counselling Association
- Sue Mizen, Faculty Chair, RCPsych Faculty of Medical Psychotherapy
- Carol Paton, POMH Clinical Lead and Chief Pharmacist, RCPsych & Oxleas NHS Foundation Trust
- Felicitas Rost, President, Society for Psychotherapy Research
- Paul Salkovskis, President, British Association for Behavioural and Cognitive Psychotherapies
- Dave Smithson, Operations Director, Anxiety UK
- Toby Sweet, Chief Executive, Sunderland Counselling Service, British Association for Counselling and Psychotherapy
- Chris Williams, former President, British Association for Behavioural and Cognitive Psychotherapies
- Rory Worthington, *UK Council for Psychotherapy*

Members of the Steering Group are asked to declare any conflict of interest at the outset and prior to each meeting. This is included as a standing item on the agenda.

Should a conflict of interest affecting the conduct or results of the audit be declared, the member may be asked to absent themselves from all or part of the discussion, at the meeting and subsequently.

APPENDICES

WHO RESPONDED TO THE SURVEY?

Of the 447 adults who answered the free text query in the service user survey:

The average age was 52. The youngest person was 20 and the oldest was 95.



Male:



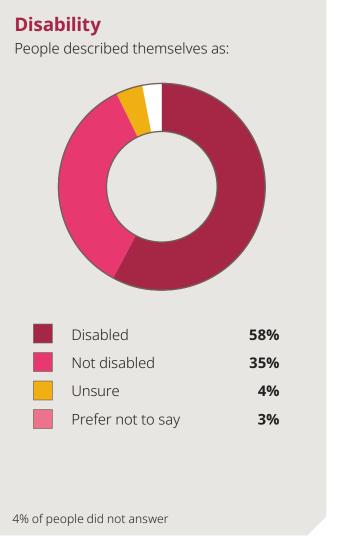
Female:



Non-binary/ other: 0.2%

4.3% of people did not answer the question about gender. 1.3% preferred not to say.

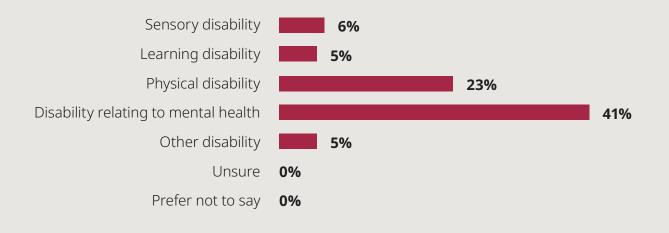
Sexual orientation People described themselves as: Heterosexual 81% Gay/Lesbian 4% Bisexual 3% Other 2% Prefer not to say 8% Questioning/unsure 1% 5% of people did not answer



^{*} Percentages have been rounded to the nearest whole number for ease of reading.

Type of disability

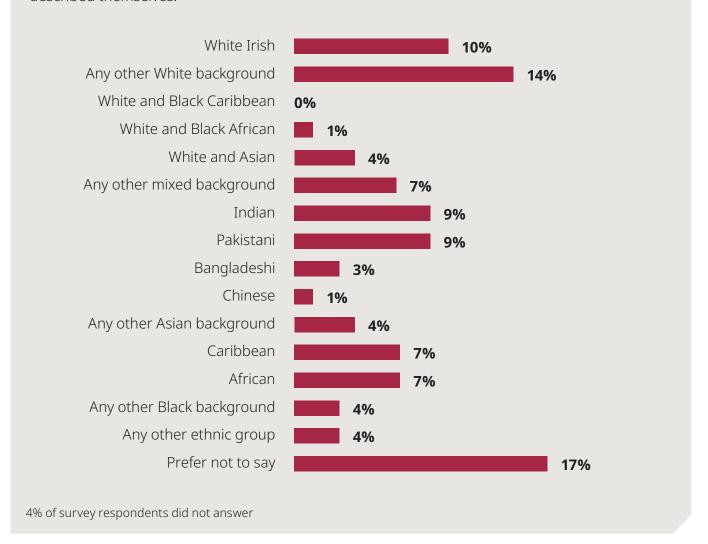
People who identified as disabled described themselves as having:



Ethnicity

People could select as many as applied

82% of people described themselves as White British. This is how the other 18% of people described themselves:



ONLINE APPENDICES

The following online appendices can be found on the NCAAD webpages (www.rcpsych.ac.uk/ncaad).

