



Schizophrenia – Time to Commit to Policy Change

Updated Report 2024

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Preface

Schizophrenia is recognised as one of the most complex mental health disorders, entwined in both misconceptions and truth. Historically, those diagnosed with schizophrenia have been subjects of both fear and admiration, with their lives often marked by significant challenges, including early mortality. Nonetheless, individuals like Swedish musician Ted Gärdestad, mathematician John Nash, and writer Zelda Fitzgerald have made remarkable contributions in fields such as art, music, mathematics, and science, demonstrating exceptional talent amidst their struggles.

During my time at university, a friend shared his experiences with psychotic episodes — tumultuous journeys often culminating in disaster, and the vital role mental health professionals played in his recovery. This period coincided with Sweden's phasing out of its last mental health institutions, a move debated sparingly at the time. We now understand that deinstitutionalisation, often executed without adequate alternative care, led to severe consequences for many. Although care standards have improved, people with schizophrenia still face a reduced life expectancy, emphasising the need to address their specific requirements in mental health care and policy discussions.

First published in 2014, this report arose during an era when mental health was perceived as a static field. More recently, I've observed a revival in the importance of mental health policy, largely driven by the onset of COVID-19 and an increasing awareness of the interconnection between mental and physical health. This has propelled mental health on the policy agenda. Organisations like the EU and WHO, along with various countries, now regard mental health care as a priority. The realisation that mental health challenges can affect anyone, together with the acknowledgment of the advantages of mental health awareness in the workplace and the clear link between mental and physical well-being, has fuelled this positive shift in policy.

However, amidst these broader changes in mental health policy, there's a risk that the distinct needs of those with severe mental illnesses, such as schizophrenia, might be overshadowed. We all acknowledge the benefits, both individual and societal, of addressing mental health through legislation and guidelines. The question remains: does this effort adequately cover the requirements of severe mental illnesses? The approach undoubtedly requires more complexity. It needs to be comprehensive, encompassing policy formulation, treatment guidelines, and scientific innovation, all working together to facilitate real advancement.

The authors of the original report played a pivotal role in raising the profile of mental health in policy discussions. I express my profound gratitude to them and to the 13 authors of this latest version. Their exceptional expertise in mental health, particularly in schizophrenia, offers invaluable insights into advancements in science, healthcare, and policy. Their dedication and empathy have been evident throughout the development of this report.

Innovation in neuroscience, especially in drug research and development, continues to be a challenging and intricate field. We are grateful to organisations like Lundbeck and Bohringer Ingelheim for not only sustaining their interest in advancing this area but also providing independent educational grants to promote knowledge in this field. These contributions have been essential in facilitating the creation of this report.

This report delves into the specific needs of people with schizophrenia, exploring supportive measures for their welfare. While it may be too late for some, like my university friend, it's never too late to initiate change. This is highlighted by our practical and achievable recommendations for change. Our message to all nations, policy makers, payers, and healthcare professionals is unequivocal: aim for excellence, but most importantly – start somewhere!

Kajsa Wilhelmsson, LLM and MSc Acting Director, Oxford Health Policy Forum CIC.



A word on language

How best to refer to people with schizophrenia is an emotive and sometimes controversial, question. The word 'patient' is appropriate in a medical context, but may be too clinical for a person living in the community. Terms such as 'service user', 'client' and 'consumer' are used in some countries and settings, but they often do not translate well elsewhere. In this report, the authors have chosen to use the word 'patient' when the setting is strictly clinical, but 'person with schizophrenia' (or similar) is used in other contexts.

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Executive summary

This report builds on the **previous version published in 2014**,¹ providing a comprehensive overview of the current understanding and consensus among a global panel of mental health professionals, scholars, patients, and caregivers with expertise and experience in the field of schizophrenia. The necessity for this revision stems from advances made in the last ten years, encompassing improvements in practice standards, policy development and emerging science. The heightened focus on mental health by policymakers indicates potential for broader change.

The overarching theme is clear: prioritising every individual's access to quality care and social support, regardless of geographic or economic barriers, is paramount. Furthermore, recognising and valuing the vital contributions of families and other caregivers is crucial. This is especially true in the context of severe mental health disorders like schizophrenia, whose story is one of need and neglect. Whose story is also one of extraordinary individuals making significant, innovative contributions to our societal and cultural fabric.

The term schizophrenia describes a mental disorder characterised by abnormal thinking, perceptual disturbances, diminished or exaggerated emotional expression, diminished speech and psychomotor abnormalities.² It is estimated that schizophrenia directly affects at least 24 million people worldwide, and twice as many are indirectly affected by it (e.g., as caregivers) resulting in high costs to individuals as well as the healthcare system and wider society.² Studies have shown that compared to other mental health conditions schizophrenia has the highest median societal cost per patient worldwide.³

Schizophrenia commonly emerges in early adulthood, significantly impacting lifelong quality of life. Individuals with this condition face a 15–20-year reduction in life expectancy compared to the general population.⁴⁻⁶ People with schizophrenia frequently face comorbid mental health conditions from childhood,⁷ where initial diagnoses may mask or delay the identification of schizophrenia as they transition into adulthood. Early intervention services have shown lasting improvements in symptoms over a 5-year span.⁸ Therefore, prompt diagnosis, comprehensive management of schizophrenia symptoms, and treatment of coexisting

mental and physical illnesses are crucial, necessitating an integrated, cohesive approach from healthcare professionals and robust support from the health and care system.

Current antipsychotic medications effectively manage acute psychotic episodes and alleviate early schizophrenia symptoms in 85% of patients.⁹ With long-term use, they also demonstrate a 60% reduction in psychotic relapses¹⁰ and reduce suicidal behaviour.¹¹ Currently available medications, however, have limited effects on the most disabling 'negative' symptoms such as a lack of motivation, known as avolition and cognitive impairment.¹² There is strong evidence that these affect important aspects of life, such as work, interpersonal relationships and everyday life activities.^{13,14} Without addressing these disabling factors people with schizophrenia will still struggle in their daily lives. The necessity for novel treatments targeting these aspects is crucial and underway, showing promising progress.

In addition to antipsychotic medication, psychosocial interventions not only bolster recovery but also provide cost-effective solutions,¹⁵ reducing relapses and hospitalisations by 20% with family involvement in treatment.^{16,17} Deinstitutionalisation, is promoted as offering the best possible outcome, yet significant financial, structural and strategic investment in community-based services is needed to implement these strategies.¹⁸

An environment which supports the recovery of people with schizophrenia can help. For example, people with schizophrenia are 6–7 times more likely to be unemployed than the general population, and only 10–20% are in competitive employment.^{19,20} Up to one-third of homeless people in the USA have schizophrenia and 15% of people with schizophrenia in Europe have experienced homelessness.²¹ Contact with the criminal justice system is also common.²² Consider the increased risk of homelessness or a jail sentence associated with schizophrenia. Consider too that people with schizophrenia are at an increased risk of dying prematurely from conditions such as heart disease or infectious diseases, or from suicide or homicide.^{4-6,23,24}Add to this the burden that this illness places on caregivers, and it becomes clear that better support is needed on all fronts. Improving the care of

people with schizophrenia should thus be a priority in healthcare policy.

Despite growing recognition, resources for mental health care remain inadequate, unevenly distributed, and inefficiently used. The number of mental health professionals is alarmingly low, with only 9 per 100,000 people globally, and an additional 1.7 million workers needed in low- and middle-income countries (LMICs).²⁵ Various initiatives like the World Bank and World health Organisation's (WHO) joint efforts, the Mental Health Action Plan, and the inclusion of mental health in the United Nations' (UN) Sustainable Development Goals signify political support. Innovative approaches, such as using non-specialists for care delivery and digital tools for screening and treatment, are being explored. However, there's a universal need for more mental health care providers, with even affluent countries facing significant service gaps. This situation calls for a global commitment to improving mental health care, adapting successful interventions across different settings, and ensuring equitable access to quality mental health services for all, particularly in underserved communities.²⁵

In this report, the author group collectively presents a thorough set of recommendations, expressing hope for strong political will and societal commitment to improve outcomes for all people with and affected by schizophrenia.



Recommendations for change

To improve the lives of people with and affected by schizophrenia and reduce societal burden, we must start making changes, no matter how small. While our analysis within this report explores various approaches and recommendations; our priority recommendations are:

Optimising schizophrenia treatment:

- Allocate public funds for research in health care, social care organisation and delivery, focusing on transdisciplinary approaches.
- Ensure direct access to specialist care including psychiatrists, specialist nurses, psychosocial and psychotherapy support.
 - Whether this is delivered through dedicated centres or community services will depend on the country, geographical context and health system.
- Ensure access to multidisciplinary teams able to provide comprehensive personal care assessment, and personalised/integrated care, as well as wider support plans.
- Ensure continuity of care during transition from adolescent to adult services.
- Make treatment plans in partnership with the patient and their chosen caregiver that includes:
 - a care and crisis management plan;
 - identification of recovery options, and personal goals for recovery;
 - warnings about potential physical and psychological side effects to prevent treatment withdrawal.
- Leverage digital innovation in research, treatment and care pathways.
- Put in place mobile crisis intervention.

Going beyond treatment:

- Integrate mental health training into all levels of healthcare training, offering additional specialised training for those pursuing mental health careers.
- Prioritise recovery, i.e. the attainment of a more fulfilled and valued life, as the primary goal of treatment.
- Ensure the involvement of people with schizophrenia and their chosen caregivers when deciding on what services are required (e.g. financial security, supported housing, contacts with social workers, vocational support and rehabilitation) and how these should be provided.
- Ensure holistic treatment plans taking into account social support and co-morbidities.

Taking care of the caregiver:

- Provide support to caregivers and families.
- Provide training programmes for informal caregivers and family members.
- Involve informal caregivers and family members in all levels of mental health policy, including development and implementation.

Empowering people with schizophrenia:

- Address stigma and discrimination.
- Ensure the rights of people living with mental health disability are recognised and held up within the context of individuals' decision-making capabilities.
- Mandate co-decision making, and right to appeal on care and support decisions for people with schizophrenia and/or (in appropriate situations) caregivers.
- Financially bolster local, regional, national and international associations supporting people with schizophrenia and their caregivers.
- Involve individuals with experience of schizophrenia in all levels of mental health policy, including development and implementation.

About schizophrenia

What is schizophrenia?

Schizophrenia is a severe mental disorder characterised by abnormal thinking, perceptual disturbances and diminished or exaggerated emotional expression. It is estimated that schizophrenia directly affects at least 24 million people worldwide, and twice as many are indirectly affected by it (e.g., as caregivers).² It is typically diagnosed in adolescence or early adulthood, and may affect a person's wellbeing throughout life.²⁶ With appropriate care and support, people can recover and live within the community, with up to 50% of individuals potentially having a good outcome.^{27,28}

The symptoms of schizophrenia

Schizophrenia significantly affects an individual's thoughts, emotions, mood, and behaviour. The range and course of symptoms experienced vary greatly among individuals, personal circumstances and cultural settings. According to the International Classification of Diseases (ICD-11), schizophrenia is classified within the "Schizophrenia spectrum and other primary psychiatric disorders." This spectrum is characterised by significant impairments in reality testing and alterations in behaviour which manifest in 'positive'²⁹ symptoms, such as hallucinations; or 'negative'²⁹ symptoms that describe loss of emotional expression or motivation.³⁰ Disturbances in mood are referred to as affective symptoms.³⁰ Cognitive functions, such as concentration, memory and planning, are almost always impaired in people with schizophrenia, and this can reduce insight into their condition, affect their employment status and their ability to live independently³⁰ (Figure 1).



Please note: Other illnesses can also cause auditory hallucinations, even in the long term, so it is important to evaluate these in all cases.



What causes schizophrenia?

Schizophrenia is multi-factorial and may be caused by a complex interaction of genetic, non-genetic and biological factors **(Figure 2)**.³⁴⁻³⁸ Psychosocial factors may also affect the onset and course of schizophrenia.^{39,40} Effects of psychosocial stress can be alleviated by medication, social support, coping strategies and a good understanding of mental illness.¹⁹

Genetics, which are passed on in families and inherited from parents, have an influence on schizophrenia predisposition and development.^{34,38} Non-genetic factors, which are factors a person is exposed to during their life in their living environment, also have an impact on schizophrenia development.^{36,37} Non-genetic factors can be chronic, with exposure consistently over a long period of time; or acute, occurring suddenly and for a short period of time.⁴¹ Importantly, research suggests that none of the genetic or non-genetic risk factors for schizophrenia are strong enough to cause the disease on their own and that interactions between them are key to the development of schizophrenia.

When combined, genetic and non-genetic risk factors can cause brain changes, which can predispose individuals to developing schizophrenia.^{35,36} Not all people who have biological schizophrenia-associated changes to their brain show clinical presentation and develop the condition. Schizophrenia often presents clinically following exposure to an acute non-genetic risk factor, but this is not the case for all people with schizophrenia.⁴¹

Figure 2: Causes of schizophrenia

The potential causes of schizophrenia are complex, multi-factorial and still a constantly developing area of research.



Time

Genetic factors^{34-38,41}

Genetics are passed on in families and inherited from parents. It is a combination of many inherited genes that increase the chance of schizophrenia. In the general population, there is a ~1% lifetime risk of schizophrenia development. Schizophrenia risk is increased for people who have a family history of the condition: ^{34,35,38}

- The lifetime risk of developing schizophrenia for a parent, sibling or child of a person with the condition is 6.5%.
- In identical twins, if one twin has schizophrenia the other twin will have a 40% lifetime risk.

Brain and central nervous system changes³⁴

- Disruption of neurotransmitter (a chemical that transmits electrical impulses between nerve cells) pathways in the central nervous system, including dopamine, serotonin, glutamate and γ-aminobutyric acid systems.
 - Dopamine and glutamate are thought to play a particularly important role in pathophysiology of schizophrenia.⁴²
- Abnormal neurodevelopment pre- and postnatally leading to progressive, abnormal brain changes, could play a part.³⁴ Associated structural changes in the brain can be seen on magnetic resonance imaging.³⁵

Schizophrenia clinical presentation

- Not all people with the genetic, environmental or biological risk factors will develop schizophrenia.⁴¹
- Some people develop schizophrenia without obvious genetic, environmental or biological risk factors.⁴¹

Non-genetic factors^{34-36,39,40}

Non-genetic factors, are factors a person is exposed to during their life in their living environment. Some non-genetic factors increase the risk of schizophrenia development. Nongenetic risk factors for schizophrenia include:

- Complications at birth (e.g., prematurity, low birth weight and lack of oxygen).
- Living in an urban area.
- Chronic lifestyle-associated stress and low-grade inflammation.Cannabis use has been shown to double the risk of developing
- schizophrenia symptoms; however, only a minority of people who use cannabis develop schizophrenia.
- Microbe exposure and neuroinflammation.
- Chronic psychosocial stressors: social isolation, bereavement, sudden trauma (e.g., childhood trauma or abuse), migrant status (being in a minority), family tensions.

