Rethink Mental Illness and Boehringer Ingelheim

Rethinking Schizophrenia

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rethink.org

This project has been commissioned by Boehringer Ingelheim Limited to support Rethink Mental Illness's work in understanding more about the experiences of those living with schizophrenia. Boehringer Ingelheim were in regular communication with, and provided data upon request to Rethink Mental Illness, in addition to attending a number of engagement sessions in an observational capacity. Rethink Mental Illness have editorial control of all content, which has been reviewed by Boehringer in line with the ABPI (Association of British Pharmaceutical Industry) Code of Practice. The independence of Rethink Mental Illness has been maintained.

The opinions and accounts expressed by patients and Rethink Mental Illness in this report are their own and do not necessarily reflect the views, policies or positions of Boehringer Ingelheim. These testimonials are included solely to share individual lived experiences and should not be interpreted as official Boehringer Ingelheim statements.

The report contains quotes of people's experience with medications. Licensed medications have demonstrated benefits for appropriate patients, as well as having side effects. It is important that these are communicated and monitored by healthcare professionals (HCPs). The decision to use a particular medication should be made by a HCP, along with the patient and/or carer.

The motivation behind the project was to find out more about what it is like to live with – or care for someone with – a diagnosis of schizophrenia in today's world. We particularly wanted to find out about the impact of symptoms, and especially what may be unrecognised cognitive symptoms, on people's daily lives. What we heard was so much more than this and this report is a moving account of daily life and often the daily struggles of the very many people affected by schizophrenia.

> “We would like to thank all the Experts by Experience who contributed to the project as well as Boehringer Ingelheim for funding the project.”

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Executive Summary

1. Introduction

Rethink Mental Illness, funded by Boehringer Ingelheim, has co-produced a landmark project engaging 46 people with lived experience of schizophrenia - including families, carers, and friends - to explore what wellbeing and a fulfilling life mean for those living with a schizophrenia diagnosis. This initiative represents the largest engagement with this community in a decade and highlights essential policy and practice considerations to improve care and support.

2. Key Themes

The report presents nine key themes reflecting the voices of Experts by Experience (EbEs), with clear recommendations for policymakers:

Quality of Life

Supportive relationships, structured routines, and access to effective treatments improve wellbeing. Policies must move 'beyond stable' to a more ambitious, person-centred approach focusing on quality of life. The NHS must address gaps in mental health workforce recruitment and retention.

Identity and Intersectionality

Personal experiences vary based on age, gender, neurodiversity, culture, and other factors. Cultural competency training and policy reforms such as the Mental Health Act review must address systemic biases and ensure equitable care.

Family and Carer Involvement

Carers provide vital support but often feel overlooked. Mental Health Act reform should ensure carers are fully involved in care planning and receive necessary support, including training, financial assistance, and peer support.

Physical Health

Mental and physical health must be integrated into care. Medication side effects, smoking cessation, and lifestyle interventions should be prioritised, along with government investment in preventative interventions like Physical Health Checks for those with severe mental illness.

Mental Health Services

Accessibility, crisis care, and continuity of care must improve. Investment in early intervention, community support, and nationwide rollouts of 24/7 mental health centres can enhance service effectiveness.

Having Purpose

Employment, education, and volunteering are crucial for self-worth. Expanding Individual Placement and Support (IPS) and developing inclusive workplace standards will improve participation opportunities for people living with schizophrenia.

Life Circumstances

Stable housing and financial security are fundamental to recovery. The government must increase high-quality supported housing options and implement social security reforms, including a statutory duty of care within the Department of Work and Pensions.

Stigma

Public misconceptions fuel discrimination. Targeted awareness campaigns and training within healthcare and social services can help dismantle stigma and promote inclusion.

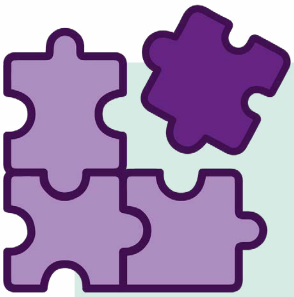
Thriving

A holistic approach, as outlined in Rethink's *Communities that Care* model, is necessary. Multi-agency collaboration must ensure people living with schizophrenia receive comprehensive, integrated support across all aspects of life.

3. Our Approach

The project followed a rigorous co-production model, ensuring meaningful engagement at all stages:

- Recruitment & Engagement: 60 people expressed interest; 46 participated (20 with schizophrenia, 26 carers/family/friends). Group discussions and one-on-one interviews ensured accessibility.
- Psychological Safety & Ethics: Safeguarding protocols were followed, and all participants provided informed consent.
- Inclusivity: 70% of participants completed diversity monitoring forms, and all communication materials complied with ABPI guidelines.



Considerations for Policy and Practice

Since the 2012 *Schizophrenia Commission* report *The Abandoned Illness*, some progress has been made, but significant gaps remain in housing, physical health, and long-term care. This report calls for urgent policy action to ensure that in another eight years, the landscape for people living with schizophrenia is fundamentally improved. Co-production must remain central to future initiatives, ensuring that lived experience informs meaningful and lasting change.

1

Introduction

In 2024, Rethink Mental Illness co-produced a project about schizophrenia and quality of life – this is the largest engagement we have had with people from all backgrounds and experiences of schizophrenia in the past 10 years. As the charity for people severely affected by mental illness, including schizophrenia, we are ideally placed to deliver such a project. The purpose of the project was to engage with a diverse range of people with lived experience of a diagnosis of schizophrenia, including families, carers and friends, to gather their views and experiences about what achieving and maintaining wellbeing looks like when living with this diagnosis, as well as exploring what a good quality of life, and fulfilment looks like. This report describes how we undertook the project and presents what we heard from the 46 Experts by Experience (EbEs), who so generously shared their experiences, views and opinions with us.

We have included direct quotes as the report is led by the voice of lived experience, with some ‘Considerations for Policy and Practice’ from Rethink Mental Illness. We also present feedback from the EbEs and some reflections on the process of undertaking the project. We hope that what we heard will influence readers to take action to improve the experiences of people living with schizophrenia and enhance their wellbeing and quality of life. As you will read now, there is much that need to be done to ensure people are supported to lead the best possible lives.

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About us

At Rethink Mental Illness, we are committed to transforming mental health care, challenging societal misconceptions, and improving lives. People severely affected by mental illness are at the heart of everything we do and these experiences shape our work, from tackling health inequalities to ensuring accessible services and driving policy change.

The Lived Experience Innovations team sits within the wider Policy and Practice department and connects with wider teams via a matrix working approach. Our team develops new ways of working within mental health spaces by ensuring those with direct experience shape and direct progress. We connect commissioners, researchers, and professionals with EbEs to unlock insights, challenge barriers, and drive meaningful change.

Co-production is central to our work. We collaborate with EbEs across planning, delivery, and evaluation stages to create inclusive and accessible platforms that amplify often unheard voices, including underrepresented groups. By fostering meaningful engagement and creating safe, supportive spaces, we enable people to influence the services that affect them by sharing their stories.

Our mission is to bridge the gap between mental health systems and the people who use them, ensuring lived experience drives innovation, influence, and impact.

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What is schizophrenia?

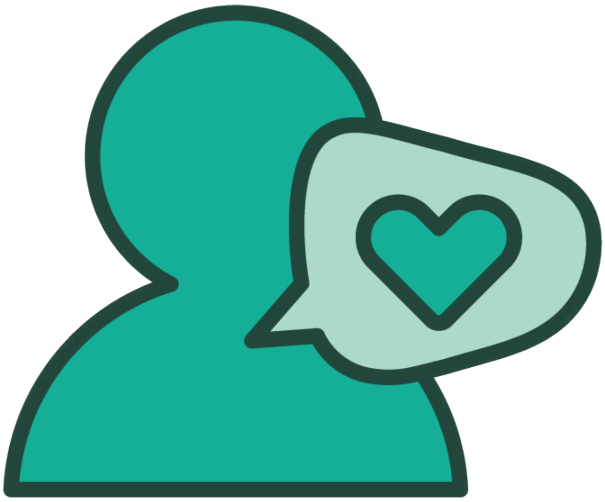
Schizophrenia is a severe mental health condition that affects how people think, feel and behave. It may result in a mix of hallucinations, delusions, and disorganised thinking and behaviour (Mayo Clinic, 2024). Around 1% of the population have a diagnosis of schizophrenia (Rethink Advice and Information, 2023) Whilst that sounds like a small number, it equates to around 565,000 people in England (GOV.UK, 2022).

The onset of symptoms generally occurs in someone's late teens or twenties. Symptoms of schizophrenia can be categorised in three areas: positive, negative and cognitive, the personal impact of which are discussed later in this report.

Symptoms vary between people. Positive symptoms include delusions and hallucinations as well as disorganised speech; negative symptoms include social withdrawal, lack of motivation, decreased energy, loss of interest in usually enjoyable activities, a flattened mood and an inability to feel pleasure (called anhedonia). Cognitive symptoms include impairments in memory, difficulty expressing thoughts and reduced processing speed. These symptoms are common and can affect everyday life, affecting someone's quality of life. Cognitive symptoms often remain after positive symptoms have been treated with medication.

Experiences of symptoms are just one of the areas that we heard affect quality of life and this report covers nine key themes, summarising what we heard: Quality of Life; Identity and Intersectionality; Family and Carer Involvement; Physical Health; Mental Health Services; Having Purpose; Life Circumstances; Stigma; and Thriving. Each key theme, and corresponding sub-themes, is presented in the words of EbEs and is followed by our 'Considerations for Policy and Practice', which constitute our reflections on what we heard and what we think needs to change. We hope that this report will help drive that change.

There are many myths about living with schizophrenia and these, along with further information about Rethink Mental Illness, and our work to support people living with schizophrenia, are described along with much more information in the background pre-reading we shared with EbEs, which can be found in the Appendix.



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Our approach

Introduction

Here we describe how we prepared for and carried out the project, which followed a staged process starting with planning using a co-production approach, and then a series of group sessions and individual engagement meetings.

To initiate the project, we held a 'kick-off' meeting with the commissioners Boehringer Ingelheim to ensure the project stages and timelines were communicated and agreed. We then set up regular fortnightly catch-up meetings with the commissioner to provide updates about the project progress, and we also exchanged ad-hoc communication through email about the project and arranged issue-specific meetings when needed.

Desk review

To prepare for the project ahead of the recruitment and co-production stages, we created a Rethink Mental Illness schizophrenia-specific evidence review including some data sent from the commissioners. The output was a light touch report providing an evidence-based understanding of schizophrenia to inform the co-production stage; that is, what is known about quality of life and schizophrenia already as a form of background information for participants.

During the co-production phase, EbEs reviewed the desk review as a background discussion material. The group suggested creating a shorter version. As a result, we produced an abridged version that focused more on lived experiences and included fewer academic research findings. This shorter version was shared with EbEs in the engagement phase, who were able to request the longer version if they wished to read it. This process highlights our commitment to fostering meaningful collaboration with EbEs from the beginning of the engagement phase of the project.

Recruitment

The Rethink Mental Illness Lived Experience Programmes Team shared the opportunity and an online Expression of Interest Form to participate in the engagement project via a range of channels including:

- Our Involvement Community
- Social media and webpage audience
- Internal staff
- Lived Experience Advisory Board
- Carers Advisory Board
- Inpatient services

We reviewed the responses that people sent about why they would like to be involved in the project, and we then organised introduction calls with the selected EbEs using predetermined eligibility criteria. To encourage accessibility, we gave people the option of speaking to them over the phone or via an MS Teams video call – where people could also keep their camera off if they wished.

We assessed their understanding of the project, willingness and interest in participation, and their current capacity and wellness levels. We also checked what support they may have needed to participate. To understand the demographics of the EbEs in the recruitment processes, we asked people to complete optional Equality and Diversity monitoring forms.

A couple of people dropped out ahead of the sessions, after expressing interest or could only attend one of the sessions – where it was an appropriate alternative, we offered people the option for a 1:1 engagement meeting and worked together to co-ordinate a time and day that worked for the person and our internal facilitation team.

Everyone participating in any kind of session – co-production, engagement, pre-meet or debrief was offered payment of £15 per hour in line with the Rethink Mental Illness Reward and Recognition policy. Support was given to people for whom there may have been difficulties regarding the potential effect on benefits, such as offering vouchers.

Co-production

We started the project with 3 co-production sessions:

- Session 1: Understanding the desk review
- Session 2: Co-designing engagement sessions
- Session 3: Refining sessions and exploring creative methods

These 3 sessions were run with 1 group of 6 EbEs – we ensured that during the selection process the group was as representative as possible across age, gender, ethnicity – we had people from a lived experience diagnosis perspective and 2 people who were speaking as a family, friend or carer.

In the first session our goal was to build on findings from the evidence review to create a shared understanding and inform the next steps of the project. We actively engaged with EbEs, drawing on their lived experiences to expand on the desk review findings, and framed this within their current experiences. We asked EbEs if the findings aligned with their personal experiences and explored any gaps they identified.

We worked through people's understanding of the desk review, then in the last session went through the plan for the sessions, discussed safety and safeguarding, reviewed the questions and how they were formulated. We then discussed how the sessions should be facilitated, run and managed before, during and after. We asked EbEs in the co-production group for their thoughts on breakout rooms, but the consensus was that a group of 8 people speaking is a good number for a dialogue but that a group of 4 people in a breakout room is uncomfortable and puts people on the spot.

The preference was for the engagement session to be run in 4 groups with 2 sessions each, keeping group size between 6-9 EbEs.

The two engagement sessions per group were divided into "Achieving and Maintaining Wellbeing" and "Quality of life & Thriving". Pre-meets and debriefs were considered positively by the co-production group, to allow space for people to ask questions, or follow up after a session and to check in on wellbeing given the nature of the topic.

Pre-meet sessions

We hosted an online pre-meet session before each engagement session, totalling four altogether. This gave the chance for EbEs to meet others who were engaging in the project, with the aim of making everyone feel more comfortable and psychologically safe when sharing their experiences.

The sessions also allowed us to discuss the main themes and questions of the engagement sessions and the group agreement beforehand, allowing more time in the engagement sessions for collaborative discussion.

The commissioning team expressed an interest in joining 2 engagement sessions with the understanding and agreement that if one EbE would be uncomfortable with this, we would not go ahead with the idea. We shared this within the pre-meets and discussed if people would be comfortable with having an observer from the Boehringer team join. EbEs were pleased that the commissioners were taking such an interest in what they had to say, and no negative concerns were shared. Therefore, a member of the team was invited to join 2 sessions where they introduced themselves to the group and then kept their camera off to observe.