- Methodology
- Eligibility criteria
- Audit tool

Full list of recommendations for future audits



SOURCES OF SUPPORT

If you need support for your own mental health or that of a loved one, below are some helplines and links that you may find helpful:

Adfam

National charity working with families affected by drugs and alcohol. Publications and resources, online message board and local support groups.

www.adfam.org.uk

Anxiety UK Infoline

Telephone: 0344 477 5774

Offers practical advice and information on support services that are available. Open weekdays 9.30am to 5.30pm. You can also email support@anxietyuk. org.uk or chat online via their website.

www.anxietyuk.org.uk

Carers Direct

Telephone: 0300 123 1053

Confidential information, advice and support for carers. Lines are open 9am to 8pm, Monday to Friday, 11am to 4pm at weekends.

Request a free call back or an interpreted call back in one of more than 170 languages.

www.nhs.uk/conditions/social-care-andsupport-guide

Carers UK

Telephone: 0808 808 7777

Information, advice and support for carers including information about practical issues, looking after yourself and details of local support groups. Lines are open Monday to Wednesday, 10am to 4pm (listening service available Mondays and Tuesdays, from 9am to 7pm).

www.carersuk.org

HOPELine

Telephone: 0800 068 4141

Offers confidential advice and support to young people under the age of 35 having thoughts of suicide.

Open 10am to 10pm weekdays, 2pm to 10pm weekends. You can also text 07786 209697 or email pat@papyrus-uk.org.

www.papyrus-uk.org/hopelineuk

Mind

Telephone: 0300 123 3393

The Infoline offers information and advice on all issues relating to mental health and information about Mind associations and other support services in your area. Lines are open 9am to 6pm. Email info@mind.org.uk

www.mind.org.uk

National Self-Harm Network

Network supporting people and their families on issues around self-harm. Information, campaigning and practical support, including discussion forums. NSHN, PO Box 7264, Nottingham, NG1 6WI Email info@nshn.co.uk

www.nshn.co.uk

National Survivor User Network

A diverse, inclusive user-led network which aims to improve the lives of people who experience mental distress. NSUN, PO Box 74752, London, E11 9GD Email info@nsun.org.uk

www.nsun.org.uk

NHS Direct

0845 46 47 or **111**, depending on where you live.

A 24-hour telephone advice and information service which is part of the NHS. (NHS Direct has an obligation to call out emergency services if they are concerned about your safety.)

Samaritans

FREE Helpline: 116 123

Confidential emotional support for anyone, 24 hours a day, 7 days a week. You can also email jo@samaritans.org for support, or write to: 'Chris' P.O. Box 9090, Stirling, FK8 2SA. Some centres also offer face to face support, usually by appointment.

www.samaritans.org

Saneline

Telephone: 0300 304 7000

Offers practical care and support to anybody affected by mental health problems. Open every day of the year between 4:30pm and 10:30pm.





The British Psychological Society

We act as the representative body for psychology and psychologists in the UK. We are responsible for the promotion of excellence and ethical practice in the science, education and application of the discipline. **www.bps.org.uk**



The McPin Foundation

We are a mental health research charity. We champion experts by experience in research so that people's mental health is improved in communities everywhere. **www.mcpin.org**



Royal College of Psychiatrists

We work to secure the best outcomes for people with mental illness, learning difficulties and developmental disorders by promoting excellent mental health services, training outstanding psychiatrists, promoting quality and research, setting standards and being the voice of psychiatry. www.rcpsych.ac.uk

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