Diagnosis of schizophrenia

In terms of clinical presentation, there is no single test for schizophrenia and a diagnosis usually requires at least one assessment by a mental health specialist. Guidelines for diagnosing schizophrenia include confirming the presence of different aspects over time, which can include:⁴³⁻⁴⁵

- Delusions.
- Hallucinations.
- Disorganised speech or thinking.
- Experiences of influence, passivity or control:
 - This could include the experience that thoughts are not generated by the person, that they are being placed in the person's mind or withdrawn from it by other people, or that the person's thoughts are being broadcast to other people.

- Grossly disorganised behaviour:
 - This could include unpredictable or inappropriate emotional responses or behaviours that appear bizarre or purposeless.
- Negative symptoms.
- Psychomotor disturbances:
 - This could include restlessness or agitation or other disturbed movement.
- Social/occupational dysfunction.
- Assessing and excluding other conditions that may explain these behaviours.

Ongoing progress in neuroscience research means that the list of potential outcomes that may be used to validate a diagnosis of schizophrenia in the future might include genetic, biological and chemical changes as well as cognitive assessments.



The impact of schizophrenia

First person account

The stress of graduate school, along with other factors, triggered the beginning of my illness. I began fearing for my life because I thought that people wanted to harm or kill me. I believed that my house was bugged, that people could read my mind, and that people were trying to insert evil/ destructive thoughts in my mind. The television and radio began to send me secret messages and were referring directly to me in their broadcasts. I felt incapacitated and depressed. I could do nothing and I lost all hope in myself and in life.

For several years, I lived in darkness and despair. Fortunately, I had people in my life, like my mum, who genuinely loved me and who believed in me and never lost hope in me. With her steadfast support, along with that of my psychiatrist and the rest of my family, and along with my faith that guided me through the darkest hours of my life, I very, very slowly began to recover. Recovery was not some magic wave that swept over me. I had to learn to live life all over again, and it occurred in painstakingly small, tiny steps over long periods of time.

From Scotti P. Schizophrrenia Bulletin 2009.46

The impact on people with schizophrenia

Previous global estimates ranked schizophrenia 14th in terms of years lived with disability.⁴⁷ In 2019, schizophrenia resulted in 15.1 million disability adjusted life years (DALYs), which is equivalent to 12.2% of the total DALYs associated with all mental disorders.⁴⁷ DALYs reflect the overall disease burden associated with a condition, expressed as the number of years lost to ill-health, disability or premature death and provide a way of comparing overall levels of health and life expectancy across countries. The burden associated with schizophrenia is also increasing, with this DALY total reflecting a 13.5% increase between 2010 and 2019.⁴⁸

Importantly, an assessment of these findings reported that they may also underestimate the burden of schizophrenia because of limited information connecting schizophrenia and physical health outcomes and reduced reporting of data from low-income countries.⁴⁸ One of the most fundamental issues is that people with schizophrenia die 15-20 years earlier than the general population.⁴⁻⁶ Under-diagnosis and under-treatment contribute to this high death rate. It is therefore important not only to manage the symptoms of schizophrenia but also to treat coexisting physical illnesses. Furthermore, global estimates are yet to quantify the impact of the COVID-19 pandemic on schizophrenia burden fully.⁴⁹ It has been shown however that people with schizophrenia have a worse prognosis following COVID-19 infection compared with the general population.⁵⁰ In a study conducted in the UK, people with schizophrenia were less likely to have been vaccinated than the general population, but the authors concluded this was less to do with vaccine reluctance and more to do with not having the right support to enable them access to the vaccine.⁵¹ The authors concluded that support programmes for people with schizophrenia living in the community, taking into consideration ethnic differences in reasons for vaccine hesitancy, may be beneficial in increasing vaccine uptake in this vulnerable group.⁵¹

Despite the improvements in societal attitudes, many people with schizophrenia still face social isolation, prejudice and discrimination, making it more difficult for them to live a productive life in society. This discrimination can prevent them from seeking help for their condition and can also disrupt their personal relationships and employment. Schizophrenia can adversely affect a person's earning potential in adulthood because it often develops during adolescence and can severely disrupt education.^{52,53} People with schizophrenia are 6–7 times more likely to be unemployed than those without the condition,^{19,20} and they are also particularly likely to come into contact with the criminal justice system, either as perpetrators or more likely, as victims.⁵⁴ A study in Sweden found that people with schizophrenia are 1.8 times more likely to be victims of homicidal death than those without mental illness.23



Stigma and discrimination associated with mental health conditions occurs at different levels (Figure 3).⁵⁵ The impact of stigma and discrimination in mental health is wide ranging and can often be overlooked. At a structural level, it can impact legal frameworks, human rights, and the delivery of psychosocial interventions.⁵⁵ It also has far-reaching implications on health and social care systems,⁵⁵ contributing to worsening symptoms and reduced likelihood of getting treatment.⁵⁶ In addition, self-stigma in severe mental health can lead to negative effects on recovery.⁵⁶ Stigma and discrimination can impact social and economic spheres, particularly in the context of employment.55,57 People with schizophrenia may face restrictions in certain jobs, either personally, as a consequence of their condition and their ability to carry out certain types of jobs, or work in certain environments.⁵⁸ Or legally, for example jobs in public transport where typically licensing authorities or insurance companies will need to assess each case individually.^{58,59}The impact of stigma and discrimination may be especially severe for people with multiple stigmatised characteristics (e.g., ethnic minority status or sexuality as well as having a mental health condition).⁵⁵

Combating stigma and discrimination in schizophrenia involves acknowledging the profound impact of discrimination and misunderstanding on individuals with this condition. It fundamentally involves enforcing legislative measures to tackle discrimination; but encouraging open, stigma-free conversations about their experiences, such as hallucinations and delusions, can also be significantly beneficial.⁵⁶ This approach, as exemplified by methods such as those of Romme and Ether (1989)⁶⁰ and the International Hearing Voices Movement,⁶¹ can foster a more positive and supportive atmosphere for people with schizophrenia.^{62,63}

A study across 27 countries, including European Member States, highlighted that people with schizophrenia face significant stigma and discrimination in personal relationships and employment.⁶⁴ Interestingly, almost half believed they were discriminated against even when this was not the case, underscoring the importance of addressing perceived discrimination alongside actual instances.⁶⁴ To combat these barriers, anonymous and private treatment



methods, such as computerised or online interventions, have been proposed. In Finland, web-based patient support systems offering psychoeducation for schizophrenia have shown positive results, with a high rate of engagement and task completion among participants.⁶⁵ This method, as reported in the **Joint**. **Action on Mental Health and Wellbeing's 2017 report** on depression, suicide prevention, and e-health, presents a promising approach to reducing stigma and discrimination and improving access to care.⁶⁶

The Global Anti-Stigma Alliance (GASA), established in 2012, unites mental health experts from various countries. The organisation aspires to eliminate the stigma and discrimination associated with mental illness worldwide. GASA's mission is to share knowledge and best practices to improve outcomes for those facing mental illness stigma. Emphasising collaboration, integrity, and inclusion, the GASA leverages lived experiences and credible research to advocate for mental health improvements and anti-stigma awareness globally.⁶⁷

First person account

My opinion is that the root cause of my paranoia and hallucinations was feeling that whatever appeared in my mind was true...Feeling that something was true without reason was not an event I detected as abnormal. On the contrary, this feeling made me try to prove the thought...I kept expanding the sphere of my paranoia due to my paranoid mindset. I went from picking up people's words to picking up news, thinking they were talking about me. It ran step by step until it went beyond my immediate world and was replaced by my imaginations. There were so many rationales and new pieces of "evidence" I encountered once my imagination set in...My major symptom was voices in the form of inserted thoughts.

From Rudy Tian. Schizophrenia Bulletin Open 2022. 68

First person account

My mother is 76 years old and has had schizophrenia for over 50 years. She suffers from hearing voices and sometimes having hallucinations. She lives at home on her own and is cared for by the family. She is housebound due to arthritis and she has other health issues related to cardiovascular disease, kidneys and diabetes due the side effects of the drug given to manage her schizophrenia. She does not understand that she has a mental illness, yet she knows she needs to take her medicine in order to feel better. She denies she has an illness, so reasoning with her can be difficult. We monitor her everyday to ensure she takes care of herself, in terms of eating, washing and general moving around. We organise ourselves around her, we shop, clean the house and make her food while we also work in our own jobs and take care of our own families. We have to arrange our holidays so that someone is able to stay with her. We have grown up knowing that there was something not right with my mother. As we became adults, we started to understand the extent of her illness. But there has never been any explanation from our GP on how it occurs and how we can handle her when she goes into one of her episodes or starts talking about things that do not exist. Sometimes she can be very lucid and perceptive but most of time we have to explain to her that what she is saying is not correct. We try not to have too many visitors as we worry that she would offend people with her conversation.

I worry that, as the illness is genetic, I will pass it on to my children, so I am very vigilant for signs. We have done a lot of internet searching to understand what she is going through and to understand what is best for her. We have not been trained to take care of someone living with schizophrenia. We guide ourselves by reading around the subject. My mother is lucky that she has a supportive family to whom she can invest her energy with. I believe without that support she would have gone downhill very quickly.

Davi Kaur, Caregiver, Antwerp, Belgium

The impact of schizophrenia on caregivers and families

Schizophrenia also imposes a heavy toll on families and friends, who bear much of the day-to-day burden of care. A survey on this found that 68% of caregivers are parents or step-parents of the person with schizophrenia, 12% are siblings and 7% are spouses/ significant others.⁶⁹ Many caregivers experience challenging emotions such as grief, exhaustion, anger and fear for the future.⁵⁴ Some caregivers may find the burden of care so excessive that they cannot continue in their role.

Figure 4: Burden on family caregivers: what is the bigger picture?

At the age of onset of a child's mental illness, the age of family caregivers (40–60 years) and the possibility of separation or divorce mean that they are at a time of great family stress and pressure.



According to a **Value of Caring report**

commissioned by the European Federation of Associations of Families of People with Mental Illness (EUFAMI): On average informal caregivers provide more than 43 hours of care every week, well in excess of the average working week. Those who live with the person they support provide significantly higher levels of care; on average more than 65 hours a week.⁷⁰



Compared with the general population, caregivers of people with schizophrenia are at an increased risk of developing stress-related disorders and physical health problems. In one survey in the USA, 41% of caregivers had provided care for more than 10 years, and over half found it challenging to take care of their own health when caring for somebody with a mental illness (Figure 5).⁶⁹





Socioeconomic impact of schizophrenia

The economic burden of schizophrenia is substantial, including direct treatment costs, social welfare expenses, and indirect costs such as productivity losses affecting both people with schizophrenia and their caregivers.⁷¹ Indeed, despite its low prevalence, schizophrenia was found to account for 8% of the total costs associated with mental health conditions in the UK.⁷²A systematic review of 143 cost of illness studies, including patients with a diagnosis of at least one mental disorder, across 48 countries revealed that compared to other mental health conditions schizophrenia had the highest median societal cost per patient worldwide at USD 13,256 purchasing power parity (PPP) (mean 18,313; IQR = 13,671; range 3255–96 466) **(Figure 6)**.³

Furthermore, a systematic literature review of the societal cost of schizophrenia revealed significant variations in annual costs across countries, ranging from as low as USD 819 in Nigeria to as high as USD 94,587 in Norway,⁷³ without adjustment for purchasing power

parity. However, it is important to consider the potential impact of adjusting for purchasing power and the year that estimates come from. Additionally, the review highlighted that productivity losses were the primary cost driver, accounting for 32-83% of the total cost.⁷³ The review mainly focused on studies that looked back at past data. More recent improvements in treatment, care, and changes in society may explain decreases in the proportion of indirect expenses relative to the total societal costs.⁷³

What drives high costs for individual patients are results of both individual, structural and treatment related factors,⁷⁴ which is why it is crucial to look at how social care, co-morbidities and treatment is organised.

Socio-economic factors also need to be taken into account, not least as data show that younger people, males and those without stable housing are most likely to be associated with higher cost. The variability may also be explained by differences in healthcare systems, welfare system reforms, patterns of resource

Figure 6: Taken from Christensen MK, et al. Epidemiology and Psychiatric Sciences. 2020. Societal cost per patient in US dollars adjusted by country's purchasing power parity and inflation until year 2018 (USD PPP 2018) by disorder group and country, ranked by USD PPP 2018.3

Australia -	
United States -	
Unitied Kingdom -	
Thailand -	
Luxembourg -	
Switzerland -	
Germany -	
Norway -	
Iceland -	
Belgium -	
Austria -	
Netherlands -	
Denmark -	
France -	0+0 000 002 01 ×+ +
Sweden -	
Ireland -	○ • ◎ ○ □′□ 4 <u>□</u> × +
Italy -	
Finland -	0 +0 000 0 D/1 3 /12+× +
Europe - +	
Spain -	
Greece -	0+0 00 0 Z \= * +
Cyprus -	+ + 40 00 0 40
Portugal -	0+0 00 0 0 0 + +
Malta -	
Slovenia -	+ ×+ △ (200 + 0 0 000 + 0 0
Czech Republic -	
Hungary -	
Romania -	$+ \circ \Box \Delta \Delta \times +$
Poland -	
Slovakia -	0 0+ 000 0 00 AD × +
Estonia -	00 100 0 0 D D D A × 1
Latvia -	o +> ∞ ∞ • ∞ + +
Lithuania -	
Bulgaria -	+ 0
Bulgaria -	+ o

Societal cost per patient in USD PPP 2018 (log scale)

Disorder aroup

- Behavioural disorders
- Developmental disorders
- △ Developmental disorders, behavioural disorders
- + Eating disorders
- × Intellectual disabilities
- Mood disorders Neurotic disorders
- △ Personality disorders

- + Schizophrenia
- Substance use

utilisation or diversity in the populations and data sources assessed.

Research also indicates that different forms of supported employment opportunities for people with severe mental health conditions, can improve long-term employment participation, for example as seen in Scandinavia.⁷⁵ Notably, nearly 40% of the studies did not account for caregiver productivity losses, or productivity losses due to premature mortality, which are significant societal costs in themselves. The review also highlighted the significant variability in methodologies used when assessing the economic burden of schizophrenia.⁷³ This variability largely stems from differing interpretations of what constitutes direct and indirect costs across countries. Such differences become particularly evident during economic evaluations of schizophrenia treatments.^{76,77} Consequently, the conclusions of one analysis may not be universally applicable, limited to the specific context and defined by the chosen methodology.76,77

For the purpose of this report, we understand the different types of costs to typically be:

- Direct healthcare costs: inpatient, outpatient, emergency department, long-term care, pharmacy costs and other medical care.
- Direct non-healthcare costs: social services. homelessness facilities, law enforcement.
- Indirect costs: wider socioeconomic costs such as productivity losses from unemployment, and costs such as informal caregiving.

Other costs such as the impact of stigma and discrimination and premature mortality should not be underestimated, although they are difficult to assess.

