

INFORMING A DECISION GUIDE FOR PSYCHOLOGICAL TREATMENTS FOR DEPRESSION

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Expert by Experience Consultation

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BACKGROUND

The National Institute for Health and Care Excellence ([NICE](#)) produces evidence-based guidance and advice for health, public health and social care practitioners. They recommend the most effective ways to prevent and manage specific conditions and to improve health and manage medicines in different settings. They do this by collating the research evidence and consulting with the people affected by their work, including patients, carers and members of the public, as well as healthcare professionals, social care practitioners, NHS organisations, industry, social care businesses and local government.

The process undertaken by NICE in preparing its evidence-based guidelines includes prioritising 'randomised controlled trials' (research studies with strict conditions and criteria using diagnosis and other formal approaches etc). The depression guideline in particular looks at trials that report short-term symptom-focused outcomes (8-12 weeks normally). The evidence is reviewed by researchers and statisticians and converted into a hierarchy of 'effective' treatments which GPs are required to follow.

NICE has been working on a new depression guideline for several years. The [NICE guideline for depression](#) is a very long and technically complex document with several technical appendices. It includes a set of treatment recommendations aimed at health professionals. NICE acknowledges that treatment decisions should be made in discussion with patients and that patients should be given a choice. But there is currently no evidence-based patient-centred information resource (or "guide to patient choice") which could support patients to take a fully informed role in understanding their options for psychological therapies and discussing these with their GP.

AIMS OF THIS CONSULTATION

The aim of the consultation was to inform the development of a guide to choice in psychotherapy (specific to depression). It was funded by the University of Essex ESRC Impact Acceleration Account. This was a user-led consultation, intending to form part of a larger study to be conducted in collaboration with partners from the University. The conduct of the consultation was led by Alison Faulkner and Premila Trivedi on behalf of NSUN and Shaping Our Lives, both of which are user-led organisations, with the aim of starting with the voices, views and experiences of people with lived experience of psychological therapy for depression.

We used focus groups and individual interviews to help to identify the outcomes, evidence and benefits of psychotherapy most valued by potential clients/service users, as well as the barriers and the information that people would find useful before embarking on therapy. This is a first step: the consultation has informed a more detailed funding application for developing the guide.

THE FOCUS GROUPS

In order to scope the issues arising for people entering or considering psychological therapies for depression, we carried out three focus groups. Via NSUN and Shaping Our Lives networks, we invited a range of people with lived experience of seeking or receiving psychological therapies for depression (although a formal diagnosis was not a requirement). Although the first two focus groups included a small number of people from backgrounds other than White British, we carried out a third focus group just with people from Black, Asian and mixed heritage backgrounds. We were aware of the lower offer and take-up for psychological therapies amongst these groups but also the lack of research into their concerns and priorities. ([IAPT BAME Positive Practice Guide: Mental Health Statistics for England 2020](#)).

We carried out additional individual interviews for people who were unable to participate in online focus groups. Undertaking this piece of work under COVID-19 lockdown led to additional barriers for some participants, but also made the use of online focus groups more accessible for others.

In total we spoke to 28 people with lived experience across three focus groups and six individual interviews:

- 7 participants: six women and one man; four white, one Indian British woman, one Greek and one Black British.
- 8 + 1 participants: two men and six women, all white; plus one additional interview with a Black British woman who had no internet connection on the day. One Jewish, two wheelchair using Disabled women.
- 7 + 5 participants: two men and five women, from Black, Asian and mixed heritage backgrounds; plus 5 additional interviews: one man and four women.

CONSULTATION FINDINGS

The three focus groups were very different, so we have dealt with them separately here first before drawing out some common themes. The first two groups were facilitated by Alison Faulkner, the third by Premila Trivedi with Alison assisting.

FOCUS GROUP 1

This was a group with some knowledge and experience of research as well as of psychotherapy and, for some, experience of secondary mental health services. Many of the participants talked of a powerful appreciation of what therapy had given them: *'it helped me survive and thrive'*, it helped some become more resilient, form better relationships; *'I wouldn't be here'* without psychotherapy. The value of finding understanding and acceptance were repeated concepts: *'a level of acceptance I have never experienced before in therapy'*. For some members of this focus group, more opportunity for choice had been possible as they were able to pay for therapy at times.

EXPECTATIONS AND OUTCOMES

In the early part of the discussion, some participants struggled to put into words what they were looking for in psychological therapy. One person talked of the *'magic'* she did not want to lose by trying to pin it down in terms of outcomes. People struggled with the clinical or therapy-oriented words that came to mind when thinking of outcomes, such as resilience or symptom reduction. One person wanted to understand her family history and inter-generational trauma through therapy, but another felt that therapy does not understand trauma well: rather, it seeks to place the source of difficulties within the individual. Other people talked of wanting containment, safety, empowerment and strength. One described wanting *'a different way of thinking for myself or ability to think, or do emotions for myself'*. The need for better understanding - of self, family relationships - was shared with several participants, one of whom said they had not found this in therapy to date.

