NEED
Needs Examination, Evaluation and Dissemination

KCE REPORT 418

NEED

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Federaal Kenniscentrum voor de Gezondheidszorg
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NEEDS EXAMINATION, EVALUATION AND DISSEMINATION (NEED): IDENTIFICATION OF UNMET HEALTH-RELATED NEEDS ASSOCIATED WITH PSYCHOTIC DISORDERS



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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ATC	Anatomical Therapeutic Chemical
BeBOD	Belgian Burden of Disease
CBT	Cognitive-behavioural Therapy
CBTp	Cognitive-behavioural Therapy for psychosis
CHR-P	Clinical High Risk for Psychosis
DBS	Deep brain stimulation
DSM-V	Diagnostic and Statistical Manual of Mental Disorders V
ECT	Electroconvulsive therapy
EEG	Electroencephalogram
EQ-5D-5L	EuroQol 5 dimensions 5 levels
EU	European Union
FEP	First episode psychosis
FGAs	First Generation Antipsychotics
GABA	Gamma-aminobutyric acid
GBD	Global Burden of Disease study
GDP	Gross Domestic Product
GP	General practitioner
GWAS	Genome-Wide Association Studies
HIS	Health Interview Survey
HRQoL	Health-related Quality of Life
IMA – AIM	Inter-Mutualistic Agency
IMHS	Inpatient mental health service
IPS	Individual Placement and Support
IQR	Interquartile range
NEED	Needs Examination, Evaluation and Dissemination
NIHDI	National Institute for Health and Disability Insurance
NICE	National Institute for Health and Care Excellence
OASIS	Outreach and Support in South-London
OCD	Obsessive Compulsive Disorder

OOP	Out-of-pocket payments
PD	Psychotic disorder
SD	Standard deviation
SGAs	Second Generation Antipsychotics
SSD	Schizophrenia-spectrum disorder
TMS	Transcranial Magnetic Stimulation
VAS	Visual Analogue Scale
YLDs	Years Lived with Disability
YLLs	Years of Life Lost

SCIENTIFIC REPORT

1 INTRODUCTION

CONTEXT

Psychotic disorders (PD) represent a major public health concern with substantial unmet needs affecting individuals, their caregivers, and society at large. The KCE report 391: Identification, evaluation and selection of health conditions for the NEED research programmes highlighted that unmet needs may be particularly high in this area. Schizophrenia was among the 118 health conditions identified through the Belgian call for proposals and the Belgian Burden of Disease Study as having potentially significant unmet needs. It has since been prioritised within the NEED research programme.[1]

Schizophrenia, the most frequent and more intensively researched psychotic disorders, is a condition associated with substantial individual and societal burden, because of its early onset, chronic and relapsing nature, and wide-ranging impact on functioning, quality of life, and mortality. Next to disease-related needs, patients may also frequently face stigma, housing instability, and social exclusion, as well as difficulties accessing integrated care and support services.[2-4] Existing care pathways may overlook or inadequately address these broader needs, particularly those related to daily functioning, autonomy, and participation in society.

Developing more person-centered and effective mental health(care) management strategies for individuals with psychotic disorders, requires a nuanced understanding of their unmet health-related needs. Despite growing recognition of the complexity of these conditions, the perspectives of people living with a PD, and those of their caregivers, remain underrepresented in both research and policy development. Understanding these perspectives is crucial, as unmet needs often extend beyond symptom management and can include domains such as physical health, social life, daily functioning, and access to appropriate care and support services. By systematically exploring these domains, this study sought to provide a comprehensive overview that aims to inform policy decisions, improve service design, and ultimately contribute to more tailored and inclusive models of care for people with a psychotic disorder.

THE NEED PROJECT

Launched at the end of 2022, the NEED (Needs Examination, Evaluation and Dissemination) initiative was introduced with the objective of developing and testing an innovative, evidence-based methodology to identify unmet health-related needs to support the transition to a more needs-driven healthcare policy and innovation system. Currently, the health innovation landscape remains predominantly supply-driven, with private research and development efforts often targeting areas with the highest potential for financial return, rather than those addressing the most pressing needs of patients and society.

Early 2024, the first results of the NEED project were published and presented during the Belgian presidency of the Council of the European Union (EU). This included, among other things, the NEED assessment framework[5] which defines criteria and indicators to evaluate unmet health-related needs of patients and society (including caregivers). The framework was piloted on two health conditions: Crohn's disease and malignant melanoma[6, 7] for which the results were incorporated into the online publicly accessible NEED database.[8] In addition, the project evaluated the NEED framework's applicability to rare diseases, taking into account specific considerations when assessing unmet needs in the context of rare diseases.[9]

In 2025, a revision of the NEED assessment framework and its core version was published based on an expert consensus at the European level. Whereas the initial version had been primarily reviewed by Belgian stakeholders, this update reflects the NEED initiative's ambition to deliver a methodology suitable for EU-wide application and cross-border policy support.

Building on this revision and the insights gained from earlier case studies, the team developed a standardized research protocol, referred to as the "NEED protocol", to guide researchers through the process of conducting a NEED study.[10] Accompanying this protocol is the NEED toolbox[11], a practical collection of instruments designed to facilitate the assessment of unmet needs.

The current report presents a new case study, focused on patients suffering from Psychotic disorders, which allows for the application of the NEED protocol and various methods developed to date.

2 OBJECTIVES

The primary objective of this study is to systematically identify and assess the health-related needs of individuals living with a psychotic disorder in Belgium. Specifically, the study aims to:

1. Capture unmet needs across health, healthcare, and social domains as reported by patients themselves or their legal representatives;
2. Explore how these needs vary according to socio-demographic and clinical characteristics, including type of psychotic disorder, time since diagnosis, gender, living situation, and region of residence; and
3. Generate evidence to inform healthcare providers, policymakers, and patient organisations on tailoring services and interventions to better support this population.

Ultimately, the study seeks to contribute to a more patient-centred and needs-driven approach in the organisation of health care for individuals living with a psychotic disorder in Belgium.

3 SCOPE

This report includes all psychotic disorders as defined in the DSM-5 (namely: "*Schizophrenia Spectrum and Other Psychotic Disorder*s"), with the exclusion of psychotic disorders due to a medical condition, and with the inclusion of bipolar disorder with psychotic features. Diagnostic boundaries within psychotic disorders are known to shift over time, reflecting the heterogeneous and dynamic nature of psychotic experiences. Consistent with this evolving perspective, the present study uses the term *psychotic disorder* (PD) to encompass individuals who have experienced one or more psychotic episodes across their lifetime. This definition includes, but is not limited to, individuals diagnosed with schizophrenia, as well as those with other conditions in which psychosis is a prominent feature, such as bipolar disorder with psychotic features. Acknowledging the sensitive and potentially stigmatizing nature of this terminology highlights the importance of identifying and addressing the unmet needs of individuals affected by PD, their caregivers, and society more broadly, not only with respect to clinical treatment but also in promoting inclusion, recovery, and social participation.

4 DISEASE DESCRIPTION

The aim of this chapter is to provide a brief overview of psychotic disorders including their epidemiology, clinical presentation, diagnosis, and management.

KEY POINTS

- Psychotic disorders are a heterogeneous group of mental health disorders characterised by psychotic symptoms (hallucinations, delusions, and disorganised thinking or speech, and disorganised or catatonic behaviour). Common diagnoses include schizophrenia, schizoaffective disorder, delusional disorder, and schizophreniform disorder.
- Incidence is estimated at about 26.6 cases per 100 000 person-years, though figures vary due to differences in diagnostic criteria and study design. Rates are higher among men, younger individuals, migrants, urban residents, those living at higher latitudes, and those experiencing socioeconomic disadvantage.
- Psychotic disorders typically begin in late adolescence or early adulthood. Their course is heterogeneous, ranging from single episodes with substantial recovery to chronic or recurrent trajectories with persistent symptoms and functional impairment.
- Aetiology is multifactorial. Psychotic disorders are commonly categorised as primary psychotic disorders, substance-induced psychoses, and psychoses due to a medical condition (the latter being outside the scope of this report). Primary disorders arise from complex interactions between genetic vulnerability, neurodevelopmental factors, and environmental exposures.
- Diagnosis is clinical, as there are no biomarkers or imaging tests with sufficient sensitivity and specificity for routine diagnostic use; investigations are primarily used to exclude secondary causes, particularly at the first episode.
- Reduced illness awareness is common in patients with schizophrenia spectrum disorders (approximately 50–80%) and is associated with poorer treatment adherence and prognosis.
- Treatment combines pharmacological and psychosocial approaches. Antipsychotics primarily target positive symptoms and have limited effects on negative and cognitive symptoms. Psychosocial interventions improve functioning and selected symptom domains.
- Antipsychotics are associated with significant adverse effects: first-generation agents are more commonly linked to extrapyramidal symptoms, whereas many second-generation agents increase metabolic risk. Despite treatment, many individuals experience incomplete remission, adherence difficulties, and functional impairment. Approximately 20% show insufficient response to antipsychotic treatment, and a substantial proportion discontinue medication over time.
- Primary prevention is limited by the multifactorial aetiology. Current strategies mainly focus on identifying clinical high-risk states and early intervention, but these criteria have limited positive predictive value and intervention effects vary across settings.
- Persistent inequities are observed, with migrant and socioeconomically disadvantaged populations experiencing higher risk and poorer access to care, while stigma and social exclusion contribute to a self-reinforcing cycle of disadvantage.

While the prognosis of psychotic disorders can vary, for many patients they are chronic and often severe mental health conditions, which have been linked to considerable morbidity, a profound social and economic impact, and premature mortality.[12] Schizophrenia alone was ranked among the top 15 causes of disability worldwide in 2023.[13,14]

Our understanding of psychosis has historically been defined in many different ways, originating from the Greek term for abnormal condition of the mind, it has evolved considerably over time, and its classification remains a subject of debate.[15] Before 1980, the term "psychotic" referred to a very broad concept, used to describe individuals whose mental abilities were so disrupted that they struggled to manage everyday responsibilities.[15] With time and successive updates of the DSM, psychotic conditions were redefined according to explicit diagnostic criteria, and psychotic symptoms now denote specific disturbances in cognition and perception.[15] Today, the DSM-V-TR recognises distinct clinical disorders under the category 'Schizophrenia Spectrum and Other Psychotic Disorders', which are differentiated based on factors such as symptom profile, symptom duration, relationship to mood episodes, and underlying causes (idiopathic, substance-induced, or due to medical illness).

Psychotic disorders are now regarded as a group of mental health conditions that are characterized by features such as hallucinations, delusions, and disorganised behaviour.[16] The most frequent conditions are schizophrenia, schizoaffective disorder, delusional disorder, and schizophreniform disorder.[15]

Schizophrenia is the most widely researched and historically defining psychotic disorder, which shaped how psychosis is clinically understood.[17] Together with schizoaffective disorder, schizophrenia is generally considered among the most severe primary psychotic disorders, characterised by the involvement of multiple symptom domains and exclusion of secondary causes.[18]

Schizoaffective disorder is also considered a primary psychotic disorder, meaning it is not attributable to any other condition or external cause. It is characterised by symptoms of schizophrenia together with the presence of a major mood episode (depressive or manic). It remains a complex and debated diagnosis. It shows wide variation in clinical presentation and has low diagnostic stability and validity.[19, 20] There is continued exploration of whether it should be considered a subtype of schizophrenia, a form of bipolar disorder, a separate condition, or part of a continuum that blends psychotic and mood-related features in varying degrees.[19]

Brief psychotic disorder and schizophreniform disorder are characterised primarily by shorter symptom duration.[17] Differentiation between psychotic disorders often requires longitudinal assessment, as diagnostic boundaries may only become clear over time. [21]

Substance-induced psychotic disorders constitute secondary psychotic conditions triggered by intoxication with or withdrawal from psychoactive substances. Stimulants, cannabis, cocaine, and synthetic psychotomimetic substances may precipitate psychotic episodes that clinically resemble primary psychotic disorders.[22] Among individuals already diagnosed with a psychotic disorder, it can be particularly challenging to distinguish between substance-induced psychosis and the exacerbation of a pre-existing psychiatric condition.[22] To be considered a substance-induced psychotic disorder, the hallucinations and delusions must be in excess or persist beyond the expected duration of substance intoxication or withdrawal.[23, 24]

Psychotic disorders secondary to another medical condition, such as dementia, tumours, or autoimmune diseases[15], are also considered 'Schizophrenia Spectrum Disorders' in the DSM-V.[25-27] Nevertheless, we chose to exclude these conditions from our study due to the distinct pathophysiological mechanisms involved and the likely divergence in unmet needs, as well as the treatment and prevention strategies required.

Residual diagnostic categories (e.g. Psychotic Disorder Not Otherwise Specified) are used when clear psychotic symptoms are present but full criteria for a specific psychotic disorder are not met.[28]

It is worth noting that psychotic symptoms may also occur in other psychiatric conditions, such as during major depressive episodes or mania in bipolar disorder. In obsessive-compulsive disorder, intrusive thoughts may occasionally reach a level of conviction resembling psychotic phenomena.[25] These conditions differ from schizophrenia spectrum disorders, as they are mainly defined by mood or behavioural disturbances rather than psychosis. Mood symptoms are not central to schizophrenia spectrum disorders, except in schizoaffective disorder, which combines features of

psychosis with symptoms of bipolar disorder or depression and requires that psychotic symptoms are present for at least two weeks without significant mood symptoms.[29]

The lack of clear boundaries between different specific diagnoses within the psychotic disease spectrum is not only evident in clinical practice. Indeed, it also makes the interpretation of evidence from the scientific literature more challenging, as studies differ widely in scope. A disproportionate number of studies concentrate exclusively on schizophrenia, while a minority address related disorders, such as 'Schizophrenia-Spectrum psychotic disorders' and 'Non-affective psychotic disorders'. The diagnostic scope of these umbrella terms varies across studies, particularly for non-affective psychotic disorders, which encompass substantial heterogeneity. In this report, we prioritise evidence concerning 'psychotic disorders, and 'Schizophrenia-Spectrum psychotic disorders', while also including findings for 'Non-affective psychotic disorders'. Where only data specific to schizophrenia or another single disorder are available, this will be explicitly acknowledged.

4.1 Epidemiology

A recent meta-analysis on the occurrence of psychotic disorders, encompassing data primarily from Europe, North America, and Australia, reported a pooled incidence of all psychotic disorders at 26.6 per 100 000 person-years (95% CI: 22.0–31.7).[12] The pooled incidence for non-affective PD was 18.7 per 100 000 person-years (95% CI: 14.8–23.7), and 4.8 per 100 000 person-years (95% CI: 3.3–6.9) for affective PD.[12] For schizophrenia specifically, the median incidence was 21.7 per 100 000 person-years (IQR: 5.6–52.0).[12] The study showed that measuring these estimates remains challenging due to substantial variability in the diagnostic categories included across studies and the heterogeneity of study designs. For instance, incidence rates are notably higher in registry-based studies compared to first-contact designs. Concerning schizophrenia only, which is the most widely studied of the PD, it is thought to have a lifetime risk of around 0.7%.[30]

Concerning prevalence, for schizophrenia only, meta-analysis of 17 estimates provided a mean 12-month global prevalence of 4.51 per 1000 persons (Q25;Q75: 2.22–4.21). For non-affective psychosis this estimate was of 5.12 (3.42-6.55).[13]

There is convincing evidence that the incidence of psychotic disorders differs consistently across demographic, geographic, and social factors. Higher risk is observed among men and younger individuals, as well as among migrants of low socioeconomic status and their descendants (see section 2.6 'Inequities' for more detail). Higher rates are also reported in urban environments and regions located at higher latitudes. Additionally, increased incidence is linked to socioeconomic disadvantage and inequality.[12, 31]

4.2 Pathophysiology

4.2.1 Clinical presentation

The most common primary psychotic disorders, such as schizophrenia and schizoaffective disorder, typically develop in late teen or early adult life (peak age 20.5 years), although earlier presentations in children under 13 have more rarely been reported.[31-34] Delusional disorders tend to develop later, in middle age, whereas psychotic disorders secondary to drug abuse or prescribed medications can occur at any (generally adult) age.[15]

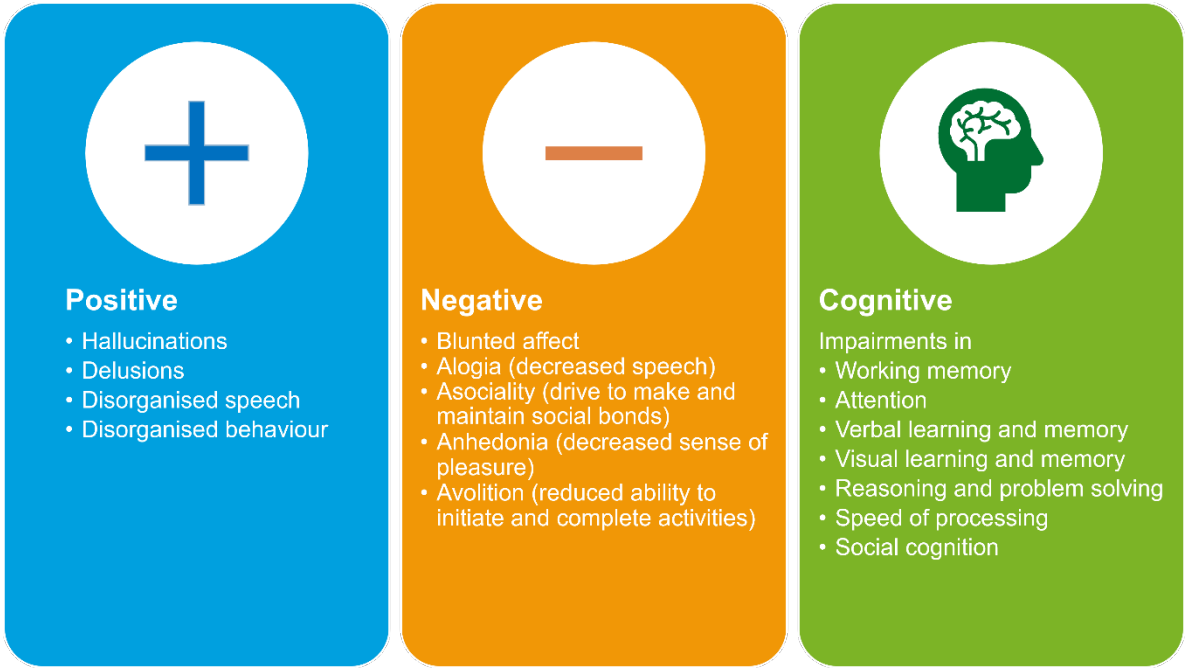
Symptom onset may be abrupt or insidious. Early manifestations often involve subtle changes in cognition, perception, mood, and social functioning, including social withdrawal, reduced motivation, and attenuated perceptual disturbances, which may precede the first acute psychotic episode.[35]

The types of psychotic symptoms and their frequency of occurrence depend on the specific disorder, and even differ between individuals with the same diagnosis.[15, 16] They also vary widely in severity and in their impact on individuals meaning that the course of illness is often unpredictable and highly heterogeneous.[16] Some individuals experience isolated episodes

followed by substantial recovery, while others develop a chronic, relapsing pattern with frequent acute episodes and persistent functional impairment. Nevertheless, disorders tend to be long-lasting, prone to recurrence, and typically marked by only partial recovery.[27]

The range of symptoms occurring in psychotic disorders can be categorised into three main groups: positive, negative, and cognitive symptoms (Figure 1), although other modes of classification have also been reported.[31, 36, 37]

Figure 1 – The three symptom groups of psychotic disorders: positive, negative, and cognitive. *Adapted from Rosenbrock et al. (2023)*[38]



4.2.1.1 Positive symptoms

Positive symptoms represent core features of psychotic disorders and reflect distortions or exaggerations of normal mental functions. These symptoms include delusions, hallucinations, and formal thought disorder.[39, 40] According to the DSM-V, hallucinations concern "perceptions that occur without an external stimulus, most commonly auditory, but less commonly visual, tactile, and olfactory".[25] Delusions are defined as "fixed beliefs that are not amenable to change in light of conflicting evidence".[25] Persecutory delusions are the most common type and concern the belief that one is going to be harmed or harassed by an individual or organisation. Referential delusions are also common and include the belief that certain gestures, comments, environmental cues etc, are directed at oneself.[25] Formal thought disorder is generally manifested through disorganised speech, which may become incoherent, with disconnected ideas, abrupt interruptions, and generally difficult to follow, sometimes to the point of incomprehensibility. Disorganised behaviour concerns behaviour that is inappropriate, unpredictable, including childlike behaviour or unpredictable agitation. Severe positive symptoms can substantially disrupt daily functioning and place considerable burden on patients and their caregivers.[41]

4.2.1.2 Negative symptoms

As currently understood, the domains of negative symptoms include blunted affect, alogia (i.e., reduced speech or difficulty in engaging in conversation), asociality (i.e. lack of drive to make and maintain social bonds), anhedonia (i.e., inability to feel pleasure), and avolition (i.e. loss of motivation).[39, 42-47] Unlike positive symptoms, negative symptoms are often more persistent and less responsive to standard treatments, significantly impairing social and occupational functioning.[44, 46] While they can appear at any stage of the disorder, they are often reported by

patients as the first symptoms.[45, 46] Negative symptoms may be primary or secondary, in the latter case arising as a consequence from psychotic symptoms or from comorbid conditions, medication side effects, depressive symptoms, or adverse environmental circumstances.[45, 46, 48]

4.2.1.3 Cognitive symptoms

Cognitive symptoms only started to be fully recognised as part of psychotic disorders in the late 1990s.[31] These symptoms include impairments in working memory, attention, verbal and visual learning, reasoning and problem-solving, speed of processing, and social cognition. [25, 39, 49, 50] They vary greatly in degree from one patient to another. Some patients remain neuro-cognitively normal, or even have superior intellectual ability, while others have important deficits particularly in executive function, memory, and sustained attention.[31, 51, 52] Cognitive symptoms can emerge before the onset of a psychotic disorder and persist even after successful treatment of positive symptoms with antipsychotics.[53, 54] Cognitive impairments often receive less clinical attention than positive symptoms, despite accounting for a substantial proportion of long-term morbidity and functional disability.[39, 54] These cognitive deficits significantly contribute to the functional challenges faced by patients in everyday life but also to the long-term burden associated with a psychotic disorder.[39, 55, 56]

4.2.1.4 Catatonia

Catatonia represents a distinct psychomotor syndrome characterised by marked alterations in motor behaviour, reactivity, and volition, including immobility, mutism, or stereotyped movements.

4.2.2 Natural history

In the absence of timely and adequate intervention, psychotic disorders may be associated with substantial long-term consequences, including persistent cognitive impairment, functional disability, social exclusion, comorbid substance use, increased exposure to violence (primarily as victims), and elevated mortality.[15, 57-60]

Despite advances in clinical characterisation, disease course remains highly heterogeneous, and reliable predictors of long-term functional outcome or relapse remain limited.[27]

4.2.3 Aetiology

Given the slow pace of progress in psychiatry, the elusive nature of psychosis comes as no exception. Despite decades of research, the mechanisms underlying psychotic disorders remain incompletely understood. While advances in neuroscience and genetics have opened new windows into brain function, these insights still connect only loosely to the clinical realities of psychotic disorders, with no unified model linking biological, psychological, and social mechanisms.[17]

Psychotic disorders are commonly categorised into primary psychotic disorders, substance- or medication-induced psychoses, and psychoses due to underlying medical conditions[15], though the latter are beyond the scope of this report. These aetiologic categories are somewhat arbitrary, highlighting the gaps in our understanding of psychotic disorders, and will likely evolve as ongoing research uncovers their underlying pathology and causes.[15]

Focusing on primary psychotic disorders, their aetiology is widely recognised as multifactorial, involving a dynamic interplay of genetic, neurobiological, environmental, and psychological influences.[61] Among these, genetic factors play a particularly prominent role. Individuals with a family history of an idiopathic psychotic disorder, have been observed to have 10-15 times higher incidence rates.[15, 62] This genetic predisposition is polygenic in nature: genome-wide association studies have identified numerous common genetic variants associated with schizophrenia, each exerting small effects and collectively explaining only a portion of overall genetic liability.[63-66]

Moreover, less than one in ten individuals with schizophrenia report a family history, suggesting that other mechanisms are also at play.[67, 68]

In addition to genetic findings, neurobiological research has highlighted structural and functional brain abnormalities in individuals with psychosis. These include lateral ventricular enlargement, reduced brain volume, as well as disruptions in neural connectivity and neurotransmitter systems.[31, 61] It is thought that psychotic symptoms are caused by altered neurotransmission in the dopamine and glutamate pathways of the prefrontal cortex, hippocampus, midbrain, and corpus striatum.[15, 31] The molecular basis for this, likely involve disturbances in gamma-aminobutyric acid (GABA), aspartate, and glycine, although other molecular mechanisms may also be involved (e.g. cannabis receptor agonists).[15, 69]

While substantial progress has been made in mapping the genetic architecture of psychotic disorders, the 15–40% of risk attributed to environmental factors remains less clearly defined.[63] Over the last decades, a range of early-life exposures such as winter or spring births, obstetric complications, infections, and adverse childhood experiences have been shown to be potential contributors. Later-life exposures, including urban living, migration (particularly during adolescence and of racially minoritised groups), and cannabis use, have also been associated with psychotic disorders.[63,70]

Among environmental influences, neurodevelopmental factors, that is deprivation during key developmental stages, such as caused by maternal infections, exposure to toxins, and poor nutrition, as well as birth complications and postnatal trauma, can increase vulnerability. Although each factor may exert only a limited individual effect, these environmental influences are thought to interact with genetic predispositions to elevate the risk of developing a psychotic disorder. [15, 63]

Psychosocial trauma during childhood has also been linked to increased incidence of psychotic disorders. Experiences of emotional, physical, or sexual abuse are frequently reported among affected individuals.[71]

Studies also indicate that other psychosocial and socioeconomic factors likely contribute to the risk of PD. These include parental mental illness, poor family communication, bullying, and living in socioeconomically disadvantaged urban areas. Indeed, immigrants, refugees, and asylum seekers face a greater risk of psychosis than native populations. Observed protective factors include social support and marriage; other aspects such as family and community resilience remain under-researched.[72]

Cannabis use has also been widely investigated as an aetiologic factor. While cannabis use alone is not considered sufficient to cause psychosis in the general population, it may trigger psychotic symptoms in individuals who are genetically vulnerable.[63]

Genetic and environmental risk factors are thought to interact dynamically rather than acting additively. Their effects can interact, meaning an individual's genetic makeup can influence how environmental exposures impact them. These gene-by-environment interactions help explain why only some exposed individuals develop these disorders. However, studying these interactions is especially challenging, as it demands larger sample sizes than examining genetic or environmental factors alone – an obstacle that's particularly limiting when researching conditions that affect relatively few people.[63]

4.3 Diagnosis

Regardless of what's known on different aetiologic mechanisms, psychotic disorders are **diagnosed clinically**, primarily through patient history, self-reported experiences, observed behaviour, and findings from the mental state exam.[15]

Investigations (e.g. brain imaging, EEG, and laboratory tests including toxicology where indicated) are typically used to exclude secondary causes, particularly in first-episode psychosis, atypical presentations, late onset, or when substance use or medical comorbidity is suspected. Although investigations may reveal group-level differences relevant for research, no biomarker or test

currently has sufficient diagnostic performance to be used as a definitive, standalone diagnostic tool for psychotic disorders in routine clinical practice; tests therefore remain adjunctive rather than primary diagnostic instruments.[15]

The absence of diagnostic biomarkers places greater weight on clinical judgement, particularly during acute presentations, and may contribute to diagnostic uncertainty and,[73] in some cases, reluctance to accept the diagnosis. Because psychosis can be secondary to medical conditions or substances, a first or new-onset psychotic presentation should prompt a structured assessment to exclude secondary causes before attributing symptoms to a primary psychotic disorder.

Given substantial symptoms **overlap across psychotic disorders**, differentiating specific diagnostic categories—especially early in the course—can be clinically difficult and often requires longitudinal information. For example differentiating attenuated psychosis from transient or emerging disorders, relies on assessing the timing, duration and evolution of symptoms, as well as the presence or severity of manic or depressive symptoms.[64, 74] Indeed, core features such as hallucinations, delusions, and disorganised thinking and behaviour are not unique to a single disorder, complicating early diagnostic differentiation.

Moreover, the clinical picture may evolve over time, and diagnostic stability is often limited early in the course; the more enduring pattern of symptoms, mood episodes, and functional trajectory may only become clear with follow-up. Consequently, **follow-up and repeated assessment** are often required to refine diagnosis and guide management, particularly during first-episode presentations.[75] In early presentations, diagnostic formulation often remains provisional until symptom persistence, recurrence, and longitudinal patterns are clarified and secondary causes are reasonably excluded. This iterative process may take time and should include assessment of potentially modifiable contributors, including substance use and relevant medical conditions.[17]

Diagnostic differentiation is further complicated by the dimensional nature of psychotic-like experiences and their **partial overlap with non-pathological phenomena**, particularly at lower intensity or early stages.[76] While certain cases clearly fall outside the spectrum of common psychological states, others are more nuanced, making it sometimes challenging to draw a clear line between pathological psychosis and normal psychological variation, particularly in early disease.[17]

Although **psychotic disorders in children** fall outside the scope of this report, it is important to note that diagnosing very early-onset schizophrenia and related conditions remains fraught with uncertainty. Diagnosing psychosis in children is complex, as young children often struggle to articulate psychotic experiences and symptoms frequently overlap with other conditions like autism or mood disorders. Diagnostic accuracy in childhood is low, and there is no clear age threshold beyond which such diagnoses can be considered reliably established.[77]

Importance of early diagnosis:

There has been increasing focus on **early detection and early intervention**, with evidence indicating that specialised first-episode psychosis (FEP) services improve engagement with care and a range of clinical and functional outcomes compared with usual care.[78-80] Youth-oriented early diagnostic programs are now widely acknowledged as essential for prompt identification and effective secondary prevention. The following sections describe these integrated early intervention services in more detail.[81, 82]

4.4 Treatment and management

4.4.1 Current treatment for psychotic disorders

In recent decades, there has been increasing recognition of the clinical complexity of psychotic disorders and of the limitations of current treatments in terms of efficacy, tolerability, and long-term outcomes.[83]

The management of psychotic disorders involves a combination of pharmacological and evidence-based psychological and social interventions.[84] Antipsychotic medications are a central component of treatment and are effective in reducing positive symptoms such as hallucinations and delusions, but have limited and variable effects on negative and cognitive symptoms. Moreover, treatment response is highly heterogeneous[27] and antipsychotics generally do not achieve a disease-modifying effect[15], unless initiated very early, during the first psychotic episode.[61]

Psychological and psychosocial interventions—including cognitive-behavioural therapy (CBT) for psychosis, family interventions, and social skills approaches—are recommended alongside pharmacological treatment and play a key role in recovery and functional improvement.[85]

Treatment aims include symptom reduction, relapse prevention, and support of functional recovery. However, outcomes remain variable, and a minority of patients show a limited response to treatment.[86-88]

Antipsychotic medications are classified into first-generation antipsychotics (FGAs), and second-generation antipsychotics (SGAs).[69, 89]

The FGAs, also known as **typical antipsychotics**, primarily target dopamine D2-receptors to reduce dopamine hyperactivity. While effective for positive symptoms, first-generation antipsychotics are associated with a higher risk of **extrapyramidal adverse effects**, which may limit tolerability and long-term adherence. These include Parkinson-like symptoms (tremors, rigidity, and slowness), akathisia (feeling of restlessness and a compelling urge to move), dystonia (involuntary muscle contractions), and tardive dyskinesia (repetitive facial movements).[90] These motor disturbances can be painful, socially stigmatising, and chronic in some cases, posing major barriers to long-term adherence and daily functioning.

The SGAs, also known as **atypical antipsychotics**, similarly target dopamine activity at D2 receptors, but in addition also target serotonin receptors, which helps alleviate some negative and cognitive symptoms as well as positive symptoms, while reducing the risk of motoric side effects. Second-generation antipsychotics are often preferred in long-term treatment because of lower rates of extrapyramidal symptoms, although their overall efficacy is broadly comparable to first-generation agents.[69] Nevertheless, they come with another set of side-effects, as they are associated with **metabolic adverse effects**, including weight gain, dyslipidaemia, and increased risk of diabetes and cardiovascular disease.[69, 86] These adverse effects not only emphasise the long-term physical health burden of individuals with a psychotic disorder, contributing to the already elevated cardiovascular morbidity and mortality in this population, but can also negatively impact self-image, motivation, and social participation.[91]

Clozapine is a second-generation antipsychotic recommended for individuals with treatment-resistant psychosis, with superior efficacy in this population. Its use requires careful monitoring because of the risk of rare but potentially serious adverse effects, including agranulocytosis, myocarditis, and seizures. However, substantial evidence suggests that these risks have historically been overestimated.[15]

Individual response and tolerability to different antipsychotic medications vary considerably, necessitating **shared decision-making** and **individualised treatment selection**.[92 93]

Pharmacological treatment alone is often insufficient to address the full spectrum of symptoms and functional difficulties associated with psychotic disorders.[44, 46, 94] The fact that many patients

experience incomplete symptom relief together with frequent side effects also has an impact on pharmacological treatment adherence. This poses a great challenge in clinical practice, as medication non-adherence and discontinuation are common and represent substantial obstacles to long-term management.[27, 95]

On this backdrop, non-pharmacological treatments play a significant role in the comprehensive management of psychotic disorders, particularly in addressing negative and cognitive symptoms.[96] NICE for instance, recommends **cognitive-behavioural therapy** for psychosis and **family interventions** as core components of care, with **cognitive remediation therapy** (CRT), considered where cognitive impairment limits functioning.[84] CBT helps individuals critically evaluate their experiences with symptoms and their responses to them, to reduce distress, improve coping-strategies and prevent relapses.[97] CRT is a behavioural training-based intervention that aims to improve cognition.[98] Family interventions support people with psychosis and their relatives, strengthening relationships through problem solving and improving understanding of the illness and its treatment.[99] Evidence indicates that combining psychological interventions with pharmacological treatments yields superior outcomes compared to pharmacotherapy alone[97], but the evidence for psychological interventions in children and adolescents and remains sparse.[100, 101]

Guidelines recommend promoting **physical activity** and **healthy lifestyle interventions**; **arts therapies** may be considered as adjunctive interventions where appropriate.[102]

Digital interventions are being explored as adjunctive tools for symptom monitoring, relapse prevention, and engagement, but evidence remains variable.

Electroconvulsive therapy (ECT) is a clinical procedure where a brief controlled electrical stimulus is given to trigger a seizure while the patient is under general anaesthesia, with the aim to rapidly reduce symptoms. This is not recommended for routine treatment of psychotic disorders but may be considered for severe, life-threatening catatonia or, in selected cases, treatment-resistant psychosis under specialist supervision.[103, 104]

Transcranial Magnetic Stimulation (TMS) is a non-invasive treatment technique in which repetitive magnetic field pulses are delivered through the scalp, stimulating brain tissue underneath.[103] Non-invasive brain stimulation techniques such as TMS remain investigational, with insufficient evidence for routine clinical use.[105, 106]

Reduced illness awareness is common and may affect engagement and adherence, associated with poorer prognosis.[107-109110-112] Collaborative, non-coercive approaches are recommended to support engagement.[93]

Early intervention services

Since the early 2000s, growing attention has been directed toward early detection and improved treatment strategies. **Early intervention services** for early psychotic symptoms or first-episode psychosis are strongly recommended, as they improve engagement, reduce relapse and hospitalisation, and support functional recovery.[78-80] Indeed, a longer duration of untreated psychosis has been associated with poorer clinical, social, and functional outcomes, including more social withdrawal and negative symptoms.[113-115] There is evidence that for individuals in the early stages of schizophrenia or schizoaffective disorder, initiating treatment at the first episode of psychosis can shorten the length of psychotic episodes, decrease the likelihood of relapse, and help prevent the gradual deterioration of cognitive and functional abilities.[15]

Given the frequent onset of psychotic disorders in late adolescence and early adulthood, early diagnostic services, designed to be **adapted for the young population** are increasingly recognised as a pivotal aspect for timely diagnosis and secondary prevention. Consequently, early intervention services have been developed to include evidence-based interventions, adapted to the needs of FEP patients and delivered generally through a **coordinated care model**.[81, 82] Early

intervention services typically use a coordinated specialty care model integrating pharmacological treatment, psychological therapies, family support, and vocational or educational interventions into a comprehensive **plan that is tailored to the needs** of each patient. Instead of referring patients to different healthcare providers, these approaches rely on the **integrated provision of care** from one team within a service. This approach emphasises early intervention, **shared decision-making** with patients and families, approaches like cognitive behavioural therapy, and **crisis intervention**.

The hope for novel therapies

There remains a need for antipsychotic drugs with **improved efficacy for negative and cognitive symptoms** as well as a **safer profile**. To achieve this, research is focusing on new molecular targets and innovative compounds capable of addressing the diverse symptom dimensions of schizophrenia. Current and future strategies include: 1) Refining existing mechanisms to produce drugs with equal or improved efficacy and safety compared to current anti-psychotic drugs; 2) Developing novel, likely non-D2, mechanisms to create new classes of antipsychotics; 3) Designing adjunctive treatments that enhance anti-psychotic drug efficacy by targeting specific symptoms, especially those resistant to conventional therapy. Additionally, genetic studies are being explored to determine whether schizophrenia susceptibility genes could serve as viable drug targets.[86, 116] So far, numerous novel non-D2 mechanisms of action, adjunctive treatments, and treatment combinations have been investigated, mostly with modest effects and insufficient evidence of effectiveness. Cobenfy™ is the first approved and effective non-dopaminergic antipsychotic drug, appearing to have fewer adverse effects of weight gain and extrapyramidal symptoms.[117, 118] Nevertheless, long-term efficacy and safety must still be confirmed.[15, 86]

4.4.2 The Belgian landscape

Healthcare organisation (adapted from KCE Report 318)[119]:

Responsibility for health care policy in Belgium is shared between the Federal Government, and the Dutch- , French-, and German speaking community/regional Ministries of Health, resulting in a complex healthcare system.[120] This system is founded on equal access and patient choice, operating through mandatory national insurance and providing a broad range of services. Patients typically cover expenses upfront and later receive partial reimbursement from their health fund.

Belgium's mental health care has undergone several reforms over the last decades, aimed at reducing hospital-based care and promoting community-based recovery and reintegration. Between the 1970s and late 1990s, new mental health care facilities were created and hospital beds converted to create psychiatric care homes, initiatives for sheltered living, and to a lesser extent, psychiatric home nursing. Semi-ambulatory services like day centres and hospitalisation units were established, but despite successful expansion, residential care remained the dominant feature of Belgium's mental health system.

In 2002, Belgium restructured mental health care around target groups and networks to deliver tailored, patient-centred support within personal living environments. This included psychiatric home care teams, work-activation projects, counselling initiatives, and improved discharge management in hospitals. Despite these movements of decentralisation, Belgium has still the second highest ratio of in-patient psychiatric beds among OECD countries.[119]

In 2010, Belgium launched the Article 107 projects, marking a major reform that shifted mental health care from hospital-based treatment toward community networks and mobile teams. These projects aimed to reduce residential care and promote recovery and reintegration. The reform introduced a model that integrated hospitals with community services, strengthened cross-sector collaboration, and fostered multidisciplinary professional networks. Aligned with international trends, the new approach emphasised patient-centred, personalised care by improving accessibility and adaptability, ensuring individuals could remain in their social environments through tailored and timely therapeutic pathways.[121] The reform specifically sought to strengthen mental health promotion and prevention by enhancing early detection, screening, and diagnosis of

disorders, achieved through improved collaboration among medical centres, general practitioners, and other frontline care providers.

A few years later, the 6th state reform in Belgium (2014) shifted many mental health care responsibilities – such as sheltered living initiatives, psychiatric care homes, and consultation platforms – from the federal government to the federated communities. Psychiatric hospitals remained under federal hospital law, while pricing agreements and conventions were also transferred to regional authorities. The situation in Brussels is particularly complex and fragmented as policy and delivery of mental health care in the capital is the responsibility of five policy institutions.

In 2015, OECD estimated Belgium's mental health costs at 5.05% of GDP, among the highest in Europe. These figures are likely underestimated, as indirect costs such as social benefits and reduced employment were not fully included.

It also has the second highest number of psychiatric beds compared to the number of inhabitants among OECD countries and more than 80% of the financial resources for mental health care are going to residential care, particularly acute care.[122] The Belgian mental healthcare networks are constituted of psychiatric hospitals and of psychiatric departments within general hospitals. Hospitalisation for psychiatric patients can be either residential (with day and night stay) or partial (only daytime or nighttime). In 2021, schizophrenia and psychoses accounted for almost one quarter (23%) of hospitalisations in psychiatric hospitals, and for 9% of psychiatric hospitalisations in general hospitals.[122]

Management of psychotic disorders, early detection and intervention services:

While there are no specific Belgian guidelines for the management of schizophrenia and other psychotic disorders, mental health professionals rely on international guidelines such as those by the European Psychiatric Association.[102, 123, 124]

Compared to centralised approaches, like England's OASIS programme, Belgium is more regionally organised, with only a few specialised early detection and intervention programmes which are embedded in university hospitals and community mental health networks. Mobile crisis teams in some areas compound this offer, but overall funding for early detection and early intervention remains sparse.[125, 126]

Reimbursement of healthcare and treatment:

In Belgium, people with a psychotic disorder (and covered by public health insurance) receive partial reimbursement for medications, including antipsychotics and long-acting injectables. Psychiatric hospitalisation, interventions by mobile teams, care provided in residential care and consultations with psychiatrists are largely reimbursed, with patients paying only limited copayments, further reduced for those with low income or chronic illness.[120, 127]

Access to reimbursed psychotherapeutic and psychosocial interventions for people with psychotic disorders is distributed across care settings and often temporary. While psychological support is provided during hospitalisation and through mobile teams, continued access before or after discharge is limited and not systematic for all patients. After hospitalisation, hospitals may continue to offer reimbursed psychological support, but as their capacity is limited this is only for part of the patients. Mobile teams also deliver long-term supportive care, but also this is limited to some patients with chronic psychiatric disorders. The centres for mental health (CGG in Flanders (Centra voor Geestelijke Gezondheid) - CSM in Wallonia (Centres de Santé Mentale)) also provide psychological consultations to patients with psychotic disorders.

The 2021 reform expanded access to first-line psychotherapy for people with mild to moderate mental health difficulties, a group that generally does not include individuals with psychotic disorders, unless they are in remission and stable. In addition, access to reimbursed specialised psychological care was introduced, for up to 20 individual sessions per year. This specialised care requires referral to the local network of specialised psychological services, which must have an

agreement with the mental health network, and it must be based on a functional assessment demonstrating that a specific specialised intervention is necessary.

This pathway therefore depends on mandatory referral, the availability of sufficient conventioned psychologists within the local mental health network, and a capped number of reimbursed sessions.[128] [120, 127]

Long-term outcomes

Many individuals diagnosed with a psychotic disorder experience persistent difficulties in social, occupational, and relational functioning, even when symptomatic improvement occurs. Common long-term challenges include social withdrawal, reduced opportunities for intimate relationships, stigma, social exclusion, unemployment, and housing instability. In Europe, unemployment among affected individuals ranges from 70% to 90%.[31, 129]

Individuals with a psychotic disorder, particularly schizophrenia, face a significantly increased risk of **premature mortality** compared to the general population.[14] Epidemiological studies consistently report a two- to three-fold increase in mortality risk, corresponding to a reduction in life expectancy of approximately 12–15 years.[14, 130] The excess mortality among this population arises from both natural and unnatural causes. Suicide is a major contributor to excess mortality, with lifetime suicide risk in schizophrenia estimated at approximately 5%, approximately twelve times greater than that observed in the general population.[130]

In addition, a large proportion of premature deaths is attributable to somatic comorbidities, particularly cardiovascular disease, diabetes, and respiratory conditions.[131] These physical health conditions are often exacerbated by several interrelated factors: barriers to accessing somatic healthcare; metabolic and cardiac side effects associated with long-term antipsychotic medication use; unhealthy lifestyle habits such as smoking and poor diet; and comorbid substance use.[14] Social determinants such as poverty, stigma, social isolation, and fragmented care pathways further exacerbate health risks by reducing engagement with preventive care and continuity of treatment.

Collectively, these findings underscore the urgent need for integrated care models that bridge mental and physical health services, prioritise early intervention, and mitigate risk factors. Management of somatic comorbidities, particularly cardiovascular risk, should be regarded as a core component of long-term care for psychotic disorders to reduce the persistent mortality gap.

Prevention

Currently, prevention in psychotic disorders primarily focuses on **secondary prevention**, through early identification, timely intervention, prevention of relapse, and management of physical health risks associated with long-term treatment.

Primary prevention remains challenging due to the multifactorial and interactive nature of risk factors for psychotic disorders, involving an interaction of genetic, neurobiological, and environmental factors.[61, 63, 90, 132]

Nevertheless, substantial evidence supports the value of identifying individuals at **clinical high risk for psychosis** (CHR-P) as a strategy for early intervention and secondary prevention.[133,15] Indeed, a period of emerging or attenuated symptoms, including attenuated positive symptoms and shifts in behaviour across social, work, school, and family life, may represent a window of opportunity for early intervention.[134]

Consequently, **preventive strategies** targeting young people at clinical high risk for psychosis have become a central focus in both research and clinical practice.[133, 134] There is consensus that the key elements of the CHR-P paradigm encompass three related steps: detection, prognosis and intervention.[135] The first step involves identifying individuals who accumulate risks for psychosis. Secondly, individuals undergo psychometric interviews to distinguish between those meeting CHR-P criteria, those already psychotic, and those not at risk, enabling a group-level prognosis. Thirdly,

CHR-P individuals receive needs-based care and, when available, targeted preventive interventions.[135]

CHR-P individuals are by definition help-seeking. They tend to be slightly more frequently male, present with attenuated psychotic and negative symptoms as well as reduced functioning, and accumulate several sociodemographic risk factors, including substance use, comorbid mental disorders, suicidal ideation, or self-harm.[134]

The Outreach and Support in South-London (OASIS) service is an example of a preventive service addressed at young people at clinical high risk for psychosis and has become an established model of care for early detection and intervention. Created in 2001, it is one of the first and largest CHR-P services worldwide.[136] We will describe some of its main characteristics which exemplify how preventive services can address the needs of the young at high risk of psychosis.

OASIS is integrated within primary care, offering a **youth-friendly entry into mental health support**.[133] Most referrals to this service originate from community mental health services, with significant contributions from GPs and first-episode services. Other sources include child and adolescent mental health services, emergency departments, schools, social services, and self-referrals.[136]

Its care relies on **multidisciplinary teams**, comprising psychiatrists, psychologists, nurses, social workers, occupational therapists, and support staff, who provide **rapid responses**, including **home visits** within 24 hours, and referral to specialised services including first-episode psychosis programs.[136] It is a **transitional service**, bridging care for both adolescents and young adults from paediatric to adult services.

A cornerstone of this programme is its **outreach strategy**, which raises awareness on the risks for psychosis, promotes signposting, and educates professionals. Outreach extends across healthcare providers (children and adolescent mental health services, GPs, inpatient mental health services, perinatal and sexual health services), schools, youth centres, housing and employment services, religious institutions, charities, and even local businesses such as barber shops and cafes. Special emphasis is placed on reaching **minority ethnic groups, asylum-seekers, and refugees**, fostering **culturally sensitive** approaches and building **trust** with diverse communities. A **youth-friendly website** (https://www.meandmymind.nhs.uk), was also created, co-produced with a service user group, which helps the programme to **reduce stigma** and **tailor services to young people's needs** taking into account **cultural background**.[136]

The limitations of preventive services include the fact that the existing **criteria for detecting individuals at high risk of psychosis** produce an exceptionally high number of false positives.[15] Furthermore, no robust evidence yet exists to favour any indicated intervention over another (both in adults as well as in children) for preventing psychosis.[134,135] In adolescents, some interventions—including family-based approaches and cognitive remediation—may improve symptoms and functioning, although evidence remains limited and heterogeneous.[135]

4.5 Inequities

Incidence

As described in section 4.2.3 on Aetiology, a number of structural social determinants increase the likelihood of developing a psychotic disorder. These include **poverty**, **living in socioeconomically disadvantaged urban areas, social exclusion**, and being a **refugee, asylum seeker** or **immigrant** of low socioeconomic status.[31, 72] Some studies also report higher incidence in second generation migrants, suggesting that the social and environmental vulnerability including **discrimination and social isolation** accompanying migration likely play an important role.[63, 137] A leading hypothesis is the social-defeat theory, which suggests that social stressors, which are more often experienced by marginalised, vulnerable, socially excluded, or minority groups, can heighten an individual's predisposition to developing psychiatric disorders.[63, 138]

Social exclusion and psychotic disorders: a reinforcing loop

At the individual level, psychotic disorders often lead to chronic functional disability, often limiting a person's ability to pursue education, maintain employment, and live independently. Cognitive impairment, social withdrawal, and symptom severity contribute to high unemployment rates, with estimates suggesting that 70% to 90% of individuals with a psychotic disorder in Europe are unemployed.[129] This loss of productivity can result in social exclusion, stigma, and reduced access to stable housing and healthcare. The prevalence of PDs, particularly schizophrenia, is estimated to be up to 30 times higher among individuals who experience homelessness or social marginalisation, reflecting a cycle of disadvantage in which both the health condition and deprivation reinforce each other.[72, 139, 140] These inequities contribute not only to personal suffering but also to a disproportionate economic burden on healthcare and social systems.

5 METHODS

This section describes the methods used to identify unmet health-related needs of individuals with a psychotic disorder, including database research, an online survey for patients and individual semi-structured interviews, and an expert questionnaire, according to the NEED framework.

5.1 Patient survey

5.1.1 Data collection tool

5.1.1.1 Development of the online patient questionnaire

The NEED generic patient questionnaire

The questionnaire used in this study is an adaptation of the generic NEED questionnaire.[11] The generic questionnaire was developed through a literature review and expert consultations. Subsequently, the questionnaire was validated via a Delphi process involving representatives of umbrella organizations of patient associations and sickness funds. The generic version is available in French, Dutch, and English. The generic version must be adapted to the health condition under consideration, based on information about symptoms, treatments, side-effects and possibly other specificities obtained from the available literature or expert consultation.

The primary aim of this tool is to capture multiple dimensions of unmet health-related needs from the perspective of individuals living with a psychotic disorder. Additionally, a few questions, addressed only to informal caregivers, assess caregiving burden. The questionnaire is meant to be filled in by individuals living with a psychotic disorder. In case they are unable to complete it themselves, legal representatives are allowed to participate on their behalf, responding to the questions as if they were the person affected by a PD.

Adaptations of the NEED generic patient questionnaire for psychotic disorders

To tailor the instrument to the specific context of PDs, an iterative adaptation process was undertaken by one researcher (CS) in collaboration with two psychiatrists (RvW and PO). Adaptations were informed by:

1. A pragmatic literature review assessing disease-specific features including symptoms, treatment modalities, and side effects; and
2. Feedback from pilot testing with patient representatives to evaluate the survey's clarity, comprehensibility and wording.