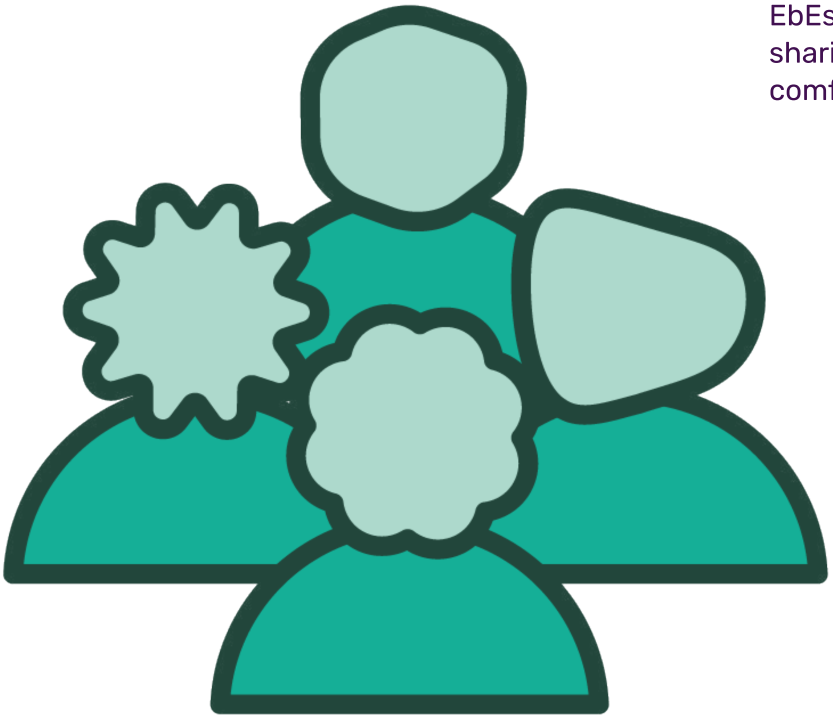
The pre-meet sessions were undertaken successfully, and no safeguarding concerns were raised.

Group Engagement Sessions

We were able to engage with more than the anticipated 32 people. From 60+ people who expressed an interest we managed to select and engage with 46 people from across England. We engaged with 20 people with direct lived experience of schizophrenia and 26 family members, friends and carers. Further information about the EbEs can be found in the EbE information subsection below. The four groups had 2 engagement sessions each, which were held online using Microsoft Teams.

Prior to the sessions, we shared a Readiness and Signposting document and a Consent Form for each participant to read through and sign. This ensured understanding of wider resources available for support if they felt this would be helpful as well as fully informed consent ahead of the sessions. The group engagement sessions were undertaken successfully, and no safeguarding concerns were raised.

We also held 1:1s for people who mentioned not feeling comfortable in a group setting and/or who didn't have availability due to other commitments on the date of the engagement sessions.



1:1 Engagement Sessions

To enable accessibility and psychological safety, we also offered the option of 1:1 engagement meetings via video call or phone call during the recruitment introduction calls. We also asked EbEs if they preferred this to be over Microsoft Teams, Zoom or phone call, depending on what format they most felt comfortable with.

If social anxiety, privacy or availability was expressed as a barrier, we would offer the option of responding to the engagement questions via Microsoft Forms with streamlined questions as opposed to verbally sharing in a group or 1:1 meeting. We decided to add this engagement option in order to respond to hesitation that was expressed with some of the EbEs whilst ensuring the option to not engage was also explained so not to put pressure on any individual person. We also offered additional 1:1 calls to EbEs who raised further topics and were more comfortable sharing outside of the group sessions.

In total, we held a 1:1 engagement meeting with 22 EbEs, (inclusive of the 3 formats: video call, phone call, written form).

This flexibility ensured we met the needs of the EbEs and allowed psychological safety when sharing experiences and engaging in the project comfortably.

Debrief Sessions

We also provided 2 online debrief sessions after co-production sessions and 4 after the group engagement sessions totalling 6 debriefs altogether. This allowed EbEs to share anything additional that they felt was relevant and that they didn't manage to mention at the group sessions. The debrief space also allowed for checking in on everyone to see how the groups were feeling after discussing and sharing personal experiences about sensitive topics in the sessions.

We were able to use this opportunity to provide useful signposting and resources as required and remind the group of the resources we shared at the beginning of the project.

The debrief sessions were undertaken successfully. People involved in sessions were reminded of the payment offer and process. No safeguarding concerns were raised.

Note-taking

We had a note-taker during each session. Notes were written up with the person's "code" and their comments, as close to verbatim as possible. Any identifying information was anonymised. Explicit consent was gathered for all special category data that people share, e.g. ,diagnoses, race and is held securely. Any special category data provided in this report is fully anonymised so as not to identify anyone.

Notes were then cross-checked for anonymisation when inputting into the report, ensuring that people involved cannot be identified.

Feedback loop

After the sessions, we followed up with all the EbEs who were involved in the engagement phase and sent a thank you for their participation via email. Throughout the process, we offered the opportunity for people to reach out to us between sessions in case there was anything further they wanted to share. Several people provided additional information to be included in the report via email. We shared the draft report with the co-production group for comment prior to its finalisation. Throughout the project we said to EbEs that we hoped the report would be influential in supporting positive changes to the mental health system.

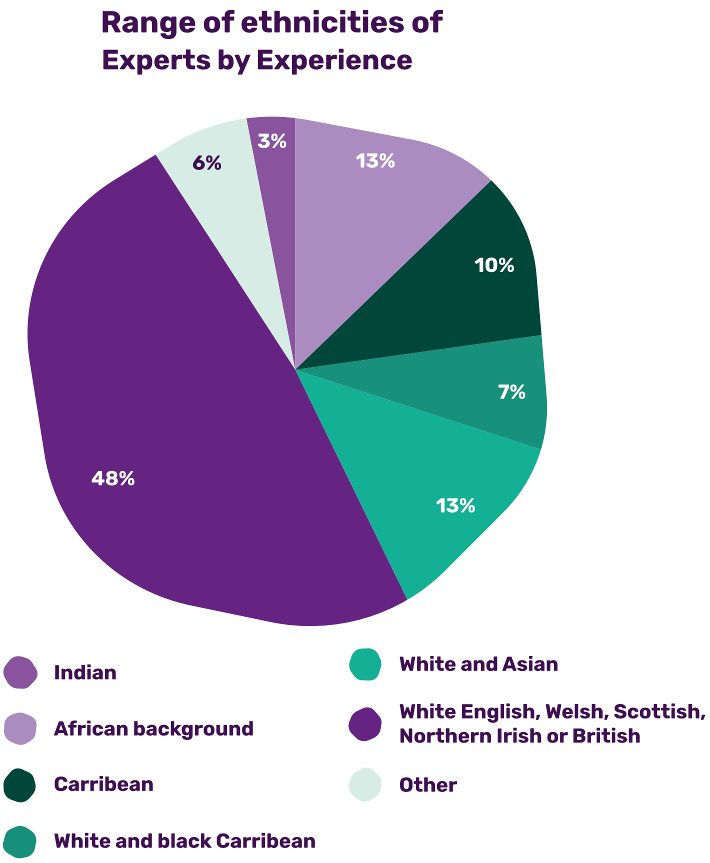
Compliance

All communications and assets that were developed for the project, such as the desk review document, digital communications and information sheets, were certified by Boehringer Ingelheim to be compliant with the Association of the British Pharmaceutical Industry (ABPI) guidelines. They also all carried a mutually-developed disclaimer which emphasised the independence of the relationship between Boehringer Ingelheim and Rethink Mental Illness. EbEs were made aware of this throughout the project and there were no concerns raised.

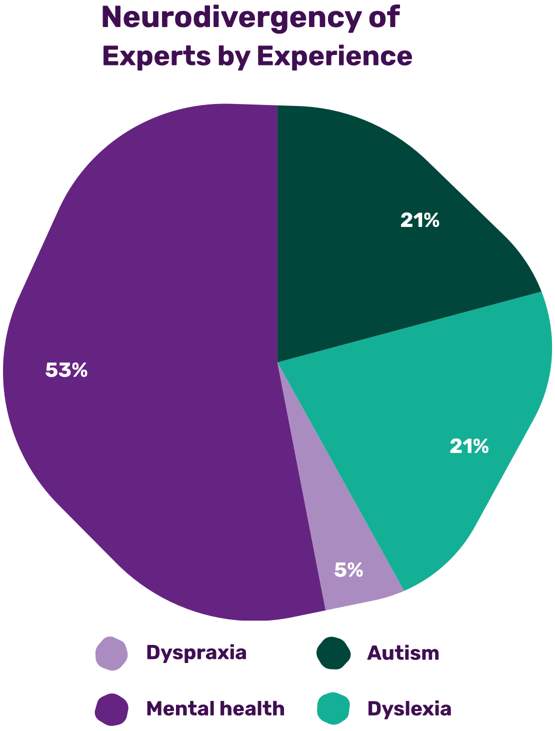
Expert by Experience information

We received Equality and Diversity monitoring forms back from 32 EbEs of the 46 involved in the project. We ask people to complete these forms to help us monitor how diverse we in our engagement projects. These forms are not mandatory. Therefore, the below is not a full picture of the demographic data for those involved.

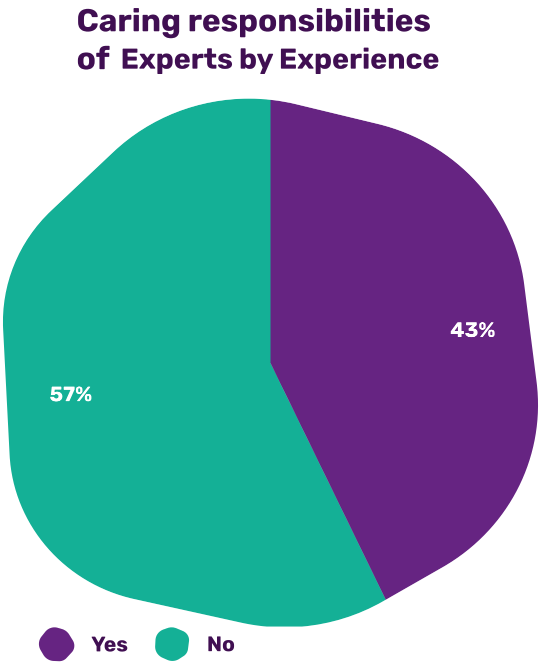
Range of ethnicities of Experts by Experience



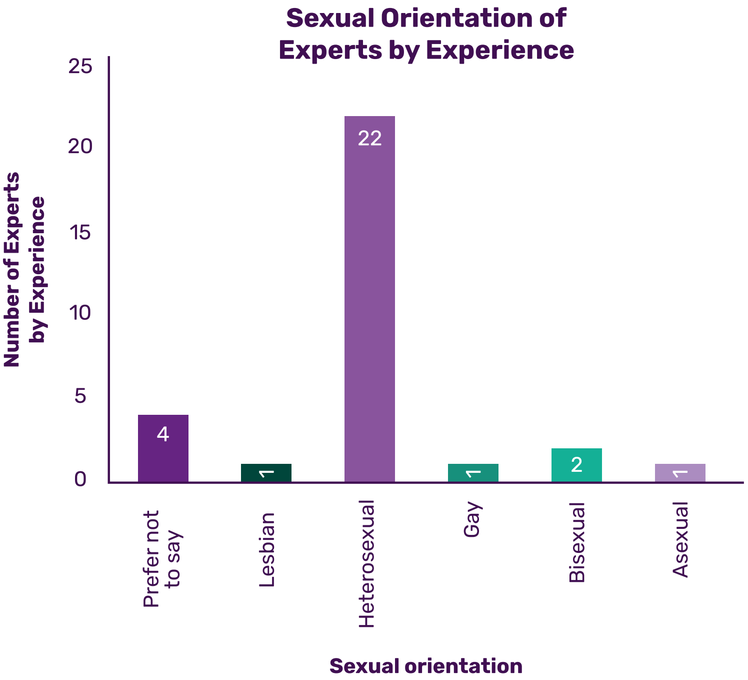
Neurodivergency of Experts by Experience



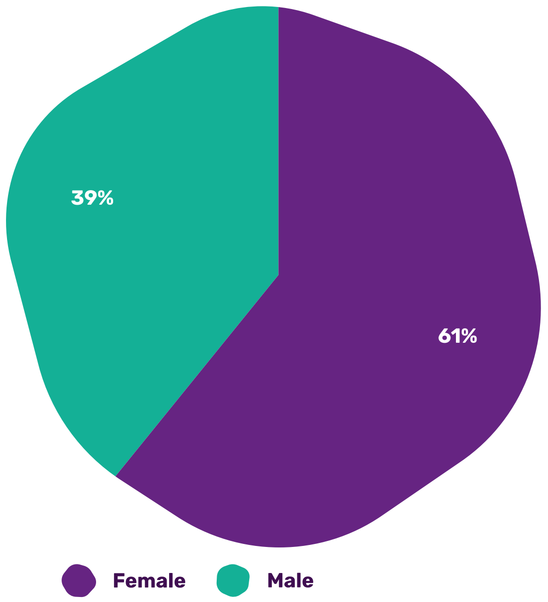
Caring responsibilities of Experts by Experience



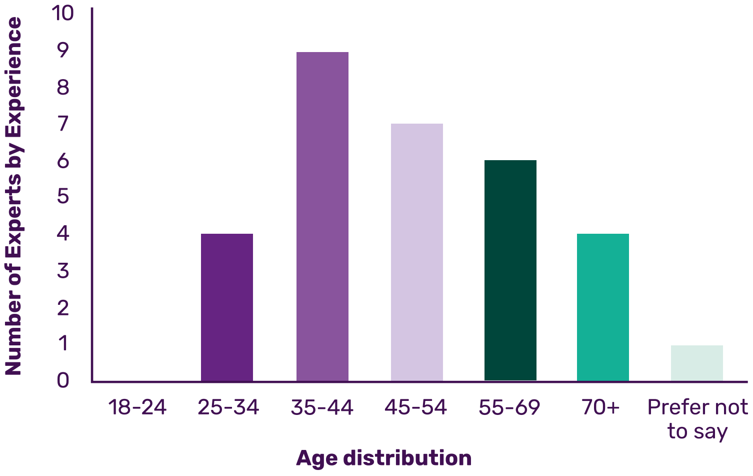
Sexual Orientation of Experts by Experience