Looking at direct healthcare costs:

It is important to remember that studies focusing on these costs may underestimate the overall burden.⁷⁸ According to a 2020 overview in Europe, the annual cost per patient varied from EUR 533 in Ukraine to EUR 13,704 in the Netherlands, with inpatient costs comprising the largest component. Drug costs accounted for less than 25% of the direct healthcare cost per patient. The study suggested potential savings could be made through reduced hospitalisations, targeted interventions, and improved patient adherence to therapy.79

These findings align with a study from the USA, which reported that two-thirds of the costs associated



with rehospitalisation were due to lack of treatment efficacy, and approximately one-third were attributed to lack of adherence.⁸⁰ A reduction in the rate of relapses underpinned the cost savings associated with lurasidone (74 mg) compared to quetiapine XR (300 mg), as assessed from the National Health Service perspective in Spain and Italy.⁸¹

Looking at non-healthcare costs:

Patients adhering to treatment have been found to be cost saving, in a study from the Netherlands,⁸² and incremental cost savings per patient have been observed when symptom burden is controlled. Indeed, higher general Global Assessment of Functioning (GAF) scores were associated with cost savings in Sweden.⁸³ The GAF scale measures how much a person's symptoms affect their daily living on a scale of 0 to 100 (with higher scores indicating improved functioning compared with lower scores). These findings suggest that attempts to improve personal and societal functioning and avoid hospitalisation have the potential to reduce the societal costs associated with schizophrenia.

Contact with the criminal justice system is common, incurring societal cost.²² However, this can be mitigated by high-quality, early intervention services. Such services can also reduce hospitalisations and increase employment rates, leading to significant healthcare and societal cost savings.²²

Looking at indirect costs:

A critical indirect cost associated with schizophrenia is the loss of patient productivity, as well as unemployment, and caregivers' loss of productivity.78,84 Related to this is the impact of negative symptoms.⁸⁴ Difficulty in defining and measuring these symptoms may mean they remain an underestimated aspect of schizophrenia burden.^{85,86} Despite the limited data availability, studies suggest that negative symptoms contribute to higher healthcare cost.^{84,87} Negative symptoms are a major component of long-term morbidity and impaired functioning with respect to the ability of people to live independently, maintain relationships and to participate actively in society.^{13,14,84,88,89} A study on the impact of the negative impacts also showed a link to the significant increase in the number of workdays missed by caregivers.⁹⁰The limited efficacy of current antipsychotics in alleviating negative symptoms associated with schizophrenia may therefore increase the cost burden.^{84,91,92}

Direct and indirect cost studies covering various countries across Europe (Ireland, Germany, the Netherlands, Spain, Sweden, UK), the Americas (Canada, Puerta Rico, USA), and Asia Pacific (Japan, South Korea), indicated that the economic burden associated with schizophrenia was primarily driven by indirect costs. Indirect costs contributed to between 50% and 85% of overall costs in 12 of the aforementioned studies.⁹³ Similar results were observed from four studies in low and middle-income countries (People's Republic of China, India, Sri Lanka and Thailand).⁹³

A review including 28 studies revealed significant variations in caregiver burden across regions. Caregivers in the USA spend on average 36 hours per week, in Europe 29 hours, and in Asia around 8 hours per week caring for people with schizophrenia. Annual caregiver costs ranged from USD 1,586 in China to USD 30,591 in the USA. In many cases, the burden of informal care often exceeded that of formal care, with 4% to 19% of caregivers stopping work due to caregiving responsibilities. Loss of work productivity emerged as a major driver of caregiving costs, with significant variations across countries.⁷¹ Indeed, a multi-national survey of 712 caregivers of people with mental health conditions conducted between August 2019 and April 2020 found that informal care costs are substantial, with mean weekly costs of care per caregiver ranging from EUR 660 to EUR 2,223 depending on living arrangements and valuation method. Overall mean weekly hours of care were 43.42, rising to 65.41 for caregivers living with care recipients.⁹⁴ These commitments also meant that 46% of the people surveyed were balancing employment and caregiving responsibilities and across all respondents, working hours were reduced by 19 hours per week. These changes may help to explain why more than half of respondents were worried about their finances.

Recent studies highlight the higher average hours and costs associated with schizophrenia caregiving in Western countries (USA and Europe) compared to other regions.⁷¹ Such differences may stem from cultural, societal, and economic factors, as well as from methodological differences in the studies. The severity of symptoms has also been reported as a strong predictor of indirect costs.⁹⁵

The patient pathway

The experience of every individual with schizophrenia will be different, but here is a visual representation of what that journey could look like.





The goal of treatment: towards recovery

There is a widespread acceptance that some degree of recovery is possible, despite the presence of residual symptoms, and that some people with schizophrenia may achieve full recovery.^{28,101-105} Long-term studies have shown that up to 50% of people with schizophrenia may eventually reach some form of recovery.²⁸ This relatively optimistic view stands in stark contrast to the previous belief that schizophrenia should be regarded as a chronic disorder with little hope of a good life.

Recovery in schizophrenia is defined in various ways. Medical criteria for improvement or recovery generally rely on changes in symptoms and measures of functioning, assessed using various objective rating scales; hence, clinical recovery is often defined as the remission of clinical symptoms together with a satisfactory level of functioning in the main life domains, such as interpersonal relationships, work, school and household.^{106,107} For the person with schizophrenia, definitions of recovery focus on progression beyond the psychological effects of schizophrenia towards a meaningful life in the community.¹⁰²

Importantly, the recovery movement has been led by people with schizophrenia. From their perspective, recovery can be viewed as a process of personal growth despite the presence of mental illness;¹⁹ thus, recovery focuses on attainment of a fulfilled and valued life, rather than on elimination of symptoms alone.^{19,108} Affected individuals therefore consider themselves to be 'in recovery' and learning to live with their disorder, rather than having 'recovered from' it.¹⁰²

Recovery goals for schizophrenia should be determined by the patient, as only they truly understand their experience. Their recovery plan should therefore be guided by their own choices and aspirations.

Scientific advances in schizophrenia

Advances in diagnostics

Diagnostic criteria for schizophrenia are based on subjective assessment of the presence and duration of specific psychopathological symptoms and exclusion of other conditions.¹⁰⁹ This approach has limited predictive value, particularly in the early disease stages. Today however relevant biomarkers for timely schizophrenia diagnosis are available:^{109,45}

- **Neuroimaging:** Used to reveal changes in the brain.
- Peripheral biomarkers: Blood tests revealing brain processes.

These biomarkers fall into two categories:

- Persistent biomarkers: Genetic markers that categorise disease risk and potential benefit from early diagnosis.
- Symptom-related biomarkers: Useful in assessing disease progression and treatment response.

Despite these recent advancements in the possibility of identifying genetic, inflammatory, neurotransmitter, peripheral, and metabolic biomarkers for schizophrenia,¹⁰⁹ biomarkers for the prodromal phase (i.e., characterised by early diseases signs and non-specific symptoms) remain an unmet need.¹⁰⁹ Additionally, validated biomarkers for patient subpopulation stratification to allow for more personalised treatments are yet lacking.¹¹⁰

In terms of genetic and peripheral biomarkers, understanding of schizophrenia's genetic background is growing. People with schizophrenia exhibit gene expression alterations,¹¹¹ genomic variations,¹¹² and single nucleotide polymorphisms.¹¹³ Yet, this may only identify a small patient subset (potentially less than 7%),¹¹⁴ indicating a need for additional cerebrospinal fluid and/or peripheral markers. Heterogeneous proteomic results¹¹⁵ and shared immune marker changes between schizophrenia, bipolar disorder and major depression^{116,117} mean that multimodal approaches may still be required to accurately identify positive signals.^{102,118,119}

Regarding neuroimaging and electrophysiological biomarkers, consistent brain morphology changes in schizophrenia patients are apparent,^{45,120,121} but

lack specificity and sensitivity for distinguishing schizophrenia from other conditions.¹²²⁻¹²⁴

Although the fundamental importance of relationships between healthcare professionals and patients within care models also means that technological approaches are unlikely to replace existing models entirely;¹²⁵ wearable technologies and passive monitoring also show promise in augmenting diagnosis and monitoring disease progression.^{126,127} Platforms like Health Outcomes Through Positive Engagement and Self-Empowerment (HOPES), and Mobile Therapeutic Attention for Treatment Resistant Schizophrenia (m-RESIST) are exploring the role of wearable devices in schizophrenia management.¹²⁶Current information mainly comes from small-scale studies showing feasibility from the last 5-years,¹²⁶ with approaches like sleep pattern monitoring and real-time autonomic dysregulation tracking.¹²⁸⁻¹³⁰ Continued work is needed to improve comparisons of findings against clinically relevant assessment tools and prioritise interventions that demonstrate improvements in outcomes important to patients, such as treatment adherence (the extent to which medication is actually taken as prescribed) and relapse prediction.¹³¹ Nevertheless, past studies indicate that young people with a psychiatric history generally view wearables positively,¹³² finding them acceptable while not inducing any significant paranoia.133

Advances in new drug targets and brain stimulation interventions

Before we get further into this section, for those that are unfamiliar with the science, we want to give you a quick lay analogy, to help you digest the advances in this area.

The electrical signals that flow through our brains are carried by specialised cells called neurons. These electrical signals convey and transfer information, that help to control how we think, move, experience emotion and act. The transfer of information between neurons, which happens throughout our brains, can be likened to the flow of goods around the world. In this analogy, our neurons act like packing and distribution hubs and neurotransmitters can be thought of as the parcels that are shared between hubs. When a signal needs to be sent from one neuron



to another, neurotransmitter parcels are prepared and sent across the gaps between them. Precise signals can be orchestrated because receptor sites at the next distribution hub, or neuron, are designed to only accept certain parcels, in this case neurotransmitters. When another distribution hub accepts a parcel, the flow of goods is propagated. The intricate cycle of sending and receiving neurotransmitter parcels allows signals made up of multiple different parcel types to be moved between distribution hubs across the brain to their final destination with incredible accuracy. This cycle and balance can be very delicate, with disruption sometimes leading to mental health conditions such as schizophrenia.

Schizophrenia is complex, because multiple 'parcels' or neurotransmitters in the brain may be affected, in their balance, or transfer of information between neurons. In schizophrenia, the neurotransmitters affected are thought to be:

- Dopamine
- Glutamate
- Serotonin (5-HT)
- Acetylcholine

There may be other neurotransmitters and neurons affected in schizophrenia, and we are still uncovering the role of these neurotransmitters in schizophrenia symptoms. Medications for schizophrenia aim to address the balance of neurotransmitters.

Over the last decade progress in understanding, diagnosing, and treating schizophrenia has been slow. However, we now finally seem to be facing the possibility of a meaningful improvement in treatment. In phase 2/3 clinical trials, drugs targeting the balance of neurotransmitters and neuronal signalling have shown promise. For example:¹¹⁰

- Muscarinic acetylcholine receptors: Stimulation of M4 muscarinic auto-receptors has been shown to drive a number of processes that may be beneficial in the management of schizophrenia symptoms, including reducing dopamine transmission and enhancing glutamatergic signalling.^{110,134-139}
- TAARs: The activation of TAAR1 (a G-coupled receptor activated by endogenous trace amines) has been seen to modulate presynaptic dopamine neurotransmission and signalling and regulate glutamatergic signalling.^{92,110,140,141} Taken together these studies suggest TAAR1 modulation may play a

role in schizophrenia. Nonetheless, additional research is necessary to fully grasp the effects of TAAR1 full and partial agonists on dopaminergic signalling and schizophrenia pathogenesis.¹⁴²

- Serotonin: Drugs targeting the serotonin 5-HT_{2A} and 5-HT_{2C} receptors have shown promise in the treatment of psychosis in Parkinson's¹⁴³ and potential effects on negative symptoms in schizophrenia.¹⁴⁴ There is also evidence that add on (augmentation) therapy with drugs targeting 5-HT_{1A} receptors further alleviate positive and negative symptoms and cognitive impairment, in patients already treated with existing antipsychotic drugs.¹⁴⁵
- Glutamate: Altered glutamatergic transmission might contribute to schizophrenia,⁴² with initial treatment attempts falling short.⁹² However, therapies that inhibit glycine reuptake^{146,147} or d-amino acid oxidase have shown some potential in improving cognitive deficits, prompting further research.¹¹⁰
- Anti-inflammatory drugs: There may also be potential benefit in using anti-inflammatory medications as add-on therapies. Anti-inflammatory medications seem to effectively target the underlying inflammatory states present in a subgroup of patients with schizophrenia.^{39,148-150,157} Using such agents as add-on therapies has shown promise in first episode psychosis and in patients with predominant immune alterations.^{148,152,153} Future trials will aim to assess the consistency of these promising initial findings.

These trials show the future potential to treat with therapies that target different neurotransmitter systems, or treat inflammatory processes, especially if such approaches can be combined with biomarkers to stratify patients. Importantly, many of the emerging therapies for schizophrenia have shown positive results in subgroups of patients and/or on certain symptom domains, underlining the potential value of personalised approaches.

Beyond pharmacological interventions, non-invasive brain stimulation methods including transcranial magnetic stimulation and transcranial direct current stimulation (tDCS), have been shown to provide potential adjunctive interventions for patients with schizophrenia.¹⁵⁴ Specifically, repeated administration of tDCS has been shown to alleviate positive and negative symptoms,¹⁵⁵ as well as cognitive impairment¹⁵⁶ associated with schizophrenia.

Advances in adherence to antipsychotic medicine

Adherence^{**} to antipsychotic medication can be improved by understanding an individual's reasons for non-adherence and by involving the patient in treatment decisions. Adherence therapy, combining cognitive behavioural therapy and motivational interviewing, is one way to ensure better adherence. A systematic review of randomised trials assessing the value of additional adherence therapy compared with treatment as usual found a significant effect of controlling psychiatric symptoms but only a minimal effect on medication adherence.¹⁵⁷ Combining educational and motivational strategies shows potential benefits for adherence.¹⁵⁸ Tailored multidisciplinary approaches are most likely to succeed,¹⁵⁹ considering the strengths and weaknesses of various methods. The future might see telemedicine playing a role in improving adherence, though more guidance is needed on its optimal use.¹⁶⁰

Long-acting injections (LAIs) of antipsychotics are another method to enhance medication adherence. Despite evidence of improved rehospitalisation and relapse rates,¹⁶¹ barriers still exist that prevent the widespread adoption of LAIs and their use is often limited to patients with established non-adherence and a history of relapses.¹⁶² Education for patients and healthcare professionals is crucial to overcome awareness, knowledge, and confidence issues in prescribing LAIs.^{162,163} This includes understanding newer LAIs with fewer side effects, proper administration techniques, and the timing of efficacy.¹⁶⁴ Considering patient preferences is vital, and that LAIs may be perceived as coercive, earlier adoption may help to encourage patients acceptance of the treatment.¹⁶³ Furthermore, from a systematic review of clinical practice guidelines, almost all (n = 18/19 [94.7%])mentioned LAIs, and 5 (27.8%) recommended use of LAIs for first-episode schizophrenia.¹⁶⁵

A survey by the Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe) found that being a member of a patient organisation/selfhelp group has a positive influence on adherence.¹⁶⁶ Collaborating closely with caregivers and providing comprehensive education can also prevent relapses and support adherence.

^{**&#}x27;Adherence' requires patient participation and an effective partnership with the healthcare provider, whereas 'compliance' has more to do with following directions.



Treatments for schizophrenia: introduction

Schizophrenia arises from a multifaceted interplay of biological, genetic, and environmental factors (**see Figure 2: Causes of schizophrenia**).³⁴⁻³⁸ Consequently, its management typically involves a blend of pharmacological treatments and psychosocial interventions, alongside careful attention to physical health and the treatment of comorbidities. Notably, progress can be achieved even in the absence of some of these components; it's not a binary scenario but rather cumulative – the more we do (of the right thing), the better.

Treatments for schizophrenia

Drugs that treat the symptoms of schizophrenia (known as antipsychotic medication) form a cornerstone of schizophrenia care.¹⁶⁷ However, standard therapies used to treat schizophrenia are only symptomatic and provide control rather than cure.¹⁶⁸ Psychosocial therapies are not always initiated until symptoms are controlled. Medication, however, does not work in isolation to improve symptoms. Moreover, there is some evidence that not all people with schizophrenia require long-term medication.¹⁶⁹ Identifying patients who no longer need treatment is very difficult, and important to get right.

Management of comorbidities

In addition, coexisting physical illnesses (comorbidities) are common in schizophrenia and need to be managed alongside the psychiatric symptoms. Patients with schizophrenia have a higher risk of cardiovascular disease compared with the general population,¹⁷⁰ accounting for 17.4% of premature deaths of people living with schizophrenia.¹⁷¹ Thus, the psychiatrist should be part of a multidisciplinary team, consisting of mental health and other medical professionals, social service providers and other relevant agencies (e.g., housing authorities and employment agencies).

Importance of early intervention

There is a growing body of international literature observing the benefits of early intervention in psychosis assessed in randomised trials.¹⁷²⁻¹⁷⁵ Furthermore, longitudinal studies, observing a group of patients with schizophrenia for 10-years after their first episode, have shown that the first year is a key period for social function interventions. In these patients, social function interventions received within the first year were demonstrated to improve long-term outcomes, changing the trajectory away from disability. This highlights the importance of multifaceted interventional support early in the patient's illness.¹⁷⁶ Research has found that a combination of pharmacotherapy, psychological therapy, and case management is optimal for improving outcomes in early psychosis, particularly in reducing psychotic symptoms and enhancing social functioning. In a recent study, psychological interventions showed greater effectiveness than pharmacotherapy alone in reducing negative symptoms of schizophrenia at 3-months and positive symptoms at 1-year. Case management was also found to be more effective than pharmacotherapy alone in reducing positive and negative symptoms at 1-year¹⁷⁷

Involving patients in treatment decisions

Treatment options should be discussed with and agreed upon by the patient, who has the right to be fully informed about their condition and available treatments. This collaborative approach, where the patient's consent and understanding are at the centre, ensures more effective and ethical recovery. It is important to note however, that in cases where the patient may be a risk to themselves or others, this approach might not always be suitable. Other factors, such as facilitating the removal of an individual from a stressful environment to one in which they feel safe, can also play a key role in recovery.¹⁷⁸

Figure 8: GAMIAN-Europe's Charter for the Rights to Treatment and Care for People with Schizophrenia.⁹⁹



In 2019, GAMIAN-Europe produced a 'Charter for the Rights to Treatment and Care for People with Schizophrenia,'⁹⁹ co-developed with individuals living with and affected by schizophrenia. The purpose of the Charter was to define the rights to mental health care and treatment and responsibilities of governments and service providers.⁹⁹ Key recommendations from the Charter include:⁹⁹

- 1. Maintain patient rights, entitlements and expectations for effective and safe treatment and care.
- 2. Create mental health services that are respectful and maintain patients' dignity and confidentiality.

- 3. Provide a safe space prior to and during a crisis episode, including alternatives to psychiatric hospitals.
- 4. Ensure the provision of relapse prevention, early intervention, wellbeing interventions and physical health screening and care.
- 5. Provide recovery and beneficial social inclusion activities including employment, voluntary and other meaningful activities.



Treatments for schizophrenia: antipsychotic medications

Potential benefits and limitations of current antipsychotic medications

Figure 9: Long-term (maintenance) antipsychotic medication significantly reduces the number of relapses (at 7–12 months) and the number of hospitalisations in patients with schizophrenia, compared with placebo (data from a combined analysis of 65 clinical trials).¹⁰



Most available antipsychotic medications primarily act by blocking the effects of a neurotransmitter called dopamine in the brain.¹⁷⁹ Early introduction of antipsychotic medication, can deliver sustained demonstrable improvement in symptoms over 5-years.⁸ Maintenance therapy, or long-term medication has also been shown to reduce the risk of relapse in people with schizophrenia (**Figure 9**).¹⁰ However, medications are usually not given early enough, not until the severity of symptoms brings an individual to the attention of psychiatric services.

Currently available drugs also have significant limitations (**Table 1**). Full remission is achieved in only 30% of patients⁷⁹ and recovery in less than 15%.¹⁰⁶ In between 20% and 50% of cases they may not control positive symptoms¹⁸⁰ and notably, they do not adequately treat negative symptoms or cognitive impairment, and many patients continue to experience persistent psychotic symptoms.^{***,12,91,92} This is a major concern, because negative symptoms constitute a significant barrier to independent living as they impact workability as well as managing day-to-day chores and social engagement.^{12,32,181,182} Indeed, negative symptoms are more closely related to impaired functioning than positive symptoms.¹⁸³

Cognitive impairment affects functions such as verbal fluency, memory, attention, processing speed, prioritising tasks and making decisions.^{167,179} It usually manifests years before the onset of full psychosis.^{167,184} Any improvements seen in cognitive impairment from current antipsychotics appear to be due to reductions in other symptoms, rather than direct effects on cognition.^{12,184,185} Some have argued that effective treatment of cognitive symptoms is the most urgent priority for the medical treatment of schizophrenia.¹⁷⁹

Many patients show only a partial response to treatment. Even when remission is achieved, few people are completely symptom-free.^{167,179} In addition, up to onethird of people with schizophrenia show a poor response to antipsychotic medication, and some may develop

Table 1. Potential benefits and limitations of current antipsychotic medication

Benefits

- Reduction of positive symptoms
- Treatment of acute episodes
- Reduced risk of relapse
- Provision of stability and a platform for other treatments
- Reduction of aggression and hostility
- Reduced suicidal behaviour

Limitations

- Limited efficacy against negative symptoms
- Inadequate treatment of cognitive impairment
- Troubling side effects or tolerability issues
- Low acceptability to some patients
 - Poor adherence
 - Negative perceptions

***For a description of symptoms see: Figure 1: Symptoms of schizophrenia

treatment-resistant schizophrenia.¹² Treatment resistance is common,¹⁸⁶ and in about 10% of cases it is apparent after the first episode.¹² Symptoms can be improved in some patients with treatment-resistant schizophrenia.^{187,188} Careful and specialist management and monitoring are required in such cases,¹⁸⁹⁻¹⁹¹ and timely intervention may help to avoid prolonged treatment with ineffective medications. The potential effectiveness of clozapine in addressing key clinical aspects of schizophrenia is reflected by its inclusion in national and international treatment guidelines.¹⁹² Despite this, barriers to its use persist, resulting in a low proportion of patients receiving the drug and/or delays of several years prior to its use.¹⁹³ Systematic reviews of previous research studies highlighted the need for education and training alongside the utilisation of interdisciplinary teams who can deliver integrated care as potential ways to address these challenges.^{193,194} Adaptations may be required at the level of individual prescribers and healthcare systems, while expanded use of technology and development of clinical monitoring checklists may also help.^{194,195}

Antipsychotic medication is also associated with a number of side effects (**Table 2**).¹⁹⁶⁻¹⁹⁹ These can be severely troubling and may limit adherence to treatment, thereby reducing the potential for recovery. Individual agents differ in their side-effect profiles, but among the most common effects are motor symptoms, metabolic disturbances and hormonal disturbances. Adherence is often low in people with schizophrenia at about 50%.^{12,200,201} Discontinuation of medication can lead to serious consequences for the patient including relapses and potential withdrawal syndrome; hence, accurate, detailed clinical assessment is crucial in all cases. Studies observed rates of recurrent episodes following discontinuation of antipsychotic medication of between 77% and above 90%,²⁰² with non-adherence to medication repeatedly cited as a driving force.²⁰³ Nonadherence is a complex concept and appears to involve interactions between patient attitudes and perceived stigma, healthcare systems factors as well as clinical and treatment challenges.²⁰⁴ Furthermore, patients with major psychiatric disorders are predisposed to being non-adherent as a result of lack of insight about their conditions and impaired reasoning.²⁰⁵ Individuals who respond well to medication may be those who benefit the most from continuing treatment and subsequent psychosocial therapy.^{12,206} Most guidelines suggest that antipsychotic medication for people with a first episode of schizophrenia should be maintained for at least 6-months to 2-years. 12,15,207

Table 2. Potential chronic side effects of current antipsychotic medication ¹⁹⁶⁻¹⁹⁹			
Movement symptoms	 Slow, stiff movement and tremor (parkinsonism) Abnormal muscle tone or muscle spasms (dystonia) Involuntary movements (tardive dyskinesia) Subjective experience of restlessness and restless movements (akathisia) 		
Metabolic changes These can increase the risk of metabolic syndrome or cardiovascular disease	 Increase in blood glucose levels Increase in cholesterol levels Increase in triglyceride levels Weight gain 		
Symptoms caused by changes to levels of acetylcholine	 Dry mouth Blurry vision Slower than usual heart rate Constipation 		
Physiological changes	 Low blood pressure (hypotension) Irregular heart rhythm (corrected QT (QTc) interval prolongation) Sleepiness (sedation) Seizures Changes in the level of the hormone prolactin, which can lead to sexual dysfunction 		



Treatments for schizophrenia: psychosocial therapies

Psychosocial therapies play an important role in the treatment of schizophrenia. These therapies are aimed at improving the patient's functioning in the community, which in turn can result in clinical improvements, such as reductions in the number of relapses or hospitalisations. Substantial evidence already supports the use of many psychosocial therapies in schizophrenia, including cognitive behavioural therapy‡ (CBT) for psychosis, cognitive remediation and social skills training.^{15,19,202,208,209} Several other approaches also show promise (**Table 3**).¹⁹ The disability associated with schizophrenia is often wide-ranging, so psychosocial therapies may be combined to address multiple issues. For example, social skills training might be provided as part of an integrated programme that also includes family psychoeducation, cognitive remediation and cognitive behavioural therapy.¹⁹

Table 3. Many psychosocial interventions have been shown to improve outcomes in schizophrenia (evidence-based approaches), and others are being developed and evaluated (promising approaches).^{19,208}

Evidence-based approaches

- Assertive community treatment
- Cognitive behavioural therapy for psychosis
- Cognitive remediation
- Family therapy/psychoeducation
- Peer support and self-help strategies
- Social skills training
- Supported employment
- Integrated treatment for coexisting substance abuse disorder

Assertive community treatment (ACT)

The assertive community treatment (ACT) model was developed to address the rise in relapse and hospitalisation rates that followed the shift from institutionalised to community care in the USA from the 1980s.¹⁹This approach, aimed at a subgroup of patients who are high users of services, involves a multidisciplinary team working in the community to provide a range of services, including medication management, practical support (e.g., with housing) and rehabilitation. It is characterised by a high frequency of patient contact and low patient-to-staff ratios, thus making substantial demands on healthcare resources.^{19,208} However, for this and other psychological therapies, the increased time spent with patients may in itself contribute to positive outcomes.

Promising approaches

- Cognitive adaptive therapy
- Healthy lifestyle intervention
- Interventions targeting older individuals
- Prodromal stage intervention
- Social cognition training
- Social rehabilitation (Clubhouse Model)

Research from various countries indicates that ACT leads to lower rates of homelessness and hospitalisation compared to standard care. Previous analyses have shown that patients receiving ACT were more likely to live independently and ACT was also found to reduce rates of homelessness.²¹⁰ Evidence also suggests that ACT provides a cost-effective option while reducing the average length of hospital stays and rates of rehospitalisation.²¹¹

Although ACT can help people with schizophrenia to live stably in the community, the available evidence suggests that it has only a limited impact on other outcomes, such as core illness symptoms, social functioning, employment or arrests and imprisonments.^{19,210}

+Cognitive behavioural therapy: a talking therapy that helps people manage their illness by changing the way they think and feel

Cognitive behavioural therapy (CBT) for psychosis

Psychotic symptoms may persist despite antipsychotic medication, and this can create a significant barrier to recovery.¹⁹ CBT directed towards psychotic symptoms aims to reduce the severity and resulting distress. Many studies have shown that this approach improves social functioning, reduces positive and negative symptoms and decreases mood disturbances, compared with control groups.^{19,212} Other studies, however, have not shown such improvements, and the effects of CBT on outcomes such as hospitalisations, depression, suicidality and insight have not been clearly established.²⁰⁸ A systematic review concluded that CBT offers no clear advantage over other psychosocial therapies, including family therapy and psychoeducation.²¹³

Cognitive remediation

Cognitive remediation programmes usually involve exercises designed to improve aspects of cognition, often combined with teaching strategies to enhance performance of these exercises; they may also include strategies for coping with cognitive impairment.¹⁹ Most studies have found that this approach is effective in improving cognition, but its effects on psychosocial functioning are more variable.^{19,214,215} Cognitive remediation models differ considerably, however, and the number of robust studies in this field is limited.²⁰⁸ It has been suggested that cognitive remediation enhances the effects of other forms of psychotherapy by increasing the ability to learn new skills.¹⁹ Furthermore, there is some (very limited) evidence that it may protect against schizophrenia (related to loss of grey matter in the brain over a 2-year period)²¹⁶ and improve the number and functionality of nerve cell connections in the brain.²¹⁷

Family therapy/psychoeducation

Many people with schizophrenia live with their families, so family therapy (also known as family psychoeducation) can play an important role in promoting recovery.^{19,218} This process of educating individuals and families about the nature and symptoms of the illness enables them to develop adaptive coping strategies, capitalise on their strengths and learn selfcare. An educated individual (and their family) is then better able to participate in shared decision-making. Family psychoeducation offers a valuable opportunity for people with schizophrenia, their families and healthcare professionals to exchange insights about their personal experiences of schizophrenia and the care available. Importantly, family members can provide continuity for a person with schizophrenia, even if healthcare professionals involved in their care change.

The family therapy/psychoeducational approach aims to foster collaboration among family members and healthcare professionals. Studies have consistently shown that family psychoeducational approaches are effective in reducing relapses and hospitalisations, and to some extent in improving social functioning. ^{19,208,219,220} There is also evidence that these benefits persist during long-term therapy (5-years).²²¹ One early analysis showed that relapses and hospitalisations could be reduced by about 20% when families were included in the treatment, compared with usual care.¹⁶ In another study, the relapse rate at 2-years was 40% in patients whose families received psychotherapeutic support, compared with 75% in those whose families received no help.²²² The greatest benefits of family psychoeducation appear to be seen in people with a first episode of psychosis or a recent onset of schizophrenia.²²³ Furthermore, the benefits of psychoeducation also extend to family members, who report reduced levels of distress, improved family relationships and enhanced coping and empowerment. 54,208,221

Multifamily group psychoeducation

Multifamily group psychoeducation is another useful family-based intervention. In this model, trained staff lead a group of individuals with schizophrenia and their families, who are provided with information about the course and treatment of psychotic disorders. They are also trained in the use of structured problem-solving exercises designed to help them meet the challenges of living with or caring for a person with a psychotic disorder.^{224,225} Such a multifamily approach can reduce relapse rates to a greater extent than single-family psychoeducation, which itself improves relapse rates to a greater extent than treatment without family psychoeducation.^{226,227} Moreover, the addition of multifamily group psychoeducation to antipsychotic medication approximately doubles the effect size of medication alone.^{226,227}

Paradoxically, however, the provision of information can increase 'self-stigmatisation' among people with schizophrenia, causing them to anticipate prejudice and discrimination.^{64,228,229} Nevertheless, in the long term, psychoeducation – supported by appropriate



antipsychotic and psychosocial therapies – appears to be effective in reducing the burden felt by many people with schizophrenia and their families.²²¹

Supported employment

The right employment opportunities are shown to improve emotional and psychological well-being in people with schizophrenia living in the community.²³⁰ For people with schizophrenia, that have experienced psychotic episodes, some jobs may be less suited to their condition and support from a psychiatrist to navigate this and/or their career may be beneficial.

Lost employment is one of the largest causes of cost burden of mental health, to society.²³¹ Supported employment programmes help people in joining or re-entering the workforce.²³¹ Programmes adopt a "place and train" method, emphasising competitive employment as the target, with continued support for job retention.²³¹ The Individual Placement and Support (IPS) approach, a subset of supported employment, is guided by eight core principles, including employment specialists integrated into mental health services, playing an intermediate role to match jobseekers preferences with employers in a competitive job market, and initiating rapid searches for competitive employment.²³¹ Systematic reviews indicate supported employment interventions, particularly IPS, are highly effective in helping people with mental health conditions into work.231

Telemedicine

Telemedicine, encompassing tools such as video calls, online forums, apps, texts, and emails, has become increasingly important in mental health care, its effectiveness particularly highlighted during the COVID-19 pandemic's isolation periods. This technology enables flexible access to psychiatric services for individuals with schizophrenia, either from their homes or specialised facilities.²³²

While telemedicine's accessibility and convenience are invaluable for the continuous management of schizophrenia, particularly for those geographically or physically restricted from reaching their healthcare team, it also brings to the fore numerous ethical and regulatory issues that are yet to be resolved. These include concerns about patient privacy and data security, especially given the sensitive nature of psychiatric information. The need for robust frameworks, for example as laid out in the <u>Mental Health</u> <u>Commission of Canada's Assessment Framework</u> <u>for Mental Health Apps</u>, or the <u>Australian</u> <u>Government's Guide for Service Providers</u> becomes crucial in this context. These frameworks must address not only the safety and quality of digital mental health applications but also the ethical implications of their use.^{233,234} Furthermore, there is a pressing need for clear regulatory guidelines to govern telemedicine practices, ensuring that they comply with medical standards and protect patient rights. While telemedicine offers significant benefits for managing mental health conditions like schizophrenia, its ethical and regulatory challenges must be carefully navigated to fully realise its potential in a responsible and patient-centric manner.²³⁵

Peer support and self-help strategies

People with and affected by schizophrenia, can offer powerful and eloquent insights into the condition. As a result, peer-led interventions have an important place in schizophrenia care, and this approach has been actively promoted.^{28,236,237} Peers play an active role in mutual support or advocacy groups.^{36,218} Peer-led groups such as the **National Alliance on Mental Illness (NAMI)**, **EUFAMI** and **GAMIAN-Europe** work together to help both themselves and the people they care for. Such groups can provide support in a number of areas (**Table 4**).²³⁷

Table 4. Areas in which peer-led and advocacygroups can provide support to people withschizophrenia.237

- Social environment
 - Provision of feedback about current status and experiences
- Psychoeducational information
- Cognitive and environmental antidotes
 - Beliefs and attitudes that define the activities of group members
 - The recovery model is an example of a cognitive antidote that can change an individual's attitude to their illness
- Patient and family education

In a report from the UK Schizophrenia Commission, 48% of people with schizophrenia identified selfmanagement strategies as an important factor in their recovery.⁵⁴ The importance of peer-led interventions is highlighted by experience with the **Wellness Recovery Action Plan**^{*} programme, which represents an important landmark in the application of self-help strategies in schizophrenia. This programme has been shown to improve symptoms, hopefulness and quality of life compared with standard care, in patients with severe, persistent mental disorders.²³⁸ Such support can substantially improve patients' wellbeing and quality of life and should be available to all people with schizophrenia.

There is also some evidence that self-help strategies may be useful in postponing readmission to hospital, although one study found no differences in clinical or social outcomes between individuals who participated in self-help groups and those who did not.²³⁹ It has been suggested that peer-led strategies in mental health reduced psychiatric inpatient bed use in the US and Australia, resulting in cost savings which outweigh the costs of the intervention.²⁴⁰

Social skills training

In people living with schizophrenia, problems with psychosocial functioning are related to impairments in social skills that may be present before the onset of illness and that persist if not addressed.¹⁹ Social skills training can improve social and daily living skills, community functioning and other aspects of social functioning. This approach also has a small but significant effect on relapse rates.^{209,241} The value of social skills training may be limited somewhat by decreased attention in people with schizophrenia.²⁰⁹ However, attention-shaping therapy or cognitive remediation (i.e., strategies to improve

Table 5. Potential benefits of psychosocial therapies ^{19, 208, 243, 244}		
InterventionAssertive community treatment	Potential benefitsReduction in rates of homelessness and length of	
,	hospital stays	
 Cognitive behavioural therapy for psychosis 	 Decreases in both positive and negative symptoms and mood disturbances, and improved social functioning 	
 First episode intervention for psychosis 	 Improvements in quality of life, social functioning and adherence 	
 Cognitive remediation 	 Improvements in cognition and psychosocial functioning 	
 Family psychoeducation 	 Some improvement in social functioning, and family coping and empowerment 	
 Peer support and illness self-management training 	 Enhancement of empowerment and ability to cope with the illness 	
 Social skills training 	Improvements in social functioning	
Supported employment	 Increases in employment rates, hours worked and wages earned. Gains in self-esteem and quality of life 	
 Integrated treatment for coexisting substance abuse disorder 	 Reductions in substance use and arrests; improved functioning 	



attention and cognitive performance) appears to be useful in improving the acquisition of social skills in schizophrenia.²⁴²

Limitations of psychosocial therapies

Psychosocial therapies may not be appropriate unless symptoms are significantly well controlled, and patients have insight into their condition and the need for treatment. Patient selection, for example, may be important for a successful outcome. Highly motivated individuals generally respond to cognitive remediation better than those who are less motivated.²⁴⁵ Moreover, some people with schizophrenia may, if not treated with antipsychotic medication, worsen when stressed by psychosocial interventions.²⁴⁶

The cost of some therapies, such as cognitive behavioural therapy, may be prohibitive in countries where they are not available through public health services. Where public funding for cognitive behavioural therapy is available, priority may be given to patients with other mental health problems deemed to have a high likelihood of remaining in paid employment.²⁴⁷ In the USA, many psychiatrists will not accept Medicaid patients (covering low income US adults, children, pregnant women, elderly adults and people with disabilities),²⁴⁸ who are therefore excluded from potentially beneficial psychosocial therapies. Similarly, family psychoeducation for relatives is not currently funded in many countries. The use of cognitive behavioural therapy could be extended by using specialised therapies to treat individual symptom domains; however, this raises the important question of how to identify people who might benefit from this approach, and how it should be funded.

With regards to telemedicine, while countries like the Netherlands, Sweden and the US have advanced telemental healthcare by easing legal barriers, challenges persist. Many nations lack the infrastructure for widespread remote care. Further, the digital divide, influenced by racial and economic disparities, hinders access.²³²

In addition, it is important to consider cross-cultural differences in belief systems, including religion and spirituality, which may have an impact on mental health.²⁴⁹ Such factors are relevant during diagnosis, when spiritual ideas need to be differentiated from delusions. They are also important from a treatment perspective, when religious beliefs can potentially help in the recovery process by encouraging help-seeking behaviour and engagement with treatment.²⁵⁰

Treatments for schizophrenia: management of co-morbidities

Healthcare professionals sometimes pay too little attention to treating physical illness in people with mental illness,⁶ despite it being well documented that schizophrenia is associated with a substantial burden of physical illness. On average, people with schizophrenia die 15–20 years earlier than the general population (**Figure 10**)^{4-6,251,252} – a situation that has been described as "a scandal".⁶ This burden is the result of a number of factors, including:²⁵²

- A high frequency of poor health behaviours (e.g., poor diet, poor oral health hygiene, lack of exercise, high rates of smoking and alcohol or substance abuse).
- Under-diagnosis of physical illness.²⁴
- Decreased access to health care compared with the general population (furthermore, when care is provided it is often too late and of poor quality).^{54,6}
- Suicide.
- Self-stigmatisation (people with schizophrenia may be reluctant to seek health care because they fear prejudice and discrimination).
- Self-neglect or inadequate self-care, as a consequence of schizophrenia.

The scale of the problem is illustrated by a survey of people with mental health problems in 27 European countries, 20% of whom had schizophrenia. This survey found that 86% of participants had at least one physical health problem, of which the most common were weight gain (45.7%), smoking (38.3%) and heart problems (25.2%).²⁵³ Physical conditions such as microbiota changes, immune system changes, thyroid and other hormone changes, breathing (oxygen supply) have an impact on symptoms, but these are often under-assessed in many countries.

Weight gain and metabolic problems are common in people with schizophrenia. It is not uncommon, for example, for an individual to gain up to 5 kg or 6 kg in weight within 2-months of starting antipsychotic medication,²⁵⁴ and in many cases this can result in an increased risk of conditions such as obesity, type 2 diabetes mellitus or heart disease.²⁵² Poor diet and lack of physical exercise may also contribute to these changes, with previous studies concluding that diet may often be poor in people with severe mental illness.²⁵⁵ Figure 10: People with schizophrenia die earlier than the general population. The figure shows the mean decrease in life expectancy at birth in people with schizophrenia, compared with the general population, in London, UK.⁵



Increased rates of heart disease, compared with the general population, are major drivers of early death and ill health among people with schizophrenia. A study from Sweden has shown that deaths from heart disease, while decreasing in the general population, are increasing among people with schizophrenia.²⁵⁶ Underdiagnosis and under-treatment may contribute to this high mortality.

Data from the USA shows that individuals with diabetes mellitus and schizophrenia are less likely to receive statins to lower their cholesterol levels, than those without schizophrenia.²⁵⁷ In one study, people with both diabetes mellitus and mental illness were less likely to be hospitalised for treatment of diabetic complications than those without mental illness.²⁵⁸

There may be potential in the use of glucagonlike peptide receptor-1 agonists for the treatment of cardiometabolic risk factors in patients with schizophrenia. A previous systematic review demonstrated that use of such agents reduced

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weight gain and improved key metabolism markers.²⁵⁹ However, barriers exist with respect to monitoring and managing cardiometabolic risk factors in patients prescribed antipsychotic medication, and there is a need for clear guidelines and educational resources to try and address these.²⁶⁰

Smoking is another major cause of ill health in people with schizophrenia. Smoking is often combined with a poor diet and obesity.²⁶¹ Interventions to stop smoking should therefore form part of schizophrenia care.^{12,262} Evidence suggests that smoking cessation strategies that work in the general population are also effective in people with schizophrenia.²⁶³

Alcohol and substance abuse is common in people with schizophrenia: about 50% have a substance use disorder at some time in their lives, compared with about 15% of the general population.¹⁹ Such individuals are often specifically excluded from clinical trials, meaning that the evidence base for interventions in this population is limited. Alcohol and substance abuse are associated with a poor outcome in terms of relapses, hospitalisations, impaired functioning and physical illness.^{12,264} Cannabis abuse is of particular concern, given that it is a recognised risk factor for the development of schizophrenia, particularly in young individuals.³⁷ For these reasons, reducing substance abuse in people with schizophrenia is a priority.¹⁹ Ideally, substance abuse should be treated using a combination of medication with psychological and behavioural therapies.²⁶⁵ Such treatment should be integrated into psychiatric care, rather than being provided by discrete agencies.¹⁹

In recent years increased attention has been given to physical illness in people with schizophrenia, resulting in better coordination of healthcare services, with primary care physicians playing an increasing role. A study looking at the economic burden of schizophrenia in patients in economically underdeveloped areas of China came to the conclusion that to reduce the burden of schizophrenia on society, attention should be paid to actively preventing other physical illnesses; reducing the length of stay in hospitals; and improving community care.²⁶⁶

Caregivers too are becoming increasingly involved in monitoring the physical wellbeing of people with schizophrenia, forming a 'therapeutic alliance' with healthcare professionals. Indeed, family members and physicians often recognise physical health problems more readily than people with schizophrenia themselves.⁵⁴

The policy landscape for schizophrenia

The policy landscape for schizophrenia: historical context

Throughout the nineteenth and early twentieth centuries, psychiatric hospitals were the primary care facilities for those with mental health issues in Europe and beyond.²⁶⁷ From the mid-twentieth century, due to the rise of the human rights movement and the **Universal Declaration of Human Rights in 1948**, there was increased scrutiny on the treatment of psychiatric patients.^{267,268} Research indicated that psychiatric hospitals had little therapeutic impact and upheld patients' disorders or even made them worse.²⁶⁷

In some countries for example the Soviet Union, psychiatry and diagnosis of "sluggish schizophrenia," was used to suppress political dissent, exemplifying the misuse of medical practices for political control.²⁶⁹ Documented cases by Amnesty International and others show numerous individuals were wrongfully confined in psychiatric facilities for opposing the state. This issue, which led to the Soviet Union's withdrawal from the **World Psychiatric Association (WPA)**, underscores the ethical challenges in psychiatric diagnosis and the risks of its exploitation for political repression.²⁶⁹

The emergence of 'typical' antipsychotics from the 1950's initiated the closedown of larger mental health institutions.²⁷⁰ From the 1960s, health policy reform, in response to the rise of the human rights movement and the availability of 'typical' antipsychotics, led to dehospitalisation in many European nations, transitioning from hospital-based to community-based care.²⁶⁷ Italy's 1978 Mental Health Reform (Basaglia Law or Law 180) exemplified this shift, with Italy closing its psychiatric hospitals in favour of community services.²⁷¹⁻²⁷³ Shortly after, community mental health centres and acute psychiatric units began operating in the USA and other countries,²⁷⁴ and community-based interventional programmes started to emerge.²³² Countries like Italy introduced protected housing and diverse support services, for example the **Clubhouse psychosocial** rehabilitation model or Housing first, with many nations following suit.²³² These were developed as a potential approach to provide recovery-oriented, evidence-based, long-term care in the community for people living with severe mental illnesses like schizophrenia.232

In some countries deinstitutionalisation was supported by corresponding welfare reform, for example USA President John F Kennedy's October 1963 Amendment to the US Social Security Act, which aimed to make it more possible for people with mental health conditions to live independently.²⁷⁵ In other areas, such as Bulgaria, deinstitutionalisation and a reduction in bed numbers occurred with limited corresponding increased community support, and this had negative impacts on those affected.²⁷⁶

The mid-twentieth century also saw the emergence of non-government organisations (NGOs) focused on mental health.²⁶⁷ Then in the early 1990s, the UN highlighted the need for improved mental health care practices globally, in relation to the inhumane and then still prevailing bad practices in mental health care.²⁶⁷ In 1991, the UN General Assembly endorsed the **Principles for the Protection of Persons with** Mental Illness and for the Improvement of Mental Health Care, 277 which provided 25 guiding principles starting from fundamental freedoms and basic rights, prioritising life in the community, regulating medical examinations and medication, defining standards of care and treatment, requiring informed consent to treatment and informing patients of their rights. These principles serve as a reference for interpreting international human rights conventions. The WHO²⁷⁸ and the Council of Europe²⁷⁹ have subsequently released their own guidelines and recommendations based on these principles.

Based on the 1950's <u>Convention for the Protection</u> of Human Rights and Fundamental Freedoms, in 2004 the Committee of Ministers of the Council of Europe approved a set of guidelines on the Protection of Human Rights and Dignity of Persons with Mental Disorder,²⁷⁹ and later recommendations on how to monitor and implement these guidelines. Together these form a <u>toolkit for the development of an</u> optimal organisation for human rights based on an integrated community-level mental health service system.²⁸⁰

In 1993, the UN General Assembly adopted the **Standard Rules on the Equalisation of Opportunities for Persons with Disabilities**,²⁸¹ emphasising the societal construct of disabilities


and promoting equal opportunities for all. The 22 rules concerning people with disabilities consist of four chapters – preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism – and cover all aspects of life.²⁸¹ Following on from this, in the early 2000s WHO introduced a series of publications as part of their **mental health policy and service guidance package** and initiated the Mental Improvements of Nations Development (MIND) project.²⁷⁴

In 2006, the UN General Assembly approved the legally binding **UN Convention on the Rights of Persons** with Disabilities (CRPD),²⁸² which has transformed the discourse on disability rights.²³² The CRPD recognises that people with disabilities, including those with mental health conditions, should enjoy the same human rights and fundamental freedoms as others and promotes their full inclusion and participation in society.²⁸² It represents a shift from a traditional biomedical model of disability, which views disability as an individual impairment requiring medical intervention, to a social model emphasising that disability results from environmental barriers denying equal rights.²³² The adoption of the CRPD, has spurred deinstitutionalisation efforts in many European countries,²⁸² and numerous advances in law reform, rights based clinical practice and supported decision making^{tt} in countries around the world. 232, 283

Article 12 of the CRPD affirms that people with disabilities should make their own decisions, which must be respected by others.²⁸⁴ The right to legal capacity encompasses both formal decisions, like marriage or property transactions, and informal day-to-day choices. Additionally, they should have an equal right to property, financial control, and have equal assurance of access to financial credit.^{284,285} Often, these rights are overlooked, with decisions made by guardians or health professionals, a practice also know as coercion. Denial of legal capacity can occur in various settings, including homes, schools, workplaces, mental health facilities, and even detention centres.²⁸⁵ The distinction between "legal capacity" and "mental capacity" is crucial here; the former is an inherent right, while the latter refers to decision-making abilities. Support in decision-making should be available, but with safeguards against abuse. It should be proportional, free from undue influence, and regularly reviewed by a trusted authority.²⁸²

The WPA advocates for non-coercive mental health care alternatives,^{286,287} aligning with CRPD principles.²⁸⁶ In 2020, the WPA emphasised collaborative efforts to respect patient rights and improve care standards.²⁸⁸ Their position advocates for patient involvement and early intervention in psychiatric care, highlighting the need for change led by psychiatrists.²⁸⁸

However, the application of the CRPD in mental health, particularly for individuals with schizophrenia, remains contentious.^{289,290} The debate revolves around the concept of "legal capacity" and the undefined term "will and preferences."290 Critics argue that the CRPD's strict stance, especially in Article 12, could be detrimental to the very individuals it aims to protect.²⁸⁹ Some UN bodies and academic circles guestion whether the CRPD's strict interpretation ignores the nuanced reality of decision-making capabilities.²⁸⁹ By prohibiting any involuntary intervention for disabled individuals, some argue that this rigid interpretation risks harming those incapable of making sound decisions, as they cannot be compelled to accept necessary help.²⁸⁹ Critics suggest that the CRPD needs reinterpretation, amendment, or, in some cases, selective application to address its problematic aspects effectively.²⁸⁹

The policy landscape for schizophrenia: today

The creation of a supportive environment in which people with schizophrenia can work towards recovery is central to schizophrenia care. Indeed, it may be a prerequisite for all other approaches discussed in this report to be effective. A supportive environment is a wide-ranging concept comprising various social and legal factors (**Table 6**). At present, however, many people with schizophrenia are not in a supportive environment.

Attention to environmental needs can pay dividends in helping people with schizophrenia achieve their desired outcomes. Key environmental needs include the ability to perform work tasks adequately, good financial management and secure interpersonal relationships; social function often improves when these needs are addressed.²⁹¹ People with schizophrenia, however, often face prejudice and discrimination when seeking employment or training, or when trying to form close relationships.⁶⁴

⁺⁺Supported decision making a tool that allows people with disabilities to retain their decision- making capacity by choosing supporters to help them make choices. A person using supported decision making selects trusted advisors, such as friends, family members, or professionals, to serve as supporters.

Table 6. Factors contributing to a supportiveenvironment.

- Supportive legislation
- Social inclusion
- Employment
- Housing
- Befriending
- Protection against discrimination
- Promotion of competence/capacity
- Use of the least restrictive treatment possible
- Family support and provision of childcare during acute episodes
- Provision of social services

In creation of a supportive policy environment, prioritisation of mental health continues to evolve at a supranational level although generally with a focus on general mental health and rarely directly addressing the very specific and urgent needs of those living with severe mental health disorders. Multilateral organisations including the WHO, Organisation for Economic Co-operation and Development (OECD), UN, Asia Pacific Economic Cooperation (APEC), the European Commission, The Council of Europe, The Council of the European Union and the European Parliament currently highlight the need for prioritisation of mental health.

Much of the guidance and recommendations can be prioritised under the following themes:

- 1. Policy prioritisation of mental health
- 2. Policy guidance on access to quality mental healthcare
- 3. Fostering a comprehensive, integrated health and social care approach for serious mental health conditions

Policy prioritisation of mental health

The **WHO Constitution** and the **UN 2030 Sustainable Development Goals** are acknowledged as frameworks guiding the pursuit of the highest attainable standard of mental health, advocating for Universal Health Coverage and quality essential health care services.²⁹²

Emphasis is placed on strengthening leadership and governance in mental health policy, in line with the **WHO's Special Initiative for Mental Health (2019-2023)**, which aims to enhance access to mental health

services in 12 priority countries.²⁹³ The WHO envisions that by 2030, countries will have revamped their mental health policies and laws to resonate with international human rights standards.²⁹⁴ In the Asia Pacific region, the APEC underscores the need to rejuvenate mental health post-the COVID-19-pandemic, emphasising research and policy enhancement.²⁹⁵ Concurrently, the UN accentuates the pivotal role of governments in achieving **Universal Health Coverage**, which indispensably includes mental health services,²⁹⁶ and advocates for resource allocation, knowledge sharing, and international cooperation.²⁹⁷

The concept of "Mental Health in all Policies" has gained traction.²⁹⁹⁻³⁰¹ The Council of the European Union, in its 2023 Conclusions on Mental Health, highlights a comprehensive approach to mental health, focusing on well-being, coping with life stresses, and contributing to community.²⁹² This approach recognises the impact of the COVID-19 pandemic and other societal challenges, stressing the integration of mental health policies across various sectors, including employment, education, and digitalisation.²⁹² Similarly, the European Commission promotes cross-sectoral collaboration, urging sectors beyond health, such as education, employment, and social protection, to embed mental health considerations into their policies.^{302,303} The European Commission believes this holistic approach can foster social inclusion and destigmatise mental health.³⁰² This is supported by the 'Healthier Together' initiative, which addresses mental and neurological disorders among other NCDs. The OECD echoes this sentiment, calling



Figure 11: Percentage of countries with a stand-alone mental health policy as of 2020, by region.²⁹⁸



for social protection systems to be more attuned to the needs of those with mental health conditions. $^{\rm 304}$

Furthermore, on the EU level the European Commission has spotlighted the need to enhance mental health through innovative care models, with a keen focus on long-term care challenges.³⁰¹ Their strategy revolves around reinforcing mental health systems, enhancing access to treatment and fortifying community services.³⁰² In parallel, the European Parliament has urged its Member States to merge mental and physical healthcare, recognising the intrinsic link between the two.³⁰⁵

Lastly the participation of patients in shaping mental health policies is deemed crucial. The UN encourages a participatory approach, involving those with psychosocial disabilities and those requiring mental health services in policy formulation and implementation.²⁹⁷

Policy guidance on access to quality mental healthcare

A review by the WHO's World Mental Health Report highlights a stark disparity in global mental health care access: a mere fraction of those in need have access to effective, affordable, and quality services.³⁰⁶ Worldwide, 71% of individuals with psychosis remain untreated.³⁰⁶ While 70% receive treatment in high-income countries, this figure plummets to 12% in low-income countries.^{306,307} Better lives for people with schizophrenia is an achievable goal. Significant strides have been made in recent years, but there is a substantial journey ahead. Key to this progress is an integrated team approach, necessitating the collaboration of psychiatrists, a range of healthcare professionals, social care providers, and other external agencies. Critically, this approach must include active participation and partnership with people with schizophrenia, their caregivers, families and other support systems.

The Council of the European Union's **2023 Conclusions** on Mental Health,²⁹² and related reports and actions by major organisations like the WHO,³⁰⁶ UN,²⁹⁷ European Commission,³⁰² and OECD,³⁰⁴ collectively underscore the urgent need for accessible and affordable high-quality mental healthcare.

To address these issues, the European Commission's **Communication on a Comprehensive Approach to Mental Health** outlines principles for accessible prevention, quality healthcare, and societal reintegration.³⁰³ The focus is on integrated, multisectoral policies and services, combating the stigma and discrimination associated with mental health issues, and promoting equality and anti-discrimination in mental healthcare. The programme consists of 20 flagship initiatives and is backed by EUR 1.23 billion in funding.³⁰³

The WHO has been prioritising mental health in its **13**th General Programme of Work (GPW13) for 2019-2023. In line with this, the WHO Special Initiative for Mental Health, with a funding goal of USD 60 million over 5 years, aims to extend quality and affordable mental health care to an additional 100 million people in 12 priority countries.²⁹³ This initiative is complemented by recommendations from the **WHO World Mental** Health Report which recommends strengthening mental health care by changing where, how, and by whom mental health care is delivered and received.³⁰⁶ Here they emphasise community-based networks and a range of services that integrate mental health into general healthcare and use of digital technologies for self-help and remote care.³⁰⁶ Through their **Comprehensive Mental Health Action Plan 2023-**

2030, WHO have set an ambitious target of doubling community-based mental health facilities.³⁰⁶ This is seen as a pivotal step towards achieving Universal Health Coverage, ensuring that mental health services leave no one behind.^{297,305}

Capacity building and training are also key. The OECD highlights training primary care workers to identify and treat mental health conditions,³⁰⁴ while the European Commission and UN focus on building capacities, especially for displaced populations, and recruiting and retaining skilled health workers in underserved areas.^{297,302} This holistic approach is aimed at improving mental well-being across the EU, emphasising collaboration between Member States and the Commission to enhance mental health resilience and ensure high-quality care.²⁹²

In countries or areas with a low psychiatrist-topopulation ratio, the role of psychiatrists is increasingly complemented by Psychiatric Certified Nurse Practitioners (PHMNPs) and physician assistants with psychiatric certification. These professionals often work under the supervision of a medical director, providing essential services. This approach can help address the significant demand for mental health services.

For private healthcare systems, aligning reimbursement mechanisms is also essential to support and sustain high-quality care. Adequate funding is essential for successful care. Investment should match that for other major conditions like cancer and heart disease. This funding is vital for research, treatment, services, and education of future mental healthcare professionals. Currently, the availability of potentially effective psychosocial therapies, funded by public healthcare systems, varies widely across countries, often denying many patients access to essential treatment. More support is also urgently needed for independent studies to explore and validate potentially beneficial interventions.

Fostering a comprehensive, integrated health and social care approach for serious mental health conditions

In their **2023 Conclusions on Mental Health**, the Council of the European Union, recognises the urgent need to transform mental health services from hospitalcentred to community-based settings, fostering a comprehensive, integrated approach.²⁹² The **WHO European framework for action on mental health 2021–2025**³⁰⁸ and the **WHO Comprehensive Mental Health Action Plan 2023-2030** further underscore this need, highlighting the importance of responsive, integrated mental health and social care services in community settings, the aim being that people living with mental health issues:²⁹⁴

- find it easier to receive mental health and social care services;
- are offered treatment by skilled health workers in community-based settings;
- participate in the reorganisation, delivery and evaluation of services so that treatment better suits their needs;
- gain greater access to government disability benefits, housing and livelihood programmes, and better participate in work and community life.

All 194 WHO Member States have signed up, committing them to global targets for transforming mental health by 2030. The WHO monitors progress through their **Mental Health Atlas**,³⁰⁹ produced every three years and their **Mental Health Gap Action Programme (mhGAP)**,³¹⁰ which provides evidencebased guidance and tools to advance towards achieving the targets of the **Comprehensive mental health action plan 2013–2030**.²⁹⁴

The European Commission's '<u>A Comprehensive</u>

Approach to Mental Health', announced in June 2023 recognises mental health as more than a health issue, it involves education, digitalisation, employment, research, urban development, environment, and climate. The Communication outlines 20 flagship initiatives, with financing opportunities worth EUR 1.23 billion, to support Member States in this comprehensive approach.³⁰³

In October 2023, the WHO and the Office of the High Commissioner for Human Rights jointly developed **Mental health, human rights and legislation: guidance and practice**. This guidance sets objectives for mental health systems to adopt a rights-based approach, outlining legal provisions for deinstitutionalisation, access to quality community mental health services, addressing stigma and discrimination, and eliminating coercion in mental health services. It includes a checklist for countries to align their laws with current human rights standards.³¹¹

Additionally, the OECD August 2021 report, <u>A New</u> <u>Benchmark for Mental Health Systems: Tackling</u> <u>the Social and Economic Costs of Mental III-Health</u>,

offers an analysis of mental health system performance, highlighting recent reforms and identifying promising approaches for better meeting mental health needs. This report establishes a framework for understanding mental health performance with internationally comparable indicators, a method expected to grow as more data becomes available.³¹²



What more can be done?