Although the instrument was primarily guided by DSM-5-TR classifications, the survey adopted a broader, experience-based approach to reflect how diagnoses are communicated and understood in clinical practice. Certain conditions that are no longer listed as standalone categories in DSM-5-

TR, such as induced delusional disorder or shared psychotic disorder, were retained in the questionnaire. This decision reflected the understanding that some patients may still identify with these diagnoses because of past clinical communication. Similarly, the category 'bipolar disorder with psychotic features' was included because, in routine clinical practice, affective and psychotic symptoms can overlap or fluctuate over time. When participants self-identified during the research call as having "a psychotic disorder", this indicated that psychotic features were a prominent aspect of their experience. By contrast, individuals who reported having bipolar disorder only (without psychotic features) were excluded from the study.

Because participation relied on respondents self-identifying as having a psychotic disorder, the instrument aimed to capture the full spectrum of conditions in which psychotic symptoms play a central role, ensuring that the questionnaire remained aligned with both clinical reality and patient experience. All proposed adaptations were reviewed by professionals, researchers, and patient representatives and are described in Appendix 1.

The finalised questionnaire was programmed in LimeSurvey and tested internally by the full research team in both French and Dutch languages to ensure functionality and clarity.

Pilot testing of the NEED questionnaire for psychotic disorders

Pilot testing was conducted with four participants: two Dutch-speaking and two French-speaking (including one legal representative). Participants completed the survey using the think-aloud method, providing real-time feedback on clarity, interpretation, and usability. Each pilot was followed by an internal discussion, leading to a few targeted revisions in both content and design. After four pilots, no further adjustments were necessary, and the final version of the survey was confirmed.

5.1.1.2 The NEED questionnaire for psychotic disorders

The questionnaire consists mainly of multiple-choice questions, with few open-ended questions (Appendix 1). For every multiple-choice question, respondents are also given the possibility to indicate that they 'don't know' or, in some cases, 'don't want to answer'. Some questions are conditional on the answer to a previous question.

The questionnaire started with an introduction to the study, describing the objective, requirements for participation, and confidentiality policy. Respondents were asked to provide their informed consent before participation.

The questionnaire consisted of 77 questions, organised around the following 7 themes (Table 1).

Table 1 – Domains and variables included in the NEED questionnaire for psychotic disorders

Domain	Variables
Descriptive background	
	Gender
	Age
	Place of residence
	Level of education
	Housing situation
	Country of birth
	Employment status (before and after onset of the PD)

	Financial situation
	Specific diagnosis*
	Time since diagnosis
	Associated health conditions*
	Other health conditions
	Hospitalisation for the psychotic disorder
Health	
	General health-related quality of life before onset and today using EQ-5D-5L[a]
	Self-reported health status before onset and today (VAS scale)
	Received treatments*
	Side-effects* and their burden
	Burden of treatment aside from side-effects
	Symptoms* and their burden
	Impact on sexual life
	Impact on reproductive life
Healthcare	
	Time between first symptoms and first psychiatric consultation*
	Time between first appointment and diagnosis
	Organisation and planning of care
	Coordination of care
	Continuity of care
	Received information
	Involvement in decision-making
	Forgone care
Social Impact	
	Impact on education
	Reduction of working time
	Productivity loss
	Financial impact
	Impact on relationships
	Forgone social support

[a] https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/ (last access: 27 February 2025)

Priority Needs	
	Unmet needs to be addressed as a priority
General	
	Additional unmet needs (open question)
Impact on Informal Caregivers	
	Impact on caregiver's physical and psychological health
	Impact on caregiver's social life
	Informal caregiving time burden

**Questions adapted to the context of psychotic disorders*

At the end of the questionnaire, participants were asked whether they would be willing to participate in an individual one-to-one interview with a member of the research team (MS). Information of respondents who indicated their willingness was retained for shortlisting and, if meeting the inclusion and segmentation criteria, respondents were contacted (see section 3.2.1 Selection of participants).

5.1.2 Recruitment of participants

Recruitment strategy

The recruitment strategy was developed in close collaboration with a representative of the Flemish patient organisation Uilenspiegel and two psychiatrists (RvW and PO) affiliated with psychiatric and general hospitals in Flanders and Brussels. Their involvement was essential to ensure the recruitment plan was feasible and aligned with the needs and realities of the target population.

The selection of organisations for participant recruitment was based on input from (i) the research team, (ii) collaborating clinicians and (iii) a patient representative, with the aim of ensuring that all organisations perceived as relevant were contacted at least twice. Initial contact was made via email, followed by a second email reminder. If no response was obtained, organisations were approached by telephone when a number was available. Only when repeated attempts failed, or when organisations explicitly declined participation, they were not included in the recruitment network. The types and numbers of organisations contacted and those that agreed to participate is provided in Table 2.

Table 2 – Overview of contacted and included organisations in the recruitment strategy

	Wallonia*		Flanders*		Brussels*		Belgium	
Organisation type	**Contact**	**Included**	**Contact**	**Included**	**Contact**	**Included**	**Contact**	**Included**
Community health centres	34	30	38	11	10	10	82	51
General Hospitals	6	2	25	9	5	3	36	14
Patient organisations	6	3	7	4	1	0	14	7
Primary care	5	4	6	5	4	3	15	12
Psychiatric care homes	1	0	5	4	4	1	10	5

Psychiatric Hospitals	19	7	31	17	5	2	55	26
Research Institutions	0	0	1	1	2	2	3	3
Sickness Funds	9	0	8	1	1	0	18	1
Total	**80**	**46**	**121**	**52**	**32**	**21**	**233**	**119**

** Belgium is composed of three regions: Wallonia, Flanders, and the Brussels-Capital Region, each with its own institutions and specific cultural, linguistic, and administrative characteristics.*

Participating organisations were invited to support recruitment through one or more of the following channels: displaying posters and flyers in waiting rooms, sharing information via their social media platforms, and including the call for participation in newsletters. Recruitment was further strengthened through dissemination via KCE social media channels. Each organisation could choose the recruitment method that best fit their setting and audience.

Clinical sites, including primary care centers, general hospitals, psychiatric hospitals, psychiatric care homes, sheltered housing, and community health centers (e.g., 'Centrum voor Geestelijke Gezondheidszorg' and 'Maisons Médicales'), primarily supported recruitment by displaying posters and flyers in locations frequently visited by patients. In addition, some centers chose to disseminate the materials through their own communication channels, such as social media, intranet or newsletters. Members of the research team further assisted recruitment efforts by visiting selected psychiatric hospitals and community health centers in person to provide information and encourage participation.

Recruitment was also supported by sickness funds, patient organisations, and the participating research institutions. These organisations primarily relied on digital channels, including social media platforms and newsletters, to distribute study information and reach potential participants. This strategy enabled a broader dissemination of the call for participation beyond clinical settings and contributed to increasing the diversity of the study sample.

The recruitment aimed to reach a broad and diverse group of individuals with lived experience of a PD to support the goal of obtaining a representative sample across regions and care settings.

A QR-code and survey link were included on all physical and digital materials, directing participants to a study website containing information about the project, eligibility criteria, informed consent, and access to the survey.

The questionnaire was launched on May 12th, 2025, and ran until August 31st, 2025. Throughout the three-month period of data collection, the recruitment strategy was subject to continuous monitoring. This allowed adapting the strategy, for instance increasing recruitment in the French-speaking regions when mostly Dutch-speaking individuals responded to the survey.

Inclusion and exclusion criteria

To be eligible for participation, individuals had to meet the following criteria:

- Being 18 years of age or older;
- Having received a diagnosis of a psychotic disorder;
- Living in Belgium (main residence).

In cases where participants indicated "other diagnosis" in the survey question asking about the specific type(s) of psychotic disorder they had been diagnosed with, their eligibility and diagnostic classification were subsequently reviewed by a psychiatrist (RvW). This review was based on multiple survey components, including the open text-field specifying the 'Other diagnosis', any additional reported PD diagnoses, reported symptoms, treatment history, and related health conditions. In total, 20 respondents selected 'Other diagnosis'. Eight reported this as their sole

diagnosis and were reclassified based on clinical review. An additional eight respondents selected 'Other diagnosis' alongside one specified PD and were therefore classified according to the specified diagnosis. The remaining four selected 'Other diagnosis' in combination with multiple diagnoses and were also reclassified into the appropriate diagnostic category and included in the analysis accordingly. Incomplete responses to the survey were retained in the dataset, as long as questions were answered on the first part including socioeconomic and demographic background, diagnosis (question ID: DSD1), and HRQoL (question ID: H1 – H12) (Appendix 1). As a result, the total sample size may vary across questions and variables.

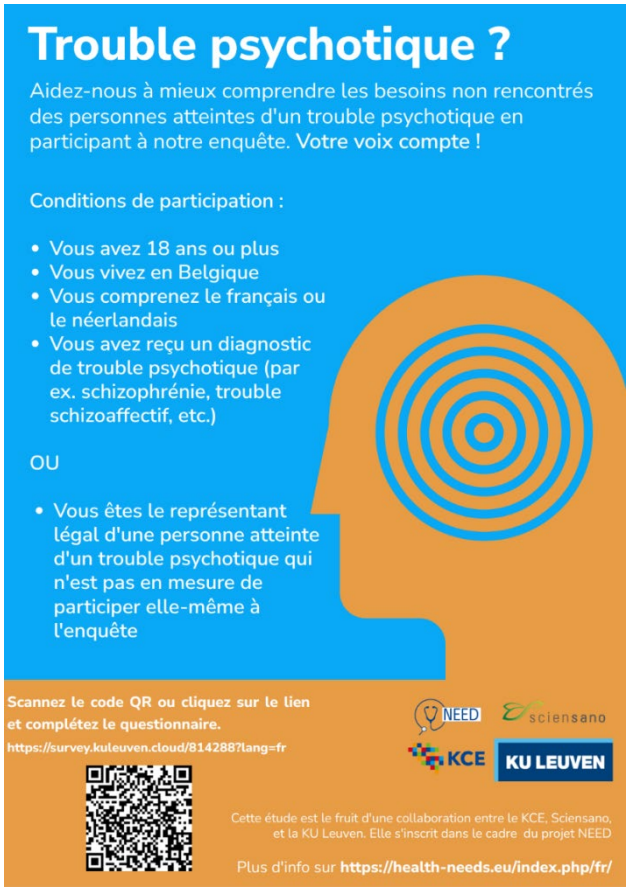
If the individual with a psychotic disorder was unable to complete the survey themself, a legal representative (e.g., parent or caregiver) could do so on their behalf, answering the questions from the perspective of the person they represent.

Individuals who did not meet the inclusion criteria were directed to the end of the survey and provided with an explanation for their ineligibility.

Recruitment material

Posters and flyers were developed in both French and Dutch (Figure 2) and were distributed on active base to inform potential participants and direct them to the online survey via QR-code. The materials were carefully designed to be accessible, clear and inviting, with deliberate attention to layout, language (e.g. using the least stigmatising terms for 'psychotic disorder') Appendix 2.

Figure 2 – Example of a French poster used for recruiting eligible participants



5.1.3 Quantitative data analysis

For all continuous variables, the median with interquartile range (IQR) was calculated for normally and non-normally distributed data. For categorical variables, the associated percentages were calculated. Responses indicating *"I don't know"*, *"not applicable"*, or *"I don't want to answer"*, as well as unanswered items, were treated as missing values and excluded from the analysis, except in the question regarding involvement in treatment choice. The effective sample sizes therefore vary across questions.

HRQoL scores were derived from respondents' EQ-5D-5L health state descriptions. These scores were collected within the same survey for two time points: retrospectively before the onset of the first symptoms and at the time of survey completion. Utility values were calculated based on the national value set.[141] A one-sided t-test on the difference in scores was performed to determine whether the change in HRQoL score between the two time points was significantly different from 0.

In addition, exploratory sub-group analyses were conducted across predefined participant characteristic for several indicators to explore potential differences within these groups. The subgroups of interest are presented in Table 3. An overview of the subgroup analyses performed for each indicator are presented in Appendix 3.

Subgroup analyses were conducted to provide additional insight about potential variations across predefined subgroups with specific characteristics, rather than formally testing subgroup effects. The study was not designed within a confirmatory and multiple-testing framework, and no formal sample size calculation was performed to compare subgroups. Therefore, no adjustment for multiple testing was applied. All the results of the subgroup analyses should thus be interpreted with caution and considered as descriptive and hypothesis-generating.

Table 3 – Subgroup variables of interest and respective categories for subgroup analyses

Variable	Categories
Gender*	Male, Female
Time since diagnosis	< 10 years, 10+ years
Diagnosis	Schizophrenia, other psychotic disorders
Age groups	< 30 years, 30–50 years, >50 years
Geographical region	Wallonia, Flanders, Brussels
Living situation	• Alone (alone or with children) • With others (e.g., as a couple, with one or both parents, in colocation/shared housing, in a psychiatric care home, in sheltered housing, in supervised housing, in a hospital (temporarily), or in a nursing home)
Financial situation**	Comfortable, strained
Involvement in treatment decisions	Yes (certainly, to some extent), No (not really, certainly not, but I didn't want to get involved anyway)

Respondents were asked with which gender they mostly identify with. Due to the very small number of respondents identifying as other (n = 3), this category was excluded from the sub-analyses, which was therefore restricted to respondents identifying as male or female. Respondents' financial situation was measured using the question: "Taking into account all the incomes in your household, to what extent do you manage to make ends meet at the end of each month?" For analysis, responses were grouped into*

comfortable (very easily, easily and fairly easily) and strained (with some difficulty, with difficulty, with great difficulty).

Continuous variables were compared between predefined subgroups using paired Student's t-test or Wilcoxon rank sum test for two-group comparisons, and Kruskal–Wallis test for comparisons involving more than two groups. Ordinal variables were compared using Wilcoxon rank-sum tests for two-group comparisons, and Kruskal–Wallis tests for comparisons involving more than two groups. Chi-square or Fisher's exact tests were used for categorical variables. Fisher's exact test was used in cases of small sample sizes less than 5, as a Chi-square test was applied when a large sample size was applicable.

Each characteristic was examined separately in relation to the EQ-5D-5L score. Age was originally collected as a continuous variable but was categorised into multiple groups (<30; 30-50 and >50) and analysed as a categorical variable. For other categorical variables including diagnosis, living situation, financial status, time since diagnosis and educational level, the categories were grouped together (Table 3). The significance level was set at <0.05 for all statistical tests. All statistical analyses were performed using R Studio version 4.4.3 (R Foundation for Statistical Computing, Vienna, Austria). The R code is available on GitHub.[11]

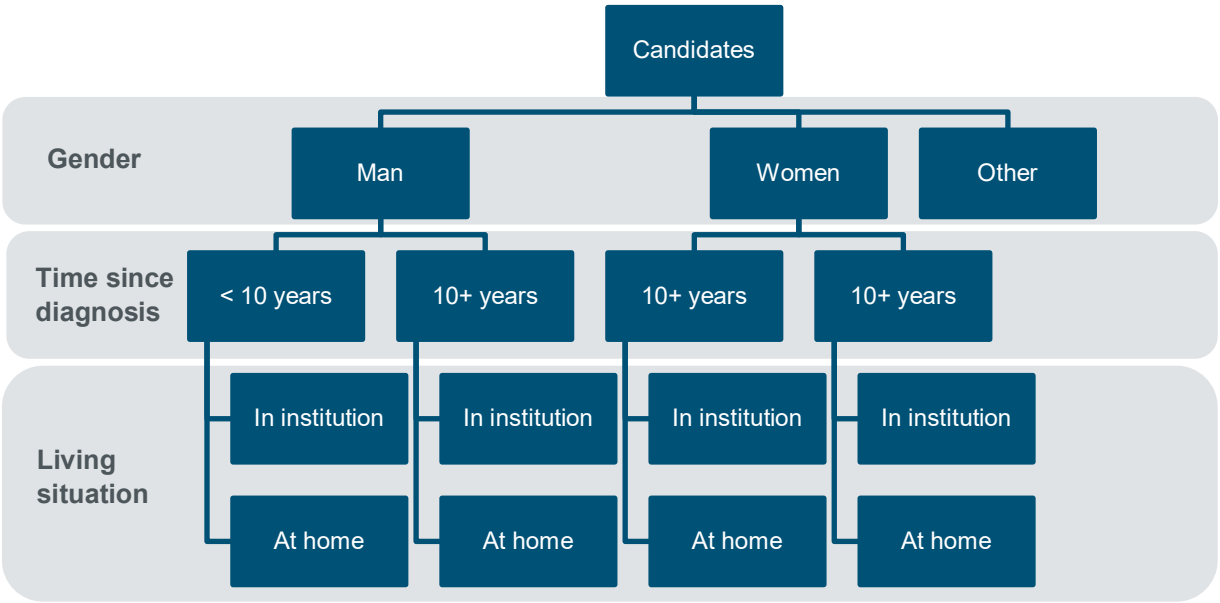
Open field responses were recoded into existing or newly defined categories when appropriate (e.g. answers to "other" categories) or analysed thematically (in the case of the open question on additional unmet needs). Any recoding was done by preserving the main idea(s) behind the initial response and was verified by another native-speaking member of the research team. If the response could be interpreted in different ways, the response was classified under 'Others' to avoid misinterpretation.

5.2 Qualitative interviews

5.2.1 Selection of participants

All interviewees were selected from survey respondents who indicated their willingness to participate in a subsequent in-depth interview. The aim was to conduct 24 individual interviews, 12 in French and 12 in Dutch. To ensure a broad representation of respondent profiles, the researchers prioritised the recruitment based on the segmentation criteria outlined in Figure 3.

Figure 3 – Segmentation criteria for the recruitment of interview participants



5.2.1.1 Contact procedure

Participants selected to participate in the interviews were contacted by phone or email to confirm their willingness to participate. Once participants confirmed their interest to take part in an interview, a date was scheduled. If a selected candidate did not respond to three phone call attempts and e-mailing, or refused to participate, another candidate within the same segment was randomly selected. Non-selected candidates were informed of this via e-mail to ensure transparency regarding the selection process.

While all interviews were primarily conducted online, in-person sessions could be arranged for participants who expressed a strong preference for this format. Prior to the interview, participants received an e-mail confirmation including practical details of the interview such as the scheduled time, date, and a direct Teams® link in case the interview was held online. In a separate e-mail, participants received the informed consent document as well as the information on how to sign it via Adobe® sign. In case participants were unable to sign the informed consent form via Adobe Sign, scans of originally signed informed consent forms were accepted. Once the informed consent forms were signed by both parties (the participant and the researcher leading the interview), participants received another e-mail with a copy of the signed document.

5.2.2 Qualitative data collection tool

5.2.2.1 Development of the interview guide

Generic interview guide

The semi-structured interview guide used for this study was developed based on the generic version for both patients and proxies (legal representatives) as described in KCE Report 348[142].

The generic interview guides covered the following topics:

- Impact on psychological and physical health;
- Symptoms;
- Daily life functioning, including sexual and reproductive life;
- Interaction with other health problems;
- Patient journey leading up to diagnosis;
- Experience with treatment (received, refusal, administration);
- Therapeutic needs: information needs, forgone care, accessibility, care network;
- Perception of quality of care: coordination, continuity, relationship with care providers;
- Financial burden;
- Administrative burden;
- Impact of the disease on social activities, relationships, work, education and finance;
- Identification of formal and informal support networks: received and forgone support;
- Identification of potential solutions to adress unmet needs in healthcare themes;
- Unmet needs expressed throughout the interview that should be adressed as a priority;
- Impact of on informal caregivers' health, time,social life, support and information needs.

Disease-specific adaptations were subsequently made to the generic version to ensure its applicability and relevance in the context of psychotic disorders. All adaptations to the interview guides are described in the following section.

Adaptations made for psychotic disorders

To ensure relevance for individuals living with a psychotic disorder, disease-specific modifications were made to the generic interview guide of KCE Report 348.[142] Both patient and proxy interview guides were made available in French and Dutch (Appendix 4).

These adaptations were informed by feedback received during pilot testing with patient representatives as well as findings from a literature review. Some adaptations were made to language, for instance, the term 'illness' was replaced with 'psychotic disorder' to ensure terminological consistency and reduce ambiguity for participants.

Following the pilot interviews, additional disease-specific questions were added to the patient interview guide as they emerged as particularly salient in the context of this study. They included:

- How did you experience your first encounter with the care offered for your [psychotic disorder]?
- How would you evaluate the follow-up of your health problems during your hospitalisation?
- *Follow-up question:* Did you experience stigmatisation from others in relation to your [psychotic disorder]?

The full interview guide is provided in (Appendix 4).

As a requirement by the Ethics Committee, the definition of what constitutes a proxy was narrowed for this study, restricting proxies to legal representatives only. This differs from the broader proxy definition in the NEED protocol[11], which includes additional categories of informal representatives.

The three questions added to the patient interview guide (first psychiatric consultation, evaluation of follow-up, and experience of stigma) were likewise included in the proxy-reported version but reframed to be answered from the proxy's point of view, in the same manner as the other proxy interview items. This ensures that proxies could reflect on the patient's experience while maintaining consistency across both interview guides (Appendix 4).

5.2.3 Qualitative data collection process

Interviews were scheduled with participants who met the eligibility criteria outlined in the selection tree (Figure 3), who had expressed their willingness to participate and had confirmed their involvement by signing the informed consent form. While all of the interviews were conducted online, in-person sessions could be arranged for participants who strongly preferred this format. One-on-one interviews were conducted via Microsoft Teams©, over the period of August to October 2025 by a trained, bilingual researcher (MS) with expertise in qualitative interviewing, allowing sessions to be held in either Dutch or French according to the participant's preferred language. For the first Dutch and French pilot interviews, close collaboration was maintained between MS and the researchers involved in the subsequent analysis (LK, IW, and VS) to ensure that the objectives, structure, and key points of interest of the interviews were clearly understood. More specifically, researcher LK was present during the first pilot interview to assess the clarity and comprehensibility of the questions and verify that key topics were adequately addressed. During data collection, researcher MS collaborated with researchers VS and IW on logistical aspects, including interview scheduling, informed consent procedures, and handling additional questions from participants. Following completion of the interviews, data analysis was conducted by researchers LK, IW, and VS.

Each interview lasted approximately 90 minutes, was audio- and video-recorded, and an automated Microsoft Teams transcript was generated during the session. Transcripts were then checked and completed *ad verbatim* by a bilingual student, using the Microsoft Teams automated transcript as a reference. Native French- and Dutch-speaking team members (LK, IW, and VS) then reviewed and completed the transcripts specifically to ensure linguistic accuracy and completeness. All names of participants, institutions, and care providers were pseudonymised, with access to the coding key restricted to the authorised members of the research team.

5.2.4 Qualitative data analysis

Qualitative interview data were analysed using the thematic framework analysis approach, in line with the QUAGOL protocol, combining both inductive and deductive coding strategies to capture emerging themes while also addressing pre-specified topics of interest. All coding was performed using NVivo Software versions 14 and 15.

A preliminary coding tree was developed by two researchers (IW and VS) based on the topics included in the patient questionnaire and interview guides (Appendix 5). The coding tree was subsequently validated through pilot coding of six interviews, three conducted in Dutch (IW and VS) and three in French (LK). This iterative piloting process enabled refinement of the coding tree, including the addition or removal of codes and sub-codes, resulting in a finalised coding framework to be applied across all interviews.

Following the pilot coding, the remaining interviews (n = 18) were coded independently, with French interviews coded by the native-speaking researcher LK, and Dutch interviews coded by the native-speaking researchers IW and VS.

To illustrate the qualitative findings, original participant testimonials were incorporated in the report using literal quotations drawn directly from the interviews. As interviews were conducted in the participants' mother language (Dutch or French), all selected quotes were forward translated into English using the DEEPL translation tool. Subsequently, translated quotes were reviewed by French (LK) and Dutch (IW, VS) native speakers of the research team to ensure correct translation and interpretation. For transparency, each translated quote is linked to a corresponding reference number [x], and the original quote in its source language can be consulted in Appendix 6.

5.3 Databases

The estimates of Years of Life Lost (YLL) (section 6.2.1), Years Lived with Disability (YLD) (section 6.2.2.1), and prevalence (see section 7.1.1) for schizophrenia were obtained from the Belgian national Burden of Disease study (BeBoD)[143], which provides standardized and nationally representative assessments of population health loss across a wide range of causes.

Schizophrenia prevalence estimates were generated by synthesizing data from administrative registry, Intego[b], with adjustments for underreporting (ICPC-2 code P72). The Intego sentinel GP network has been selected as the best estimate to yield the prevalence of schizophrenia in Belgium. As these results only reflect the situation in Flanders, a correction factor is applied, which is calculated as the ratio of the use of antipsychotics in Brussels and Wallonia, respectively, by sex and by age groups, and the use of antipsychotics in Flanders, using the health insurance data (minimal treatment duration of 3 months). The Intego sentinel GP network prevalence of schizophrenia is therefore multiplied by the different ratios obtained to get the prevalence of schizophrenia in the regions of Brussels and Wallonia. It must be noted that the ICPC-2 code P72 used for schizophrenia in the Intego dataset includes conditions and disorders that go beyond the strict definition of schizophrenia such as different kind of delusions, delusional disorder, paranoia, etc. which could lead to an overestimation of the prevalent cases of schizophrenia.

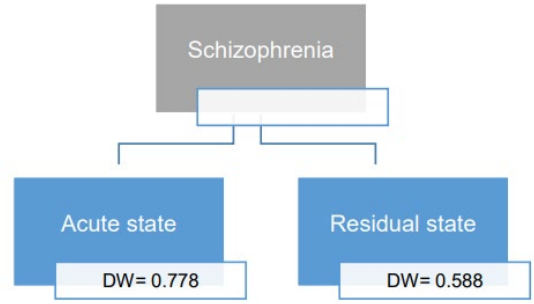
Mortality data were obtained from national vital registration systems and mapped to schizophrenia-related causes. YLL were calculated by multiplying the number of deaths attributable to schizophrenia by the remaining life expectancy at the age of death, based on a reference life table to ensure comparability across years. For the BeBOD study, the most recent GBD life expectancy table is used, which corresponds to the life expectancy table used in the GBD 2019 study.

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[b] Intego, available at: https://www.intego.be/en/over-intego

YLDs were quantified through prevalence-based modeling. YLDs were calculated as the product of disease prevalence and cause-specific disability weights, reflecting the average severity of health loss associated with schizophrenia (Figure 4).

Figure 4 – Schizophrenia disease model used for YLDs calculation



The disability weight for acute state schizophrenia was 0.778[144] and acute state is defined as "*hears and sees things that are not real and is afraid, consused, and sometimes violent. The person has great difficulty with communication and daily activities, and sometimes wants to harm or kill himself (or herself).*" For the residual state, a DW of 0.588 was used[144], and residual state is defined as "*hears and sees things that are not real and has trouble communicating. The person can be forgetful, has difficulty with daily activities, and thinks about hurting himself (or herself).*" The proportion of patients in the different health states considered in the schizophrenia disease model is 63% for acute state and 37% for residual state, based on Ferrari et al. 2012.[145]

Forecasted prevalence and forecasted YLD per case were produced using BeBoD's projection framework, which extrapolates past trends observed over the 2013–2022 period. These projections rely on statistical time-series and regression-based models that account for demographic changes, including population growth and ageing, while assuming stability in diagnostic practices and disease severity.[143]

5.4 Literature review

Evidence on the environmental impact of standard of care (see section 7.8) was searched using the search terms from the standardised search strategy, "Psychotic Disorders", "schizophrenia", "antipsychotics", and "Belgium" in Pubmed and Google Scholar. This secondary data collection consisted in a pragmatic (non-systematic) review of the literature, which was conducted between October and December 2025. We prioritised Belgian data and if none was available reported on other European studies.

5.5 Clinical expert survey

The NEED clinical expert questionnaire was used to collect data on five indicators: implementation of primary prevention strategies (see section, appropriateness of diagnostic timing, treatment effectiveness, availability of treatment, and research gaps. The survey can be found in the NEED Toolbox.[11]

Ten selected psychiatrists with extensive experience in caring for patients with psychotic disorders (e.g. as heads of department), working in large psychiatric units (either in a general hospital or in a psychiatric hospital) and with academic experience (published articles), working across the Belgian territory (Flanders, Wallonia, and Brussels), were invited to participate in the expert survey. Of these, six (60%) fully answered the questionnaire and were thus included in the final estimates. No significant conflicts of interest were reported.

The multiple choice answers used to estimate the five indicators were analysed according to the following methodology, as also described in the NEED protocol.[11]

In order to present a single answer category for each indicator assessed through the expert survey, the distribution of responses was examined to determine the proportion falling within the same category, as well as the proportion falling in adjacent or more divergent categories.

- **Strong Majority with Adjacent Disagreement** If 75% or more of respondents selected the same category, and the remaining responses were in an adjacent category (e.g. three out of four say *Major gap*, one says *Moderate gap*), the majority category was retained as the consensus.
- **Non-Adjacent Disagreement** ***This scenario did not occur in the present analysis and was therefore not applied.*** According to the protocol, if any response were to fall into a category that is non-adjacent to the majority (e.g., three respondents rating an item as a *Major gap* and one respondent rating it as a *Minor gap*), the item would be flagged for further review. The outlying response would then be examined alongside any qualitative comments to understand the underlying reasoning and, if necessary, to revise the consensus. In such cases, the protocol also notes that a Delphi process may be considered.
- **No Clear Majority or Mixed Responses** In cases where no clear majority exists (e.g., responses are evenly split or span multiple categories), a weighted scoring technique was applied:
    - Each category was assigned a numerical weight:

      No gap = 0

      Minor gap = 1

      Moderate gap = 2

      Major gap = 3

      Don’t know = excluded from scoring

        - The average score was calculated from included responses.
        - The average was then mapped back to a category using predefined ranges:

      0.0–0.49 → *No gap*

      0.5–1.49 → *Minor gap*

      1.5–2.49 → *Moderate gap*

      2.5–3.0 → *Major gap*

The protocol also noted that if discrepancies arose in the use of the 'Not Applicable' category, that is when more than one respondent selects *'not applicable*' for a given category while others provide a categorical assessment (e.g. three identify *minor gaps* in biomarkers while two consider the category ‘*not applicable*’) this divergence must be discussed with respondents, as it reflects a fundamental difference in perspectives. If only one respondent selects the ‘not applicable’ category, this response can be excluded while the other responses are treated according to the criteria specified above.

The open text responses from clinical experts, submitted to provide further explanations of their categorical ratings were summarised and presented narratively. Microsoft Copilot was used as an aid to process these, but the structuring, interpretation, and final checks were performed by a researcher.

5.6 Cost data

For the cost data reported in section 6.4.4.1 on out-of-pocket costs and 7.4.1 on healthcare costs, we obtained data from Sciensano (Harry Vranken) for the year 2022. The data are based on the Permanent Sample of the Intermutualistic Agency (IMA–AIM).

In the IMA–AIM data, individuals with psychosis are identified through the delivery of medication as defined in the 'Pharmaceutical Cost Groups'[c] (FKG). This field for FKG is based on a list from the Dutch National Health Care Institute (Zorginstituut Nederland). For psychosis, included are individuals who were delivered antipsychotics above a minimum threshold DDD-value (which is determined at the level of the Anatomical Therapeutic Chemical (ATC) code) in the reference year.

The presented cost data are adjusted for factors that may also influence healthcare costs, such as age, gender, reimbursement status (as an indication of income or disability) and the region where a person lives. Resultantly the data show only the marginal or additional costs attributable to the health condition of psychosis (although there can still be some residual confounding).

Out-of-pocket costs based on IMA–AIM data include co-payments and supplements paid for hospitalizations and outpatient visits, as well as for medication.

Total healthcare costs based on IMA–AIM data include costs associated with hospital admissions and outpatient visits, as well as reimbursed medication. These costs may be covered by compulsory health insurance (paid directly as third-party payment or reimbursed to patients after they have paid), or paid out of pocket by patients. Note that healthcare services are only included in the analysis as far as they relate to services that are (partly or fully) covered by compulsory health insurance, so non-reimbursed consultations of a psychotherapist e.g. are not included.

More precisely the average costs attributable to psychosis were calculated as follows:

1. A regression model fitted to the personal expenditure of all individuals in the IMA's Intermutualistic Agency with age, gender, region, increased allowance (proxy for socio-economic status) and having psychosis (0/1; based on medication delivery)
2. The coefficients were used to predict the cost in all individuals (i.e. no use of the observed costs)
3. The coefficients were used to predict the cost in an alternative scenario in which no one had psychosis (remains identical for those without psychosis)
4. The difference was calculated between the predicted cost in the observed scenario and the predicted cost in the alternative scenario in which no one had psychosis (= 0 for those without a diagnosis)
5. The average of the difference was taken to obtain the average incremental cost per patient

5.7 Ethical approval

The methodological approach was centrally approved by the ethics committee of the 'Erasmus Hospital Brussels' (Ref. P2024/592). Given the broad recruitment strategy, several collaborating centres and hospitals required additional approval from their own institutional ethics committees before engaging in recruitment activities (e.g., displaying posters, distributing flyers). In such cases, supplementary contracts between the institutions and research partners were established to comply with institutional and regulatory standards. Recruitment at these centres was initiated only upon receipt of their local approval. Each newly approved site was subsequently added to the

[c] Pharmaceutical costs group, available at: https://metadata.ima-aim.be/nl/app/vars/FKG_XXX_Pa (last access: 26 January 2026)

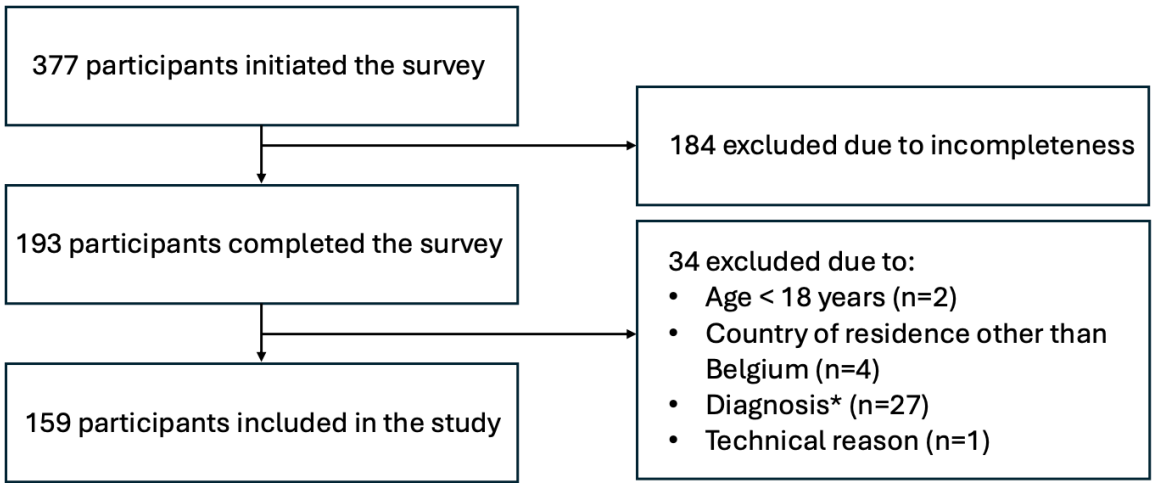
overarching Erasmus protocol via an amendment to ensure that the central ethical dossier remained accurate and up to date.

Informed consent procedures were tailored to the data-collection format. For the online questionnaire, the informed consent form was presented at the beginning of the survey, and participants could only proceed after having read and accepted the terms. Participants selected for interviews received a study-specific informed consent form by e-mail. After receiving sufficient information, participants provided consent either electronically or in writing (for face-to-face interviews), with assistance from the researcher conducting the interview if needed. The document was then countersigned by the researcher, and the final signed copy was sent to the participant by e-mail.

6 RESULTS – UNMET PATIENT NEEDS

As part of this study, a survey was conducted to explore the perspectives of individuals living with a psychotic disorder. Between May 2025 and August 2025, 377 individuals initiated the survey. Of those, 168 respondents completed the full questionnaire. Given the large number of incomplete surveys, respondents were also included in the analysis if they had completed at least the sections on background information, diagnosis and health-related quality of life (HRQoL), corresponding to the first 31 out of 77 questions (40.3%) of the survey. Applying this criterion resulted in 193 eligible responses. Of these, 34 respondents did not meet inclusion criteria concerning age, country of residence, and specific diagnosis and were therefore excluded, yielding a final sample of 159 participants (Figure 5).

Figure 5 – Flow diagram of the respondents participating in the online survey



Respondents were excluded if they reported any of the following diagnoses **without an additional diagnosis of a psychotic disorder that met the inclusion criteria: bipolar type I or II without psychotic features, post-traumatic stress disorder, borderline personality disorder, depression, post-partum psychosis, anorexia, or no-defined diagnosis.*

6.1 Description of respondents

6.1.1 Surveyed respondents

The survey sample consisted of 55% female respondents, 43% male and 2% identifying as other (Table 4). In total, 88% of the questionnaires were completed directly by people with a psychotic disorder, while 12% were completed by a legal representative. Geographically, Flanders emerged as the most represented region of residence, accounting for 56% of respondents. In terms of language, 62% of respondents filled in the questionnaire in Dutch. Most survey respondents were aged between 30 and 50 years old (55%), 13% were younger than 30, and 32% were older than 50 years.

Most respondents were diagnosed over 10 years ago (60%), 42% had completed at least secondary education, and 45% had a higher-level education degree. A small proportion had no formal diploma or only primary education (5%), while 3% reported another type of diploma. Regarding living situation, nearly half of the respondents (47%) lived at home with or without children, and almost a quarter (23%) resided in a supervised setting such as a hospital or protected housing. Four in ten reported managing to make ends meet by the end of the month with relative ease while almost six in ten reported experiencing financial hardship.

Table 4 – Sociodemographic and clinical distribution of online survey respondents (n=159)

Variable	n (%)
Respondent	
Individual with a psychotic disorder	140 (88%)
Legal representative	19 (12%)
Gender	
Female	87 (55%)
Male	69 (43%)
Other	3 (2%)
Survey language	
French	60 (38%)
Dutch	99 (62%)
Region of residence	
Wallonia	45 (28%)
Flanders	89 (56%)
Brussels	25 (16%)
Age group (in years)	
<30	20 (13%)
30-50	88 (55%)
>50	51 (32%)
Time since diagnosis	
<6 months	5 (3%)
6 months to 2 years	14 (9%)
2 years to 5 years	19 (12%)
5 years to 10 years	24 (15%)
10 years to 20 years	44 (28%)
>20 years	51 (32%)

Highest level of education	
*No diploma or primary education**	8 (5%)
*Secondary education***	67 (42%)
*Higher education****	71 (45%)
*Other diploma*****	4 (3%)
Living situation	
At home, alone with or without children	75 (47%)
At home, with other people (partner, friends, and/or parents)	43 (27%)
In a supervised setting (e.g. hospital, protected housing)	37 (23%)
Financial situation[1]	
Comfortable	64 (43%)
Strained	90 (57%)

** No diploma or primary education, ** Lower secondary education, Upper secondary education; *** Bachelor's, master's, or doctoral degree; **** Other diploma, not sure; [1] Responses from financial situation were grouped into comfortable (very easily, easily and fairly easily) and strained (with some difficulty, with difficulty, with great difficulty).*

Respondents' demographics regarding their occupational status showed a marked shift between before the onset of first symptoms and the time of data collection (Table 5). Just before symptom onset, over half of respondents (53%) were in paid employment, whereas only a minority were employed at the time of the survey (17%). This decline coincided with a substantial increase in individuals having a disability status at the time of survey completion (61%) compared to before symptom onset (8.7%).

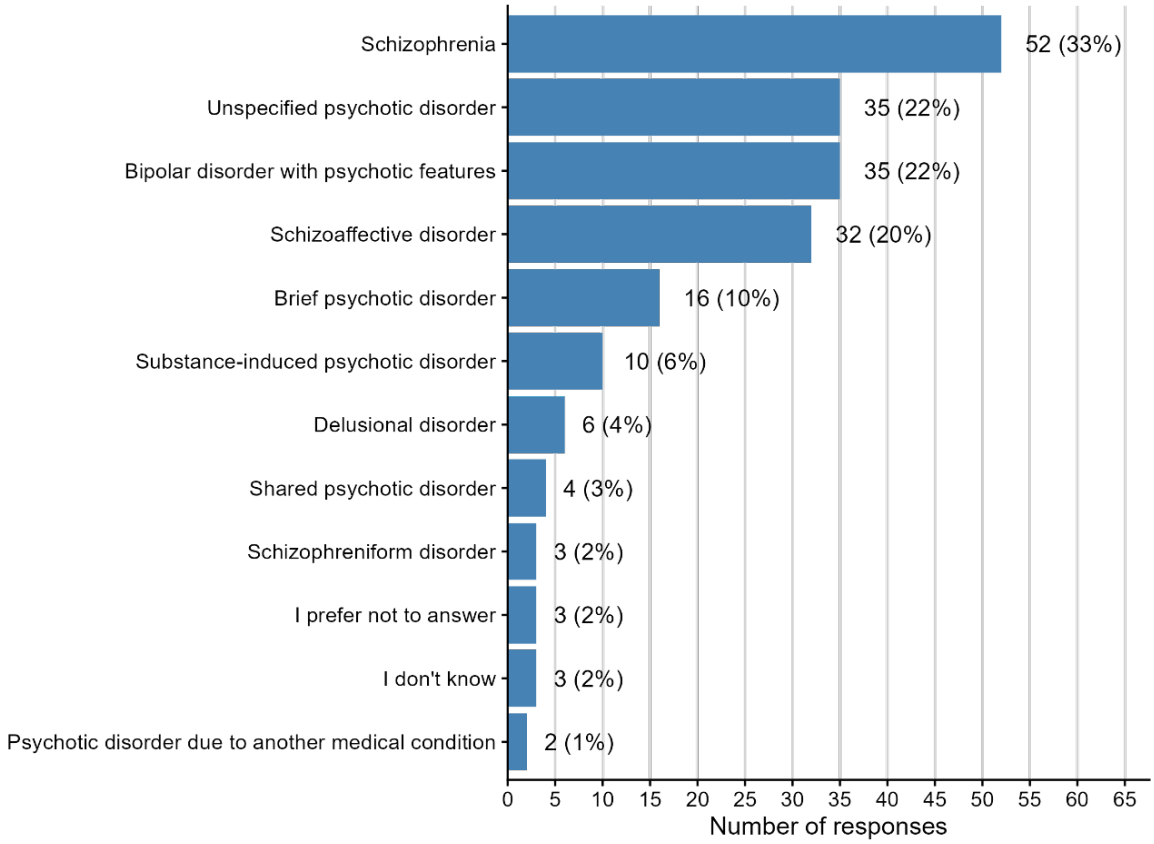
Table 5 – Respondents' occupational status before onset of first symptoms vs today

Main professional status		
	Before symptom onset n = 150	**Today** n = 145
In paid employment	79 (53%)	25 (17%)
Job seeker, unemployed, social assistance recipient	18 (12%)	13 (9%)
Homemaker, no income	2 (1.3%)	4 (2.8%)
Student	38 (25%)	5 (3.4%)
Retired	0 (0%)	9 (6.2%)
Disability status/invalidity allowances	13 (8.7%)	88 (61%)

Figure 6 presents the distribution of reported psychiatric disorder diagnoses. As respondents were allowed to indicate multiple diagnoses, the percentages add up to more than 100%. Schizophrenia was the most frequently reported diagnosis, accounting for 33% of responses. Both unspecified psychotic disorder and bipolar disorder with psychotic features were each reported by 22% of respondents. Schizoaffective disorder constituted 20% of diagnoses, followed by brief psychotic disorder at 10%. Other diagnoses included substance-induced psychotic disorder (6%), delusional disorder (4%) shared psychotic disorder (3%), and schizophreniform disorder (2%). Responses such as *"I prefer not to answer"* (n = 3), *"I don't know"* (n = 3), or *"psychosis secondary to another medical condition"* (n = 2) were only retained when they were reported in combination with at least

one diagnosis compatible with the inclusion criteria. These responses therefore only concern the 'other' category and were not included as stand-alone diagnoses.

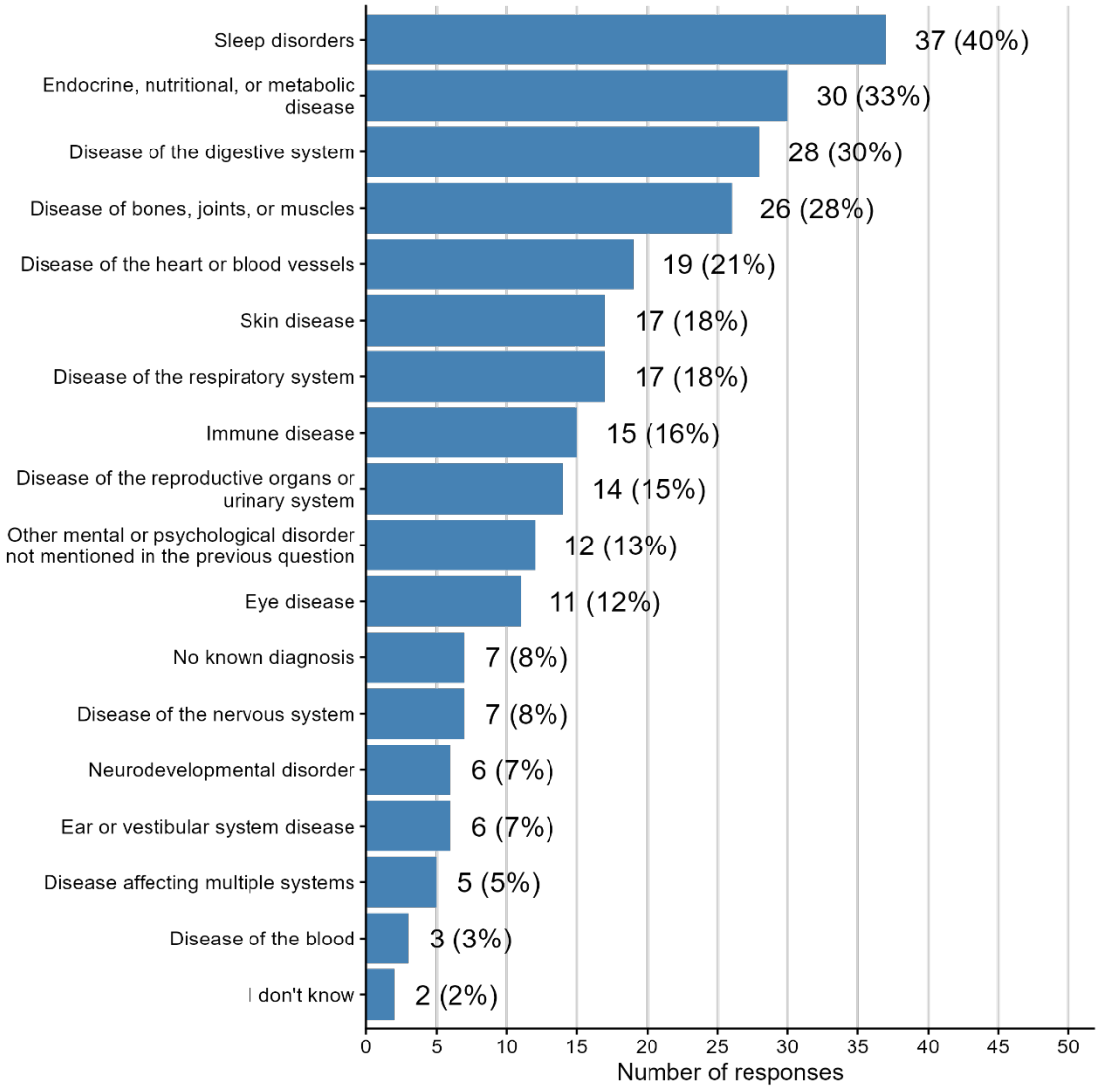
Figure 6 – Reported diagnoses (n = 201) by online survey respondents (n=159)



As respondents could indicate multiple diagnoses, these numbers correspond to the number of responses, rather than the number of respondents. Participants selecting "I don't know" or "I don't answer" were included in the survey only if they also reported at least one diagnosis meeting the inclusion criteria. Individuals who reported having solely a "psychotic disorder secondary to another medical condition" were excluded from the survey.

In addition to the reported psychotic disorder(s), 58% of respondents reported at least one comorbidity (Figure 7). Among these, sleep disorders were most common (40%) followed by endocrine, nutritional, or metabolic conditions (33%) and conditions affecting the digestive system (30%). Approximately one in four reported musculoskeletal conditions (28%) and about one in five experienced cardiovascular diseases (21%).

Figure 7 – Reported comorbidities by online survey respondents (n=92)



6.1.2 Interviewed participants

Out of the 159 participants that were included in the survey, 67 expressed their willingness to participate in a qualitative interview. Ultimately, 24 interviews were conducted (Table 6).

Table 6 – Description of interview participants (n=24)

ID	Language	Gender	Time since diagnosis	Housing situation
F1	FR	Other	2 – 5 years	In sheltered housing
F2	FR	Female	10+ years	At home
F3	FR	Male	10+ years	Other (revalidation centre)
F4	FR	Male	6 months – 2 years	At home
*F5**	FR	Male	5 - 10 years	In a nursing home
F6	FR	Male	10+ years	At home
N1	NL	Female	2 - 5 years	At home
N2	NL	Female	10+ years	At home
N3	NL	Male	10+ years	At home

N4	NL	Female	2 - 5 years	At home
N5	NL	Male	6 months - 2 years	At home
N6	NL	Female	10+ years	Other (monastery)
N7	NL	Male	10+ years	At home
N8	NL	Male	10+ years	In sheltered housing
N9	NL	Female	10+ years	At home
N10	NL	Female	10+ years	At home
N11	NL	Female	10+ years	At home
N12	NL	Female	10+ years	At home
N13	NL	Male	10+ years	At home
N14	NL	Female	10+ years	At home
N15	NL	Male	10+ years	At home
N16	NL	Female	5 - 10 years	At home
N17	NL	Male	10+ years	Involuntary admission
N18	NL	Female	10+ years	At home

**Participant F5 was a proxy; FR: French-speaking; NL: Dutch-speaking.*

6.2 Unmet health needs

KEY POINTS

- In Belgium (2022), schizophrenia causes a substantial overall health burden, with high disability per patient (0.71 YLDs per case) and significant premature mortality (22 years of life lost per death), even though deaths are relatively few.
- Self-reported quality of life was lower at the time of survey completion than before symptom onset.
- Fatigue or exhaustion was frequently reported as a physical symptom and also perceived as highly burdensome.
    - Participants experienced a perceived link between severe fatigue and the recurrence or intensification of psychotic symptoms.
- Pain and discomfort were more frequently reported at the time of survey completion than before symptom onset, with a shift towards higher reported pain/discomfort.
- Psychological symptoms including depression or sadness, anxiety, concentration problems, and stress were widely reported and often perceived as highly burdensome, linked to challenges in resuming everyday roles and social functioning.
- Mobility issues were more common at the time of survey completion and were often related to driving, which was considered unsafe or more difficult due to ongoing symptoms or treatment side-effects.
- Difficulties in self-care and engagement in usual activities was more common at survey completion with respondents describing challenges in work, household and family life.
- Approximately two-thirds of respondents reported a moderate to extreme impact of psychotic disorders on sexual life, while nearly half reported an impact on reproductive life.