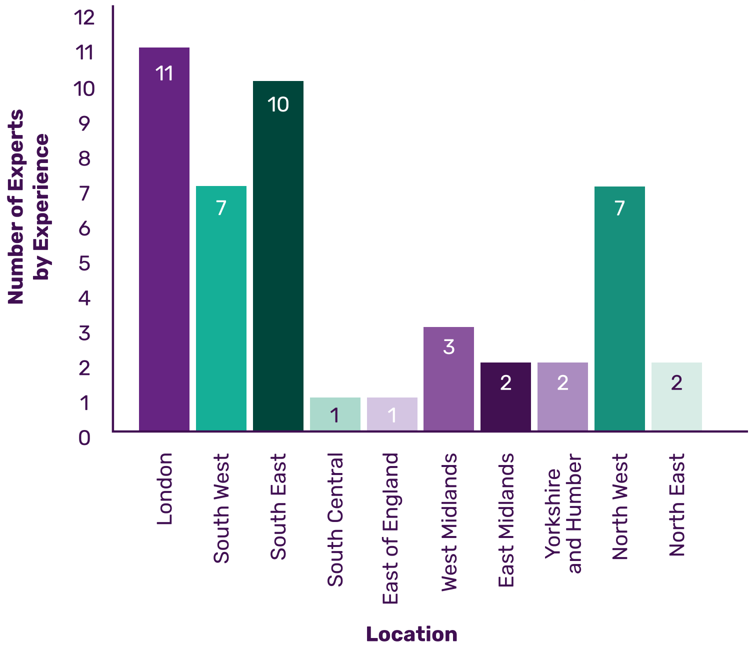
Gender distributions of Experts by Experience



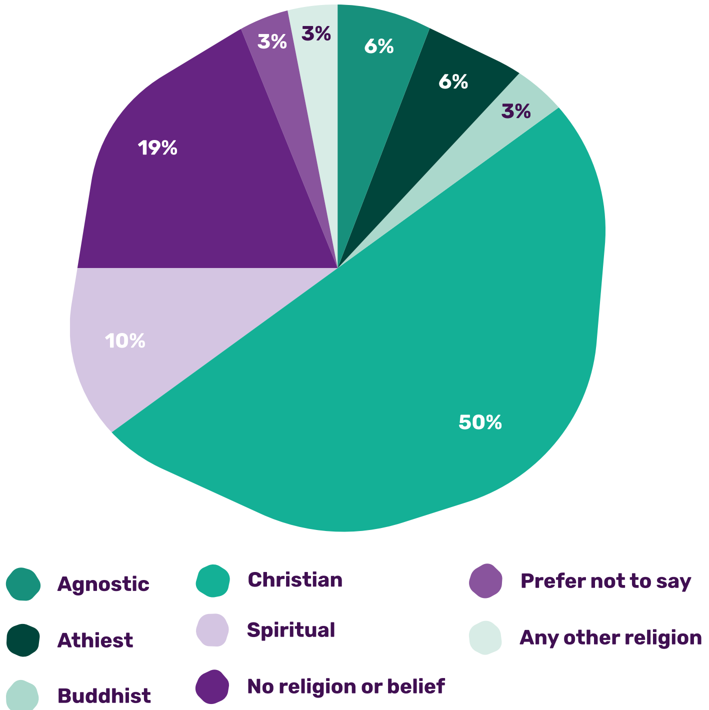
Age distribution of Experts by Experience



Geographical location of Experts by Experience across England



Religious beliefs of Experts by Experience



We recieved forms back from 32 EbEs of the 46 involved in the project.

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Key themes

Quality of life

During both the group and individual sessions, we asked people what helps and doesn't help achieve and maintain wellbeing. Here we have broken down people's responses into sections ranging from having hope through to crisis support when things can seem hopeless. Other aspects of wellbeing are described under other themes later in the report. One thing that was very clear was that people felt that simply addressing symptoms, particularly positive symptoms, was not enough. Instead, people wanted to move 'beyond stable' and live a good quality of life.

Hope

'Hope…our story is one of hope' said one of the EbEs, as they told us about the recovery of their loved one. People gave us lots of examples of ways in which hope is developed and held – often by families, carers and friends when the person themselves feels hopeless:

"Having supportive people around them and access to wellbeing activities."

"Good family or friends so don't feel on their own at all."

"People that are interested and care and have empathy help."

"Rethink workers didn't tell my sister what to do. They empowered and enabled her to make her own decisions, so long as she is able to, which my sister was."

Similarly, people told us that having a routine was an important aspect of achieving and maintaining wellbeing and retaining a sense of hopefulness:

"Routine is really important. That would help."

"Making small steps like personal hygiene and laundry helps with daily life."

"Be able to see family, friends throughout occasions and day-to-day life."

"Have a cup of tea, share food, be able to share the good and the bad."

> “Listening to people who made good recoveries, gave me hope.”

Experiences of symptoms

People told us of the experiences they had – or their loved one had – related to their symptoms, some of which were very distressing and debilitating. Here we divide symptoms into commonly described categories as described in the 'What is Schizophrenia?' section, although many people told us that symptoms overlapped and often couldn't be described in such reductive ways. Indeed, for some people, such categorisation was meaningless and, in particular, the category of 'cognitive symptoms' was a new concept, although they were able to describe symptoms ascribed to this category very vividly. Here we present just a small sample of the ways in which people described their experiences.

Positive symptoms

"He has lots of auditory hallucinations. He will suddenly laugh out loud."

"[He is] Listening to more things in head than listening to you."

"[He] Thought he wrote all Bob Marley CDs and had to reason with him."

"He cut a tree down in the garden so he has an exit route and he had large amounts of money, in cash, in his bedroom."

"For a long time he would look behind him, and you'd ask him what he was looking at, and he said he could see something behind him."

"I used to take tablets but [was] worried about being poisoned. After my last stay in hospital, I agreed to have a monthly depot – still paranoid about getting poisoned and my mind being controlled."

> "He's not able to talk about symptoms – sometimes he can't tell the difference between reality and his hallucinations. There's a debate – whether meds have induced symptoms, difficult to tell."

Negative symptoms

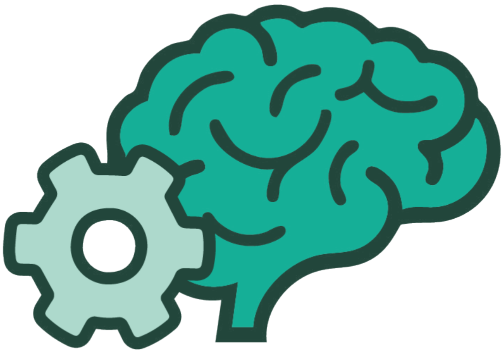
We heard a lot about the lack of motivation: "Tiredness, lack of motivation taps self-confidence." "Lacks motivation. Quite fit generally." **and people told us of the impact of negative symptoms on their everyday life:**

"In my case – I struggle to get out of bed in the morning. I have no motivation at all. I feel like the difficulties I have in my life at the moment are completely inescapable."

"It's difficult to motivate myself, I'm not very sociable especially with autism. Partly negative symptoms. Don't really get voices on depot. Not so delusional."

"He won't wash his clothes or brush his teeth. This could be a symptom of schizophrenia, but this will hold him back."

For some people it was a combination of different types of symptoms that were causing difficulties: "Not being able to do things when you should either because of symptoms such as auditory hallucinations or lack of motivation and anxiety." "If not well, just shuts himself off and too miserable to do anything."



Cognitive symptoms

This is what we heard when we explained and asked about symptoms relating to cognition, e.g. concentration, memory, problem solving and difficulties with thinking:

"[He]…can't understand many things and do many things."

"Poor concentration, can't watch a film or football match."

"Trouble following conversations or completing tasks at work."

"It affects concentration, focus and memory, and makes it difficult to retain information."

"[After reading a book] He wouldn't be able to tell me what it's about or remember details."

"Concentration and memory affect me most. It's a short-term memory loss; I can't remember what I'm doing, which is difficult."

"He could not focus on anything anyone was saying. He would sit there, and his nurse would come around, and as soon as she got through the door, he would ask 'can we go now… I need to go…' and often he would just leave."

However, for one person, it was unclear whether such symptoms were related to medication: "Slowing down of thinking is associated with most medication, and it does leave you feeling like a zombie."

Clearly, cognitive symptoms are very debilitating and for many people have a significant effect on their wellbeing. When explored further, people recognised that these symptoms were more prominent than they had previously thought and affected their ability to lead a good quality of life.

Experience of medication

'Licensed medications have demonstrated benefits for appropriate patients, as well as having side effects. It is important that these are communicated and monitored by HCPs. The decision to use a particular medication should be made by a HCP, along with the patient and/or carer.'

Medication was mentioned in every session and by almost everyone we spoke to individually, including benefits and drawbacks and the overall role it plays in someone's recovery. These are some of the positive things we heard:

"I'm quite lucky event though I'm demotivated and fatigued, even though I'm pretty stable on my medication. It's helped to really cut down my delusions and positive symptoms."

"Finding the right [medication] can make all the difference. Doctors giving the right medication to the right patients makes a big difference because it might be the difference between the patient having more or less energy to complete tasks."

For other people, there were problems associated with medication, which are described in more detail below:

"Over time we have had a lot of changes in medication, it seems to be trial and error, but can't prove anything, I was anticipating medication having a much stronger effect."

We also heard that medication was only part of what was necessary: "I feel like professionals see the goal as not having psychotic symptoms, but there are other things in my life affected by having schizophrenia and it would have been useful to have support to build my life up again."

The important role that professionals – and good communication – play in supporting people with their medication was described by one person:

"How were changes in medication communicated? Until recently, there wasn't much of a duty for mental health professionals to go into detail with people about medication. There wasn't much need or impetus to explain to service user the medication, side effects, etc. Although recently she spoke to a psychiatrist who did explain everything, what this medication is and what it does. My sister actually wanted to up her dose. But the psychiatrist didn't think this was a good idea and she could clearly explain why."

Someone summarised the importance of good communication by saying: "Active listening; explain why a certain medication was suggested whilst another choice was not recommended."

The impact of medication management – among other things – on the lives of families and carers was described in detail by the parent of someone:

"My wife and I…, there are certain things we have to do. We can't really go away, medication is significant because it includes managing dosages of things….We are constantly going to the mental health team and making sure medication is right and counselling is in place. Once that is finished it will just be psychiatry. He should be given a support worker. It has influenced us a lot in our lives, but we are educated people so we can push the right buttons to get the right support."

Active listening; explain why a certain medication was suggested whilst another choice was not recommended.

Medication side effects

There was much discussion about medication and its side effects, which are described here as well as in the Physical Health section below:

“I think more research should go into the medication and the side effects.”

“...feeling like a zombie due to medication effects.”

“With my medication, it has led to weight gain and more physical symptoms. This impact on my physical health doesn’t make me feel better.”

“Meds can cause side effects, make them put on weight, more susceptible to diabetes, can make them drowsy which can impact on things.”

“My son is in his sexual prime, and the medication means that he can’t ejaculate, so that’s why he doesn’t want to take the drugs.”

“He has been putting on weight because of the medication, and that is a cycle – it can stop people wanting to go out.”

> “Medication dulls emotions and stops me writing poetry.”

“With [my son], he sometimes had adverse reactions to the drugs, he was jittery and not feeling well, which isn’t good. If they have a good relationship with a CPN [Community Psychiatric Nurse], that can really help.”

“Quite a lot because of the medications I take for my mental health, it’s really important to manage the side effects which affect your physical health like for diabetes and cholesterol (which you don’t really appreciate before you start taking them).”

Some side effects were very upsetting in other ways: “The antipsychotics had side effects which caused him to wet himself in the night.” **While their effects on day-to-day life were also mentioned:** “People with mental health problems are seen as lazy or not pulling their own weight when they can’t manage tasks due to the sedative effects of medication.” **As another person told us:** ”My meds make me put on a lot of weight which gives me physical health problems... I find it difficult to leave the house so can’t exercise properly, so a bit of a snowball really.”

> “With the treatment for schizophrenia comes a lot of unwanted side effects, physical and mental.”

Relationships

We heard a lot about the importance of relationships for achieving and maintaining wellbeing and to someone's overall quality of life. People spoke about a variety of relationships and one person summed up their importance by saying: "Any encouragement to stay positive from family and professionals helps."

Families, carers and friends

"Having family members who understand the diagnosis makes a difference."

"Supportive family, particularly when things are quite acute."

"It's important to have someone who recognises when things aren't going well."

"For family and friends, it's really about having people there – I'm married, but I don't expect my husband to understand everything."

However, one person pointed out some potential pitfalls: "Friends gave another avenue for him to take his mind off his issues. The trouble is they are the people he would get off his face with."

Professional relationships and continuity of care

There was a lot of discussion about the importance of trusting relationships with professionals and care teams in general, which impacted on continuity of care:

"For professionals: not being one-track focused, not having only conversations about mental health. Also talking about your interests, goals, and other things in life."

"Stop changing doctors every few months. We need long-term relationships with care teams."

"Being listened to – my current psychiatrist is the first that really listens. In the past, I'd have short appointments, and the psychiatrist was only interested in meds. Currently, they're concerned about my general wellbeing, and I get the full half hour with them (previously only 10-15 mins or so)."

"My brother has paranoid schizophrenia. He has trust issues with himself and others – he sometimes doesn't trust his own judgement and that of others. The way the system is set up, e.g., staff changeovers, doesn't help the above issue with trust. He might start to trust someone, and then they leave."

"Early intervention teams in psychosis can be very well resourced – it's called a family safeguarding model. There's a multidisciplinary team and appropriate interventions. Treating the person holistically. That's what's needed. But systemically, that's not in place."

"I think, you know, holistic support and considering what people need. Open dialogue focusing on the person and the people around them. What's best for someone, whether that be therapy, social prescribing, or other things."

"Care in the community: A fully resourced team around them that can effectively intervene when they are unwell. Currently, what's happening is not that."

People especially talked even more specifically about the importance of continuity of care:

"You need a consistent person who knows the person and can check in regularly."

"Continuity of care is a massive one because when someone is very unwell, having a change of team multiple times is really crap for their recovery. It's totally disruptive."

"Sister used to have support that checked in 3 times a day, checking meds and wellbeing, but this has trailed off and now there is no one checking in."

"If I am being positively supported, say by a CPN, then when that stops, things break down—so I need constant support. With the support, any opportunities have better outcomes."

Feeling safe

During both the group and individual sessions, we asked people what helps them to feel safe. We heard a lot about this in terms of both care teams providing support as well as the importance of other support from organisations. We heard frequently that 'safety planning' and having a physically safe space in which to live were of utmost importance:

"People need a safety plan, they need good insight into what they feel like when they are unwell. But you ask it when they are well."

"They need to have advance choice documents – where they say what types of meds they want and don't want, and who they want in their care."

To maintain someone's safety people said that:

"How people are discharged should include 13 weeks of post-discharge support in the community."

"Wraparound support is needed so people can live in their home, not a hospital bed."

"I think they need good housing in a safe space. So often, my experience is, once the social worker gets them housing, the box is ticked. It could be a very unsafe area, but it doesn't matter they see the box as ticked."

Someone's family member said that feeling safe meant: "Not going out, making sure he is comfortable, it's about respecting his view and not forcing him to do something. If he doesn't want to do something, we can't bang on about it. He needs a space where he is warm, well fed, not feeling possessed."

"In many ways, it's not moving him on [from parents' house] though not sure if that is the right thing either, I think we need baby steps in terms of psychology. Really small steps."

"Again a safe area. They can go to church it's wonderful, but if they don't believe there's no point. I wish there was something secular to replace the church. Going to church on Sundays was great for community."

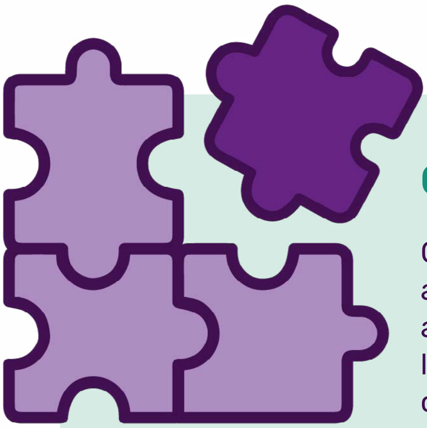
We also heard about the importance of support from outside agencies to help people feel safe:

"My sister was really well empowered by Rethink – she was supported and felt she was in a safe space – she didn't feel like she'd be laughed at. My sister was quite ill but also quite intelligent so she liked to feel respected and empowered."

"Rethink is all I can talk to, I haven't engaged with others (charities / groups about schizophrenia) but if there are others, please let me know."

"They help you access services you didn't know existed like the Listening Space, which I didn't know about before. They do really practical things, like have a hot meal. I was struggling to make tea, because of a thought I had about hot water, and they helped me make tea which was really valuable for me."

The importance of good crisis support in order to feel safe and held was mentioned by several people, as described in the Mental Health Services section.



Considerations for Policy and Practice

Care and support must move beyond simply managing symptoms and supporting people to remain ‘stable’, towards a more ambitious, person-centred approach that emphasises quality of life. For symptoms that are more difficult to control, such as many cognitive symptoms, this is crucial to supporting people to live the best possible life.

This approach is defined as one that enables people to feel safe, understood and empowered on their recovery journey. It is enabled by things like continuity of care and clear, two-way communication and trusting relationships with professionals. Recruitment and retention of the right workforce is fundamental to achieving all of these things. **The government’s planned revision of the NHS Long-Term Workforce Plan is an opportunity to review and plan what roles are needed to address gaps in the mental health workforce and improve recruitment and retention.**

Participants in this project highlighted a range of professionals that had made a difference in their lives and treatment – from psychiatrists to community psychiatric nurses – but not all of these were in the NHS. VCFSE services and those in the social care sector also have a role to play, but **a long-term and sustainable funding solution and plan for mental health social care is needed to ensure the stability of these sectors.**

Another way quality of life can be achieved is through expanding people’s access to the right treatments. Our findings demonstrate that people with schizophrenia and their families generally recognise the benefits of medication in managing symptoms and preventing declining mental health, but medications can also have a debilitating effect on day-to-day life, and can contribute towards poor physical health.

Mental health clinical research is needed to increase the range of effective treatments available to those living with schizophrenia, both in terms of medication, and other help such as psychological therapies. This requires **equitable funding and addressing historical underinvestment in mental health clinical research, and overcoming barriers such as poor recruitment onto clinical trials and lack of clinician capacity to engage in research, to create a culture of research and innovation within the NHS.**

Identity and intersectionality

We asked people about the impact of different aspects of their identity and how these interacted with their experiences – and especially where there were 'intersections' of different identities.

These are some of the things that we heard:

Age

Two quotes really stood out about the impact of age – one from an older person:

"I've lost so much because of my illness and have been discriminated against because of my illness."

Another about a younger person: "He's conscious that he's in his twenties and a young person who should still have opportunities."

Gender

The impact of gender came across in some group and individual discussions:

"Black men far more likely to be diagnosed with schizophrenia than other ethnic groups. Also underlying and implicit racism."

"Gender, from an Indian context, intertwined with age and upbringing also impacts how open to help people are."

"Taboo – him as a male talking about loneliness and voicing this."

One person told us about the potential effects of expressing emotions for men: "I have often wondered if my brother being male and the stigma around expressing emotions has had an impact on his lived experience. He was acutely distressed before his first episode at university - and I wonder how it might have been different if he had peers he could open up to emotionally."

Another person told us about the joint challenges of gender and living with severe mental illness: "It's difficult, it's so hard. It doesn't help you stay well. If you are different gender, two things to battle with severe mental illness and your gender, if people are aware of that, you're living life of misery. You want to be accepted as you are, it's hell, if you're in the minority, it piles on the challenge."

> "Women in particular are vulnerable to abuse and financial abuse."

Issues that are rarely spoken about by care teams were also raised in some individual discussions:

"Menopause and mental health – I haven't been talking about this in the groups because we are a mixed-gendered group… whenever I have spoken to psychiatrists about it, they don't want to talk about it… it's really hard to get a discussion with anyone about it."

Neurodiversity

We heard from many people about the difficulties associated with being neurodivergent as well as living with schizophrenia:

"Dealing with both schizophrenia and autism makes social situations harder."

"He has ADHD and dyslexia." "He had ADHD and there was always a question about whether he was autistic or not, he has some autistic traits."

"He's living independently. He does get anxious and has suspected OCD but he is good and such a caring and understanding person, because of what he's been through."

One person told us about the importance of receiving a diagnosis of autism:

"I got a diagnosis of autism at 28, quite down the line, but getting the diagnosis resulted in people changing how they speak to me, which was useful as it meant I was less likely to walk out on people in sessions. The diagnosis meant I was seeing consultants rather than registrars when I was getting support. I was seen more complex. It helped me explain things to my husband, to explain why certain things were not improving yet."

However, another person explained the difficulties with diagnosis: "It shows that a number of people have dual diagnoses. They could have ADHD, autism, other forms of neurodivergence. Not everything is always picked up. Features could mask other disorders. It's very complex and is difficult for mental health practitioners to know what someone should be diagnosed with."

> "Mental health is often denied or misunderstood in certain communities."

Ethnicity and Culture

We heard about the different community-based and cultural understandings of mental health:

"My wife comes from a different ethnic group, where there is far less understanding of mental health."

"In my culture, doctors will ask about physical history but not mental history. So we need to normalise at this point talking about the mental side of things."

As well as hearing about the specific experiences of racially minoritised groups of people:

"He's mixed race, his dad is Jamaican heritage, that's had a big impact on his lived experience…"

> "African Caribbean people more likely to be diagnosed. We need some sort of commission or investigation into why this is. We need to know what's happening in society to affect Afro Caribbean people."

'"Her condition went a lot of time untreated. Being in an African Caribbean household, it was seen as a taboo. It was perceived as very negative in our household. In addition to people knowing about my older brother who is autistic."

We also heard about generational differences relating to culture: "I think it's quite generational for my mum to not want to listen to difficult stories." as well as the impact of culture on stigma: "Culture impacts levels of perceived versus actual stigmatization from society; the journey of acceptance as a family, extended family and friends which then impacts how families respond and pick approaches to address the diagnosis."

Some people told us about the 'racist' nature of their symptoms and also the impact of racism on being able to stay well:

"With my son, his identity impacts him. He experienced a lot of racism from school days and he experienced during his last visit to hospital. When he hears voices, he hears racist taunts."

"My sister had a breakdown and there was racism in her psychotic episode. It was all about people coming after her because of her race. When she hears the voices, she says there are racist elements in there."

"Following on from my point above, unfortunately my son's experience with racism in person and online (as many of us experience) will impact his ability to stay well. He is likely to not move on from the trauma of racism and the racist voices he hears."

For some people, there were concerns relating to the mental health system and the police:

"I had the ongoing worry of how my brother would be treated in the mental health system as a Black man both in crisis care and perception he may be a threat to society. I don't want my brother to do a step out of line because of how services might respond and how quickly things could escalate. He's more vulnerable to drugs and many things that can make things so much worse. He's exposed to police and I worry about all the preconceptions. I want to say to him stay still, don't make things worse."

"Race impacts everything. Black men are four or five times more likely to be detained under the Mental Health Act. Race and intersectionality affects everything. It's difficult isn't it. There is no effective intervention going on. Living with that trauma…affects everything like recovery. It fundamentally affects your living experience."

> "Race impacts everything. Black men are four or five times more likely to be detained under the Mental Health Act."

Combination of Identities

Several people told us about the impact of having a combination of identities, such as the intersection between race and religion:

"I'm a Christian and I'm Black. These two identity things – it's quite taboo in both these communities to talk about mental health."

"I'm mixed race and having family from different religious and ethnic backgrounds, like kind of means they understand your mental health in very different ways. For me, it's like the outside understanding like my white family's understanding, my Asian family's understanding. There's lots of different levels to it."

Another person had experienced homophobia in addition: "Was attacked in hospital because of my faith and beliefs. When you are recovering you can be stigmatised by fellow mental health patients due to stigma and phobia. Xenophobia and homophobia happens in the hospitals."

There were some perspectives from families and carers, and in particular siblings, that resonated with the notion of identity:

"Siblings are often othered if they are a carer for a person with a mental health diagnosis."

"There's also an issue with being the 'well' sibling. My brother is the unwell one. So there is pressure on me to always be well and healthy. I struggle to take days off work as a form of over-compensation. I need to always be fine."

"It's hard to know how much of this is my authentic brother as he's always been really stubborn. But then I ask how much of this is the medication?"

And others said: "We [as a family] have a resistance to asking for help, for example if you hurt your leg, we might just hobble about instead of asking for help." "My mum has found him a careers coach, but he doesn't want to do it because my mum found it."

The impact of identity on self-worth was described by someone who said:

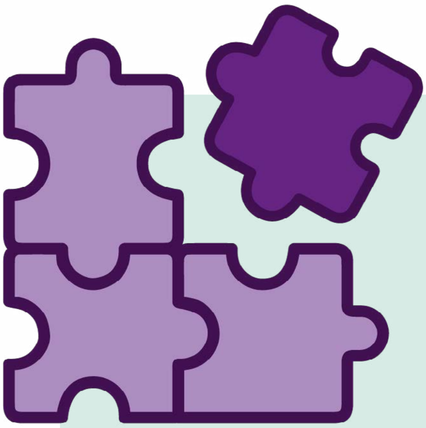
"They have a loss of self-worth as they don't feel like a full person. They feel like just a part of their former self."

For others it was intertwined with religion: "On the faith side, we are not a religious family, but my brother has a strong relationship with religion – I think as a way to help him understand what feels like, and can be, unexplainable."

For someone else it related to their sexuality: "I'm gay and for my entire life I've struggled to come to terms with this. Had massive detrimental effect on my mental health. Put myself into perspective and I look after myself better now. I think we need to celebrate our diversity."

For another person, a loss of identity led to being unwell: "Identity was important for my sister – trying to be an educated, professional lady making her way in the world – and she couldn't be this. She subscribed to the system and how you are meant to be as opposed to making her own choices about what her identity actually was. This sense of failure made her ill."

> “I'm a Christian and I'm Black. These two identity things – it's quite taboo in both these communities to talk about mental health.”



Considerations for Policy and Practice

These findings demonstrate the very significant role that race can play in a person's mental health, how that is managed within their existing support networks, and the diagnosis, treatment and support they receive from particular services. The need for cultural competency among professionals is clear – to ensure that identities and the potential impacts these can have are recognised, understood and appreciated.

To deliver this, **NHS England's Patient and Carer Race Equality Framework and Black Mental Health Manifesto should be implemented by all providers, with related training introduced relating to the former to ensure fair, equitable and unbiased treatment and support.**

Steps must additionally be taken, including through the current reform of the Mental Health Act, to address the disproportionate diagnosis and detention of racially minoritised communities.

The government should also consider what actions could be taken to ensure timely, inclusive and non-discriminatory care for all people. **Actions could include reinstating the previous LGBT+ Action Plan, which included steps to improve healthcare for LGBT+ people and improve awareness of LGBT+ issues and identities to improve patient care.**

More broadly, training around the Equality Act would help to ensure that professionals consider peoples' needs and preferences as relates to their age, gender, culture, religion, neurodiversity, and the relationship between these, and provide opportunities for people to express these, acknowledging the difficulties people may have in doing so.

Family and Carer Involvement

In addition to the importance of the relationships that people have with their families, carers and friends described under the Quality of life section, we heard many other accounts of the role of family and carer involvement:

> “Carers act as intermediaries between their loved ones and professionals.”

and “I have had to be an advocate and voice for my family member when they are in crisis.”

We also heard how greater involvement would be beneficial:

“Carers should be included in care planning because we know our loved ones best.”

We also heard about the challenges that come with supporting loved ones:

“I felt comfortable accessing support much much later after my brother’s diagnosis. At the start of this journey, I did not feel comfortable enough to challenge doctors, to question the system. We should be empowered to do all this stuff to access support right from the start.”

And from someone else: “We had no support for years and had to figure everything out ourselves.” “When my son went into crisis, there was no plan to support us.” “Nobody seems to understand what you’re going through and that you’re doing your best.”

The enormous burden and emotional toll on families and carers came across loud and clear:

“Staff have called me to comfort my family member when they are in hospital, which makes me feel guilty.”

“…there is pressure on me to always be well and healthy. I struggle to take days off work as a form of over-compensation. I need to always be fine.”

“I feel the responsibility to keep my sister in a well enough space. It often feels burdensome. I have a couple of health conditions of my own”

“Navigating benefits and housing for my loved one is exhausting and financially draining.”

“If you’re working full time, as a carer I don’t know how you’re supposed to find the time to do this.”

“Provide respite care and training for carers. We’re exhausted and need support too.”

“Carers often feel undervalued and judged by society.”

“Carer-specific resources, like helplines and forums, would make a huge difference.”

“Siblings are often othered if they are a carer for a person with a mental health diagnosis.”

"From a carer point of view, myself and my family feel guilty doing things for ourself as we know our brother is not able to do these things and enjoy them in the same way."

"That contact needs to be there. I was there as much as I could. I told my sister I wouldn't be able to be a carer and also do my full-time job. I couldn't give the support I wanted to give and what my sister wanted to receive."

"At times for me, and my own quality of life, it would be better if I didn't have a sibling with this illness and having to think about the things that I do."

"Sometimes they don't want to see me as a carer and I don't want to be a carer. Especially now my own health is failing, they are taking care of me."

"You are dismissed as a carer. That's changing because people are starting to realise how important we are. But a lot of the time when you go to carers groups, you hear how carers were ignored and then the mentally ill person has gone on to take their lives. Going from a headteacher at a massive secondary school and then going to meetings were I'm barely listened to was a massive shock."

"As carers, we haven't been supported by the system at all. You do feel let down as a family member for multiple reasons. The main one being the disjointed ways of working going on."

"Feels that support falls to the carers. Discussed the desire to have paid days allocated off work for carer responsibilities – employers are not necessarily supportive of caring responsibilities and in turn this has an impact on the carers own health. Feels like the system 'hopes love is enough' to support someone living with illness but states clearly 'we need time and support' to undertake the responsibilities and feels the system uses the carers community."