Acceptance was another shared goal: *'Achieving acceptance is one way of achieving some form of peace, potentially, which would be a good outcome'*. There was a strong thread about therapy having the potential to help people to come to an acceptance of themselves and of the fact that life is tough, that there are no easy answers, perhaps no *'cure'* - but that therapy can help you towards a better understanding and acceptance of this. People talked of a deep acceptance, about life and what you can and can't change *'an acceptance of the soul'*. Having your words, feelings and experiences believed and not judged was experienced as profoundly powerful.

'I saw a CBT therapist, believe it or not, who was incredible, and I could have happily seen for years, because every single thing I said he believed. There was no negotiation, no persuading, no justifying why I felt a certain way.[...] and on top of that he was never judgmental.'

FOCUS GROUP 1

Some people expressed the wish for therapy to help them to cope in the world: to provide them with the skills and tools to aid self-help, but also learning to manage emotions for yourself, form and manage relationships in a more healthy way. Therapy was also experienced as a space away from negative family dynamics.

The therapeutic relationship itself was experienced and described as different from other relationships, as a powerful therapeutic thing in and of itself.

'But then the more process-y side is that relationship thing and how you can develop a positive relationship with somebody that is maybe different to relationships that were previously experienced, which can be a powerful therapeutic thing in and of itself without any specific outcome being achieved.'

Several people talked of the significance of endings, and one talked of being able to work through with the therapist *'not exactly what I'd gained, but what, you know, what I would leave with that would help me carry on without that sort of dependency.'*

THE THERAPIST

The nature of the individual and the relationship formed with them was central to some of the key outcomes people were seeking: *'the outcome is dependent on the individual therapist that you see and the relationship that's forged'*. Empathy and understanding were mentioned, as was the ability to listen without being shocked by a range of traumatic experiences or behaviours, such as self-harm.

'I think it's this woman had this something also of being with people. I think, you know, you could feel she was with you when you were telling her about very difficult stuff.'

Consequently, discussion about the therapist also emerged in relation to the information required from a decision guide, as people wanted to know something about the therapist they would be seeing: their gender, ethics, approach and training - as well as what to do if they did not get on with a therapist.

BARRIERS AND CHALLENGES

Some people talked of damaging experiences, including therapists overstepping boundaries and it was not clear how to understand what was acceptable and what was not. Some talked of wanting to achieve better understanding of themselves through therapy: of their feelings and experiences, of family relationships and inter-generational trauma. It was notable in this group that a couple of people talked of the failure of therapy to address cultural and social issues, or finding that if they did raise these issues, they were dismissed or not responded to.

'The problem is where psychotherapy limits that through its singular ways of understanding which don't necessarily tally with trauma and abuse ways of understanding.'

There was a strong discussion thread about the power of therapists: that some withhold their knowledge or information, particularly about the rules or conventions of therapy, which could be intimidating at the start of therapy. One person described the painful experience of meeting her therapist in an NHS facility and walking to the lift and the therapy room in silence without any personal acknowledgement. *'I found that so excruciatingly difficult to then get started. And it took me such a long time to get used to that rule. And there were many other rules like that that I just didn't understand and she did.'*

It was suggested that some therapists possibly do not believe clients capable of understanding what is going on in the therapy space or in the relationship and therefore they are unwilling to discuss the process or what it was meant to achieve.

'But there's something about the power of 'only we can hold this or manage this', and 'you won't be able to understand it anyway.'

There was a sense that any criticism of therapists or of the process would be turned back on to the individual - and seen as part of their pathology, rather than listening and being open to discussion.

'And they say, 'this reveals something very interesting about you and I'll make a note on your file'. You know - willfully ignoring the implications of what I'm saying, Yeah, locating everything within the individual rather than being willing to take a step back and reflect on potentially damaging practices.'

FOCUS GROUP 1

There was a concern that psychological therapies are in general inherently individualised, locating everything in the individual, and not being able to see the social context or wider economic and socio-political issues. This could be particularly difficult, even damaging, for people from marginalised and racialised communities wishing to raise issues rooted in their social identity. This made the value base of therapists of particular importance.

'The cultural thing is so important that, you know, words like independence and autonomy, freedom don't mean the same. They're not really my, you know, where I come from even though I was born here and lived here all my life. You know, my upbringing has very much been about interdependence, you know, and community.'

DECISION GUIDE: INFORMATION NEEDED

Participants in this group felt that a decision guide for psychological therapies should include information about the rules and conventions of the therapeutic approaches on offer, sharing information that could reduce the power imbalance in the relationship from the start. They also felt that there should be information about the potential harm of psychological therapies as well as the potential outcomes, and the challenge that engaging in therapy can represent.

Participants suggested a number of types of information that should be included:

- *Therapeutic model: with some idea of what that this practically looks or feels like*
- *Constraints of choice: funding, timing, availability*
- *Drop-out rates for particular therapy and/or in a particular service*
- *Rules of therapy: outline what is expected of you when you turn up, how the therapist will be if s/he meets you outside (and why) / how the therapist will be with you (e.g. they will use reflective questions to help you understand, they may not speak much, or they will structure sessions, give you homework, etc)*
- *Potential harms and challenges: that engaging in therapy is hard in itself: but also be transparent about the potential for harm*
- *Who to turn to: who can clients turn to when they feel there is something wrong in their therapy?*
- *Shared experiences: people would like opportunities to talk to other people who have been in therapy - get ideas about what to expect, what it might be like.*
- *The therapist: want to know something about the person/therapist: need to know their value base, cultural awareness, knowledge of different cultural contexts for people*
- *What to do if you don't get on with this person: the option to change to a different therapist*

FOCUS GROUP 2

This focus group had eight participants: two men and six women, all white plus one additional interview with a Black British woman who had no internet connection on the day. One woman was Jewish, and two were wheelchair using Disabled women. This group also included someone who identified as a carer, someone with dyslexia, and someone with previous alcohol issues. As with the first focus group, many were very positive about the contribution of psychological therapy in their lives.

EXPECTATIONS AND OUTCOMES

There was a strong thread in the early part of this discussion about the importance of empowerment and choice, and the need for therapy to equalise or minimise the power imbalance between therapist and client: *'empowering me to make choices, allowing me to be active in the role of what I wanted to achieve, listening. And starting with my narrative, and what I wanted to achieve.'* Another person said therapy should be collaborative, *'like we were working together on something rather than you know, someone just telling me what was wrong with me kind of thing.'* A third person agreed but said she had not always had this experience:

'So I think good therapy for me is to be made to feel like an equal, you know, that it's not, they haven't got their power, which is sometimes, you know, I felt that they had they had, you know, they have to talk to me and I felt quite, you know, disempowered a lot of the time.'

A couple of people talked about the value of finding acceptance, and of being able to share things they had not shared with anyone else. One person, with experience as a carer, talked of learning to put boundaries in her life and to put herself first. She had achieved this through a process of finding acceptance in the relationship with the therapist, *'that lived feeling of trust'*, with the outcome that she was able to share things with the therapist that she was unable to share anywhere else.

Several people talked about accessibility as an essential element of therapy; this was partly in relation to physical access for wheelchair users (*'I can't separate out access from choice'*) but also barriers created by services in relation to alcohol use: *'I think there could have been some therapy I could have attended or some support groups to help me with both mental health and alcohol.'*

In a different vein, some people talked of wanting strategies, ideas for ways of coping on a daily basis: *'I wanted help. I wanted strategies. I didn't want something that was almost gonna pat me on the head, which is what was happening.'* In relation to this, one person had been given homework which they found helpful if challenging and another was given notes of her sessions.

FOCUS GROUP 2

One person told of the powerful impact of working with a psychologist who was able to get her to challenge some of her negative thoughts and fixed beliefs: *'over the course of three months, my therapist just turned that around and I was really empowered. I just wish I hadn't been 25 years into my journey before I had that'*. This therapist typed up the notes from their sessions so that the person finished therapy with resources she could use in the future. One person felt that the outcomes she wanted would vary, *'according to where I'm at'*:

'I mean, some occasions it might just be to feel less confused, to know more about my own identity. At other times, it might be strategies as others have discussed. And I think it's such a personal thing.'

In terms of outcomes, one person said they *'would know I'd got something from the therapy if I felt like I didn't need therapy anymore at the end of it'* and another said that it would have made things *'manageable enough for me to be able to kind of continue on my own'*. One person described having a collaborative review of the therapy with the therapist half way through, which they had found very helpful.

BARRIERS AND CHALLENGES

People in this group talked of not having choices: of not being able to choose when to have therapy or what type of therapy to have: *'it was basically a case of, you know, this is all that we can offer. So, you know, you pretty much take what you get offered.'*

'The Gestalt therapy I had... it's paid for by a charity, but I couldn't have that. And, and it was brilliant. But I couldn't have chosen that and I think that's, that's really annoying, that you actually don't have the range of choice that meets your needs.'

Disability access was the subject of much discussion, as previously mentioned. For people in wheelchairs, the choice of therapist became confined to those with ground floor rooms or rooms large enough to permit a wheelchair. Others talked about dyslexia and the failure of therapists (and other professionals) to understand the implications of this. An example was given of getting years and dates muddled. Access and choice for Disabled people were inextricably linked, so the group discussed the need for disability awareness training for therapists.

In relation to the lack of information about the type of psychological therapy, one person said therapy *'should have a huge warning sign, you have no clue what you're getting yourself into.'* And a few people talked of experiences of not having a positive outcome from therapy: it *'crushes imagination sometimes in terms of what actually is possible.'*

FOCUS GROUP 2

'One of the therapies I experienced which was for five years was actually quite damaging. That was about 15 years ago. It was financially and emotionally abusive essentially. To the extent that I took out formal complaints, and this therapist had her registration removed from the BACP and other complaints as well I mean, she was removed from the NHS also.'

Following this experience, the person had found it very difficult to trust another therapist.

Several people talked of wanting to be followed up after finishing therapy: that they would appreciate contact with the therapist or service after a period of time as a form of after-care. They talked of this as a parallel to forms of physical health care, giving cancer treatment as an example. In a similar vein, some people talked of the value of being put in touch with other people who had been through similar treatment. For two people, this had happened for relatives going through cancer treatment and had been experienced as a very positive experience; they could see it working for psychological therapy.

The conversation also turned to discussion of having support around the therapy, as a kind of back-up support. As with the third focus group, people talked of the value of peer support, this time as a way of introducing you to different types of therapy or having someone to help you understand that journey.

DECISION GUIDE: INFORMATION NEEDED

It was felt that asking for a choice at all was a basic request for people being offered psychological therapy: *'it also seems as though we're not actually asking for very much. So we're asking for somebody to do a good job actually, and have a bit of choice about it so it's not, you know, earth shattering.'* In terms of making an informed choice, participants made the following suggestions for a decision guide:

- *Information about different types of therapy /the type of therapy on offer, what to expect*
- *The guide needs to be fully accessible, disability friendly, easy read, no acronyms; available in different formats*
- *Chance to ask questions; need to be able to talk to someone about the therapy, not just be given a leaflet;*
- *The opportunity to talk to someone who has been through the same type of therapy - perhaps through peer support or Recovery Colleges;*
- *Examples of what people have said about their experience of the therapy, little narratives.*
- *Warning about potential risks of therapy / where to go or who to ask if you are not comfortable about what is going on in the therapy;*
- *Honesty and transparency about the chronic aspects of depression, it will not go away with a short spell of therapy [hence the need for follow-ups]*
- *Being able to change therapists and how to go about it.*

FOCUS GROUP 3

(Incorporating 5 additional interviews)

This group had seven participants from Black, Asian and mixed heritage backgrounds, along with the two facilitators, Premila Trivedi (British Indian) and Alison Faulkner (White British). We also interviewed five additional Black, Asian and mixed heritage people, one man and four women. Therefore we spoke to a total of three men and nine women from racialised communities. Two of the women described themselves as having a carer role as well as using therapy and other services themselves. There was a wide diversity of age, ethnicity, time in mental health services and type of therapy - although there was a prevalence of CBT. There was also diversity in relation to education and training, and experience of working in mental health, service user involvement and peer support. In spite of this wide diversity, issues that came up around therapy and experiences of therapy were remarkably similar; for example: the difference between what people felt they wanted or needed and what they actually got, the absence of explicitly culturally informed and racism-aware therapy, little or no choice of type of therapy offered, and long waiting times alongside short durations of therapy. In the third group, the issues of racism and the whiteness of psychological therapies (and the mental health system as a whole) needed to be given space; consequently the group did not cover the questions about the information needs of a guide to choice in psychotherapy. We can, however, draw conclusions about the latter from the discussion that did take place.

We found that the group members were remarkably open and honest about their experiences, despite the fact that group was so diverse and for several participants it was the first time they had met each other. This may have been due to commonalities in their experiences of therapy which engendered trust or perhaps a rare opportunity to talk about often unspoken issues in relation to life experiences of racism, oppression and discrimination. Whatever the cause, many found the focus group a profoundly moving group to be a part of and wanted to extend the conversation.

ACCESS AND EXPECTATIONS

Access to psychological therapies was a significant issue; in contrast to the first focus group, many were dependent on statutory services and this limited both choice and access. Several people talked of fighting or almost begging for talking therapy, sometimes after years of using mental health services and mainly being offered medication. *'And I knew that that wasn't what I was after'*. One person said they needed *'something new'* after years of going round in circles, in and out of hospital.

Many people acknowledged that they did not know what they wanted or what to expect from psychological therapy; *'And then suddenly, I'm in this place called therapy, and I had no clue what, you know what road we're gonna go down while I was there, what they were there for, and so on.'* A couple of people said they just wanted help: *'I wasn't in a frame of mind to think about what I wanted. It was, it was an emergency type situation.'*

FOCUS GROUP 3

For many people, it seemed to be about wanting to talk and to be heard. *'So for me, it was like I wanted almost to be taught the art of how to just talk, talk about my feelings.'* One said she wanted to be heard, *'because I felt that I had never been heard. My psychiatrist is very much of the old school that you have to take your medication, ... you just do as I say.'* Another talked of the layers that needed uncovering *'and I need a facilitator to help me do that'.*

One person who had been a carer for many years said she needed to be able to talk about previously unspoken experiences; *'it was about like sharing secrets because my caring role was very hidden for the entire time it existed'*. Having said that, talking to a person in a professional role could feel quite alien; it could feel like sharing secrets outside of the family and community. It could also feel unfamiliar because it was not a reciprocal relationship, but entailed an inherent power imbalance: *'There was no reciprocity, the conversation I was having with, it was like they want to just to unpack my head, you know, get into my head and understand me, but I couldn't get into that. So it wasn't a conversation.'*

Some people talked explicitly of wanting to understand or deal with the racism and oppression they were experiencing. *'I wanted somebody to help me deal with the racism that I was thinking, right? [...] I wanted a space to be able to deal with that scene'*. Another said: *'the structural systemic oppression that I experienced when I came to this country was actually what I needed to examine and what I needed to, to try and cope with.'*

What became evident from the focus group as the conversation developed (and from the individual interviews) was that there was a strong need to talk about racism within therapy and beyond.

THE BENEFITS OF THERAPY

The benefits from therapy identified by people in this group included the opportunity to talk and to be heard, to deal with some of their issues and the *'opportunity to get away from all of the things that was probably causing the challenges in my mental health'*. A couple of people gained an understanding of the psychological impact of their experiences, or realising *'that my trauma was more complex than I thought it was'*. Another said the understanding was important: *'I think probably by making myself more self aware, it opens up a possibility of then doing something about it in a more conscious way'*. One person said she was determined to get something out of it, having fought so hard for it.

One person, interviewed individually, described a profoundly positive experience of receiving psychotherapy from a Black therapist:

FOCUS GROUP 3

'She just had the insight and understanding. I mean, when I was in there, first of all I was, I thought I was going for six months. Straight away after she assessed me, she said 'no, no, no, you're staying here for two years'. She knew, she was just a very empathic, insightful, understanding, knowledgeable.'

However, for many people, it seemed that the benefits of therapy were to some extent obscured by the challenges and difficulties, amongst them being a lack of cultural awareness with the offer being essentially white Eurocentric therapy. *'I've never quite found what I want. And I think a lot of that is to do with my Indian-ness, my issues around that.'*

THE THERAPIST

For some people, the race of the therapist was important, as in the positive example above. Several people talked of the difficulties of engaging with someone who *'didn't look like me'*, that it could take more time to trust and build up rapport: *'this time it is with a black male. So naturally, we've kind of been able to build up rapport and trust quite quickly'*. One of the participants, determined to get some benefit from the therapy she had fought so hard for, had two different therapists, both white: *'I think that I could have got into more perhaps with someone who had some knowledge around cultural competency and have some understanding about my cultural needs as part of the therapy.'*

For others the race of the therapist was not important - they felt that the awareness and openness of the therapist could override a shared understanding of racism. For example, one person, who brought significant concerns about institutional racism and oppression, found a white therapist to be very helpful because of her broader understanding:

'She is white, but she does come from that place of understanding, that feeling of oppression, structural stuff, you know, I think it's also because she has some experience herself, of psychological trauma. And that's what attracted me to her because she, she did understand from her own experience what I was talking about. And I think that was really important.'

One participant described almost having to educate her therapist in her first few sessions, telling her firmly that she needed to talk without interruption: *'I'm just gonna be assertive to let you know this is what I need. And this is what I need off you and is your profession going to work for me?'*

BARRIERS AND CHALLENGES

Mental health system.

A significant barrier that several people talked about was the system itself - how it is perceived and how it in turn perceives Black, Asian and mixed heritage people: presenting a barrier to trust and to opening up in the first place. This was a system that people had felt victimised by and which they had fought against; making it very hard to trust. One person said that the system was replicating colonialism:

'They couldn't help but be manifesting power, could they? Because they were part of the structure that was doing something to me. And actually, that was still the model that I had in my mind of colonialism, because that's what I grew up with. And so, so it was just replicating it.'

One interviewee told her therapist that she needed to talk about institutional racism, and talked of having observed many black service users in hospital being over-medicated in comparison to their white counterparts:

'At first she looked a bit uncomfortable coz I told her that I think what I'm going through is institutional racism. She said 'what do you mean by that'. I said 'before they used to brand my ancestors with iron, now they brand us with needles coz if I'm shouting, and a white person is shouting, they will inject me and rattle and shatter my brain!'

The implications of an awareness of this discriminatory treatment on people were considerable: *'If you know that you're not treated fairly in a situation you're going to be scared to even talk about what you're going through in your personal life coz you know how they will treat you.'*

Interpersonal.

One-to-one interactions in therapy could be characterised by that same huge gap of understanding, and resultant lack of trust; meaning that it could take a long time to form the basis of a trusting relationship in which the individual could open up and talk about what mattered to them. One person said they had only just begun to trust the therapist by the time the ten sessions had come to an end. It took a long time to build up the confidence that they would not be judged:

FOCUS GROUP 3

'I know that sounds a weird thing, because when he said at the beginning of the session, we won't judge you. But when it's someone that really doesn't look like me that I've had bad experiences of someone that looks like, well, in that when I was 22, he was a white male and I can think of my experiences in encounters with the police and them being white male and putting them together. The confidence of building up a non-judgmental approach of talking is what interested me a lot, you know, to then open up a bit more.'

Cultural barriers of understanding the nature of therapy emerged for people whose country and culture of origin was more community oriented: *'there was no reciprocity, the conversation I was having, it was like they want to just unpack my head'*. However, this could also serve to highlight the strengths of a community based culture, where an equality of sharing was at its foundation.

Race and racism in therapy.

More complex than not being seen or recognised within the other person is the silence and denial of racism experienced by Black, Asian and mixed heritage people in therapy. These issues were explored towards the end of the focus group as the group decided together to continue this discussion about race and racism in therapy and put aside the planned questions about a decision guide. One way in which this racism manifested itself was through silence, a lack of acknowledgement or validation, causing discomfort about raising racism as an issue in therapy and the perpetuation of silence about race and culture in a predominantly white society. This was mirrored through the focus group discussions, where the issues were barely raised in the first two focus groups, but were explored in depth in the third, where permission to discuss them was made explicit.

'And you don't even know how to, how to, how do you even approach that topic? You know, you feel like you're the bad person for kind of raising that you're feeling uncomfortable because you are getting some type of racist air off that person or they're just completely disconnected from you and completely lacking empathy and unmoved by anything that you're saying.'

'The therapy that I have had, has not really been able to engage that much with [issues of race and culture]. Particularly, I had to say when it was, why therapy is predominantly white therapists or in a white kind of environment, which has been most of my therapy kind of experience. There is a lack of engagement with the issues, which replicates a kind of invisibilisation of issues, which I feel I have to kind of do anyway, in a predominantly white environment.'

FOCUS GROUP 3

There was also a sense in which, where someone was the only Black member of a therapy group, the responsibility to raise or address issues of race within the group or as an issue within wider society, was placed on them, and some people experienced outright denial from white practitioners.

'...being mixed race has been really difficult for me being in therapy - white therapists had a spectacular ability to down play any racism I experience. I remember vividly one therapist saying 'I was playing the race/victim card.' They made no effort to understand how being mixed [race] is incredibly isolating - especially as I grew up in a very white, very middle class area. On the other hand, having a black therapist made me involuntarily downplay my problems, like any racism I had experienced wasn't really valid.'

Some people held low expectations of therapists being able to address issues of race and culture within therapy: *'they haven't studied it, they haven't covered it, they haven't lived it'*.

DECISION GUIDE: INFORMATION NEEDED

Drawing on the discussions from the third focus group, the following information would be appreciated by people from Black, Asian and mixed heritage communities seeking therapy.

- *Information about whether or not the therapy and therapist works in a way that is informed by anti-racism and cultural awareness, by structural power imbalances as they affect individuals;*
- *The race and gender of the therapist - and some choice about the therapist they are assigned;*
- *What to expect from a psychological therapy: the rules and the way in which it works;*
- *Information about choice - or the lack of choice;*
- *Clear information about waiting times;*
- *Access to peer support as an adjunct or alternative to therapy.*

SUMMARY OF KEY THEMES

We have considered each focus group in turn, with the intention of respecting the unique characteristics of the discussions that took place. Here, we take an overview of the themes that arose across all of the groups and interviews. The first four are highlighted as the most significant themes, with the remainder outlined under the relevant headings.

- **Choice and access.** Firstly, it was notable that few people experienced having any choice in the psychological therapy they could access through the NHS. Many talked of difficulty accessing therapy at all, of fighting for it, and of being subject to long waiting lists. Clearly, access and choice were influenced by personal economic resources. Disability access was another strong theme, with choice further restricted by lack of wheelchair access and poor awareness of the effects of, for example, dyslexia.
- **Therapy expectations.** Many people talked of having little idea of what to expect from a psychological therapy other than in general terms: i.e. the expectation that they would have the opportunity to talk and to be heard. People received little information in advance, and, for those entering psychoanalytic therapy, the rules were often obscure and confusing.
- **Power and powerlessness.** Power (and powerlessness) was experienced at many levels. One of these was the power of the therapist in situations where it felt that the therapy modality relied on the therapist retaining and withholding knowledge and information. Another area in which power emerged was in relation to the white euro-centricity of the majority of psychological therapies. People from Black, Asian and mixed heritage experienced psychological therapies and therapists, for the most part, as potentially damaging in their alignment with a structurally racist system and failure to acknowledge the existence of structural racism and its impact on people of colour. This was associated with the ethos of most therapies to individualise and render the therapeutic relationship as separate from the dynamics and oppressions of the social world. There were exceptions to this, but they were few and far between. The significance of this is that it undermines the therapeutic relationship and its potential to offer trust, acceptance and validation.
- **Finding acceptance in therapy.** Another strong, almost universal, theme was acceptance. Many people talked about needing acceptance or the powerful experience of finding acceptance through psychological therapy. This was often associated with trust and being believed and validated in their identity and experiences.

Hope and expectations

- People talked of needing or wanting simply to talk and to be heard; for some people, it might be the first time they had ever talked of issues held secret within their families or kept to themselves. People wanted to be believed, not judged and validated, characteristics associated with trust. Another common theme was people's desire to understand more about their identity and to feel genuinely accepted within the therapeutic relationship.
- Several people talked of needing to be able to talk about the impact of trauma in their lives, and sometimes of inter-generational trauma.
- The issue of identity came up powerfully in relation to race and culture, for people who found themselves marginalised by the predominant White euro-centric culture - and how that extends into the intimate world of psychological therapy. The need to talk about and deal with racism within the therapeutic relationship was not often realised.
- In the first group, people talked of wanting different ways of thinking and of dealing with emotions and relationships, which suggests a need for personal change. In a similar vein, some people were quite clear that they wanted strategies and ways of coping, quite practical tools to manage in the world away from therapy.
- Across all three groups, people talked of wanting empowerment and the sense of an equal or reciprocal relationship that would feel empowering and collaborative.

Benefits of therapy

- Finding acceptance was one of the main benefits people experienced, just as it was something people were hoping for from therapy (see above).
- One of the main benefits experienced by people in this study was the opportunity to talk and to be heard. Indeed, one of the participants more or less told her therapist to stay quiet so that she could simply tell her story. Several people related that they talked about things in therapy they had never talked about before.
- A few people talked of the importance of becoming more self-aware and more aware of the extent of their trauma and its impact upon them.

- Several people, particularly in group 2, talked of the value of forming a collaborative relationship in therapy, a sense of both working together with shared goals in an equal relationship. Linked to this was the issue of empowerment: many people talked of this as an outcome they had experienced and valued.
- Other benefits discussed included: empathy and understanding, containment, safety.

Barriers and challenges

- One of the key barriers for many people was simply access to therapy and a lack of choice in what kind of therapy they might have: 'you get what you're given'. A significant barrier to both access and choice, as mentioned earlier, was the poor awareness or action around Disability access. Another was having the financial resources to access therapy privately.
- This small study has shed light on the significant barriers to therapy for people from Black, Asian and mixed heritage backgrounds. This is complex, in that the barriers take place on a number of levels. Psychological therapies take place within a system that holds predominantly white Eurocentric approaches to thinking about mental health and mental illness, but also many psychotherapy modalities are themselves shot through with the same values and attitudes. This may mean that the individual therapist would have to work quite hard to retain anti-racist and culturally aware principles in their work. In any case, many of the Black, Asian and mixed heritage people in our study had struggled to find therapists who were able to provide the support they needed to talk about and deal with racism in all its forms. Not everyone wanted to address racism specifically in therapy, but being unable to refer to it within a context of understanding and awareness, was a significant barrier to trust and engagement in therapy, silencing and negating people's experiences.
- Another challenge encountered by many people was the power within the psychological therapy system that rendered (some) therapy modalities obscure, with the result that therapists held a lot of power. At the individual level, this power was a barrier to equality in the relationship and often experienced as disempowering.
- Some people talked specifically about their damaging experiences of therapy and negative outcomes. It was felt that this aspect of psychological therapies is rarely acknowledged, perhaps overlooked in contrast to the damaging effects of medication and coercion in mental health services, but that it should inform the development of a decision guide.

Information required from a decision guide

A decision guide for people considering psychological therapy needs to be fully accessible: disability friendly, easy read, no acronyms; and available in different formats in order to be fully inclusive. These are the information needs articulated by the people in this study:

1. Information about therapeutic model/type: some idea of what to expect, the rules and boundaries with which it operates;
2. Information about Disability access;
3. Constraints of choice: transparency about funding, timing, availability, choice, waiting times;
4. Information about whether or not the therapy and therapist works in a way that is informed by anti-racism and cultural awareness, and by structural power imbalances as they affect individuals;
5. Warning about the potential risks and challenges of therapy;
6. Who or where to contact if you have concerns about your therapy or wish to change therapist if you don't get on with them;
7. Snapshots, narratives, shared experiences from people who have experienced this therapy;
8. Information about the therapist: race, gender, their training and approach, whether they work in a culturally and racially informed way;
9. Information about sources of support, e.g. peer support, as an adjunct or alternative to therapy - particularly when on a long waiting list.

DISCUSSIONS & REFLECTIONS

In this consultation, we spoke with 28 people with lived experience of seeking or receiving psychological therapy for depression (with or without a formal diagnosis). We asked about experiences of accessing and receiving psychological therapies and views on how a decision guide could enable service users to be more involved in choosing a psychological therapy for depression. Although there was a wide range of experiences and views expressed among people who took part in the consultation, there were some key themes which emerged which have directly informed our plans for developing a decision guide.

We are also continuing to reflect on the process of carrying out this research, particularly the issues associated with race, racism and whiteness that arose from focus group three. Premila Trivedi and Alison Faulkner are planning to take this work forward in order to explore these issues further.

WHY DEVELOP A DECISION GUIDE?

'Patient Decision Aids' are a type of healthcare tool which aim to guide patients through relevant information and support them to make choices about their treatment. We are not aware of any Patient Decision Aid that focuses on choices between psychological treatments for depression. In fact, Patient Decision Aids for depression (in adults) mostly seem to exclude psychological therapy options altogether or focus on the choice between medication and a single psychological therapy option. It seems that most of these tools are aiming to improve 'adherence' to medication rather than to genuinely enable or facilitate choice. We are also not aware of any Patient Decision Aid that has been designed for the UK context in terms of availability and access to therapies; nor have any tools been developed collaboratively with people with lived experience. Tools for supporting patient decision making tend to be based on existing guidelines, which in turn are developed without prioritizing the types of treatment outcome or goals that people with lived experience are concerned about. Given that there are several different types of psychological therapy provided in the UK for depression and that there is no existing tool to help people choose among them, this consultation indicates that a decision guide could be a useful tool if developed in collaboration with people with lived experience.

Some previous research has suggested that people with depression are not able or willing to be involved in making decisions about their treatment. Other research has suggested people do want to be involved in decisions but that to do so they need more and better information. The views and experiences of people who took part in this consultation support the latter. They indicate that people are able and willing to take part in decision making about their own care as well as to collaborate in research to develop a decision making tool.

WHAT TREATMENT OUTCOMES DO PEOPLE WITH LIVED EXPERIENCE WANT TO KNOW ABOUT FROM RESEARCH?

Findings from our consultation indicate that people with lived experience of depression prioritise a range of treatment goals and outcomes that go beyond standard symptom severity ratings (which are the basis of most national guidelines for depression including NICE guidelines). There is other existing research that points to this too, such as [a large international survey on what outcomes are of interest to patients with depression](#). This research suggested that aspects of 'functioning' like family life and relationships are essential to service users; the authors recommend that future treatment outcome research in depression should measure these outcomes.

Themes emerging from our consultation indicate that the outcomes people are concerned with are more complex than what researchers call 'functioning'. People talked about the wider context of their lives, their social and family context as well as broader political and socio-economic issues, some of which are rarely attended to by psychological therapies. This is particularly well illustrated in findings from focus group 3 with people from Black, Asian and mixed heritage backgrounds in which issues of culture and race were explored in relation to therapy. Often it is assumed that therapy services just need to match therapist and client background to address this. Our findings indicate this is not so straightforward and that what people would like is not to feel so powerless or discriminated against throughout the process of seeking, accessing and receiving therapy. People want to feel heard and believed and for therapy to lead to a sense of acceptance and self-worth, which interacts in complex ways with social and family context, self-identity and any past trauma including experiences of racism and other intersectional issues. Involvement, choice and empowerment for people from all different backgrounds are therefore important from the outset of engaging with services.

We think that in order to develop a Patient Decision Aid for psychological treatments for depression, we therefore need to start with an evidence review that is different to the traditional systematic reviews that inform NICE guidelines. The evidence synthesis would be carried out collaboratively with people with lived experience and would prioritise outcomes identified by them as most important. This would include qualitative and quantitative outcomes, because qualitative research on treatment experiences can provide context and explanations for some of the patterns seen in quantitative outcome research. Qualitative research can also provide more detail on why some people may not find particular therapies helpful when others do. There is some indication from the first focus group that being better informed about therapy and research led to better outcomes, although some members of this group had accessed therapy privately. Equally, the third focus group highlights the failure of many therapies and therapists to be able to address race and culture within therapy. This consultation is therefore particularly informative in terms of enabling people to make more informed choices based on their individual context - which fits with the idea of 'personalised care' as promoted in physical healthcare settings.

WHAT OTHER TYPES OF INFORMATION SHOULD BE PART OF A DECISION GUIDE?

A Patient Decision Aid would not just provide information about treatment outcomes as there may be other issues that could influence an individual's choice of treatment. Findings from our consultation overlaps with, but also extends, findings from previous research. Our consultation indicates that the types of information needed to support people to make informed decisions about psychological therapies include information about therapy models and rules, therapists, accessibility, potential harms of treatments and information about how to switch therapist, raise concerns or ask questions. Some of these latter points highlight a more general wish for minimising the power imbalance in the therapist-patient relationship. This applies to making a decision to engage in therapy as well as a decision to remain with a particular therapy or therapist. Participant suggestions also indicate a need for equalising service-user-researcher relationships in the development of any tool, meaning a collaborative process to ensure content is meaningful, useful and accessible.

NEXT STEPS

Psychological treatment services in the UK (known as "IAPT") have high non-engagement and drop-out rates at the moment (Davis and others, 2020 Predicting Patient Engagement in IAPT Services). Also, Black Asian and Minority Ethnic (BAME) communities are under-represented in referrals to IAPT, are less likely to complete treatment, improve or 'recover' as measured in terms of symptoms (IAPT BAME Positive Practice Guide 2019). Engagement and drop-out could be improved with greater involvement, choice, flexibility, patient empowerment and better information. We think that a decision guide (or 'Patient Decision Aid') for people wanting psychological therapy for depression could support and enable greater involvement and choice and should be developed collaboratively with people with lived experience. Our consultation findings suggest that a decision guide for this purpose should be based on information and treatment outcomes prioritized by service users in order to support 'personalised care' and fully informed decision making. We have written a full research proposal to develop such a tool in this way and our proposal has been informed by this consultation and written collaboratively with NSUN and Shaping Our Lives. If the proposal receives funding, we plan to invite anyone who took part in this consultation to continue their involvement in the next stage of the work and to invite other people with lived experience to get involved too.