6.2.1 Impact on life expectancy

6.2.1.1 Years of life lost per death

Based on the national Belgian Burden of Disease Study, the 2022 estimates for schizophrenia amount to 828 years of life lost and 37 deaths in Belgium, corresponding to **22 YLLs per death**.[143] Estimates for other psychotic disorders are not available.

6.2.1.2 Years of life lost per case

For schizophrenia, the Belgian national Burden of Disease Study estimated 44 770 cases in 2022, corresponding to **0.02 YLLs per case**.[143] Estimates for other psychotic disorders are not available.

6.2.2 Impact on general health-related quality of life

6.2.2.1 Years of life lived with disability per case

In 2022, schizophrenia accounted for 31 683 years lived with disability across 44 769 cases in Belgium, resulting in **0.71 YLDs per case**.[143] Estimates for other psychotic disorders are not available.

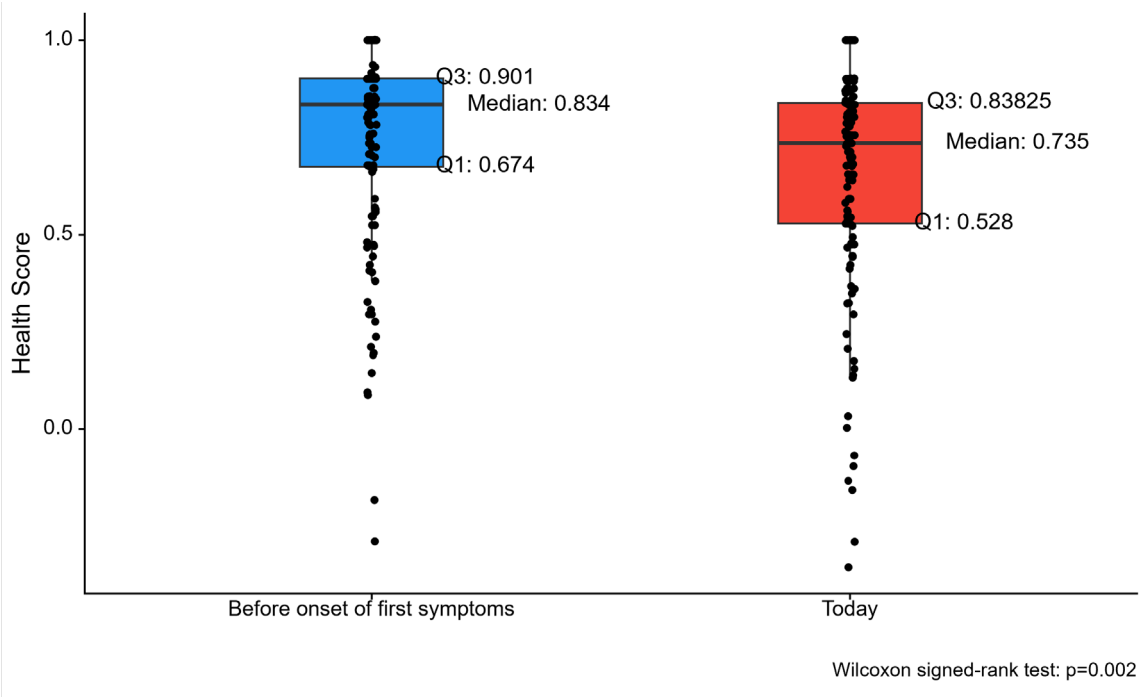
6.2.2.2 EQ-5D-5L score

The following section reports the results derived from the patient survey, based on respondents' answers to survey questions H1 until H5 and H7 until H11. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated in the description to further contextualise these findings.

The impact of living with a psychotic disorder on patients' general HRQoL was assessed by calculating the difference between EQ-5D-5L scores reported in the survey by each participant. One score retrospectively referred to their status before the onset of psychotic symptoms, and the other reflected their current situation at the time of survey completion ("today"). The difference between these scores was used to estimate the change in HRQoL. As shown in Figure 8 the median EQ-5D-5L health score for the sample (n = 132) for the period before symptom onset was 0.834 (IQR = 0.674 - 0.901), and 0.735 (IQR = 0.528 - 0.838) at the time of survey completion. For each patient, an individual change in score was calculated (i.e., health score at survey completion minus health score before symptom onset). A one-sample t-test showed that the mean change in HRQoL differed significantly from zero (p = 0.003), reflecting a decrease in HRQoL over time.

To contextualise the observed change in HRQoL among respondents living with a PD, the results were compared to the Belgian population reference values for the EQ-5D-5L, as reported by Sciensano. Based on data from the Belgian Health Interview Survey of 2018, the **general Belgian population aged 15 years and older had a mean EQ-5D-5L index value of approximately 0.84,** with variations across age and sex.[146] In the present study, respondents retrospectively reported a median EQ-5D-5L score of 0.834 prior to the onset of psychotic symptoms, which is slightly lower than the Belgian population norm. **At the time of survey completion, the median EQ-5D-5L score dropped to 0.735**, indicating a substantial reduction in HRQoL. The median difference between these scores highlights a marked deterioration in perceived health status, placing respondents well below the average HRQoL observed in the Belgian general population. This comparison underscores the considerable impact of psychotic disorders on overall HRQoL.

Figure 8 – General HRQoL before the onset of first symptoms and at present, measured using EQ-5D-5L scores (n=132)



Exploratory subgroup analyses did not indicate statistically significant overall differences in EQ-5D-5L scores across financial situation (comfortable vs strained, p = 0.2) age groups (<30, 30-50 and >50 years; p = 0.10), time since diagnosis (<10 years vs >10 years; p = 0.2), gender (men vs women; p = 0.12), level of education (basic, secondary, higher; p = 0.069), and diagnostic group (schizophrenia diagnosis vs other psychotic disorders; p = 0.3) (Appendix 7).

Findings from the interviews showed that, although PD primarily affected mental and emotional functioning, individuals also experienced a broader impact that extended into their physical health. Even when symptoms were relatively stabilised with medication, ongoing effects continued to shape day-to-day functioning. Elements of disorganisation were also noted, sometimes influencing routine, structure, or the pace at which activities were carried out.

> *"Yes, if I have psychotic symptoms, like I did recently, then that does have a big impact on my family life. I can no longer fulfil that role, I can no longer take on tasks within the household." (N2)[1]*

Overall, interview findings illustrated how PD can affect energy levels, functioning, mobility, self-care, and overall physical well-being, even when core symptoms are under control.

> *"Difficulties of psychosis? Yes, getting everything organized and doing what other people do. For example, going to work, going to school, contributing constructively, maintaining social contacts, doing groceries. For the household, cooking, doing all the laundry. What are the possibilities? Yes, everything that has to do with life, really." (N7)[2]*

> *"At first, riding the tram was difficult because it was too crowded. Now I can manage it, but if I haven't had much sleep and then I'm on a crowded tram, it becomes difficult again." (N5)[3]*

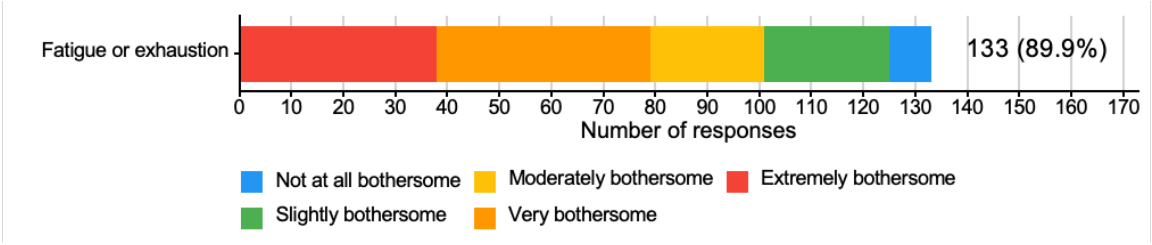
6.2.3 Impact on physical health

The following section reports the results derived from the patient survey, based on respondents' answers to questions: H13 and H13B. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

6.2.3.1 Experienced burden of physical symptoms related to psychotic disorders

While most symptoms assessed in the survey were related to psychological wellbeing, fatigue or exhaustion was the only symptom related to physical health and therefore classified separately (Figure 9). **Fatigue or exhaustion was reported by nine out of 10 participants. When looking at the perceived burden, the majority reported this to be moderately bothersome (17%), very bothersome (31%), or extremely bothersome (29%).**

Figure 9 – Presence of physical symptoms and severity of their perceived burden (n=148)



Fatigue emerged as a persistent and burdensome experience in both quantitative and qualitative findings, as it affected participant's daily functioning. It was often linked to a lack of energy, reduced concentration and diminished motivation.

> *"I'm very tired, and I've been asking myself how I'll ever be able to work again if I'm so tired every day and can't concentrate." (N16)[4]*

During the interviews, sleep emerged as an important aspect of physical recovery. Participants reported that their night-time sleep had generally become better regulated over time. However, persistent fatigue and reduced motivation to engage in daily activities or undertake new tasks remained common experiences.

> *"So, I sleep very little and I have to be very careful about that... If you sleep very little, at some point the auditory hallucinations become so strong that you might hurt yourself, for example by banging your head against the wall because you don't want to hear them anymore, and then you do that." (N6)[5]*

Sleep deprivation was also described as an important trigger for the onset of psychotic symptoms or subsequent crises. Participants linked poor sleep to periods of heightened vulnerability for psychotic symptoms.

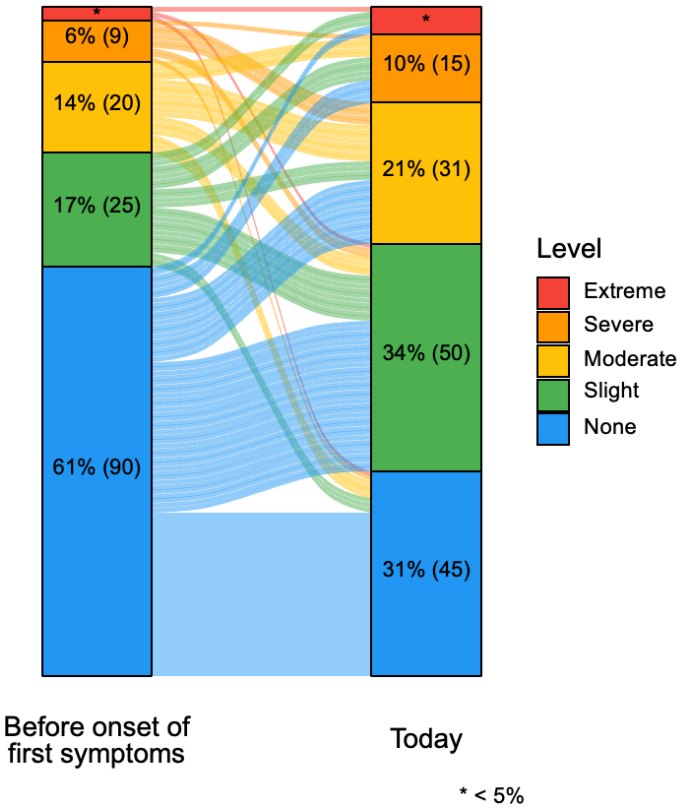
> *"Then I basically didn't sleep for almost 10 days. And that was an acute trigger for my first psychosis." (N17)[6]*

6.2.3.2 Pain/discomfort before disease vs today

The following section reports the results derived from the patient survey, based on respondents' answers to survey questions H4 and H10. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

To assess changes in physical health over time linked to the development of a psychotic disorder, respondents were asked to report their levels of pain and discomfort both before the onset of their first psychotic symptoms (left) and at present (right), using the EQ-5D-5L tool (Figure 10). The Sankey diagram helps visualize how perceived pain or discomfort changed over this time. **Prior to symptom onset, most respondents reported no problems (61%) or only slight pain or discomfort (17%). Only few reported moderate (14%), severe (6%) or extreme (2%) levels of pain or discomfort. By the time of survey completion, this distribution had shifted substantially: only 31% reported no problems, while reports of slight (34%), moderate (21%) severe (10%) and extreme (4%) problems with pain and discomfort increased.**

Figure 10 – Changes in the self-reported level of problems with pain/discomfort (EQ-5D-5L) before onset of first symptoms and today (n=147).



Percentages are based on the analytical sample (n = 147). Because paired data were collected, respondents selecting "I don't know" at either time point were excluded from the analysis.

Exploratory subgroup analyses assessed whether changes in self-reported pain and discomfort differed across respondent characteristics. No statistically significant overall differences in change scores were observed by gender, age, or educational level or financial situation (Appendix 7).

6.2.4 Impact on psychological health

The following section reports the results derived from the patient survey, based on respondents' answers to questions: H13 and H13B (Appendix 1). Of note, from this survey item onwards the overall participants sample was of n=148 because 11 individuals stopped the survey after the health-related quality of life questions. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

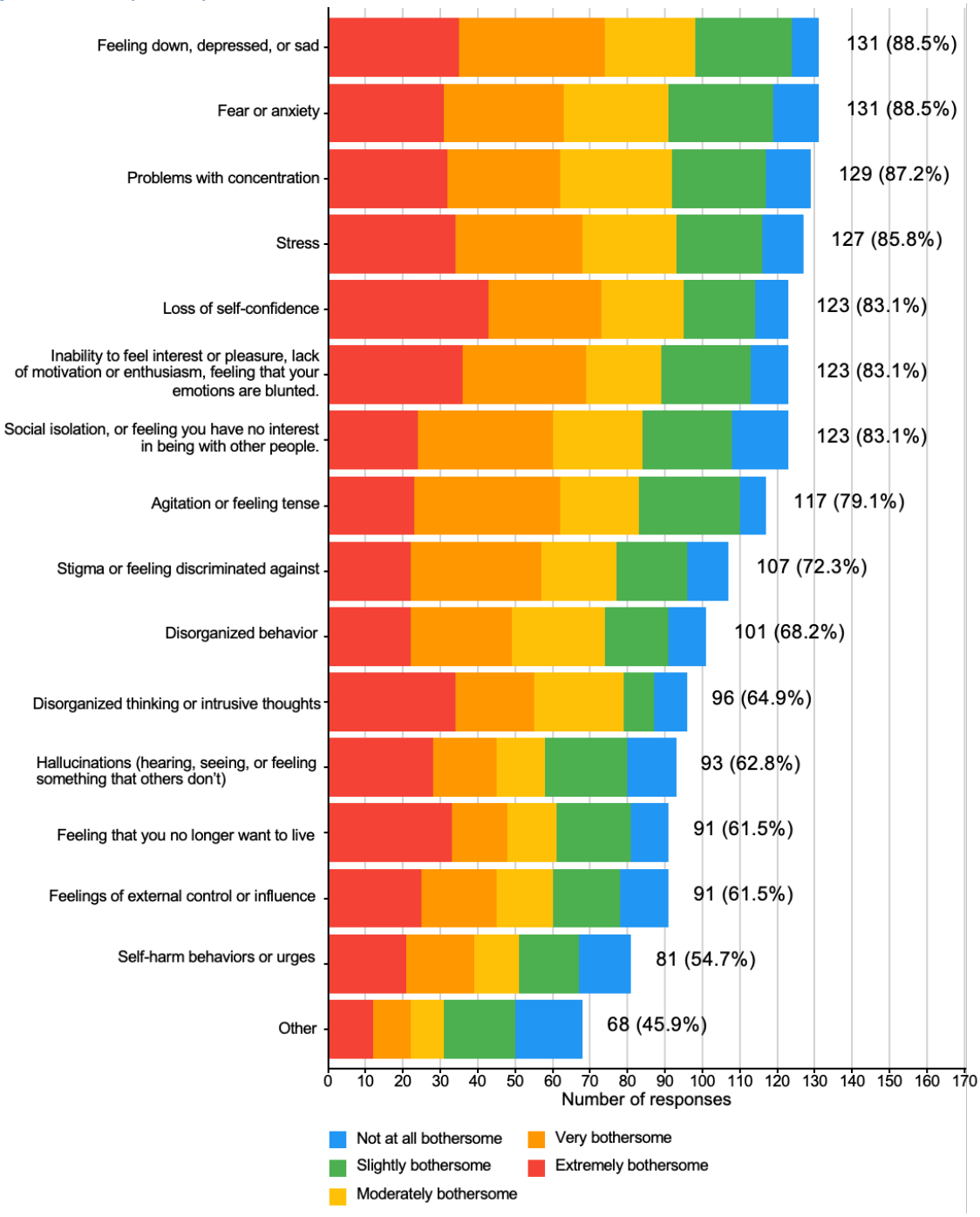
6.2.4.1 Experienced burden of psychological symptoms related to psychotic disorders

Results showed that, during the period in which respondents were being followed up or treated for their psychotic disorder, the condition had a great impact on their psychological health. Figure 11 presents the prevalence and reported burden of psychological symptoms (n = 148). **Nearly 9 out of 10 respondents reported experiencing symptoms such as feeling down, depressed, or sad (88.5%) and fear or anxiety (88.5%).** Most respondents reported that **feeling down, depressed or sad was extremely burdensome (27%), very burdensome (30%) or moderately burdensome (18%). Similarly, fear or anxiety was also mostly considered extremely burdensome (24%), very burdensome (24%) or moderately burdensome (21%).**

Psychological symptoms including **problems with concentration (87.2%) and stress (85.8%) were also very frequently experienced by patients. Problems related to concentration were frequently considered extremely burdensome (25%), very burdensome (23%) or moderately**

burdensome (23%). Three quarters of respondents indicated stress to be extremely bothersome (27%), very bothersome (27%) or moderately bothersome (20%).

Figure 11 – Prevalence of psychological symptoms and their perceived burden, ordered by prevalence (n=148)



The category "Other" was not accompanied by an open-text field so no further details are available.

Exploratory subgroup analyses examined whether differences in the reported burden of psychological symptoms varied across respondent characteristics (Appendix 7). Differences in burden levels were observed across age groups for feeling down, depressed or sad ($p = 0.005$). Younger respondents (<30 years) more frequently reported this to be extremely (47%) or very (41%) burdensome compared with those aged between 30-50 years (28% each) and those above 50 years (15%; 28%). Similarly, variations were observed for

fear or anxiety (p = 0.01). Younger respondents more frequently reported this as extremely (47%) or very (24%) burdensome compared with respondents aged between 30-50 years (23% each) and those above 50 years (14%; 27%). Conversely, a difference was observed for feelings of external control or influence by those aged between 30-50 years old (p = 0.01). More specifically, respondents between 30-50 years old more frequently reported feelings of external control or influence as extremely (33%) or very (25%) burdensome, compared to those in younger (<30 years) (17%; 8%) or older (>50 years) age categories (14%; 24%).

Further exploratory analyses revealed differences in the reported burden of several psychological symptoms according to respondents' financial situation including. Firstly, variations were observed for fear or anxiety (p = 0.016), with those reporting a strained financial situation to experience this symptom more frequently as extremely (29%) of very (26%) burdensome, than those having less financial hardship (15%; 24%). Similarly, for inability to feel interest or pleasure (p = 0.035), those in financial difficulty reported this more frequently as extremely or very burdensome (33% each) compared to others (22%; 20%). For social isolation (p = 0.02), respondents in financial difficulty reported this more frequently as extremely (21%) or very (38%) burdensome than those having less financial difficulty (14%; 16%). Finally, similar variations were observed for agitation or feeling tense (p = <0.001), with those reporting a strained financial situation to experience more frequently as extremely (26%) or very (41%) burdensome compared to those in a more comfortable financial situation (7%; 22%).

Variations were also observed across educational levels for fear or anxiety (p = 0.04). More specifically, those with secondary education levels more frequently reported this as extremely (29%) or very (27%) burdensome compared to those with basic (33%; 0%) or higher (16%; 26%) education. Conversely, social isolation (p = 0.03) was less frequently reported by those with higher levels of education as extremely (13%) or very (26%) burdensome, compared with those having basic (20%; 40%) or secondary (22%; 37%) levels of education. Finally, agitation (p = 0.02) was mostly reported by those with secondary education as extremely (23%) or very (42%) burdensome, compared to those with basic (25% each) or higher (15%; 30%) education.

No statistically significant overall differences in psychological symptom burden were observed for gender or diagnostic group (Appendix 7).

The interview findings provide further insights into the emotional impact associated with psychotic episodes. Participants described experiencing feelings of shame and hatred about what had happened to them or about their behaviour during these episodes. These feelings often shaped their interactions towards friends, family, or the broader social environment or could even play a role in new or developing relationships.

> *"Sometimes I get flashes of hatred, (...) When I go to have lunch and I open the door and bump into my mum. I say, "Hi Mum, etc ?" and then she tells me about something that annoys me, and she ends up with a bloke who's going to give a half-hour monologue with terrible energy." (F4)[7]*

> *"You feel a little ashamed, because I happen to live in [city] now. And the psychiatry is here, and then you see that everyone has prejudices." (N18)[8]*

Participants reported that awkwardness or social discomfort during a psychotic episode could result in anxiety or depressive feelings during the recovery process. Anxiety was sometimes linked to the fear of relapse, while depressive experiences were associated with difficulties in regaining daily routines or with periods of social withdrawal. Depressive symptoms could be accompanied by suicidal thoughts, illustrating the psychological strain and vulnerability that may arise after a psychotic episode.

> *"Yes, in the beginning after my first psychosis, people didn't know how to deal with me either. So, I had no contact with anyone, and no one contacted me either. Then I fell into a depression, and I had myself admitted again to the hospital, because then I was having serious suicidal thoughts." (N18)[9]*

Stress in particular was described as a contributor to sleep difficulties and a recurrent trigger for psychotic episodes. Interviewees explained that stressful periods could lead to a resurgence of positive symptoms, such as auditory hallucinations, distrust, or feelings of suspicion towards their environment.

> *"At a certain point, the stress becomes so intense that your heart beats very, very fast, your sleep is very light, and you feel physically weak." (F4)[10]*

> *"Because the stress causes me to hear a lot of those malicious voices, which actually drown out the voices of the other parts… And, yes, then I just have to stop working." (N14)[11]*

Participants described pronounced emotional dysregulation, characterised by overwhelming and intrusive emotional experiences. These emotions, ranging from intense anger and fear to confusion were reported as difficult to manage and were sometimes associated with obsessive or compulsive patterns of thinking. Interview participants noted that emotionally charged situations, such as conflicts or new romantic relationships, could act as triggers for symptom exacerbation.

> *"She was a friend I had known for a long time. She was someone I was very close to and actually I had too many feelings for. (...) So I had, an obsessive disorder, actually." (F6)[12]*

> *"There are extremely overwhelming emotions that are much more intense than the feeling of hunger. (...) The feeling of hunger is very minimal compared to the other sensations that run through my body, which are feelings of immense anger, feelings of immense fear, well, it is often anger, or it can be a kind of despair and confusion." (F4)[13]*

A pronounced lack of motivation emerged as a key challenge, often limiting people's ability to initiate or sustain daily activities. As a result, reduced engagement and a sense of decreased autonomy were common experiences.

> *"I recall a day when I told someone, 'Today I was able to go for a walk and do some exercises' and that was a personal victory for me. I got out of bed, I was able to take off my pyjamas, I was able to shower, get dressed, go downstairs, I had breakfast and then I managed to go outside and just take a walk around the block. And that was, that was a victory for myself." (N3)[14]*

Participants with PD, particularly with bipolar disorder or schizo-affective disorder, described alterations in their affective experiences. They reported a reduced intensity of emotional expression and difficulty experiencing enthusiasm or emotional engagement. It remained unclear whether these affective changes occurred in the context of the disorder itself, the use of antipsychotic medication, or a combination of both.

> *"But I don't have to laugh at everything. It's, it's a bit flatter than with someone else." (N14)[15]*

> *"So that makes it very difficult to be enthusiastic about something, even if you know it's fantastic. It's hard to really feel like doing an activity. I do have hobbies and I enjoy doing them, but I find it very difficult to be truly enthusiastic about anything." (N17)[16]*

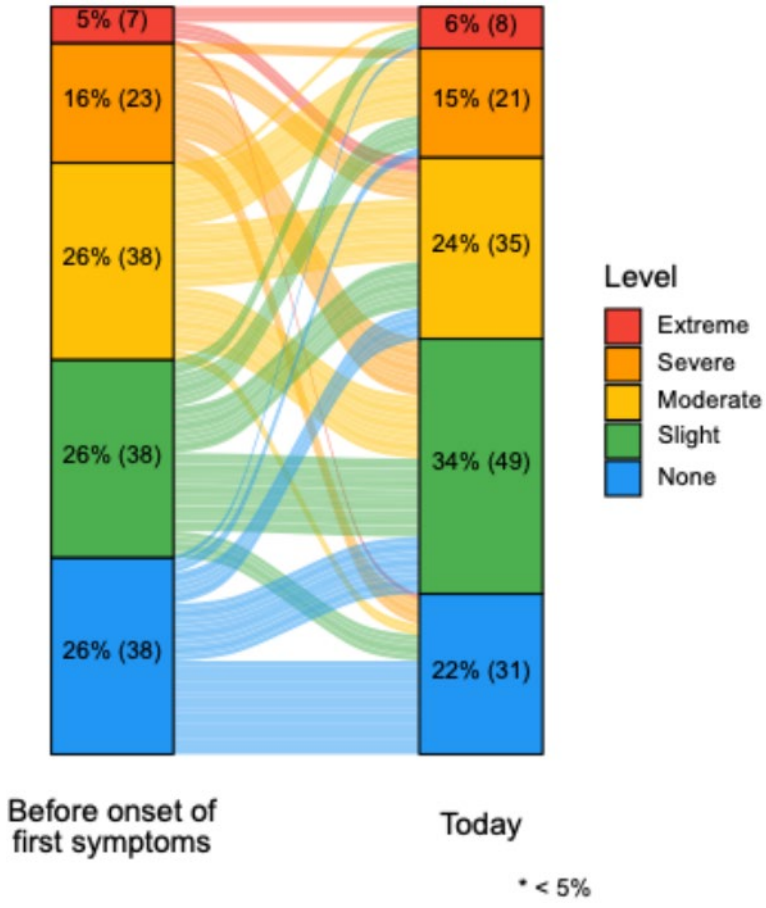
6.2.4.2 Anxiety/depression before disease vs today

The following section reports the results derived from the patient survey, based on respondents' answers to questions: H5 and H11. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

To assess changes in anxiety or depression since the onset of the first symptoms, we asked survey participants about their levels of anxiety and depression before symptom onset (left) and at the time of completing the survey (right), using the EQ-5D-5L scale (n = 144) (Figure 12). **Before symptom onset, half of respondents reported no or slight problems of anxiety or depression, while one quarter reported moderate problems (each 26%). One in six reported severe problems, and 5% extreme anxiety or depression.**

At the time of completing the survey, a higher proportion of respondents reported slight problems (34%). In contrast, the proportions reporting no problems (22%), moderate problems (24%) and severe problems (15%), decreased.

Figure 12 – Changes in self-reported level of problems with anxiety/depression of the EQ-5D-5L before onset of first symptoms and today (n=144)



Percentages are based on the analytical sample (n = 144). Because paired data were collected, respondents selecting "I don't know" at either time point were excluded from the analysis.

Changes in anxiety and depression were assessed using EQ-5D-5L anxiety/depression scores, calculated as the score at the time of survey completion minus the score before symptom onset. Descriptive statistics showed a positive median change in score among respondents younger than 30 years (median change: +1.0; IQR: 0.0 – 2.5) and among respondents with a basic level of education (median change: +1.0; IQR: 0.0 – 2.0) (Table 8).

Exploratory subgroup analyses indicated statistically significant overall differences in change score distributions by gender ($p = 0.008$), age group ($p = 0.022$), and level of education ($p = 0.014$).

No statistically significant overall differences were found for changes in self-reported levels of anxiety or depression before symptom onset versus today in relation to respondents' financial situation (Appendix 7).

Table 7 – Median difference in self-reported level of problems with anxiety/depression between today vs. before symptom onset, in EQ-5D-5L scores, by respondent characteristics.

Respondent characteristics	Changes in self-reported level of problems with anxiety/depression of the EQ-5D-5L		p-value
	Median (Q1, Q3)	Min, Max	
Gender[2] (n = 141)			**0.008**
Male (n = 62)	0.0 (0.0, 1.0)	-3.0, 4.0	
Female (n = 79)	0.0 (-1.0, 1.0)	-4.0, 3.0	
Age[1] (n = 144)			
<30 (n = 16)	+1.0 (0.0, 2.5)	-2.0, 4.0	**0.022**
30-50 (n = 82)	0.0 (-1.0, 1.0)	-4.0, 3.0	
>50 (n = 46)	0.0 (-1.0, 1.0)	-3.0, 2.0	
Education[1] (n = 133)			**0.014**
Basic (n = 7)	+1.0 (0.0, 2.0)	-1.0, 2.0	
Secondary (n = 60)	0.0 (-0.5, 1.0)	-3.0, 4.0	
Higher (n = 66)	0.0 (-1.0, 1.0)	-3.0, 3.0	

[1]Kruskal-Wallis test; [2]Wilcoxon rank-sum test; The scores reflect the median difference between the EQ5D5L scores for anxiety/depression for today and before symptom onset. A positive median change score reflects higher anxiety/depression levels at the time of survey completion compared with before symptom onset.

6.2.5 Impact on autonomy

The following section reports the results derived from the patient survey, based on respondents' answers to questions: H1 until H3 and H7 until H9. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

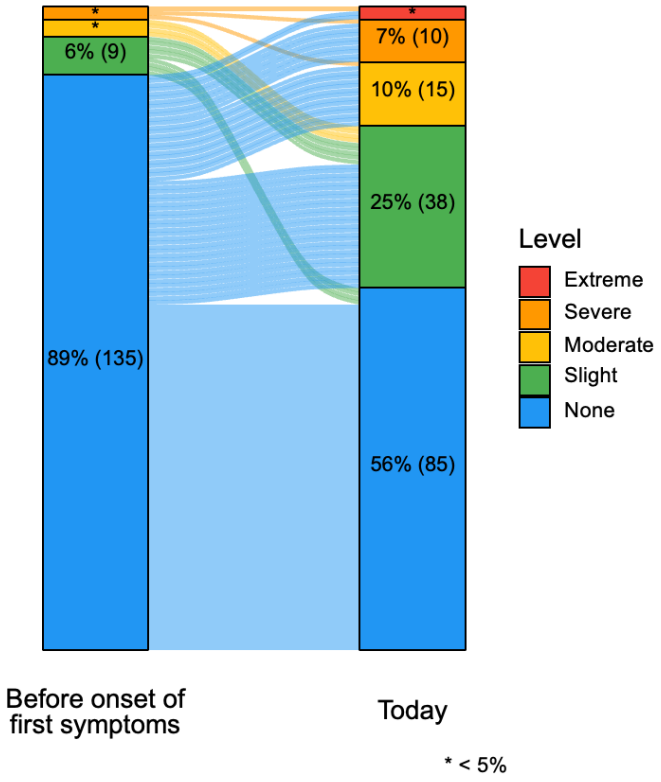
The impact that psychotic disorders have on individuals' autonomy was assessed in three ways: (i) problems with mobility, (ii) problems with self-care and (iii) problems with carrying out usual activities. The following sections highlight the key results for each aspect.

6.2.5.1 Mobility before the first symptoms vs today

Figure 13 shows the change in respondents' self-reported mobility levels on the EQ-5D-5L scale (n = 151). **Before symptom onset, 9 in 10 reported no mobility problems, with only small proportions indicating slight (6%) moderate or extreme problems (each <5%). At the time of survey completion, mobility limitations had become more common. Even though 56% still reported no problems, slight (25%), moderate (10%) and severe (7%) mobility issues were increasingly reported.**

Sub-group analysis showed no statistically significant differences for change in mobility by gender, age, education level and financial situation (Appendix 7).

Figure 13 – Changes in self-reported problems with mobility of the EQ-5D-5L, before onset of first symptoms and today (N=151)



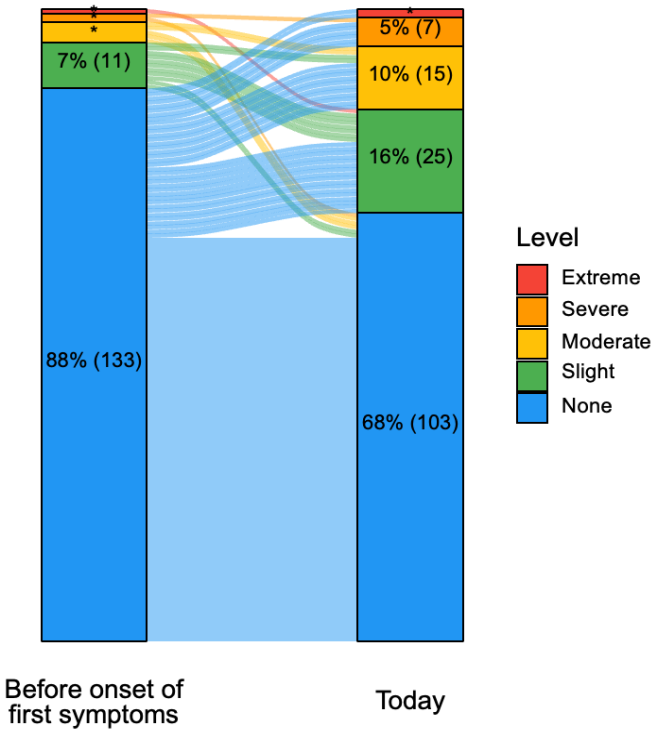
Percentages are based on the analytical sample (n = 151). Because of the paired analysis, respondents selecting "I don't know" at either time point were excluded.

6.2.5.2 Self-care before symptom onset vs today

Figure 14 presents the changes in respondents' self-reported problems with self-care on the EQ-5D-5L scale (n = 152). **Before symptom onset, the large majority reported no difficulties with self-care (88%), with only small proportions reporting slight (7%) moderate, severe or extreme problems (<5%). At the time of survey completion, the proportion of respondents experiencing slight (16%), moderate (10%) and severe (5%) problems increased.**

Overall, these results indicated a notable shift, with around 1 in 5 respondents moving from no self-care problems before symptom onset to some level of impairment at the time of responding.

Figure 14 – Changes in self-reported level of problems with self-care of the EQ-5D-5L, before onset of first symptoms and today (n=152)



Percentages are based on the analytical sample (n = 152). Because of the paired analysis, respondents selecting "I don't know" at either time point were excluded.

Exploratory sub-group analyses showed no statistically significant overall differences for change in mobility by gender, age, education level and financial situation (Appendix 7).

The qualitative interviews provided important context for understanding the increase in self-care difficulties observed in the quantitative data. Participants described recovery after a psychotic episode as a long and demanding process, during which self-care functioning may gradually improve over time. Interviewees indicated that, during periods of relative symptom stability, they are able to manage self-care and daily responsibilities reasonably well. However, participants emphasized that this functioning remains vulnerable and can deteriorate again when psychotic symptoms re-emerge or during a new episode. In such periods, self-care and daily functioning were described as becoming impaired, particularly in relation to fulfilling roles and responsibilities within the household and family life.

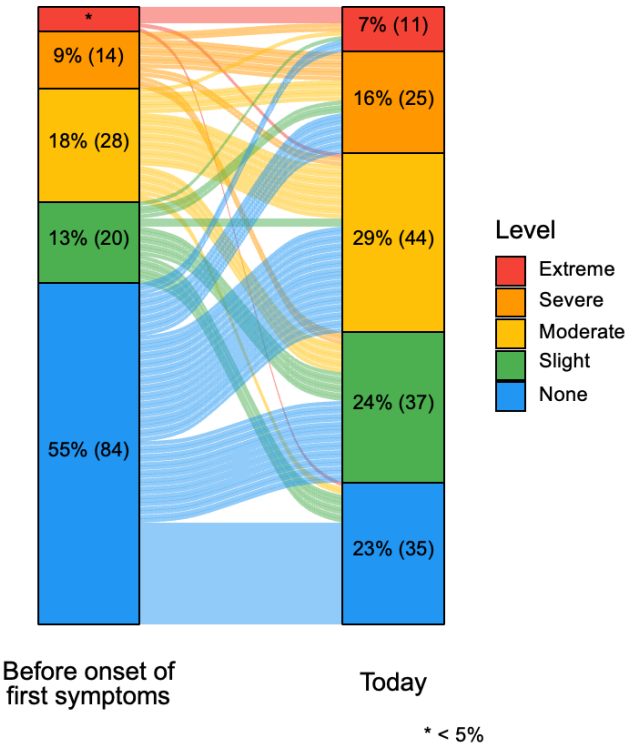
> *"Well, yes, if I have psychotic symptoms, like I did recently, then yes, that does have a big impact on my family life. I can no longer fulfil my role; I can no longer take on tasks within the household." (N2)[17]*

> *"I still have a lot of trouble, especially after having had many psychotic episodes. I have trouble taking care of myself, yes... and I also have ups and downs... but for example, going to work or something like that is too much for me." (N7)[18]*

6.2.5.3 *Problems carrying out usual activities before first symptoms vs today*

Figure 15 presents the changes in respondents' self-reported ability to perform usual activities on the EQ-5D-5L scale (n=152). **Before symptom onset, over half of the respondents reported no problems performing usual activities (55%). Smaller proportions indicated slight (13%), moderate (18%), severe (9%) or extreme (<5%) difficulties. At the time of the survey, the distribution had greatly shifted; only 23% still reported no problems, while slight (24%), moderate (29%) and severe (16%) difficulties had become more common. Reports of extreme problems also increased to (7%).** Overall, these findings suggest a substantial deterioration in respondents' ability to carry out usual activities, with notable movement from no limitations prior to symptom onset to varying degrees of functional impairment at the time of reporting.

Figure 15 – Changes in self-reported level of problems with usual activities of the EQ-5D-5L, before onset of first symptoms and today (n=152)



Percentages are based on the analytical sample (n = 152). Because of the paired data analysis, respondents selecting "I don't know" at either time point were excluded.

Descriptive statistics for median changes in self-reported problems with usual activities on the EQ-5D-5L (calculated as the score at the time of survey completion minus the score before symptom onset) are presented in (Table 9).

Descriptively, median change in scores varied across education levels, with median values of +1.5 (IQR: 0.0 – 3.0) or +1.0 (IQR: 0.0 – 2.0) among those with basic and secondary education, respectively, compared with a median change score of 0.0 (IQR: 0.0 – 1.0) for higher education. Exploratory sub-group analysis indicated a statistically significant overall difference in change of scores according to education level (p = 0.027).

Moreover, statistically significant overall differences were also observed for financial situation (p = 0.043). Descriptively, respondents reporting financial strain showed a median change score of +1.0 (IQR: 0.0–2.0), compared with a median change score of 0.0 (IQR: 0.0–1.0) among those reporting a more comfortable financial situation.

Table 8 – Median differences in self-reported usual-activities limitations (today vs. pre-symptom onset), in EQ-5D-5L score, by respondent characteristics.

Respondent characteristics	Changes in self-reported level of problems with usual activities, EQ-5D-5L score		p-value
	Median (Q1, Q3)	Min, Max	
Education level[1] (n = 140)			
Basic (n = 8)	+1.5 (0.5, 2.0)	0.0, 3.0	0.027
Secondary (n = 63)	+1.0 (0.0, 2.0)	-2.0, 4.0	
Higher (n = 69)	0.0 (0.0, 1.0)	-2.0, 4.0	
Financial situation[2] (n = 149)			0.043
Comfortable (n = 62)	0.0 (0.0, 1.0)	-2.0, 4.0	
Strained (n = 87)	+1.0 (0.0, 2.0)	-4.0, 4.0	

[1]Kruskal-Wallis rank sum test, [2]Wilcoxon rank sum test; The scores reflect the median difference between the EQ5D5L scores for usual activities today versus before symptom onset. A positive change score reflects a higher level of problems performing usual activities at the time of survey completion compared with before symptom onset.

According to interviewed participants, it was a combination of physical and psychological fatigue that made usual daily tasks more demanding. It was noted that, particularly at the start of the treatment, participants often lacked energy to get up, go outside or engage in activities they would normally enjoy. It was challenging to distinguish whether these difficulties stemmed from the disorder itself or from side-effects of treatment, which added further uncertainty to the experience of managing their condition.

> *"And then there's the fatigue, which I find the worst. That's really something I still struggle with. Getting into a regular rhythm, being a little alert, having a little energy. That's what I find most difficult." (N1)[19]*

Participants also talked about difficulties with concentration and orientation affecting their ability to carry out usual activities, explaining that they needed more time to process information and were easily overwhelmed by external stimuli. Problems with sustained attention affected their ability to follow conversations, read or watch media and complete tasks that require mental effort or planning, such as grocery shopping or finding their way. As a result, problems in concentration interfered with both functional performance and emotional involvement in everyday life.

> *"It's possible that I'm so confused that making my shopping list could take me hours. Like, I wouldn't be able to find my pen, I wouldn't be able to find my paper, and by the time I found the pen, I wouldn't be able to find the paper anymore. Then if I suddenly went to the shop like that, my whole budget would be gone in two weeks, and I wouldn't even realise it." (F4)[20]*

> *"Simple things like watching a movie and being able to follow, that's very difficult." (N7)[21]*

> *"I also struggle with finding my way around. Even when I try to navigate in cities I actually know, I get completely mixed up. Even in my hometown, I get the public transport wrong in Brussels. It's really hard to coordinate the transport, taking this bus, then that tram, knowing the stops, all of that… I get lost. Practically every time I go somewhere, I get lost, I'm late, I miss my appointment...." (F3)[22]*

Participants also explained explained that symptoms such as fatigue, cognitive difficulties and episodes of disorganisation and dissociation sometimes made physical activities more stressful, and at times, unsafe. This was particularly evident regarding driving; it was mentioned that driving a car had become increasingly difficult, noting that the possibility of experiencing symptoms such as dissociating or loss of focus while driving posed risks to individuals and their environment.

"I always had to drive to [city] by car, and I realised that it was actually becoming too stressful with all the medication… and also because I sometimes dissociated in the car, that was the last straw." (N14)[23]

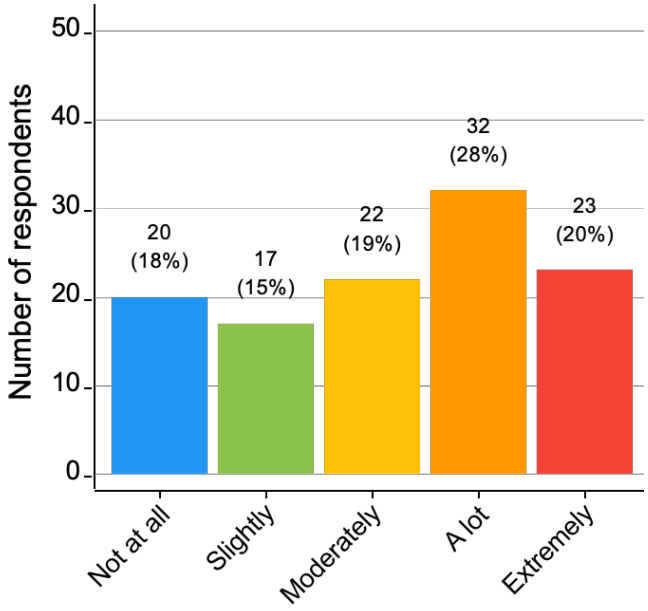
6.2.6 Impact on sexual and reproductive health

The following section reports the results derived from the patient survey, based on respondents' answers to questions: H14 and H15. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

6.2.6.1 Impact on sexual life

The perceived impact that living with a psychotic disorder had on survey respondents' sexual life was high. **Two thirds of respondents** (n =114) **reported the extent of impact to be 'moderate' (19%), 'a lot' (28%), or 'extreme' (20%)** (Figure 16).

Figure 16 – Impact of psychotic disorders on sexual life (n=114)



Exploratory sub-group analysis examined whether the reported impact of psychotic disorders on sexual life differed across respondents' characteristics (Table 11). A statistically significant overall difference in impact was observed according to respondents' financial situation ($p < 0.001$). Descriptively, respondents in a financially strained situation reported a higher median impact score (median: +4.0; IQR: 3.0 – 5.0) than those reporting less difficulty making ends meet (median: +3.0; IQR: 1.0 – 5.0).

No statistically significant overall differences in impact scores were observed by gender, age or education (Appendix 7).

Table 9 – Impact of psychotic disorders on sexual life, according to respondents' financial situation (n = 113)

Characteristics	Financial situation		p-value[1]
	Comfortable n = 48	Strained n = 65	
Median (Q1, Q3)	3.0 (1.0, 4.0)	4.0 (3.0, 5.0)	**<0.001**
Min, Max	1.0, 5.0	1.0, 5.0	

[1]*Wilcoxon rank sum test; A higher median value reflects a greater perceived impact of the psychotic disorder on sexual life.*

The interviews showed that participants' experiences with sexual wellbeing, were primarily shaped by changes in libido. The main problems were related to how participants' level of desire fluctuated over time. For instance, libido could decrease after starting medication, sometimes combined with the effects of stress. However, others noted that their libido could increase during a psychotic episode and then drop again once treatment was initiated.

> *"In my intimate life as well, I also have a lot of problems and dysfunctions, something that just… it doesn't work properly, whether it's with a woman or even on my own." (F3)[24]*

> *"Libido problems, yes. Let's say I'm with a partner, but (...) there's probably a problem with desire as well." (F6)[25]*

> *"My libido is reduced, but during a psychotic episode it increases dramatically. Then you always feel like having sex, but now, thanks to the medication and the fact that I'm slowly getting better, it's actually less, yes." (N1)[26]*

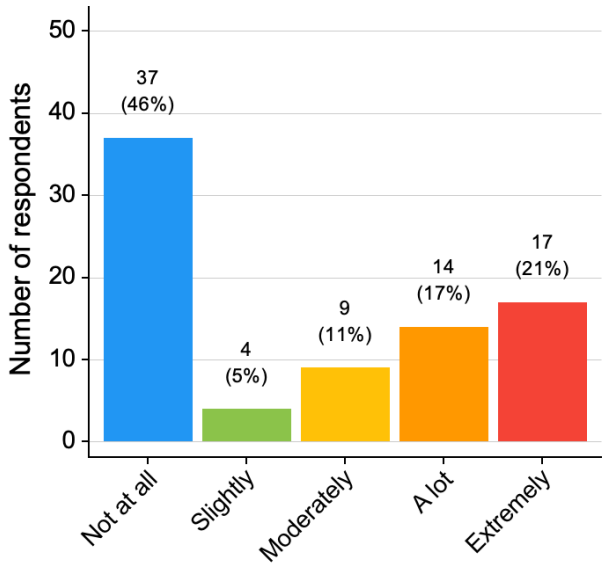
Another interviewee reflected more broadly on how sexual needs and desires were experienced, not only by changes in libido, but also by difficulties in understanding and communicating sexual needs and desires, particularly within relationships. Participants described that psychotic symptoms could blur the distinction between sexual desire and sexual need, complicating how intimacy was experiences and negotiated with a partner. This confusion was described as affecting expectations within relationships and contributing to frustration or unmet need. As one participant explained:

> *"I notice that when it comes to relationships and such, we even forget that intimacy can be a need. I make a distinction between what you desire and what your needs are. But translating desire into a need is actually important. Anyway, a need is something you have to satisfy, while a desire is something that remains open and can remain unfulfilled. But a need cannot remain unfulfilled, and it is that translation from desire to need that is sometimes very difficult, especially in relationships." (N13)[27]*

6.2.6.2 Impact on reproductive life

In total, 54% survey respondents experienced an impact on their reproductive life due to their psychotic disorder(s) had on their reproductive life (Figure 17). **Nearly half of these reported no impact, while one in ten reported the extent of the impact to be 'moderate', 17% 'a lot', and 21% 'extreme'.**

Figure 17 – Impact of psychotic disorder on reproductive life (n=81)



Exploratory sub-group analyses examining whether the reported impact of psychotic disorder on reproductive life differed across respondents' characteristics showed no statistically significant overall difference according to gender, age, education level or financial situation (Appendix 7).

The interviews revealed that participants held a wide range of perspectives regarding parenthood. For some participants, the wish to have children remained intact despite their mental health challenges, while for others, it is a conscious decision not to have children, due to concern about genetic vulnerability or the potential impact of their condition on parenting.

> *"My mother, for example, was also mentally vulnerable. I loved her, but I think that maybe it was better... Yes, I don't know, that's a bit strange to say, actually. I do think my mother was a good mother, but yes... to break that cycle, I think it's better not to have children." (N10)[28]*

> *"When I was young, I really wanted children. But now there's also the question of, OK, suppose the [received diagnosis] is correct. It is hereditary, I've forgotten by what percentage, but it was a significant percentage. That made me wonder, is that a good idea?" (N17)[29]*

In addition, prolonged periods of isolation shaped how participants reflected on the possibility of having children, resulting in the question of parenthood not arising at all.

> *"Let's say I was devastated for about ten years, so I found myself relatively alone during that period. Anyway, I was living with my parents, I had a few friends, but I didn't consider having children. Because the symptoms were very pronounced for 10 years." (F6)[30]*

Among those who did pursue parenthood, the experience was shaped by practical and medical considerations. One participant described how their wish for a child remained strong, but treatment adjustments were needed to manage pregnancy and post-partum risks.

> *"Yes, we always wanted children and yes, at a certain point we decided to go for it. But I had to... I wasn't taking antidepressants or bipolar medication yet, so I had to taper off my [medication name] during pregnancy. But I had to start taking Abilify again immediately after giving birth. I wasn't allowed to breastfeed because the Abilify would have ended up in my breast milk and been passed on to the baby." (N2)[31]*

6.3 Unmet healthcare needs

KEY POINTS

- One in five survey respondents had their first contact psychiatric care within 1-6 months of symptom onset, while around one in 10 reported delays of 6-12 months. Respondents explained that illness insight affected how quickly help was sought, with individuals who had little awareness of their condition often having family or others in their social environment seek help on their behalf.
- A substantial proportion of surveyed patients reported long diagnostic pathways between the first medical appointment and receiving a diagnosis.
- Treatment availability for psychotic disorders in Belgium is considered by clinical experts as having some gaps, mainly in terms of limited reimbursement for key non-pharmacological therapies, shortages of specialised professionals, and insufficient structural funding for early psychosis services and assertive community teams.
- Treatment effectiveness for psychotic disorders is limited because current approaches remain mainly symptomatic rather than disease-modifying. Although combined pharmacological and psychosocial treatments improve quality of life for some, many continue to face ongoing symptoms, difficult side-effect trade-offs, persistent negative and cognitive impairment, and at times treatment resistance.

