

**Rethink Mental Illness and Boehringer Ingelheim** 

# Rethinking Schizophrenia

**Executive Summary** 

NP-GB-105873/May 2025

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.

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We would like to thank all the Experts by Experience who contributed to the project as well as Boehringer Ingelheim for funding the project. **99** 

### 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.

# **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.

## **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.



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

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