"As carers, we haven't been supported by the system at all. You do feel let down as a family member for multiple reasons. The main one being the disjointed ways of working going on."

Relationships

"Good family or friends so don't feel on their own at all."

"To have someone, even a professional, to open up to and have a good relationship with" is how one person put the importance of relationships to someone's wellbeing. Another person told us: "For my family and friends, it's about wanting to understand a little bit – I don't expect them to understand but trying to, makes a difference. The people who offered me peer support have a dad's group and my husband goes to that dad's group, and although nothing miracle-working happened, it was valuable because I knew he cared and was learning more."

Similarly, for someone else: "For family and friends, it's really about having people there – I'm married but I don't expect my husband to understand everything. I have a daughter so making sure she gets to school and other places on hard days really helps. It is also important to make sure I'm not just relying on a few people, but having a full network to rely on."

Some people movingly told us of the strain that can be put on relationships, with one person saying: "The stigma affects our family relationships. My son's sister has been traumatised by the situation." **For another person:** "Lack of support networks, lack of family systems – this can often be, in my experience, in both camps, there are real patterns around broken relationships with families because of the detainment process." **Furthermore, for someone else:** "Using my own experience, our home environment isn't the best for him, there are tensions between my parents and the family is a trigger for my brother."

Being a loved one

We heard a lot about the impact on families, carers and friends: "As carers, we haven't been supported by the system at all. You do feel let down as a family member for multiple reasons. The main one being the disjointed ways of working going on." **One person told us:** "Carers often feel undervalued and judged by society." **While another person said:** "Nobody seems to understand what you're going through and that you're doing your best."

"There's also an issue with being the 'well' sibling. My brother is the unwell one. So there is pressure on me to always be well and healthy. I struggle to take days off work as a form of over-compensation. I need to always be fine" was how one person put it across to us.

Other comments included:

"I feel the responsibility to keep my sister in a well enough space. It often feels burdensome. I have a couple of health conditions of my own."

"Navigating benefits and housing for my loved one is exhausting and financially draining."

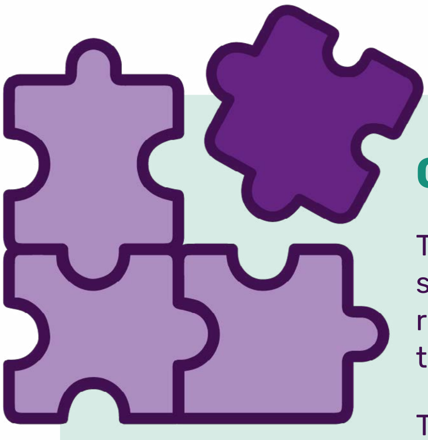
"If you're working full time, as a carer I don't know how you're supposed to find the time to do this"

"Provide respite care and training for carers. We're exhausted and need support too."

One person asked for: "Carer-specific resources, like helplines and forums, would make a huge difference." **while another movingly said:** "How do you get people to prioritise maintaining good wellbeing? **From carer point of view, myself and my family feel guilty doing things for ourself as we know our brother is not able to do these things and enjoy them in the same way." For another person:** "At times for me, and my own quality of life, it would be better if I didn't have a sibling with this illness and having to think about the things that I do."

> "Carers often feel undervalued and judged by society."

> "Carer-specific resources, like helplines and forums, would make a huge difference."



Considerations for Policy and Practice

To truly support carers and families of those living with schizophrenia, it is vital that across the system carers are recognised, included in care planning and properly supported in their own right.

These findings make it clear that carers have a vital role to play in care planning – they are often the person or people with the best understanding of the person and their needs. They must be enabled and empowered to be part of care from the very start of that journey. **The current reform of the Mental Health Act offers an opportunity to enshrine this in legislation.**

Guidance must make clear that carers should be formally involved at every stage when their loved one has consent for this. This is particularly relevant in the context of Advance Choice Documents, which allow patients to provide information about what they would like to happen with their care and treatment should they become unwell.

Whilst carers make clear that they want to support their loved ones and be involved in their care – they can struggle under the weight of the responsibility that comes with being a carer, and the expectations they face around this from professionals and society more broadly. Carers, families and loved ones of those living with schizophrenia need support in their own right. **Sufficient long-term funding is needed for mental health social care to provide carer-specific resources such as training, helplines, forums, and peer support services.**

Amid lack of understanding from existing support networks, **peer support services should be a particular target for investment to enable mutual support between carers sharing similar experiences. Financial assistance would also be of benefit, recognising the impact of caring roles on people’s ability to engage with full time employment.**

Physical Health

The impact of living with schizophrenia on people's physical health was asked about explicitly in both the group and individual sessions and here we present the most common topics discussed. We start with the notion that physical health and mental health are inextricably linked and should be considered together, which gives further meaning to the idea of 'parity of esteem' and holistic care and treatment.

'Parity of esteem'

As someone put it: "Address more than just the mental illness – look at physical health, nutrition, and social needs." **Other people put it like this:**

> “They have a knock-on effect on each other, what affects you mentally affects physically, it's a real issue.”

"Symptoms of schizophrenia manifest physically."

"Society needs to understand that everyone has mental health and they need take care of it; understand that mental health can be disrupted in different ways and also strengthened – it is an ongoing process. The term I would use is parity between the two."

"They have gyms for people who have had cardiac issues, so they should have that for people who are mentally ill. That would keep them well in so many ways."

For one person, it was partly related to their cultural background:

"In my culture, doctors will ask about physical history but not mental history. So, we need to normalise at this point talking about the mental side of things."

People talked about the broader impacts on physical health, with one person saying: "But I'm trying to explain that my mental health impacts my ability to look after my physical health and my diabetes more specifically. Mental health don't want to know about my physical health and they'll say oh you need to go and see the doctor. None of this helps as this is all pointing to, you know holistically, my body and my feelings."

Another person told us they thought there was insufficient support for this: "My friend has smoked and drunk alcohol since childhood and her physical health is very poor. She is active but has COPD and heart disease. I worry her physical health needs are not 'amplified' by health or care professionals. By amplified, I mean not taken into consideration and also not so proactively sort of pushed."

One person summarised what a lot of people told us that they thought: "Mental health is underfunded per capita compared with other services. There's still the view that mental health is less worthy than other conditions like heart [disease]."

Movement and exercise

Several people told us of the importance and impact of movement and exercise to their wellbeing and having a purpose:

“Feels good if can do weights and running.”

“Physical exercise provides structure and discipline to your day.”

“Walking in nature has an impact on my mental health, and it improves my physical health.”

“Sport in Mind is a great organisation, and he takes part in it. Outdoors, social.”

“If I’m exercising, I have more balance. If my sibling has been exercising and looking after herself, she tends to have a nicer day – it tends to have a correlation.”

“When my son’s mental health is good, he is very interested in keeping physically well - gym most days, healthy eating. When he is mentally unwell he has no interest in being physically healthy.”

“This is why exercise is so important for me. I am lucky to be able to access a gym that offers reduced rates for people on a PIP. If I didn’t, I think I would just stop taking my medication, because it would be too impactful on my health. I take my medication in the morning and then go to the gym. I enjoy it because I think it gives you a sense of achievement. Every week I can see what weight I’ve lifted, and because I’m competitive, I can see how I have improved.”

The broader benefits of exercise were also mentioned, for example: I play hockey for a team which is really good because it’s something to do every week, but it gives me the opportunity to be social.” **Another person told us that:** “I am lucky to be able to access a gym that offers reduced rates for people on a PIP. If I didn’t, I think I would just stop taking my medication, because it would be too impactful on my health. I take my medication in the morning and then go to the gym. I enjoy it because I think it gives you a sense of achievement. Every week I can see what weight I’ve lifted, and because I’m competitive, I can see how I have improved.”

The benefits to people in hospital were also mentioned: “Two weeks ago our loved one was moved to a different ward – we didn’t know that. But for a forensic setting it’s 100% men, and they have things like boxing to manage the emotions. The physical activity can release their emotions. Data around incidents on wards decreasing when there are things like gyms or pool tables.”

Managing a healthy weight

‘Licensed medications have demonstrated benefits for appropriate patients, as well as having side effects. It is important that these are communicated and monitored by HCPs. The decision to use a particular medication should be made by a HCP, along with the patient and/or carer.’

Several people told us of the side effects of medication on their weight:

“Meds have made me put on lots of weight”

“There was worry about weight gain with the antipsychotics, so there was a lot to navigate.”

“Meds make you feel hungry, so you have to watch your weight carefully.”

“With my medication, it has led to weight gain and more physical symptoms. This impact on my physical health doesn’t make me feel better.”

One person summarised what several people told us, that “If there was a way to make new medications without making them too tired and cause no weight gain, that would be a dream come true.” **while another person emphasised the importance of good support:** “Physical health support is really important. All that medication makes you gain weight and other side effects – it’s good to have that under control.”

Sleep

While we commonly hear that medications cause drowsiness, as one person commented: "Meds don't help as make him sleepy.", **we also heard about the disruption that medication causes to the quality of sleep. This was mentioned by several people who reflected on the importance of a good night's sleep:**

"My sister reports unusual sleep patterns."

"Sleep gets hard when I'm struggling."

"If I'm not sleeping, I feel really run down."

"When my brother is unwell, his sleep is disturbed, he's more distracted or he's excessively worrying."

For some people, they described sleep as being integral to good physical health: "When I'm ill, it's very difficult to look after my physical health, even basic self-care is difficult. I can't sleep properly either." and "When sleeping and eating and exercising well it helped my mental wellbeing."

Smoking

There were a few comments about smoking, particularly as it relates to being perceived as a coping mechanism:

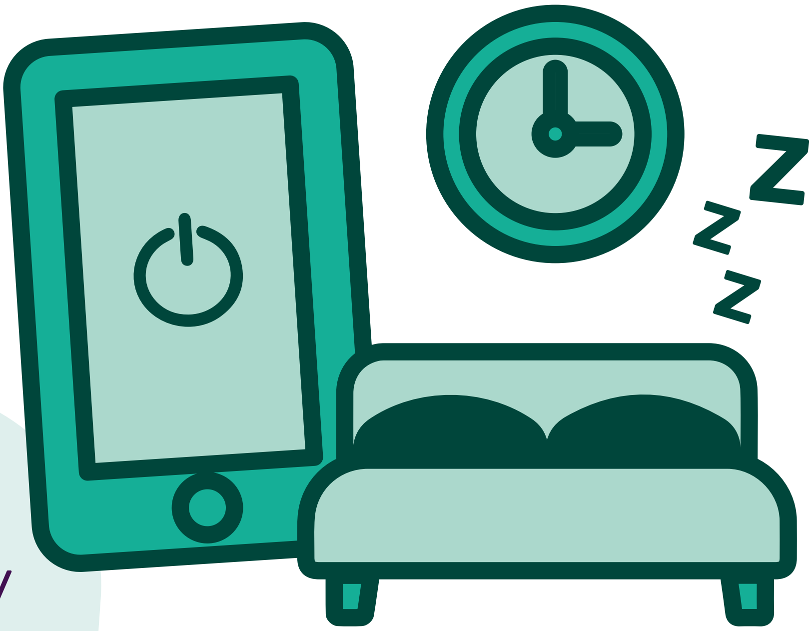
"Oh yes, my brother picks up smoking when he's not as well."

"He started smoking when he was 14 to mask some of his mental health symptoms…"

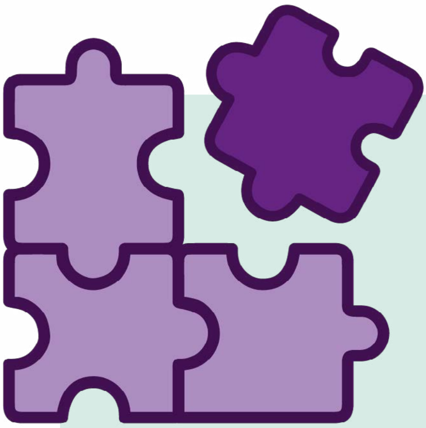
"Years ago, when he was ill quite a lot, used to smoke and drink to blank it out."

"My sister smokes like a chimney. I think she uses it as a comfort. She has smoked before she was diagnosed, so it must've been a rebellion or something like that."

Quite apart from the adverse effects on physical health, one person mentioned the effect on relationships and the impact that had: "Smoking caused issues and tensions in our household and that wouldn't have helped her mental health either."



> "Walking in nature has an impact on my mental health, and it improves my physical health."



Considerations for Policy and Practice

From reliance on tools like smoking to cope with the day-to-day reality of living with a mental illness, to the effects of medication on weight or sleep habits, living with schizophrenia can have major impacts on a person's physical health, and these are not always acknowledged and address holistically by the professionals involved in their care.

Steps must be taken to integrate consideration for physical health into mental health care. For example, as a part of medication management, professionals should always ensure that people are aware and informed regarding the potential side effects of medication, such as fatigue and weight gain, and supported to address these. More broadly, things like sleep hygiene, smoking, nutrition, and movement and exercise should be a part of conversations around care planning.

Over the past decade, Physical Health Checks for those with severe mental illness have been an important preventative intervention to ensure common risks to a person's physical health are spotted early. **Physical Health Checks for those with severe mental illness should be reprioritised by government, and more done to ensure that, where appropriate, these result in access to evidence-based and tailored follow-up interventions for those living with a mental illness.** This could include smoking cessation services that acknowledge and recognise the relationship between smoking and mental health.

The important role of exercise and opportunities for physical activity in developing positive habits and routines, providing social opportunities and supporting good mental health and wellbeing is evident in these findings. Those living with schizophrenia should be provided with more free opportunities for movement – such as gym passes or access to exercise classes. Physical Activity Navigators, piloted by Rethink Mental Illness in a Sport England-funded project, can play a role in supporting people to identify appropriate activities.

Mental Health Services

> “Every time we have an appointment, it’s a different doctor. We start from scratch every time.”

Access to mental health services

We heard from a lot of people about their experience of accessing mental health services, including the barriers to timely access, their frustrations with services as a result and other issues relating to engaging with services, such as the lack of continuity of care:

“The gap from when you go to a GP… to when you go to a community mental health team is critical. I’ve waited three months at one point and ended up in hospital in crisis. Getting care when I needed it in the first place could have prevented that outcome.”

“When he became stabilised, they said he ‘isn’t ill enough’ to have a mentor anymore.”

“We don’t see anyone for months. When we finally do, it’s someone new who doesn’t know our situation.”

Consistency and continuity in care was mentioned by several people:

“You need a consistent person who knows the person and can check in regularly.”

“Over the last 4 years I don’t know how many places he’s been in and in each detainment he’s been in a different environment.”

“Continuity of care is a massive one because when someone is very unwell, having a change of team multiple times is really crap for their recovery. It’s totally disruptive. This detainment period, our loved one has been in for nearly 2 years on and off.”

“A team around the person who they have a relationship with. That relationship is everything. With changing relationships, I believe they are unwell for a longer time. It takes a long time to build a relationship with someone with schizophrenia – they can find relationships much more difficult, social communication side of things.”

> “Changing professionals every six months doesn’t work”

For one person, re-accessing support proved difficult:

"My experience is that you get well and then you come out of support, and you go back to a GP, it is hard to re-access the system to get support again. It's hard to find someone who understands how to ask questions and what to do with your answers, but I've met with psychiatrists, psychologists and all kinds of professionals throughout my journey who can. As long as they're comfortable asking the questions, this helps."

Other factors that mattered to people in accessing mental health services included geography:

"Living in a rural area makes accessing peer groups difficult." and digital technology: "Feels there is a barrier to so many processes being online, with sister not confident or trusting of computers, fears that she will be left behind. There is a distrust and paranoia which prevents her from engaging online due to how she feels she the world related to her. Sister's fear is that thinking isn't checked the paranoia could escalate into other areas of her life. Feels that not having IT skills is like saying no to using a pen."

People told us about the variation in services in different places:

"There's a real postcode lottery which affects people all around, getting a good quality of life. That would involve different access to good healthcare. In some ways it's sorted in other ways it's really not."

One person told us about their particular difficulties accessing treatment as someone who had worked in their local service:

"A lot of people who get access to services work in services anyway. I've always struggled to access a service that I don't work at. There should be an option for people who work in the NHS to access different services. I've been to wards I've worked in which was really unpleasant."

Crisis care

We heard a lot during the sessions about crisis management and support:

"When I went into crisis, there was nothing for me."

"If someone is relapsing on a weekend, you have to wait for them to get worse or wait till Monday. It's not good for the person or their family members."

"You have to get really, really bad before services kick in. There could be things provided in the interim."

"During crises, there's no continuity – different crisis workers show up every day."

"Crisis care is inconsistent, with new people turning up every day."

"Every day, a different person would show up from the crisis team. It was distressing for him and for us."

"We need day hospitals or community hubs to provide immediate, consistent crisis support"

"It's about having access to the right treatments and support, like when I've been unwell and needed professional support to feel safe in those situations."

"In a fully resourced world – people don't realise in social work, the social worker completes your support plan, and that is updated every year. But currently, in my authority, the waitlist is around 18 months. If you don't get reviewed for that long, you get unwell. It's incredibly difficult."

However, one person told us of good support they'd received when in crisis: "There is this crisis café that has been a really important part of my experience and being able to use them as an adjunct to get respite and speak to people, meet other people with experience of mental health problems has been really important. They help you access services you didn't know existed like the Listening Space, which I didn't know about before."

Being in hospital

Some people spoke about their experiences of being in hospital and their quality of life while there, along with the importance of the hospital culture:

"I think the culture they experience on the wards in absolutely vital. The staff and the patients have lunch together. Breaking down barriers. Organised activities in the morning. I'm pleased to see seclusion rooms are being put away – but then they can be secluded to their rooms (just another name for it)."

"When I went into hospital, I'm not sure if it was due to the pandemic but there wasn't really much to do; it was really boring at least I was doing some activities beforehand. I was in hospital for two months and only had two occupational therapy appointments. I used the gym a couple of times and had a walk and cooked a meal, though generally it was just sitting around. Hospitals could be better."

Other people spoke of the importance of staffing and relational practices:

"Nurses on wards. When you know the person supporting you cares, is different. How do you quantify that feeling?"

An interesting insight was shared by one person about an alternative model, which might possibly lead to an alternative to hospital care:

"In Finland, there's something called the Open Dialogue approach. Driven by hearing voices organisation? The person is at the centre of it and the approach is to hold the person when they unwell in a therapeutic way rather than in a lock them up and throw away the key away. That approach is being looked at in the UK. But it needs to be more therapeutic. There are pockets of therapeutic intervention going on. I think there is a recovery focused approach – but when it goes wrong it can go very wrong"

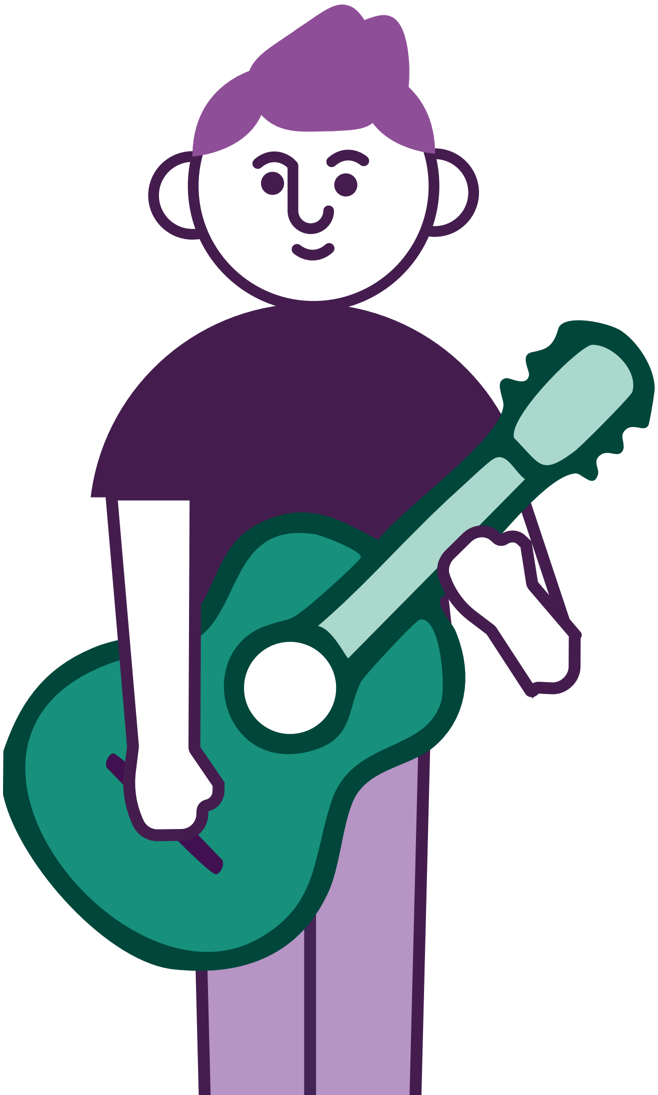
Another person also reflected that there should be alternatives to hospital: "We need wraparound support so people can live in their home, not a hospital bed. We sort of do it for older people, where they have carers and visitors helping them meal prep and get washed."

Recovery

Different elements of successful recovery were mentioned by several people, including "We need trauma-informed care and therapy as part of recovery."

Another person told us that:

"Creative therapies like art and music would be helpful, but they're not offered enough." One person told us about a service that had been very helpful to them early on in their recovery: "They help you access services you didn't know existed like the Listening Space, which I didn't know about before. They do really practical things, like have a hot meal. I was struggling to make tea, because of a thought I had about hot water, and they helped me make tea which was really valuable for me."



Discharge

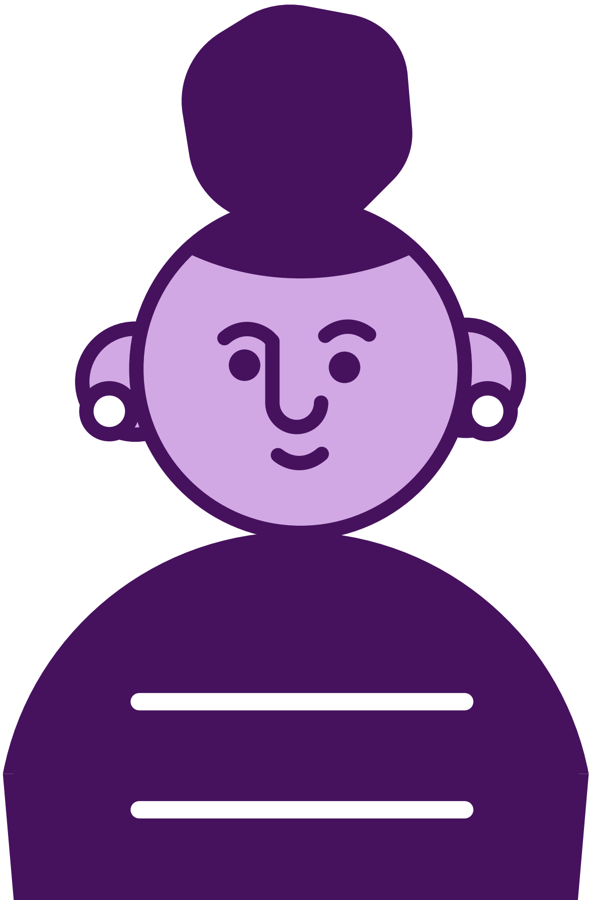
Transitioning to life outside hospital and the discharge process was something of concern for people, particularly early discharge:

"It's a very common experience, the early discharge. Me and my sister have been in care groups and the stories are on repeat. There are very clear things going on in the system side of stuff. Causing these very common themes with family members"

"He was discharged too early. He went back in for 6 months, discharged in January when he was very unwell and tried to take his own life. When he attempted, he was hospitalised. Luckily he didn't complete and he wasn't badly injured, but it was a very serious attempt"

"The way the discharge package works, it's something like ten times more risky during the first three weeks. The risk rating is exponential. When there isn't appropriate care in place, it can have massive consequences."

Another person told us of the importance of families and carers in the discharge process: "Discharge process and options should be discussed and agreed with the person and family to explore options and expectations - with a lead time of at least two weeks to ensure people have enough time to think and organise options."



Peer support

We heard a lot about the value of peer support:

"Community groups and peer support have been a lifeline for me."

"Peer support helped me feel normal and secure in myself."

"Meeting people in a similar situation helps you feel normal and secure."

"For my family and friends, it's about wanting to understand a little bit – I don't expect them to understand but trying to, makes a difference. The people who offered me peer support have a dad's group and my husband goes to that dad's group, and although nothing miracle-working happened, it was valuable because I knew he cared and was learning more."

"Massive isn't it. A role model can be so powerful for someone. The peer support worker stuff can be very powerful. If you can't see it, you can't be it."

> “Meeting people in a similar situation helps you feel normal and secure.”

Considerations for Policy and Practice

It is vitally important that the right community mental health provision is in place for people to prevent people from reaching crisis point and potentially needing inpatient care, to ensure and safe and supportive transition back into the community for those who do need hospital treatment, and to support people living with schizophrenia to live well in their own communities.

Too many people are in a position where support only kicks in when they are very unwell. Early intervention must be prioritised, with proactive steps taken to prevent people reaching breaking point.

Long waits for community mental health support should be addressed. **The government should make clear to systems that tackling mental health waits is a priority – alongside implementation of the recommended waiting time standard, to ensure more people are waiting no more than four weeks between referral and receiving treatment.**

To reduce confusion and distress, people living with schizophrenia and their families want services that are easier to navigate, with clearer pathways of care. This includes greater consistency and continuity of care, to prevent people having to repeat their story and falling through gaps in the system.

These findings demonstrate that those living with schizophrenia place considerable value in alternative, non-clinical forms of support such as community groups and in particular, peer support. Better investment in these kinds of services can both help to offer a source of support to those waiting for clinical help, and can serve as an important part of a mental health service offer alongside clinical services.

Much of what is discussed here is reflected in the ambitions of NHS England's Community Mental Health Framework, which has been rolling out across England over the past few years. While the experiences showcased here reflect the disparities in support between different locations, areas such as Somerset have achieved a more joined-up approach to care, offering better access to both clinical and social forms of support, and reducing the number of people that end up in hospital.

The government must build on the progress and lessons from the rollout of the Community Mental Health Framework, retaining important services, while recognising that more work needs to be done. This includes placing mental health at the centre of the government's drive towards a neighbourhood health approach.

Parallel work focused on crisis response has, in places, helped to improve the availability of alternative provision such as crisis cafes. **24/7 mental health centres, currently being piloted by NHS England, should be rolled out nationwide to bring together work to improve community and crisis provision and provide a high quality, around-the-clock response to mental health needs.**

Having purpose

> “Family network, wellbeing activities – people need a reason to get out of bed, the activities that need to be right for them at that time, and a sense of purpose and goals.”

During the sessions we heard from people that it is important to have a sense of purpose and achievement, for example:

As someone else put it: “Yes, having positive purpose in life is important - family roles, work, study, activism.”

People also spoke about the importance of having things with which to occupy time in enjoyable ways:

“Being able to operate independently and being able to go to the shops, use public transport, going to cinema or café. Be with other people, being around other people and having more conversation and build friendships and relationships. That’s really important because you don’t want people to feel lonely. Be around people to accept them and have a laugh and get the joy from nature or whatever stimulus you can find.”

Similarly: “I went for a coffee with my wife…I put on a clean shirt…I had a shower. I made an effort. Some people don’t have family. But most people do. To see loved ones is important. It’s good to have a vocation. It’s good to have your voice listened to. Some people can do a job and if they can hold one down that’s good. Be with friends and colleagues.”

In contrast, someone told us: “She spent a long time in her flat on her own. She didn’t have a real purpose or doing anything. Compared to me who does spend quite a lot of time in my flat on my own but I have things to do and keep busy.”

As someone else told us, what’s important is:

> “Getting enough satisfaction in life or stability and not being at the end of your tether all the time.”

Someone told us of the value of work for them: “Having a purpose and getting some good reward for that purpose. For me, I work in mental health hence why I ‘m doing a 1:1 rather than a group. After work, you feel like you’ve done well today or a young person say they had a good session – this is really important to me. When I’ve not had that, I’ve struggled a lot.”

However, for another person, the same satisfaction could come from other opportunities:

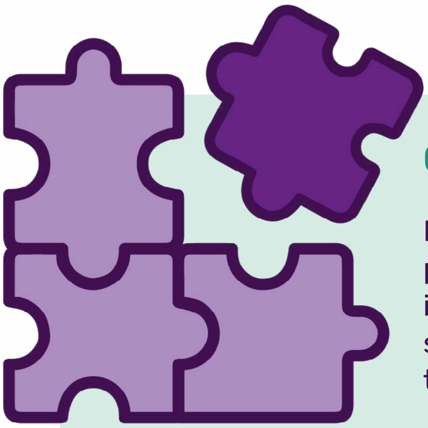
"It's very limited availability really. The DWP for instance do still have coaches, but there is a spectrum here about who is ready to get out and go to work. It doesn't have to be work, just meaningful occupation of time. There are opportunities for that but think there should be people within the mental health team waiting to support with getting people into work and maintaining it."

Someone else put it like this: "Sense of purpose – my dad thinks oh if my brother just gets a job. I am trying to break him out of this system of thinking that purpose is only having a job. We need to change our thinking."

Education

"I think they want more support when they are well. Education and funding to do education. And to get them to that stage, they need secure benefits."

The importance to people of education was mentioned a couple of times: "Identity was important for my sister – trying to be an educated, professional lady making her way in the world – and she couldn't be this. She subscribed to the system and how you are meant to be as opposed to making her own choices about what her identity actually was. This sense of failure made her ill." **While another person described a similar impact:** This was very relevant to my sister's case. She wanted to be a professional with a maths qualification. She wasn't able to do this and not being able to reconcile this made her ill and kept her ill. She couldn't achieve what she wanted to. This all stems back to failing the 11+ and how she was treated by our mother. So there was comparison in the family environment. Our mum favoured the older sister who passed the exam. So that's why my sister fled the family home."



Considerations for Policy and Practice

It is evident that participation in education, volunteering and particularly employment are important sources of purpose and identity for people living with schizophrenia, but it is clear that systemic barriers and inadequate support can create obstacles to these opportunities.

Improving access to these opportunities should be a cornerstone of the care and support that people receive, enabled by greater collaboration between sectors.

These findings also identify a need for more appropriate and mental health-aware pathways to employment. **This should include expansion of Individual Placement and Support (IPS) - a specialist service internationally recognised as best practice in supporting those living with mental illnesses to find and maintain competitive employment in line with their skills and interests. Models such as Mental Health UK's 'Into Work', which builds on the IPS model through greater collaboration with local businesses and offering support for wider issues affecting recovery and quality of life, should also be explored.**

The effectiveness of these approaches could be enhanced by removing inflexibility within our social welfare system, which creates a fear of benefit loss and prevents many from pursuing meaningful opportunities.

Establishing clear and consistent expectations around inclusive workplaces can also play a role for supporting more people living with schizophrenia to gain and maintain meaningful employment and volunteering roles. **Workplace mental health standards should be developed in collaboration with the Government, employers, people with lived experience, and relevant organisations. Employers should receive support in meeting and sustaining these standards** to ensure long-term improvements in workplace environments.

In recognition of the vital role that education, employment and volunteering play in helping people find purpose, **statutory and voluntary sector organisations should work together to incorporate these opportunities into support for people with schizophrenia,** tailored to individual interests and introduced gradually alongside medical treatments. This approach would ensure that the whole person is supported to live a life with purpose.

Life Circumstances

There were some themes that came up frequently that related to people’s life circumstances, including housing, welfare and finances, education, relationships and family and carer wellbeing.

Housing

We heard a range of experiences and views about housing and the importance of being able to call somewhere home:

> “It was good when she got her own flat… This gave her a sense of self-worth and self-pride.”

For some people, supported housing was key to their ongoing recovery and suited them well and indeed at times was seen as crucial to someone’s wellbeing:

“The supported housing has been fine. Where he is, is meeting his needs – it’s positive at the moment.”

“The therapeutic house recognised when he was ready. The social care assessment thought he could live alone, but the house challenged this – I’m very glad he was there.”

For others however, simply being housed was not always sufficient, and could be unsafe:

“I think they need good housing in a safe space. So often, my experience is, once the social worker gets them housing, the box is ticked. It could be a very unsafe area, but it doesn’t matter they see the box as ticked.”

“Supported housing is really important. But it needs to be actually supportive.”

For one person, the thought of going into supported housing was upsetting: “One of his worries is that if anything happened to me and dad he wouldn’t have anywhere to live…. Got very upset at thought of supported housing.”

> “Supported living is only safe when there is a member of staff to support.”

Welfare and Finances

“Navigating benefits and housing for my loved one is exhausting and financially draining.”

We heard a lot about issues people encountered with welfare and finances, despite the effect on people’s ongoing wellbeing:

“Finances, huge safety net. Try to do my best to earn extra money to feel safe.”

One person told us that:

“Receiving social security and welfare with housing eases the pain and suffering for people with mental health problems and helps them live independent.”

Similarly, “I think they want more support when they are well. Education and funding to do education. And to get them to that stage, they need secure benefits. If you need to give up benefits to get a job, you need to have security to come back onto it if you lose the job. In those 6 months you’ll lose your house. No one wants to dare lose their benefits.”

One family member told us:

“Having basic needs fulfilled and some money... Having a system that’s not challenging all the time e.g. universal credit reviews. Worries about officialdom. It can make you feel under threat... The future is a worry. I have concerns as a parent and carer. Rethink advice has been good – set up a trust.”

“Rethink helped her sort her benefits out”.

Some people told us that they would like more support to navigate the social security system, with one person saying:

“Provide more assistance with the benefit system. It’s difficult to fill out forms when you’re struggling. I’m lucky I have my mum to help.”

“A big problem in the benefits system is that it’s almost like they are out to prove you wrong. You have to fill all these forms and go to all these appointments, and they sanction you if you miss an appointment or do something from. The forms are like 12 pages long – you have to argue your case. It’s not easy unless you have help. You need support but it’s difficult to get it.”

“My care coordinator has [tried to support me with benefits] before, but they aren’t allowed anymore. It’s difficult for me to go out. In terms of accessing support with benefits, lots of people get really stressed about it, so there should be more support.”

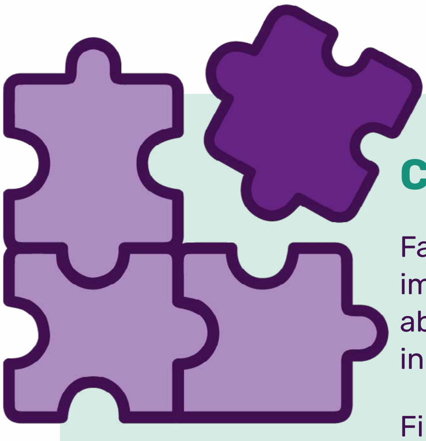
Some people spoke of the toll navigating the system took on their wellbeing:

“Accessing support with benefits has been stressful.”

“I had to go to court to get the benefits my son needed. The system is impossible to navigate.”

“Stressful, frustrating, uncertain, overwhelming and confusing are words that come to mind.”

> “It must be very hard for people coming to the system fresh and who are carers but also working full time and then having to deal with the system. It’s really shocking.”



Considerations for Policy and Practice

Factors such as housing and finances have a clear and tangible impact on mental health. Ensuring that these needs are met is absolutely fundamental to recovery, and people's ability to live well in their communities.

Finding a place to live must be more than a box ticking exercise – these findings articulate the importance of good quality, safe housing for those living with schizophrenia.

To provide this, there is a clear role for supported housing. Supported housing services can offer a safe environment in which people can recover and build their confidence, helping them to feel more able to live independently in their local community – often after a stay in hospital. However, too many people are still having poor experiences in supported housing settings. As well as **rolling out National Supported Housing Standards and the related regulatory oversight regime** to crack down on inadequate and harmful supported housing provision, **the government must also increase the supply of high-quality supported housing for those living with mental illnesses** such as schizophrenia.

Our social security system has the ability to ease pain and suffering for people living with mental illnesses by ensuring they have the resources to meet their basic needs and to live independently. **The government should implement the Essentials Guarantee, ensuring rates of social security are set at a level that ensures people can cover these fundamentals.**

Issues with our current system means that accessing this help can be a cause of stress in and of itself. **A statutory duty of care must be introduced within the Department of Work and Pensions to safeguard all claimants, and particularly those living with long-term illnesses and disability.**

People living with schizophrenia and their families want a system that works and for them, offering support to complete the significant paperwork required and navigate what can often be a complex process along the way. **The government's planned reforms of the Work Capability Assessment must replace the current approach with one led by those who have lived experience of illness and disability.**

Stigma

> “There’s such a stigma attached to schizophrenia. All the newspaper articles about schizophrenia are always about someone who’s attacked or killed someone.”

Stigma surrounding schizophrenia was mentioned frequently in all the group and individual sessions. Particularly the portrayal in the media, with someone saying:

> “I think the media does so much to make out that people with schizophrenia aren’t human like other people are human. We are still people.”

Misconceptions were also mentioned: “The reporting is doom ladened…and people are still thinking that there is split personality element too.” **Similarly,** “There’s still a massive stigma with drugs – people ask, did he take drugs? People so unaware and see things as in Hollywood, marketing campaigns need to change. More needs to be emphasised about the reality of the condition and changes in the brain.”

People described a continued ‘taboo’ surrounding mental illness, which leads to ridiculing and the association with violence: “There is a lot of misconception about the diagnosis, people relate to diagnosis to the worst-case scenarios and believe everyone with this diagnosis is likely to be aggressive, unpredictable or worse.” **In contrast, someone said:** “See them for who they are, what they’ve done, accomplishments. Not just the diagnosis – there’s a stigma with the diagnosis and that comes into safety.”

Someone had noticed a lack of tolerance by others that could be very upsetting: “People not very compassionate for difficult illnesses... Public can look at him in rude way – don’t know what his illness is by looking at him.... People judge him on how he behaves, doesn’t have many social skills. People might lose patience or say things under their breath.”

This was also reflected by someone else:

“It’s not just stigma – it’s like being ostracised by society.

My loved one was saying he was going walking past this pub and people were looking at him and stuff and its horrible its awful.”

Stigma in the workplace was often mentioned, with effects on employment and the opportunities afforded people:

“How other people perceive you, especially if people are aware of your diagnosis, that often comes with negative connotations, especially in some workplaces, which can affect your ability to get a job or stay in a job.”

Even if you’re in a gym and notice people look at you differently. I don’t actually use the word(?) schizophrenia very often; I tend to use the word psychosis because people have less negativity associated with it.”

One person did observe that they thought the situation was improving though still with some way to go, saying: “I wasn’t open about my disability in my last job as I was worried about stigma. I do wish I hadn’t been. Over 15 years ago – stigma was a lot worse than now. People are more understanding now, though some still don’t know what schizophrenia is and think that people will be dangerous.”

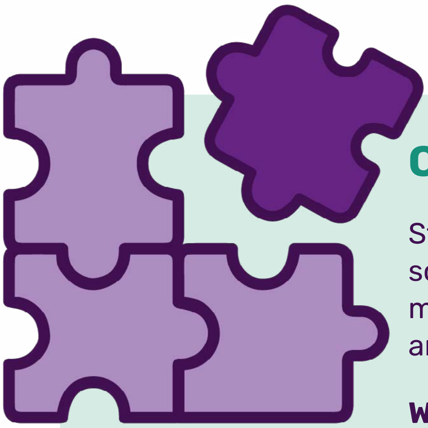
One person said, “I really struggle with the impact of stigma – not really self-stigma but that of others. The way I read about myself… It can feel dehumanising how I am described in these. Sometimes derogatory and lacking compassion. I feel like I am excluded”. **Even from professionals, at times people experienced stigma:** “Clinical professionals can have a massive impact on how the person, families and carers think and approach the illness and the symptoms. My brother can sense judgement, care, professionalism and respect and distance himself accordingly.”

Stigma within families was also mentioned:

“With the stigma thing, for me, even though my family had known I have psychosis, it took me over a year and a half to tell them about the schizophrenia diagnosis.”

Likewise, cultural factors also come into play: “Her condition went a lot of time untreated. Being in an African Caribbean household, it was seen as a taboo. It was perceived as very negative in our household…. So my sister had many challenges that were never resolved and this is what made her stay unwell.”

The impact of self-stigma “reinforcing negative thinking leading to further anxiety, paranoia and suffering” **was mentioned by several people:** “Fear of stigma stops me from sharing my diagnosis at work.”, “The stigma makes it hard to share what we’re going through with our friends or community” and “to a degree, for myself, I can’t do what I’ve always wanted to do in my life because I feel like I’ve put myself in a box and that box is difficult to get out of.” **For one person,** “I don’t tell too many people about schizophrenia. Even my mum didn’t know until it was in a bio about me.”



Considerations for Policy and Practice

Stigma can profoundly impact the lives of people living with schizophrenia. Harmful media portrayals leading to widespread misconceptions of people living with schizophrenia results in real and perceived discrimination from across society.

When it comes to stigma from our health, social care and social security systems, the Department of Health and Social Care and Department of Work and Pensions must tackle this through improved training, policies and procedures.

Reshaping perceptions of schizophrenia among the broader public requires a multifaceted approach. Public awareness campaigns, educational interventions and other efforts to improve mental health literacy, especially if co-produced with those who have lived experience of mental illness, all have a role to play in correcting misinformation, challenging misconceptions and negative attitudes and shining a light on the reality of living with schizophrenia.

Grassroots initiatives that include opportunities to engage in in positive interactions with their local communities can simultaneously tackle stigma whilst building individual confidence and promoting recovery. As mentioned elsewhere in this report, the VCFSE sector is well-placed to deliver these initiatives, such as peer support workers and groups. The non-judgemental and non-discriminatory environments fostered by these approaches can also help to combat self-stigma.

Thriving

> “Thriving is about your freedom, happiness, relationships, and things you look forward to.”

For the final key theme, we turn to the concept of thriving, which brings together many of the preceding themes. As one person put it: “For me, thriving is feeling happy and having purpose.” **For another person** “Thriving means seeing my loved one in a safe, empowered state. It reduces the constant worry.” **People spoke to us about the importance of independence, which was difficult to achieve though gave a sense of confidence –** “even small steps help”. **Having a place to call home and being able to make choices – not necessarily just about money – was said to be important.** “If he had more independence, he might thrive.”

Life satisfaction and having purpose and meaning were also considered important aspects of thriving: “Yes, having positive purpose in life is important - family roles, work, study, activism.” **This was often linked to occupation, including work and volunteering, which were said to give a sense of** “accountability and structure”. **However, for some thriving meant that** “Just getting out of bed has been a major achievement in the early stages of recovery.”

For one family member, the attitudes of others contributed to a sense of thriving: “Hearing people talking about my brother in a good way makes me feel better.” **While for another person it was important to have validation from other people, saying:** “People that are interested and care and have empathy help.”

Barriers to thriving included a lack of purpose or engagement, such as spending a long time not doing anything, with one person saying: “...people need a reason to get out of bed, the activities that need to be right for them at that time, and a sense of purpose and goals.” **Or as another person put it:** “Not just being stuck inside on your own.”

Social isolation and loneliness were themes picked up by others:

> “Loneliness will prevent someone from thriving. This isn’t a need met by your GP or care coordinator or things like that.”

For another person, “Not having accountability and support system or network is a barrier to thriving. Not having people to encourage you to go outside your comfort zone.”

Other barriers to thriving included housing and financial insecurity: "What can stop people from thriving is not having somewhere good to live. **As one person put it:** "It made me think about the Hierarchy of Needs. When you think about fulfilling and thriving, you think about basic needs like a roof over your head and food." **Another person said:** "Finances, huge safety net. Try to do my best to earn extra money to feel safe."

Many people described the importance of relationships, especially with families and friends, as being crucial to being able to thrive: "Be with other people, being around other people, and having more conversation and build friendships and relationships. That's really important because you don't want people to feel lonely." **As someone else put it:** "To have someone, even a professional, to open up to and have a good relationship with." "People that understand what's going on, like family, can make a big difference. It's about understanding without judgment."

Many people spoke of the importance of relationships with professionals to their being able to thrive: "For professionals: Not being one-track focused, not having only conversations about mental health. Also talking about your interests, goals, and other things in life." **One factor that several people said was an important factor in this was the amount of time spent with professionals:** "My current psychiatrist is the first that really listens. In the past, I'd have short appointments, and the psychiatrist was only interested in meds. Currently, they're concerned about my general well-being, and I get the full half hour with them (previously only 10-15 mins or so)." Similarly, "My son has a good CPN who keeps things ticking over. It's so important to have a point of contact you can rely on." **Someone summarised this by saying:** "A team around the person who they have a relationship with. That relationship is everything. With changing relationships, I believe they are unwell for a longer time."

Finally, being part of a community that cares, was said to be crucially important: "Being part of a community, having a sense of belonging, routine, and constant support – mentally, emotionally, financially."

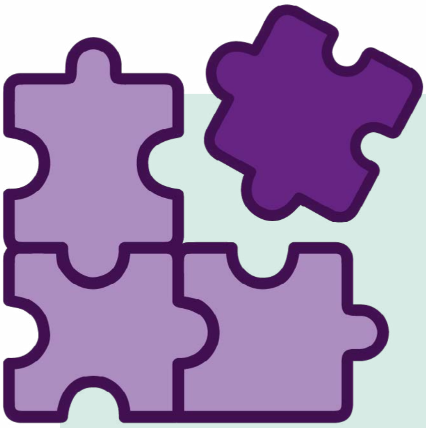
Communities that Care

Following on from the January 2019 NHS Long-Term Plan, in April 2019, Rethink Mental Illness surveyed people affected by severe mental illness, and carers about their support needs. Findings indicated the lack of support people received with their involvement in community initiatives, activity levels, housing, financial benefits and employment opportunities.

Six pillars were identified as holistic needs that people severely affected by mental illness want assessed and addressed:

- Access to treatment and support – the right treatment and support at the right time, in the right place
- Social Connectedness – develop meaningful social connections
- Physical Health – enjoy good physical health and improved life expectancy
- Housing – have a safe and secure place to call home
- Finances – have the financial security to make ends meet
- Employment and Volunteering – have the chance for meaningful employment, education, training and volunteering

The research informed the establishment of Rethink Mental Illness' report called, Building Communities that Care (Rethink, 2019), which revealed how wider community support could help people living with severe mental illness to thrive, not just survive. The report calls for supporting people's holistic needs through a community model of care, to ensure that people are supported at the right time and so that they can have the best quality of life possible. What we have found in our Rethinking Schizophrenia project is that these pillars ring true for people today as much as they did six years ago.



Considerations for Policy and Practice

People living with schizophrenia need the help and support that allows them to not just survive, but thrive. These findings illustrate the factors that help people to do so, such as housing, financial security, and social connectedness. People want a team of people and services working around them, working in partnership, to help them address these challenges and meet their wider goals.

These findings echo Rethink Mental Illness's previous report, Building communities that care, which indicated that people wanted more support for their social, as well as their clinical needs. What we have found in our Rethinking Schizophrenia project is that these pillars ring true for people today as much as they did six years ago.

The NHS, working with its partners, must adopt multi-agency collaboration, working across traditional boundaries with housing, employment, benefits, and community services to develop care plans that address all aspects of a person's wellbeing. A holistic 'no wrong door' approach is needed to ensure that regardless of where someone first seeks help—whether through their GP, a community organisation, or a crisis service—they can access appropriate care without having to tell their story repeatedly or face rejection because they've approached the 'wrong' service.

We need investment into and integration of VCFSE organisations offering a range of support, including services that facilitate peer connections, creative expression and personal growth, into the mental health service offer. These organisations can address needs that traditional health services often cannot, creating spaces where people can build relationships and develop new skills in supportive environments.

As discussed elsewhere in this report, NHS England's Community Mental Health Framework has been rolling out across England over the past few years and has gone some way towards making this a reality, particularly in some areas, but this should be a reality for those living with schizophrenia nationwide. **The government must build on the progress and lessons from the rollout of the Community Mental Health Framework, retaining important services, while recognising that more work needs to be done. This includes placing mental health at the centre of the government's drive towards a neighbourhood health approach.**

5

Feedback from EbEs

In total, 22 EbEs provided feedback on the process by completing a survey that was shared following all engagement and 1:1 sessions. These responses provide valuable insights into the experiences of the project, highlights and areas for improvement.

Overall, the responses were highly positive, with key themes emerging around peer support, learning opportunities, and the impact of the project on EbEs' confidence. 100% of respondents agreed with feeling a positive impact from sharing their experience and expertise as part of the project and also that they felt heard, listened to and valued. 73% felt the process had a positive impact on their mental health as well as on their confidence and self-esteem. 95% of respondents felt supported by the Rethink team during the project.

> “I felt that the project was run sensitively and respectfully. I felt supported before, during, and after each session... The project has made me feel valued and heard.”

Social connection was another valued aspect of the project with 73% of respondents reporting to have experienced peer support during their involvement. The project was also recognised as a meaningful learning experience, with 73% of EbEs agreeing that they gained new insights and 91% felt that they were being part of system change.

> “I found the sessions really empowering. They have given me confidence to speak out on other issues and engage in other programmes.”

While the feedback was overwhelmingly positive, EbEs also provided constructive suggestions for improvement. One EbE felt that greater continuity in session facilitators would help build trust and consistency, although they appreciated that this can be a challenge logistically. Several respondents were keen to learn more about other involvement opportunities and to continue to connect with Rethink and peers. A strong interest in receiving further communications around the long-term impact of the project and how their insights would be used to drive change was also expressed, reinforcing the importance of ongoing communication and transparency.

Overall, the project was widely regarded as a positive and valuable experience. EbEs appreciated the supportive and respectful environment, which made them feel heard and valued. While there were suggestions for follow-up communications and clearer pathways to impact, the feedback underscored the importance and value of creating safe spaces where lived experience insights are recognised, shared, and used to inform meaningful change.

6

Reflections *from Rethink Mental Illness*

1. Successes

Recruitment

The project was successful in engaging more Experts by Experience than anticipated. Over 70 people responded to social media posts and email communications and expressed an interest to be involved. The final number of those we engaged with was 46. This level of engagement was largely due to thorough planning and management of the recruitment process in which we built on existing channels and expanded outreach to new EbEs. A strong focus on inclusive recruitment ensured diverse representation.

Representation

The team prioritised diverse and inclusive language and outreach methods in order to platform the voices of those from often underrepresented communities, including LGBTQ+, neurodiverse, Black and ethnically minoritised people and those with co-occurring needs. We recognised the unique challenges faced by people who come from racialised communities, such as navigating stigma, so organised dedicated group sessions with representative facilitators in order to create a more safe and comfortable space for sharing personal experiences.

Additionally, carers were well represented within the project as well as those with direct lived experience. 26 people identified as either a friend, family members or carer – some of these also with their own direct lived experience. Their unique insights added valuable perspectives to the project.

Co-production

The co-production phase, where 6 EbEs collaborated with Rethink staff to plan the engagement phase, established a strong foundation for the project. We created a comfortable space in which this group built an understanding rapport with each other and facilitators. We achieved this through the co-production sessions, supporting people to feed in whilst leaving space for their views to shape the content. This led to achieving consensus in the co-production group and a level of proactive commitment leading to all 6 people also taking part in the engagement phase themselves.

Positive Feedback

The project received overwhelmingly positive feedback from the 22 EbEs who completed the survey following their engagement. Key themes around the benefits of peer support, learning, confidence and self-esteem were reported as well as praise on how the project was run by the team: "I felt that the project was run sensitively and respectfully. I felt supported before, during, and after each session… The project has made me feel valued and heard."

A full breakdown of responses can be found within the 'Feedback from EbEs' section of this report.

Wellbeing

The team prioritised ways of working that supported all EbE's wellbeing throughout their engagement in the project. This included a process of individual introductory calls with everyone who had submitted an Expression of Interest. This ensured everyone taking part fully understood the nature of the project and their role beforehand. The process also helped to build relationships with members of staff that continued throughout the project.

Psychological safety was also supported during optional and paid pre-meets and debriefs to give people an open space to meet with fellow EbEs. This allowed people time to build relationships with one another and feel comfortable before being asked to share their own lived experiences and to reflect on the experience together afterwards.

The team also offered flexible engagement options in order to suit the needs of people and ensured timely and consistent communication. We carried out engagement in many forms including group meetings, 1:1 video calls, phone calls and written responses. These options were presented and helped ease anxiety felt by some and removed barriers for engagement.

Evidence, impact and co-production

Embedding evidence and impact and co-production from the start was essential in moving beyond anecdotal accounts to create a robust, actionable knowledge base. Our thematic analysis and structured evaluation captured both the depth of lived experience and its broader systemic implications, ensuring insights are meaningful and applicable to policy, service design, and advocacy.

Co-producing questions with EbEs was not just inclusive, but reshaped how we approached knowledge production. This allowed thematic priorities to be shaped by lived experience, leading to more relevant and insightful discussions where groups evolved dynamically. The design of the groups and space facilitated recognised the diverse experiences of schizophrenia and how intersecting factors—such as culture, stigma, and access to services—shape experiences.

Thematic analysis was rigorous yet flexible, working collaboratively to ensure robust reflection of EbEs' realities, consolidating insights while preserving nuance. The Evidence and Impact framework provided a clear methodological path, integrating qualitative and quantitative elements to ensure transparency and practical application.

The engagement highlighted the need for tangible service improvements such as continuity of care, autonomy, medication impact, and systemic barriers. This work reinforces the importance of embedding lived experience in policy design to create services that genuinely meet people's needs.

Matrix working

The scale and success of the project was made a reality by managing a core team with support from wider Rethink departments. As well as the Lived Experience Programmes team, wider teams involved included Evidence and Impact, Policy, Public Affairs and Partnerships enabling a wide range of expertise and skills to feed into the project. This was especially evident during the in-depth thematic analysis process whereby 6 members of staff across teams collaborated on the process of coding insights and capturing a wide range of perspectives.

The regular communications and meetings with commissioners was also a strength in that partnership was extremely important to the project. The process of certification for assets ensured compliance with the Association of the British Pharmaceutical Industry (ABPI) guidelines and demonstrated the close partnership working between Boehringer Ingelheim and Rethink. Whilst this required planning of multiple resources and moving parts ahead of time, we achieved timely certification and often rapid responses to assets as needed. This process also made it transparent to EbEs who was commissioning the project and how their data would be used.

Unlocking further opportunities

The project led to other involvement opportunities, such as 2 Experts by Experiences being invited to speak at a Parliamentary roundtable. We also heard of people involved enjoying the process and experiencing benefits such as confidence by sharing their story and so there was a desire to engage in further projects in the future.

2. Challenges

Technology

Although the sessions overall ran smoothly, there were a few instances where people struggled to access the technology needed to engage with the project. For example, trouble opening email attachments, issues completing forms to be returned and errors connecting with Microsoft Teams. While the team made efforts to support people as these issues arose, we acknowledge there was a level of frustration from some people at the limitations on accessibility that this form of engagement can incur.

Representation and diversity

As we do not require diversity monitoring forms as mandatory, we do not have complete demographic data from our EbEs. We can see a spread across ethnicity, religion, gender, age, region and neurodiversity. However, our representation within sexual orientation and gender identity was mainly heterosexual and cisgender. We could have had more representation from lesbian, gay, bisexual, asexual as well as transgender people to ensure even more diverse and representative input.

We also recognise that the EbEs involved were mainly people who are university-taught, and we can in future aim to broaden our reach to people from different educational backgrounds.

7

Summary

In 2011, Rethink Mental Illness founded the Schizophrenia Commission. This commission brought together experts in the field, people with lived experience of schizophrenia, and other stakeholders to examine the state of care for people with schizophrenia in the UK. The commission published a groundbreaking report in 2012 titled "The Abandoned Illness" which highlighted gaps in care, treatment, and support, and offered recommendations for improvement (The Schizophrenia Commission, 2012). Sir Norman Lamb MP (then Minister of State for Department of Health) spoke at length about the report and its findings in parliament (Parallel Parliament, 2012).

In 2017, the Schizophrenia Commission released a progress report which found evidence of real success in some areas (including the introduction of access and waiting times standards for psychosis) and other areas where there is still significant progress to be made (for example, access to supported housing, and the premature mortality rate of people living with severe mental illnesses including schizophrenia). The report we present here highlights that there is still a long way to go before people living with schizophrenia and their families and carers received the support and opportunities needed to lead a thriving and fulfilling life.

We have heard again of the importance of supporting people more in almost every aspect of their lives – symptom control, physical health, co-occurring needs, timely access to mental health services, more recovery-focussed services and better discharge planning from hospital stays, as well as with social aspects of daily living such as housing, occupational activities, education and social security. One or two people did say that over the past few years improvements had been made and are being experienced, though overwhelmingly people with lived experience and their families, carers and friends told us that much still needs to be improved in health and social care.

Stigma is still a huge issue that affected everyone we spoke to – within families, society, workplaces, health and social care and also not surprisingly, we heard about self-stigma and the effects of so much 'external stigma' on people's confidence and self-esteem. This, despite improvements in attitudes in society in general towards more common mental ill health – for people living with schizophrenia and their families and carers, much still needs to change in order for people to not suffer the effects of other people's attitudes and behaviours.

The importance of relationships with loved ones and relational working between people and professionals came across loud and clear in all of our group sessions and individual meetings. People told us how highly they valued positive and supportive relationships with others, be they family and friends, peer support workers, professionals involved in their care and even with people who they didn't know well, such as peers in hospital. This concurs with what we know about the adverse impacts of loneliness and social isolation on people's mental health and this is a strong call for relationships of every kind to be supported and nurtured wherever possible.

Throughout our report, we present 'Areas for consideration' along with 'Policy Perspectives' aimed at a range of actors in the mental health system – individual practitioners, care teams, Trusts and other providers, commissioners and regulators of the mental health system and policy makers, including government. Our hope is that this report will be read, digested and acted upon in order to address the fundamental challenges faced by people living with schizophrenia and their families, carers and friends. This report should provide urgency to the actions needed – it is eight years since the Schizophrenia Commission progress report.

We urge future projects and policy developments to embed co-production at their core, ensuring that people with lived experience of schizophrenia and their friends, families, and carers are actively involved. The voices of Experts by Experience in this project have made it clear that having a seat at the table is not only beneficial for confidence, empowerment and peer connection, but also essential for shaping solutions that truly reflect lived realities. Genuine respect, empathy, and psychological safety must be the foundation of this work. By embracing the approach presented in this report, we can drive meaningful progress and create lasting, impactful change.

> **We very much hope that any follow-up report to this in another eight years' time will be very *different from this one.***

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Appendices

1. Evidence and impact

2. Background reading

Rethink
Mental
Illness

We are the charity for people severely affected by mental illness, no matter what they're going through.

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