- Treatment was regarded by experts as having lower effectiveness in patients with multimorbidity or intellectual disability, individuals with substance use, adolescents and older adults, people facing socioeconomic vulnerability, and patients with limited illness awareness.
- Despite recognising the necessity and usefulness of treatment, many participants experienced their treatment as burdensome due to side-effects, which commonly included weight gain, fatigue or drowsiness, emotional blunting, memory problems and sexual dysfunction.
- Beyond side-effects, treatment was also experienced as burdensome or stressful, particularly due to intensive treatment trajectories, and frequent adjustments in medication or dosage.
- Two thirds of patients reported that care was always or often well organised and planned, while nearly half indicated good continuity of care as they always consulted the same healthcare professional.
- Care coordination was considered by patients as challenging, both across inpatient and outpatient settings. Reasons included limited communication, the necessity to repeat their medical history, and differing advice.
- Respondents generally experienced a lack of support transitioning from inpatient to outpatient care, as it often required substantial personal initiative to navigate services and identify appropriate healthcare providers.
- Structural and organisational issues such as fragmented care, inconsistent community support, insufficient specialised healthcare professionals leading to long waiting times, and limited physical health monitoring, were reported by clinical experts as also restricting outcomes, leaving functional recovery and social reintegration uneven.
- Participants described variability in the quality of their relationships with healthcare providers. Positive experiences involved trust and the sense that professionals were empathetic and listened actively, whereas less positive encounters were marked by feeling rushed or perceiving the interactions as impersonal.
- Information needs varied across respondents, with many indicating a need for clearer information on the disorder, treatment rationale and side-effects, as well as longer-term and future-oriented topics including family planning.
- Many participants reported little or no involvement in treatment decisions. While one in four explicitly preferred not to be involved, the majority would have liked to be more involved.
- A considerable share of participants reported having foregone care in the past year. This was primarily attributed to organisational barriers such as waiting times and staff shortages, psychological barriers including fear of medical settings, financial constraints, and practical barriers related to distance and transportation.

6.3.1 Treatment effectiveness

6.3.1.1 Description of treatment use

Exploratory analysis outlines whether self-reported treatment use differed across respondent characteristics. Use of typical antipsychotics differed by gender, with higher proportions reported by men (38%) than women (19%) (p = 0.009). Treatment use also varied by age group for antidepressants and tranquilizers. Respondents aged under 30 years reported higher use of antidepressants (70%) compared with those aged 30–50-year-olds (38%). and >50-year-olds (40%) (p = 0.03). Similarly, tranquilizer use was reported more frequently among respondents aged under 30 years old (70%) than among those between 30-50 years old (42%) and those aged over 50 years (29%) (p = 0.008).

Differences were further observed by educational level for electro convulsion therapy (ECT), with ECT use reported more frequently among respondents with basic education levels (13%) compared to those with secondary (5%) or higher (0%) education levels (p = 0.037). Treatment use also among respondents with schizophrenia (25%) than those with another diagnosis (9%) (p = 0.009), whereas psychotherapy use was higher for the other diagnostic groups (49%) than those with schizophrenia (29%) (p = 0.022).

No overall differences in treatment use were found for time since diagnosis and financial status (Appendix 7).

6.3.1.2 Effectiveness of current overall treatment (standard of care)

In the clinical expert survey, psychiatrists classified treatment effectiveness for psychotic disorders as ‘moderate’, meaning that “with current treatment the disease generally has a good prognosis over time, although some symptoms or complications persist”.

This choice was largely attributed to current **approaches remaining primarily symptomatic** rather than disease-modifying. While antipsychotic medications can prevent relapses and, in that sense, alter the disease trajectory, **no treatments directly modify the underlying vulnerability**. For individuals **with less severe forms** of psychosis, combining psychotherapy, exercise, diet, and medication **can substantially improve quality of life**, yet this does not change the fact that available interventions mainly target symptoms rather than the core mechanisms of the disorder.

A second reason relates to the marked **heterogeneity of psychotic disorders**. Psychosis can manifest along a continuum, from transient and short-lived complaints to persistent and severe impairment. **Some individuals recover completely** and often disappear from mental-health services, whereas others continue to experience enduring symptoms and require ongoing care. For this latter group, **appropriate pharmacological options are not always available**, and achieving an **acceptable balance between symptom control and side effects can be difficult**. Persistent negative symptoms, cognitive impairment, and **treatment resistance** remain major challenges, and, of these, few patients regain their full pre-onset potential.

Structural and organisational factors further contribute to moderate treatment effectiveness. Although antipsychotic medication combined with psychosocial interventions can lead to substantial improvement, real-world outcomes are limited by **fragmented care pathways**, **variability in assertive community support**, and **inconsistent access to structured rehabilitation programmes**. **Long waiting times** for ambulatory care can worsen symptoms before treatment begins, increasing the risk of relapse. Despite reforms aimed at modernising services, indicators of severe distress—such as involuntary committals and emergency visits—have not improved as expected. In addition, physical-health monitoring remains a critical gap. Evidence-based treatments such as **clozapine and long-acting injectables**, which significantly reduce rehospitalisation risk, **are underused** in ordinary clinical practice. As a result, while many patients achieve symptomatic improvement, sustained functional recovery, social reintegration, and optimal physical-health outcomes remain uneven.

Clinical experts identified several **sub-populations** for whom current treatments for psychotic disorders are **only 'somewhat effective' or 'not effective'**.

A first group includes individuals with **treatment-resistant schizophrenia and those with a chronic relapsing–remitting course**. For these patients, treatment may be effective in the acute phase and in relapse prevention, yet many continue to experience recurrent episodes throughout life, even with medication or psychotherapy. Those with treatment-resistant illness face persistent positive symptoms, severe functional impairment, and higher hospitalisation rates. Clozapine remains the only evidence-based option, but even then, many achieve only partial remission, and real-world use is limited by delayed initiation, tolerability issues, and the need for intensive monitoring.

A second group consists of patients with **psychiatric multimorbidity** or **intellectual disability**. These individuals may present with four- or five-fold diagnoses—such as intellectual disability with autism or another neurodevelopmental disorder, severe psychotrauma, or substance misuse. Cognitive limitations and cultural differences make it more difficult to discuss illness severity, achieve adherence, or ensure timely help-seeking. They are often excluded from standard interventions, which are rarely adapted for cognitive challenges, and antipsychotics may carry increased metabolic risks requiring better monitoring. Training gaps among primary-care physicians and specialists' further complicate care.

A third group includes **adolescents and older adults**, who face age-specific barriers. A persistent "transition gap" between child and adult psychiatry disrupts continuity of care, while in older adults' antipsychotics are widely used in nursing homes without adequate monitoring or deprescribing strategies, with ageism sometimes influencing treatment.

A fourth subgroup comprises patients with **comorbid substance use**, particularly cannabis or stimulants. Substance use reduces antipsychotic response, increases relapse and hospitalisation, and undermines adherence. Drug abuse is persistent and a frequent cause of relapse and poor compliance.

A fifth category includes individuals facing **socioeconomic vulnerability**, such as precarious immigrants, non-native speakers, homeless populations, and prison inmates. Language and cultural barriers hinder diagnosis and engagement, while discrimination and financial constraints can lead to unsafe undertreatment. Homelessness and lack of integrated housing, social, and mental-health services create a burden greater than the illness itself. In prisons, limited resources, lack of specialised personnel, and the absence of an integrated forensic psychiatric model result in prolonged incarceration without adequate treatment.

Finally, a sixth group consists of **patients with limited insight**, whose lack of awareness leads to non-compliance. Assertive care may temporarily stabilise symptoms, but this is often not sustained, and repeated relapses progressively worsen prognosis.

Interview findings revealed a nuanced perception as to how individuals with a psychotic disorder perceived the effectiveness of their treatment. Participants described recovery as a gradual and often fragile process, characterised by periods of relative stability but also continuous vulnerabilities. While medication was generally acknowledged as contributing to symptom control, particularly in relation to acute psychotic symptoms such as hallucinations, delusional thinking, and disorganised behaviour its effectiveness was not perceived as complete. Participants described that finding the right medication and dosage was not always straightforward and often involved a period of trial and adjustment. It was emphasised that although medication helped participants regain stability, it did not fully eliminate symptoms or restore functioning to-pre-episode levels.

> *"I know that medication, I have stopped taking it or reduced the dosage in the past. And then after a while I had another psychotic episode, so the medication is effective." (N11)[32]*

> *"I don't find it very effective. No, but well, I think that if I didn't take them, I might be a lot worse… we don't know, but I personally think I don't need the medication, and I think I'd feel much better without treatment. But anyway, that's a completely personal opinion, and it could*

be influenced by the illness itself, and it might not even be true! Maybe it's an illusion and I do need medication! In any case, if I stop from one day to the next, then for sure I'll have a serious relapse." (F3)[33]

"I think my first admission, and treatment plan in the day clinic, followed by further outpatient care, was definitely good. In terms of the treatment itself, I think it was okay." (N1)[34]

Hospitalisation was also interpreted ambivalently. For some, (first) hospital stays were considered traumatic and destabilising due to abrupt routines, limited personalised attention, lack of humanity, or feelings of disorientation. A commonly expressed perspective was that in-patient care was useful mainly for managing acute crises, while long-term recovery required broader psychological support, continuity in (follow-up) care and a stable living environment. Survey respondents also mentioned that being in a psychosis-specific ward was not always easy, as contact with others in acute psychosis could intensify personal symptoms.

"There was really no care at that psychiatric ward in [city]. Just yes, just a lot of medication and they left you to your own devices. So I didn't have a good experience with that. (N11)[35]

"I think the care I received, and all the arrangements afterwards. And especially the admission, which was mixed up with that psychosis, that... I'm actually just traumatized by what I experienced in the institution." (N5)[36]

"So at the hospital, it's still, well, it lacks a bit of humanity, you know? So, well, with my personality, I mean, I get along with everyone, but I still found that the people who were there, because I had seen them walking around quite a bit, so there was a lack of activity. Lock them up like that in a unit where we go round and round, I think there's a way to do better, I know there's a way to do better." (F5, proxy)[37]

Participants also reflected on the follow-up and available psychotherapy. For instance, the support received via community health centres or other mental health settings that offer follow-up support was greatly valued by interviewees, who indicated that consistent and respectable therapeutic relationships with healthcare providers was fundamental in their recovery. However, interviewees did stress the fragmented and inconsistent follow-up, affecting their sense of stability during recovery. More specifically, interviewees highlighted the beneficial effects of having one-on-one conversations with, for example, a therapist or psychologist to openly discuss the challenges they have experienced.

"I see a psychologist (...) every three weeks, in addition to my psychiatrist. And that too has been beneficial, going at my own pace and putting certain things into words, deconstructing certain things..." (F1)[38]

"The sessions with the therapist are... They reduce stress, yes. And that's ultimately the goal, isn't it?" (N12)[39]

Mixed experiences with psychological care over time were reported. One the one hand, negative encounters with initial healthcare services were mentioned, followed by more positive perceptions as participants received more appropriate or supportive care. In contrasts, participants also remained disappointed with the psychological care they had received, citing short and fragmented follow-up contacts that failed to meet their needs. These experiences were described as offering little sense of progress or meaningful support and, in some cases, led to discouragement and discontinuation of treatment.

"I've had psychological follow-ups from time to time, yes, but they never really worked, they never helped much, so I stopped, or I went to see someone else. But it was always these short follow-ups, ten sessions or so, and I never got anything out of them (…) they never really managed to help me, and that's why (…) I was the one who ended it… because it was pointless, and when it's pointless you're not going to keep paying sixty euros every week for things that aren't useful." (F3)[40]

Participants emphasised the importance of finding a psychologist who aligned with their personal needs and preferred approach to therapy. They described how a sense of compatibility was essential for building trust and experiencing genuine support.

> *"I really found the psychologist who suits me perfectly because we discuss clinical psychology, (...) which is a very down-to-earth approach. But she is also a spiritual person, so she is someone with whom I can discuss these topics. And that's something I was missing in my previous network." (F2)[41]*

Peer support was not taken up by everyone, but among the interviewees who did, it was consistently described as highly meaningful and effective, especially when combined with medication and professional therapy. Speaking with individuals who had lived through similar experiences provided understanding, validation and hope. These were elements that participants sometimes felt were missing in formal care. Peer interactions helped some participants make sense of their experiences and could reduce feelings of isolation or shame. For others, peer groups or buddy support systems offered a sense of belonging and a safe environment to share doubts and fears.

> *"I joined a support group that organises discussions, and that really helped me break out of my isolation. Because I realise that "okay, psychosis is something very special to experience," and even my best friends, you can't explain what that is. You can't explain what it does to you either. You can talk about the heaviness of it for a while, but at the end of the day, everyone has their own problems, and I felt that I needed more support, so that helped me to recover a little, to find the words and regain some of the strength to face it." (N3)[42]*

6.3.2 Burden of treatment

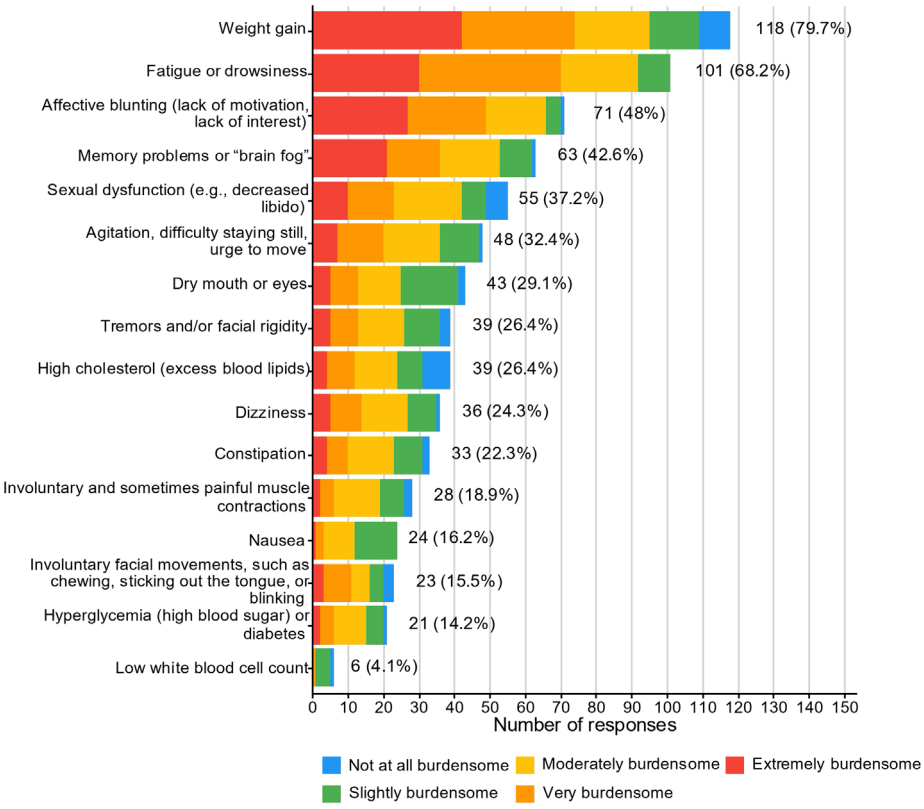
The following section reports the results derived from the patient survey, based on respondents' answers to questions: HC4, HC4B, HC5 and HC6. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

6.3.2.1 Experienced burden of treatment side-effects

Results showed that participants experienced various treatment-related side effects over the past 5 years (Figure 18). **Among respondents, weight gain (80%) and fatigue or drowsiness (68%) were the most frequently reported treatment side-effects and perceived as among the most burdensome. For instance, weight gain was mostly considered extremely (36%) burdensome, very (27%), or moderately (18%) burdensome. For fatigue or drowsiness, most respondents experienced this to be extremely (30%), very (40%) or moderately (22%) burdensome.**

Other commonly reported side effects included affective blunting (48%), memory problems or "brain fog" (43%), and sexual dysfunction (37%). For affective blunting, respondents mostly experienced the level of burden as extremely (38%), very (31%) or moderately (24%) burdensome. Memory problems or brain fog were similarly distributed, with most respondents indicating these to be extremely (33%), very (24%) or moderately (27%) burdensome. Finally, sexual dysfunction was considered moderately (35%), very (24%), or extremely (18%) bothersome by respondents.

Figure 18 – Presence and severity of treatment-related side effects reported by respondents, ordered by prevalence (n=148)



Exploratory sub-group analyses revealed no statistically significant overall differences between the prevalence of treatment related side effects and gender, age, or time since diagnosis ($p > 0.05$) (Appendix 7).

Differences in the reported burden of treatment-related side-effects across respondent's characteristics are presented in Appendix 7. Variations in perceived burden were observed by gender for weight gain $p = 0.030$). Women reported weight gain more frequently as extremely burdensome (42%) or very burdensome (28%) compared to men (27% vs 23%, respectively). Moreover, the side-effect of dry mouth or eyes was more frequently reported by men as extremely burdensome (15%) or very burdensome (25%) than for women (9.5% each) ($p = 0.039$).

Next to that, differences were also observed across age groups for fatigue or drowsiness ($p = 0.017$). Respondents aged younger than 30 years old more frequently reported this as extremely burdensome (59%) compared with those aged 30-50 years old (27%) and older than 50 years (18%).

In addition, respondents with financial difficulty more frequently rated several treatment-related symptoms as extremely or very highly burdensome compared with those reporting less financial difficulty. This pattern was observed for weight gain (44%; 30% vs 25%; 23%), fatigue or drowsiness (37%; 42% vs 18%; 35%), memory problems or brain fog (43%; 30% vs 14%; 14%), and involuntary facial movements (13%; 47% vs 0%; 14%). No overall differences were found for time since diagnosis, education level, and diagnostic group (Appendix 7).

Interview findings showed that particularly weight gain, fatigue and drowsiness, emotional blunting, and cognitive decline weighed most heavily on participants' daily functioning and well-being.

Weight gain was frequently described as one of the most distressing effects of medication, affecting self-image, confidence, and motivation. Several participants reported gaining weight rapidly or unexpectedly, often expressing a sense of losing control over their body. Others described the

psychological impact of these changes, noting that weight gain compounded the emotional challenges of recovery:

> *"I weigh a lot more than I should according to my BMI. And yes, that does determine, well, yes, that is indirectly a consequence of my psychotic problems. And that does determine my life at the moment. Well, yes, I am a little more insecure about my appearance and so on, and yes. If you can describe that as decisive, then yes, it does determine my life." (N2)[43]*

> *"My weight gain, this binge-eating. I stuffed myself until my gut felt like it was going to burst. I couldn't control it anymore, for god's sake. I've never lost control of my own behaviour like that in my entire life. Never. I was shoving food in and I could feel my stomach cracking, like there was no space left, and I still couldn't stop putting things in my mouth and swallowing them. What the hell is this?" (F4)[44]*

Moreover, this side effect could also impact participants' therapy adherence, as one participant mentioned:

> *"At one point, I weighed 87 kg. Every time I went to the doctor, it was the same old story, which eventually led me not to take my medication properly, and then it flared up again because my self-image took a dive." (N6)[45]*

Fatigue and drowsiness were also prominent burdens, often experienced as an overwhelming physical and mental exhaustion that limited activity levels, motivation, and daily routines. Participants spoke of struggling to initiate tasks or maintain energy throughout the day.

> *"It makes you feel tired, dead tired. Your motivation decreases. For example, I can sit on the couch all morning doing nothing." (N6)[46]*

Emotional blunting further contributed to the burden of treatment. Participants described feeling emotionally muted or disconnected, as though their natural emotional range had been significantly reduced. This often left individuals feeling less engaged in daily life, affecting social interactions, motivation, and overall quality of life. In addition, participants reported that the realisation of being vulnerable for the rest of their lives, was difficult to accept.

> *"My thinking is becoming dulled. My emotions are becoming dulled." (N12)[47]*

> *"The difficulty of the whole thing is that I will remain vulnerable for the rest of my life. And that I will never get rid of it. Well, that bothers me." (N12) [48]*

Finally, participants reported substantial cognitive difficulties, such as slower processing, reduced concentration, impaired memory, or difficulty following conversations or films. These changes made routine tasks more effortful and sometimes undermined confidence in social or professional contexts. For some, this cognitive slowing interacted with fatigue and emotional blunting, reducing mental sharpness and functional capacity within the professional context.

> *"Things are starting to get better now, but I... I still remain someone at some point, I forgot everything. I forgot everything, it was so bad. I mean, it ruined my daily life. ... someone would tell me something, I wouldn't remember, and it got to the point where, just as an example, a friend told me that his father, who was very ill, had died on Tuesday, and on Saturday I asked him how his father was doing. I mean, it got that bad." (F2)[49]*

> *"And then I became stupid. I couldn't think straight anymore, I couldn't reason properly, I couldn't make judgments, and I couldn't interact with people anymore. So I just endured it. I was 50% disabled [because of my psychotic disorders], and then I became 300% disabled [because of the medication]." (F4)[50]*

Differences in prevalence of self-reported treatment-related side effects were observed according to respondents' level of involvement in treatment decision-making (Table 11). Across several side-

effects, respondents who reported not being involved in treatment decisions consistently reported higher prevalence than those who felt involved.

In particular, agitation or restlessness, dry mouth/eyes, tremors or facial rigidity, constipation and involuntary facial movements were reported by substantially more respondents who were not involved in treatment decisions, with prevalence rates often close to twice those by respondents who felt involved. Corresponding percentages and p-values are provided in Table 11.

The topic of treatment involvement is further discussed in section 6.3.3.3.

Table 10 – Frequency of self-reported treatment-related side effects, by involvement in treatment decisions (n = 130)

Treatment-related side effects	Involvement in treatment decision-making		p-value[1]
	Yes n = 95	**No** n = 35	
Weight gain	80 (84%)	27 (77%)	0.3
Fatigue or drowsiness	65 (68%)	24 (69%)	> 0.9
Affective bunting (lack of motivation, lack of interest)	46 (48%)	20 (57%)	0.4
Memory problems or "brain fog"	45 (47%)	16 (46%)	0.9
Sexual dysfunction (e.g., decreased libido)	38 (40%)	13 (37%)	0.8
Agitation, difficulty staying still, urge to move	26 (26%)	17 (49%)	**0.016***
Dry mouth or eyes	24 (25%)	17 (49%)	**0.011***
High cholesterol (excess blood lipids)	29 (31%)	9 (26%)	0.2
Tremors and/or facial rigidity	21 (22%)	14 (40%)	**0.041***
Dizziness	23 (24%)	10 (29%)	0.6
Constipation	18 (19%)	13 (37%)	**0.031***
Involuntary and sometimes painful muscle contractions	15 (16%)	10 (29%)	0.10
Nausea	15 (16%)	9 (26%)	0.2
Involuntary facial movements, such as chewing, sticking out the tongue, or blinking	11 (12%)	10 (29%)	**0.020***
Hyperglycaemia (high blood sugar or diabetes)	17 (18%)	3 (9%)	0.2
Low white blood cell count	3 (3%)	4 (11%)	0.084

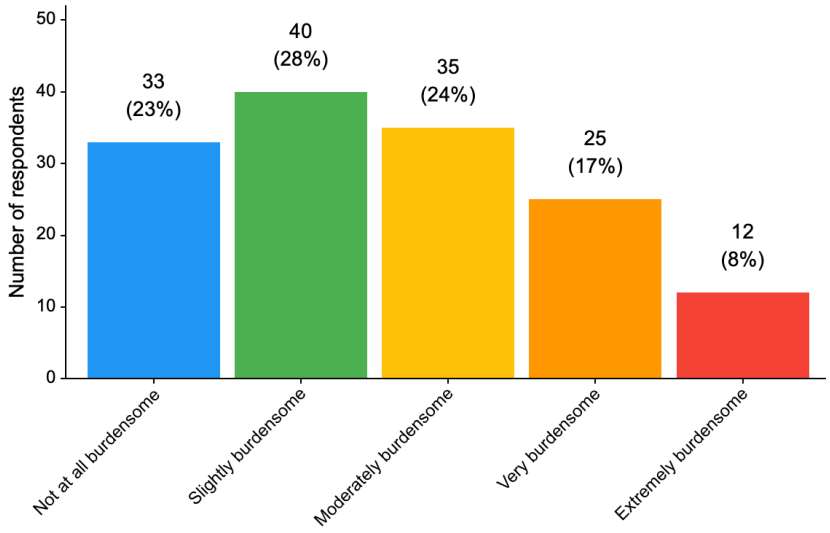
*[1]Pearson's Chi-squared test; Fisher's exact test; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

It should also be noted that there may be some overlap between the symptoms of the disease, those of associated comorbidities, and potential treatment-related side effects. In order to minimize confusion as much as possible during the survey, we provided a predefined list of symptoms and potential side effects.

6.3.2.2 Experienced burden of treatment

More than half of respondents reported experiencing treatment burden beyond treatment side effects (Figure 19). **Nearly 1 in 5 considered the treatment to be 'moderately burdensome' (24%), whilst 17% indicated this to be 'very burdensome'. A smaller proportion (8%) reported the treatment to be 'extremely burdensome'.**

Figure 19 – Experienced treatment burden other than treatment side effects (n=144).



Exploratory subgroup analyses observed a difference between respondents' treatment burden other than treatment side effects and their financial situation (Table 12) ($p > 0.001$). Respondents with a strained financial situation were substantially more likely to report high levels of burden. Specifically, 39% of financially strained individuals described the burden as *very* or *extremely* burdensome, compared with only 8.3% among those who were financially comfortable. Conversely, respondents who were financially comfortable were more likely to report low or no burden: one-third (33%) reported the situation as *not at all burdensome*, compared with only 15% of those in a strained financial situation. Overall, financial strain appears to be associated with a markedly higher perceived burden. No differences were observed for other respondent characteristics including time since diagnosis, gender, education level, diagnostic group or age (Appendix 7).

Table 11 – Experienced treatment burden other than treatment side-effects, according to respondents' financial situation (n=142)

Characteristics	Financial situation		p-value[1]
	Comfortable n = 60	Strained n = 82	
Extremely burdensome	2 (3.3%)	10 (12%)	<0.001
Very burdensome	3 (5.0%)	22 (27%)	
Moderately burdensome	18 (30%)	17 (21%)	
Slightly burdensome	17 (28%)	21 (26%)	
Not at all burdensome	20 (33%)	12 (15%)	

[1]*Wilcoxon rank sum test.*

Across interviews, participants described a substantial burden associated with the different treatments they received. For instance, medication, whether taken orally or through long-acting injections, was most frequently cited as burdensome. The burden of treatment was also linked to medication management itself. For example, a proxy participant highlighted that finding the right medication and dosage took quite some time:

> *"So over five years, the medication has changed very, very often. So, at one point, they tried to reduce the neuroleptic, and then each time there was a manifestation of behavioural disorder. Eventually, I didn't like the behavioural disorder at a given moment. Well, "he was a little more himself", so in opposition." (F5, proxy)[51]*

Moreover, adjusting dosages, and maintaining adherence created additional stress, particularly when side effects were unpredictable or intensified during dose changes. These experiences sometimes led participants to refuse treatment or proposed medication changes and contributed to reduced trust in the treating physician.

> *"Then, after trying all kinds of medication, at some point you end up with swollen feet and legs and splitting headaches. I said, look, I'm not taking that anymore, which means that eventually you end up resisting the psychiatrist because you simply don't trust them anymore." (N6)[52]*

A further source of burden came from the accumulation of multiple treatments and appointments. Participants that were already further advanced in their recovery explained that attending frequent psychotherapy sessions, medication follow-up consultations, and other therapeutic appointments, while considered effective, could sometimes be overwhelming. The mental load of keeping track of different professionals, schedules, and therapeutic expectations was described as demanding. Also the perceived benefit of psychotherapy was strongly influenced by the continuity and quality of the therapeutic relationship; long waiting times, or short, infrequent sessions reduced its effectiveness and added frustration. One person noted that after a long therapeutic trajectory, there could also be a sense of reaching saturation, describing a feeling as though their story had been told repeatedly and that continuing to revisit the same narrative became emotionally exhausting. This participant reflected on the inner conflict between wanting to move forward and still being expected to engage in therapy, highlighting how this tension could become burdensome over time.

> *Yes, I sometimes feel like I've just run out of things to say or something. For example, at (organisation), I sometimes feel like we've known each other for so long and they've been with me through the whole process, seeing each other two or three times a week, you know everything that's happened. And sometimes I feel a kind of shame or guilt about still talking about it. Because I think, 'you already know that and I've already said it.'" (N4)[53]*

6.3.3 Quality of care

The following sections report the results derived from the patient survey, based on respondents' answers to questions: HC1 and HC7 until HC11 (see Appendix 1). In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

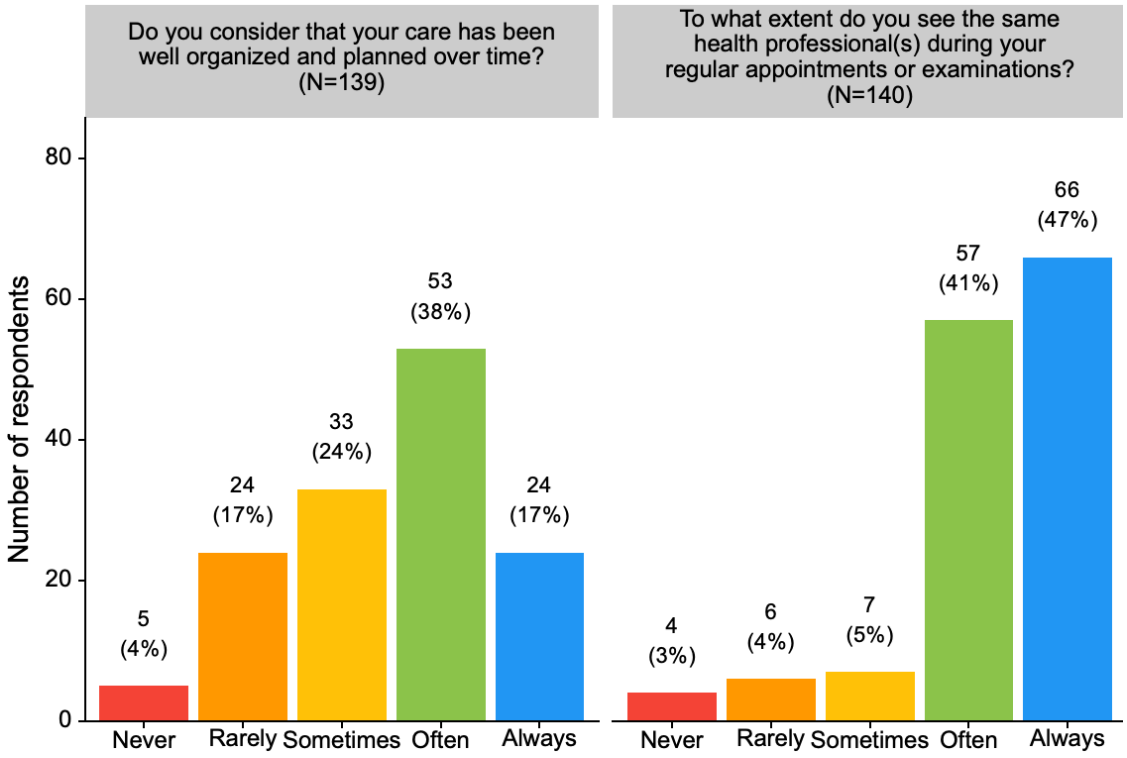
6.3.3.1 Coordination and continuity of care

Figure 20 presents respondents' experiences with care organisation (left) and continuity of care by recurrence of the same healthcare professional (right).

Results indicated that coordination and organisation and planning of care were variable. A substantial proportion of respondents reported that **care organisation and planning were 'always' (17%) or 'often' (38%) well organised, together accounting for nearly two thirds of responses. Further, 24% indicated that care organisation occurred 'sometimes'. In contrast, 17% described their care as 'rarely' organised and only 4% reported 'never' receiving organised care.**

The level of care continuity (i.e., seeing the same healthcare professional during regular visits) was remarkably higher than care organisation. **Almost half of respondents (47%) reported 'always' seeing same the healthcare provider, and an additional 41% reported that this happened 'often'. Only smaller proportions reported 'sometimes' (5%), 'rarely' (4%), or 'never' (3%) seeing the same healthcare provider.**

Figure 20 – Respondents' experience with the organisation and continuity of care



Exploratory sub-group analysis did not indicate overall differences in respondents' experiences of care organisation or continuity across regions of residence (Appendix 7). Similarly, no differences were observed between experiences of care organisation or continuity and respondent characteristics such as gender, age, education level, and finical situation (Appendix 7).

In the interviews, participants' perspectives on the quality of care widely varied, but several consistent themes emerged. A central issue was the lack of coordination across care settings. Participants described frequent transitions between professionals, moving from crisis units to outpatient psychiatrists and re-hospitalisations in different centres. These were perceived to be burdensome, especially since there was a general lack of adequate communication between them, resulting in repeated explanations of their medical history, contradictory advice, or delays in support.

> *"Psychiatrists who do not consult with each other about which medications are effective and which are not." (N6)[54]*

> *"The healthcare landscape is, um, far too fragmented. I have a psychiatrist here, a general practitioner there, and a, um, and there, and there is no cooperation between all these institutions." (N7)[55]*

Participants also reported variability in the quality of relationships with care providers. Positive experiences were characterised by trust, empathy, active listening, and clear explanations. However, many described interactions that felt rushed, impersonal, or insufficiently aligned to their needs.

> *"I sometimes feel that so much time is spent on administration… that they actually lose touch with people a little bit, the real connection with people and that there are so many people that they can't really work with anyone, and just a little bit with everyone." (N4)[56]*

Another theme was the degree of self-management required once individuals left hospital care. Participants described a system in which they needed to take considerable personal initiative to

navigate available services, identify suitable healthcare providers, schedule follow-up appointments, and advocate for themselves. Few tools, guidance mechanisms, or structured pathways were offered to support this transition from inpatient to outpatient care. As a result, patients felt left on their own at a vulnerable moment, unsure where to turn or which services to contact.

> *"Then the follow-up just disappears and you just have a psychiatrist, but that's really only for the medication. You can discuss something once, but that's far too short. So, if you want further help, you have to figure it out on your own, that's my impression." (N10)[57]*

> *"To find out the procedures, to find out who to contact, to find out where to go, to find out how to do it. Yes, I had problems with all of that." (F3)[58]*

> *"Well, for me anyway, when I'm in crisis, I'm not always in a state where I can ask for help… for example, the mental-health service I go to — from one day to the next, I just stopped going. Not a single person called me to ask what was going on or anything. I realise you have to go and chase things yourself. Erm… I think home-based follow-up is really extremely good. But except for the mobile emergency teams which, like I told you, the last two times weren't even accessible to me… (F2)[59]*

> *"I don't have a real appointment now either. I have to make an appointment myself if I want one. Um, but yes, I get the impression that they give medication and then just let things take their course, at least as far as my care is concerned, I think." (N10)[60]*

Despite these challenges, participants emphasised that strong therapeutic relationships, timely follow-up, and personalised care could substantially improve their experiences. Home-based care was also described as particularly supportive, as it allowed care to be delivered in a familiar environment. Overall, the interviews paint a picture of a system where quality varies strongly, with significant room for improvement in coordination, communication, information provision, and shared decision-making (Box 1).

Box 1 – Opportunities for improvement and proposals suggested by participants to enhance the coordination and continuity of care

"The hierarchical model needs to be abandoned. For example, open dialogue discussions should be possible. If this has been started at home, it should be able to continue in the hospital, and hospital staff should also participate in this. It shouldn't be a case of 'yes, but that started at home, we're not involved in that anymore'." (N6)[61]

"The healthcare landscape is, um, far too fragmented. I have a psychiatrist here, a general practitioner there, and a, um, and there is no cooperation between all these agencies." (N7)[62]

"Provide enough people to support and listen to people and draw up a concrete plan for people with psychotic vulnerability. That needs to be responded to in such and such a way." (N12)[63]

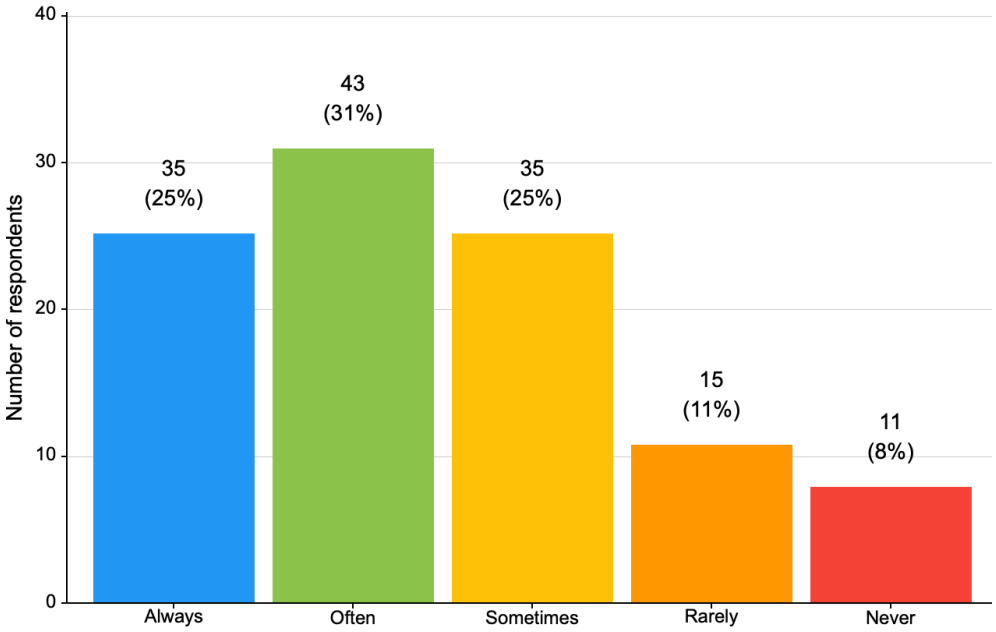
"Someone who really, yes, really one-on-one. Not just in a group, if it's your first time. Later on, it doesn't matter anymore. But your first time, if you've never had any symptoms before and you're new to this, you go to the general practitioner and that general practitioner can clearly see that this is a psychosis. Then you need to be able to receive one-on-one support, not just be thrown into a group." (N18)[64]

You help me organise my time, you help me organise... you help me with everything, and I want a human being who is... who helps me, and that's it! I want human beings who help me with love, I don't need anything else, and besides, I don't think there are many of them, I haven't seen any." (F4)[65]

6.3.3.2 *Received information*

Figure 21 summarises respondents' experiences with both the quality and quantity of the information they received from healthcare professionals. **More than half of respondents reported receiving sufficient clear and understandable information either 'often' (31%) or 'always' (25%). However, 44% of respondents indicated this to be the case only 'sometimes' (25%), 'rarely' (11%) or 'never' (8%).** These findings suggest variability in how consistently information needs were met.

Figure 21 – Extent to which respondents received sufficient useful and understandable information (n = 139)



Exploratory sub-group analysis examined whether respondents' satisfaction with the information received varied across individual characteristic (Table 15). Differences were observed according to respondents' financial situation (p = 0.037). Descriptively, respondents reporting more financial strain had a higher median satisfaction score (median: 2.5; IQR: 2.0 – 3.0) than those reporting a more comfortable situation (median: 2.0; IQR: 1.0 – 3.0).

No differences were observed across geographical region, gender, age, and education level (Appendix 7).

Table 12 – Extent to which respondents received sufficient useful and understandable information, by financial situation (n = 136).

Characteristics	Financial situation		p-value[1]
	Comfortable n = 58	Strained n = 78	**0.037**
Median (Q1, Q3)	2.0 (1.0, 3.0)	2.5 (2.0, 3.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test; Higher median values indicate higher levels of satisfaction with the information received.*

Across interviews, information provision was described as a critical yet often insufficient, contrasting with survey results indicating that information was usually adequate. Participants reported limited explanations about their disorder, treatment rationale, side-effects, and long-term expectations, particularly in the early stages, leading to confusion and uncertainty. Survey

respondents also expressed unmet needs regarding information about long-term aspects of the disease, including guidance on future-oriented topics such as family-planning choices. In addition, they reported that they had no way to consult their own patient dossier, which further restricted their ability to understand their treatment and participate actively in decisions about their care. This communication gap persistent during acute episodes and care transitions, where information about medication changes and follow-up was often inconsistent.

> *"I wasn't given enough information. So, at some point they told me, yes, you have psychosis or you are experiencing psychosis. But what exactly is that? They didn't explain that to me. They didn't explain to me that I would be susceptible to it for the rest of my life." (N12)[66]*

> *"Oh, no information at all — I wasn't informed in the slightest. And honestly, I still don't understand much about any medication. I've changed medication loads of times, and I've never had any information about the products I was taking! So when I read the leaflet a bit, well obviously I nearly had a heart attack, practically. But when I talked about it with the psychiatrists, they start getting annoyed, saying, 'Yeah, but you always come back with the side effects, with this and that, you're not supposed to read the leaflets, they're not meant to be read!' Well, I wonder why they make them then! So no, at that point I had really incomplete information — actually, I'll say it: I didn't get any information, none at all." (F3)[67]*

> *"So when they give someone medication, they should also explain why they are doing so. I mean at the beginning, when we are first admitted or something. You don't know what's happening to you when you are admitted with psychosis for the first time." (N8)[68]*

> *"I wasn't informed that the medication would cause me to gain weight. That ultimately created a new problem, because I have a history of eating disorders and that was just normal. To this day, I still struggle with that, so I find it difficult." (N4)[69]*

At the same time, participants recognised that during an acute crisis, even well-intentioned information was often not be retained or accepted. Limited awareness of their condition, combined with mistrust or disbelief during psychotic episodes, made it difficult to understand or retain explanations provided by clinicians.

> *"That understanding of the disease only came later, as I just said, even though it had already been explained to me. I didn't believe it. I thought, no, it's different for me, and I have it under control. And I wanted to turn it into a positive story for myself first, and in the meantime, I've managed to do that. But at the time, that really wasn't an option." (N17)[70]*

Participants mentioned that their context (e.g. living environment, social network, …) should be more involved in their care trajectory, and that their social environment should also receive the necessary information about the disease and treatment. This was further confirmed, as one participant expressed their appreciation after an organised network meeting with their friends and family.

> *"Context, it is so important to take context into account. And not just the context at home; my network consists mainly of my friends, who have helped me cope with this. Because at home, they don't know how to deal with it." (N6)[71]*

> *"At the end of the process, they [the health care personnel during hospitalisation] also organised a network meeting with my best friends and family. And then we actually talked about what it's like to have psychosis and how we can best deal with it and so on." (N11)[72]*

> *"That was certainly communicated to my partner; the word 'psychosis' was used with my partner, but not with the rest of the family. Not with my parents, not with other people, and also not with regard to the medication I was receiving at the time and its side effects. Because that's what went wrong during my admission to (city)." (N1)[73]*

Participants suggested a couple of implementable action points to improve communication and information. For example, providing brochures or written guidance at the time of diagnosis or admission, as well as incorporating psychoeducation on mental health into the school curricula to promote earlier recognition and help-seeking (Box 2).

Box 2 – Participants' opportunities and proposals for receiving information

"At the doctor's office and in the waiting room, you see very little documentation about mental health. Why is that? There could easily be brochures there: what is schizophrenia, what is borderline personality disorder? Why aren't there any? There's all kinds of information about skin creams, acne, the flu, but what about mental well-being? I find it incomprehensible that this is still not the case today." (N6)[74]

"The only thing I do blame them for is that they didn't even give the family a brochure or something about what was wrong with me. So I think they could have at least done that." (N1)[75]

"Now, if, for example, at school, I know, if during biology or something like that, in addition to sex education, they also taught mental health education or something like that, then it would have been much more logical to make that connection. Yes, and then I might have acted on it sooner or been able to see that things were going wrong and that I actually needed to seek help before it got out of hand." (N17)[76]

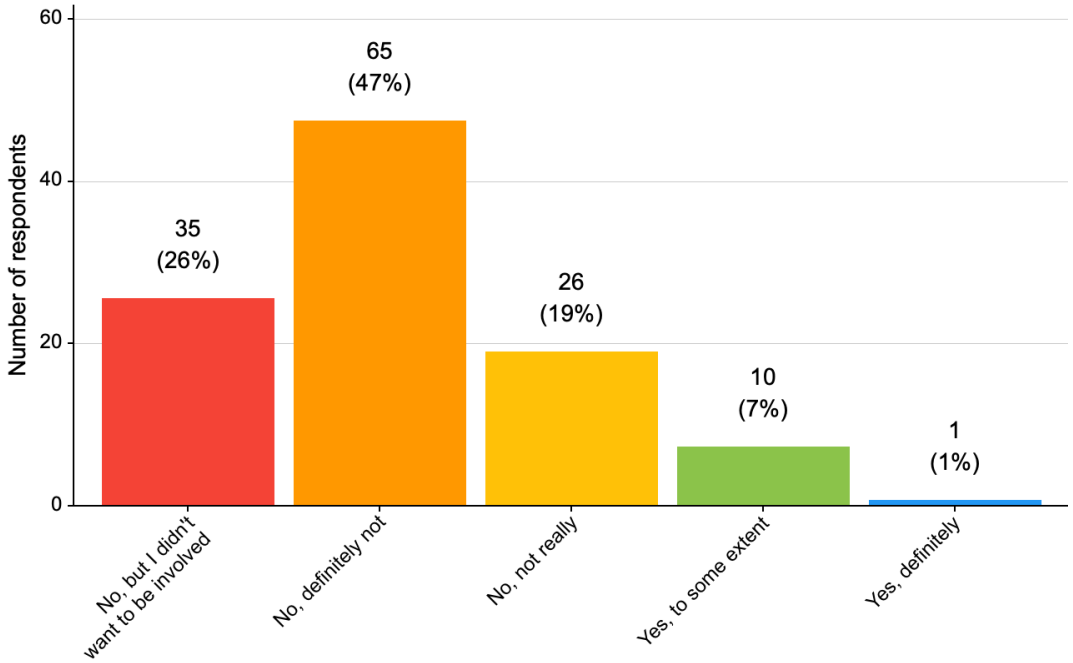
6.3.3.3 Involvement in treatment decisions

Figure 22 presents respondents' level of involvement as much as would like to be in treatment decision-making.

Nearly two-thirds of respondents reported no participation in treatment decisions with 47% indicating 'no, definitely not' and 19% 'no, not really' being involved as much as would like to be.

However, a quarter expressed that non-involvement aligned with their preferences (26%). In contrast, participation in treatment decision-making as much as would like to be, was 'rare', with only 7% and 1% reporting involvement 'to some extent' or 'yes, definitely', respectively.

Figure 22 – Level of involvement in treatment choice as much as would like (n = 137)



No differences were observed between the reported level of involvement in treatment choice and any of the respondent characteristics examined, including geographical region, gender, age, education level, or financial situation (Appendix 7).

Qualitative findings showed that patient involvement in treatment decisions varied substantially across the course of illness, with particularly limited participation during acute phases. At the time of crisis, medication was often administered under coercive circumstances, leaving little room for discussion or choice. In these moments, patients reported having minimal clinical insight and strongly opposing treatment, which further reduced the feasibility of shared decision-making. Notably, one participant described feeling threatened by their psychiatrist with the administration of medication they did not want, highlighting the intensity of perceived coercion in some treatment encounters.

> *"Yes, that team decided, that's how it was, and you may have been informed about it, but you had little to say in the matter." (N2)[77]*

> *"And then at some point I said, look, I'm not taking that anymore, and my psychiatrist threatened me and he did it, he said I'm going to give you injections, I'll come to your house to give you injections, which made me feel really trapped, like I was stuck between a rock and a hard place, I had no say in the matter." (N6)[78]*

As patients stabilised, experiences with involvement became more diverse. Decisions about medication changes were discussed between the clinicians and the patients, with patients following recommendations without fully understanding or questioning them. Or treatment adjustments, such as dose reductions or transitions from depot injections to oral medication were discussed jointly and tailored to the patient's evolving needs.

> *"So I wanted to taper off together with the psychiatrist who agreed to taper off. And so I first had a depot, I don't know why. That was the psychiatrist's suggestion, and I actually followed it blindly, I must say." (N10)[79]*

> *"After a few productive conversations with the psychiatrist who has known me for years, we decided that it could actually be reduced quite quickly, because my issues now have a completely different background or context than before. Yes, they are special events, but I don't think that's so important right now. So I can taper off very quickly. I'm already back on 10 mg, and the idea is to go down to 5 mg after two weeks, if all goes well. And if things are still going well after two weeks, then to nothing." (N17)[80]*

6.3.3.4 Time from first symptoms to diagnosis

Interview findings revealed that the first psychotic episode was mostly experienced as a loss of connection with reality, describing sensations of living *"in a film"* or *"in a dream,"* and struggling to discern what was real from what wasn't. Moreover, participants mentioned vivid examples of delusional ideas, associative thinking, conspiracy-like interpretations, or what some described as *"otherworldly experiences."*

> *"It is essentially a form of detachment from reality, which no longer aligns with the reality as perceived by other individuals. So, you are convinced that your reality is accurate, while the reality perceived by others is actually quite different." (N10)[81]*

> *"Yes, it's more like your senses start interpreting things in your environment differently, for example certain messages that aren't actually there, causing you to live in a kind of alternate reality. Because your perceptions are wrong, the things you think are wrong, and you can no longer trust yourself." (N16)[82]*

Early manifestations did not initially feel like signs of an illness. Participants described subtle or ambiguous changes such as disturbed sleep, social withdrawal, escalating anxiety, unusual thoughts, which were frequently normalised or attributed to external factors such as fatigue, work

pressure, interpersonal difficulties, substance use, or spiritual explanations. Therefore, the formal diagnosis was commonly delayed due to the late recognition of their symptoms, with individuals receiving a definitive classification only after multiple episodes or prolonged deterioration.

> *"It's hard to say what the first signs were, but in any case, what led to the hospitalisation was initially a disappearance and completely inappropriate behaviour in public." (F5, proxy)[83]*

> *"The diagnosis was only made after my second psychosis because I had suffered from depression in between, and they actually said that it was kind of related to that. The actual diagnosis of schizoaffective disorder took at least two years. (N9)[84]*

The time between the onset of first symptoms and first psychiatric contact varied widely across participants. While some eventually sought help when symptoms became frightening or disruptive, others described delays lasting months or even years. These longer delays were linked to difficulties recognising the problem or minimizing symptoms, contributing to prolonged periods without formal support.

> *"The first outbreak was when I was 18 years old, during my puberty. I was still in school at the time. And that was the most serious experience I've ever had. And then it only lasted a few days and then I quickly ended up in a psychiatric ward." (N7)[85]*

> *"Suppose I started experiencing psychotic things, for example, around November or December. But the moment I called the GP and said, 'This is really getting out of hand,' was in August or September." (N4)[86]*

The illness awareness generally developed only later in their trajectory, often after repeated episodes of psychosis, starting treatment, and personal reflections. As participants gained a clearer understanding of their condition over time, they reflected on the broader implications of their psychotic disorder for their daily functioning and well-being. While many described a sense of relative stability in their current situation, they also emphasised that the disorder had left a lasting imprint on their lives. Acceptance of their diagnosis was portrayed as a gradual and emotionally demanding process, requiring patience, adjustment, and personal reflection.

Interview participants described that their psychotic disorders developed in the context of cumulative or acute stressors including childhood trauma, sleep disturbance, and major emotional events.