Implementing the recommendations set out in this report requires a collective and committed effort from all stakeholders. Policymakers at every level, clinicians, public agencies, and society at large must engage proactively to drive change. This engagement should also address the specific needs of LMICs where disparities in healthcare access and resources are more pronounced. Adapting global recommendations to local contexts, acknowledging resource constraints, and leveraging existing community resources are crucial for effective implementation in these regions.

With commitment and concerted action from all involved, this report envisions a future where schizophrenia is not only effectively managed through medical and psychosocial advancements but also approached with a deep understanding and empathy. The goal is a world where people with schizophrenia are comprehensively supported, leading to improved lives, social inclusion, and a more empathetic global community. The collective efforts and commitment of all stakeholders can transform this vision into a reality, ensuring that individuals with schizophrenia receive the care and support they need and deserve.

Treatment: what more can be done?

Promote early/pre-morbid detection or diagnosis of those at risk of mental health conditions: Implement comprehensive programmes for early/ pre-morbid detection or diagnosis, and early intervention to address first episode psychosis.

The overall costs associated with schizophrenia reflect the chronic and pervasive nature of psychotic illnesses.¹⁷⁴ Current evidence clearly highlights the potential value of early intervention to address first episode psychosis, with the intention of interrupting the accumulation of burden and suffering that schizophrenia drives, including both negative symptoms and the impact on cognition.^{174,313}

For effective early detection of schizophrenia, a multifaceted approach is essential. This approach

should integrate large population-based research to understand neurobiological mechanisms, coupled with identification of biomarkers, blood examinations, functional brain imaging techniques, EEG for brain activity analysis, and polygenic risk scores for assessing genetic predispositions.³¹⁴ Although our understanding of psychotic disorders' neurobiology is advancing,³¹⁴ and biomarkers for schizophrenia are evolving,^{109,45} there's still a pressing need for more research to pinpoint effective biomarkers.³¹⁴

Ensure early implementation of psychosocial therapies: Increase awareness of psychosocial therapies and promote use as a primary treatment approach.

The evidence base for many forms of psychosocial therapy is so strong that there is a good case for trying them before other potential treatments, for which less supporting evidence is available. Clinicians and payors need to understand the potential benefits of psychosocial therapies better if these treatments are to be made more widely available.

Ensure personalised, shared, and integrated treatment plans:³¹⁵ These should take into account the individual's illness characteristics and support needs, and involve an in-depth characterisation of the patient's condition and comprehensive needs assessment, with a focus on social function interventions.

Understanding each person's illness and the personal support they may need is essential in providing optimal care. In order to implement a personalised, shared, and integrated treatment plan, the person's condition should be characterised in depth, with their needs fully assessed.³¹⁵ This is particularly important during and following a first schizophrenia episode,³¹⁶ especially during the first year.¹⁷⁶ In addition, assertive community treatment has been demonstrated to improve social motivation, depressive symptoms and quality of life in first episode and multi-episode patients with schizophrenia.³¹⁷

Integrate physical health management in schizophrenia care: Implement multi-disciplinary care models to ensure effective physical health interventions and lifestyle modifications, and empower psychiatrists to actively monitor and manage risk factors.

The management of physical ill health in schizophrenia remains far from ideal.²⁵³ Healthcare systems vary, leading to differences in care pathways and ambiguity in the responsibility for physical health management. In some regions, primary care physicians are responsible for treating physical illnesses in schizophrenia patients, while in others, psychiatrists take the lead. To enhance physical health management in schizophrenia, an integrated approach involving clear coordination and defined responsibilities among healthcare professionals, including primary care physicians and psychiatrists, is crucial.

As part of this, psychiatrists as medically trained professionals, should play a proactive role in monitoring the physical health of their patients. This involves being equipped with the necessary tools and training to measure cardiovascular risk factors such as obesity (measured by body mass index or waist circumference), high blood pressure, raised blood glucose and disrupted levels of fats in the blood (including raised cholesterol and triglyceride levels). It should also involve supporting patients to access treatments for their co-morbidities, including medication where appropriate, to reduce cardiovascular risk.^{170,171,318}

The role of health coaching, community engagement, and a multidisciplinary approach involving general practitioners, psychologists, dietitians, and other health professionals is indispensable. They not only encourage adherence to these interventions but also provide comprehensive care.

Include lifestyle interventions as a cornerstone of schizophrenia management: *Emphasise the importance of lifestyle interventions such as a nutritious diet, regular exercise, quality sleep, and abstaining from smoking and substance abuse. Engage a multidisciplinary team including general practitioners, psychologists, dietitians, and other health professionals to support these interventions and provide comprehensive care.*

Lifestyle interventions³¹⁹ are critical in supporting people with schizophrenia. Adopting a nutritious diet, regular exercise, quality sleep, and abstaining from smoking and substance abuse can improve mental and physical

health. These interventions are crucial for addressing conditions such as cardiovascular and respiratory diseases, diabetes and metabolic syndrome. A positive development is the increasing availability of exercise equipment and other lifestyle measures in schizophrenia clinics. Consistent monitoring and intervention are key to ensuring the best physical and mental health outcomes in these patients. Such evidence-based lifestyle therapies are essential for enhancing the quality of life for those living with schizophrenia.

Ensure continuity of care during transition from adolescent to adult services: *Maintain continuous care for people with schizophrenia during their transition from adolescent to adult services, emphasising the importance of a strong therapeutic relationship between clinician and patient to improve medication adherence, work performance, symptom management, and reduce hospitalisations.*

Continuity of care for people with schizophrenia when they transfer from adolescent services to the adult care system is crucial. A strong therapeutic relationship between the clinician and patient has the potential to yield improvements in adherence to medication,³²⁰ work performance³²¹ and symptoms, and reductions in hospitalisations.³²² Both parties should work together to agree on treatment goals and to review progress in meeting these goals.

Advance tele-mental healthcare globally: through legislative reform and inclusive best practices.

Many countries face the challenge of insufficient infrastructure to support widespread remote care, compounded by the digital divide, which is significantly influenced by racial and economic disparities.²³² Addressing these issues through targeted legislation and the implementation of best practices is crucial. Ensuring equitable access and maintaining privacy in remote care not only prepares us for future crises but also extends comprehensive support to individuals with psychosocial disabilities.²³²

Going beyond treatment: what more can be done?

Train educational staff for early mental health intervention: Enhance the training and knowledge of school nurses, guidance staff, college health teams, and therapists in educational settings to aid in early identification and management of mental health issues, particularly among young adults.



Educational interventions for school nurses, guidance staff, college health teams, and therapists can play a vital role in early identification and management of mental health issues, especially among young adults. Enhancing their training and knowledge can significantly improve early intervention and support.

Involve people with lived experience of schizophrenia and informal caregivers in mental health policy, research and training development: Actively involve individuals with firsthand experience to ensure policies and practices are truly relevant and effective.

Standardise mental health data for enhanced digital innovation and research: *Promote research and practices integrating digital technology with mental health improvement efforts, while also ensuring mental health data is standardised to enable international comparison.*

The Council of the European Union, in their **2023 Conclusions on Mental Health**, and APEC both emphasise the importance of routinely gathering current, comparable data for monitoring progress and directing investment in areas requiring improvement, with an emphasis on international coordination.^{292,295} This includes the imperative of standardising data collection and meticulous curation to effectively shape policy and practice.²⁹⁵ Concurrently, the WHO advocates for systematic methodologies in mental health research and data. They recommend that countries biennially gather and disseminate a fundamental set of mental health indicators, using their national health and social information systems.³⁰⁶ Findings are incorporated into their Mental Health Atlas, which maps progress against indicators within their Mental Health Action Plan.³⁰⁶ Furthermore, the WHO has set an ambitious target to double the global research output on mental health, emphasising the need for a deeper understanding in this field. 306,307

Gather data for marginalised communities: Building on digital innovation and research, gather data on mental health in marginalised communities and evaluate the accessibility of mental health services in these areas.

The European Commission has spotlighted oftenoverlooked segments of society.³⁰² They urge nations to gather data on the mental health status of vulnerable groups, such as the homeless and assess the accessibility of mental health services in marginalised and geographically challenging areas.³⁰² Improve awareness of cannabis and illegal substance risks in vulnerable populations: Educate healthcare providers, including primary care physicians and paediatricians, about the risks of cannabis and illegal substances, especially in individuals predisposed to psychosis.

Healthcare providers at all levels, including primary care physicians and paediatricians, should be wellinformed about the potential risks of cannabis and illegal substances, particularly for individuals with a higher genetic predisposition to psychosis. This knowledge is essential for advising patients, especially teenagers and young adults, about the risks associated with cannabis use.

Maximise cost savings with vocational rehabilitation and/or supported employment: Significant cost savings can be realised through ensuring people with schizophrenia stay in the workforce.⁷³

Supported employment interventions can lead to substantial savings in healthcare and societal costs, and may decrease the likelihood of hospitalisation. Studies show that at least half of those with schizophrenia who participate in supported employment programmes eventually secure competitive employment.²⁰⁸ Key features of these interventions include a focus on competitive employment, rapid job searching, integration of employment and psychiatric services, emphasis on the individual's job preferences, and ongoing job support.²⁰⁸

Despite their capacity and willingness to work, many people with schizophrenia struggle to find and sustain stable employment due to a lack of support systems.³²³ Typically, only 10–20% of individuals with schizophrenia are engaged in competitive employment,¹⁹ and they are 6–7 times more likely to be unemployed compared to those without schizophrenia,²⁰ Access to suitable employment can positively influence mental health, but it is crucial that the employment is of the right sort: poor-quality jobs can result in job strain, which can itself lead to poor mental health.²⁰ This is an important issue, because employers often have low expectations of people with schizophrenia, and hence these individuals may end up in low-skilled jobs with little responsibility, or in non-competitive (voluntary or sheltered) work.³²⁴ Paid employment may be beneficial to people with schizophrenia, even if this entails the risk of disrupting established routines and habits - the socalled 'dignity of risk'.¹⁰³

The OECD is leading the charge in this area, emphasising the importance of recognising the work capacity of those living with mental health conditions, advocating for early identification and provision of medical and vocational support.³⁰⁴ They also stress the need for tools to identify work capacity, outreach tools for jobseekers with mental health conditions, and strategies to combat workplace stigma and discrimination.³⁰⁴

Crucial to these efforts is the implementation of workplace accommodations for employees with schizophrenia. Employers should adopt measures to support individuals with schizophrenia, such as:

- allowing flexible scheduling if needed (e.g., if the employee is experiencing drowsiness as a side effect of their schizophrenia medication);
- providing a quiet working environment free from distractions;
- allowing the employee to make up for time lost due to doctor's appointments;
- permitting home working when appropriate;
- dividing large assignments into smaller tasks with clearly achievable goals;
- providing support and encouragement.

Integrate employment strategies with other

interventions. Supported employment measures alone may not improve long-term employment and economic independence in people with schizophrenia. Thus, integrating these strategies with other interventions such as cognitive behavioural therapy, cognitive remediation and social skills training, is crucial.²⁰⁸

Where paid employment isn't viable, offer volunteering opportunities. For individuals where paid employment may not be viable, voluntary work can offer a sense of purpose and engagement. Such roles, providing a 'worthwhile day', can be beneficial even if paid employment is not possible.

Do similar in educational settings: Implement Individual Placement and Support (IPS) principles

in educational settings. Schizophrenia often develops during adolescence and can disrupt education, adversely affecting earning potential in adulthood. Studies have shown that applying IPS principles to education can help these young people complete their education and find paid employment.^{52,53} Educational establishments should modify their policies and practices to address the unique needs of students with schizophrenia, with the potential for long-term benefits

First person account

A lot of my peers say that they want to work. To be honest, I doubt their sincerity because sometimes I see tears in their eyes when talking about their work. What can one do when one's essentials depend on others? I am on the other side: I hope the doctors, hospitals, and governmental institutions give me the option of not working and enjoying my leisure so that I have something to celebrate in my life. This request of mine extends to the general public. In addition, I hope society can provide some places for me to meet some friends and do something with peers so that I am not so isolated. As a matter of fact, I have the above two right now, but only hope they will not be taken away. I also hope that the medications are innovated so that they provoke less sedative effects or do not have to lower the level of dopamine.

From Rudy Tian. Schizophrenia Bulletin Open 2022.325

including increased vocational potential and reduced interactions with law enforcement. $^{\rm 294,326}$

Taking care of the caregiver: what more can be done?

Mitigate caregiver burden in schizophrenia

To alleviate the economic and emotional stress of caregiving for schizophrenia, it is crucial to recognise the dual burden of financial and psychological pressures. These strains not only diminish quality of life, affecting work, social interactions, and physical health, but also lead to significant productivity losses and societal costs. Enhancing training and support for caregivers is a key strategy for mitigating these impacts and achieving substantial cost savings.^{71,73} Another approach is to offer respite to the caregivers, so that they are able to take time for self-care. Ensuring caregiver health and wellbeing is crucial for both the caregiver and the person living with schizophrenia. Caregivers must be seen beyond their role, deserving a life of fulfilment and joy. Friends and family of caregivers should learn to facilitate this, which can be achieved through organised trainings or workshops. To support caregivers EUFAMI have developed an **interactive playbook** to offer guidance for people in this role.³²⁷



Incorporate caregiver burden into Health Technology Assessments

Despite up-to-date data on indirect costs, a comprehensive global understanding of the economic burden of caregiving is still lacking.⁷¹ Integrating caregiver experiences and impacts into the evaluation criteria of Health Technology Assessments (HTAs) would promote a more inclusive and effective approach to assessing treatment. Although HTAs aim to optimise population health by considering all direct health impacts, including those on caregivers, they often neglect the aspect of caregiver burden. Bridging this gap is critical for enabling HTA bodies to make well-informed decisions, especially considering the significant strain on caregivers. Potential methods to incorporate caregiver impact include its integration into Randomised Controlled Trials of treatments or the utilisation of real-world evidence.³²⁸

Empowering people with schizophrenia: what more can be done?

Address the complexities of legal capacity and involuntary treatment in line with human rights: Implement non-coercive alternatives in mental health care, emphasising supported decisionmaking and defining legal capacity for individuals with psychosocial disabilities, in alignment with human rights principles. Transition towards community-oriented, evidence-informed, and individual-focused mental health interventions, guided by the UN CRPD and global human rights benchmarks.

There is broad consensus that coercive and compulsory methods are overused, and evidence supports the adoption of non-coercive alternatives.²³² Supported decision making^{‡‡} initiatives are gaining momentum.²³² That said, clinical practice and policy making continue to struggle with questions relating to the exact scope of legal capacity for people living with psychosocial disabilities.²⁸⁷ They struggle with the nature of supports that might be appropriate and contextually relevant, and with how to go about regulating these matters.²³²

Some countries, like Germany³²⁹ and Norway³³⁰ have suggested that restraining legal agency when a person can't make decisions in their best interests, even with full support, aligns with the CRPD and doesn't undermine legal status.²³² Denmark³³¹ and France³³² have similarly argued that, while legal standing is an inherent and universal right, legal agency can be restricted when required.²³² Debates also surround involuntary treatment, with concerns about safeguarding individuals and public safety.²³² Indeed, Freeman MC, *et al.* (2015) argue that the CPRD's requirements deviate in a problematic way from previous internal agreements on human rights and previous WHO recommendations.³³³ They fear a paradoxical effect of the General Comment of the UN Committee, through which fundamental human rights could be violated instead of better protected. However, advocates argue that coercion perpetuates discrimination and can lead to abuse.²³²

As we touched upon earlier, the WPA's initiatives focus on implementing coercion-free mental health care worldwide.²⁸⁶⁻²⁸⁸ Acknowledging the overuse of coercive practices, the WPA calls for action to ensure high-quality, rights-respecting care.^{286,288} This includes involving patients in care decisions, promoting early intervention, and creating recovery-oriented systems.^{286,288} The WPA encourages stakeholders to consider evidence-based alternatives and actively develop and implement them. The goal is to improve mental health care standards, respecting the rights and promoting the well-being of patients and their families.^{286,288} Similarly, the WHO has introduced best practice guidelines as part of its 2017 **QualityRights** Initiative.²⁸⁵ The WHO has also made significant investments in training for this care model globally, collaborating with policymakers and disability rights advocates.²⁸⁵

EUFAMI advocates for mandatory training in deescalation, human rights awareness, medical ethics, understanding mental health laws, exploring noninvoluntary admission options, responsible use of coercive measures, rights to appeal processes, and promoting a recovery culture in mental health care.³³⁴

The UN **CRPD** emphasises international collaboration in framing mental health policies, plans, and laws in line with human rights principles, particularly in humanitarian contexts.²⁸² The call is for a shift to community-oriented, evidence-based, and individualfocused care.²⁸² A UN-commissioned literature review for the Special Rapporteur on the Rights of Persons with Disabilities examined literature on alternatives to coercive practices. This review found various effective practices, policies, and interventions at multiple levels,

underscoring the need for a comprehensive policy framework. It emphasised the critical role of both high-level and grassroots leadership, including peer involvement, in fostering a culture that minimises coercion. The review identified the necessity for new community-based crisis services and redefined mental health support as 'crisis resolution' and 'general support'. Effective strategies for reducing coercion include national oversight, organisational culture shifts, and independent advocacy. The report encourages future research focused on mental health care policies that respect dignity and autonomy while reducing institutional coercion.³³⁵ Both the European Commission and the WHO support this approach, urging countries to align their mental health strategies with global human rights benchmarks by 2030.294,303

Combat Stigma: Collaborate with a wide range of organisations to reduce mental health stigma, fostering an environment of understanding and acceptance, through initiatives such as public education programmes and awareness campaigns.

The European Commission, in tandem with the OECD, are working on dismantling the stigma and discrimination tethered to mental health.^{303,304} The overarching goal is to cultivate an environment where mental health is devoid of prejudice and misconceptions.^{303,304} Still, this is an area where efforts needs to be made on a local level, across multiple communities and cultural settings. In Canada, the "Bell Let's Talk" initiative focuses on enhancing mental health awareness and acceptance, emphasising four main pillars: combating stigma, expanding access to healthcare, funding top-tier research, and setting the standard in workplace mental health.³³⁷ For example through this programme a collaboration between a drop-in centre and a Toronto university has resulted in a monthly 30-minute radio show about mental health, hosted by clients of the centre. This programme's episodes are available on platforms like Google Podcasts and Apple Podcasts, with this type of initiative bringing about tremendous change in the community through public education.337

Improve the availability of peer-led support and guidance: Acknowledge the significant role these interventions play in recovery-focused care, even amidst the difficulties arising from disjointed schizophrenia services.

Peer-led interventions are gaining acknowledgment as a vital component of recovery-focused care, notwithstanding the hurdles created by the segmented nature of schizophrenia services. They are particularly crucial for young individuals with schizophrenia.²⁰⁸

Improve access to disability benefits for people with schizophrenia: A comprehensive approach to general support should encompass both information provision and assistance in accessing available benefits.

One study in France, in which more than half of the participants became unemployed following the onset of schizophrenia, demonstrated a median delay of four years between the onset of the disorder and the first application for disability benefits. In many cases, the financial hardship caused by this delay exacerbated the social consequences of their schizophrenia.³³⁷ Accessing information on available benefits can be challenging, particularly for individuals with limited literacy. This issue is especially pertinent in immigrant communities, where cultural and language barriers may impede service access.⁵⁴

In the USA, about 80% of individuals with schizophrenia qualify for disability benefits. However, many who initially fail to secure these benefits actually meet the criteria, but struggle with navigating the appeal process.³³⁸In contrast, in the UK, individuals with mental health issues often face prolonged unemployment, and those applying for benefits are less likely to succeed compared to applicants without mental health problems.²⁰

This situation contrasts with that in Australia, where there is an effective 'one-stop' system for identifying claimants with mental health problems.²⁰ Meanwhile, in Belgium, individuals with mental health disorders who become unemployed typically receive unemployment benefits instead of disability benefits. This approach keeps them connected to the labour market, thereby aiding in their eventual re-employment.³³⁹



Start somewhere: inspirational cases for every setting

Start somewhere: Not every nation, community or institution will achieve all global recommendations. The key is to start somewhere. Even small changes can make a difference.

While supranational organisations provide a blueprint for best practices in mental healthcare, the implementation can be challenging, especially in LMICs. The provision of adequate measures to decrease the burden of illness, both mental and physical, among people with schizophrenia depends on local legislation in each country. In addition, such provision requires effective coordination of services and funding, continuity of health and social care, and synchronisation with the criminal justice, benefits and employment systems. Extensive evidence exists that initiatives designed to improve continuity of care can produce a favourable outcome.^{340,341}

For serious mental health conditions such as schizophrenia, in some countries up to 90% are unable to access proper care.^{342,343} For example, despite deinstitutionalisation being promoted as being in the best interest of patients, in practice, it requires significant financial, structural and strategic investment in community-based services¹⁸ and is not always available as an option. Achieving it remains challenging, and varies greatly within and between countries.^{17,18} Overall 2 out of 3 dollars of scarce government spending on mental health is allocated to centralised, long-term hospitalisation,³⁰⁶ while other countries delay deinstitutionalisation with a focus on hospital-based care.^{18,344}

Invest in community-based services and extend care with non-specialists: Utilise the Mental Health Gap Action Programme (mhGAP) model or the C4 Framework to empower non-specialists in LMICs to provide essential mental health services.

Investigating how to extend care to these individuals is crucial, but there has been a lack of empirical evidence on utilising available human resources in LMICs.³⁴³ The development of the Mental Health Gap Action Programme (mhGAP) by WHO suggested that the most feasible pathway to extend mental health care in resource-constrained settings is to empower nonspecialists to provide the bulk of the required service.^{343,345}

This approach was tested in Kilifi County, Kenya, as part of a larger study.³⁴⁶ Primary healthcare workers in all public health facilities received mhGAP-IG training in a staggered, randomised manner over 16 months. Results showed improved mental health knowledge, tolerance, and attitudes among these workers, though there was no significant increase in diagnosing psychotic disorders. This method proved viable and effective, reducing the treatment gap and stigma, and improving patient outcomes in mental, neurological, and substance misuse disorders.

Drawing on this, Bolton *et al.* (2023) offer a framework for comprehensive, collaborative, and communitybased care (C4) for accessible mental health services in low-resource settings (**Figure 12**).³⁴⁷ The framework delineates types of workers based on their skills to focus on: basic psychoeducation and information sharing; community-level, evidence-based psychotherapeutic counseling; and primary medical care and more advanced, specialised mental health services for more severe or complex cases.³⁴⁷



Figure 12: From Bolton *et al.* (2003), comprehensive, collaborative, and community-based care (C4) framework for LMICs.³⁴⁷

Training nurses in Mongolia and the UK:³⁴⁸

The **MoMeNT** (Mongolian Mental Health Nurse Training) project, a 3-year programme initiated in 2018 and spearheaded by Professor Fiona Nolan, is a key development in mental health nurse training in a low-income country. With the challenge of limited resource and access to modern approaches to mental health care services, MoMeNT emerged as a response to strengthen the skills of nurses working in mental health services. This initiative received a EUR 1 million grant from the European Commission's **Erasmus+** programme for 'Building Capacity in Higher Education'. A collaboration among six universities from the UK, Finland, the Netherlands and Mongolia led to the creation of a pioneering 6-month postgraduate certificate programme in mental health nursing. This groundbreaking programme, the first of its kind in Asia, is specifically designed to address the unique legal, cultural, and economic factors of Mongolia. It aims to bridge a gap in specialised training for nurses working in mental health services, enhancing their skills and status within the healthcare system, while also increasing awareness about mental health in a setting with limited resources. With support from entities like the Mongolian Ministry of Health and the WHO, the MoMeNT project stands as a foundational movement in the progression of mental health services, and more specifically of the nursing profession, in Mongolia. The training has potential to transfer to any country or setting in which nurses would benefit from university accredited, modern specialist training in mental healthcare, incorporating values of recovery, co-production and engagement with people with lived experience of mental illness and their families.

Concurrently, in the UK, faced with increasing vacancy rates and difficulties in attracting local populations to work in mental healthcare, there has been a significant focus on recruitment of internationally educated nurses, particularly from low-income countries. Recruitment of these nurses to work in UK mental health services has been challenging, due to a lack of specialist training in their countries of origin. The UK Royal College of Nursing (RCN) is currently working with Professor Nolan to adapt the training materials from the MoMeNT project to fit the UK's mental health laws and other specific requirements with the aim of providing a centralised resource, accessible across the UK, to support the transition and effective integration of internationally educated nurses. This approach demonstrates a commitment to inclusive, adaptable education in mental health care, aiming to support the transition of internationally recruited nurses and serving as a model

for quality care and professional development in mental health services.

Street Medicine and Mobile Teams in the USA:³⁴⁹ have shown promise in providing effective care for people with schizophrenia. Programmes like **Operation Safety Net** in the USA, demonstrate the benefits of such approaches. These teams typically consist of a nurse who assists with medical appointments and care coordination, and a peer support specialist who is often someone with a diagnosis of schizophrenia. Such programmes not only provide immediate care but also play a crucial role in long-term management and support, showing that schizophrenia can be managed effectively, allowing individuals to lead fulfilling lives. This model can be particularly beneficial in areas with limited resources for large facilities or community mental health centres.

Training civic duty leaders working in the community, in Ireland:³⁵⁰ The "Responding to Mental Health Distress in the Community Workshop" for senior managers of Ireland's national police service marked a significant effort to better support those with mental health distress. It educated law enforcement on mental health issues, incorporating interactive elements, group activities, and insights from facilitators who had experienced mental health distress. Key focuses included differentiating mental health and illness. balancing safety, policy adherence, and individual wellbeing, and the necessity for more structured support from Mental Health Services. Valued for its empathybuilding and practical insights, the workshop's success has prompted Mental Health Ireland to further refine its content and expand learning resources for their police service, demonstrating a proactive stance in addressing mental health within law enforcement.

Similar training or guidance could also take place for other community leaders, for example religious leaders and others with civic responsibilities, who may find themselves working with but not knowing how to best to support people with schizophrenia and other mental health conditions.

Addressing stigma in Denmark: 351 "ONE OF US"

is an anti-stigma initiative in Denmark, aiming to reduce discrimination and social exclusion related to mental health conditions, particularly focusing on schizophrenia. Launched in 2011 it is organised as a part of The Danish Health Authority, where the programme is managed nationally. At the regional level ONE OF US is located in the regional divisions called PsykInfo (Psychiatric Information Centre) that



are part of each of the 5 regions of Denmark. The national and regional levels of ONE OF US work closely together. The programme, supported by various public and private organisations, targets people with mental health conditions, youth, the labour market, health professionals, and the media. Its core strategy involves increasing knowledge and understanding of mental illnesses, decreasing the stigma, and fostering inclusion in all societal aspects. A key element is the use of ambassadors, individuals with lived experience of mental illness, who engage in various activities and dialogues to break down prejudices and encourage a society where mental illness is not a barrier to a fulfilling life. Evidence shows that this approach of social contact is highly effective in reducing stigma.

Social Outcomes Partnerships in the UK:^{323,352}

The **UK's Life Chances Fund** has been instrumental in pioneering innovative approaches to securing meaningful work in the community. By utilising the mechanism of Social Outcomes Partnerships, also widely recognised as Social Impact Bonds, in the UK the Life Chances Fund invests in outcomes-based contracts that align societal goals (for example helping individuals with schizophrenia develop vocational skills, gain confidence, and ultimately integrate into the workforce) with financial returns for investors. Social Outcomes Partnerships facilitate partnerships between the public, private, and voluntary sectors, converging on the shared objective of generating tangible social impacts and outcomes (**Figure 13**).

Figure 13: From UK Government, Social Outcomes Partnerships and the Life Chances Fund: Key partners in a Social Outcomes Partnership.³⁵²

Example approach for a Social Outcomes Partnership: 323,352

- A local non-profit organisation proposes a supported employment programme for people with schizophrenia.
- Clear metrics are established to determine success.
- A private investor seeing potential social value, fronts the initial costs.
- The government pays for improved social outcomes through Social Impact Bonds.
- If the process succeeds the investor will be repaid with interest. If it fails, the investor takes that risk.
- The Life Chances Fund matches the funding, doubling the resources to the non-profit organisation, enabling the programme to scale up and reach more people.
- If goals are met, the government repays initial investors using the funds they would have otherwise spent on unemployment benefits, healthcare and other related costs for these individuals.
- The public benefits from having more of its citizens employed and healthy, the participants benefit from the support and employment, and the investors benefit from their returned investment with interest.



VCSE: Voluntary, community and social enterprise

Abbreviations

Assertive Community Treatment
Asia Pacific Economic Cooperation
Cognitive Behavioural Therapy
Convention on the Rights of Persons with Disabilities
Critical Time Intervention
Disability Adjusted Life Years
Extrapyramidal Symptoms
European Federation of Associations of Families of People with Mental Illness
Global Assessment of Functioning
Global Alliance of Mental Illness Advocacy Networks
Global Anti-Stigma Alliance
Health Outcomes Through Positive Engagement and Self-Empowerment
Health Technology Assessment
International Classification of Diseases 11
Individual Placement and Support
Long-Acting Injections /Injectables
Life Chances Fund
Low- and Middle-Income Countries
Mental Health Court
Mental Health Gap Action Programme
Mental Improvements of Nations Development
Mongolian Mental Health Nurse Training Project
Mobile Therapeutic Attention for Treatment Resistant Schizophrenia
National Alliance on Mental Illness
Non-Government Organisation
National Institute for Health and Care Excellence
Non-Profit Organisation
Organisation for Economic Co-Operation and Development
Psychiatric Certified Nurse Practitioners
Purchasing Power Parity
Randomised Controlled Trials
Supported Decision Making
Small or Medium Enterprise
Social Outcomes Partnerships
Transcranial Direct Current Stimulation
United Nations
Voluntary, community and social enterprise
World Health Organization
World Psychiatric Association



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