

## Report from the National Clinical Audit of Psychosis (NCAP) Service User Reference Group workshop

9 March 2022

### Overview

Eight people with lived experience of psychosis (directly or as a carer) attended a workshop to discuss the findings of the National Clinical Audit of Psychosis (NCAP) for Early Intervention in Psychosis (EIP) services.

Before presenting the findings of the NCAP the group discussed their motivations for joining the workshop as well as sharing some of their experiences. Most expressed hope, in using their experiences to improve EIP services, as well as wider mental health service provision for people experiencing psychosis.

*“I want to give my views on how to make services better, I think it’s very important.”*

*“My son was diagnosed with paranoid schizophrenia in 2019. He was supported by EIP before, and was severely let down. He’s now in a medium secure unit. I see a lot of failures in the mental health system, not just from a personal perspective, but from my clients I hear it every single day.”*

*“I’ve got a lot of anger towards mental health services. I want it to change so I want to share my opinion about why I’m angry about it, to improve it.”*

*“I’m a registered and paid carer for my wife who’s suffering from schizophrenia, which is ‘headline’ for every other illness. I want to be involved and contribute from a carer’s view. I lead a lot of carer’s discussions, particularly around mental illness, and I think our voice should be heard as well, and our input is as important as others.”*

The data was split into two sections, **‘Performance over time’**, and **‘Health inequalities’**. These sections were reviewed differently. The **‘Performance over time’** section looked at 8 standards, which are detailed below. During this section, the NCAP team ran through all the data points, explaining the standards and the evolution over the last 4 years of the audit for each. Some questions were asked, and initial reactions captured from the participants, but the full discussion happened at the end of the data review. Not all standards were discussed in detail, as the conversation was led by participants and they brought forward the standards that they chose to prioritise for discussion. Therefore, for some datapoints in this section, there limited reflections captured in the report.

For the **‘Health inequalities’** section, we reviewed each datapoint, followed by a discussion with participants about that specific datapoint.

## Performance over time

For this section, the following data points were explained:

- Standard 1: [Timely access to treatment](#)
- Standard 2: [Psychological interventions: CBTp](#)
- Standard 3: [Psychological interventions: Family Interventions](#)
- Standard 4: [Pharmacological interventions](#)
- Standard 5: [Supported Employment and Education Programmes](#)
- Standard 6: [Physical Health: Screening](#)
- Standard 7: [Physical Health: Interventions](#)
- Standard 8: [Carer Focused Education and Support Programmes](#)
- [Outcome measures](#)

The following questions were then asked as part of a rich discussion of the data:

- Having seen the results, does this match with your experience as a service user or carer?
- What is the most important thing that could be changed, that would have the biggest impact on the quality of care for people experiencing a first episode of psychosis?
- In your opinion, what area has the greatest potential for improvement?

## Health inequalities

For this section, the following data points were explained:

- [Gender](#)
- [Age](#)
- [Ethnicity](#)

The following questions were asked after each data point:

- Having seen the results, does this match with your experience as a service user or carer?
- What is the most important thing that could be done to reduce the inequality found in the audit?
- In your opinion, what area has the greatest potential for improvement?

Below is a summary of the discussions. Where possible, this includes direct quotes from experts by experience. We have reflected the language they have used.

## Performance over time

### 1. Standard 1: Timely access to treatment

#### General feelings

A couple of the participants pointed out that the data they were shown pertained to 2018/19 through to 2021/22 but the access standard was set in 2016.

They thought it would be interesting to see how this standard had developed over time as they reflected that they believe that like the 2018/19 average, timely access to treatment was better in previous years.

#### Reactions to data

*“People were being seen at a higher rate, higher than they are seen presently. More people were being seen at that stage than they are now.”*

*“How does it compare to previous years before 2018?”*

#### Experiences

One participant shared that,

*“Access is a massive issue. Interventions, some work for some people, some don't work for other people. It's not just the medical model that is effective, sometimes the alternatives are far more effective and less side effects than the medical model.”*

*“People need to have a sense of those choices that are out there. Many people would prefer to leave the medical model out and focus on the alternatives. Stuff around football therapy, cycling, music, art, a number of things that are effective.”*

*“Important need to listen to rather than talk to or talk down. Finding safe space to engage nonmedical, in the community.”*

As was outlined in the [Overview](#), limited reflections were captured for some datapoints, or for some questions asked. Under this datapoint, there were no notable reflections for the question about the **‘most important thing that could be changed, with the biggest impact’** or the **‘area with the greatest potential for improvement’**.

## 2. Standard 2: Psychological interventions: CBTp

### General feelings

Several participants expressed that they did not think that CBT or CBTp is an effective therapy intervention for people experiencing psychosis.

A number of participants reflected on when they or their loved ones were offered CBT. While some expressed that this was not the best intervention to be offered during a psychotic episode others felt it had been offered too late. These comments further emphasised the wider theme that the group focused on, the need for personalised therapy to be offered.

Many of the participants expressed other therapies that have been beneficial and as there are so many different types, they felt these should be offered in conjunction with CBT so that everyone would get the personalised support that they need.

### Reactions to data

*"I think there needs to be a broader use of services so it meets the individual needs."*

*"I'm a little bit pessimistic about CBT when looking at someone with psychosis"*

One participant explained that this standard *"should not be a tick box exercise"* and that personalised therapy should be offered.

A carer explained that CBT is normally over 6 sessions which was not appropriate considering the length of time support for someone with psychosis is needed. For her son they needed personalised support for someone with psychosis. *'His delusions and hallucinations were taking over; he was not able to sit still'*

A participant reflected,

*"The stats speak for themselves in that we might be too pre-occupied with traditional therapy. Not enough emphasis on allowing the patient to have any action because these people are going to continue to burden the health system."*

One participant with experience of psychosis explained that they were not offered CBT.

*“I was never offered it at all throughout my 4 years with EIP. Ironically, I was having CBT before being referred but it had to get stopped because I ended up having a psychotic episode and that was the last I heard about having any CBT.*

*I was never offered it at all. I didn't even know it was a thing until just now. I was having CBT before I was referred, so that was the end of that. I haven't been offered anything since.*

*Just to add, I also have autism and found it difficult to engage with the CBT I was having prior to being under EIP services”*

One participant expressed the wider importance of psychological interventions by explaining

*“It's all about giving independence to the patient, not just about therapy but people need to be empowered to have autonomy rather than reliance on services”*

## Experiences

One carer explained that when their son was offered CBT he was *“in the throes of psychosis”* and he was not able to engage in CBT. Furthermore, they explained that their son has autism and so CBT was not the best intervention to offer him.

One participant with experience of psychosis explained why they think CBT is not an effective intervention for people experiencing psychosis.

*“It builds very little rapport and I believe this is the fundamental reason why it is ineffective.”*

*“I also think it's rather reductive in how it sees the patient. I believe most people could analyse the process and outthink the therapist. I believe a long-term informal approach would work better (and did for me but outside the services).”*

*“I couldn't build a rapport with the therapist very well. It wasn't very engaging. The process was a bit too obvious, a bit too forced it seems. No potential for anything else.”*

One carer explained that CBTp in their experience took too long to be offered.

*“He had a good experience when it happened, but it took too long. The olanzapine kept going up and up to a really high level, at the highest level before CBT was offered. I didn't think it would do anything. I felt quite worried about it. He had one therapist and it didn't work, and they offered it at the home as he couldn't leave the home for a long time. But the new therapist, they worked well together.”*

The carer went on to share the way that the intervention was explained to them. That they would be offered one block of CBTp and then they would be offered 'booster' sessions later. This carer explained *"There were regular symptoms, and we thought he could do with more."*

One participant shared their experience to emphasise the need for a personal approach to therapy.

*"To sum up my experience some of the most unpleasant people I've met were in psychiatric hospitals and EIP. They constantly flared up distrust amongst my family and myself resulting in 5 years of confusion. I eventually found insight and support in other ways and now people would never know I have been in a psychiatric hospital. Therapy can be massively overcomplicated-it's too much of a mechanistic medical approach rather than a relational humanistic one."*

One participant shared their experience on how they were not offered tools to gain independence under EIP:

*"They don't promote independence and pass you off as 'crazy people who are incapable of doing anything.' I spent 3 years of my time under EIP in and out of inpatient settings, sometimes over very minor incidents and I was never given the tools to help to deal with being unwell. It was always just 'either go to hospital informally or we'll section you'"*

### **Important thing to be changed, with biggest impact**

A number of participants expressed different forms of therapy that were beneficial for them. The group expressed that they think there needs to be more variety offered in terms of therapy. As well as the need to be more creative in how CBT is offered. Different types of therapies that were mentioned included; art therapy, music therapy, football therapy, animal therapy, walk and talk therapy

One carer explained,

*"There are so many types of therapy, talking therapy and music and art therapy and walk and talk therapy. It needs to be something that they can engage with in a physical way."*

*"Someone with autism struggles to interact with someone, in a room, for example. If you allow it to happen naturally, engaging with the natural world while walking, that automatically brings anxiety and stress levels down."*

*"I think these need to be offered in conjunction with CBT, there are so many ways to delivering therapy that are more engaging and personalising. CBT can even be offered in a more creative way."*

One participant shared that,

*“I think ideas for more diverse therapy options other than CBT would be walk and talk therapy or some sort of creative therapy or music therapy where the client is engaged in therapy in a different way. You can't always think yourself out of psychosis”*

One participant shared their experience of inpatient services and how that impacted their autonomy:

*“This is the thing with the NHS, I was in hospital, in my opinion I didn't need it. It's up for debate. I see people in there who thought they couldn't cope with life, and they're being told they can't cope with life. But how are they going to move forward. I don't know what the answer is, but I definitely feel like we take away people's power.”*

One carer shared,

*“I would really like to see young people's social prescribers based within EIP teams”*

### **Greatest area for improvement?**

This was an area that all the participants felt strongly needed to improve. Namely, a more personalised and creative approach to psychological interventions for people experiencing psychosis. This needs to promote independence and empowerment, rather than reliance and reflect their personal needs. CBT doesn't necessarily offer what people need.



### 3. Standard 3: Psychological interventions: Family Interventions

#### General feelings

It was felt by the majority of participants that effective education for the family of people experiencing psychosis was lacking.

It was felt by some that when it is offered in the process could affect uptake and interest in the offer. The best time to offer this intervention will depend on personal circumstances but should perhaps be offered more than once given the nature of psychosis.

Much of the feedback given to this datapoint linked closely with [Standard 8](#). We have therefore captured all the reflections under this standard.

#### Reactions to data

A carer shared their insights on the data,

*“The thing that’s always rested a bit heavy with me is the family interventions. I’m quite shocked about how low the uptake is. Really shocked.”*

*“I can kind of now, see why it’s at 20%. It’s a shame because I know family intervention when I read about the evidence, it’s a really key thing to do when your loved one becomes unwell.”*

A participant with experience of psychosis shared *“In my experience there was a lack of effective education for my family; this I believe why such treatment was ineffective.”*

Many people expressed their disappointment at the low family intervention statistics.

*“I think the stats on the family interventions and employment what add enrichment to people’s lives speak for themselves”*

*“The family interventions/employment stats rest heavy with me as these are crucial elements to work with an individual to help them rebuild their life, albeit it may be a different life following psychosis”*

#### Experiences

One carer shared their experience of family intervention through EIP services, which their son is still under.



*“It’s something me and my husband really wanted to do. We were all interviewed individually for family intervention, the pandemic had just happened, about an hour and a half each of interviews ... there’s a lot of stuff in your head when you’re going through this. The period of them doing all that, it took ages, to finally being offered it, was months and months and months.”*

*“I feel it was very slow to be offered, it all took too long in terms of getting the interviews. It might have been 9 months before we were brought back together. The first one didn’t go very well. I know that obviously our son was still unwell. We suspect our son has autism. I don’t think the session was delivered in a way that made him comfortable. He wouldn’t engage again. Neither would our daughter.”*

*“I read about it and thought it would be really good. They offered it again just for me and my husband. It didn’t go well again.”*

A participant with experience of psychosis shared,

*“[Family intervention] was offered but I was in the middle of a psychotic episode, so I was like no. It was never offered again. At the time they offered it wasn’t the most appropriate time. It would have been good for my family.”*

One carer shared,

*“We weren’t offered any CBT or family intervention. There is no conjunction within the teams, sadly. They will look at ‘there’s a tag of an illness’, and then thereafter it’s left to us to deal with it.”*

*“There is a positive here, only when we met a clinical psych who we met individually and collectively. We understood all where we were in this scenario. We had an in input. Honest truth, they say these therapies are not offered any more as they’re too expensive.”*

*“We’re always left out of it, we don’t know how to deal with things, individually or collectively. It’s a collective effort that will bring success. But if they’re not doing it cohesively, it will not work together if we do it all as individuals.”*

One participant pointed to a wider issue that can develop when the family don’t have the education they need.

*“Isolation is a massive issue. Sometimes people don’t have any friends, their family members don’t know how to really manage and support them, and they’re almost on their own, sitting at home literally don’t know what to do and just building up more issues.”*

### **Important thing to be changed, with biggest impact**

One carer went on to explain what they felt was missing from the services currently.

*“We need accountability here. What is the journey we’re taking? Where are we going with this? Who’s going to assist us? At what stage of the journey?”*

*“For some of us it’s for life, all the time. We are left all alone to deal with it, as carers and service users, to deal with it.”*

*“The person right at the centre, the service user, they should always be respected because we’re all there for that person and each other.”*

A member of the group who has experience psychosis explained,

*“I think it’s really important families get education. 2 hours with services, but the rest of the time they’re living with them. If they don’t know how to deal with it, they won’t know how to support people.”*

One participant shared that they felt it would be important to understand why the services are not offering this or people are not accepting it. As they explain *“Most of the work happens outside therapy in my humble opinion.”*

### **Greatest area for improvement?**

Most of the group felt that this was a crucial area for improvement to ensure people had the support they needed outside of the EIP services as well as for the enrichment of peoples lived beyond the EIP services. They felt that education for family and involving carers was fundamental in supporting someone experiencing psychosis.

#### 4. Standard 4: Pharmacological interventions

##### General feelings

A connection between anti-psychotic medication and weight gain was widely accepted amongst the group and they felt it is not sufficiently addressed and supported by clinicians. This made this Standard and Standard 6 & 7 linked in the discussion.

##### Reactions to data

*“What is the reason behind using clozapine as a third opportunity to reduce psychosis? Is it purely the cost to the NHS?”*

##### Experiences

One participant shared that they had not been made aware of the side-effects of antipsychotics, particularly the weight gain. They felt this should be linked in the nutritious support immediately and psychological health. Needs to be addressed in a proactive way and joined up with the knowledge of the medication that can have an impact on weight.

One member of the group with experience of psychosis shared,

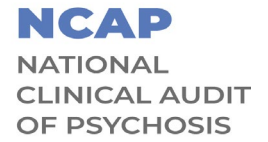
*“about not having any support about side effects. I had CBTp before for an [eating disorder] ED. I went from 11 to 19 stone in 4 years [during EIP services]. My psychiatrist was adamant it was nothing to do with antipsychotics”.*

A carer shared,

*“My son is on clozapine and he is in a medium secure hospital and he has not gained weight as he goes out for walks with his OT twice a week and he goes to the gym 3 times a week. I believe the clozapine gave him his motivation back since it completely distinguished the psychosis.”*

##### Important thing to be changed, with biggest impact

It was clear from the group that awareness and understanding of side-effects of antipsychotics was needed for both service users and the clinical and community teams involved in their care. This also needs to be cohesive with support offered for physical health also and integrated within the care package.



Again, as outlined in the [Overview](#), there were no notable reflections for this datapoint for the question the 'area with the greatest potential for improvement'. However, a noteworthy reflection was that some participants felt there was an important link between this standard, and standards 6 and 7, on physical health screening and interventions.

## 5. Standard 5: Supported Employment and Education Programmes

### General feelings

There was a general understanding that there was little offered to the group in the way of employment or education programmes.

There was also a link identified between the lack of this standard with Standard 3: Family Intervention.

### Reactions to data

This standard was linked in people's minds to the low offer/uptake of family interventions, for this reason we share the same reactive quotes under this standard also.

*"I think the stats on the family interventions and employment what add enrichment to people's lives speak for themselves"*

*"The family interventions/employment stats rest heavy with me as these are crucial elements to work with an individual to help them rebuild their life, albeit it may be a different life following psychosis"*

*"Quite shocked the levels are what they're at in the audit."*

### Experiences

One participant who has experience of psychosis shared,

*"To understanding WHY the services don't do such things would be very beneficial. [Supported Employment and Education Programmes] will be the only way that people can move on. After lots of time I had attachment to the services. There's too much emphasis on talking about your experiences, but in order to make this affective people need to be encouraged to act."*

A carer shared that,

*"Our son hasn't been in any education for 2 years, he's got an education healthcare plan, even having that there's no provision and everything he's doing now has really been because I've changed my job to try and support him. Find things for him. He's never been offered anything like from the audit."*



### **Important thing to be changed, with biggest impact**

As with Standard 5, the group felt that this was an important element to support someone who experiences psychosis and the stats speak for themselves in that it is not being offered or taken up. This is what needs to be addressed here.

As described in the [Overview](#), there were no notable reflections for this datapoint on the question the '**area with the greatest potential for improvement**'. This datapoint was given much less time and commented on much less than other datapoints by the participants.

## 6. Standard 6: Physical Health: Screening

### General feelings

This Standard was linked heavily with a discussion on antipsychotics relating to Standard 4 as well as being spoken about on par with Standard 7: Physical Health Interventions.

The group generally agreed that there was a need to be more cohesion between the teams delivering the physical health screening and interventions with the clinical and community services.

### Reactions to data

One carer shared,

*“It really rested heavy with me, knowing the side effects of antipsychotics. You’ve got a really big programme around PH monitoring and interventions. Antipsychotics have been brilliant, gently improve and engage, but the side effects – particularly weight gain – is problematic. Why aren’t we linking them in with nutritional support straight away, exercise on referral (when prescribing antipsychotics)?”*

One participant shared,

*“I think it’s great we’re looking at this – how many we’re offering Physical Health screenings. But how much harm are we causing at the end, in those Physical Health conditions like diabetes.*

*“I think this isn’t being proactive enough for me. I think there’s more that can be done in EIP services, but that isn’t in place as services change. In terms of integrated workforces.”*

### Experiences

One participant with experiences of psychosis and the EIP services shared more detail regarding their experience where they told us,



*“My psychiatrist was adamant [weight gain] was nothing to do with antipsychotic.”*

*“With Physical Health screenings, I had one in the first year, then never again. While waiting for the appointment, the CPN said ‘you don’t want to end up as an inpatient, you’ll end up smoking and being overweight’.*

*“There was no place for me to have help for that. It was never really addressed, ‘that’s a ‘you’ problem now”*”

Another participant responded to this sharing:

*“Makes my blood boil, lying to you and not telling you the truth. It’s about putting the trust in the patient, ‘you can’t help yourself, and if you doubt us we’re going to put you in hospital’ – I don’t like that.”*

*“I think it’s all about giving independence to the mental health patient, if you don’t trust they’re going to do it themselves, they’re not going to do it. It’s up to them.”*

### **Important thing to be changed, with biggest impact**

It was clear from the group that awareness and understanding of side-effects of antipsychotics was needed for both service users and the clinical and community teams involved in their care. This also needs to be cohesive with support offered for physical health also and integrated within the care package.

As detailed in the [Overview](#), there were no notable reflections for this datapoint for the question the **‘area with the greatest potential for improvement’**.

## 7. Standard 7: Physical Health: Interventions

### General feelings

This Standard was linked heavily with a discussion on antipsychotics relating to Standard 4 as well as being spoken about on par with Standard 6: Physical Health Screening.

The group generally agreed that there was a need to be more cohesion between the teams delivering the physical health screening and interventions with the clinical and community services.

### Reactions to data

One participant highlighted that alcohol-induced psychosis can be experienced and described it as 'costly' and shared they thought there needed to be more information and personalised approach to this specific issue.

### Experiences

A carer explained how the services and psychical health interventions were not matching up with the support in their areas,

*"After a while they referred him to a cooking group. Every single thing he's cooked every week is 'sweet treats'. I just don't think we're getting that bit right in terms of giving the individual enough support around what an antipsychotics can do. You're looking at the weight, but a lot of the comes from an antipsychotics". Something to think about in a proactive way.*

A carer explained how they had interacted with physical health interventions

*"My wife had issues with physical health. Anyone on antipsychotics, there are adverse effects on the body. Lots of complications begin earlier."*

*"This is a difference between primary and secondary care. If they're not aligned, problems always arise. My own experience, very rarely do the psychologists and psychiatrists speak to the GPs. It's only a note sent from one office to another. Maybe after 6-12 months, another."*

*"If we could improve the cohesion between primary and secondary, I don't know how.. the new Trusts were set up to address this problem. But I don't see it. Some clinics have CPNs, but that didn't work very well, so I don't know what's going on there. That really needs to be looked into."*

### Important thing to be changed, with biggest impact

It was clear from the group that awareness and understanding weight-gain and how that can be connected to antipsychotics was important to the group. Both service users and the clinical in primary and secondary settings and community teams need to be cohesive in their approach.

One participant felt,

*“We need to try and at least find ways of supporting people in the wider community in terms of voluntary, community and social enterprises rather than mental health orgs etc.”*

One participant highlighted,

*“It’s all about early intervention in terms of a public approach from the outset with an individual under EIP - social prescribers to work very early with a family /individual to prevent physical health problems”*

As detailed in the [Overview](#), there were no notable reflections for this datapoint for the question the ‘**area with the greatest potential for improvement**’.



## 8. Standard 8: Carer Focused Education and Support Programmes

### General feelings

It was felt by the majority of participants that effective education for the family and carers of people experiencing psychosis was lacking.

Given the way the discussion developed, many conflated the Family Intervention and Carer Focused Education and Support Programmes as one and the same. Please see Feedback on [Standard 3](#) for reactions, experiences, and important elements for improvement.



## 9. Outcome measures

There were no reflections on the Outcome Measures during the discussion on the performance over time of the eight standards. Given the rich discussion around many of the other datapoints, it's possible that this dataset was either missed or deprioritised by participants. This could have been due to the limited time available to comment on all of the standards they felt compelled to discuss.

There was no general discussion of the data for '**Performance over time**' as this was all captured in the discussion sections for each dataset.

## Health inequalities

### 1. Gender

#### General feelings

There was general surprise that Clozapine was offered to women less than men. The group speculated as to why this may be such as wondering if the medication affected reproduction and if so, is this why it is not being offered?

There was less surprise at less men than women taking up CBT, given there is a stigma around men not talking about their feelings. Though the group felt this should not prevent EIP teams offering the therapy.

#### Reactions to data

*“Why would any health professional offer less clozapine if it’s beneficial, to females? I’m very surprised about this study.. why would anyone not offer women clozapine, if it’s beneficial. If it’s automatic, it should be offered. What is the purpose of not giving it to women?”*

*“The first is regarding the CBTp, and that is potentially just from general stigma, ‘men can’t talk about their feelings’.”*

One participant shared that they felt that this data was important, and it is interesting to know more about what the data is telling us.

One participant looked at the gender statistics and highlighted that,

*“It’s also interesting to see that there is less than 1 percent of non-binary/other people. how did they collect this data? since the only genders that are legally recognised are male and female, have services gone by what their legal gender is to present these statistics, or have they gone by what the person identifies as?”*

#### Experiences

One participant shared that,

*“With the clozapine, I live in supported accommodation, nothing to do with EIP services, but everyone who’s on clozapine here is female.”*

She went on to explain that she has had difficulties accessing certain medications based on the effect on reproduction.

*“I don’t know much about side effects of clozapine, perhaps anything about reproduction? I have a massive issue with this, males can have it because it doesn’t affect you if you can’t have a baby. I’ve experienced issues with medication because I’m of child-bearing age. I’ve been refused some meds because of that.”*

*“It was very much ‘you can’t have it’. Bearing in mind I’m a lesbian and I do not want kids ever in my life, but it was still like ‘no, you can’t’. The psych had another patient who got pregnant after being put on it, who was a lesbian. But that’s not the same, that’s an isolated case.”*

*“I’m not that informed on what the guidelines are regarding clozapine. I still think it should be the choice of the individual so they can make an informed decision about what goes into their bodies, especially if it is something that could be hugely beneficial to their mental health”*

A carer explained how their son related to CBT.

*“It also made me think about the number of males not taking up CBTp. We really didn’t think he would take it up. I wondered how many of those males have autism. There’s evidence around CBTp and family intervention that it might not be as effective for someone with autism, and that figure doesn’t tell us that.”*

*“I know I’m generalising, but generally males do find it more difficult to open up. We really didn’t think our son would engage, but successfully, the team have been tenacious, and it worked for us. I can see why that would be lower for males.”*

*“He started with 1 therapist, and it didn’t work, or maybe our son wasn’t ready to engage. They stopped quickly, said wait for a bit, tried with someone new, tried cautiously. He would come home and say ‘I’m not going to carry on again’.”*

*“So, they changed their approach. ‘Poked a little bit too much there, we’ll slow down’. It wasn’t ‘here you go, start it’, it was stop start stop start, with different therapists, and it worked in the end.”*



One participant with experience of psychosis explained,

*“There is of course stigma with males not been able to talk about their feelings, but I think we should be cautious of been reducing it to this psycho-social reason. Genders relate differently. Yes, males find it difficult to talk, but in order to do this they need to be given a reason a motivation to do this. Again, it comes down to relating well personally, as well as knowing all the clinical theory.”*

*“I’d go as far to say that by talking about the the stigma or cultural stereotype they are only flaring it up within the service users. If they bypass the conversation around stigma and see people, then it would be different. I think some clinicians see people as a group or a statistic sometimes. Relationships in therapy should be based on respect like any other relationships. I’m talking the worst case scenario here but I think things like this do happen and people should voice such experiences.”*

### **Important thing to be changed to reduce this inequality**

The group expressed that regarding clozapine the decision whether to take up this medication should be a consultation between the service user and the clinician. Unilateral decision should not be made by the clinician and the personal circumstances of the service user should be given weight when looking to prescribe clozapine.

Regarding CBT the group reiterated the need for a personalised approach to ensure engagement in the intervention.

As detailed in the [Overview](#), there were no notable reflections for this datapoint for the question the ‘**area with the greatest potential for improvement**’.

## 2. Age

### General feelings

The group had a number of different perspectives on this health inequality as there were experiences relating to a number of the different age groups identified and each provided with a specific example of how they see the statistics reflected in their experiences.

As the health inequality related to clozapine, there was further discussion on the monitoring and support offered for side-effects when prescribed anti-psychotics and the lack of such support in many areas.

### Reactions to data

*“The age %, demographic, it’s really interesting for me to see that. Our son was 15 when he became unwell. He was already under services then, and then a bit of time, he was 16 when he was under EIP services.. I raise that as I was aware he was in the minority, not a big amount of people that age. He was in a very adult-focused service, and was very young. They were lovely, 2 CPNs, worked very differently. IT was very ‘adulty’ and he was a young adolescent, and I think there needs to be some young peoples’ social prescribers”*

### Experiences

One participant who has experience of psychosis highlighted the need to look at these health inequalities intersectionality:

*“I was thinking that as for me, I’m 18-35, with the 65%. I’m Black minority, and male – 61%. I think the best thing is to compare the social economic group of those who are at a higher and lower end. So as to find how finances won’t be of much cost for the minority. I think we should integrate health”*

One participant shared the story of someone who is between 50-65 years and started their meds approximately in her 40s

*“I know individuals who have been prescribed but do not take their medication. For a number of years, but do not take it. I remember having a conversation about this with the individual. The individual initially took the medication for about 3 months, and then did not take the medication for the rest of the 9 months – for the whole year.”*

*“I could see behavioural issues displayed in the individual, just by observing. I’m just wondering when people are prescribed in terms of monitoring – what goes on? We all know that the psych is the one who prescribes, in this case, and sometimes the individual doesn’t see a psych for 2 years, so they’re left with this medication that is a repeat prescription, but they never take it.”*

*“I’m just wondering how, if any data captures any of this stuff at all? I know for example on your prescription you get a review from your GP, once a year. It tells you your reviews coming up. The pharmacy will ring you up and speak to you about your meds, and then you have an opportunity to discuss with the pharmacy about that. Out of that convo an adjustment can be made. But if a psych is only seeing you 2 years down the line. That’s a long time and if you’re not being honest, what’s going on in your head and body.”*

*“Having that support would help them adhere to taking the medication. When we have a conversation, I can try and encourage her to take her medication regularly, and she says, ‘I’ve been on it for 13 years, and I don’t want to be on it’, but she hasn’t discussed with her psych.”*

A carer shared their son’s journey with antipsychotic medication that was offered.

*“I just want to know why clozapine offered after the previous 2? [Medication name not heard, potentially Haloperidol or Aripiprazole] then Olanzapine, which is why he refused to take any meds at all. He didn’t see that anything was helping. The [Medication name not heard, potentially Haloperidol or Aripiprazole] was making him worse and aggressive. Speaking to him now on Clozapine, the wonder drug, he wouldn’t take anything else or stop.”*

*“I wonder why they aren’t using it more when it clearly works. I know some people can’t take it for health reasons. I realise it’s got to be monitored more, is it cost? It stops all the symptoms. It’s like they’re wasting so much time. Once the person is more stable on Clozapine, once the delusions have finished, then the therapy can really take place. You can’t really get to that place until they’re not in the psychosis.”*

One participant with experience of psychosis shared their experience of antipsychotics

*“That is a very good point regarding not taking medication. I on and off refused to take medication for around 2 years which is why I was given various differing antipsychotics and mood stabilisers because it appeared to the psychiatrist that the medication wasn't working. it's interesting that I wasn't offered clozapine because as far as they were concerned, the medication wasn't working, yet if clozapine can be offered after 2 unsuccessful trails of other antipsychotics, why was it not offered to me between the ages of 20-24?”*

*“I was put on different things. The medication wasn't working. Then when I was taking it, 4 different things. I haven't been offered Clozapine. The Trust that I'm under have a 'they don't prescribe it unless you're in hospital'. It's interesting that I was never offered it despite other things not working. To start was because I wasn't taking it. Where's the point where they'll try Clozapine? If it's supposed to be after 2.”*

There was lots of agreement that perhaps monitoring of side effects was better facilitated in Hospital than in the community.

A carer explained how they have seen monitoring of medication change over the years

*“Certain Trusts do have outreach teams to see who's not taking meds, especially if they're vulnerable. It could be younger or older people. It's been cut because of funding cuts. They were connected to community psychiatric teams. Unless they come under some sort of criminal investigation, they will never be explored.”*

*“The social care department are demolished, finished, the city council – same story. This has had an adverse effect. The younger ones are suffering more, because they didn't even know that service was available, to nudge you to have your medication. Not to compel, a casual conversation, even those things have stopped.”*

*“A lot of pressure comes onto carers like myself. I monitor. People not taking it get depot, once ever 2 or 4 weeks. Same meds through injection. That's it. No problem. The only issue, that obviously has to be decided by a psychiatrist. It is an intravenous. It's not tablets. It's a totally different way it's monitored. Then you obviously meet with the team on that therapy.”*

*“The good Trusts will obviously chase, even a meeting with the CPN or Care Coordinator every 4 weeks or less. The Trusts finances are in such difficulty. I don't know the answer.”*

One carer explained how the EIP team in their area could not provide their son with the support that was needed:

*“My son went through a legal process, and he has now has the most amazing care, whereas the EIP was near enough useless. It appears things have to go very wrong before individuals get help they need.”*

### **Important thing to be changed to reduce this inequality**

The most important thing to come out of the discussion was that different age groups need different things. Under 18s may require more support specifically aimed at young people. People 18-35 felt there was a need for an intersectional approach to not just look at their age as a singular characteristic, but take into consideration their gender, ethnicity and socio-economic situation. With the 50-65 demographic it was highlighted that there is a need for continued support around medication, some feel there is an arms-length approach to their prescriptions and supporting care.

People from all different age ranges acknowledged that not taking medication was also a significant contributor to whether a medication was working or not in the eyes of the psychiatrists and this should be taken into consideration.

There was also general disappointment that despite Clozapine being a drug that worked, there weren't the mechanisms in certain areas to monitor the side-effects which meant that people were not in a position to be offered a medication that could be beneficial for their recovery.

### **Greatest area for improvement?**

The group discussed to various degrees the monitoring of medication for different age groups and the support that is, or in many cases is not, available to support people to engage with medication.

### 3. Ethnicity

#### General feelings

There were concerns about the data collection itself and how the different categories were defined.

There were also concerns that people are refusing to disclose their ethnicity and this is important to understand and address.

#### Reactions to data

One participant shared their initial reaction to the demographic breakdown of the ethnicity data.

*“I’m curious about the stats. You’ve got 13% for Black British, 13% for Asian. I’m really interested in 4% of ‘mixed’. What is this telling us? I’m thinking within these stats, racism is actually coming through this data. 4% of ‘mixed’ is going to suggest that the way Black British and Asian is seen, and the way ‘mixed’ is seen, is actually telling me that there’s something else going on. That could be institutional. There’s a number of issues that would sit behind this data.”*

A carer also shared their initial reaction to the demographic data.

*“Police have different data e.g., Black Africans, Black Caribbeans. It could mean that people who don’t want to say which community they’re from, or it could be that the system is looking at them the way police handle data.”*

*“Indians for example are ‘British Indians’, but the reality is, a huge majority of British Indians or Asians are not from India they’re from Kenya, over 90% of them in England. This is something that needs looking into more. Is this data dependent? We need clarification on this. Make it clear, give them the option.”*

Regarding the health inequality data presented one participant shared their initial reaction:

*They should be very concerned about those that refused to give their ethnicity. The refusal could be a number of reasons. It could include race, culture, disability issues, lots of different issues. For me those figures are far too high to make sense of anything.”*

*“It’s a good indication that there’s lot of other things going on as to why people are not comfortable in disclosing that information.”*

## Experiences

One participant with experience of psychosis explained the difference in representation in their community and in hospital:

*“In terms of having been in inpatient wards, I live in a predominantly Asian area and whenever I’ve been in hospital, the majority of people in there are white which doesn’t match the demographics of the area”*

As the data related to physical health screenings there were further comments on more general interventions that could benefit people experiencing psychosis under EIP regarding physical health.

*“It just brings me back all of the time to thinking about the place where people start when they find themselves under an EIP team, maybe for the first time going on an antipsychotics. I don’t believe there is enough done right at the outset, around how that medication has consequences for their PH. It definitely does.”*

A carer explained that,

*“My wife had issues with psychical health. Anyone on antipsychotics, there are adverse effects on the body. Lots of complications begin earlier”*

This is explored fully under Standard 6 & 7.

### Important thing to be changed to reduce this inequality

A few of the group had questions regarding the credibility of the data and difficulty making sense of the data that was presented. Complete and robust is needed to understand the inequality. Then it is possible to understand and explain what needs to be changed.

As detailed in the [Overview](#), there were no notable reflections for this datapoint for the question the ‘**area with the greatest potential for improvement**’.



## Final Thoughts

One participant highlighted the transformation of community mental health services as an opportunity to address the gaps in services that were explored in the discussion

*“We know from April [2022] – [integrated care systems] ICS service should kick in, the idea is to join up services. We’ve all expressed the gaps between services and in particular GP as private business etc. I can only speak about what’s going on in my local Trust (Merseyside and Cheshire), in terms of the comm MH services, including people with lived experience contributing to development and implementation of community mental health services.”*

*“That’s happening in other places as well, I know it’s happening here. That should at least narrow the gap between services so we’re all talking to each other and not having to keep repeating ourselves in each service area. Outcomes should be better for the individual.”*

A carer also shared optimism at developments they are seeing:

*“It’s great to see roles developed around peer support workers within Mental health teams. EIP have also embarked on this, good news!”*

A carer expressed their thoughts on the group as we closed the session:

*“Thank you to all of you. It’s really great to see so many carers involved. We must never forget that the service user is the most important person in all of this, it’s who we fight for.”*