> *"And you have problems that stem from trauma; you experienced things in your childhood and youth that caused you to become psychotic." (N11)[87]*

> *"It is triggered by stress, but overwhelming stress." (N12)[88]*

> *"The only thing I think I take into account anyway is that I get enough sleep and have a good rhythm. Because yes, lack of sleep can be a trigger, or it can kind of contribute to it." (N16)[89]*

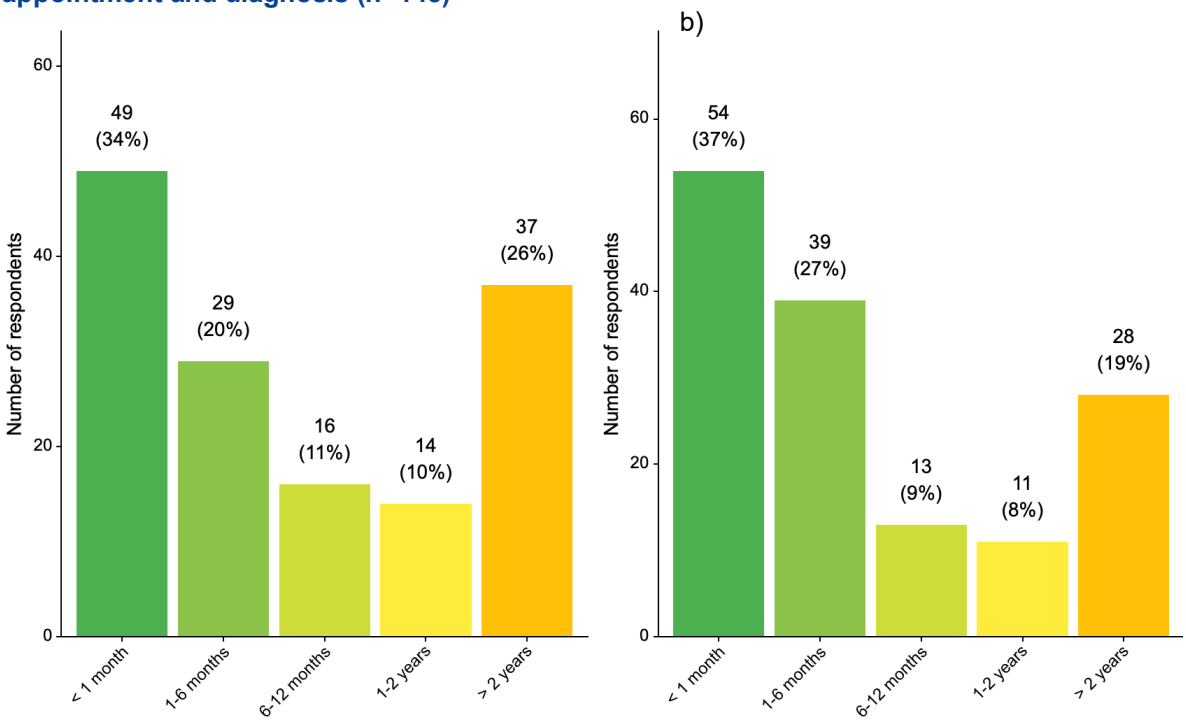
> *"In 2013, I got divorced, and the emotional shock of the divorce plunged me into a terrible crisis that lasted for months." (F2)[90]*

Figure 23 presents the reported time intervals between (a) the onset of first psychotic symptoms and the first contact with a psychiatrist, and (b) the first medical appointment and the formal diagnosis (n = 145).

Although a third of respondents reached a psychiatrist relatively quickly (i.e., less than a month) after the onset of psychotic symptoms (34%), delays were common. One in five respondents had a first psychiatric contact 1 to 6 months after symptoms onset. One in ten saw a psychiatrist only after 6 to 12 months, and the same proportion after 1 to 2 years. Moreover, one in four reported the first psychiatric contact only after two years.

A similar pattern was measured when examining the time between the first medical appointment and receiving a diagnosis. **While 37% received a diagnosis within the first month, many respondents experienced prolonged diagnostic pathways: 27% waited between 1 and 6 months, 9% between 6 and 12 months, and 7% between 1 and 2 years. Moreover, nearly one in five (19%) experienced a diagnostic delay of more than two years.**

Figure 23 – Timing between a) first symptoms and first psychiatric contact, b) first medical appointment and diagnosis (n=145)



Sub-group analysis examined differences in timing between onset of first psychotic symptoms and first contact with psychiatric care across regions of residence (n=145). Differences in the distribution of reported delays were observed across Flanders, Brussels, and Wallonia (p = 0.007) (Table 15). Respondents living in Flanders more frequently reported shorter delays, with 46% indicating a delay of one month, compared with 13% in Brussels and 23% in Wallonia.

Longer delays (>2 years) were more common in Brussels (46%) and Wallonia (28%) than in Flanders (19%). Delays in the intermediate categories (1–6 months, 6–12 months, 1–2 years) were more evenly distributed across regions.

Table 13 – Time between first symptoms and care by region (n = 145)

Time between first symptoms and care[1]	Geographical region			p-value
	Flanders n = 81	**Brussels** n = 24	**Wallonia** n = 40	
< 1 month	37 (46%)	3 (13%)	9 (23%)	
1-6 months	16 (20%)	5 (21%)	8 (20%)	
6-12 months	5 (6.2%)	2 (8.3%)	9 (23%)	**0.007**
1-2 years	8 (9.9%)	3 (13%)	3 (7.5%)	
> 2 years	15 (19%)	11 (46%)	11 (28%)	

[1] *n(%)*

Sub-analysis showed no differences in timing between onset of first psychotic symptoms and first contact with psychiatric care across gender (Appendix 7).

Differences in the reported time between the first medical appointment and receiving a diagnosis were observed across geographical regions (p = 0.034) (Table 17). Respondents from Flanders and Brussels more frequently reported shorter delays, with 41% in both regions indicating that a diagnosis was received within one month, compared with 27% in Wallonia. Longer delays (> 2 years) were more frequently reported by respondents in Wallonia (39%) than by those in Flanders (11%) or Brussels (14%).

Table 14 – Time between first medical appointment and receiving a diagnosis by region (n = 145).

Time between first medical appointment and receiving a diagnosis[1]	Geographical region			p-value
	Flanders n = 82	**Brussels** n = 22	**Wallonia** n = 41	
< 1 month	34 (41%)	9 (41%)	11 (27%)	**0.034**
1-6 months	24 (29%)	6 (27%)	9 (22%)	
6-12 months	10 (12%)	1 (4.5%)	2 (4.9%)	
1-2 years	5 (6.1%)	3 (14%)	3 (7.3%)	
> 2 years	9 (11%)	3 (14%)	16 (39%)	

[1] *n(%).*

Because illness insight was often absent during the first episode, interviewees reported actively resisting the idea that something was wrong, even as their symptoms intensified. Voluntary help-seeking was therefore rare and contact with psychiatric care occurred when the situation became unsafe or unmanageable. In such cases, the first point of contact was typically crisis-driven: individuals were brought by relatives or police to a general practitioner, who then referred them to emergency services, resulting in an urgent or involuntary hospital admission. Participants often described this moment as abrupt, overwhelming, and characterised by rapid decisions made without their involvement.

> *"People who are delirious are often taken care of by the police or people like that, and I think it would be worthwhile for people to be better trained or something. (...) And I think that very often, when you arrive at the emergency department etc., there isn't really any time. People, caregivers, don't have time to sit down with you for half an hour or an hour because you're agitated, to talk to you or for you, they just don't have the time, so they lock you up in a corner." (F2)[91]*

Participants with PD frequently mentioned that family members, friends, or colleagues were the first to notice significant behavioural or emotional changes. These observers sometimes raised concerns or sought help on the participant's behalf, particularly when the person did not acknowledge any difficulties. This highlights the important role of the social environment in initiating access to care when early awareness is lacking.

> *"I was very suspicious about it and I didn't really believe that there was anything wrong with me, and it was because my parents constantly emphasised that they were there to help me and not to do the opposite, not to hurt me. And it was a hard lesson to learn that that was the case. So yes, I was very suspicious of it at first, but time changed that." (N7)[92]*

"There were a few years when I felt worse and worse. And I would say that for two or three years, it got worse. My parents decided to take me to see a psychiatrist (...) to find out what was going on." (F3)[93]

Participants described early consultations as fragmented, with clinicians initially addressing isolated complaints such as sleep difficulties, stress, or anxiety without placing them within a broader diagnostic framework. This led to confusion about what was happening and uncertainty about whether a diagnosis had been made at all. Interviewees noted that although professionals implicitly treated them as having a psychotic disorder, the exact diagnosis was not explained or was only communicated much later, sometimes after multiple hospital admissions and diagnostic re-assessments.

"Because I was given antipsychotic medication and I read the diagnosis of schizophrenia and so on. And I was actually shocked, because yes, because I had already heard that it wasn't such a positive thing. And I asked my psychiatrist if I had that." (N10)[94]

"I ended up in the psychiatric unit and was admitted there for six weeks and... Yes, the diagnosis was made quickly. Like, yes, you have psychosis." (N12)[95]

In contrast to the first episode, participants noted that relapses were recognised more quickly, both by themselves and by their social environment. Having prior experience with psychosis helped individuals identify early warning signs such as disrupted sleep, increased paranoia, agitation, or loss of functioning. This increased awareness often led to faster contact with psychiatric services, although relapses still frequently resulted in hospitalisation due to the rapid escalation of symptoms.

6.3.3.5 Appropriateness of diagnostic timing

In this section we report on the results of the expert survey (see section 5.4).

Delayed diagnosis

In the expert survey, delayed diagnosis was defined as 'a situation where a disease is identified later than would have been optimal. This refers to cases where an earlier diagnosis could have enabled more effective treatment or intervention, improving outcomes such as quality of life or survival.'

The delayed diagnosis of psychotic disorders was considered, overall, by the surveyed clinical experts as **frequent** (affecting around 30-40% of patients). Clinical experts described delayed diagnosis of psychotic disorders in Belgium as the result of several interacting causes, involving lacking awareness and stigma among the general public limiting early presentation, difficulties in first-line clinical recognition leading to alternative diagnoses, and broader structural weaknesses such as the absence of screening.

A first reported challenge lies in the nature of early symptoms themselves. Before the first psychotic episode, many individuals experience **cognitive, negative, or affective changes that are subtle, non-specific, and often only recognised *post-hoc***. Families may interpret these early manifestations as personality traits or temporary "life phases," and **stigma** surrounding psychiatric labels can lead individuals to conceal distress. **Lack of insight**, which is common at the beginning of the illness, further contributes to long delays before patients present to healthcare professionals.

A second cause concerns difficulties within the **first line of care**. General practitioners and non-specialist clinicians **may fail to recognise early or "insidious" symptoms**, frequently attributing them to anxiety disorders, obsessive–compulsive disorder, autism, or developmental issues. Psychologists may interpret obsessive–compulsive symptoms as OCD rather than early psychosis. Furthermore, the fact that psychosis is often **regarded as an adult disorder**, leads to **younger patients being overlooked**, and child and adolescent psychiatrists may not be

sufficiently familiar with early psychotic pathology. Screening for premorbid signs in children and adolescents is limited, and **stigma** can discourage clinicians from implementing available tools.

Delays are further reinforced by weaknesses in the second line and by **systemic shortcomings**. **Early intervention programmes** exist but are **not widely implemented**, and few specialised early psychosis teams remain (e.g. shutdown of services such as the VDIP teams in Flanders). **Long waiting lists**, sometimes exceeding six months or more than a year, slow access to psychiatric assessment. **Fragmented responsibilities** between federal and regional authorities reduce visibility and coordination of prevention pathways, and systematic screening is largely restricted to high risk or research contexts. **Disparities linked to migration status and gender**, as well as the widespread normalisation of cannabis and other prodopaminergic substances, further complicate timely detection. As a result, many patients enter care only at the stage of crisis or hospitalisation, well beyond the optimal window for early intervention.

Over-diagnosis

In response to the question on the extent that over-diagnosis of psychotic disorders is a concern in Belgium, clinical experts overall responded that it is only a **slight concern**. Over-diagnosis was defined as 'the diagnosis of a disease at a stage when it is not (yet) causing harm–such as pain, dysfunction, or suffering–and for which early treatment offers no advantage over treating it later. In these cases, early diagnosis may lead to unnecessary treatment, including side effects, or anxiety-inducing watchful waiting.'

Clinical experts described over-diagnosis of psychotic disorders as relatively uncommon, noting that clear functional impairment and psychotic symptoms are usually present by the time individuals reach clinical services. Nevertheless, a limited risk exists in situations where adolescents or young adults present with **non-specific or transient psychotic-like experiences** that may be misinterpreted as emerging psychosis. In these early-phase contexts, **heterogeneous training across services** and **inconsistent use of structured diagnostic tools** can contribute to premature labelling and, at times, unnecessary exposure to antipsychotic medication. Although such cases remain infrequent, they justify a low-level concern regarding potential misclassification.

Experts also highlighted that what is described as over-diagnosis often reflects misdiagnosis, particularly in relation to the growing awareness of autism in Belgium. The **overlap between autism, psychosis, and even catatonia creates complex diagnostic boundaries**, and symptoms may be misattributed across these conditions. This gap in clinical practice can lead to treatments that inadvertently worsen another underlying disorder. Overall, however, over-diagnosis is not viewed as a major systemic issue, and the limited risks are outweighed by the well-documented harms associated with delayed diagnosis and intervention.

6.3.4 Access to care

The following sections report the results derived from the (i) clinical expert survey and (ii) patient survey, based on respondents' answers to questions: HC12 and HC13. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

6.3.4.1 Treatment availability

Results from the expert survey showed that treatment availability for psychotic disorders in Belgium was described by participants as having '**some availability problems',** i.e. 'treatment that is available for a majority of the population but too expensive for some, or there are some stock problems or some other availability problems (e.g. some lack of specialised professionals)'.

Experts reported that shortages of specific drugs do occur, but they emphasised that these remain relatively limited and are certainly not the main issue. The core difficulties appear to lie elsewhere.

A first barrier is the **lack of reimbursement for key nonpharmacological therapies**: while medication, hospital stays, day therapy, and medical appointments are reimbursed, intensive long term ambulatory psychotherapy, physiotherapy, diet therapy, and many rehabilitation services are not, which restricts practical access.

A second reported problem concerns **shortages of specialised professionals**. There are insufficient psychiatrists, psychologists, case managers, neuropsychologists, and speech therapists to provide the level of care required, and professionals' knowledge of psychosis is not always adequate.

Limited structural funding contributes to **low coverage of early psychosis services and assertive community teams**, which remain unevenly implemented and structurally underpowered.

Experts also highlighted **variable access to structured psychosocial interventions**, including cognitive remediation, family interventions, supported employment, and rehabilitation programmes. These services often involve **long waiting lists** or **partial reimbursement**, creating **regional disparities**.

Finally, clinical experts perceived an **underuse of certain evidence-based therapies**, particularly clozapine and long-acting injectables, not because they are unavailable or unreimbursed, but due to organisational barriers, uneven monitoring capacity, and delays in initiation.

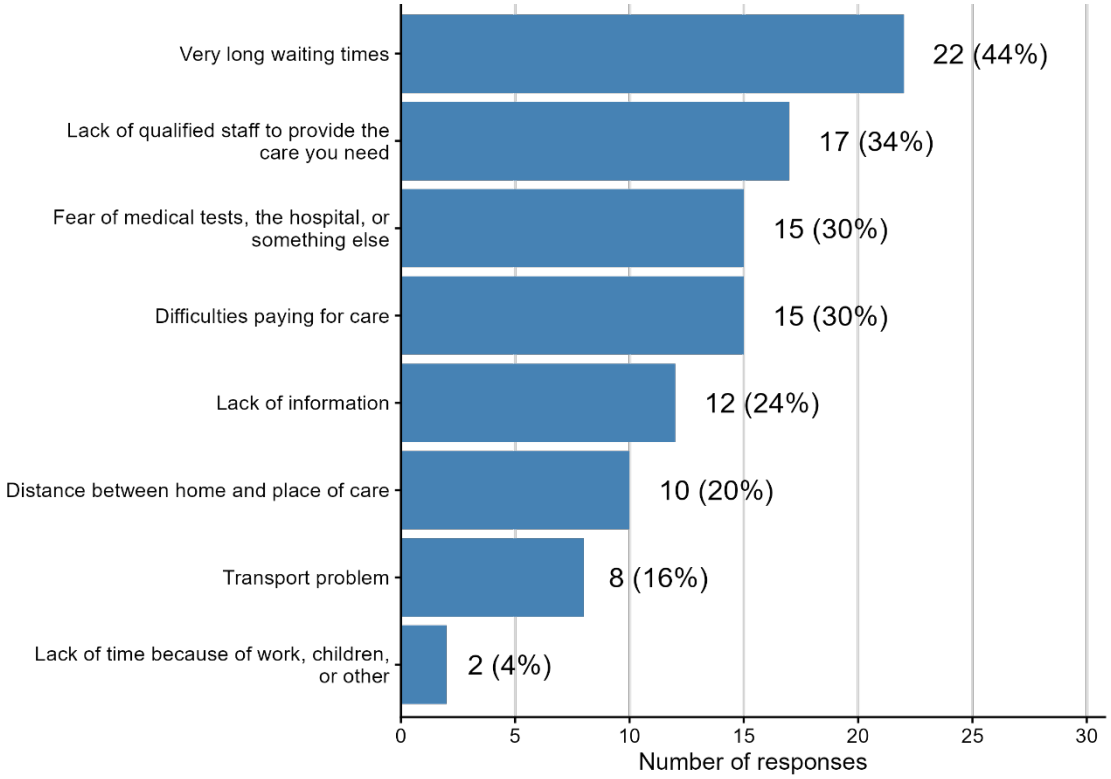
As a result, although treatments are widely available on paper, real-world access remains only moderately adequate.

6.3.4.2 Forgone care

Out of 143 responses, 35% reported experiencing forgone care in the past 12 months. This was defined as any treatment or care (e.g. a consultation, treatment, medical test, rehabilitation, or other type of care) for the psychotic disorder that was needed but not received.

Figure 24 presents respondents' experiences with foregone care in the past 12 months, including the reasons for not receiving needed care. Among those experiencing forgone care, the most frequently cited reason was very long waiting times (44%), followed by lack of qualified staff available at the time of need (34%). Psychological and financial barriers were equally present: fear related to medical tests, hospitals, or other, and difficulties paying for care were each reported by 30%. Information gaps also played a role, with 24% indicating that they lacked sufficient information to access or pursue care. One in five reported distance to the care site as being a reason (20%), and 16% reported transportation problems.

Figure 24 – Causes of forgone care in the last 12 months (n=50)



Differences in reports of foregone care due to distance between home and the health facility were observed by gender (p = 0.028), with men (42%) reporting this barrier more often than women (9.5%) (Table 17).

Table 15 – Forgone care by gender (n = 40)

Reasons for forgone care[1]	Gender		
	Male (n = 19)	**Female** (n = 21)	**p-value**[2]
Waiting times	8 (42%)	13 (62%)	0.2
Fear for medical intervention	9 (47%)	5 (24%)	0.12
Lack of time	1 (5.3%)	1 (4.8%)	>0.9
Lack of information	6 (32%)	6 (29%)	0.8
Distance between house and health facility	8 (42%)	2 (9.5%)	**0.028***
Lack of qualified staff	9 (47%)	7 (33%)	0.4
Transport problem	6 (32%)	2 (9.5%)	0.12
Difficulty paying	6 (32%)	8 (38%)	0.7

*[1]n (%); [2]Pearson's Chi-squared test; Fisher's Exact Test; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

Similarly, differences were observed by age (p = 0.020), where respondents aged under 30 years reported distance between house and health facility (63%) more frequently as a reason of forgone care compared with those aged between 30-50 years (12%) or those over 50 years (20%) (Table 18).

Table 16 – Forgone care by age-group (n = 42)

Reasons for forgone care[1]	Age			
	<30 (n = 8)	**30-50** (n = 24)	**>50 (n = 10)**	**p-value**[2]
Waiting times	7 (88%)	12 (50%)	3 (30%)	0.056
Fear for medical intervention	4 (50%)	8 (33%)	3 (30%)	0.7
Lack of time	1 (13%)	1 (4.2%)	0 (0%)	0.4
Lack of information	2 (25%)	8 (33%)	2 (20%)	0.9
Distance between house and health facility	5 (63%)	3 (13%)	2 (20%)	**0.020***
Lack of qualified staff	5 (63%)	9 (38%)	3 (30%)	0.4
Transport problem	2 (25%)	4 (17%)	2 (20%)	0.9
Difficulty paying	1 (13%)	9 (38%)	5 (50%)	0.3

*[1]n (%); [2]Fisher's Exact Test; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

No differences were found between the reported reasons for forgone care and geographical region (p > 0.05) (Appendix 7).

Interview findings indicate that forgone care was often the result of structural barriers throughout the care trajectory rather than a lack of willingness to seek help. Participants described a system in which the burden of navigating care frequently fell on their own shoulders, especially after hospital discharge. Interviewees emphasised that they had to actively search for the right services, initiate contact with providers, or manage long waiting lists with little guidance from professionals. This lack of coordinated support contributed to periods in which needed care was postponed or not received.

> *"I really do feel that way... It doesn't just fall into your lap. If you want to get better, you have to seek it out yourself." (N12)[96]*

> *"At the end of the day, a lot of thought goes into it, but essentially it has to be about who is sitting here in front of me and how can we get that person back on track? And I feel that in the large institutions, they have become too big, and that they have become more like managers, who are mainly managing management processes. The essence of what good care is, is sometimes forgotten." (N3)[97]*

Long waiting times were a recurring theme in the interviews and strongly echoed the quantitative findings. Participants described waiting months to access psychotherapy or specialised support, noting that available services were limited. This lack of timely access was particularly burdensome during vulnerable post-crisis phases.

> *"Because the psychologist has a waiting list of several months, while I had been struggling with these issues for a long time before I asked for help, or before I realised that I needed help. And then, when you finally take that step, you still have to wait months." (N17)[98]*

Another major barrier was the limited availability of professionals. Some respondents recounted moments of acute need when no one was reachable or when staffing shortages resulted in minimal support. Others described situations in which seeking help produced only superficial responses, such as medication instead of dialogue, because staff had insufficient time to engage with them.

> *"There are so many people in rehabilitation there, each with their own story, each with their own program and their own team. And you just notice that, in my opinion, they don't have enough time to really engage with the people, um, that you just do what the program says, yeah." (N4)[99]*

Geographical and mobility barriers also emerged in the interviews. Mobile teams were described as valuable but often difficult to reach due to distance, especially for those living outside cities.

"It used to be nearby, but now I have to walk 45 minutes." (N8)[100]

6.3.5 Scientific research

6.3.5.1 Research gaps

This section reports the results derived from the clinical expert survey.

Pathophysiology: knowledge of the causative factors, pathophysiological mechanisms, and natural history

Overall, clinical experts reported that the research gaps in the pathophysiology of psychotic disorders is considered as '**moderate'**, i.e. 'significant knowledge gaps exist that limit understanding or effective action in this area.'

Pathophysiology remains insufficiently understood: despite extensive neurobiological interest, the interplay between genetic vulnerability, neurodevelopmental trajectories, immune–inflammatory mechanisms, and environmental exposures such as cannabis, trauma, or urbanicity remains unclear. This heterogeneity of psychotic disorders limits the development of integrated mechanistic models, social determinants restrict model development, and the pathophysiology of negative symptoms remains particularly elusive**.**

Diagnosis: knowledge of diagnostic criteria, disease classification, and effective diagnostic tools

The research gaps in terms of diagnostic aspects were considered by clinical experts to be '**moderate'**.

Diagnostic criteria for psychotic disorders are operationalised, but gaps in **diagnosis** concern the lack of objective diagnostic biomarkers, with boundaries between attenuated psychosis, transient psychotic-like experiences, and emerging disorders remaining poorly defined. Comorbidity with other psychiatric disorders cannot be differentiated through biomarkers but only through symptom evolution.

Pharmacopredictive biomarkers: knowledge on methods to predict disease sensitivity to treatment

The gaps in terms of knowledge on pharmacopredictive biomarkers in the context of psychotic disorders were considered to be '**major'**, that is 'critical gaps in knowledge that severely hinder understanding or effective action, and require urgent research attention'.

The absence of **pharmacopredictive biomarkers** means clinicians cannot predict pharmacological or psychosocial treatment response, treatment resistance, or clozapine responsiveness. Genomic, neuroimaging, and inflammatory markers remain inconsistent and are not ready for clinical use. Belgium is considered to lack a standardised, reimbursed framework for pharmacogenomic testing.

Prognostic biomarkers: knowledge on methods to predict disease progression

Knowledge gaps concerning prognostic biomarkers were evaluated as '**major'** by clinical experts.

Prognostic biomarkers were perceived as lacking: clinicians cannot reliably estimate long-term functional outcomes, physical health outcomes, relapse risk, or vulnerability requiring assertive care, and existing models show limited generalisability.

Treatment: knowledge on effective treatments, including preclinical research and high-quality clinical trials.

The research gaps in terms of knowledge on treatment were considered by clinical experts to be '**minor**', i.e. 'some gaps in knowledge exist, but they are not critical barriers to understanding and effective action in this area'.

In terms of **treatment**, reported gaps concern both effectiveness and innovation. There are insufficient effective treatments for negative symptoms and comorbid substance use. Some older treatments are disappearing and being replaced by new expensive treatments without a national strategy, and certain options, such as injectable clozapine, require further research. Real-world effectiveness and long-term outcomes remain under-evaluated, including optimal clozapine pathways and combined pharmacological–psychosocial strategies.

Primary prevention: knowledge on effective primary preventive strategies

Knowledge gaps concerning primary prevention were evaluated as '**moderate**' by clinical experts.

Although modifiable exposures are well established epidemiologically (e.g. the causal mechanisms linking factors such as cannabis potency, childhood adversity, or migration-related stress to psychosis incidence), clinical experts highlighted that evidence on effective population-level preventive strategies remains sparse because interventions have not been evaluated in controlled or scalable designs.

Inequities: research gaps in specific patient populations (e.g. defined by ethnicity, socioeconomic status or other)

The gaps in terms of knowledge on inequities in the context of psychotic disorders were considered to be '**moderate**'.

Data on socioeconomic, ethnic, and regional disparities in incidence, pathways to care, and outcomes remain incomplete. Research on structural determinants (housing instability, discrimination, poverty) and their influence on psychosis onset and prognosis also remains limited.

Other identified research gaps

Despite mental health research undergoing a shift toward "practice-oriented" and "participatory" research, experts noted several significant research gaps persist in the actual **organization and experience of care,** particularly when compared to models used in chronic diseases. Belgian research has not yet developed a systematic, **nationwide "care path" for psychosis**. Also, research into the specific **impact of "case management"** (coordinating medical, social, and psychological care) was considered underdeveloped. Furthermore, expert survey participants pointed to a lack of research on the **transition between intensive mobile team support and regular primary care**, often referred to as the "black hole" of psychiatric discharge.

6.4 Unmet social needs

KEY POINTS

- Foregone support mostly concerned psychological support, followed by administrative, peer and medical support.
- Family and friends can play a crucial supportive role, but experiences are mixed; While many participants described emotional or practical support from close relatives, others received little or no support due to misunderstanding or stigma.
- Partner relationships were frequently strained.; while some participants maintained stable partnerships and felt supported, others reported breakdowns linked to psychotic events. Starting new relationships was also difficult due to stigma and fear of disclosure.
- Housing instability and difficulties in independent living after hospitalization were common. Some individuals returned to live with family or moved to sheltered housing.
- Stigma was widely reported across social contexts. It affected interactions with friends, neighbours, family members, and employers, often resulting in concealment of the diagnosis or withdrawal from social life.
- Social isolation was frequently present in the early course. Many individuals struggled to maintain social engagement. As stability improved, participants increasingly engaged in social activities, including volunteer work and peer support groups.
- Many individuals reported interruptions in their education and described significant challenges related to continuing or completing their studies.
- Work participation was heavily affected; Needing to stop working or reducing the workload was often reported. Long absences from work were common as well as reduced productivity, increased fatigue, and challenges with workload were persistent barriers to sustainable employment.
- Financial difficulties were common. Reliance on sickness or disability benefits, often remained insufficient to cover living costs and treatment expenses.
- A substantial administrative burden was described regarding health insurance, disability benefits, and social services. Navigating those was considered complex and poorly coordinated. While some individuals received support from relatives or social workers, others struggled to manage the administrative burden on their own.

6.4.1 Impact on social life

The following sections report the results derived from the patient survey, based on respondents' answers to questions: S6 and S7. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

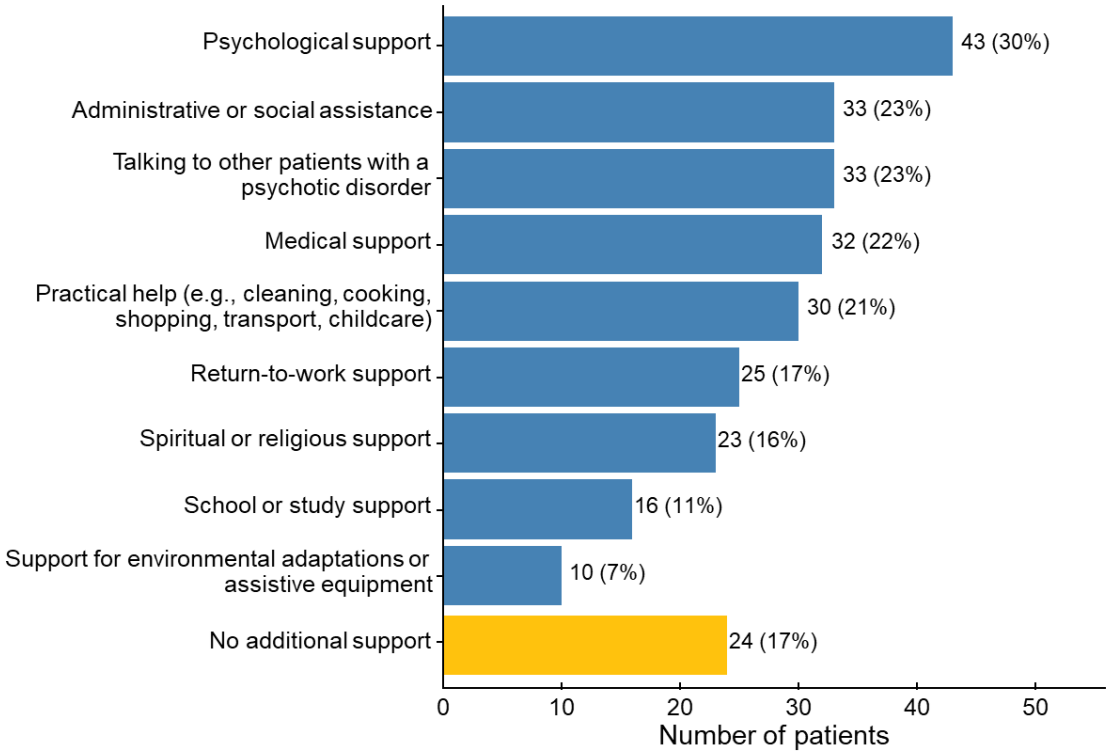
6.4.1.1 Forgone social support

More than 8 out of 10 respondents indicated (83%) experiencing forgone social support in at least one area. Among those, the most frequent support needed but not received was psychological support (30%) (Figure 25). This was followed by administrative or social assistance, opportunities to talk with other patients with a PD, and medical support (23%).

Similar proportions reported needing but not receiving practical help, such as assistance with cleaning, cooking, shopping, transport, or childcare (21%). Smaller but still notable groups reported

a lack of return-to-work support (17%) or spiritual or religious support (16%). Unmet needs related to school or study support (11%) and environmental adaptations, or assistive equipment (7%) were less often reported.

Figure 25 – Reported needs for additional support left unmet (n=143)



Differences in reported support needs were observed across several respondent characteristics (Table 19). Variation by region was observed for multiple types of support. For medical support, respondents from Wallonia more frequently reported a need for such support (49%) compared with respondents from Flanders (12%) and Brussels (29%) ($p < 0.001$). Similarly, for school or study support, respondents from Wallonia more frequently reported a need (24%) than respondents from Flanders (8.3%) and Brussels (6%) ($p = 0.048$).

Differences in living situation were also observed, where respondents living with others more frequently reported needs for practical support (33%) and administrative or social support (38%), compared with those living alone ($p = 0.047$; $p = 0.012$, respectively). Moreover, gender differences indicated that men more frequently reported a need for practical support (35%) than women (18%).

Variations were further observed across educational levels. Respondents with higher education levels less frequently reported a need for additional support systems (33%) than those with secondary (13%) or basic levels (0%) of education ($p = 0.033$). In contrast, respondents with a basic level of education more frequently reported a need for peer support (50%) compared with those with secondary (37%) or higher (16%) education ($p = 0.027$).

Additional differences by educational level were observed for administrative and social support environmental adaptations and school or study support. These needs were more frequently among respondents with basic education (67%; 33%; 33%, respectively) than for those with secondary (35%; 15%; 19%, respectively) or higher education (18%; 0%; 4%, respectively).

Finally, respondent's financial situation also showed a difference in administrative and social support, with respondents reporting financial strain more frequently indicating such needs (36%) than those reporting less financial hardship (18%) ($p = 0.038$).

No differences were found for age (Appendix 7).

Table 17 – Forgone support needs by respondents' characteristics (n=143)

Respondent characteristics[1]	Foregone support needs									
	No support needs	Talking to peers	Return-to-work	Spiritual and religious	Psychological	Practical help	Administrative and social	Medical	Environmental adaptations	School and study
Region (n = 118)										
Flanders (n = 60)	16 (27%)	13 (22%)	13 (22%)	14 (23%)	18 (30%)	12 (20%)	12 (20%)	7 (12%)	4 (6.7%)	5 (8.3%)
Brussels (n = 17)	3 (18%)	3 (18%)	5 (29%)	1 (5.9%)	6 (35%)	3 (18%)	7 (41%)	5 (29%)	2 (12%)	1 (5.9%)
Wallonia (n = 41)	5 (12%)	17 (41%)	7 (17%)	8 (20%)	19 (46%)	15 (37%)	14 (34%)	20 (49%)	4 (9.8%)	10 (24%)
Living situation (n = 115)										
Alone (n = 54)	11 (20%)	13 (24%)	10 (19%)	6 (11%)	20 (37%)	9 (17%)	9 (17%)	13 (24%)	2 (3.7%)	5 (9.3%)
With others (n = 61)	13 (21%)	20 (33%)	13 (21%)	15 (25%)	22 (36%)	20 (33%)	23 (38%)	19 (31%)	7 (11%)	9 (15%)
Gender (n = 117)										
Men (n = 51)	9 (18%)	19 (37%)	14 (21%)	12 (24%)	21 (41%)	18 (35%)	15 (29%)	17 (33%)	7 (14%)	9 (18%)
Women (n = 66)	14 (21%)	14 (21%)	11 (17%)	11 (17%)	22 (33%)	12 (18%)	18 (27%)	15 (23%)	3 (4.5%)	7 (11%)
Education level (n = 107)										
Basic (n = 6)	0 (0%)	3 (50%)	2 (33%)	3 (50%)	3 (50%)	2 (33%)	4 (67%)	3 (50%)	2 (33%)	2 (33%)
Secondary (n = 52)	7 (13%)	19 (37%)	13 (25%)	9 (17%)	24 (46%)	13 (25%)	18 (35%)	16 (31%)	8 (15%)	10 (19%)

Higher (n = 49)	16 (33%)	8 (16%)	7 (14%)	7 (14%)	15 (31%)	13 (27%)	9 (18%)	11 (22%)	0 (0%)	2 (4.1%)
Financial situation (n = 115)										
Comfortable (n = 45)	11 (24%)	11 (24%)	7 (16%)	9 (20%)	15 (33%)	9 (20%)	8 (18%)	10 (22%)	4 (8.9%)	4 (8.9%)
Strained (n = 70)	12 (17%)	20 (29%)	18 (26%)	14 (20%)	28 (40%)	21 (30%)	25 (36%)	22 (31%)	6 (8.6%)	12 (17%)

[1] *n (%)*

Participants described having forgone support during periods of illness and recovery, particularly when transitioning out of hospital care. Limited guidance following discharge were identified as important gaps in the support system. Participants also indicated that administrative responsibilities or household tasks were difficult to manage without assistance during the early recovery phase. The need for continuous, easily accessible personal support, such as a buddy or coordinator to guide care outside institutional settings, was emphasised.

> *"Psychotherapy, that's something that could be more... yes, more accessible. That people can guide you there more easily, and that there is also more room for it after a hospitalization." (N10)[101]*

> *"Especially the administrative part. That you indeed have help with that, especially during the first three months or so, even if you're not hospitalized, that there is someone who can take over certain things." (N1)[102]*

> *"Actually, there is need for a buddy that is available 24/7, someone who can provide all necessary information" (N7)[103]*

> *"An individual support person or a coordinator who creates some kind of care pathway for things that need to be done outside the institution." (N17)[104]*

> *"That someone can come and do your housework, that someone can come and cook for you. That such things can be arranged very easily for a short period of time, because I was simply no longer able to do such things myself." (N4)[105]*

6.4.1.2 Impact on personal relationships

Most respondents reported that their personal relationships were disrupted due to their PD (Figure 26). **More specifically 34% of respondents reported the impact as 'a lot' and 17% as 'extremely', indicating that half of the sample perceived relational strain due to their PD. Moderate effects were also common, with 24% respondents experienced a 'moderate' impact on their personal relationships.**

Figure 26 – Impact of the PD on personal relations (n = 140)

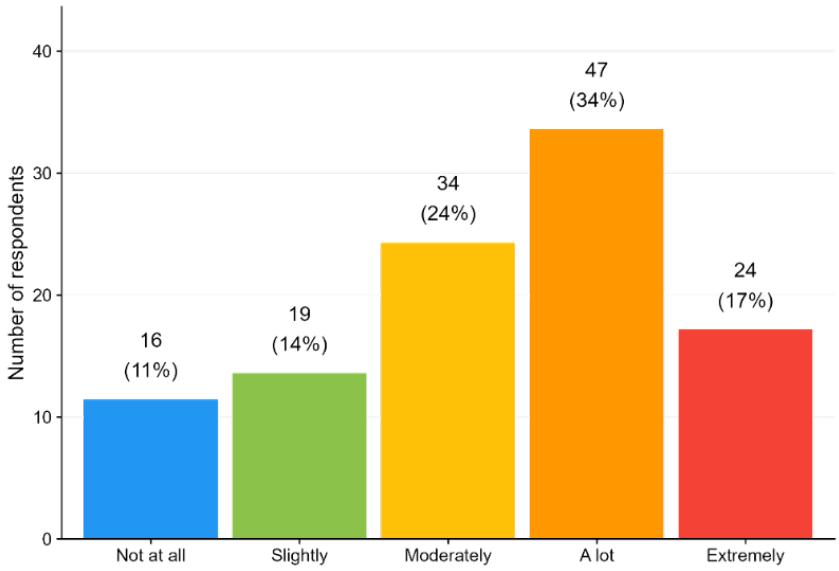


Table 19 shows a statistically significant association between financial situation and the perceived impact of psychotic disorder on personal relationships (p = 0.002). Participants with a strained financial situation more frequently reported severe negative impacts on their personal relationships. In this group, 61% reported that the disorder affected their relationships "extremely" or "a lot,"

compared with 35% among those in a comfortable financial situation. Conversely, respondents with a comfortable financial situation were more likely to report that the disorder affected their relationships only slightly or not at all (39% vs. 16%). No differences were observed for gender, age, educational level, or living situation (Appendix 7).

Table 18 – Impact of psychotic disorder on personal relationships by financial situation (n = 136)

Characteristics	Financial situation		p-value[1]
	Comfortable n = 57	Strained n = 79	0.002
Extremely	5 (8.8%)	17 (22%)	
A lot	15 (26%)	31 (39%)	
Moderately	15 (26%)	18 (23%)	
Slightly	14 (25%)	5 (6.3%)	
Not at all	8 (14%)	8 (10%)	

[1]*Wilcoxon rank sum test*

During the interviews, participants indicated that at the onset of their first symptoms, the PD had a great impact on their social network. They mentioned that many people in their network did not fully understand what psychosis is, and how to deal with it. This led to misunderstanding and feeling unheard within their environment.

> *"What I find difficult is that no one really understands what you're going through. Even if you say things, if you've never experienced a psychosis, then you just really don't know, well, that's what I think." (N4)[106]*

> *"At the beginning of my hospitalization, it was mainly my parents who came to visit me. I think my brothers and my sister didn't really know what I had." (N8)[107]*

> *"Then, regarding my social circle, the whole music scene I was in, I lost all contact with those people. It was very difficult to live with because I realized that no one, apart from two people, no one reached out to me. (...) I simply fell of radar and felt very, very alone." (F2)[108]*

> *"My mother had a hard time understanding schizophrenia. She really thought I was going to kill her in her sleep, for example. And she thought I was possessed because she is very religious (…) Actually, the psychiatrist explained it to her, and after that, things got better." (F1)[109]*

Impact on the family and friends

The support of family and friends was reported to be important during the care trajectory. Parents, siblings, partners and close friends were involved actively, showing interest in understanding the condition and supported practical assistance. Participants could speak openly about their experiences without stigma. Despite this support, difficulties in living independently after a psychotic event sometimes forced participants to move into protected housing or return to their parents' home, reflecting the impact of the disorder on their living situation.

> *"My mom is much more involved in the whole psychosis thing, and my sister as well, and my partner. Those are the three who are the closest to me, who also read up on what a psychosis is, and what the causes are." (N1)[110]*

> *"Today things are okay. But I'm living at my mother's place, you know, she's the one who does the groceries, and thanks to that help it's okay. (...) But in the years before I came back to my mother's place, from when I was 25 to 30, I was completely alone, more or less. I mean, at*

one point I was living without curtains, without a blanket, and I didn't even realize it because the physical sensations are so difficult to manage." (F4)[111]

"I had visitors almost every day during those 40 days, there were only a few days when no one showed up. My plants were watered and so on, so I have support from my friends. It has been reorganized somewhat, you do notice there are fewer people for example, but still, there is a lot of support." (N5)[112]

"During my depression, I deliberately didn't seek any help because I was afraid of it. I didn't want help, and I went to live with my parents because I couldn't cope anymore, and then I had another psychotic episode." (N9)[113]

However, there were also parents or friends that showed incomprehension. As a result, participants received little to no support from their social network. Their psychotic vulnerability remains a difficult topic to discuss openly, which has led to strained or broken relationships and in some cases, a complete loss of contact with certain family members or friends.

"There was a lot of stigmatisation from those around me. (…) Because I made some delusional statements, it scared people. However, there were not aggressive statements or anything, but some people were scared and ended up cutting ties completely." (F2)[114]

"My cousin, she doesn't avoid the topic but doesn't really understand it. And my father avoids the topic because he simply doesn't understand it and because he also can't handle that his daughter is mentally ill. It is unmentionable in our family." (N12)[115]

"For example with my brother, he experienced me at a time when I was really in a psychotic crisis and he concluded that I can't really help him with anything. Or, that my way of handling the world, actually doesn't make any sense for him. And that I miss opportunities because the way I think." (N13)[116]

A sense of powerlessness also emerged in the accounts of family members and friends, who often felt unable to influence or support their loved one during an acute episode. Family members also experienced profound emotional distress related to disappearance of their loved ones.

"I know it makes my mother anxious, (...), they searched for me, they issued a missing person notice for two weeks. (...) So yes, I imagine that it must have been complicated for my parents." (F1)[117]

"I can clearly see that for them, seeing someone they love disappear like that into a kind of madness, into incoherence, and not being able to help, is so unbearable that they would rather suffer greatly themselves trying to help me without succeeding." (F4)[118]

The family can experience strain during a psychotic episode, as they can be confronted with intense emotional challenges and unpredictable interpersonal tensions. Such experiences illustrate how a psychotic episode can put pressure on family bonds, and an emotionally changed environment in which ordinary interaction became difficult to navigate for both the individual and their relatives.

"But above all, sometimes I get flashes of hatred (...) when I go to have lunch and I open the door and bump into my mother. I say, "Hi, Mom," and then she tells me something that annoys me, and she ends up with some guy who goes on and on for half an hour with terrible energy. You see. And my poor mom, she's seventy years old and frankly, it really pisses me off!" (F4)[119]

On the other hand, participants also made new contacts, usually with other people who shared similar backgrounds or were involved in supporting groups. Such connections were described as easier to build because these individuals understood their experiences and provided a sense of acceptance.

"Now I do feel that I am socially engaged. I have also built a circle of friends. And sometimes I take a course, or I look for a hobby. I have really grown a lot in that regard." (N4)[120]

"I have a social life for about two years now, and my new friends… Well, there are some old friends and some new friends. My network, I have them, they are completely aware of my illness because I have no choice, and they are very supportive. Yes, and they are my safety net now." (F2)[121]

The relationship with their children was also affected, and participants reflected on how their psychotic disorder may have influenced their children's lives. They described reduced contact or subtle changes in family dynamics to accommodate the person with the psychotic disorder.

"There are also his three children, but for the children it's complicated. So the bond is not broken, but he doesn't see them very often." (F5, proxy)[122]

"In recent years I've had a number of psychoses, and I do feel that the children, they are now 31 and 28, tend much more to turn to my husband if they need something or want to tell something. But I feel that… yes that they kind of… spare me, I don't know, and that I have less contact with the children actually." (N11)[123]

"I wonder what it has done to my children? That is a question I have no answer to. Because they also went through a number of things. Yes, they were still small at the time. We've also talked a little about it, like 'Do you remember when dad was a bit sick in his head and doing a few crazy things?'." (N3)[124]

Impact on partner relationships

Psychotic episodes could strain romantic relationships, although partners could also provide significant support and showed understanding. Despite periods of difficulty, their bound remained meaningful and intact.

"Well, for a long time, I thought that [the psychotic disorder] would be an obstacle in our relationship, that it would be over the next day. But now he always seems to emphasize 'That was not bad, it's good for you that you were hospitalized', and things like that." (N14)[125]

"It had a very heavy impact, you know. It was very close, we almost broke up." (N3)[126]

Finding a new partner was described as challenging, because it was not easy to start a new relationship due to stigmatisation or feeling shame when explaining a history of psychosis. Or because individuals with PD preferred to focus on their own recovery first, aiming to achieve greater symptom stability and independence.

"Men are just afraid when they hear about it. I also find it very difficult to deal with. Normal dating, online, it just doesn't work. They ask, 'What is your job?' and that's already the beginning. So you can only meet people occasionally who ultimately want to look past it, but that is very difficult. (N9)[127]

"I think I'm mostly afraid of showing who I am and what my life history is. Afraid of showing my vulnerabilities and being judged for them." (N4)[128]

"So I haven't been in a relationship since then, so it's been a while. Not necessarily because I don't want one, but because I don't always feel ready. First, my symptoms need to be under control before I let someone else into my life, and step into someone else's life." (N17)[129]

"When I had a crisis and told my girlfriend that I needed help, she started crying, saying she always ends up with crazy people. And right now, I tell myself I'm going to put something in place to be stable without needing to ask help from the person who shares my life, because people who otherwise share my life become nurses, so they're also being exploited by the system! And I don't want to exploit my loved ones!" (F4)[130]

Making connections with partners in a psychiatric setting was reported to be easier to establish, as participants felt more supported by them. However, this was not always an ideal situation, as such interactions could also be a trigger for new psychotic events.

> *"I have the impression that I can only find partners in the psychiatry because those people, well, because we have a similar background." (N10)[131]*

> *"But it's easier to start a relationship with someone who has the same illness. Then they know what it's about and of course they understand it better. With other people, I haven't had many relationships, just flirt moments for a few days, a few weeks, or a month or so, but then I always kept it a secret." (N15)[132]*

> *"During my second psychosis I did have a relationship, but that was a totally wrong person, because I later found out that she had borderline personality disorder. So that was certainly not the most stable relationship to start with. And it's actually that relationship that pushed me into my second psychosis. (N17)[133]*

Engagement in social activities and social isolation

Social isolation emerged as a recurring experience during or after a psychotic episode. Participants showed a reduced desire for social interaction and engagement.

> *"Socially? Well yes, I have very few contacts. There's really no one who calls me, I don't call anyone. Because what do I have? I really have no one I can count on. I don't have my parents, I don't have a social circle, I don't have friends, I don't have a boyfriend, I don't have a girlfriend, I don't have a partner, a girlfriend, I haven't built a family…" (F3)[134]*

> *"During that period when I was studying at the VUB, when I came back from my admission, I was shut down. Yes, I was insecure, in shock, traumatized, all those things. And I still hung out with them, but there was much less initiative from my side just to talk. Simply because I felt so insecure and felt so bad." (N16)[135]*

> *"I was completely isolated. Yes, at that time I had maybe one friend, I think. But I don't know if that was necessarily because of my psychoses. I think it was also because of being in psychiatry, that I isolated myself anyway and was kind of afraid of the world. But yeah, I really didn't see anyone for months." (N4)[136]*

Participants reported deriving satisfaction from self-care, forming new social connection and participating in activities such as peer support groups, volunteer work and (psycho-)educational programs.

> *"I moved to [city], I didn't know anyone here, and I really needed to get to know people, and I find that not easy. It still isn't easy. And I thought, I'm going to do volunteer work in a social setting where I can meet people. But I also searched for that myself, I did it myself." (N9)[137]*

> *"The fact that I ended up at a volunteer organization also shaped my social life differently. In that sense, I started seeking another kind of relationships with people, in which authenticity became much more central, so regarding my network and social life, that also had some consequences." (N3)[138]*

Stigmatization of the social environment

Stigmatization was a pervasive experience for individuals, affecting how they are perceived and treated by family, neighbours and colleagues. Participants described concealing their diagnosis due to shame or fear of discrimination. Misunderstanding, labelling and social exclusion were reported during interviews, highlighting the emotional and social burden of stigma in everyday life.

> *"I notice that there are still a number of sisters, even outside in other congregations, who basically say, "Yes, you have psychosis, so we're going to take over everything. You're no*

longer allowed to take responsibility." It's so patronizing. Yes, I don't know how difficult that is." (N6)[139]

"Some people are curious, and the things they think they know aren't correct. Or people think we are dangerous, which sometimes can be the case, but mainly they don't understand what it is. (…) But that is stigmatization, it has an enormous impact. Because I know so many patients who just keep it a secret, who are ashamed that they are in the hospital, in psychiatry." (N7)[140]

"But when you have the status of being disabled, let's say for me, it was embarrassing. It was stigmatizing because people don't understand why you no longer work, why you stay in bed, why you do nothing?" (F6)[141]

"For example, I am a volunteer, and I don't dare to say what my vulnerability is. Well, I'd rather not say it. I used to be very open about it, but I've become increasingly reserved because you can feel that they look at you differently and treat you differently, and I don't want that." (N9)[142]

"Only people who have known me since before the illness take the time to say, 'Poor thing, what's happening to him?' The others discriminate me immediately. It takes 10 minutes, you know. Basically, it happens very quickly. I am discriminated against very fast, it's frustrating." (F4)[143]

6.4.2 Impact on education

6.4.2.1 Impact on education

The following sections report the results derived from the patient survey, based on respondents' answers to question S1. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

The perceived impact of psychosis on education in terms of attendance, performance, success, or study choices shows a polarized distribution in terms of impact on respondents' studies or schooling (n = 109) (Figure 27). **More than 60% of respondents reported experiencing an impact on their education, with the majority reporting this impact to be 'extreme' (33%), 'a lot' (17%), or 'moderate' (17%). Only a smaller proportion experienced a 'slight' (6%) impact on their education.**

In total, 28% of respondents indicated that the impact of PD on their education was not applicable (not shown in the Figure), as the onset of the symptoms occurred after they had completed their education. Conversely, 27% of respondents reported no impact at all.

Figure 27 – Impact of PD on education (n = 109)

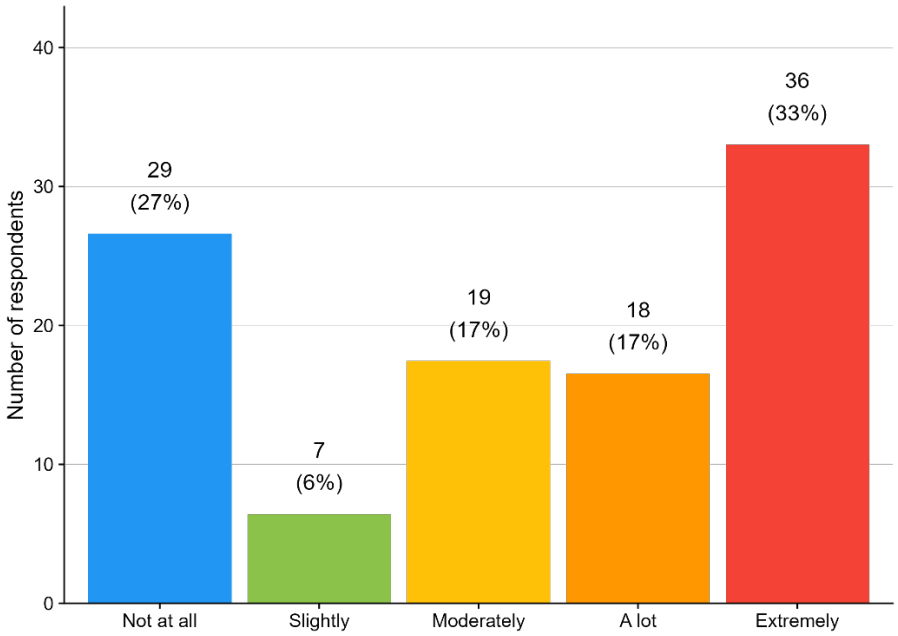


Table 20 shows that the perceived impact of psychotic disorder on education varies significantly by gender, age, education level, and financial situation. **Men, younger respondents (<30 years), individuals with secondary education, and those in a strained financial situation more frequently reported that the disorder affected their education "extremely."** In contrast, women, older respondents, those with higher education, and financially comfortable participants were more likely to report little or no educational impact. Overall, the results suggest that social and demographic factors influence the extent to which psychotic disorder disrupts educational trajectories.

Table 19 – Impact of PD on education by respondent characteristics.

Respondent characteristics	Impact on education[1]					p-value
	Not at all	Slightly	Moderately	A lot	Extremely	
Gender (n = 107)[2]						
Men (n = 51)	12 (24%)	4 (7.8%)	4 (7.8%)	7 (14%)	24 (47%)	**0.027**
Women (n = 56)	17 (30%)	3 (5.4%)	14 (25%)	11 (20%)	11 (20%)	
Age (years) (n = 109)[3]						
<30 (n = 18)	2 (11%)	1 (5.6%)	2 (11%)	3 (17%)	10 (56%)	**0.030**
30-50 (n = 57)	13 (23%)	5 (8.8%)	13 (23%)	7 (12%)	19 (33%)	
>50 (n = 34)	4 (41%)	1 (2.9%)	4 (12%)	8 (24%)	7 (21%)	
Education level (n = 101)[3]						
Basic (n = 6)	2 (33%)	0 (0%)	0 (0%)	2 (33%)	2 (33%)	**0.048**
Secondary (n = 49)	9 (18%)	3 (6.1%)	6 (12%)	9 (18%)	22 (45%)	
Higher (n = 46)	14 (30%)	4 (8.7%)	11 (24%)	7 (15%)	10 (22%)	
Financial situation (n = 105)[2]						

Comfortable (n = 44)	15 (34%)	5 (11%)	8 (18%)	7 (16%)	9 (20%)	**0.030**
Strained (n = 61)	14 (23%)	2 (3.3%)	11 (18%)	10 (16%)	24 (39%)	

[1] n (%); [2]Wilcoxon rank sum test; [3]Kruskal-Wallis rank sum test.

The onset of the symptoms only developed for some individuals in early adulthood and had no impact on school and education. While others developed the symptoms during their period in higher education and were forced to (temporarily) interrupt their studies or adapt the rhythm of their studies.

> *"I completed my first year successfully, my second year over two years. I asked for an exemption to repeat my third year for the third time, and that's when the decompensation happened, with a hospitalisation in a psychiatric hospital. (…) Well, I passed all my exams in June, so that was when I was in my third year. And then in fourth year, I did my fourth year anyway, but it just wasn't working anymore, I wasn't able to study. I had cognitive problems, so I had problems linked to the illness." (F6)[144]*

> *"It was constant puzzling like, 'look, now I'm ill, but I still need to obtain enough study credits to receive a study grant, so I'll only take theoretical courses now, combined with therapy.' (…) And then at a certain point I also pushed myself a bit like, 'okay, to finally be able to finish the program even a little, it's important that I do another internship, but then, for example, with fewer hours or spread out more.'" (N4)[145]*

> *"It was really hard for me that I could no longer study properly with all that Haldol and so on. I felt like it all took too long. And I just wanted to go back to studying, but yeah, that wasn't possible with all that [antipsychotic medication]." (N8)[146]*

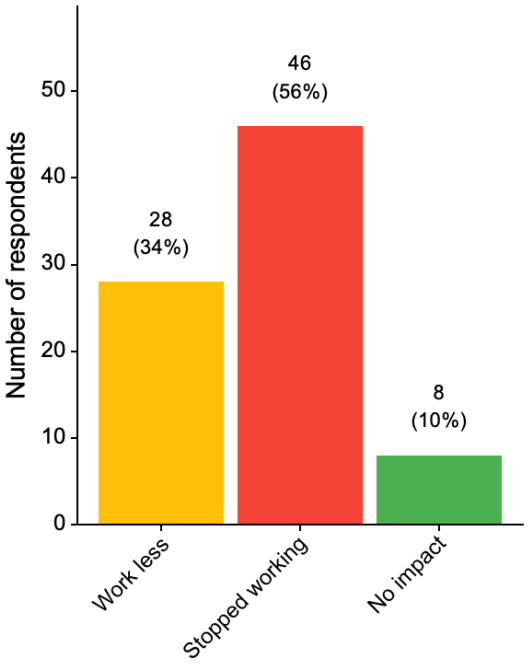
6.4.3 Impact on work

The following sections report the results derived from the patient survey, based on respondents' answers to question S2. In addition, relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise these findings.

6.4.3.1 Reduction in working time

Figure 28 presents the impact of PD on respondents work intensity. Nine in ten respondents reported a substantial impact on work intensity: 56% indicated that they had stopped working, while 34% reported working less. Only 10% reported no impact on work intensity.

Figure 28 – Impact of PD on work intensity (n = 82)



There were no observed differences in the impact of PD on work intensity when comparing groups based on time since diagnosis, gender, education level, financial situation, or living situation (Appendix 7).

Psychotic symptoms could make it difficult to continue functioning in the workplace, resulting in an interruption of their work career. Even after attempts of trial and error in a reassignment within the company or in a trial of a new job position, it often ended in a negative outcome due to psychotic symptoms.

> *"Well, I tried to keep working for five years after my first psychosis, and it always failed. I was eventually dismissed for medical reasons. I also wanted that, because I no longer dared to go back to work since I had also done things there during a new psychosis." (N9)[147]*

> *"The only thing, the only thing I realized was that I needed to rest. That I needed to stay home and rest and wasn't able to go to work." (N12)[148]*

> *"I just changed jobs as well when I went through that second psychosis. And then I was on long-term sick leave, which led my employer at a certain point to think, 'yeah, this isn't going to work either,' so they found a way to put me on a side job. So I also had to reorient myself professionally." (N3)[149]*

> *"And then between 2013, when I quit all my jobs, and 2017, each time I'd find work again, then I'd start deliring, so I wouldn't be kept on after the trial period, and so on. And I'd just bounce back and forth like that …delusion, finding a job, delusion, finding a job." (F2)[150]*

> *"I tried once again, with the help of a job coach. It was a job I had done before and really enjoyed. And I thought, I'll do that again because it's the only thing I can still see myself doing. But then I think I became psychotic at work again, and so I stopped with that." (N18)[151]*

The interviews further indicated a reduction in work productivity following a psychotic episode. Participants reported needing more time to complete tasks than previously and requiring extended periods of rest after a workday.

"On top of that, just the workload too. At the moment I started working progressively, it was already a part-time job. It was so demanding that I genuinely needed the rest of the week to recover, to go for little walks, or to somehow regain my energy." (N3)[152]

"I actually work slower than an average person. Well, much slower, because I've just received that on my evaluation in the sheltered workplace." (N10)[153]

Reintegration into society became an important goal for those with a relatively good recovery. Returning to work was describes as a way to rebuild structure, regain purpose and achieve financial stability. It was further emphasised that going back to work contributed to improved self-esteem and a feeling of social value. However, reintegration was not always straightforward, as respondents reported limited professional support and workplace adversity.

"That's a bit of a problem, the bridge to the world, for example the regular labor market is much more difficult. But I've always tried very hard to keep in contact with the world of work, hoping that I could still mean something." (N13)[154]

"By going back to work, my feelings improved a lot, so my self-esteem really improved." (N12)[155]

"Well, I can't work, even though I would really like to. But the health insurance refuses to let me work because they won't give me the authorizations and the appropriate forms, even though I could work. I think I could at least work part-time." (F3)[156]

"For example, in The Netherlands, as soon as someone falls into psychosis or schizophrenia, there is immediately a team that takes charge of the person in order to reintegrate them into some kind of occupation, whether professional or otherwise." (F6)[157]

Among those who returned to work, opinions were divided: some reported that they do not enjoy their job because it is below their skill level, whereas others would like to work more hours but find this psychologically too demanding.

"Well yes, with work too, it was below my level, if I'm allowed to say that. Because I always had to work in sheltered workshops." (N15)[158]

"Yes, I just have to be careful not to have too much stress. So working two days a week is fine. But before that I worked in education, and then I basically worked 4/5 or full-time, and that was too much." (N11)[159]

"They need to check all persons on disability allowance that there should at least be adapted work for them. And by adapted work I mean fewer hours, and also accessible work, where they take your vulnerability into account. And in my opinion that doesn't exist, except for volunteer work." (N9)[160]

Participants also expressed a desire to obtain greater fulfilment from their professional activities. Some reported achieving this by engaging in experiential or peer-based work, allowing them to transform their mental health history into a meaningful and functional contribution.

"A position opened up for a peer worker, and I could actually decide myself how many hours I wanted to work, and then I was hired. So the month after I was put on early retirement, I was able to start there. I actually never had the feeling that I was without work." (N11)[161]

"I would really like to start working again in a role that suits me. And that's always a search, and maybe even more when you're dealing with a vulnerability. It just takes more time to find your place, but you can't also take too much time then you will end up getting stuck." (N13)[162]

"Then I decided, 'okay, I'll just go back into mental health care myself.' My first degree is in psychology, so I thought, 'okay, then I can try to use my own experience and my background to support others on their path or with the things they're going through." (N3)[163]

Others engage in volunteer work, either within psychiatric services or in the broader community. Participants described this as important, as it provides a sense of meaningful daily structure and enhances their feeling of belonging within society.

> *"Because I do a bit of volunteer work within an association, those kinds of reflection meetings of a network group, to still contribute into healthcare." (N7)[164]*

> *"Actually, I am an expert by experience, and I am involved in patient representation. (...) So patient representation is about how we can better align primary psychological care with our society. Because people are still investigating whether primary psychological care should always be one-on-one, whether they should start with groups around what anxiety is, providing psychoeducation, yes, those kinds of things." (N6)[165]*

6.4.4 Financial consequences

6.4.4.1 Out-of-pocket healthcare costs (per patient)

This section reports the results derived from Belgian database analysis (IMA–AIM, see section 5.5), complemented with quotes from the patient interviews.

In the year 2022, **the average co-payments and supplements attributable to psychosis accounted for €1 791 per patient** (95% CI: €1 550 - €1 980).

Payments for non-reimbursed goods and services are not captured in the IMA–AIM database. For patients with psychotic disorder this may concern for instance relaxation therapies or alternative treatments such as osteopathy. Some of these treatments may also be (partly) reimbursed by the voluntary schemes from the health insurance funds.

> *"There's always a portion that you have to pay yourself. Well, yes, and now I'm in therapy, because I still have increased reimbursement through my health insurance, so I get my therapy at a reduced price. But if you have to pay for the regular sessions, that's €75. That's a serious chunk out of your budget." (N12)[166]*

> *"And for psychotherapy, I think 10 sessions are reimbursed at €10 or so by the health insurance fund. And osteopathy, which falls under alternative treatments, is also reimbursed, but only very little." (N17)[167]*

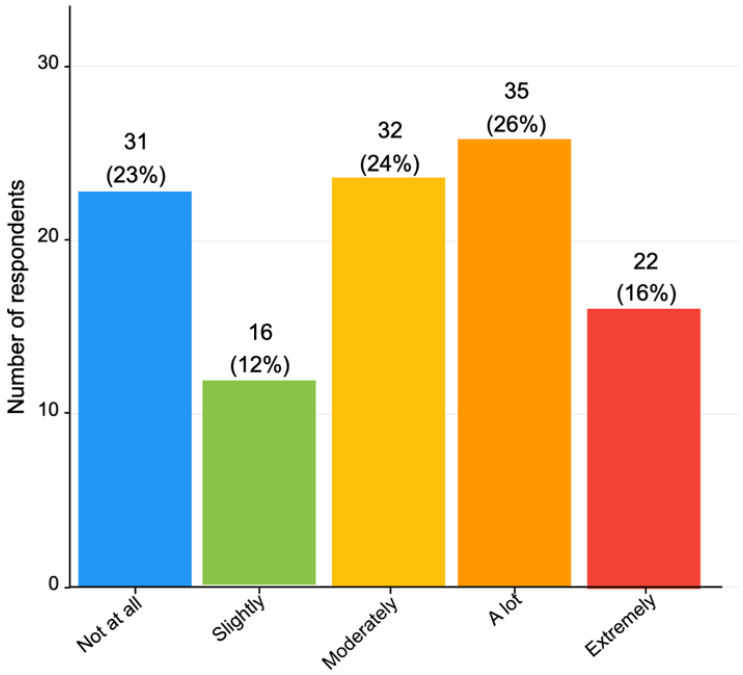
> *"I don't pay much for relaxation, as most of it is reimbursed. I think for 10 sessions, I pay maybe €20 or so. My psychiatrists are €8 per session, I think, which is also okay. And my psychologist is €4, I think, so yeah. That's okay." (N4)[168]*

6.4.4.2 Perceived financial difficulties related to the health condition

This section reports the results derived from the patient survey, based on respondents' answers to question S5: "*To what extent is your psychotic disorder causing you financial difficulties?".* Relevant in-depth themes emerging from the qualitative interviews were integrated to further contextualise the findings.

Of 136 respondents, 66% reported experiencing financial difficulties related to their health condition (Figure 29). More specifically, nearly one quarter of respondents reported 'moderate' financial difficulties (24%). In addition, 26% reported experiencing 'a lot' of difficulties, and 16% reported 'extreme' financial difficulty. Conversely, 23% reported that their psychotic disorder had no financial consequences. These results suggest that PDs frequently compromise financial stability, underscoring the importance of employment support and social safety net interventions in this population.

Figure 29 – Extent to which PD caused financial difficulties (n = 136)



Exploratory sub-analysis observed differences across respondent characteristics including living situation and gender (Appendix 7).

During the interviews, participants noted persistent financial challenges, some especially during the acute phases of the disorder, some in the longer run. Because full-time employment was not always feasible, reliance on sickness benefits often became the primary source of income. Some survey respondents mentioned that financial subsistence depended largely on family contributions, as they were unable to generate income beyond disability benefits. Despite this support, managing financial stability remained difficult.

> *"When I couldn't work for eight months, I received my sickness benefit from the health insurance, and that's not nearly as much as when you're working. Plus, it also gets taxed, so that was a bit… well, hard to swallow. And I'm a single mom as well." (N12)[169]*

> *"I don't get that much from my replacement income, and my husband has gone through some crisis years at work, so now we're really struggling with our reserves, our savings account." (N14)[170]*

> *"Since I hadn't been doing well in the months before going on sick leave, I had been working fewer hours. In mutual agreement with my boss, I reduced my hours. But that has a very harmful consequence: the health insurance fund calculates your benefit based on the average salary of the last three months. And because I was no longer working full-time, I ended up with only around 800 euros per month from the health insurance fund." (F2)[171]*

> *"I had an enormous loss of income of course, and many costs for medication and healthcare. I lost a lot of income because I now receive a social allowance, since I don't have a job, I don't have professional income. I had many setbacks, I was scammed many times, which was due to my illness, my vulnerabilities, all of that led to many financial problems." (F3)[172]*

The impact of delusional beliefs resulted in abrupt job resignations and prolonged periods without financial support.

> *"I quit all my jobs because I thought the universe would provide for my needs. So I ended up in a disastrous financial and personal situation. Because my delusions pushed me to quit all*

my jobs. And I didn't take any steps with the authorities to get replacement income... So I spent months wandering around like that." (F2)[173]

During the interviews it was reported that there are difficulties accessing necessary care due to limited reimbursement. As certain services were not fully covered, obtaining adequate treatment posed financial challenges despite the clear need for support.

"I actually do need, perhaps more body training, or even a psychotherapist that I could choose myself, but financially that's just not feasible." (N9)[174]

"I was lucky that my previous job was well-paid, so I received the maximum allowance. But to have a decent life and pay for your own therapy, it's not enough, especially considering that over the past year, besides my psychiatrist, I have two other therapists, which costs more than €200 per month. And for someone who must live solely on the allowance and has no savings, you just can't manage." (N17)[175]

Participants' living arrangements were reported to be influenced by financial constraints. Limited income forced some to rely on social housing, illustration how economic difficulties affected their previous living situation. Survey respondents also expressed a need for housing that was adapted to their requirements, together with support in accessing financial assistance.

"I applied for sheltered housing and social assistance and explained my situation, that I couldn't be completely independent at the moment. And they accepted my application. (F1)[176]

"And the waiting lists for social housing and apartments and so on. I had to wait about 11 years for an apartment." (N15)[177]

6.4.4.3 Non-healthcare costs

This section concerns costs that patients must cover for aspects other than medical care, but that are nevertheless a consequence of the disease. In line with the NEED protocol[10], the checklist for non-healthcare costs was filled out (Table 22). This checklist comprises a comprehensive list of cost groups which may applicable to a certain health condition or not. This checklist was filled out based on input from collaborators of a patient organisation (UilenSpiegel) and a peer support organisation (Fil Rouge d'ISoSL). The obtained information was confirmed by quotes from the patient interviews.

Note that the response options for the checklist are:

- Applicable to a majority of patients:
  - One-off costs
  - Recurring costs - short term (< 1 year)
  - Recurring costs - long term (> 1 year)
- Applicable to a minority of patients:
  - One-off costs
  - Recurring costs - short term (< 1 year)
  - Recurring costs - long term (> 1 year)
- Not applicable.

Table 20 – Checklist for non-healthcare costs

Non-healthcare cost group	Applicability of the cost group to PD
Transport to and from healthcare facilities using various modes of transportation, including private vehicle (including costs such as parking and tolls), shared car, bus, train, airplane, and ferry. Also includes taxis if public transport is inaccessible, as well as adapted transport services for people with reduced mobility.	Applicable to a majority of patients: recurring costs – long term After hospitalisation there is often lifelong treatment by psychiatrist or psychologist Remark: during the hospitalization there is also the cost of transport for visiting family
Accommodation nearby the healthcare facility if the healthcare facility is a long way from home. This concerns accommodation outside the healthcare facility, as this indicator concerns non-medical costs. Accommodation outside the healthcare facility may, for instance, be required when the treatment takes place abroad.	Not applicable There are sufficient hospitals in Belgium.
Adaptations of the home, the workplace or the car. These adaptations can take form in many ways, e.g. adapting a room to accommodate a home dialysis machine, making doors wider so that a wheelchair can pass through, installing a stair lift, ergonomic furniture, etc. Adaptations may be required in different parts of the house: kitchen, bathroom, toilet, living room, bedroom….	Not applicable
Support and assistance for day-to-day activities when provided by professional (paid) caregivers, for example, for • Personal care: washing, dressing, toilet • House maintenance, cleaning, laundry, meal preparation, gardening, … • Activities in the community: shopping, transport outside the house Note that when this support is provided by family or friends (i.e. informal caregivers), then this often does not lead to expenditures for the patient. Productivity losses incurred by informal caregivers are also a cost, but these are considered in a separate indicator.	Applicable to a majority of patients: recurrent costs – long term Many patients require support for house maintenance, (however often patients cannot afford this). Support for personal care is generally not required. Support for shopping is also generally not required but may be needed by a small minority of patients.
Institutionalisation in case the patient needs to be institutionalised (e.g. persons with young dementia who are in a residential care centre).	Not applicable However, a minority of patients live in sheltered living
Specialised equipment: e.g. wheelchair, scoot mobile, assistive devices for communication, insoles, walker (rollator).	Not applicable
Technology and subscriptions: devices or software to assist with daily tasks, such as voice-activated systems, health-monitoring apps or personal alarms.	Not applicable Patients can use free apps to follow-up e.g. their state of mind
Education, training or work reintegration programme: to learn new skills to adapt to limitations or to re-enter the workforce.	Not applicable Some Individual Placement and Support (IPS) projects are ongoing, aimed at reintegrating people with psychotic disorder in paid employment. Participation to these projects

	usually do not imply additional costs for the patient.
Personal hygiene items: e.g. incontinence products, bandages, wound care material.	Not applicable
Specific diets or nutritional supplements: these should only be considered when they pose supplemental costs compared to a regular diet.	Not applicable Remark: patients taking antipsychotics may gain weight as a side effect of the medication.
Prescribed sporting activities: e.g. cardiac rehabilitation after a cardiovascular event.	Not applicable Exercise is often recommended, but usually there are free possibilities like walking.
Specially adapted clothing/shoes/…	Not applicable
Additional energy costs: heating, electricity or water costs, if someone's condition requires an above average temperature maintained in the home, for example, or for charging wheelchairs.	Not applicable
Additional waste costs: e.g. when using certain medical devices	Not applicable
Additional costs for leisure activities or travel: e.g. because a patient has to pay extra to bring medical equipment, has to use adapted facilities,...	Not applicable There may be difficulties however with holiday cancellation insurance: the policies sometimes state that people cannot invoke a psychotic phase to cancel a trip.
Additional insurance costs: insurers may demand higher insurance premiums or reject applications for mortgages, life insurance, health insurance, travel insurance, etc.	Applicable to a majority of patients: one-off costs Sometimes people pay more than double for mortgage protection insurance when purchasing a home.
Other costs	If a person is admitted to hospital, the cost of renting an apartment/house continues.

In summary, patients with PD face extra costs outside the healthcare sector mainly for:

- transport to and from the healthcare facilities,
- support and assistance for house maintenance,
- additional insurance costs.

The problematic of additional insurance costs was also raised in some of the patient interviews:

> *"And we went to ask for a loan from the bank, and then you have to fill out a questionnaire, which asks about both physical and psychological antecedents. I filled it out honestly, stating what I had suffered from, that I had experienced psychosis, and then there was a follow-up questionnaire, which I also filled out very honestly. And then I received a quote in the mail that was five times higher than what was initially proposed. So that was also quite a struggle." (N3)[178]*

6.5 Other unmet patient needs

In addition to the structured survey items, respondents were invited to elaborate on unmet needs through an open-ended question at the end of the survey. Based on 60 responses, several additional themes emerged that were not covered in other parts of the report.

First, respondents highlighted the **need for a more human and respectful approach to psychiatric care**, particularly in crisis situations. Acute interventions were described as traumatising or dehumanising, with references to isolation, restraint, and forced medication that left lasting emotional consequences. These accounts reflected a strong call for crisis care that was more human, gentle, and trauma-informed, with interventions focused on emotional rather than control. Beyond the procedural aspects, respondents also expressed a broader wish to be recognised and valued as individuals, rather than being defined solely by their diagnosis.

> *"Not good at all. Some nurses were good, others were less good. But I felt that the whole policy was simply about exercising power and keeping you as calm as possible by giving you a lot, a lot of medication, and by locking you up in the isolation cell. I also sometimes had the feeling that they were laughing at me. When they don't treat you well, you end up doing strange things because of fear and feeling unsafe, things you normally wouldn't do. And then they started laughing. I found that very, very distressing." (N11)[179]*

> *"Those people are so harsh with you there. And there is just no empathy. I also had certain experiences with nurses where they said things to me that afterwards I thought: what on earth made you say that, what added value does that have?" (N12)[180]*

> *"And certainly not fixation, right? In a psychosis that must be hell. I think coercion is something they really should use as little as possible. Also, coercion to take medication, you have delusions, you're suspicious, and then they force you to take something or give you an injection. That doesn't seem okay to me. Of course, when you're very deep in those delusions, you can't decide for yourself: 'Okay, I'll take that pill because it will make me better.' In that moment, you simply can't." (N1)[181]*

Second, respondents drew attention to the importance of meaning, trauma, and peer connection in recovery. Many felt that the **personal or symbolic aspects of their psychotic experiences were rarely explored in care settings, and that links between psychosis and trauma were insufficiently acknowledged.** Peer networks were portrayed as vital sources of understanding, validation, and belonging, yet information about such initiatives was not always readily available, contributing to feelings of isolation. These accounts suggested that recovery-oriented care required greater emphasis on connection, shared experience, sense-making, and an approach that recognised each individual's unique needs and vulnerabilities.

> *"Peer networks has been very helpful, but there could be a little more information about 'look, this is how you can reach your fellow sufferers' because it just makes you feel good to know that you are not alone and that there is a kind of community. I think that can be beneficial for a lot of people, so that is something I would really like to see." (N16)[182]*

> *"Yes, and yet I think there are some very valuable initiatives that deserve more publicity. If you look at what psychosis means for people who are searching, it's a very valuable platform where people share 'I tried that and it worked for me'. So I got a lot of support from that." (N3)[183]*

> *"While I needed help with the content, what happened? Um, where did that come from? And that was absolutely not addressed, and it's not long-term, right? While I think that with psychotic vulnerability, you may need psychological help for longer, so I don't have that at all. I can't afford it either." (N9)[184]*

> *"Yes, during the admission, giving more meaning to your, well, not really giving meaning to your delusions, but talking to you about them, asking 'what thoughts did you have and how did you experience that'? Because they didn't talk about that. It was more like, 'yes, how did you*

end up here and what kind of person are you?' And that's all very positive but going into more detail about how it was for me, my experience or yes." (N16)[185]

Finally, a complex array of administrative tasks was also considered as a burden. Participants reported that interacting with healthcare systems, insurance providers, and social services requires significant time, effort, and cognitive resources.

"Communication was very difficult with the health insurance in the beginning. They were not open at all because mistakes had happened, financially, my allowance was way too little. I really had to move heaven and earth before they openly explained how it was calculated, and how it could be corrected." (N9)[186]

"Even on an administrative level, I had quite a few problems. I was the only one at home who always kept track of all the paperwork, paid the bills, and knew what had to be done. I couldn't do that anymore. It was a chaos of papers, and I didn't really know, 'what does this mean here, and what am I supposed to do with it?" (N3)[187]

"Well, it's really complicated because the procedures are extremely complex. You don't understand how it works, you don't understand what you have access to, who to contact, the opening hours, how to send back the papers… It really feels like it's designed so you can't get anything! It seems like it's really meant to trap the person. And so, communicating with the administrations is very difficult." (F3)[188]

Conversely, participants reported minimal challenges with administrative tasks, either due to their own competence in managing such responsibilities or because members of their care network such as family or social workers assisted in completing these tasks.

"Because you are in a convent community, you are already protected in that sense, because they take over for you, there's a central administration where everything is handled for you. But I notice with other patients that it's difficult for them." (N6)[189]

"I did bookkeeping in school, and I'm reasonably precise with administration. So filling out papers is kind of my thing, I follow it up properly." (N10)[190]

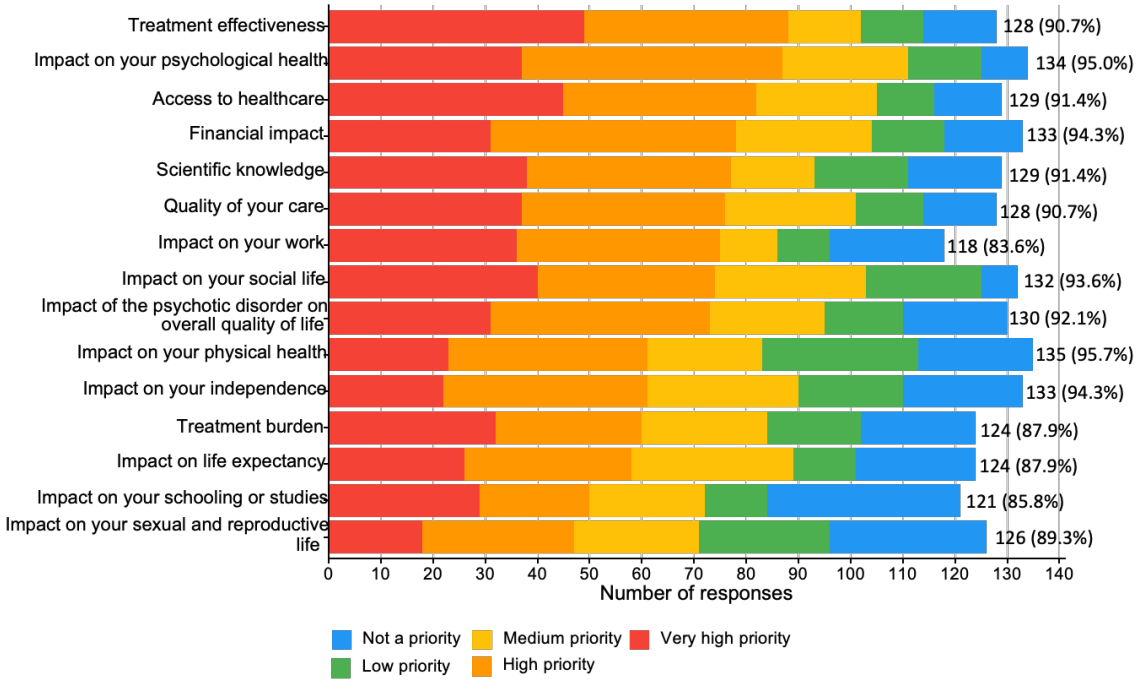
"My sister works at the health insurance fund and she always helps me complete my papers. I think if I didn't have my sister, it would be difficult, because it's not so simple what you always have to fill in." (N11)[191]

"There are social workers who help with certain administrative procedures, etc. And that's valuable, but again, you still have to look for it, ask for it." (F2)[192]

6.6 Prioritisation of patient needs

Survey respondents (n =141) were asked to provide a priority ranking to a list of 14 need categories, offering a comprehensive view of perceived importance across domains of living with PD (Figure 30). Treatment efficacy, psychological wellbeing and healthcare access received the highest proportions of 'high' and 'very high' priority ratings, with each domain prioritised by a large majority of respondents. More specifically, **the majority indicated treatment effectiveness to either be a very high (38%) or high (30%) priority. In addition, psychological health was mostly considered a very high (28%) or high (37%) priority. According to respondents, access to healthcare should also receive increasing attention, with most respondents indicating this to be a very high (35%) or high (29%) priority.**

Figure 30 – Priority rating of need categories, ordered by level of priority (n=141)



Differences were observed in the prioritization of unmet needs across several respondent characteristics (Appendix 7).

Participants younger than 30 years more frequently reported a high or very high priority for several domains compared with older age groups. This included the psychological impact of the disorder, which was prioritised by a higher proportion of respondents under 30 years as very high (46%) or high (41%) compared with those aged between 30-50 years old (31%; 41%) or those aged over 50 years (18%; 37%). A similar pattern was observed for the quality of care received, with younger respondents (<30 years) more often assigning a very high (71%) or high priority (12%) than respondents between 30-50 years (24%; 40%) or those aged more than 50 years (29%; 34%). In addition, younger participants more frequently assigned high or very high priority to the impact of the disorder on work (60%; 20%), overall quality of life (46% each) and schooling (40%; 20%), compared with older age groups. Among respondents aged 30-50 years, high or very high priority ratings were reported for work (34%; 41%), quality of life (28%; 34%), schooling (38%; 22%), while among those aged over 50 years, corresponding priorities were reported for work (30%; 52%), quality of life (20%; 43%); schooling (21%; 37%).

Differences in reported priority ratings were also observed according to respondents' financial situation. Respondents reporting greater financial difficulties more frequently assigned a very high (38%) or high (39%) priority to the financial impact of the disease compared with those reporting fewer financial difficulties (6.5%; 41%). Similar patterns were observed for treatment burden, with those reporting a strained financial situation assigning a very high (35%) or high (29%) priority compared to those reported less financial hardship (24%; 26%).In addition, the perceived impact on life expectancy was more frequently reported as very high (29%) and high priority (36%) by those in financial difficulty, compared to those with less financial hardship (18%; 28%). Finally sexual and reproductive life was reported as very high (18%) or high (31%) priority for those in financially difficulties compared to those reporting a more comfortable financial situation (21%; 29%).

Differences in priority ratings were also observed for scientific knowledge according to time since diagnosis and geographical region. Respondents who had been diagnosed for more than 10 years more frequently reported scientific knowledge as a very high (37%) or high priority (43%) compared

with those diagnosed within the last 10 years (31%; 21%). In addition, respondents living in Wallonia less frequently prioritised scientific knowledge as very high (33%) or high (30%) compared with those living in Flanders (33%; 40%) or Brussels (39%; 28%).

Variation by time since diagnosis was also observed for priorities related to physical health. Respondents diagnosed more than 10 years ago more frequently assigned a very high (21%) or high (37%) priority to the impact on physical health than those diagnosed within the past 10 years (20% and 29%, respectively). Moreover, differences were observed for life expectancy, with respondents diagnosed more than 10 years ago more frequently reporting this to be a very high (30%) or high (34%) priority than those who received their diagnosis within the past 10 years (17%; 28%).

No variations were found for gender, living situation and educational level (Appendix 7).

Participants reported that having treatment that was effective and tailored to their individual needs was one of the main priorities. They emphasized the importance of being listened to and involved in decisions regarding their care, rather than having interventions imposed upon them. The psychological impact of the disorder was described as profound, with emotional stress, anger, fear, and confusion affecting daily life and requiring careful management. Participants also highlighted the need for good access to care, including follow-up support and psychotherapy, to ensure continuity and comprehensive management of the disorder.

> *“Through molecules tailored to individuals... I mean, depending on different profiles, I think it's really important to listen to patients and what they have to say. Personally, I felt at first that something was being imposed on me. But maybe that's part of schizophrenia too.” (F1)[193]*

> *“There was no treatment plan, at least there was no treatment plan to offer for psychotic disorders. It was really only focused on treatment and medication. Because, as the psychiatrist explained to me at the time, these were drugs that were not harmless. So it was absolutely necessary to be monitored by a psychiatrist, which was done. But that was really all there was to it."(F5)[194]*

> *“So yes, well, I notice that when something quite emotional happens to me, it's because of emotional stress that I still sometimes find it difficult *laughs*, that I have a tendency to slip into that and that I really have to counteract it.”(N9)[195]*

> *“That psychotherapy is something that should be made more accessible, that people should be able to refer you to it more easily, but also that more space should be made for it after such an admission.” (N10)[196]*

7 RESULTS - UNMET SOCIETAL NEEDS

KEY POINTS

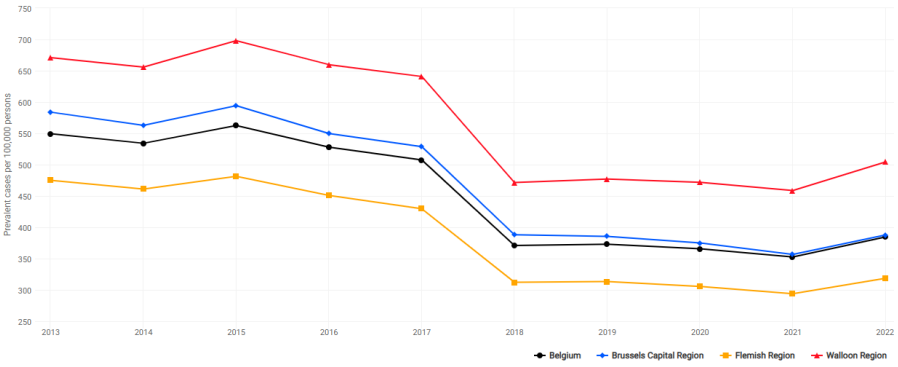
- The prevalence of schizophrenia is estimated at 384.5 per 100 000 in 2022 in Belgium and is slightly higher in men than in women.
- The average annual healthcare cost of psychosis in 2022 was €8 293 per patient, with most costs occurring in ambulatory care and largely covered by compulsory health insurance.
- Primary prevention for psychotic disorders in Belgium remains minimally implemented, with major modifiable risk factors addressed only through isolated, locally variable, underpowered, and insufficiently monitored initiatives, with no integration into a coordinated psychosis-specific mental health strategy.
- Patients with psychotic disorders experience prolonged work absenteeism, with most reporting 1–5 years of inability to work and a substantial proportion absent for over 10 years.
- Psychotic disorders are associated with moderate but highly variable work productivity loss, with a median impact score of 5 out of 10 among patients who continued working.
- Caregivers of individuals with psychotic disorders spend a substantial and variable amount of time providing support, with a median of 16 hours per week.
- Caring for a person with psychotic disorder has a substantial impact on caregivers' health, with nearly 80% reporting a high or extreme effect.
- The main contributors to the environmental footprint of psychiatric care are energy use during appointments and hospital visits, rather than the medications or injection materials themselves.
- Psychiatric medications persist in the environment and can harm aquatic organisms, highlighting the need for better pharmaceutical waste management and mitigation strategies.

7.1 Frequency

7.1.1 Prevalence

In 2022, **the prevalence of schizophrenia in Belgium was estimated at 384.5 per 100 000 population**.[143] Prevalence was slightly higher among men (408.2 per 100 000) than women (361.6 per 100 000). Regional differences were observed, with lower prevalence in Flanders (318.7 per 100,000) compared to Brussels (397.7 per 100 000) and Wallonia (504.4 per 100 000) (Figure 31). Age-specific data indicate that schizophrenia was most prevalent among individuals aged 45–64 years and those aged 85 years and older (Table 23).

Figure 31 – Prevalence of schizophrenia in Belgium, by region, 2013-2022



Source: Sciensano, BeBOD

Table 21 – Prevalent cases of schizophrenia in Belgium, per 100 000 population, per age-group, 2022

AGE	VALUE
0-4	0.0
5-14	25.9
15-44	1 497.3
45-64	2 452.2
65-84	2 418.4
85+	2 590.1
ALL	384.6

7.2 Transmissibility

7.2.1 Contagiousness

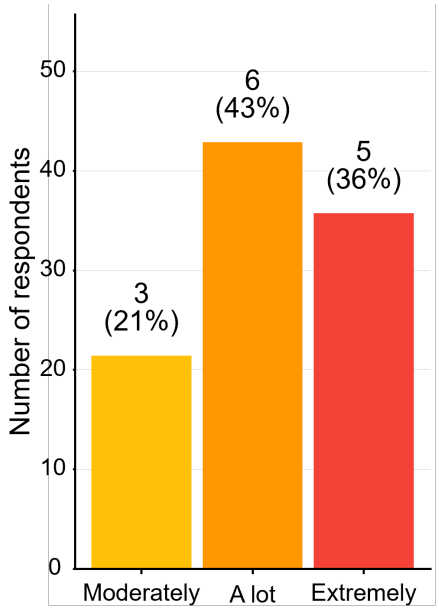
Not applicable

7.3 Burden on informal caregivers' health

7.3.1 Impact on informal caregivers' health

Caregivers who participated in the patient survey on behalf of a person living with PD (n = 14) were questioned on the impact of caring for a person with PD on their health (Figure 32). **Results showed that caregivers experienced substantial health effects, with nearly four in five (79%) describing the impact as a lot or extreme. More specifically, 43% reported a lot of impact, and 36% experienced an extreme impact on their own health. A smaller proportion (21%) reported the impact on their own health to be moderate.**

Figure 32 – Impact of PD on caregiver's health (n = 14)



7.4 Value for money of standard of care

7.4.1 Healthcare costs relative to the effectiveness of standard of care

7.4.1.1 Healthcare costs of standard of care

In the year 2022, **the average total healthcare costs attributable to psychosis accounted for €8 293 per patient** (95% CI: €7 675 - €8 850).

About 60% of healthcare costs occur in ambulatory setting. About 20% of the costs relate to hospital setting. For the remaining costs (about 20%) the setting is undetermined (see Figure 33).

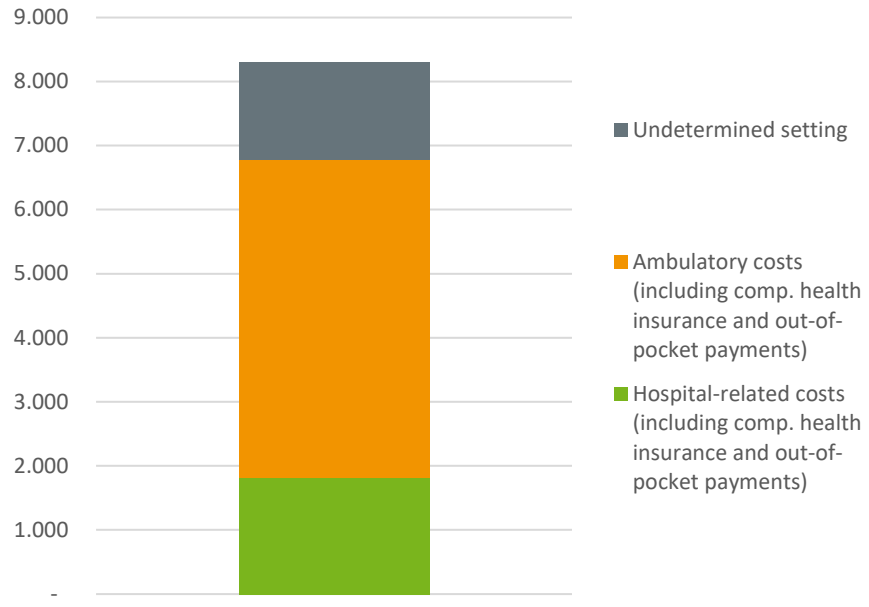
About 20% of the total healthcare costs are paid by the patient. The remaining 80% is covered by compulsory health insurance (see Figure 34).

Figure 33 and Figure 34 show how this total incremental cost splits up into different cost categories. Note however that the sum of the average incremental cost of the cost categories is not exactly equal to the total average incremental cost (= €8 293) due to the way it is calculated (see section 5.5).

About 60% of healthcare costs occur in ambulatory setting. About 20% of the costs relate to hospital setting. For the remaining costs (about 20%) the setting is undetermined (Figure 33).

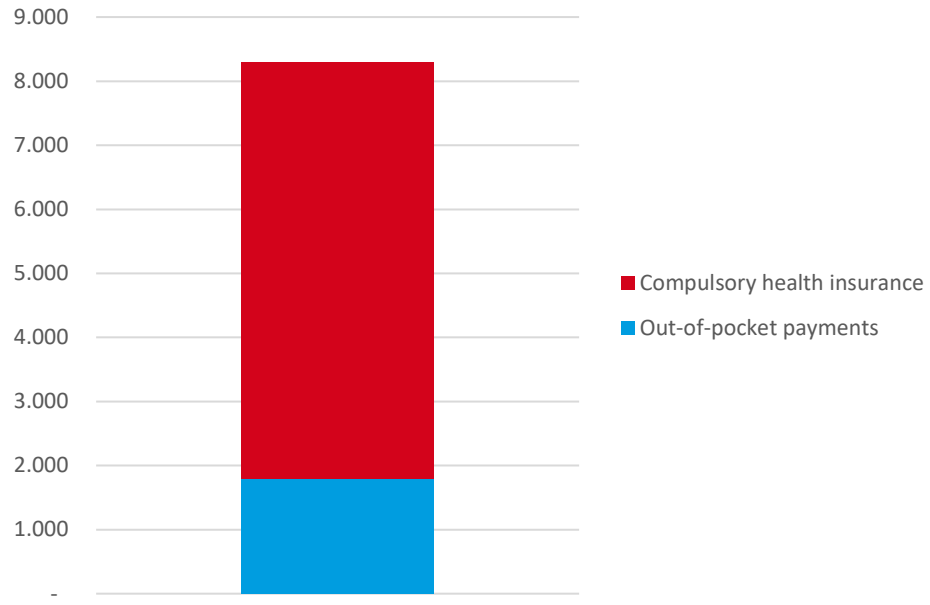
About 20% of the total healthcare costs are paid by the patient. The remaining 80% is covered by compulsory health insurance (Figure 34).

Figure 33 – Average incremental healthcare cost attributable to psychosis by cost category (2022)



Source: Based on calculations from Sciensano (Harry Vranken).

Figure 34 – Average incremental healthcare cost attributable to psychosis: out-of-pocket payments versus compulsory health insurance (2022)



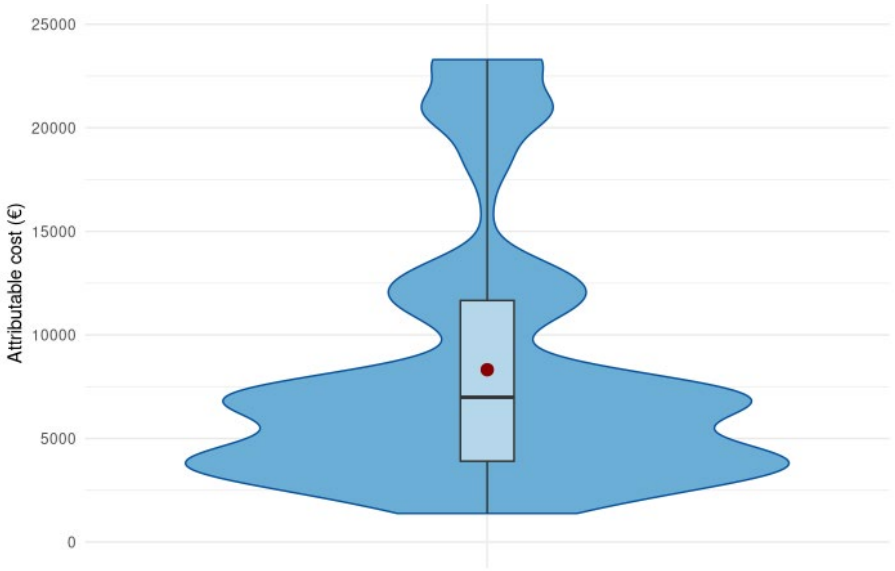
Source: Based on calculations from Sciensano (Harry Vranken).

A boxplot and violin plot is used to summarize the distribution of healthcare costs per patient attributable to psychosis (see Figure 34). Note that due to the way how the cost per patient is calculated, only a number of predicted values are possible, equal to the number of observed

combinations between the predictive variables (age categories, gender, region, increased reimbursement). The box plot therefore shows several “bumps” at the amounts where such a combination occurs, with gaps between the bumps. This is because the costs are predicted and not observed. The reason predicted rather than observed amounts are used is because this is the only way the incremental cost (the cost resulting from having psychosis) can be calculated.

The mean cost is higher than the median cost and the mode (the value that appears most frequently) lies below the median. This means that for most patients costs are situated at the lower end (below or near the median) and that there is a tail toward higher costs. This tail represents a relatively lower number of patients incurring very high costs and this is what pulls the mean upward.

Figure 35 – Distribution of healthcare costs (per patient) attributable to psychosis (2022)



Source: Graph provided by Sciensano (Harry Vranken). Dot: mean, Bold line in middle of box: median, Upper line of box: Q3, Bottom line of box: Q1, Upper whisker end: maximum, Lower whisker end: minimum

7.4.1.2 Effectiveness of standard of care

For the evaluation of the effectiveness of standard of care (current treatment), we refer to the following indicators and sections:

- Effectiveness of current overall treatment/management (section 6.3.1)
- Years of life lived with disability per case (section 6.2.2.1)
- Years of life lost per case (section 6.2.1.2)
- Years of life lost per death (section 6.2.1.1)

7.5 Preventability

7.5.1 Implementation of effective primary prevention strategies

The following section reports the results derived from the clinical expert survey.

Primary prevention for psychosis in Belgium was described by clinical experts as only '**minimally implemented'**, i.e. few or isolated efforts exist to address the health condition through primary prevention strategies, with little impact on population health.' Clinical experts noted that primary prevention would require **systematically addressing** several well-established **modifiable risk factors**, yet current efforts remain very limited.

Within these modifiable risk factors, high-potency **cannabis use** is targeted mainly through general addiction-prevention programmes, but experts note that the emphasis lies largely on legal and repressive aspects, with too little attention to mental-health consequences or the risk of developing psychosis. **Childhood adversity**—including bullying, growing up in poverty, social exclusion, and exposure to violence—is recognised as an important determinant, and while there are initiatives such as OCJ or *pleegzorg* programmes for children in dire circumstances, these remain isolated rather than part of a broader preventive framework. Preventive programmes addressing **obstetric complications**, **social deprivation**, increasing **green spaces**, and **organised sports activities** for young people (particularly **for families living in poverty and for migrants**) are also cited as initiatives that could make a difference but which are currently patchy and not coordinated within a comprehensive strategy. It was also noted that addressing these modifiable risk factors would only capture a portion of the overall risk of developing psychotic disorders.

Across the responses, experts emphasise that **Belgium has no coordinated national strategy** addressing these determinants. Current initiatives are described as **fragmented**, **locally variable**, **underpowered**, **not psychosis-specific**, and **insufficiently monitored** for population impact. There is no systematic measurement, risk assessment, or follow-up, and prevention efforts are not integrated into a comprehensive mental-health strategy. Although national reforms such as PSY107 have strengthened community-based care, these developments are seen as primarily supporting early detection and treatment (i.e. **secondary and tertiary prevention**) rather than preventing onset in the general population. As a result, psychosis-specific primary prevention remains patchy and limited in effectiveness.

Survey participants also reflected on the need for better prevention strategies. They indicated that that there remained a need for a structured prevention plan, encompassing aspect such as guidance on how to approach and communicate with a person during a psychotic episode, the designation of a confidant and/or representative, and support in addressing the potentially traumatic experiences associated with isolation and restraint.

7.6 Productivity losses

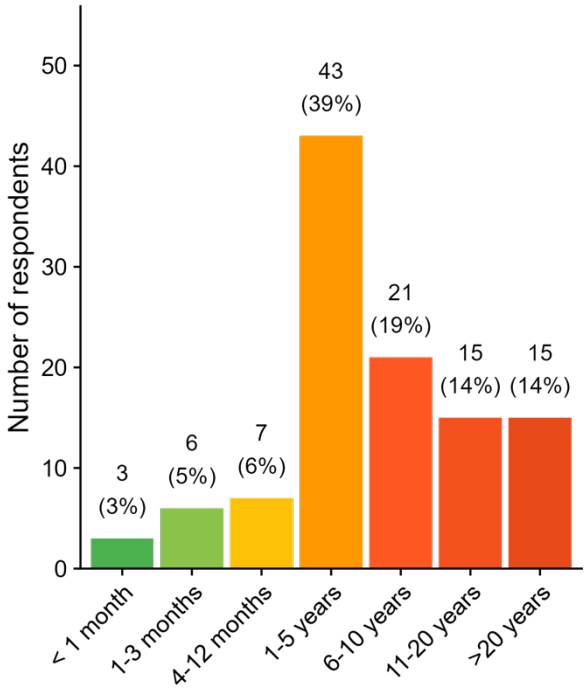
7.6.1 Absenteeism of patients

The following section reports the results derived from the patient survey, based on respondents' answers to questions: S3, S3B, D13 and D13B. Data from the Knowledge Centre for Work Incapacity from RIZIV–INAMI were not yet available at the time of publication of this report, but will be added in the NEED database when available.

In question S3 respondents were asked to estimate the total duration for which they had been unable to work due to their psychotic disorder, including all periods of sickness leave regardless of whether these were consecutive. Response options were categorical and included: *less than one month*, *one to three months*, *four months to one year*, and *more than one year*. Respondents selecting *more than one year* were subsequently asked in question S3B to provide an estimate of the total number of years they had been unable to work.

Psychotic disorder leads to long periods of absence from work and there is considerable variation between the patients. Of 110 responses, the most frequent reported duration was 1–5 years (39%), followed by 6–10 years (19%), and both 11–20 years and ≥20 years with 14% each. Shorter interruptions such as 4–12 months (6%), 1–3 months (5%), and less than 1 month (3%), were less common.

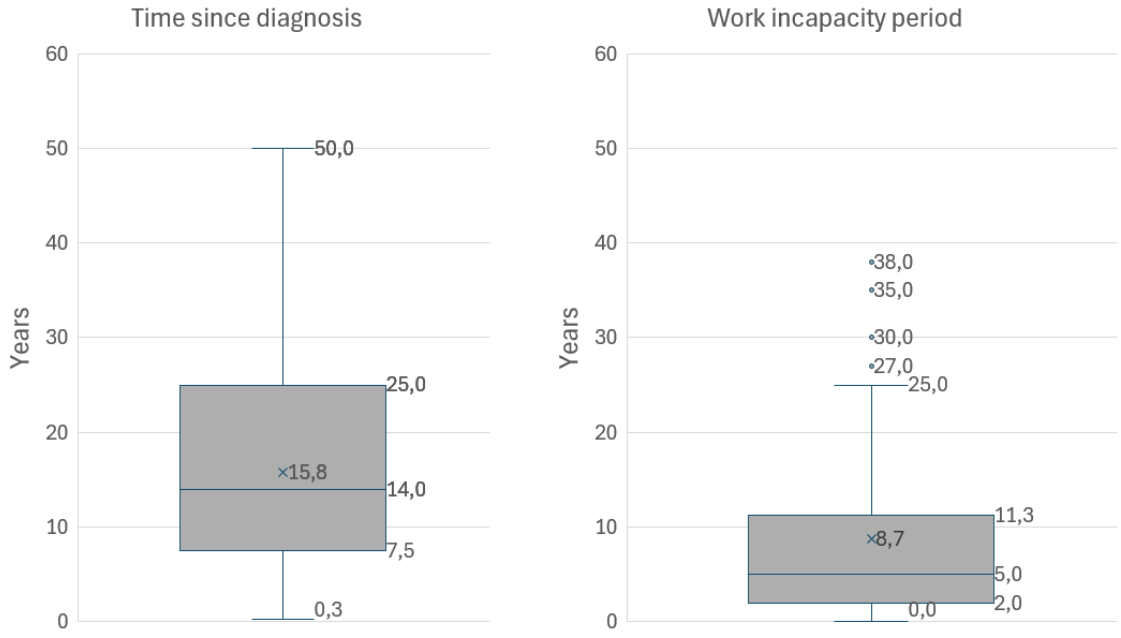
Figure 36 – Impact on time not working because of the illness (n=110)



As the duration of work incapacity may vary with time since diagnosis, the results on the two corresponding questions in the survey (questions D13 and D13B) were put side by side (Figure 37). For the respondents with a work incapacity period of more than one year we obtained a numeric value for the total number of years. For the other respondents we obtained a categorical response (e.g. *from one to three months*). In order to also include the categorical responses in the figure, we converted these categorical responses into numeric values by taking the midpoint estimate (the average of the lower and upper limit of the response category). The same approach was followed for the time since diagnosis. Note that there were less respondents for the question on 'work incapacity period' (n=110) than for 'time since diagnosis' (n=157). This is mainly due to the fact that there were 31 'I don't know' answers for the work incapacity period.

The median time since diagnosis was 14 years whilst the median work incapacity period was 5 years. The mean time since diagnosis was 15.8 years whilst the mean work incapacity period was 8.7 years. Whilst the time since diagnosis varied from 0.25 ('less than six months') to 50 years, the total work incapacity period varied from 0.04 ('less than one month') to 38 years.

Figure 37 – Time since diagnosis (left) (n=157) and total work incapacity period (right) (n=110)



*X: mean, Line in middle of box: median, Lower line of box: Q1, Upper line of box: Q3, Lower whisker end: Q1 – 1.5*IQR, Upper whisker end: Q3 + 1.5*IQR, Dots outside whiskers: outliers*

In line with the NEED protocol, a ratio was calculated dividing the work incapacity period by the time since diagnosis (Figure 37). Before performing this calculation, respondents who were only recently diagnosed (< 6 months ago) were excluded. The resulting median ratio was 0.5, indicating that – at the median - the work incapacity period was half the time since diagnosis**. The ratio varied however considerably, from close to zero (people answering work absence less than three months whilst having received the diagnosis many years ago) to higher than one (people who were absent from work for a period longer than the time since diagnosis)** (Figure 38). The latter can be explained by the fact that some people were already (getting) sick and absent from work before receiving the diagnosis.

Figure 38 – Ratio of work incapacity period to time since diagnosis (n=106)



*X: mean, Line in middle of box: median, Lower line of box: Q1, Upper line of box: Q3, Lower whisker end: Q1 – 1.5*IQR, Upper whisker end: Q3 + 1.5*IQR, Dots outside whiskers: outliers*

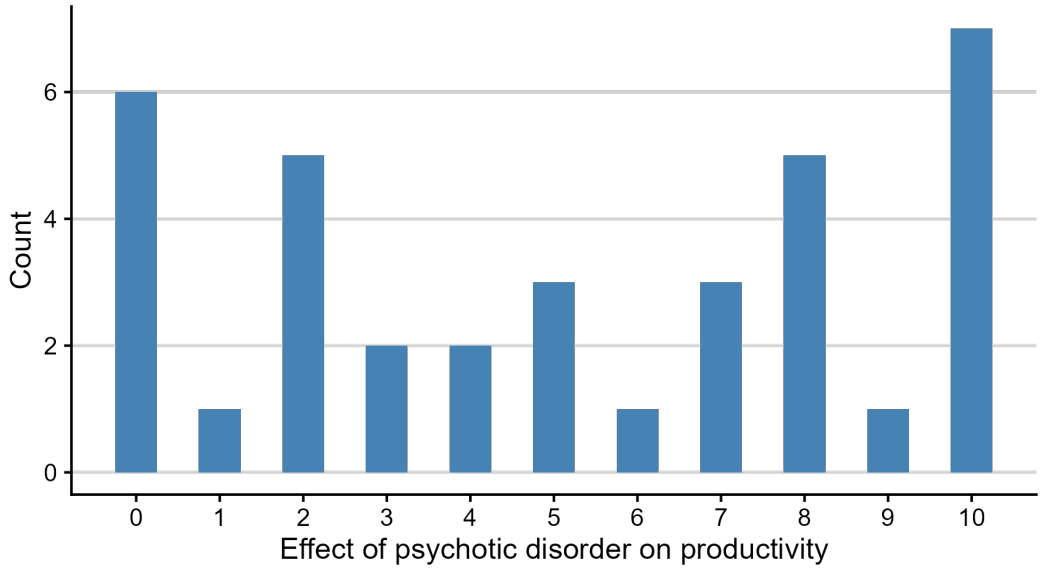
7.6.2 Presenteeism of patients

The following section reports the results derived from the patient survey, based on respondents' answers to question: S4: "*To what extent has the psychotic disorder affected your productivity at work over the past seven days*? Think about the days on which you were limited in the amount or type of work you could do, the days on which you achieved less than you wanted, or the days on which you could not perform your work as carefully as usual. If your psychotic condition had little impact on your work, choose a low number. Choose a high number if your psychotic disorder had a large impact on your work." This question was only asked to patients who did not stop working. As response, a number could be given on a scale from 0 to 10:

The psychotic disorder has not had an impact on my work	0 1 2 3 4 5 6 7 8 9 10	Because of my psychotic disorder I have not been able to work at all

Figure 39 shows that many patients experienced a substantial loss of productivity at work. Responses were widely distributed across the scale, indicating considerable variability in how the disorder affected work performance, with some patients responding a zero impact on productivity up to some patients responding that working was not possible at all. Overall, **the median productivity impact score was 5 with IQR 2-8, reflecting a moderate level of productivity loss** and underscoring that a psychotic disorder is commonly associated with meaningful impairments in workplace functioning.

Figure 39 – Patients' loss of productivity at work (n = 36)



0: The psychotic disorder has not had an impact on my work; 10: Because of my psychotic disorder I have not been able to work at all

7.6.3 Work reduction or early labour force exits of patients

See section 4.4.3.

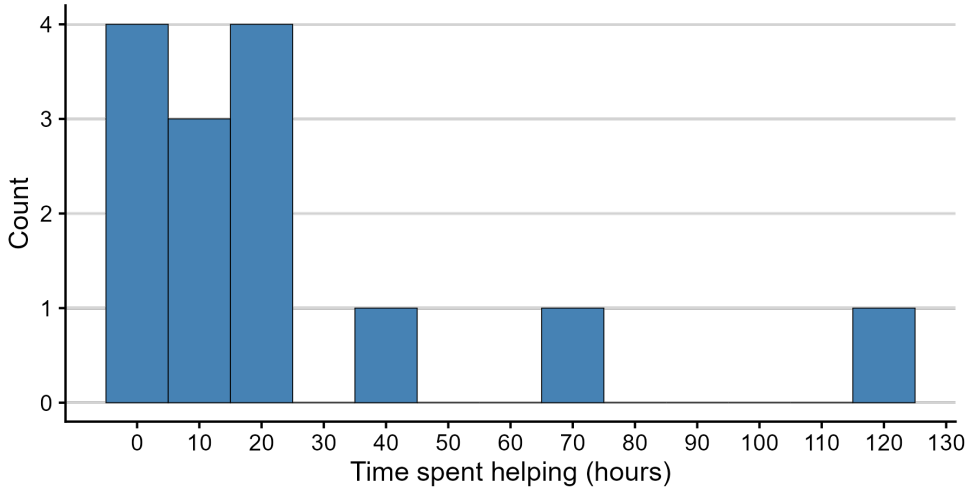
7.6.4 Informal caregiving time burden

The following section reports the results derived from the patient survey for informal caregiver, based on respondents' answers to question CG5: "*How much time did you spend during the past week helping the person with activities that he/she would normally have done on their own if they were in good health? For example, personal care (e.g., dressing and undressing, using the toilet, …), household tasks (e.g., preparing meals, cleaning, …), or practical support (e.g., accompanying to medical or other appointments, …)*". Respondents were asked to provide the number of hours they spent on this in the past week. In addition, relevant in-depth themes emerging from the qualitative interviews for proxies were integrated to further contextualise these findings.

It should be noted that this question was only asked in case it was a caregiver who filled out the questionnaire. So in case it was the patient him/herself who filled out the questionnaire, this question was not asked. This could lead to a bias in the results in the sense that when caregivers fill out the questionnaire, it may concern especially those patients who have higher support needs.

The caregivers who responded to the survey devoted a substantial amount of time to assisting the person with a psychotic disorder with activities they would normally perform independently. Responses varied widely, indicating considerable heterogeneity in caregiving intensity (Figure 40). The median time spent helping during the previous week was 16 hours, with an interquartile range of 5 to 20 hours, highlighting that caregiving often involved a significant weekly time commitment.

Figure 40 – Caregivers weekly time spent on providing help (n = 14)

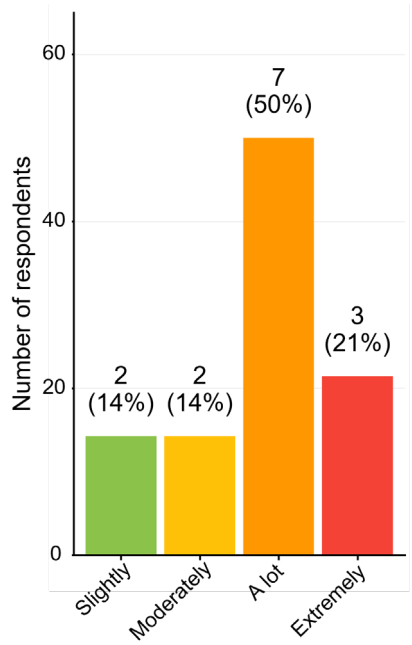


7.7 Burden on informal caregiver's social life

7.7.1 Impact on informal caregivers' social life

The perceived impact of the respondent's illness on their caregiver's social life (n = 14) are presented in Figure 41. Reported impacts ranged from slight to extreme, with no respondents indicating no impact. Specifically, two caregivers (14%) reported a slight impact, two (14%) a moderate impact, seven (50%) a lot, and three (21%) an extreme impact. Overall, more than two thirds (71%; n = 10) reported a strong or extreme level of disruption linked to the respondent's illness.

Figure 41 – Impact on social life caregiver (n = 14)



Percentages may not sum to 100% due to rounding

7.8 Environmental impact of standard of care

The environmental consequences of psychiatric care extend beyond direct clinical outcomes, encompassing greenhouse gas emissions, energy consumption, resource use, and the generation of hazardous waste.

7.8.1 Greenhouse gas emissions related to the standard of care

The environmental footprint of psychiatric care is shaped by multiple lifecycle stages — from pharmaceutical manufacturing and distribution to healthcare facility operations and patient travel. Current evidence suggests that **the dominant contributors to greenhouse gas emissions in standard care pathways are energy use associated with healthcare delivery and patient appointments, rather than the materials used in medications themselves.**

In Belgium, Debaveye et al. found that psychiatrist visits and hospital care were the principal drivers of the carbon footprint for long-acting injectable antipsychotic treatment, largely due to energy consumption in outpatient services and inpatient settings.[147] Similarly, Maughan et al. reported that in England **the majority of the carbon footprint was attributable to energy demands for appointments (approximately 195 000 kg CO_2e) and medication production and distribution (≈90 300 kg CO_2e),** with the physical materials used for injections contributing a substantially smaller portion.[148]

These findings suggest that strategies to reduce greenhouse gas emissions in psychiatric care should focus on energy efficiency in clinical setting, the optimization of appointment scheduling, and the potential expansion of telepsychiatry services.

7.8.2 Hazardous waste related to standard of care

Psychiatric medications, including antipsychotics and antidepressants, **have been increasingly detected in environmental matrices, such as municipal wastewater, hospital effluents, rivers, lakes, marine environments, and even treated drinking water**.[149, 150] primary pathways for environmental contamination include excretion of unmetabolized drug residues by patients, improper disposal of unused medications, and insufficient removal during conventional wastewater treatment processes. Ecotoxicological studies indicate that chronic exposure to psychiatric medications can adversely affect aquatic organisms. For example, Argaluza et al. demonstrated that antidepressants can alter behavior, reproduction, and physiological processes in fish, while antipsychotics may disrupt enzymatic activity and microbial community structure in freshwater ecosystems.[151] These compounds are persistent in the environment and have the potential to bioaccumulate, raising concerns about long-term ecological impacts and the effects of chronic exposure on higher trophic levels. Effective mitigation of pharmaceutical contamination in the environment requires comprehensive measures, including the development of drugs with improved biodegradability, and enhancements in wastewater treatment technologies capable of removing complex organic compounds.

7.8.3 Use of natural resources and raw materials related to standard of care

No relevant studies were found. The absence of such studies highlights a notable knowledge gap, as resource use is a fundamental component of the broader environmental impact of healthcare.

8 RESULTS - UNMET FUTURE NEEDS

KEY POINTS

- There are currently very few robust estimates of predicted needs related to psychotic disorders both globally and nationally.
- Schizophrenia prevalence in Belgium is projected to decrease by 2040.

8.1 Forecasted burden of disease

8.1.1 Forecasted prevalence

The following section reports the results derived from a database analysis using BeBOD. The prevalence of schizophrenia in Belgium is expected to decrease from 44 770 cases in 2022 to 21 037 cases (95% Credibility Interval: 19 301- 22 607) in 2040.[152] The forecasted prevalence of schizophrenia in Belgium is estimated at 171 per 100 000 in 2040. These results are based on past observed trends and therefore represent a continuation of historical patterns. The observed decline in the forecasted prevalence of schizophrenia may largely reflect changes in diagnostic criteria, diagnostic substitution, and evolving case definitions.[153]

8.1.2 Forecasted years of life lost per death

Not available

8.1.3 Forecasted years of life lost per case

Not available

8.1.4 Forecasted years lived with disability per case

The forecasted years lived with disability per case will remain stable and is estimated at 0.71 YLDs per case in 2040.[152]

8.2 Forecasted healthcare costs

8.2.1 Forecasted healthcare costs attributable to the health condition

Not available

8.3 Forecasted productivity losses

8.3.1 Forecasted productivity losses attributable to the health condition

Not available

9 INEQUITIES

KEY POINTS

- Financial hardship amplifies the impact of psychotic disorders across clinical, social, and care dimensions, including symptom severity, HRQoL decline, personal relationships, sexual health, and access to support.
- Age, gender, and educational attainment create additional inequities, influencing symptom burden, psychological impact, daily functioning, and educational or social support needs.

Within the Belgian context, the NEED framework explicitly recognises equity as a transverse dimension in assessing unmet health-related needs. It emphasises that unfair and avoidable differences in health outcomes, care accessibility, and social participation exist among individuals with PDs often determined by socio-economic status, ethnicity, and migration status.

Across the analyses, an equity gradient emerges, showing that the burden of PDs and the experience of unmet needs are not evenly distributed across the population. Socio-economic position, age, gender, education, and time since diagnosis consistently shape both disease impact and access to adequate support.

Financial situation emerged as the most consistent and cross-cutting determinant. Exploratory analyses revealed differences in the reported burden of several psychological symptoms according to respondents' financial situation, including fear or anxiety ($p = 0.016$), loss of self-confidence ($p = 0.007$), inability to feel interest or pleasure ($p = 0.035$), social isolation ($p = 0.02$), and agitation or feeling tense ($p = <0.001$), fatigue or drowsiness ($p=0.003$), memory problems or brain fog ($p < 0.001$), weight gain ($p = 0.012$), and involuntary facial movements ($p=0.016$). Beyond symptoms, respondents in a strained financial situation reported a higher median perceived impact on personal relationships (median 4.0 vs 3.0, $p=0.002$) and sexual health (median 4 vs 3, $p<0.001$), and respondent's financial situation also showed a difference in administrative and social support, with respondents reporting financial strain more frequently indicating such needs (36%) than those reporting less financial hardship (18%) ($p = 0.038$). Respondents in a strained financial situation were more likely to report that PD affected their education "extremely" (39%) compared with those in a comfortable financial situation (20%), while comfortable respondents more often reported no impact (34% vs. 23%).

Those reporting financial strain had a higher median burden score for treatment burden ($p<0.001$), impact on life expectancy ($p=0.034$), and sexual and reproductive impact ($p=0.032$), compared with those reporting less financial strain. Illustrating a cumulative disadvantage across clinical, social, and care dimensions.

Age-related differences further highlighted equity concerns. Differences in burden levels were observed across age groups for several symptoms, including feeling down, depressed or sad ($p = 0.005$) and fear or anxiety ($p = 0.01$), with additional differences observed for feelings of external control or influence among respondents aged 30–50 years. In parallel, differences in age categories for the psychological impact ($p=0.007$), quality of care ($p=0.008$), impact on work ($p=0.009$), quality of life ($p=0.031$), and schooling ($p=0.035$) was observed.

Some **gender differences** were observed, for instance, the prevalence of PD is higher in men than (408.2 per 100 000) than women (361.6 per 100 000) and men were more likely than women to report a severe educational impact, with nearly half of men (47%) indicating that PD affected their education "extremely," compared with 20% of women.

Educational attainment showed a social gradient. A positive median change in score was observed among respondents with a basic level of education for anxiety and depression (median change: +1.0; IQR: 0.0 – 2.0). Also, differences were observed between participants' level of education in usual activities (p=0.027), administrative and social support (p=0.022), environmental adaptations (p=0.001), school and study support (p=0.018), and peer support (p=0.027), and overall additional support needs (p=0.033).

Finally, **time since diagnosis** influenced both symptom burden and perceived priorities. Statistically significant differences in reported burden were observed according to time since diagnosis for agitation (p = 0.039) and disorganised thinking (p = 0.039), physical health (p=0.037), and life expectancy (p=0.008).

10 DISCUSSION

10.1 Summary of results

In this mixed-methods study, survey data were collected from 140 individuals with a psychotic disorder and 19 legal representatives and were complemented by 24 in-depth interviews with patients or their proxies, expert survey and database analysis. The patient survey sample was predominantly female (56%), mainly aged 30–50 years (55%), and most respondents had been diagnosed more than 10 years earlier (61%). **One-third of patient survey respondents reported a diagnosis of schizophrenia** (33%), while a substantial proportion reported an unspecified psychotic disorder (22%).

Patient unmet health needs

Respondents reported a statistically significant deterioration in HRQoL from the period before symptom onset to the present. While few studies directly measure "pre-onset" HRQoL retrospectively, the effect aligns with meta-analytic evidence showing substantially reduced HRQoL in schizophrenia compared with the general population, and persistent impairment across the different stages of the disorders.[154]

Symptom burden extended well beyond the positive type of symptoms. For instance, fatigue and exhaustion were reported by 90% (n=133) of respondents and were frequently rated as moderately to extremely bothersome. This is closely aligned with emerging systematic review and meta-analysis evidence indicating that fatigue is common in psychosis and is associated with clinical and functional correlates.[155] High levels of affective symptoms were also reported, including depressed mood and anxiety (both 89%), alongside concentration problems (87%,) and stress (85%). This is consistent with findings from meta-analysis indicating that depressive disorders and anxiety disorders are frequent comorbidities in schizophrenia, and contribute meaningfully to disability and poorer outcomes.[156, 157] Concentration problems are also consistent with the large and robust literature indicating broad, clinically relevant cognitive impairment in schizophrenia, including in early illness stages.[158]

Finally, many respondents reported impacts on sexual and reproductive health, which is consistent with high-burden sexual dysfunction in schizophrenia-spectrum disorders reported in literature, often linked to antipsychotic adverse effects and comorbid depression.[159]

Patient unmet healthcare needs

Care for psychotic disorders typically involves a combination of pharmacological and non-pharmacological interventions, including psychotherapy and psychosocial support. In the expert survey, psychiatrists rated treatment effectiveness for psychotic disorders as 'moderate'. This reflects that **existing approaches remain mainly symptomatic rather than disease-modifying**: combined pharmacological and psychosocial interventions can prevent relapses and improve quality of life but do not alter underlying vulnerability or target the core mechanisms.

Clinical experts highlighted the **heterogeneity in the course of psychotic disorders**, which range from transient complaints to severe, persistent impairment. Despite treatment, many patients face ongoing symptoms, difficult side-effect trade-offs, persisting negative and cognitive impairment, and sometimes treatment resistance. All these challenges also emerged from the patient survey.

Experts identified subgroups for whom treatment has particularly limited effectiveness, including those with treatment-resistant illness, multimorbidity or intellectual disability, adolescents and older adults, individuals with substance use, people facing socioeconomic vulnerability, and patients with limited illness awareness.

Structural and organisational issues such as **fragmented care, inconsistent community support, long waiting times, limited physical health monitoring**, and underuse of clozapine and long-acting injectables were reported by clinical experts as also restricting outcomes, leaving functional recovery and social reintegration uneven. Treatment availability for psychotic disorders in Belgium shows some gaps, mainly in terms of limited reimbursement for key non-pharmacological therapies, shortages of specialised professionals, and insufficient structural funding for early psychosis services and assertive community teams.

In addition to the only partial treatment effectiveness, the current **treatments for psychotic disorders also carry a significant burden**, **particularly in terms of side effects**. In the patient survey, treatment-related side effects were common and perceived as burdensome. Weight gain was reported as a side-effect by 74% of respondents, fatigue or drowsiness by 64%, and affective blunting by 45%.These adverse effects closely overlap with the literature that shows that commonly prescribed antipsychotics are associated with weight gain, sedation, and emotional blunting, thereby reinforcing symptom burden and negatively affecting quality of life and adherence.[160] Even beyond side effects, almost half of patient survey respondents rated their overall treatment as moderately to extremely burdensome, despite perceiving it as necessary.

Treatment availability for psychotic disorders in Belgium was described by clinical experts as having “some problems.” The main barriers to adequate treatment included the **lack of reimbursement for key nonpharmacological therapies**, which restricts access to long-term psychotherapy, physiotherapy, diet therapy, and rehabilitation. **Shortages of specialised professionals**, causing long waiting lists and insufficient knowledge of psychosis, further limit care. Moreover, **insufficient structural funding** was described as reducing coverage of crucial early psychosis services and assertive community teams. **Organisational barriers** limiting the use of evidence-based therapies such as clozapine and long-acting injectables were also mentioned as factors contributing to only moderately adequate real-world access to treatment.

Organisation and continuity of care emerged as recurrent concerns by patients in both the qualitative interviews and the survey data. Almost half of respondents reported that their care was never to sometimes well organised or planned over time, while 88% reported always or often seeing the same healthcare professional. **Difficulties in navigating services** were reported by interview participants as particularly salient in ambulatory care settings, where respondents described limited access to coordination or guidance compared with inpatient settings, where dedicated staff are more readily available. In addition, 44% of respondents indicated receiving sufficient clear and understandable information only ‘sometimes’, ‘rarely’ or ‘never’. These findings are consistent with a previous KCE report, reporting persistent weaknesses in mental healthcare delivery in Belgium for people with severe mental illness, including fragmentation, poor continuity, and insufficient care coordination.[161]

A large majority of respondents reported **little or no involvement in treatment choices** (92%). Nevertheless, nearly one-quarter of respondents (26%) explicitly indicated a preference not to be involved. Previous reviews show that, despite strong policy endorsement of shared decision-making in mental healthcare, routine implementation remains limited, and many patients continue to experience care as clinician-driven.[162, 163] Of course, preferences for involvement vary across individuals and can also evolve over time, making it important for clinicians to openly address the person’s desired level of involvement. During acute psychosis, impaired illness awareness can limit

shared decision-making, yet best-practice guidance stresses listening, preserving dignity, and keeping patients and families involved as much as possible, even when urgent safety decisions must override the person's wishes.[164, 165] Literature suggests that even modest, preference-sensitive increases in perceived involvement are associated with improved satisfaction, self-efficacy, adherence, and therapeutic alliance.[166]

Among 143 patient survey respondents, 35% indicated having forgone care in the past 12 months. Long waiting times were reported by 44% of those experiencing forgone care (n=22).[161] Among the patients who reported forgone care (n=50), fear of medical procedures or hospital environments was reported by 30%, which might be partly linked to stigma-related fears or illness-related anxieties limiting care use.[167-169] Moreover, financial barriers were a frequently reported reason for not receiving needed care, with 30% of those who forwent care citing difficulties paying for it. European data show that affordability is socially patterned and particularly salient for mental healthcare, with EU-wide analyses documenting substantial socioeconomic inequalities in mental healthcare.[170, 171] Distance between home and place of care (20%) and transportation difficulties (16%) were also reported by survey respondents as reasons for not receiving the needed care, particularly in contexts where mental health services are unevenly distributed.

Patient unmet social needs

The most frequently reported unmet needs for additional support concerned psychological support (30%), administrative or social assistance (23%), and opportunities for peer contact (23%). These findings are consistent with literature indicating that people with severe mental illness often encounter insufficient integration of social, administrative, and welfare-related support within mental healthcare services.[172, 173] Social relationships were profoundly affected, with approximately three quarters of respondents reporting moderate to extreme disruption of personal relationships. This impact was significantly greater among individuals in a difficult financial situation, reinforcing evidence that economic strain is correlated with social exclusion and relational vulnerability.[168] These results align with extensive literature documenting social withdrawal, loneliness, and loss of friendships among people with psychosis, particularly during acute and early phases, with difficulties frequently persisting after clinical stabilization.[173] While supportive relationships are widely recognised as critical for recovery and quality of life, stigma, communication difficulties, and comorbid depressive symptoms often impede social reintegration perpetuating a vicious cycle.[168, 173]

Educational trajectories were disrupted for more than half of survey respondents, reflecting known patterns of interrupted education, delayed completion, and dropout following onset of psychosis, especially when illness emerges during adolescence or early adulthood.[174, 175] Existing literature shows that educational outcomes vary according to age at onset, illness course, and availability of support, which might explain the heterogeneity in experienced educational impact in the present study.[175] Finally, psychotic disorder had a major impact on employment: of those who reported to be working before the onset of the symptoms 56% of respondents stopped working and 34% reduced work intensity. This closely mirrors international evidence showing persistently low employment rates and prolonged labour market disengagement among people with schizophrenia spectrum disorders.[176, 177] Importantly, these impacts can be mitigated with appropriate support. Meta-analyses demonstrate that Individual Placement and Support (IPS), which is also available in Belgium (e.g. De Hulster), significantly improves competitive employment rates and job retention compared with usual services, including in early psychosis populations[174, 178], underscoring the importance of early, sustained vocational support as a core component of psychosis care.

Clinical experts reported research gaps across several domains of psychotic disorders. They highlighted major gaps in pharmacopredictive and prognostic biomarkers, noting that clinicians cannot predict treatment response, long-term outcomes, relapse risk, or the need for more intensive care. Experts also reported limited evidence on effective primary preventive strategies. They described gaps in knowledge on inequities, with incomplete data on socioeconomic, ethnic, and regional disparities in incidence, pathways to care, and outcomes, and limited research on structural determinants and their influence on psychosis onset and prognosis. Experts further noted

gaps in understanding pathophysiology, as the interplay between genetic vulnerability, neurodevelopment, immune–inflammatory mechanisms, and environmental exposures remains unclear, and negative symptom mechanisms remain elusive. They also reported diagnostic gaps, including the absence of objective biomarkers and poorly defined boundaries between attenuated, transient, and emerging psychosis or differentiation between psychiatric pathologies.

Unmet societal needs

Primary prevention for psychosis in Belgium remains a major challenge. It was described by clinical experts as minimally implemented, with major modifiable risk factors, such as high-potency cannabis use, childhood adversity, obstetric complications, social deprivation, limited green spaces, and lack of organised youth activities, addressed only intermittently. Existing initiatives are isolated, locally variable, underpowered, and insufficiently monitored, and because they are not integrated into a coordinated national or psychosis-specific mental health strategy, psychosis-specific primary prevention remains patchy and largely ineffective.

This study demonstrates that psychotic disorders generate a substantial societal burden that extends beyond affecting the lives of those living with a psychotic disorder, particularly affecting both patients' and caregivers' productivity, but also caregivers' health and social lives. Productivity losses emerged as an important component of the societal burden. Among survey respondents with psychotic disorders**, long-term work interruption** was common, with more than one in three reporting employment interruptions of one to five years and almost half reporting interruptions exceeding five years. This is consistent with longitudinal evidence showing persistently low employment rates and substantial lifetime productivity losses in schizophrenia-spectrum disorders.[176]

Furthermore, the study found an **impact on the productivity** of caregivers. In literature, it has been reported that informal caregiving for individuals with psychosis often involves substantial weekly time commitments and is associated with reduced work participation and absenteeism.[179] In the current study, the impact of informal caregiving on productivity was not directly assessed, but the median reported hours of caregiving per week was of 16 hours (IQR 5–20). However, this information was only collected when the questionnaire was completed by a legal representative with a role as caregiver (and this concerns likely those patients with the highest care needs). When patients completed the questionnaire themselves, caregiving hours were not assessed. As a result, the data offer a partial view on the caregiving time required per patient.

Caregivers reported **pronounced health impacts**, with nearly four in five (79%) describing the impact on their own health as 'a lot' or even 'extreme'. These findings reinforce a broader international literature showing that caregivers of individuals with psychotic disorders experience high levels of psychological distress, physical health complaints, and reduced wellbeing, often exceeding those observed in caregivers of other chronic conditions.[179, 180] Social functioning of caregivers was also markedly affected. A large majority of caregivers (85%) reported a 'moderate' to 'extreme' impact on their social lives, confirming patterns of social withdrawal, reduced leisure time, and strain on personal relationships associated with long-term caregiving for psychosis described in literature.[181] Other studies have described stigma surrounding psychotic disorders to further exacerbate social isolation among caregivers and to limit access to informal and formal support.[168] This wasn't directly reported in our study, but could well have contributed to the significant impact on caregivers' social lives.

Future unmet needs

There are currently very few robust estimates of predicted needs related to psychotic disorders both globally and nationally. In Belgium, projections from the Belgian national Burden of Disease (BeBOD) study—which uses Bayesian models and demographic forecasts to estimate future disease prevalence—suggest that the number of people living with schizophrenia in Belgium might decline from 44 770 cases in 2022 to approximately 21 037 cases (95% Credibility Interval: 19 301–22 607) by 2040 following the previous trend in the registry. Considering a steep decrease

in the number of registered diagnoses in 2018, the projected number of cases is more likely between 21 037 cases and 45 000 cases (assuming a constant trend).

This projected decline in Belgium contrast with global trends in schizophrenia burden from comparable modelling studies. For example, data from the *Global Burden of Disease (GBD) Study 2023* indicates that the morbidity burden of schizophrenia in Belgium is likely to remain stable up to 2050 (170 YLDs per 100 000).[182]

Equity

Equity analyses of the patient survey showed a clear social gradient in psychosis burden and unmet needs. Financial strain was associated with worse outcomes, including larger declines in health and functioning, such as higher symptom burden, higher negative impact on social and sexual life, and more unmet administrative or social support compared to patients in a more comfortable financial situation. Because our study is cross-sectional we cannot make inferences concerning the direction of causality of this association but other studies show that disadvantage is often present before onset and is associated with higher risk of developing psychosis, but psychosis and related functional impairments can also contribute to socioeconomic decline or persistent disadvantage over time, and some part of the association may be due to shared underlying vulnerability rather than a purely environmental effect.[183, 184] This aligns with the broader evidence that poverty and social disadvantage are associated with worse patient-reported outcomes and care gaps in schizophrenia and psychosis.[173, 185]

10.2 Strengths

To the best of our knowledge, this is the first time that the unmet needs of individuals with psychotic disorders have been extensively evaluated both from the patient and societal perspectives, providing an all-round view by integrating the experiences of patients on a variety of health, healthcare and social-related impacts of their health condition, as well as the perspectives of clinical experts, and population-level data. A key strength of this study is the active involvement of patients with psychotic disorders throughout all phases of the research. A patient representative with illness experience contributed to the study design, recruitment strategy, and interpretation of findings, helping to ensure that the methodological approach, instruments, and outputs are aligned with patient perspectives.

Consistent with the established NEED protocol and methodological toolbox[10, 11], the study employed a mixed-methods design with methodological triangulation. The integration of quantitative patient survey data and qualitative interviews enriched and contextualized the quantitative findings.

Recruitment efforts deliberately engaged multiple actors, including clinical centres, patient organisations, and one sickness fund, aimed at reaching a sample representative for the whole patient population. Moreover, researchers visited psychiatric centers in person to present the study to clinical staff and potential participants and offered help in completing the survey for those who needed it. These strategies supported the inclusion of participants with diverse backgrounds and experiences. Within the constraints discussed below, the resulting sample showed a relatively balanced distribution across key characteristics such as gender, educational level, living situation, and time since diagnosis.

10.3 Limitations

The questionnaire used in this study was adapted from the generic NEED adult patient questionnaire, first developed within a KCE project published in 2022 and refined through several revisions informed by Delphi studies and case applications. Additional items were, where possible, drawn from existing validated questionnaires. The final version was reviewed by clinical experts, researchers, communication specialists, and patient representatives. Although extensively reviewed and iteratively refined, the questionnaire has not undergone formal psychometric

validation. Given the lack of agreement by the Ethics Committee, it was unfortunately not possible to include adolescent patients in this study, and therefore to assess unmet needs that may be specific to this age group. This represents an important limitation, as previous studies have shown that adolescents with psychosis tend to report particularly high levels of unmet needs, especially in psychosocial, educational, and relational domains, notably related to stigma, school integration, and the development of autonomy.[186] Future research specifically targeting this population is therefore warranted.

It is frequently reported that many patients with psychotic disorders have limited illness awareness. As a consequence, it is hard to reach these patients for inclusion in survey research. Furthermore, individuals with psychotic disorders may experience cognitive and attentional difficulties, including memory impairments, which may have limited their ability to recall certain experiences and to complete a lengthy online questionnaire requiring an average of 30 minutes to one hour. Moreover, individuals with more severe symptomatology may have been unable or unwilling to participate, either because the burden of participation was too high or because their illness constrained their capacity to engage. Finally, feelings of shame or stigma related to the diagnosis may also have discouraged participation. The findings therefore possibly reflect the experiences of those who are relatively better off within the psychosis spectrum, while those experiencing the greatest illness burden and potentially the highest levels of unmet need were likely underrepresented.

Inclusion of respondents in the sample used for analysis and diagnostic classification relied on respondents' self-identification. Patients who selected "I don't know" as their sole diagnosis, and in the absence of sufficient elements based on other questionnaire items (treatment, symptoms, comorbidities) to confirm a psychotic disorder diagnosis were excluded from the analysis. Although it is recognised that uncertainty about the diagnosis may reflect real diagnostic ambiguity resulting from multiple or changing diagnoses over time, it does not necessarily imply absence of a diagnosis. Therefore, this exclusion criterion may have led to the exclusion of eligible participants.

Digital literacy constituted a further barrier to participation, as some individuals in this population may have limited access to personal digital devices or require support to navigate online tools, potentially introducing a selection bias towards participants with higher digital competence and stronger social support. This may be particularly true for hospitalised patients, or those living in extremely precarious situations.

Language distribution also represented a limitation. Dutch-speaking participants were more strongly represented than French-speaking participants. Although targeted efforts were made to engage French-speaking healthcare providers and centres, recruitment in French-speaking settings proved more challenging, potentially limiting representativeness across linguistic communities. Furthermore, patients whose knowledge of Dutch or French was not sufficient to understand and complete the survey were also excluded from this study, excluding the perspectives of a likely particularly vulnerable population.

Similar limitations apply to the qualitative interview component. Recruitment was challenging, which is widely reported in qualitative research involving people with severe mental health conditions. Patients may be difficult to reach or less able to participate due to illness-related symptoms, fluctuating symptom severity, or challenging living conditions (e.g. homeless), as well as the time and emotional investment required[187]; the use of video-conferencing may have posed an additional barrier due to requirements for digital access and trust in confidentiality[188]. Although comorbid substance use is frequently associated with psychotic disorders, it did not emerge from the open-ended questions or interviews; only one interviewee was described as having this comorbidity, without any specific implications being discussed. We recognise that this important subgroup may face distinct and compounded challenges that were not explored in depth here and would benefit from more focused attention in future studies. As no systematic comparison was made between interviewed and non-interviewed patients, no firm conclusions can be drawn regarding selection effects. However, based on observations during recruitment and data collection, and consistent with prior literature[187], participants who took part in the interviews appeared to be in a relatively more stable phase of symptoms and more engaged in their care

trajectory or patient community at the time of participation, suggesting that individuals experiencing more acute phases of illness are likely underrepresented.

Overall, when interpreting the results of the patient survey and interviews it should be remembered that these may underestimate the overall illness burden and unmet needs of the broader population of individuals with psychotic disorders. Although the causal relationship between socioeconomic status and psychotic disorders is complex and not fully understood, these conditions disproportionately affect the most vulnerable groups, including people experiencing homelessness, migrants without legal status, and incarcerated individuals. In terms of international transferability of the results, it should also be noted that the type of vulnerability might differ between countries. Nevertheless, the study provides valuable and empirically grounded insights into the health-related needs of those who were able and willing to participate, offering important evidence to inform future research, policy development, and service planning.

10.4 Lessons learned regarding research in patients with psychotic disorders

Anticipating ethical and governance complexity in multi-centre research

At the design phase, the study encountered the complexity of ethical approval processes in multi-centre research involving patients. Additional ethical agreements were required for each centre involved in recruitment, even when researchers did not physically attend the sites. These procedures proved time-consuming and required substantial coordination. Future studies should therefore define participating centres prior to study initiation and explicitly account for ethical approval timelines in overall project planning. Best practice is that the research team defines the appropriate ethics review pathway and submits the study to the ethics committee of the institution responsible for conducting the research, which then acts as the central ethics committee overseeing data collection and management, while other participating centres fall under their respective local ethics committees.

Recruitment challenges

The recruitment process underscored the importance of realistic timelines and adequate human resources. To maximise participation, recruitment should ideally be planned over an extended period and supported by early involvement of key stakeholders (patient representatives, healthcare providers…) during the survey development process. In this study, the recruitment period was extended by one month to allow additional inclusion. Further expansion of the sample would have required substantially more resources, particularly for in-person recruitment and assisted survey completion across centres. These considerations should be addressed at the design phase to ensure alignment between ambitions for representativeness and available time and resources, and account for additional resources when recruitment complexity increases.

Recruiting individuals with psychotic disorders proved highly challenging. This is likely related to the nature of the health condition, which can involve limited trust towards people, including researchers and research institutions. Establishing trust was therefore essential to enable participation and to obtain reliable responses, yet this process required continuity and personal engagement of healthcare professionals and researchers, which are often difficult to accommodate within standard research constraints. These experiences highlight the importance of embedding trust-building strategies, such as visiting centers and talking to patients, and engaging hospital staff to relay the study invitations (posters and flyers), into study design when conducting research.

Designing data collection to accommodate support needs

During data collection, the study demonstrated the added value of providing direct support to participants during survey completion. In-patient respondents required assistance to navigate the questionnaire, interpret questions, or maintain attention throughout the survey. Assisted completion can substantially improve engagement, response quality, and inclusivity, particularly for individuals with cognitive or attentional difficulties. However, such support is resource intensive. Future studies

aiming for broader participation, and upon consultation with clinical experts, may explicitly plan and budget for respondent guidance in case (a part of) the target population is expected to struggle with completing the survey independently.

In summary, these lessons indicate that research involving individuals with psychotic disorders benefits from early and careful ethical planning, extended timelines, sufficient human resources, and tailored engagement and data-collection strategies. Incorporating these considerations upfront can enhance participation, data quality, and representativeness in future studies involving individuals with cognitive challenges such as but not limited to severe mental health conditions or neurodegenerative diseases.

10.5 Suggestions to decrease unmet needs in psychotic disorders

Based on the unmet needs identified in this study, this section outlines policy-relevant implications that could help improve care and support for individuals living with psychotic disorders.

1. Strengthen early detection and rapid access to specialist care

The results show **substantial delays between symptom onset and first contact with specialist mental healthcare**, with over one third of individuals waiting more than one year, indicating a prolonged duration of untreated psychosis. Longer duration of untreated psychosis is consistently associated with poorer clinical, functional, and social outcomes, making its reduction a key objective of effective psychosis care.[189-191] Reducing duration of untreated psychosis is therefore widely recognised as a core objective of effective psychosis care.

Marked Belgian regional variation in help-seeking delays was observed, likely reflecting differences in service organisation and accessibility. Evidence indicates that **low-threshold, outreach-oriented early intervention services** reduce barriers to care and improve engagement. A Cochrane review found that specialised early intervention teams reduce relapse and hospitalisation compared with treatment as usual in early-phase psychotic disorders.[192] Nevertheless, structural funding for early psychosis services remains very limited in Belgium.

Overall, these findings support sustained and structural investment in **early detection and low-threshold early psychosis services**. Such services should combine proactive outreach, home-based assessment, and close collaboration with families, schools, primary care, youth services, and community organisations, in line with contemporary early intervention models. Particular attention is warranted for individuals whose presentation makes early recognition and engagement difficult, such as those with an insidious onset or limited illness insight, as these factors are commonly associated with delayed help-seeking and longer treatment delays. Prominent paranoid symptomatology and social withdrawal may further complicate engagement and underscores the need for assertive, outreach-oriented approaches.[114]

2. Provide phase-specific care

In this study, **people under 30 reported a higher burden for several symptom domains**, including fear or anxiety, depressed mood, and experiences of influence, control, or passivity. The literature describes early psychosis as often characterised by a phase of heightened clinical instability and disruption of age-salient developmental tasks. As psychosis typically emerges in late adolescence or early adulthood, onset often coincides with critical transitions in identity formation, relationships, education, employment, and independent living.[193, 194] This early course is also marked by elevated risk of self-harm and suicide, which is more concentrated in the period following first contact and during early illness trajectories.[195, 196] Evidence indicates that **specialised early intervention in psychosis services**, delivered during the first years of illness, improves engagement and yields better clinical and functional outcomes than usual care, although effects may attenuate over longer follow-up without sustained, recovery-oriented support.[192]

Beyond the crucial clinical benefits, early intervention offers **societal value**, with economic evaluations showing cost-effectiveness and, in some settings, cost savings through reduced

hospitalisation and improved functional recovery. Ensuring timely access through adequately resourced and sustainably embedded early intervention services is therefore likely to yield both clinical and societal benefits.

Together, these findings support **treating the first years after onset as a distinct and vulnerable phase with** dedicated care pathways that prioritise relapse prevention and functional recovery, including sustained support for education and employment, social participation, and role development. Suicide prevention as currently installed in Belgium, is a crucial routine component of early-phase services, including systematic screening for suicidal ideation and depression, collaborative safety planning, and rapid access to crisis support, with particular vigilance during the first year and during transitions in care.

3. Improve care beyond addressing positive symptoms

Findings from this study indicate that, for many individuals with psychotic disorders, the most burdensome difficulties extend beyond the typical positive symptoms. Participants most frequently reported fatigue or exhaustion, as well as affective and cognitive problems, including low mood, anxiety or fear, concentration difficulties, stress, and reduced self-confidence, and these domains tended to score highest on perceived burden. This pattern highlights a **gap between symptom domains addressed by anti-psychotic medication and those most closely linked to daily functioning and subjective well-being**.

Pharmacological treatment remains a cornerstone of psychosis care and is generally effective in reducing acute positive symptoms.[197] However, **evidence-based options for cognitive impairment and primary negative symptoms are more limited**, and treatment effects in these domains are typically modest and heterogeneous across patient groups, as also evidence by the experienced symptoms described above.[48] Nevertheless, current clinical guidance emphasises that cognitive deficits and negative symptoms are among the strongest predictors of long-term functional outcomes, including social participation, employment, and quality of life, underscoring the importance of addressing these domains more systematically in innovation and in existing care pathways.[102, 123] Moreover, pharmacological management requires careful optimisation, as **adverse effects** such as extrapyramidal symptoms, and cumulative anticholinergic burden and sedation can contribute to secondary negative symptoms and cognitive impairment, even when psychotic symptoms are adequately controlled.[198]

The continued emphasis on positive symptoms is partly reinforced by diagnostic and evaluative frameworks. In DSM-5 and ICD-11, psychotic symptoms remain central to diagnosis and case identification, while cognitive and affective symptoms are captured more indirectly through specifiers or associated features. Historically, this has also influenced clinical trial design and outcome measurement, with regulatory and reimbursement decisions relying heavily on symptom-based endpoints that are more readily observable, rather than on patient-reported burden or functional recovery. Although contemporary clinical guidelines increasingly acknowledge the importance of broader outcome domains, translation into routine practice remains uneven.

At the system level, research, evaluation, and reimbursement frameworks could place greater emphasis on interventions that improve cognition and negative symptoms, or that at minimum avoid iatrogenic worsening of these domains. Aligning therapeutic priorities more closely with patient-reported burden and functional outcomes may help reduce persistent unmet needs and support recovery-oriented care for individuals with psychotic disorders.

4. Strengthen information provision and shared decision-making

Nearly half of respondents reported receiving sufficient useful and understandable information from healthcare professionals only sometimes or less, and two in three reported **insufficient involvement in treatment decisions**. Furthermore, interview data showed that many patients were not sufficiently informed about potential treatment side-effects, limiting their ability to prepare adequately and manage them early. This highlights a need to strengthen both structured information provision and **shared decision-making** (SDM) in psychotic disorders. SDM requires

access to clear and comprehensible information on the disorder, treatment options, and potential benefits and harms. Evidence shows that improved information provision and patient involvement increase empowerment, engagement, and satisfaction in psychotic disorders.[166, 199, 200]

Shared decision-making in psychotic disorders is inherently phase dependent. Illness insight and decision-making capacity are often impaired during acute and early phases but improve as symptoms stabilise.[201, 202] Once clinically stable, many individuals want greater involvement in decisions about medication, side-effect management, and recovery goals, yet this is inconsistently implemented.[203] Establishing phase-appropriate information provision and progressively increasing patient involvement can strengthen autonomy and recovery-oriented care. Importantly, as with other health conditions, preferences vary: some service users want to be deeply involved, others prefer a more clinician-led approach; this can be handled by routinely documenting the person's desired level of involvement and revisiting it over time.

Information provision remains fragmented across care settings. Patient and family organisations play an important role in disseminating information and facilitating peer support, yet their activities often depend heavily on volunteer engagement and non-structural funding, which can limit continuity, reach, and visibility. Information resources are also unevenly accessible: digital platforms may exclude people with limited digital literacy or access, while paper-based material is frequently lost or not retained over time, particularly during periods of psychological distress.[110]

5. Address financial barriers and improve affordability of care

The findings show financial vulnerability among people living with psychotic disorders. More than half of respondents reported having stopped working and over 30% worked fewer hours, which likely contributes to the high prevalence of financial difficulties reported by the majority of the respondents. The fact that healthcare services are not fully reimbursed also leads to unmet needs. On top of the income losses, patients face care-related costs that are not fully reimbursed, leading to cumulative financial pressure over time. Particularly high levels of **unmet need were reported for psychotherapeutic support**, which was the most frequently reported unmet social support element.

Belgium has made important progress through the NIHDI (RIZIV – INAMI) convention for first-line psychological care, which keeps co-payments low and improves access to short-term support delivered via mental health networks.[204] However, this model is explicitly designed for mild to moderate psychological problems. As a result, **individuals with severe and persistent mental disorders may still face substantial** non reimbursed **healthcare costs** when longer-term or specialised psychotherapy is needed in ambulatory care. In practice, this can create a discontinuity in care: while psychological support is often accessible during inpatient admission, access after discharge may become more limited or financially burdensome, particularly when services fall outside the contracted network offer. This system-level design is consistent with qualitative observations from this study, where **respondents reported having to pay privately for psychotherapy following hospitalisation**.

This affordability gap is notable when viewed against international clinical guidance. In England, NICE guidelines recommend that cognitive behavioural therapy for psychosis (CBTp) and family interventions be offered for free all people with psychosis or schizophrenia as part of standard care, across illness phases.[205] Other European systems apply different reimbursement models, but several include psychotherapy for severe mental illness within statutory health insurance benefits, such as the Netherlands, where specialist mental healthcare is covered under basic insurance, albeit with deductibles and referral requirements.[206]

From a societal perspective, the economic literature provides supportive, though not definitive, evidence that reimbursing psychotherapy for psychotic disorders can represent good value for money. Systematic reviews of economic evaluations indicate that psychological interventions, including CBTp, can be cost-effective for severe mental health conditions, often through reductions in relapse and hospital use, although results vary by context and implementation.[207] More broadly, reviews of the economic burden of schizophrenia consistently show that indirect costs, particularly

productivity losses, account for a substantial share of total societal costs, underscoring the potential economic relevance of interventions that support functional recovery and continuity of care.[208]

Finally, while certain social and financial support measures exist for people living with psychotic disorders, stakeholders have highlighted that broader structural and administrative conditions, including complex procedures, residual co-payments, and persistent discrimination across social domains, continue to shape access to care and social participation. As emphasised by the Staten-Generaal Geestelijke Gezondheidszorg, addressing these indirect and societal barriers, alongside healthcare financing, is essential to prevent mental health policy ambitions from remaining unrealised and to reduce the risk that people with severe mental illness are left facing avoidable financial and social vulnerability.[209]

6. Reduce stigma, improve mental health literacy, and increase public and first-line awareness of psychotic disorders

A substantial proportion of respondents reported that psychotic disorders negatively affect close personal relationships, and qualitative accounts of being perceived as “not normal” align with a well-established literature showing that stigma and discrimination remain common in schizophrenia spectrum and other psychotic disorders, including within family and social environments.[169, 210, 211] Importantly, stigma is not only socially harmful but also clinically relevant, as anticipated discrimination, fear of labelling, and negative beliefs about psychiatric services are consistently associated with delayed or reduced help-seeking.[210] At the same time, delays in seeking care are multifactorial and cannot be attributed to stigma alone. Limited illness insight, symptom-related cognitive and motivational changes, low awareness about psychotic disorders, and structural barriers such as service accessibility also play an important role in delaying help-seeking, particularly during early and acute phases of psychosis. Health-system related factors sometimes compound these delays once a first contact with healthcare services has been made, including long waiting lists for referrals to secondary care due to shortages of specialised professionals, insufficient and fragmented early intervention programmes, and, from a clinical point of view, misattribution of symptoms to alternative pathologies, particularly in children and adolescents and individuals with more subtle, non-specific symptoms.

In this context, sustained investment in mental health literacy, defined as knowledge and beliefs that aid recognition, management, and prevention of mental disorders, is a plausible policy lever to reduce avoidable delays in care.[211] Improved awareness and diagnostic support in the first line could also aid to reduce the early attribution to alternative diagnoses. Important to note is that in a recent study, the lack of mental health literacy came out as the single most important factor explaining why young people in Belgium would not seek help for their mental health problems, even if the perfect service would exist. Young people believe they should manage their problems independently, that help-seeking is a sign of weakness or failure and they don’t want to burden others. Therefore, a strong sense of self-reliance is that most important reason to not visit a mental health service.[212] Improving public recognition of early psychosis symptoms may help individuals and families interpret emerging experiences as potential health problems rather than personal or moral failures, or personality traits, thereby lowering psychological barriers to seeking support.

However, **awareness raising** alone is insufficient; evidence indicates that stigma reduction and literacy initiatives are most effective when paired with clear, low-threshold pathways into care, ensuring that increased recognition of symptoms translates into timely assessment rather than frustration or longer waiting times.[210, 213] Difficulties navigating fragmented care systems, with individuals being referred from service to service before reaching appropriate support, have, for example, been explicitly targeted by the “Right care, first time” initiative in Australia. Similar concerns were raised by a government-initiated working group on mental health for transition-age youth, which identified both improving mental health literacy and ensuring timely access to appropriate care as key recommendations.

Further targeted policy measures that may further reduce stigma-related barriers include anti-stigma interventions based on structured social-contact approaches involving trained speakers with

lived experience, which consistently demonstrate stronger and more durable effects than education alone, as well as targeted training for frontline professionals who frequently interact with people with psychosis. Priority settings include emergency departments and first responders, where enhanced de-escalation skills, trauma-informed approaches, reduction of coercive practices when possible, and clear protocols for rapid psychiatric assessment may improve early engagement with care. For police and other first responders, crisis-intervention training, joint protocols with mobile crisis teams, and guidance on non-stigmatising communication and safe diversion to mental health services are particularly relevant.

The Norwegian TIPS (Early Detection and Intervention in Psychosis) programme is frequently cited as an applied example of such a combined strategy. TIPS integrated repeated public information campaigns on early signs of psychosis with low-threshold detection teams, and an evaluation reported substantial reductions in duration of untreated psychosis in early-detection areas compared with usual care.[214] Importantly, analyses showed that when intensive information campaigning was scaled back, referral patterns and treatment delays shifted again, suggesting that awareness efforts must be sustained and embedded rather than implemented as one-off interventions.[214]

11 CONCLUSION

This study highlights the substantial and multifaceted unmet needs of individuals with psychotic disorders in the health, healthcare and social domains. Patients experience persistent symptom burden even beyond psychotic symptoms, including fatigue and sexual health problems, which significantly reduce quality of life. Overall treatment is often perceived as burdensome due to side effects, limited involvement in decision-making, and fragmented care pathways. Social and vocational functioning is severely impacted, with disruptions in relationships, education, and employment, while financial strain further exacerbates these challenges. Informal caregivers also face considerable health, social, and productivity burdens, underscoring the societal impact of psychotic disorders. Importantly, there is considerable variability in unmet needs among patients, reflecting diverse experiences and priorities that require individualized approaches. Early detection, phase-specific interventions, and expanded care that addresses cognitive and affective symptoms are critical to improving outcomes. Strengthening information provision, shared decision-making, and affordability of services could empower patients and reduce barriers to care. Efforts to reduce stigma and enhance mental health literacy both in the general public, in particular among adolescents and young adults, and in the first line of care are essential to encourage timely help-seeking, early and adequate treatment, and social reintegration. Last but not least, primary prevention of psychotic disorders should be strengthened by investing in policies that reduce socioeconomic vulnerability, protect children from exposure to abuse and other forms of violence, promote fair migrant integration, and counter social exclusion.

Overall, these findings call for comprehensive, patient-centred, and socially sensitive policies to better support individuals with psychotic disorders and their families.

12 REFERENCES

1. Levy M, Maertens de Noordhout C, Claerman R, De Pauw R, Kohn L, Obyn C, et al. Identification, evaluation, and selection of health conditions for the NEED research programme. Need Report. Brussels: Belgian Health Care Knowledge Center (KCE); 2024 12/12/2024. Identification, evaluation, and selection of health conditions for the NEED research programme 391 (391C) Available from: https://doi.org/10.57598/R391C
2. Fleischhacker WW, Arango C, Arteel P, Barnes TR, Carpenter W, Duckworth K, et al. Schizophrenia--time to commit to policy change. Schizophr Bull. 2014;40 Suppl 3(Suppl 3):S165-94.
3. Kpobi L, Eager S, Lloyd-Evans B, Bousfield J, C J, Downey M, et al. Barriers and facilitators to social inclusion among people with severe mental illness: A qualitative study. PLOS Mental Health. 2025;2(4).
4. Chong HY, Teoh SL, Wu DB-C, Kotirum S, Chiou C-F, Chaiyakunapruk N. Global economic burden of schizophrenia: a systematic review. Neuropsychiatric Disease and Treatment. 2016;12:357-73.
5. Maertens de Noordhout C, Levy M, Claerman R, De Jaeger M, De Pauw R, Kohn L, et al. Needs Examination, Evaluation and Dissemination (NEED): assessment framework. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024 03/2024. KCE Reports 377C1 (377C1) Available from: https://doi.org/10.57598/R377C1
6. De Jaeger M, Van Goethem R, Dobbelaere J, Léonard U, Zhi Tan Y, Van Montfort T, et al. Needs Examination, Evaluation and Dissemination (NEED): Identification of unmet health-related needs associated with Crohn's disease. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024 03/2024. KCE Reports 377C3 (377C3) Available from: https://doi.org/10.57598/R377C3
7. Schönborn C, Léonard U, Van Goethem R, Dobbelaere J, Zhi Tan Y, Van Montfort T, et al. Needs Examination, Evaluation and Dissemination (NEED): Identification of unmet health-related needs associated with malignant melanoma. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024 03/2024. KCE Reports 377C2 (377C2) Available from: https://doi.org/10.57598/R377C2
8. NEED collaborators. Unmet health-related needs for three selected health conditions in Belgium (v2024-10-10) [Data set]. In. Brussels; 2024.
9. Claessens Z, Vanneste A, Broekmans J, Verbeke C, Wens I, Van Isterdael C, et al. Needs Examination, Evaluation and Dissemination (NEED): applicability to rare diseases. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024 03/2024. KCE Reports 377C4 (377C4) Available from: https://doi.org/10.57598/R377C4
10. Schönborn C, Obyn C, De Pauw R, Claerman R, Kohn L, Parardis J, et al. Protocol for NEED (needs examination, evaluation and dissemination) research projects. 10.57598/R406C. Brussels: Belgian Health Care Knowledge Center (KCE); 2025. Needs Available from: https://doi.org/10.57598/R406C
11. Schönborn C, Obyn C, De Pauw R, Claerman R, Kohn L, Parardis J, et al. NEED research Toolbox: instruments and tools for examining unmet health-related patient and societal needs. 2025(Needs).
12. Jongsma HE, Turner C, Kirkbride JB, Jones PB. International incidence of psychotic disorders, 2002-17: a systematic review and meta-analysis. Lancet Public Health. 2019;4(5):e229-e44.
13. Moreno-Küstner B, Martín C, Pastor L. Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses. PLoS One. 2018;13(4):e0195687.
14. Hjorthøj C, Stürup AE, McGrath JJ, Nordentoft M. Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis. The Lancet. Psychiatry. 2017;4(4):295-301.

15. Lieberman JA, First MB. Psychotic Disorders. N Engl J Med. 2018;379(3):270-80.

16. Tandon R, Gaebel W, Barch DM, Bustillo J, Gur RE, Heckers S, et al. Definition and description of schizophrenia in the DSM-5. Schizophrenia Research. 2013;150(1):3-10.

17. Heckers S, Barch DM, Bustillo J, Gaebel W, Gur R, Malaspina D, et al. Structure of the Psychotic Disorders Classification in DSM-5. Focus. 2016;14(3):366-9.

18. Keshavan M, Zimmerman M. Schizophrenia [Web page].2025 [cited 17/12/25]. Available from: https://www.msdmanuals.com/professional/psychiatric-disorders/schizophrenia-and-related-disorders/schizophrenia?_gl=1*6fz1px*_up*MQ..*_ga*OTk5ODE1NDM1LjE3NjA5NjUzNjM.*_ga_CJ792HFYYC*czE3NjA5NjUzNjIkbzEkZzAkdDE3NjA5NjUzNjIkajYwJGwwJGgw

19. Pavlichenko A, Petrova N, Stolyarov A. The Modern Concept of Schizoaffective Disorder: A Narrative Review. Consort Psychiatr. 2024;5(3):42-55.

20. Singh R, Subramaney U. Schizoaffective Disorder in an acute psychiatric unit: Profile of users and agreement with Operational Criteria (OPCRIT). S Afr J Psychiatr. 2016;22(1):790.

21. Keshavan M, Zimmerman M. Schizoaffective Disorder [Web page].2025 [cited 17/12/25]. Available from: https://www.msdmanuals.com/professional/psychiatric-disorders/schizophrenia-and-related-disorders/schizoaffective-disorder?_gl=1*154p7jk*_up*MQ..*_ga*NzY3NTk0NzMxLjE3NjA5NjQzNzM.*_ga_CJ792HFYYC*czE3NjA5NjQzNzMkbzEkZzAkdDE3NjA5NjQzNzMkajYwJGwwJGgw

22. Fiorentini A, Cantù F, Crisanti C, Cereda G, Oldani L, Brambilla P. Substance-Induced Psychoses: An Updated Literature Review. Frontiers in Psychiatry. 2021;Volume 12 - 2021.

23. Keshavan M, Zimmerman M. Substance- or Medication-Induced Psychotic Disorder [Web page].2025 [cited 17/12/25]. Available from: https://www.msdmanuals.com/professional/psychiatric-disorders/schizophrenia-and-related-disorders/substance-or-medication-induced-psychotic-disorder

24. Keshavan MS, Kaneko Y. Secondary psychoses: an update. World Psychiatry. 2013;12(1):4-15.

25. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (5th ed.). Arlington (VA): American Psychiatric Association; 2013.

26. Biedermann F, Fleischhacker WW. Psychotic disorders in DSM-5 and ICD-11. CNS spectrums. 2016;21(4):349-54.

27. Tandon R, Nasrallah HA, Keshavan MS. Schizophrenia, "just the facts" 4. Clinical features and conceptualization. Schizophr Res. 2009;110(1-3):1-23.

28. Widing L, Simonsen C, Flaaten CB, Haatveit B, Vik RK, Wold KF, et al. Symptom Profiles in Psychotic Disorder Not Otherwise Specified. Front Psychiatry. 2020;11:580444.

29. Ramain J, Conus P, Golay P. Exploring the clinical relevance of a dichotomy between affective and non-affective psychosis: Results from a first-episode psychosis cohort study. Early Interv Psychiatry. 2022;16(2):168-77.

30. McGrath J, Saha S, Chant D, Welham J. Schizophrenia: a concise overview of incidence, prevalence, and mortality. Epidemiol Rev. 2008;30:67-76.

31. Jauhar S, Johnstone M, McKenna PJ. Schizophrenia. Lancet. 2022;399(10323):473-86.

32. Solmi M, Radua J, Olivola M, Croce E, Soardo L, Salazar de Pablo G, et al. Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. Mol Psychiatry. 2022;27(1):281-95.

33. Kirkbride JB, Errazuriz A, Croudace TJ, Morgan C, Jackson D, Boydell J, et al. Incidence of schizophrenia and other psychoses in England, 1950-2009: a systematic review and meta-analyses. PLoS One. 2012;7(3):e31660.

34. Driver DI, Thomas S, Gogtay N, Rapoport JL. Childhood-Onset Schizophrenia and Early-onset Schizophrenia Spectrum Disorders: An Update. Child Adolesc Psychiatr Clin N Am. 2020;29(1):71-90.

35. Lewis DA. Catching Up on Schizophrenia: Natural History and Neurobiology. Neuron. 2000;28.

36. Liddle PF. The symptoms of chronic schizophrenia. A re-examination of the positive-negative dichotomy. Br J Psychiatry. 1987;151:145-51.

37. Mellers JD, Sham P, Jones PB, Toone BK, Murray RM. A factor analytic study of symptoms in acute schizophrenia. Acta Psychiatr Scand. 1996;93(2):92-8.

38. Rosenbrock H, Desch M, Wunderlich G. Development of the novel GlyT1 inhibitor, iclepertin (BI 425809), for the treatment of cognitive impairment associated with schizophrenia. European Archives of Psychiatry and Clinical Neuroscience. 2023;273(7):1557-66.

39. McCutcheon RA, Reis Marques T, Howes OD. Schizophrenia—An Overview. JAMA Psychiatry. 2020;77(2):201-10.

40. Kahn RS, Sommer IE, Murray RM, Meyer-Lindenberg A, Weinberger DR, Cannon TD, et al. Schizophrenia. Nature Reviews Disease Primers. 2015;1(1):15067.

41. Ruiz-Castañeda P, Santiago Molina E, Aguirre Loaiza H, Daza González MT. Positive symptoms of schizophrenia and their relationship with cognitive and emotional executive functions. Cognitive Research: Principles and Implications. 2022;7(1):78.

42. Kirkpatrick B, Fenton WS, Carpenter Jr WT, Marder SR. The NIMH-MATRICS consensus statement on negative symptoms. Schizophrenia bulletin. 2006;32(2):214-9.

43. Galderisi S, Mucci A, Dollfus S, Nordentoft M, Falkai P, Kaiser S, et al. EPA guidance on assessment of negative symptoms in schizophrenia. European Psychiatry. 2021;64(1):e23.

44. Galderisi S, Mucci A, Buchanan RW, Arango C. Negative symptoms of schizophrenia: new developments and unanswered research questions. Lancet Psychiatry. 2018;5(8):664-77.

45. Bobes J, Arango C, Garcia-Garcia M, Rejas J. Prevalence of negative symptoms in outpatients with schizophrenia spectrum disorders treated with antipsychotics in routine clinical practice: findings from the CLAMORS study. J Clin Psychiatry. 2010;71(3):280-6.

46. Marder SR, Umbricht D. Negative symptoms in schizophrenia: Newly emerging measurements, pathways, and treatments. Schizophrenia Research. 2023;258:71-7.

47. Mojtabai R, Fochtmann L, Chang S-W, Kotov R, Craig TJ, Bromet E. Unmet Need for Mental Health Care in Schizophrenia: An Overview of Literature and New Data From a First-Admission Study. Schizophrenia Bulletin. 2009;35(4):679-95.

48. Correll CU, Schooler NR. Negative Symptoms in Schizophrenia: A Review and Clinical Guide for Recognition, Assessment, and Treatment. Neuropsychiatr Dis Treat. 2020;16:519-34.

49. Carbon M, Correll CU. Thinking and acting beyond the positive: the role of the cognitive and negative symptoms in schizophrenia. CNS spectrums. 2014;19 Suppl 1:38-52; quiz 35-7, 53.

50. Fett A-KJ, Viechtbauer W, Dominguez M-d-G, Penn DL, van Os J, Krabbendam L. The relationship between neurocognition and social cognition with functional outcomes in schizophrenia: a meta-analysis. Neuroscience and Biobehavioral Reviews. 2011;35(3):573-88.

51. MacCabe JH, Brébion G, Reichenberg A, Ganguly T, McKenna PJ, Murray RM, et al. Superior intellectual ability in schizophrenia: neuropsychological characteristics. Neuropsychology. 2012;26(2):181-90.

52. Reichenberg A. The assessment of neuropsychological functioning in schizophrenia. Dialogues Clin Neurosci. 2010;12(3):383-92.

53. Sheffield JM, Karcher NR, Barch DM. Cognitive Deficits in Psychotic Disorders: A Lifespan Perspective. Neuropsychology Review. 2018;28(4):509-33.

54. Keefe RSE, Fenton WS. How should DSM-V criteria for schizophrenia include cognitive impairment? Schizophrenia Bulletin. 2007;33(4):912-20.

55. Keefe RSE. Why are there no approved treatments for cognitive impairment in schizophrenia? World psychiatry: official journal of the World Psychiatric Association (WPA). 2019;18(2):167-8.

56. McCleery A, Nuechterlein KH. Cognitive impairment in psychotic illness: prevalence, profile of impairment, developmental course, and treatment considerations. Dialogues in Clinical Neuroscience. 2019;21(3):239-48.

57. Lambert M, Conus P, Lubman DI, Wade D, Yuen H, Moritz S, et al. The impact of substance use disorders on clinical outcome in 643 patients with first-episode psychosis. Acta Psychiatr Scand. 2005;112(2):141-8.

58. Honings S, Drukker M, Ten Have M, de Graaf R, van Dorsselaer S, van Os J. Psychotic Experiences and Risk of Violence Perpetration and Arrest in the General Population: A Prospective Study. PLoS One. 2016;11(7):e0159023.

59. de Vries B, van Busschbach JT, van der Stouwe ECD, Aleman A, van Dijk JJM, Lysaker PH, et al. Prevalence Rate and Risk Factors of Victimization in Adult Patients With a Psychotic Disorder: A Systematic Review and Meta-analysis. Schizophr Bull. 2019;45(1):114-26.

60. Suokas JT, Perälä J, Suominen K, Saarni S, Lönnqvist J, Suvisaari JM. Epidemiology of suicide attempts among persons with psychotic disorder in the general population. Schizophr Res. 2010;124(1-3):22-8.

61. Faden J, Citrome L. Schizophrenia: One Name, Many Different Manifestations. The Medical Clinics of North America. 2023;107(1):61-72.

62. Tiwari AK, Zai CC, Müller DJ, Kennedy JL. Genetics in schizophrenia: where are we and what next? Dialogues in Clinical Neuroscience. 2010;12(3):289-303.

63. Robinson N, Bergen SE. Environmental Risk Factors for Schizophrenia and Bipolar Disorder and Their Relationship to Genetic Risk: Current Knowledge and Future Directions. Frontiers in Genetics. 2021;12:686666.

64. Sullivan PF, Agrawal A, Bulik CM, Andreassen OA, Børglum AD, Breen G, et al. Psychiatric Genomics: An Update and an Agenda. The American Journal of Psychiatry. 2018;175(1):15-27.

65. Ripke S, Neale BM, Corvin A, Walters JTR, Farh K-H, Holmans PA, et al. Biological insights from 108 schizophrenia-associated genetic loci. Nature. 2014;511(7510):421-7.

66. Consortium TSWGotPG, Ripke S, Walters JT, O'Donovan MC. Mapping genomic loci prioritises genes and implicates synaptic biology in schizophrenia. medRxiv. 2020:2020.09.12.20192922.

67. Yang J, Visscher PM, Wray NR. Sporadic cases are the norm for complex disease. Eur J Hum Genet. 2010;18(9):1039-43.

68. Lichtenstein P, Björk C, Hultman CM, Scolnick E, Sklar P, Sullivan PF. Recurrence risks for schizophrenia in a Swedish national cohort. Psychol Med. 2006;36(10):1417-25.

69. Patel KR, Cherian J, Gohil K, Atkinson D. Schizophrenia: overview and treatment options. P & T: A Peer-Reviewed Journal for Formulary Management. 2014;39(9):638-45.

70. Andleeb H MB, Gayer-Anderson C, Arango C, Arrojo M, D'Andrea G, et al. . Age-at-migration, ethnicity and psychosis risk: Findings from the EU-GEI case-control study. . PLOS Ment Health 2024;1(5): e0000134. .

71. Varese F, Smeets F, Drukker M, Lieverse R, Lataster T, Viechtbauer W, et al. Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. Schizophr Bull. 2012;38(4):661-71.

72. Jester DJ, Thomas ML, Sturm ET, Harvey PD, Keshavan M, Davis BJ, et al. Review of Major Social Determinants of Health in Schizophrenia-Spectrum Psychotic Disorders: I. Clinical Outcomes. Schizophr Bull. 2023;49(4):837-50.

73. McClellan J, Kowatch R, Findling RL, Work Group on Quality I. Practice parameter for the assessment and treatment of children and adolescents with bipolar disorder. Journal of the American Academy of Child and Adolescent Psychiatry. 2007;46(1):107-25.

74. van Os J, Kapur S. Schizophrenia. Lancet (London, England). 2009;374(9690):635-45.

75. Bromet EJ, Kotov R, Fochtmann LJ, Carlson GA, Tanenberg-Karant M, Ruggero C, et al. Diagnostic shifts during the decade following first admission for psychosis. The American Journal of Psychiatry. 2011;168(11):1186-94.

76. Allardyce J, Gaebel W, Zielasek J, van Os J. Deconstructing Psychosis conference February 2006: the validity of schizophrenia and alternative approaches to the classification of psychosis. Schizophr Bull. 2007;33(4):863-7.

77. Holm M, Suokas K, Liukko E, Lindgren M, Näätänen P, Kärkkäinen J, et al. Enhancing identification of nonaffective psychosis in register-based studies. Schizophrenia. 2024;10(1):20.

78. Radhakrishnan M, McCrone P, Lafortune L, Everard L, Fowler D, Amos T, et al. Cost-effectiveness of early intervention services for psychosis and fidelity to national policy implementation guidance. Early Interv Psychiatry. 2018;12(4):747-56.

79. Marshall M, Husain N, Bork N, Chaudhry IB, Lester H, Everard L, et al. Impact of early intervention services on duration of untreated psychosis: data from the National EDEN prospective cohort study. Schizophr Res. 2014;159(1):1-6.

80. Correll CU, Galling B, Pawar A, Krivko A, Bonetto C, Ruggeri M, et al. Comparison of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis: A Systematic Review, Meta-analysis, and Meta-regression. JAMA Psychiatry. 2018;75(6):555-65.

81. Groff M, Latimer E, Joober R, Iyer SN, Schmitz N, Abadi S, et al. Economic Evaluation of Extended Early Intervention Service vs Regular Care Following 2 Years of Early Intervention: Secondary Analysis of a Randomized Controlled Trial. Schizophr Bull. 2021;47(2):465-73.

82. Kane JM, Robinson DG, Schooler NR, Mueser KT, Penn DL, Rosenheck RA, et al. Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program. Am J Psychiatry. 2016;173(4):362-72.

83. Lewine R, Hart M. Chapter 20 - Schizophrenia spectrum and other psychotic disorders. In: Lanzenberger R, Kranz GS, Savic I, editors. Handbook of Clinical Neurology: Elsevier; 2020. p. 315-33. Available from: https://www.sciencedirect.com/science/article/pii/B9780444641236000229

84. Aceves SS. Unmet therapeutic needs in eosinophilic esophagitis. Digestive Diseases. 2014;32(1-2):143-8.

85. Mueser KT, Deavers F, Penn DL, Cassisi JE. Psychosocial treatments for schizophrenia. Annual Review of Clinical Psychology. 2013;9:465-97.

86. Miyamoto S, Miyake N, Jarskog LF, Fleischhacker WW, Lieberman JA. Pharmacological treatment of schizophrenia: a critical review of the pharmacology and clinical effects of current and future therapeutic agents. Mol Psychiatry. 2012;17(12):1206-27.

87. Wimberley T, Støvring H, Sørensen HJ, Horsdal HT, MacCabe JH, Gasse C. Predictors of treatment resistance in patients with schizophrenia: a population-based cohort study. Lancet Psychiatry. 2016;3(4):358-66.

88. El Abdellati K, De Picker L, Morrens M. Antipsychotic Treatment Failure: A Systematic Review on Risk Factors and Interventions for Treatment Adherence in Psychosis. Front Neurosci. 2020;14:531763.

89. Owen MJ, Sawa A, Mortensen PB. Schizophrenia. Lancet (London, England). 2016;388(10039):86-97.

90. Tandon R, Nasrallah HA, Keshavan MS. Schizophrenia, "just the facts" 5. Treatment and prevention. Past, present, and future. Schizophrenia Research. 2010;122(1-3):1-23.

91. Morgan VA, Waterreus A, Jablensky A, Mackinnon A, McGrath JJ, Carr V, et al. People living with psychotic illness in 2010: The second Australian national survey of psychosis. Australian & New Zealand Journal of Psychiatry. 2012;46(8):735-52.

92. Tyrer P, Kendall T. The spurious advance of antipsychotic drug therapy. Lancet. 2009;373(9657):4-5.

93. National Institute for Health and Care Excellence. Psychosis and schizophrenia in adults: prevention and management. Clinical guideline 2014.

94. Corbera S, Wexler BE, Bell MD, Pittman B, Pelphrey K, Pearlson G, et al. Disentangling negative and positive symptoms in schizophrenia and autism spectrum disorder. Schizophrenia Research. 2024;271:1-8.

95. Kane JM, Kishimoto T, Correll CU. Non-adherence to medication in patients with psychotic disorders: epidemiology, contributing factors and management strategies. World Psychiatry. 2013;12(3):216-26.

96. Patterson TL, Leeuwenkamp OR. Adjunctive psychosocial therapies for the treatment of schizophrenia. Schizophrenia Research. 2008;100(1-3):108-19.

97. Xu F, Zhang H. The application of cognitive behavioral therapy in patients with schizophrenia: A review. Medicine. 2023;102(32):e34827.

98. Fitapelli B, Lindenmayer JP. Advances in Cognitive Remediation Training in Schizophrenia: A Review. Brain Sci. 2022;12(2).

99. Kutlutürk Z, Aktaş M, Ayhan C. Examining the effect of family-based intervention programs used in psychosis on the disease: a systematic review. Eur Psychiatry. 2024;67(Suppl 1).

100. Anagnostopoulou N, Kyriakopoulos M, Alba A. Psychological interventions in psychosis in children and adolescents: a systematic review. Eur Child Adolesc Psychiatry. 2019;28(6):735-46.

101. Daruvala R, Kumar A, Datta SS. Do Psychological Interventions Work for Psychosis in Adolescents? Schizophr Bull. 2021;47(3):692-4.

102. Vita A, Gaebel W, Mucci A, Sachs G, Barlati S, Giordano GM, et al. European Psychiatric Association guidance on treatment of cognitive impairment in schizophrenia. European Psychiatry. 2022;65(1):e57.

103. Maley CT, Becker JE, Shultz EKB. Electroconvulsive Therapy and Other Neuromodulation Techniques for the Treatment of Psychosis. Child Adolesc Psychiatr Clin N Am. 2019;28(1):91-100.

104. Chen T, Loo C, Salvador-Carulla L, Jorm LR, Srasuebkul P, Sara G, et al. Factors associated with electroconvulsive therapy treatment for adults with serious psychiatric conditions in Australia. Aust N Z J Psychiatry. 2024;58(9):809-20.

105. Aleman A, Lange JD-d. TMS in Psychotic Disorders. In: Dell'Osso B, Di Lorenzo G, editors. Non Invasive Brain Stimulation in Psychiatry and Clinical Neurosciences. Cham: Springer International Publishing; 2020. p. 79-95. Available from: https://doi.org/10.1007/978-3-030-43356-7_7

106. Rudrappa R, Cavanna A, Rickards H, Ul HKM. Efficacy of Transcranial Magnetic Stimulation (TMS) on Negative and Cognitive Symptoms in Schizophrenia – a Systematic Review and Meta-Analysis. BJPsych Open. 2024;10(Suppl 1).

107. Drake RJ, Nordentoft M, Haddock G, Arango C, Fleischhacker WW, Glenthøj B, et al. Modeling determinants of medication attitudes and poor adherence in early nonaffective psychosis: implications for intervention. Schizophrenia Bulletin. 2015;41(3):584-96.

108. Novick D, Montgomery W, Treuer T, Aguado J, Kraemer S, Haro JM. Relationship of insight with medication adherence and the impact on outcomes in patients with schizophrenia and bipolar disorder: results from a 1-year European outpatient observational study. BMC psychiatry. 2015;15:189.

109. Sendt K-V, Tracy DK, Bhattacharyya S. A systematic review of factors influencing adherence to antipsychotic medication in schizophrenia-spectrum disorders. Psychiatry Research. 2015;225(1-2):14-30.

110. Lysaker PH, Pattison ML, Leonhardt BL, Phelps S, Vohs JL. Insight in schizophrenia spectrum disorders: relationship with behavior, mood and perceived quality of life, underlying causes and emerging treatments. World psychiatry: official journal of the World Psychiatric Association (WPA). 2018;17(1):12-23.

111. Erol A, Delibas H, Bora O, Mete L. The impact of insight on social functioning in patients with schizophrenia. The International Journal of Social Psychiatry. 2015;61(4):379-85.

112. David AS. Insight and psychosis. The British Journal of Psychiatry: The Journal of Mental Science. 1990;156:798-808.

113. Anderson KK, Norman R, MacDougall A, Edwards J, Palaniyappan L, Lau C, et al. Effectiveness of Early Psychosis Intervention: Comparison of Service Users and Nonusers in Population-Based Health Administrative Data. American Journal of Psychiatry. 2018;175(5):443-52.

114. Perkins DO, Gu H, Boteva K, Lieberman JA. Relationship Between Duration of Untreated Psychosis and Outcome in First-Episode Schizophrenia: A Critical Review and Meta-Analysis. American Journal of Psychiatry. 2005;162(10):1785-804.

115. Melton R, Blajeski S, Glasser D. Understanding Individual and Family Experiences Associated with DUP: Lessons from the Early Assessment and Support Alliance (EASA) Program in Oregon, USA. Community Mental Health Journal. 2020;56(6):1121-7.

116. Liu J, Cheng Y, Li M, Zhang Z, Li T, Luo XJ. Genome-wide Mendelian randomization identifies actionable novel drug targets for psychiatric disorders. Neuropsychopharmacology. 2023;48(2):270-80.

117. Hasan AH, Abid MA. Cobenfy (Xanomeline-Trospium Chloride): A New Frontier in Schizophrenia Management. Cureus. 2024;16(10):e71131.

118. Bukhari SMR, Btool S, Abbas J, Hussain A, Mehdi H, Raza M. Cobenfy (xanomeline-trospium): a breakthrough FDA-approved therapy redefining schizophrenia treatment. Ann Med Surg (Lond). 2025;87(6):3065-7.

119. Mistiaen P, Cornelis J, Detollenaere J, Devriese S, Farfan-Portet M-I, Ricour C. Organisation of mental health care for adults in Belgium. Health. Brussels: Health Services Research (HSR); 2019. KCE Reports (318)

120. Gerkens S, Merkur S. Health System Summary, 2024. Copenhagen: WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies.; 2024.

121. OECD. Mental Health Promotion and Prevention: Best Practices in Public Health. [Web page].Paris: OECD Publishing;2025. Available from: https://doi.org/10.1787/88bbe914-en

122. For a healthy Belgium. Offer and activity in PH and PDGH for adults. 2024.

123. Galderisi S, Kaiser S, Bitter I, Nordentoft M, Mucci A, Sabé M, et al. EPA guidance on treatment of negative symptoms in schizophrenia. European Psychiatry. 2021;64(1):e21.

124. Gaebel W, Großimlinghaus I, Kerst A, Cohen Y, Hinsche-Böckenholt A, Johnson B, et al. European Psychiatric Association (EPA) guidance on the quality of eMental health interventions in the treatment of psychotic disorders. Eur Arch Psychiatry Clin Neurosci. 2016;266(2):125-37.

125. HERMESplus. Mobile crisis team. [Web page]. [cited 19/01/2026]. Available from: https://hermesplus.be/en/im-looking-for-help/mobile-crisis-team-en/

126. Maric NP, Petrovic SA, Raballo A, Rojnic-Kuzman M, Klosterkötter J, Riecher-Rössler A. Survey of the European Psychiatric Association on the European status and perspectives in early detection and intervention in at-risk mental state and first-episode psychosis. Early Interv Psychiatry. 2019;13(4):853-8.

127. invaliditeitsverzekering Rvz-e. De terugbetaling van een geneesmiddel [Web page]. Available from: https://www.riziv.fgov.be/nl/thema-s/verzorging-kosten-en-terugbetaling/wat-het-ziekenfonds-terugbetaalt/geneesmiddelen/geneesmiddel-terugbetalen

128. Patiëntenplatform V. Wat wordt er terugbetaald van je bezoek aan de psycholoog? [Web page]. Available from: https://vlaamspatientenplatform.be/nl/advies-en-tips/wat-wordt-er-terugbetaald-van-je-bezoek-aan-de-psycholoog

129. Marwaha S, Johnson S, Bebbington P, Stafford M, Angermeyer MC, Brugha T, et al. Rates and correlates of employment in people with schizophrenia in the UK, France and Germany. The British Journal of Psychiatry: The Journal of Mental Science. 2007;191:30-7.

130. Saha S, Chant D, McGrath J. A systematic review of mortality in schizophrenia: is the differential mortality gap worsening over time? Archives of General Psychiatry. 2007;64(10):1123-31.

131. Brian A Palmer, V Shane Pankratz, Bostwick JM. The lifetime risk of suicide in schizophrenia: a reexamination. Archives of General Psychiatry. 2005;62(3):247-53.

132. Powell SB. Models of neurodevelopmental abnormalities in schizophrenia. Current Topics in Behavioral Neurosciences. 2010;4:435-81.

133. Fusar-Poli P, Estradé A, Spencer TJ, Gupta S, Murguia-Asensio S, Eranti S, et al. Pan-London Network for Psychosis-Prevention (PNP). Front Psychiatry. 2019;10:707.

134. Fusar-Poli P, Salazar de Pablo G, Correll CU, Meyer-Lindenberg A, Millan MJ, Borgwardt S, et al. Prevention of Psychosis: Advances in Detection, Prognosis, and Intervention. JAMA Psychiatry. 2020;77(7):755-65.

135. Catalan A, Salazar de Pablo G, Vaquerizo Serrano J, Mosillo P, Baldwin H, Fernández-Rivas A, et al. Annual Research Review: Prevention of psychosis in adolescents - systematic review and meta-analysis of advances in detection, prognosis and intervention. J Child Psychol Psychiatry. 2021;62(5):657-73.

136. Fusar-Poli P, Spencer T, De Micheli A, Curzi V, Nandha S, McGuire P. Outreach and support in South-London (OASIS) 2001-2020: Twenty years of early detection, prognosis and preventive care for young people at risk of psychosis. Eur Neuropsychopharmacol. 2020;39:111-22.

137. Cantor-Graae E, Selten JP. Schizophrenia and migration: a meta-analysis and review. Am J Psychiatry. 2005;162(1):12-24.

138. Selten JP, van der Ven E, Rutten BP, Cantor-Graae E. The social defeat hypothesis of schizophrenia: an update. Schizophr Bull. 2013;39(6):1180-6.

139. Ayano G, Tesfaw G, Shumet S. The prevalence of schizophrenia and other psychotic disorders among homeless people: a systematic review and meta-analysis. BMC Psychiatry. 2019;19(1):370.

140. Gutwinski S, Schreiter S, Deutscher K, Fazel S. The prevalence of mental disorders among homeless people in high-income countries: An updated systematic review and meta-regression analysis. PLOS Medicine. 2021;18(8):e1003750.

141. Bouckaert N, Gerkens S, Devriese S, Cleemput I. An EQ-5D-5L value set for Belgium – How to value health-related quality of life? Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports (342)

142. Maertens de Noordhout C, Detollenaere J, Primus-de Jong C, Kohn L, Devleesschauwer B, Charafeddine R, et al. Identifying Patient needs in Belgium: methodological approach and application. Health Services Research (HSR). Brussels: Belgian Health Care

Knowledge Centre (KCE); 2022. KCE Reports (348) Available from: https://kce.fgov.be/en/identifying-patient-needs-methodological-approach-and-application

143. De Pauw R, Gorasso V, Devleesschauwer B. Belgian national burden of disease study. Guidelines for the calculation of DALYs in Belgium/. Brussels: Sciensano; 2022. (D/2022/14.440/09)

144. Salomon JA, Haagsma A, Davis A, Maertens de Noordhout C, Polinder S, Havelaar AH, et al. Disability weights for the Global Burden of Disease 2013 Study. Lancet Glob Health. 2015;3(11):e712-23.

145. Ferrari AJ, Saha S, McGrath JJ, Norman R, Baxter AJ, Vos T, et al. Health states for schizophrenia and bipolar disorder within the Global Burden of Disease 2010 Study. Population health metrics. 2012;10(1):16.

146. Sciensano. Health Interview Survey [Web page].Brussels, Belgium;2018 [cited 10 April 2020]. Available from: https://his.wiv-isp.be/SitePages/Home.aspx

147. Debaveye S, De Smedt D, Heirman B, Kavanagh S, Dewulf J. Human health benefit and burden of the schizophrenia health care pathway in Belgium: paliperidone palmitate long-acting injections. BMC Health Services Research. 2019;19(1):393.

148. Maughan DL, Lillywhite R, Cooke M. Cost and carbon burden of long-acting injections: economic evaluation. BJ Psych Bulletin. 2015;39(4).

149. Escudero J, Muñoz J, Morera-Herreras T, Hernandez R, Medrano J, Domingo-Echaburu S, et al. Antipsychotics as environmental pollutants: An underrated threat? Science of the Total Environment. 2021;769:144634.

150. Reichert JF, Souza DM, Martins AF. Antipsychotic drugs in hospital wastewater and a preliminary risk assessment. Ecotoxicology and Environmental Safety. 2019;170:559-67.

151. Argaluza J, Domingo-Echaburu S, Orive G, Medrano J, Hernandez R, Lertxundi U. Environmental pollution with psychiatric drugs. World journal of psychiatry. 2021;11(10):791.

152. De Pauw R, Devleesschauwer B. BeBOD projections of prevalence, and years lived with disability for 33 causes, 2013-2040 In. v2024-12-12 ed; 2024.

153. Bergsholm P. Is schizophrenia disappearing? The rise and fall of the diagnosis of functional psychoses: an essay. BMC psychiatry. 2016;16(1):387.

154. Hoseinipalangi Z, Golmohammadi Z, Rafiei S, Pashazadeh Kan F, Hosseinifard H, Rezaei S, et al. Global health-related quality of life in schizophrenia: systematic review and meta-analysis. BMJ Supportive & Palliative Care. 2022;12(2):123-31.

155. Poole-Wright K, Patel A, Gaughran F, Murray R, Chalder T. Prevalence and associations of fatigue in psychosis: A systematic review and meta-analysis. Schizophr Res. 2025;279:59-70.

156. Li W, Yang Y, An FR, Zhang L, Ungvari GS, Jackson T, et al. Prevalence of comorbid depression in schizophrenia: A meta-analysis of observational studies. J Affect Disord. 2020;273:524-31.

157. Braga RJ, Reynolds GP, Siris SG. Anxiety comorbidity in schizophrenia. Psychiatry Res. 2013;210(1):1-7.

158. Heinrichs RW, Zakzanis KK. Neurocognitive deficit in schizophrenia: a quantitative review of the evidence. Neuropsychology. 1998;12(3):426-45.

159. Korchia T, Achour V, Faugere M, Albeash A, Yon DK, Boyer L, et al. Sexual Dysfunction in Schizophrenia: A Systematic Review and Meta-Analysis. JAMA Psychiatry. 2023;80(11):1110-20.

160. Huhn M, Nikolakopoulou A, Schneider-Thoma J, Krause M, Samara M, Peter N, et al. Comparative efficacy and tolerability of 32 oral antipsychotics for the acute treatment of adults with multi-episode schizophrenia: a systematic review and network meta-analysis. Lancet. 2019;394(10202):939-51.

161. Kohn L, Christiaens W, Detraux J, De Lepeleire J, De Hert M, Gillain B, et al. Barriers to Somatic Health Care for Persons With Severe Mental Illness in Belgium: A Qualitative Study of Patients' and Healthcare Professionals' Perspectives. Front Psychiatry. 2021;12:798530.

162. Drake RE, Cimpean D, Torrey WC. Shared decision making in mental health: prospects for personalized medicine. Dialogues Clin Neurosci. 2009;11(4):455-63.

163. Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions. Cochrane Database Syst Rev. 2010;2010(1):CD007297.

164. Haugom EW, Stensrud B, Beston G, Ruud T, Landheim AS. Experiences of shared decision making among patients with psychotic disorders in Norway: a qualitative study. BMC Psychiatry. 2022;22(1):192.

165. Shared decision making. NICE guideline [NG197]. National Institute for Health and Care Excellence (NICE); 2021. Available from: https://www.nice.org.uk/guidance/ng197

166. Stovell D, Morrison AP, Panayiotou M, Hutton P. Shared treatment decision-making and empowerment-related outcomes in psychosis: systematic review and meta-analysis. Br J Psychiatry. 2016;209(1):23-8.

167. Morris SB. Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies. Psychiatric Services. 2012.

168. Corrigan PW, Druss BG, Perlick DA. The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. Psychol Sci Public Interest. 2014;15(2):37-70.

169. Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M, Group IS. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. Lancet. 2009;373(9661):408-15.

170. OECD. Unmet needs for health care: Comparing approaches and results from international surveys 2020. Available from: https://www.oecd.org/content/dam/oecd/en/publications/reports/2020/01/unmet-needs-for-health-care_1e29e6c7/9c2be79c-en.pdf

171. Moran V, Suhrcke M, Ruiz-Castell M, Barre J, Huiart L. Investigating unmet need for healthcare using the European Health Interview Survey: a cross-sectional survey study of Luxembourg. BMJ Open. 2021;11(8):e048860.

172. Thornicroft G, Tansella M. Components of a modern mental health service: a pragmatic balance of community and hospital care: overview of systematic evidence. Br J Psychiatry. 2004;185:283-90.

173. Degnan A, Berry K, Sweet D, Abel K, Crossley N, Edge D. Social networks and symptomatic and functional outcomes in schizophrenia: a systematic review and meta-analysis. Soc Psychiatry Psychiatr Epidemiol. 2018;53(9):873-88.

174. Bond GR, Drake RE, Luciano A. Employment and educational outcomes in early intervention programmes for early psychosis: a systematic review. Epidemiol Psychiatr Sci. 2015;24(5):446-57.

175. Ajnakina O, Stubbs B, Francis E, Gaughran F, David AS, Murray RM, et al. Employment and relationship outcomes in first-episode psychosis: A systematic review and meta-analysis of longitudinal studies. Schizophr Res. 2021;231:122-33.

176. Marwaha S, Johnson S. Schizophrenia and employment - a review. Soc Psychiatry Psychiatr Epidemiol. 2004;39(5):337-49.

177. Luciano A, Meara E. Employment status of people with mental illness: national survey data from 2009 and 2010. Psychiatr Serv. 2014;65(10):1201-9.

178. Drake RE, Bond GR, Becker DR. Individual Placement and Support: An Evidence-Based Approach to Supported Employment. Oxford University Press; 2012.

179. Awad AG, Voruganti LNP. The Burden of Schizophrenia on Caregivers: A Review. Pharmacoeconomics. 2012;26:149–62.

180. Gupta S, Isherwood G, Jones K, Van Impe K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. BMC Psychiatry. 2015;15:162.

181. Chan SW. Global perspective of burden of family caregivers for persons with schizophrenia. Arch Psychiatr Nurs. 2011;25(5):339-49.

182. Vollset SE, Ababneh HS, Abate YH, Abbafati C, Abbasgholizadeh R, Abbasian M, et al. Burden of disease scenarios for 204 countries and territories, 2022–2050: a forecasting analysis for the Global Burden of Disease Study 2021. The Lancet. 2024;403(10440):2204-56.

183. Morgan C, Kirkbride J, Hutchinson G, Craig T, Morgan K, Dazzan P, et al. Cumulative social disadvantage, ethnicity and first-episode psychosis: a case-control study. Psychol Med. 2008;38(12):1701-15.

184. Stilo SA, Di Forti M, Mondelli V, Falcone AM, Russo M, O'Connor J, et al. Social disadvantage: cause or consequence of impending psychosis? Schizophr Bull. 2013;39(6):1288-95.

185. Kirkbride JB, Anglin DM, Colman I, Dykxhoorn J, Jones PB, Patalay P, et al. The social determinants of mental health and disorder: evidence, prevention and recommendations. World Psychiatry. 2024;23(1):58-90.

186. McGorry PD, Mei C. Unmet needs in youth mental health: Transforming models of care to improve outcomes. In: New directions in psychiatry: Springer; 2020. p. 181-91.

187. Carlsson IM, Blomqvist M, Jormfeldt H. Ethical and methodological issues in qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions: a critical review. Int J Qual Stud Health Well-being. 2017;12(sup2):1368323.

188. Archibald MM, Ambagtsheer RC, Casey MG, Lawless M. Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. International Journal of Qualitative Methods. 2019;18:1609406919874596.

189. Catalan A, Salazar de Pablo G, Aymerich C, Guinart D, Goena J, Madaria L, et al. "Short" Versus "Long" Duration of Untreated Psychosis in People with First-Episode Psychosis: A Systematic Review and Meta-Analysis of Baseline Status and Follow-Up Outcomes. Schizophr Bull. 2025;51(5):1206-30.

190. Howes OD, Whitehurst T, Shatalina E, Townsend L, Onwordi EC, Mak TLA, et al. The clinical significance of duration of untreated psychosis: an umbrella review and random-effects meta-analysis. World Psychiatry. 2021;20(1):75-95.

191. Salazar de Pablo G, Guinart D, Armendariz A, Aymerich C, Catalan A, Alameda L, et al. Duration of Untreated Psychosis and Outcomes in First-Episode Psychosis: Systematic Review and Meta-analysis of Early Detection and Intervention Strategies. Schizophr Bull. 2024;50(4):771-83.

192. Puntis S, Minichino A, De Crescenzo F, Cipriani A, Lennox B, Harrison R. Specialised early intervention teams for recent-onset psychosis. Cochrane Database Syst Rev. 2020;11(11):CD013288.

193. McGorry P. Transition to adulthood: the critical period for pre-emptive, disease-modifying care for schizophrenia and related disorders. Schizophr Bull. 2011;37(3):524-30.

194. Shinn AK, Cawkwell PB, Bolton K, Healy BC, Karmacharya R, Yip AG, et al. Return to College After a First Episode of Psychosis. Schizophr Bull Open. 2020;1(1):sgaa041.

195. Chai Y, Tang JY, Ma DCF, Luo H, Chan SKW. Self-Harm and Suicide Rates Before and After an Early Intervention Program for Patients With First-Episode Schizophrenia. JAMA Netw Open. 2024;7(8):e2426795.

196. Gohar SM, Hegelstad WTV, Auestad B, Haahr UH, Joa I, Johannessen JO, et al. Association between early suicidal trajectories in first-episode psychosis and 10-year follow-up: TIPS registry-linked study. Lancet Psychiatry. 2023;10(7):528-36.

197. Leucht S, Cipriani A, Spineli L, Mavridis D, Orey D, Richter F, et al. Comparative efficacy and tolerability of 15 antipsychotic drugs in schizophrenia: a multiple-treatments meta-analysis. Lancet. 2013;382(9896):951-62.

198. Joshi YB, Thomas ML, Braff DL, Green MF, Gur RC, Gur RE, et al. Anticholinergic Medication Burden-Associated Cognitive Impairment in Schizophrenia. Am J Psychiatry. 2021;178(9):838-47.

199. Thomas EC, Ben-David S, Treichler E, Roth S, Dixon LB, Salzer M, et al. A Systematic Review of Shared Decision-Making Interventions for Service Users With Serious Mental Illnesses: State of the Science and Future Directions. Psychiatr Serv. 2021;72(11):1288-300.

200. Fitzgerald I, Howe J, Maidment I, Wallace E, