

Phase II Optimising Schizophrenia Care Pathways in Europe

From the First Episode of Psychosis to Long-Term Care

STUDY PAPER





March 2025

For more information about Rethinking Schizophrenia, please visit: www.braincouncil.eu/projects/rethinking-schizophrenia/

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Rethinking Schizophrenia

Rethinking Schizophrenia is a research-driven project led by the European Brain Council (EBC), addressing tangible policy and care pathway changes aiming to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, endorses the biopsychosocial approach and encourages multi-stakeholder-driven policy.

Background

In March 2024, the EBC Rethinking Schizophrenia Beyond The Voices Policy Report was released and represents the first of the three "Rethinking Schizophrenia" phases. The PHASE 1 (2023-2024) policy report highlights key unmet needs of people living with schizophrenia and ways to address them. Based on semi-structured interviews —gathering insights from patients and representatives of patient associations on the question 'What are the patient's needs?'—along with survey results, the EBC Rethinking Schizophrenia Care Pathway project PHASE 2 (2024-2025) analyses barriers to care identified by patients. Key areas of focus include the importance of early neuropsychological assessment, continuity of care, shared decision-making and a recovery-oriented approach in treatment. Study objectives aimed to describe the care pathways of young patients from the first episode of psychosis (FEP) (often representing the onset of schizophrenia) to long-term care throughout the mental health system in nine European countries (Belgium, Denmark, France, Germany, Hungary, Italy, Poland, Spain and the United Kingdom). In mental disorders, there is not one single patient care pathway, but there are many. The results of this qualitative research are based on the responses obtained from health professionals working in distinct types of mental health care. During the 2025 Brain Awareness Week, the Phase 2 study paper was launched. The PHASE 3 Country Profiles - the "reality check" (2025-2026) will rethink schizophrenia at the national level. It will examine the ways how to introduce policy changes guided by these recommendations at the European and country levels, bringing a brain health approach to schizophrenia prevention and management.

Executive summary

Schizophrenia, a paradigmatic psychotic disorder, remains one of the most complex mental health conditions to manage. With typical onset in late adolescence and early adulthood, schizophrenia profoundly impacts the lives of young people and their families across Europe. The burden of schizophrenia extends far beyond clinical symptoms, encompassing significant disruptions of social relationships, education and employment. Data from the Global Burden of Disease Study highlights its status as one of the top 20 causes of years lived with disability worldwide (Lancet Psychiatry, 2024). Among those affected, 70%-90% encounter employment challenges, and stable housing remains an unmet need for many (Gowda et al., 2022). 5-10% of individuals with schizophrenia die by suicide, underscoring the critical need for timely intervention and comprehensive care that spans from the FEP to long-term management (European Psychiatry, 2023). Schizophrenia significantly increases mortality rates and shortens life expectancy; compared to the general population, people with schizophrenia die 15-20 years prematurely (Correll et al., 2022). Moreover, they have an elevated risk of comorbid somatic illnesses, however they receive less medical care (Solmi et al., 2021; Leucht et al., 2007). Despite significant advances in treatment, the pathways to effective care remain fraught with barriers, and difficult-to-treat symptoms, still pose a therapeutic challenge and significantly interfere with functional recovery.

The EBC, in collaboration with the European Psychiatric Association (EPA) and key stakeholders, has undertaken the crucial task of addressing the enablers and weak spots in the schizophrenia care pathways. To examine these factors comprehensively, an originally developed survey for the EBC Rethinking Schizophrenia Care Pathway project **PHASE 2** explored the opinions of healthcare professionals and the experiences of patients and caregivers across nine European countries, providing a robust evidence base for actionable change. Respondents emphasised the need for strengthened investment and policy action in Europe to address long-standing challenges in mental health. While the region has experienced social and economic challenges, factors that have contributed to a growing mental health problem among youth and young adults, the nine studied countries are actively working to manage and improve the mental health of their citizens. There are significant opportunities for progress by tackling funding gaps, enhancing the status of mental health services, reducing stigma, and addressing the social determinants of mental health and inequalities. While the transition from institutional to community-based care varies across the EU, this report highlights three key priorities for enhancing schizophrenia care: early assessment and intervention, continuity of care with shared decision-making, and a recovery-oriented approach.

Early assessment and intervention

The survey highlights persistent barriers that hinder timely and effective care. Fragmentation within the healthcare systems, stemming from regional disparities in resource availability, often delays diagnosis and treatment. The stigma associated with schizophrenia remains a significant obstacle; it discourages help-seeking behaviour and limits access to services. Moreover, the lack of integration between primary care, community services and specialised mental health and addiction care providers leaves many patients navigating a disjointed and inefficient system. These challenges demand immediate attention. The data emphasise the need to reduce the duration of untreated psychosis, to use clinical neuropsychological assessment methods for a more precise characterisation of the patient's cognitive and functional impairments/strengths to better understand the patient's symptoms from the very beginning, and the necessity to improve access to multidisciplinary and patient-centred care.

Continuity of care and shared decision-making

Continuity of care is essential in the long-term management of schizophrenia. However, transitions between care settings—such as from acute inpatient care to outpatient or community-based services—are often poorly coordinated, leading to interruptions in treatment and support. The survey highlights the critical role of shared decision-making, emphasising the need to actively engage patients and their families in the management plans. Empowering patients with information and involving them in treatment choices fosters trust, improves adherence and enhances outcomes. Strengthening the therapeutic alliance between patients and providers is central to achieving sustained progress.

A recovery approach in the treatment journey

Recovery in schizophrenia is not merely the alleviation of symptoms but encompasses a broader focus on quality of life, social inclusion and personal empowerment. A recovery-oriented approach prioritises the biopsychosocial approach to care that integrates pharmacological treatments with psychosocial interventions, such as cognitive training, cognitive-behavioural therapy (CBT), vocational training and family support. It also addresses the social and environmental determinants of health, improving access to stable housing, education and employment opportunities. The integration of pharmacotherapy and psychosocial interventions represents a paradiam shift in schizophrenia care. Second-generation antipsychotics (SGAs), as a cornerstone of pharmacological treatment, combined with tailored psychosocial strategies, provide a comprehensive framework for addressing the disorder's complexities. This approach may not only alleviate symptoms but also empower individuals with schizophrenia to achieve functional recovery and improve their quality of life. The survey findings reveal a growing recognition of this change in thinking in schizophrenia care among European healthcare professionals, yet considerable work remains to be done to embed recovery principles into routine care.





Characterised by disruptions in thought processes, perception and emotional responsiveness, schizophrenia is a complex mental disorder that often leads to significant disability and inferior quality of life. Its onset typically occurs in late adolescence or early adulthood, however, most people are diagnosed between 20 and 30 years old. Prodromal symptoms (**Box 3** Progression of psychosis, from the first episode psychosis to long-term care), including negative symptoms, cognitive impairment and functional decline, may start earlier and go undetected (**Box 2** Positive symptoms, negative symptoms and cognitive impairment). Early detection and intervention services during the FEP are critical for altering the course of the illness and if not implemented properly, schizophrenia can turn into a chronic condition with severe functional impairment. Timely and effective treatment can reduce the severity of symptoms, improve functional outcomes and prevent deterioration that is often associated with schizophrenia. Despite advancements in treatments and evolving models of mental health services, significant gaps and disparities persist in the ways care is delivered and accessed across European countries.

In recent years, there has been growing recognition of the importance of a recovery-oriented and patient-centred approach that integrates pharmacotherapy, neuropsy-chological, psychological and social interventions throughout the care continuum. This shift emphasises not only the reduction of symptoms (particularly negative symptoms and cognitive impairment) but also the enhancement of overall brain health, social inclusion and quality of life for people living with schizophrenia. Such an approach requires rethinking care pathways, focusing on early intervention, multi-disciplinary care and ongoing support tailored to individual needs.

"Rethinking Schizophrenia: Optimising Schizophrenia Care Pathways in Europe" draws on the insights of healthcare professionals, patients and caregivers across Europe, providing a comprehensive overview of the current state of schizophrenia care pathways. By incorporating diverse perspectives, the report seeks to illuminate the common challenges across countries while highlighting innovative practices that can inspire meaningful change.



Professor Suzanne DicksonPresident, European Brain Council

Endorsers

The following organisations endorse the "Rethinking Schizophrenia: Optimising Schizophrenia Care Pathways in Europe" Policy Report, including the call to action and policy recommendations, to help improve the care and quality of life of people living with schizophrenia in Europe.



DGPPN German Association for Psychiatry, Psychotherapy and Psychosomatics



European College of Neuropsychopharmacology (ECNP)



European Psychiatric Association (EPA)



Fondation FondaMental



GAMIAN-Europe



Mental Power Foundation



Oxford Health Policy Platform



Positive Minders



Pszichiátriai Érdekvédelmi Fórum - Mental Health Interest Forum



Recovery Cat



Rethink Mental Illness



Schizo Oui

Call to action "Towards optimising schizophrenia care pathways"

The following policy recommendations align with the study findings to bridge the gap between research and policymaking. The primary goal is to translate these findings into actionable policy implications for schizophrenia prevention and care.

Schizophrenia arises from a multifaceted interplay of biological, genetic and environmental factors. Its management typically involves a combination of pharmacological treatments and psychosocial interventions, alongside careful attention to physical health and comorbidities treatment. Pharmacotherapy integration with psychosocial interventions is a cornerstone of care, crucial in improving functional outcomes across all stages of the disorder. However, there are unmet therapeutic needs, such as negative symptoms and cognitive dysfunctions, which are major contributors to functional impairment and are not adequately managed using standard antipsychotics alone. The development and use of SGAs are essential, as they have transformed the treatment landscape by offering improved efficacy and tolerability compared to first-generation antipsychotics (FGAs). However, SGAs have only limited efficacy on cognitive and negative symptoms, and the FGAs and anticholinergics can worsen or even induce them. Therefore, there is a need for a comprehensive treatment strategy integrating pharmacotherapy with psychosocial interventions that will alleviate symptoms, enhance patients' quality of life, and promote long-term recovery (Figure 1: Pathways to care from the first episode psychosis to long-term care, integrating the new treatment paradigm with psychosocial interventions).

Strengthen early detection and intervention frameworks, starting with a clinical and functional assessment of the patient toward stabilisation and recovery

Biopsychosocial focus: Address symptoms of schizophrenia at the earliest stages, including attenuated or brief psychotic symptoms, cognitive impairments, emotional distress, trauma exposure and social challenges such as stigma or family dynamics.

Action: Implement nationwide early psychosis intervention (EPI) programmes focused on early identification of at-risk individuals, including during childhood and adolescence, through community outreach, digital tools, workplace and school screenings, and primary care integration. It is pivotal to develop reliable and user-friendly tools for the assessment of cognitive functions and negative symptoms in everyday clinical practice. Current neuropsychological evaluation is typically time-consuming and requires expertise that is not always available.

New paradigm integration: Incorporate biomarkers, artificial intelligence (AI)-driven diagnostics and personalised screening models to enable early identification and targeted interventions.

2. Facilitate equitable access to innovative treatments

Biopsychosocial focus: Ensure a comprehensive treatment approach that combines pharmacological, psychosocial and social interventions such as psychotherapy, other forms of evidence-based therapy, peer support for patients and their relatives, and psychoeducation to enhance overall functioning and quality of life.

Action: Improve access to second-generation antipsychotics (SGAs), clozapine, long-acting injectables (LAIs), and novel therapies targeting cognitive and negative symptoms. Expand the use of digital health technologies, such as telemedicine, mobile apps, wearables and virtual reality (VR) therapy, to support patient engagement.

New paradigm integration: Promote precision psychiatry, supporting clinical trials and personalised treatment plans based on individual genetic, cognitive and psychosocial profiles.

3. Promote a coordinated approach and continuity of care models

Biopsychosocial focus: Ensure seamless transitions between different stages of care, from acute treatment to rehabilitation and long-term support, while addressing biological needs (symptom management), psychological well-being (coping skills) and social reintegration (employment, housing). Address physical health aspects of young individuals with early-stage psychosis, given the increased risk of metabolic and cardiovascular comorbidities in this population. Integrating preventive measures, such as regular physical health monitoring, exercise and life style interventions, would enhance the comprehensiveness of the approach.

Action: Establish multidisciplinary care teams that include general practitioners (GPs), child and adolescent psychiatrists, adult psychiatrists, psychiatric rehabilitation technicians, clinical psychologists and neuropsychologists, nurses, social workers, peers and community support specialists to deliver integrated care that can address the complex interactions between mental health, brain health, substance use, and physical health. For patients above 18 years old, GPs could be the first contact point to access a quality care pathway and work with colleagues to ensure an interdisciplinary and coordinated approach to schizophrenia.

New paradigm integration: Leverage telehealth, mobile-based monitoring and digital case management systems to facilitate continuity of care across settings and life stages.

4. Expand access to psychosocial interventions

Biopsychosocial focus: Address both psychiatric symptoms (e.g., delusions, anxiety) and social integration needs, ensuring strong support networks to sustain recovery.

Action: Scale evidence-based psychosocial programmes, such as psychoed-ucation, cognitive-behavioral therapy (CBT), trauma-sensitive interventions, family therapy, vocational training, and structured social skills programmes. Expand peer support networks to foster long-term patient engagement in treatment.

New paradigm integration: Combine psychosocial interventions with emerging technologies like virtual reality (VR) therapy to enhance engagement and improve outcomes.

5. Address social and environmental determinants of health and its role in mental health and cognitive development

Biopsychosocial focus: Awareness campaigns on how environmental exposures during critical developmental periods shape children and adolescents' mental health and cognitive development later in life. Mitigate the impact of social factors, such as violence, poverty, discrimination and isolation on mental health and recovery.

Action: Develop public policies that ensure housing stability, financial support and access to education and employment for individuals with schizophrenia.

New paradigm integration: Align mental health services with broader social and public health interventions, fostering collaborations between mental health care, housing, education and employment sectors to provide comprehensive, wrap-around support.

6. Focus on recovery and rehabilitation

Biopsychosocial focus: Shift the focus from symptom management to long-term recovery, emphasising functional independence, social integration and sustained well-being.

Action: Implement recovery-oriented care models that support long-term medication adherence, psychological resilience and social participation. Expand community-based rehabilitation programmes that offer tailored support for employment, social engagement and independent living.

New paradigm integration: Utilise digital tools for tracking recovery progress, remote patient engagement and goal-oriented treatment planning to enhance long-term outcomes.

7. Enhance workforce capacity and training

Biopsychosocial focus: Equip healthcare professionals with the knowledge and tools needed to address the complex biological, psychological and social dimensions of schizophrenia.

Action: Expand training programs for clinicians, social workers, educators and caregivers to promote early detection, comprehensive care approaches and integration of new treatment modalities. Strengthen interdisciplinary education to improve collaboration across different sectors of care.

New paradigm integration: Incorporate training on digital mental health tools, Al-supported diagnostics and precision medicine.

8. Invest in research and data-driven decision making

Biopsychosocial focus: Investigate the synergistic effects of combining pharmacological, psychological and social interventions on patient outcomes.

Action: Support longitudinal studies and real-world evidence collection on the effectiveness of integrated care pathways using the biopsychosocial model.

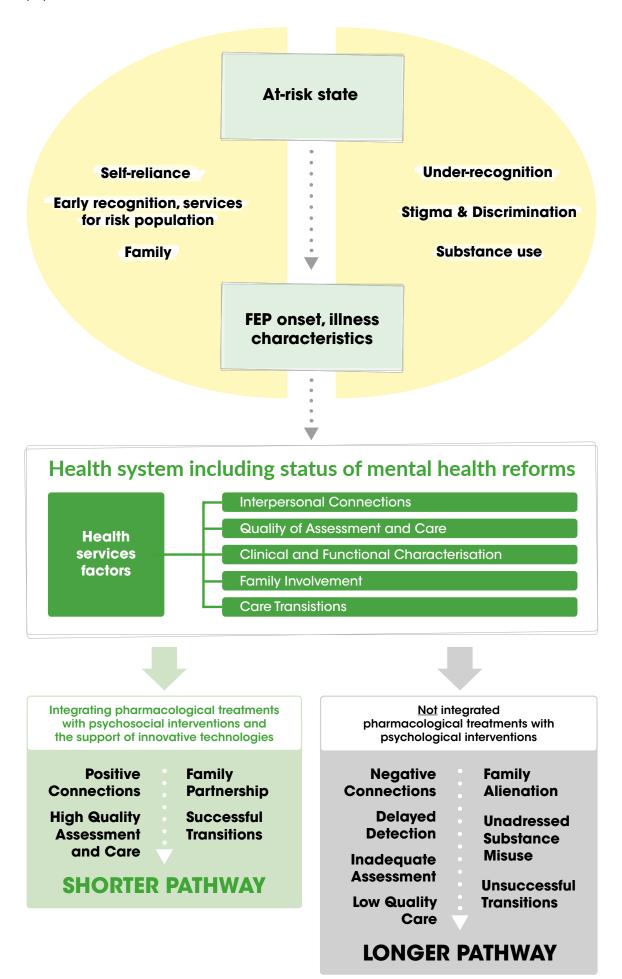
New paradigm integration: Explore how advanced technologies such as artificial intelligence (AI) and precision medicine can optimise care delivery and outcomes.

A proposed care pathway clinical model based on the Study Paper conclusions

Figure 1 illustrates the divergent pathways to care for people experiencing an first episode of psychosis (FEP), emphasising the interplay between a young individual, family and health services factors. It also highlights the integration of pharmacological treatments with psychosocial interventions. There are two contrasting pathways, one shorter and one longer, emphasising the role of integrated interventions and systemic support through the implementation of mental health reforms. It highlights the importance of integrated care to the shorter and more effective treatment path and demonstrates the challenges when such integration is absent.

The model underscores that integrating pharmacological treatments with psychosocial interventions is essential for reducing delays, improving care transitions and achieving better patient and family outcomes. Without this integration, individuals face fragmented care, family alienation and prolonged recovery pathways, affecting the success of long-term treatment for FEP.

Figure 1. Pathways to care from FEP to long-term care, integrating the new treatment paradigm with psychosocial interventions.





Optimising schizophrenia care pathways in Europe

1. Introduction

Schizophrenia is an identified leading cause of disability worldwide, with a peak age of 20.5 years (the onset of half of the cases is before age 25). It is a complex psychiatric disorder (Solmi et al., 2022) with an estimated global prevalence of 24 million people and affects 0.3-1.5% of Europeans (World Health Organization, 2022). Its phenotype may vary in terms of psychopathological features, risk factors, comorbidities, course, response to treatment and personal trajectories (Giordano et al., 2022). Schizophrenia has a profound influence on the real-life functioning of patients, with an enormous burden on families and healthcare systems, mainly because of the delayed recognition, prevention and intervention (Fusar-Poli et al., 2021). It heavily affects every aspect of life, including relationships, education and employment.

Understanding the cause of schizophrenia is challenging due to its multifaceted nature. However, there is consistent evidence supporting genetic and various risk factors contribution (Box 1 - Causes and risk factors of schizophrenia). People with schizophrenia die 15-20 years earlier than the general population, primarily due to comorbid physical illnesses such as cardiovascular disease, diabetes and respiratory conditions (Correll et al., 2022). There are several factors inherent to the disease course that contribute to the functional and social impairment in schizophrenia. Some are related to the illness, such as persistent cognitive dysfunctions and negative symptoms (Mucci et al., 2023), and others are due to the context of stigma and discrimination (The Lancet, 2022).

Schizophrenia manifests itself through a spectrum of clinical symptoms categorised into three primary domains: positive, negative and cognitive (Box 2 - Positive symptoms, negative symptoms and cognitive impairment). The period between the onset of the FEP and treatment initiation, also known as the duration of untreated psychosis (DUP), is a critical concern for the mental health system (Cabassa et al., 2018). Longer DUP is associated with negative outcomes (for example, worse functioning) (Catalan et al., 2024), thus identifying delays along the pathway to care is essential. As an indicator defined around the time to reach a diagnosis, an excessively long DUP corresponds to 43 weeks worldwide (Salazar de Pablo et al., 2023). Despite the availability of pharmacological and psychosocial treatments, approximately 75% of persons living with schizophrenia have a clinical course characterised by phases of remission and relapse, and only about 15% meet the criteria for recovery (Giordano et al., 2022). Relapse of the symptoms of schizophrenia could be due to poor medication adherence or the presence of ongoing or emerging psychosocial stressors. These elements make the course of the illness chronic and phasic (Fusar-Poli et al., 2017; Higashi et al., 2013). In addition, the relapse of schizophrenia symptoms is associated with increased crisis interventions, re-admission and emergency care visits (Correll et al., 2021; Fusar-Poli et al., 2020; Emsley et al., 2013). Therefore, there is a need to focus on the trajectory of psychosis from its onset to chronic stages, outlining best practices for long-term care and relapse prevention (Box 3 - Progression of psychosis, from the FEP to long-term care and Figure 2). Even though factors shaping care pathways for people experiencing FEP have been identified (Cabassa et al., 2018), at present, little is known about how these factors interact to facilitate, shorten or lengthen care pathways, particularly among individuals and families entering early intervention services (EIS) for FEP to long-term care.

Unmet needs range from treatments for negative symptoms and cognitive impairment (e.g., antipsychotic medications, psychosocial therapies and the management of comorbidities) to gaps in service provision. Given the variability in terms of clinical guidelines and reforms implementation across health systems and in the face of an unprecedented demand for mental healthcare for young people, it can be challenging for health services to deliver high-quality assessment and care. The World Health Organization (WHO)¹ and the EPA (EPA Policy & Guidance Papers) emphasise community-based care and timely interventional programs. These recommendations intend to integrate mental health into the community while improving accessibility, affordability and availability and promote pharmacotherapy and the psychosocial model, which meets individuals' and carers' needs (Box 4 - Holistic schizophrenia care and Figure 3).

Based on the survey results, descriptive analysis and a multi-stakeholder consensusreaching discussion, this **study paper** aims to **(i) identify barriers to care for schizophrenia patients** looking for primary cognitive assessment, continuity of care, shared decision-making and a recovery-oriented approach in the treatment journey, **(ii) rethink mental health services for schizophrenia patients** considering the new treatment paradigm, and **(iii) suggest recommendations for schizophrenia care pathways optimisation**, from the FEP to long-term care.

Box 1 • Causes and risk factors of schizophrenia

There is not one single cause of schizophrenia, but certain genetic, neurodevelopmental, environmental and psychosocial factors can increase a person's susceptibility to the condition and influence its onset and course. Risk factors include genetic susceptibility, prenatal and perinatal complications, childhood adversity, cannabis use, and other substance abuse. Children of parents with schizophrenia are more at risk of developing the disorder themselves. Substance abuse, particularly alcohol, cannabis and psychostimulant use during adolescence, is linked to an increased risk of schizophrenia (Uher et al., 2023; Radua et al., 2018; Castle et al., 2017).

Box 2 • Positive symptoms, negative symptoms and cognitive impairment

The cognitive impairment associated with schizophrenia (CIAS) is a particularly burdensome unmet need that, along with positive and negative symptoms, is insufficiently addressed by current antipsychotic treatments. CIAS is a highly impactful core symptom of schizophrenia that affects 80% of schizophrenia patients (Galderisi *et al.*, 2024; Bitter *et al.*, 2021; Galderisi *et al.*, 2021).

¹ WHO Mental Health Action Plan 2013-2020; WHO European framework for action on mental health 2021–2025; Mental Health Gap Action Programme (mhGAP) guideline for mental, neurological and substance use disorders; WHO Integrated operational framework for mental health, brain health and substance use

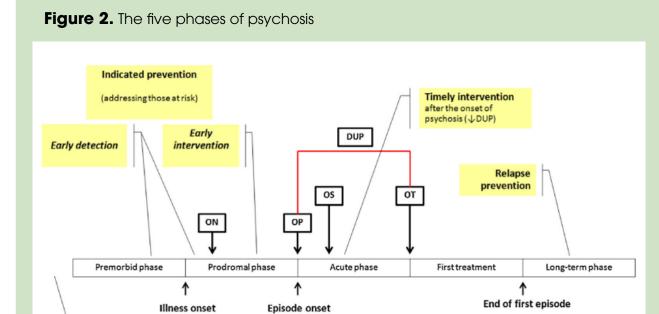
Symptom Category	Description
Positive Symptoms	These involve excesses or distortions in perception, thinking and behaviour. They include hallucinations (perceptual disturbances, such as hearing voices or seeing things that are not present), delusions (strongly held false beliefs despite contradictory evidence), formal thought disorders (disorganised thinking patterns, such as tangentiality or incoherence) and disorganised behaviour (unpredictable or inappropriate actions).
Negative Symptoms	These represent diminished abilities related to emotion, motivation, communication and social engagement. They include diminished emotional expression (reduced facial expressions and vocal tone), avolition (lack of motivation to initiate and sustain activities), alogia (reduced speech output or difficulty in conversation), anhedonia (decreased ability to experience or anticipate pleasure) and asociality (withdrawal or lack of interest in social interactions).
Cognitive Symptoms	These involve difficulties with cognitive processes essential for daily functioning. They include impairments in attention, memory, executive functions (planning and decision-making), processing speed, intellectual reasoning, spatial reasoning and social cognition (understanding and responding to social interactions). These challenges can significantly impact problem-solving, learning and independent living.

Box 3 • Progression of psychosis, from the first episode psychosis (FEP) to long-term care

The progression of psychosis can be delineated into five stages, each with distinct features:

- 1. **Premorbid Stage:** This initial phase occurs before noticeable symptoms emerge. Individuals may exhibit subtle cognitive or social impairments, but these signs are often unrecognised as precursors to psychosis.
- 2. **Prodromal Stage:** Also known as the at-risk mental state. This stage involves the gradual onset of subclinical symptoms such as mild perceptual disturbances, unusual thoughts or changes in behaviour. Early intervention during this phase is crucial in potentially delaying or preventing the progression to full-blown psychosis.
- **3. Acute Phase:** Characterised by the emergence of evident psychotic symptoms, including hallucinations, delusion and disorganised thinking. This stage often leads to significant distress and impairment in daily functioning, requiring immediate medical attention and intervention to stabilise symptoms.
- **4. Recovery Phase:** Individuals may experience acute symptom reduction following treatment initiation. During this stage, the focus is on stabilisation and the gradual return to daily functioning.
- **5. Residual or Chronic Phase:** Some individuals may continue to experience residual symptoms, such as blunted affect or social withdrawal. Ongoing treatment and support are essential to manage these symptoms and improve quality of life.

Understanding these stages facilitates timely intervention and tailored treatment strategies, potentially altering the course of the disorder and improving outcomes.



Illness duration

Psychotic episode duration

ON = onset of negative symptoms

OP = onset of positive symptoms OS = onset of syndrome OT = onset of treatment

DUP = duration of untreated psychosis

Source: EBC Study. The Value of Schizophrenia Treatment: The Patient Journey (Mohr et al., 2018)

Selective prevention (addressing the whole

population)

Recent studies have provided insights into the understanding, progression and management of the stages of psychosis and underscore the importance of early detection and comprehensive management strategies.

- Prediction of Psychosis: Research emphasises the importance of early detection and intervention in individuals at high risk for psychotic disorders, highlighting the potential to ameliorate the course of the disorder.
 (Rutigliano et al., 2022; Fusar-Poli et al., 2021; Hartmann et al., 2021; Salazar de Pablo et al., 2021; Nelson et al., 2020)
- Neurobiology of Early Psychosis: Findings indicate that brain structural alterations are present early in the illness and may predate symptom onset, underscoring the need for early assessment and intervention.
 (Schultz et al., 2023; Anticevic et al., 2022; van Erp et al., 2022; Gur et al., 2021; Pantelis et al., 2020)
- Sleep Abnormalities Across Stages: Research studies results suggest that sleep disturbances have been found to be prevalent throughout psychosis, with different stages showing both shared and distinct abnormalities in sleep quality and architecture (cyclical pattern of sleep).

 (Bagautdinova et al., 2023; Mullins et al., 2023; Reeve et al., 2022; Wulff et al., 2022; Kaskie et al., 2021; Lunsford-Avery et al., 2021)

Box 4 • Holistic schizophrenia care

Pharmacotherapy and psychosocial-environmental approaches together form the foundation of holistic schizophrenia care. Integrating pharmacotherapy with this approach enhances patient outcomes by addressing biological, social and environmental determinants of health. (Lisoni *et al.*, 2024; Giordano *et al.*, 2022; Asher *et al.*, 2017)

Pharmacotherapy: The role of Second-Generation Antipsychotics (SGAs)

SGAs have transformed the treatment landscape for schizophrenia. Compared to FGAs, SGAs offer significant advantages, including:

- Improved Tolerability: SGAs are associated with a lower risk of extrapyramidal side effects, such as movement disorders, which often deter adherence to FGAs. However, SGAs also have significant side effects, such as weight gain and metabolic side effects.
- **Broader Symptom Management:** SGAs effectively target positive symptoms (e.g., hallucinations and delusions), do not induce or worsen negative symptoms (e.g., avolition, anhedonia) and might improve secondary ones.
- Cognitive Symptom Impact: Although SGAs initially showed promise in addressing cognitive impairment interfering with functional recovery, their efficacy is
 limited in enhancing memory, attention and executive functioning.

Thus, there are unmet needs in pharmacotherapy and novel mechanisms of action should target difficult-to-treat symptoms that interfere with the patient's functioning, such as negative and cognitive symptoms.

Long-acting injectables (LAIs) introduction as part of the pharmacological toolkit further enhances adherence by reducing the dosing frequency and providing consistent therapeutic coverage.

Psychosocial interventions: Enhancing functional outcomes

Psychosocial interventions are essential complements to pharmacotherapy, addressing the psychological and social barriers to recovery. Key interventions include:

- Cognitive Behavioural Therapy (CBT): Helps patients challenge delusions and develop coping mechanisms for stress and anxiety.
- Family Therapy: Equips families with tools to support the patient, reducing caregiver burden and improving family dynamics.
- Vocational and Social Skills Training: Enables patients to rebuild functional capacities, fostering independence and reintegration into society.
- Peer Support and Self-Help Groups: Offer a perception of community and empowerment, helping patients share experiences and overcome stigma.
- Exposome Framework: Provides specific interventions targeting the lifetime totality of exposures and focusing on key lines of childhood and adolescent development to reduce adverse exposures and enhance protective factors.

Integrating SGAs with psychosocial interventions

Integrating SGAs with psychosocial interventions creates a synergistic effect, enhancing treatment outcomes by:

- Reducing Relapse Rates: Consistent medication combined with structured therapy prevents symptom exacerbation. Digital technologies (apps, wearables) can effectively assist relapse prevention.
- Improving Adherence: Psychoeducation, paired with user-friendly pharmacological options such as LAIs, encourages patients to stay on treatment.
- Fostering Recovery: Addressing the full spectrum of symptoms and challenges
 —biological, psychological and social—supports patients' ability to lead
 meaningful lives.

The approach acknowledges the complex interplay of multiple dimensions influencing mental health. When applied to care pathways, this approach seeks to optimise outcomes by addressing the diverse and interconnected needs of schizophrenia patients. Also, by integrating preventive and health-promoting strategies, prevent or treat comorbidities.

physical health metabolic neurochemistry disorders **Biological** genetic comorbidity vulnerability immune/stress response response to drug effects reward peer diet/ emotions group lifestyle self-esteem MENTAL HEALTH work school attitudes/beliefs Social **Psychological** interpersonal & Environmental relationships perceptions coping trauma socio-economic skills status grief temperament culture family social skills circumstances

Figure 2. Holistic schizophrenia care

Source: The revisited biopsychosocial model of mental health (Bolton, 2024)

2. Methods - A survey: Optimising care pathways in Europe

This qualitative research focuses on mental health services provision. A survey was co-created by the EBC and the EPA with a group of experts, including patient association representatives, based on the first phase of the project EBC Rethinking Schizophrenia Beyond The Voices Policy Report conclusions on patient unmet needs. The schizophrenia working group, led by Prof. Geert Dom, consisted of members of the EPA Board, representatives of the Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe), the European Federation of Associations of Families of People with Mental Illness (EUFAMI) and the Czech National Institute of Mental Health (NIMH). The EBC and the EPA led the study.

The survey (45 questions were defined, among which 10 opened questions) was anonymously conducted from 15 May 2024 to 31 August 2024 with the aim to describe the care pathways of patients from FEP to long-term care throughout the mental health system in different European countries with a focus on youth and young adults. Healthcare providers from the selected countries (Belgium, Denmark, France, Germany, Hungary, Italy, Poland, Spain, and the United Kingdom) shared their insights on this topic. Responses primarily reflected the country's situation, personal experiences and opinions.

Definition and data analysis: Capturing the variety of clinical pathways in patients with schizophrenia spectrum disorders through state sequences analysis

Schizophrenia care pathways refer to a structured and coordinated series of clinical, psychosocial and support services designed to guide individuals with schizophrenia through their treatment and recovery journey. These pathways encompass all stages of care, from early detection and intervention during the FEP to long-term management and reintegration into society. Care pathways are increasingly being used to enhance the quality of care and optimise the use of resources for health care (Savaré *et al.*, 2023; Mohr *et al.*, 2018).

Based on the survey results and description of real-life experiences from respondents, mental health professionals' insights were collected and extracted data were analysed. Qualitative data from opened questions were summarised to identify factors that facilitated, expedited or delayed entry or access to the care pathways. **A model emerged from our data depicting factors (Figure 1)**. In this study, recommendations regarding the sequence of care are mostly based on recent evidence and consensus-based decisions on effective treatment sequences. Obtained data were analysed by the expert's group and were used to formulate recommendations (both country-specific and at the EU level). Recommendations with the clinical model development were discussed to reach a consensus during a final consultation period (between 17 December 2024 and the end of January 2025).

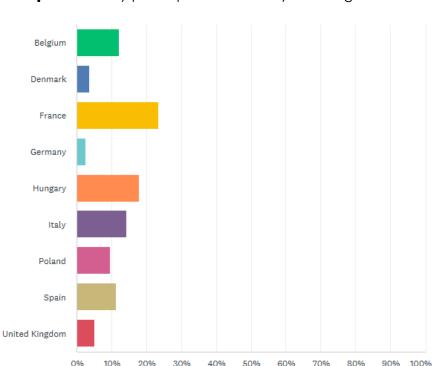
3. Results & discussion

The results of this investigation provide valuable insights into the broad challenges in the context of mental health care. We identify key factors ranging from assessment and early intervention services to continuity of care and collaborative decision-making toward recovery. The discussion of the results is based on experiences shared by mental health professionals from the nine European countries (Belgium, Denmark, France, Germany, Hungary, Italy, Poland, Spain, and the United Kingdom).

Based on recent evidence, we explain the key factors and present a clinical model to improve schizophrenia care in Europe.

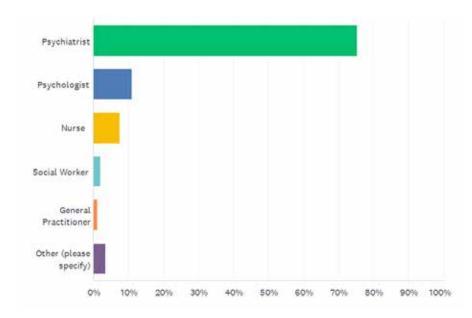
Characteristics of participants to the survey - Demographics

Responses to the survey from 203 healthcare providers (psychiatrists, psychologists, nurses, social workers, general practitioners, public health specialists and voluntary workers) were analysed (**Graph 1** and **Graph 2**). More females (52%) responded than males (48%). The mean age of healthcare providers was between 46 and 55 years old. More than 75% of participants were psychiatrists, 11% psychologists, 7% nurses, 2% social workers, 1% general practitioners and 4% public health specialists, therapists and voluntary workers. 68% of participants had more than 10 years of professional activity. The mean time of professional experience was between 11-25 years with caseload varying per healthcare practice from less than 10 to more than 100 patients.



Graph 1. Survey participants - Country coverage





Aswer Choices	Respor	nses
Psychiatrist	75,3%	153
Psychologist	10,84%	22
Nurse	7,39%	15
Social Worker	1,97%	4
General Practitioner	0,99%	2
Other	3,45%	7
Total		203

3.1 Challenges in current mental health care for schizophrenia patients



"Challenges remain in Europe to transition from institutionalised care to communitybased models, ensuring that individuals receive appropriate and timely mental health services within their communities."

Geert Dom, President, European Psychiatric Association

Schizophrenia care pathways across Europe face significant challenges at both the meso (service) and macro (system) levels, as highlighted by survey findings. These systemic issues affect the provision, accessibility and quality of care for individuals with schizophrenia, underscoring the urgent need for targeted reforms and improvements.

Meso Level: Barriers to schizophrenia care services

1. Perceptions of current care systems

Survey results revealed widespread dissatisfaction among healthcare professionals about the adequacy of schizophrenia care systems:

- 49% of respondents disagreed that their country's care system could be considered optimal, with an additional 6% strongly disagreeing.
- Only 22.5% of respondents agreed that the system was optimal, and none strongly agreed.
- 22.5% remained undecided, reflecting variability in care quality across regions.

These findings show that over half of the respondents perceive substantial deficiencies in care pathways, highlighting systemic issues such as fragmented care, lengthy delays in assessment and treatment, and insufficient access to specialised services. This agrees with other findings (Oxford Health Policy Forum, 2024; Vita *et al.*, 2022).

2. Barriers to access

A significant 70% of respondents identified persistent deficiencies to accessing mental health services, including:

- The long waiting times for appointments and treatment.
- Limited outpatient services, particularly early intervention teams.
- Poor communication and information sharing between providers, patients and families.
- Lack of equal access to trained therapists.
- Coercive strategies of the treatment teams.
- Nursing should be improved.
- Low availability of mental health centres and absence of employment programs.
- Lack of time and resources, services, facilities and mental health professionals.
- Low use of new services and methods (early detection, prevention, open dialogue, among others) and overreliance on antipsychotics with side effects.
- Delayed crisis intervention.
- Discontinuity in care pathway.
- Insufficient social support, social care; poor cooperation between medical and social care, integrated care.
- Low availability of psychotherapy and support therapy.
- Inadequate care for patients in detention, lack of forensic care programs.
- Excessive cost of LAIs.
- Discontinuity of care, transition from child to adult care.
- Stigma.

Barriers in the schizophrenia care pathway often exacerbate disparities in care quality, particularly between socio-economic groups and urban and rural areas, highlighting the need for equitable and patient-centred approaches and the right to treatment (GAMIAN, 2024; Correll *et al.*, 2023; Hudson *et al.*, 2023; Vita *et al.*, 2023; Thornicroft *et al.*, 2022).

3. Regional variability

The discrepancy of responses, including undecided participants, suggest that care quality varies significantly across different regions and healthcare settings. While some areas benefit from well-functioning systems, others face severe shortages of resources, personnel and infrastructure. Addressing these disparities requires integrated care pathways, better resource allocation and improved stakeholders' coordination (Malla et al., 2023).

It would be helpful if future European guidelines for the treatment of schizophrenia included recommendations for both well-functioning systems and systems with fewer resources.

Macro Level: The need for mental health reforms in Europe

In the provisions of mental health services, the identified deficiencies are barriers to achieving strong therapeutic collaborations. To address these challenges, it is recommended that EU Member States increasingly adopt community-based mental health care models (European Union Compass for Action on Mental Health and Well Being, 2016). However, in most countries in Europe, mental health hospitals are still the prominent model of care. Some countries have endorsed a balanced care model, with the co-occurrence of community services and mental hospitals, although this is not yet the general picture (Oxford Health Policy Forum, 2024; Vandoni *et al.*, 2024).

1. Diverse approaches to reform

The reform of mental health systems across Europe presents a complex and uneven landscape. While some countries have adopted community-based mental health care models and made strides in integrating services, others continue to struggle with systemic challenges.

 58% of respondents acknowledged their availability, only 25% reported widespread access.

This fact points to significant gaps in accessibility that hinder effective service delivery. Enhancing the reach and capacity of community mental health services is critical for fostering recovery and integration (Thornicroft *et al.*, 2016).

As reflected in the survey responses, countries focusing on early intervention and recovery-oriented care have achieved improved accessibility and engagement. Ongoing reforms in countries emphasise the **importance of multisectoral mental health care networks**, which integrate prevention, in-patient and outpatient mental health services, primary care, daycare, vocational support, housing and social care services (Simon *et al.*, 2023). Also, **investments in multidisciplinary care teams and digital health solutions are enhancing outcomes** in these regions (Berardi *et al.*, 2024; Smith *et al.*, 2023).

However, there are persistent challenges. 33% of respondents reported that reforms are progressing too slowly or ineffectively, often due to underfunded systems, workforce shortages and fragmented policies.

2. Systemic barriers

Two main systemic barriers continue to hinder progress:

Disparities in Access: Geographic and socioeconomic inequities result in uneven care availability between urban and rural areas and high- and low-income countries.

Lack of Coordination: Inconsistent policy implementation across countries limits alignment with international guidelines, such as those from the WHO or the EPA (**Box 5** - Recommendations for a shift from institutional care to community services).

The current state of mental health care systems for schizophrenia highlights significant challenges, as well as opportunities for transformative reforms. Integrating care pathways, addressing systemic disparities and adopting patient-centred approaches are crucial to achieving equitable, high-quality care across Europe. While progress has been made in some regions, sustained efforts are needed to ensure that all individuals with schizophrenia have access to the support and resources they need for recovery. Here is a summary of the situation in the selected countries (Table 1).

Table 1 Status of mental health reforms in countries under study

Country	Characteristics (population and GDP dedicated to health) OECD 2023 Data	Status of mental health reforms	References
Belgium	Population: 11.5M GDP health expenditure: ~10.9%	Reforms started in 2010 emphasise deinstitutionalisation and community-based care, with networks of mental health services aiming for better integration and continuity of care. However, challenges include addressing gaps in access and quality of care.	Good Practice Brief (2018) Mental Healthcare Reform Initiatives – For a Healthy Belgium (2024) European Observatory Belgium Health System Summary (2024)
Denmark	Population: 5.8M GDP health expenditure: ~9.4%	A new 10-year plan to improve mental health in Denmark was adopted in 2022. Known for robust social services, Denmark is advancing mental health integration into primary care and preventive measures, but pressures on the capacity persist due to rising demand.	The Danish Approach to Mental Health (2023) State of Health in the EU Denmark, country health profile 2023 (2023) European Observatory Denmark Health System Summary (2024)
France	Population: 67.5M GDP health expenditure: ~11.6%	Efforts focus on improving mental health service availability and reducing stigma. However, long waiting times and disparities in access between urban and rural areas are still problematic.	EU JA ImpleMENTAL - Country Profile France Community-based Mental Healthcare Networks: Key Facts and National Priorities (2023) European Observatory France Health System Summary (2024)

Country	Characteristics (population and GDP dedicated to health) OECD 2023 Data	Status of mental health reforms	References
Germany	Population: 83M GDP health expenditure: ~11.8%	A mental health system with comprehensive coverage has seen reforms targeting deinstitutionalisation and expanding outpatient services. Workforce shortages, particularly in psychiatry, pose ongoing challenges.	EU JA ImpleMEN- TAL - Country Profile Germany Community-based Mental Healthcare Networks: Key Facts and National Priorities (2023) European Observatory Germany Health System Summary (2024)
Hungary	Population: 9.7M GDP health expenditure: ~6.4%	Mental health reform is still developing, with challenges including underfunding and limited access to care. Efforts are being made to align with WHO recommendations, though progress remains slow.	EU JA ImpleMENTAL - Country Profile Hungary Community-based Mental Healthcare Networks: Key Facts and National Priorities (2023) European Observatory: Hungary Health Profile (2023)
Italy	Population: 60.3M GDP health expenditure: ~8.4%	The country has a history of deinstitutionalisation following its landmark 1978 reforms. Current efforts aim to strengthen community-based services, although funding and resource allocation issues persist.	Basaglia Law Anniversary Report (2023) EU JA ImpleMENTAL - Country Profile Italy Community-based Mental Healthcare Networks: Key Facts and National Priorities (2023) European Observatory Italy Health System Summary (2024)
Poland	Population: 37.8M GDP health expenditure: ~7%	Despite country's non-participation in <u>JA ImpleMENTAL</u> , recent adoption of EU community best practice EAAD-Best and <u>WHO's Mental Health Gap Action Programme</u> (mhGAP) marks attempts at introducing psychiatry to GP level of healthcare. However, with only 3.7% of the health budget spent on mental health and significant stigma, there is a pressing need for further reform.	WHO News Release, October 2023 (2023) Poland's Capital City Against Depression Movement European Observatory Poland Health System Summary (2022)

Country	Characteristics (population and GDP dedicated to health) OECD 2023 Data	Status of mental health reforms	References
Spain	Population: 47.5M GDP health expenditure: ~9.6%	Reforms aim to reduce institutionalisation and enhance community-based mental health care. Regional disparities in service provision and funding allocation present significant challenges.	EU JA ImpleMENTAL - Country Profile Region of Murcia, Spain Community-based Mental Healthcare Networks: Key Facts and National Priorities (2023) European Observatory Spain Health System Summary (2024)
United Kingdom	Population: 67M GDP health expenditure: ~10.9%	The National Health Service (NHS) has committed to expanding mental health services, focusing on early intervention and prevention. Significant reforms are taking place to improve mental health care, particularly through the proposed Mental Health Bill (November 2024). Workforce shortages and increased demand continue to strain the system.	European Observatory United Kingdon Health System Summary (2022) New NHS Mental Health Bill proposed (2024)

Box 5 • Recommendations for a shift from institutional care to community services

The WHO and the EPA emphasise the importance of community-based care and timely intervention programs in mental health services.

The WHO *Mental Health Action Plan 2013–2020* underscores the provision of comprehensive, integrated mental health and social care services in community-based settings.

Building upon this, the WHO *European Framework for Action on Mental Health 2021–2025* addresses emerging mental health challenges, including those exacerbated by the COVID-19 pandemic, and continues to advocate for community-oriented mental health services. In October 2023, WHO/Europe called on its Member States to rethink and invest in better mental health systems to build resilience amid ongoing challenges (WHO European Office, Press Release, October 2023).

The WHO Mental Health Gap Action Programme (mhGAP) aims to scale up services for mental, neurological and substance use disorders, by enhancing the ability and skills of non-specialist/primary health care workers to deliver mental health care in community settings. The implementation of the mhGAP program is limited in Europe, only implemented in Poland, Ukraine, Armenia, Georgia and Kyrgyz Republic, it is not scaled up yet, and the implementation barriers are high. In EU, most GP training systems have selected psychiatry topics as part of the curriculum, so the need for mhGAP is not crucial. In some contexts, the authority of WHO is helpful in mental health advocacy, but trainings for GPs are not going smoothly.

The WHO Integrated Operational Framework for mental health, brain health and substance use shines a light on the links between mental, neurological and substance use (MNS) conditions and the links between MNS conditions and other health conditions to show how integrating promotion, prevention and management strategies can lead to a more effective use of resources, better health outcomes, improved efficiency and cost effectiveness.

Additionally, the WHO is currently developing new quality standards to improve the quality of child and adolescent mental health care in the WHO European Region.

Complementing these efforts, the EPA has developed guidance papers (European Psychiatric Association, 2021; Gaebel *et al.*, 2020; Gaebel *et al.*, 2012) to improve the quality of mental health care in Europe, focusing on care coordination and the integration of services to ensure prompt and effective interventions.

Collectively, these policy initiatives reflect a concerted effort (sum of local and regional efforts) to transition from institutionalised care to community-based models, advocating that individuals receive proper and timely mental health services within their communities.

3.2 Early assessment and intervention



"A comprehensive and systematic assessment of neurocognitive and social cognitive domains in schizophrenia across all phases of the disorder is essential, highlighting the importance of clinical neuropsychology in both evaluation and treatment planning."

Peter Falkai, Treasurer, European Brain Council

Insights from mental health professionals across Europe reveal critical challenges and opportunities in addressing stigma, enhancing psychoeducation, improving accessibility to EIS and optimising care pathways for schizophrenia. These findings provide actionable directions to improve outcomes for individuals with schizophrenia, supported by the latest research and clinical recommendations.

Stigma and discrimination

Stigma and discrimination remain pervasive barriers affecting individuals with schizophrenia. Our survey findings reveal that:

- 48% of respondents acknowledged recent anti-stigma initiatives,
- 33% reported the absence of such efforts in their regions, and
- 19% were unaware of any campaigns.

Stigma negatively affects education, employment and social relationships, perpetuating isolation and hindering access to care. **Anti-stigma campaigns are shown to be effective in reducing discriminatory attitudes and improving community support** (Corrigan *et al.*, 2022).

Psychoeducation gap

The survey highlighted insufficient psychoeducation among healthcare professionals, including physicians, GPs and nurses. This gap undermines the ability of healthcare systems to deliver effective and informed care to patients and to informal carers. Targeted psychoeducation programs focused on understanding and managing schizophrenia are urgently needed to improve clinical outcomes (Vita *et al.*, 2022).

Evidence-based strategies, such as training programs and workshops for mental health providers, have demonstrated significant improvements in clinical practice and patient outcomes (Mojtabai *et al.*, 2023).

Accessibility to early assessment and detection services

Like other health care sectors, mental health has moved towards secondary prevention, with the effort to detect and treat mental disorders as early as possible. However, converging evidence sheds new light on the potential of primary preventive and promotion strategies for young people's mental health (Colizzi *et al.*, 2020). Early assessment and detection are essential for identifying at-risk individuals and initiating timely interventions. However, according to our results:

- · Only 46% of respondents indicated the availability of such services, and
- 41% reported a lack of access.

EIS have been shown to reduce the DUP, improve symptom management and enhance social functioning (Srihari *et al.*, 2023). **Expanding access to these services and minimising barriers is critical to improving outcomes for youth with emerging psychotic symptoms** (McGorry *et al.*, 2022).

Help-seeking and early psychosis intervention

Factors such as symptom attribution, stigma and self-reliance influence help-seeking behaviours. These factors often delay access to early psychosis intervention services, with almost half of all new psychotic disorders first diagnosed in emergency departments or inpatient settings (Drake *et al.*, 2023).

Studies highlight the importance of **family involvement and trust in mental health providers in facilitating timely help-seeking and referrals** (Malla *et al.*, 2023). Addressing barriers to early intervention requires improved **public awareness and service coordination**.

Hospitalisation for First Episode Psychosis (FEP)

Hospitalisation remains a common entry point for care in FEP. According to the survey:

- 22% of respondents indicated routine hospitalisation for FEP, and
- 63% noted it is often necessary.

The duration of hospital stays varies widely:

• 52% of respondents reporting typical stays of 2–4 weeks.

Early recognition and intervention to stabilise patients can reduce the need for prolonged hospitalisation and improve recovery outcomes (Correll *et al.*, 2023).

Rationale for neuropsychological assessments

Neuropsychological evaluations are critical in assessing cognitive impairments, particularly in young people with schizophrenia. These assessments are essential for identifying cognitive dysfunctions and implementing cognitive remediation strategies, yet many patients still do not receive such evaluations (Vita *et al.*, 2022).

Increasing awareness among mental health providers and incorporating neuropsychologists into care teams can improve functional recovery and rehabilitation.

Improving Early Intervention Services (EIS)

EIS programs aim to reduce DUP and provide timely, comprehensive care to individuals with early psychosis. Despite their demonstrated effectiveness, barriers such as difficulty recognising symptoms, lack of trust in providers and poor service coordination persist (Srihari *et al.*, 2023). Performance indicators, such as the proportion of patients hospitalised before admission to EIS, highlight the need for better pathways to care.

Studies show that involving family members and diagnosing patients in outpatient settings significantly improves access to EIS programs (McGorry *et al.*, 2022).

3.3 Continuity of care and shared decision-making



"There is a need for fostering inclusive care pathways that actively involve patients and their caregivers in treatment decisions. Continuity of care and shared decision-making strongly reinforce therapeutic collaborations between mental health professionals, patients and their primary carers for better outcomes."

John Saunders, Executive Director, European Federation of Associations of Families of People with Mental Illness

Findings underscore persistent deficiencies to seamless transitions, continuity of care, shared decision-making, multidisciplinary collaboration and the availability of community-based mental health services. Addressing these issues is essential for advancing patient-centred, recovery-oriented care models.

Transition from inpatient to outpatient care

Transitions between care settings, particularly from inpatient to outpatient services, represent a crucial juncture in schizophrenia management. According to survey respondents, a lack of coordination and unclear follow-up care options are significant barriers, often resulting in fragmented transitions. Such disruptions can lead to treatment discontinuity and poor patient outcomes. Strengthening care coordination and establishing robust referral systems are pivotal to ensuring a smoother transition and sustained recovery.

These results align with recent findings emphasising the **need for integrated care** pathways to improve schizophrenia outcomes (Javed & Herrman, 2023; WHO, 2023).

Continuous treatment and follow-up care

Survey results reveal gaps in continuous treatment and follow-up care post-discharge:

- 43% of respondents stated that most patients receive consistent follow-up,
- 21% indicated consistent follow-ups for all patients.
- However, 58% noted that outpatient care is frequently not provided by the same therapeutic team, potentially impacting treatment quality.

These findings are consistent with evidence suggesting that **continuity of care is critical for reducing relapse rates and improving patient outcomes** (Correll *et al.*, 2023).

Shared decision-making

Shared decision-making, as a cornerstone of personalised mental health care, is still inconsistently practiced. The survey indicates that:

- 27% to 35% of respondents reported consistent collaboration between patients, families and providers during treatment planning.
- Up to 22% noted that such collaboration is rare or absent.

A more inclusive care model that actively involves patients and their families in decision-making is essential for achieving better adherence and satisfaction (Drake et al., 2022).

Multidisciplinary care

A multidisciplinary approach enhances care quality by integrating the expertise of various healthcare professionals. Our results show that:

- 25% of respondents reported consistent use of multidisciplinary care at treatment initiation, and
- 55% indicated that the multidisciplinary care is employed selectively.

Standardising multidisciplinary practices is critical for providing holistic support and ensuring comprehensive care from the outset (Mojtabai *et al.*, 2023).

Role of General Practitioners (GPs)

The role of GPs in managing the physical health of individuals with schizophrenia is underutilised. According to our results:

- 28% of respondents reported shared responsibilities between GPs and mental health professionals, and
- 9% noted that GPs take primary responsibility for integrated care.

Expanding GPs' involvement is vital for addressing the physical and mental health comorbidities commonly observed in schizophrenia patients (De Hert *et al.*, 2022).

Day hospitals and social services

Recovery-oriented care relies on the availability of day hospitals and social services, such as supervised housing and supported employment as part of the overall continuity process. However, the survey revealed limited access to these resources:

- 50% of respondents noted that day hospitals are partially available, and
- 63% indicated partial availability of social services.

These findings emphasise the **need for stronger networks and targeted investments** to expand these essential services and support functional recovery and social reintegration (OECD, 2023).

3.4 Advancing recovery and functioning in the treatment journey



"Self-help groups and patient organisations provide critical peer support and resources for patients and their families, which are essential for recovery."

Péter Kéri, President, GAMIAN-Europe

Enhancing recovery and functioning for individuals with schizophrenia requires a multi-velocity and multi-strategy approach that integrates medical, psychosocial and technological interventions while emphasising patient-centred care.

Advances in schizophrenia care

Second-Generation Antipsychotics (SGAs)

Central to advancements in schizophrenia care is the availability/use of SGAs, which offer improved efficacy and tolerability compared to FGAs. However, it is significant to acknowledge their limitations:

- SGAs show limited efficacy for treating cognitive and negative symptoms, though they remain preferable to FGAs that can exacerbate.
- FGAs and anticholinergics can exacerbate or even induce these symptoms, further complicating recovery efforts (Allott *et al.*, 2024; Feber et al., 2024; Baldez *et al.*, 2021; Galderisi *et al.*, 2021; Correll *et al.*, 2020).
- Most SGAs increase weight and have metabolic side effects.

To address these challenges, integrating pharmacological treatments such as SGAs with psychosocial interventions is essential (Giordano *et al.*, 2022) to alleviate symptoms, enhance the quality of life and promote long-term recovery.

Integrated approaches and innovations

1. National guidelines for schizophrenia treatment: 68% of the respondents confirmed the presence of national clinical guidelines, with 54% noting that these include recommendations for managing both negative and cognitive symptoms. However, 14% reported an absence of such guidelines, pointing to disparities in care quality across regions.

- 2. Availability of new antipsychotics: new antipsychotics registered by the European Medicines Agency (EMA) are accessible to 65% of respondents, though 14% reported limited access. These medications play a crucial role in managing treatment-resistant symptoms and improving outcomes.
- **3. Drug reimbursement:** encouragingly, 82% of respondents reported that schizophrenia drug treatments are reimbursed by health insurance, ensuring a solid foundation for medication accessibility.
- 4. Integrated therapy outcomes: combining pharmacotherapy with psychosocial interventions significantly improves functional outcomes across all stages of schizophrenia. Cognitive remediation therapy, evidence-based psychosocial interventions (EBPIs) and non-invasive brain stimulation (NIBS) represent promising options targeting negative and cognitive symptoms (Eichner et al., 2023).
- 5. Psychosocial interventions for negative symptoms and cognitive deficits: behavioural and psychosocial interventions have demonstrated efficacy in addressing the negative symptoms of schizophrenia, often resistant to pharmacotherapy alone. These interventions are critical for enhancing recovery (Galderisi et al., 2021; Sommer et al., 2020; Kahn, et al., 2018.; Kirscher et al., 2017). Cognitive remediation and CBT have also shown promise in addressing cognitive impairment and improving recovery (Keshavan et al., 2023).

Use of new technologies

Emerging technologies such as VR, AI and telemedicine remain underutilised, with only 25% of respondents reporting their use. These tools hold promise for enhancing treatment, especially in cognitive rehabilitation and social skills training (Darekar, 2023).

Box 6 • Technologies used for treatment or recovery in mental health care

Technology integration into mental health care is transforming diagnosis, treatment and recovery pathways. It provides innovative solutions to improve access, engagement and outcomes for individuals. Key technologies and their potential applications are highlighted below.

1.Telemedicine

Telemedicine offers online consultations and teleconferences, enhancing access to care for individuals in remote areas or with mobility limitations. It has become a critical tool in bridging gaps in mental health services, especially in underserved regions. By enabling real-time interaction with healthcare providers, telemedicine improves continuity of care and ensures timely support for patients (Gentry et al., 2021; Keesara et al., 2020).

2. Mobile Apps

Web and mobile applications are gaining popularity in mental health care for their versatility. These apps are used for mental health tracking, visit reminders and computerised cognitive rehabilitation programs. Additionally, they allow patients to record changes in their mental state, fostering self-monitoring and collaboration with healthcare providers. The use of mobile apps is particularly beneficial in promoting adherence to treatment plans and providing immediate support (Firth et al., 2021; Torous et al., 2020).

3. Wearables

Wearable devices contribute to mental health care by facilitating cognitive remediation programs. These devices monitor physiological changes, providing data-driven insights to support personalised interventions. Wearables enhance the ability to track cognitive and emotional states, enabling tailored treatment approaches (Cornet & Holden, 2018; Simblett *et al.*, 2018).

4. Virtual Reality (VR)

VR has emerged as a powerful tool in mental health treatment. Its applications range from treating anxiety disorders to innovative therapies like avatar therapy for hallucinations. VR is also used in rehabilitation programs, CBT and promoting healthier lifestyles. By offering immersive and interactive experiences, VR makes psychosocial programs more appealing, especially to younger populations. It has shown promise in cognitive remediation and fostering engagement in therapy (Freeman *et al.*, 2017; Valmaggia *et al.*, 2016).

5. Artificial Intelligence (AI)

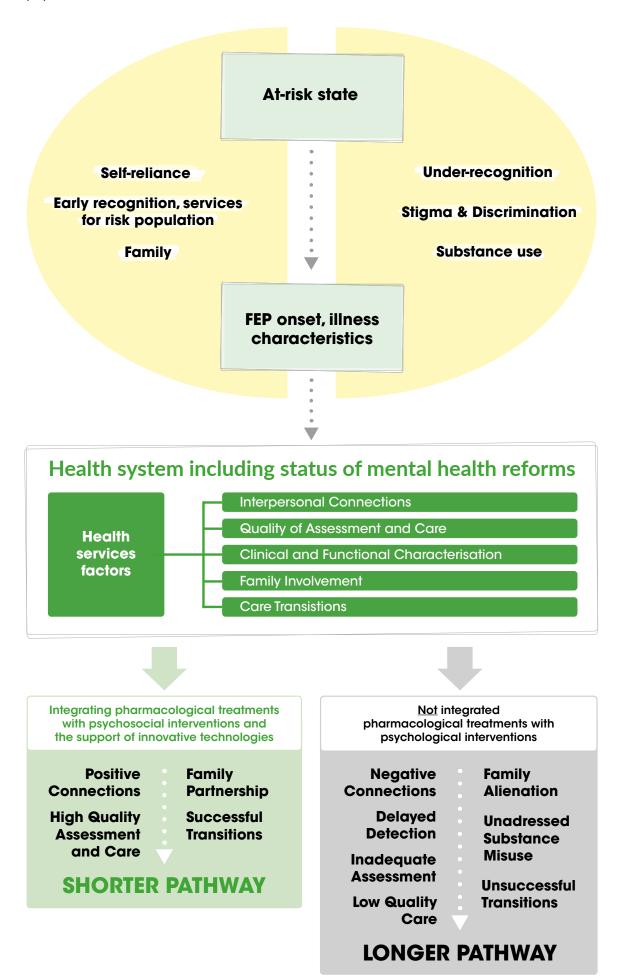
Al holds significant potential in early recognition and intervention for mental health conditions. Its ability to analyse large datasets enables the identification of early warning signs, supporting timely diagnosis and treatment. Al-powered tools also enhance cognitive remediation programs, providing adaptive and personalised interventions to address cognitive deficits (Chan *et al.*, 2021; Ryu *et al.*, 2018).

Adopting these technologies is revolutionising mental health care. These tools not only enhance access and efficiency but also improve the quality and personalisation of care. However, their potential remains underutilised, signalling the need for increased investment and training to fully integrate these innovations into treatment and recovery pathways. These advancements are paving the way for a more inclusive and effective mental health care system.

3.5 Clinical model description: Pathways to care from first episode of psychosis (FEP) to long-term care

Enhancing recovery and functioning for individuals with schizophrenia requires a multivelocity and multi-strategy approach that integrates medical, psychosocial and technological interventions while emphasising patient-centred care.

Figure 1. Pathways to care from FEP to long-term care, integrating the new treatment paradigm with psychosocial interventions.



First episode psychosis (FEP) onset and illness characteristics

The care pathway starts with at-risk young individuals and progresses into the onset of FEP, influenced by various illness-specific characteristics. This process involves key challenges, such as:

- Under-recognition of symptoms: Incorrect recognition or underestimation of symptoms.
- **Stigma and discrimination:** Negative societal perceptions that delay help-seeking behaviours.
- **Self-reliance:** Individuals and family members that rely on their judgment instead of seeking professional care.

These key entry points, influenced by family members and the affected individual, can contribute to delays in accessing appropriate care.

Health services factors

Upon engagement with the health system, the health services factors quality determines the care trajectory. Key elements include:

- Interpersonal connections: Establishing trust and communication between patients, families and providers.
- **High quality of assessment and care:** Providing a comprehensive evidence-based evaluation and care.
- Clinical and functional characterisation: Comprehensive characterisation of clinical and functional needs (especially for negative symptoms and cognitive impairment or dysfunctions), supporting personalised interventions (prediction of individual functional outcome trajectories).
- Family involvement: Integrating family members into treatment planning for better and correct support.
- **Care transitions:** Ensuring smooth, coordinated transitions across distinct stages of treatment, such as from acute to outpatient care.

These factors function as turning points since they either enable a smoother pathway or worsen with delays and failures in care. The Health Care system, including the status of mental health reforms, impacts health services factors.

Outcomes of integrated pharmacological treatments with psychosocial interventions

The shorter pathway demonstrates the impact of integrating pharmacological treatments (e.g., antipsychotics) with psychosocial interventions (e.g., family therapy, quality care programs):

- Positive connections and family partnerships improve patient and caregiver engagement.
- High-quality assessment and care promote an in-depth clinical characterisation, including cognition as well as integrated treatment plans for symptom management and functional recovery.
- Successful transitions across care settings ensure treatment continuity.

This integrated approach results in a shorter, more effective care pathway, optimising long-term recovery and outcomes. Also, technology can play a crucial role in shortening the path.

Outcomes of not integrated pharmacological and psychosocial care

The longer pathway highlights the consequences when care remains fragmented, and pharmacological treatments are unpaired with psychosocial interventions:

- Negative connections and family alienation result in reduced engagement.
- Affective symptoms such as depression, anxiety, negative self-esteem and hopelessness, as well as internal locus of control, have emerged as central predictors of personal recovery.
- Unaddressed substance misuse, specifically alcohol, cannabis and psychostimulant use and comorbidities are often associated with poor outcomes regarding independent living and social compliance.
- Low-quality assessment and care and delayed detection hinder symptom management.
- **Unsuccessful transitions** cause treatment disruptions, exacerbating uncertainty and worsening patient outcomes.

These factors lead to a longer pathway with poor care coordination and diminished chances for recovery.

The care pathway clinical model reveals the essentiality of integrating pharmacological treatments with psychosocial interventions in reducing delays in diagnosis, improving care transitions and achieving better outcomes for patients and families, with the core goal of long-term treatment success for FEP.

4. Conclusion

This survey underscores the urgent need to address barriers to recovery and functioning for individuals with schizophrenia through integrated care pathways, advanced SGAs, enhanced use of technology and expanded psychosocial resources. Evidence-based interventions targeting negative and cognitive symptoms, combined with robust relapse prevention systems and anti-stigma efforts, hold the potential to improve outcomes and quality of life for individuals with schizophrenia across Europe.

The findings highlight the urgent need for a coordinated, multidisciplinary approach to schizophrenia care. By learning from successful models and addressing persistent gaps, European countries can work toward a more unified and effective mental health care system. Key priorities include:

- Expanding access to high-quality early assessment and community-based services.
- Ensuring continuity of care, especially during transition across services and across age groups, and collaborative decision-making.
- Standardising care pathways and treatment protocols to reduce disparities.
- Strengthening the mental health workforce through training and capacity building.
- Enhancing policy implementation and accountability at national and regional levels.

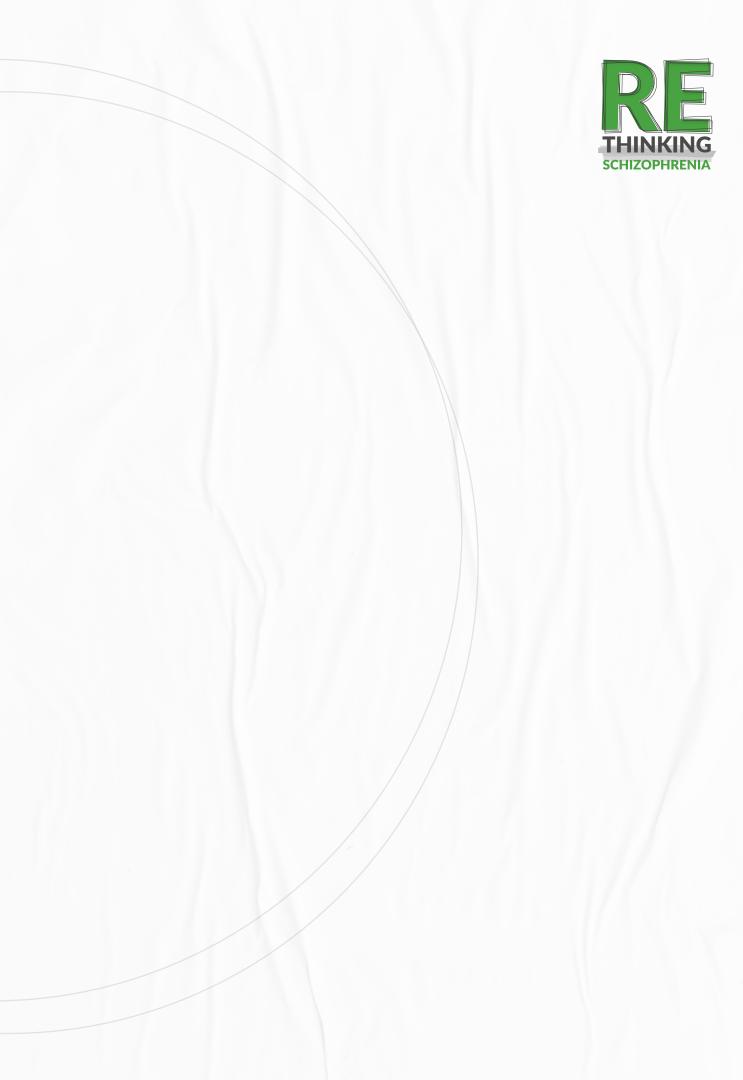
While the journey toward equitable and high-quality mental health care is far from complete, the proposed model (**Figure 1**) emphasises the importance of timely, integrated, and comprehensive care for individuals with FEP.A shorter pathway to recovery is achievable through collaboration, systemic reforms and enhanced support systems, underscoring the need for continuous improvements in mental health services.



"Schizophrenia is a journey of highs and lows, where every stumble is a chance to rise stronger. While relapses may feel like setbacks, early detection, the right care and support can help patients and caregivers to adopt their path and move forward with resilience and hope."

Asa Konradsson-Geuken, Associate Professor in Pharmacology, Uppsala university and President of the Swedish Schizophrenia Association at FENS Forum 2024²

² <u>Prioritizing Brain Health in Youth: Bringing Neuroscience to Society and Informing Policy, Lessons Learnt from the European Brain Council Expert Meeting Held at the Federation of European Neuroscience Societies Forum 2024.</u>



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Authors & experts' affiliations

Vinciane Quoidbach, European Brain Council, Brussels, Belgium, University of Warwick, Coventry, United Kingdom

Pavel Mohr, National Institute of Mental Health, Prague, Czech Republic

By alphabetical order:

- Agata Szulc, Department of Psychiatry, Medical University of Warsaw, Poland
- Ana Catalan, Department of Neuroscience, University of the Basque Country UPV/ EHU, Bilbao, Spain.
- **Andreas Meyer-Lindenberg**, Central Institute of Mental Health, Heidelberg University/Medical Faculty Mannheim, Germany
- Antonio Vita, University of Brescia, School of Medicine, Brescia, Italy
- Boris Chaumette, Université Paris Cité, Institute of Psychiatry and Neuroscience of Paris (INSERM U1266), GHU-Paris Psychiatrie et Neurosciences, Institut Pasteur (CNRS UMR3571), Paris, France
- **Cédric Duarte**, EFPA Standing Committee on Clinical Neuropsychology, Brussels, Belgium, Department of Psychology, Hôpitaux Robert Schuman, Luxembourg, Luxembourg
- Celso Arango, Child and Adolescent Department, Institute of Psychiatry and Mental Health, Hospital General Universitario Gregorio Marañón, CIBERSAM, IISGM, School of Medicine, Universidad Complutense, Madrid, Spain
- Geert Dom, Collaborative Antwerp Psychiatric Research Institute, University of Antwerp, Antwerp, Belgium
- Istvan Bitter, Department of Psychiatry and Psychotherapy, Semmelweis University, Budapest, Hungary
- Janusz Rybakowski, Department of Adult Psychiatry, Poznan University of Medical Sciences, Poznan, Poland
- Jerzy Samochowiec, Department of Psychiatry, Pomeranian Medical University, Szczecin, Poland
- João Vasco Santos, MEDCIDS and CINTESIS@RISE, Faculty of Medicine, University of Porto, Porto, Portugal; Public Health Unit, ULS Santo António, Porto, Portugal

- **Julian Beezhold**, Great Yarmouth Acute Service, Norfolk and Suffolk NHS Foundation Trust, Northgate Hospital, Great Yarmouth, United Kingdom
- Merete Nordentoft, Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark
- Oliver Howes, Department of Psychosis Studies, King's College London, UK
- Paolo Fusar-Poli, Department of Psychosis Studies, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom
- Patrice Boyer, European Brain Foundation, Brussels, Belgium
- **Peter Falkai**, Department of Psychiatry and Psychotherapy, Munich University Hospital, Munich, Germany Max-Planck-Institute of Psychiatry, Munich, Germany
- Péter Kéri, GAMIAN-Europe, Brussels, Belgium
- Piotr Toczyski, The Maria Grzegorzewska University in Warsaw, Poland
- **Silvana Galderisi**, Department of Mental and Physical Health and Preventive Medicine, University of Campania "Luigi Vanvitelli", Naples, Italy
- **Sonia Dollfus**, University Caen Normandy, Inserm U1237, Centre Hospitalier Universitaire, Department of Psychiatry, Caen, France
- Wolfgang Gaebel, LVR-Klinikum, Department of Psychiatry and Psychotherapy, Medical Faculty, Heinrich-Heine-University, Dusseldorf, Germany

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About Rethinking Schizophrenia

"Rethinking Schizophrenia: Optimising the Care Pathway in Europe" is the second part of a research-driven project offering tangible policy and care pathway changes to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, recognises the essential role of social support and encourages multistakeholder-driven policy.



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About the European Brain Council (EBC)

The EBC is a network of key players in the "brain space," with a membership encompassing scientific and professional societies, patient organisations and industry partners. A non-profit organisation based in Brussels, its main mission is to promote brain research with the main goal of improving the lives of those living with brain conditions, neurological and mental alike. For more information about "Rethinking Schizophrenia", please visit the project page.



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European Brain Council

Rue d'Egmont, 11 **BE-1000 Brussels** Belgium

Tel: + 32 (0) 2 513 27 57

info@braincouncil.eu















EPA Brussels Office

Rue d'Egmont, 11 **BE-1000 Brussels** Belgium

Tel: + 32 (0) 2 511 02 30

Contact form









europsy.net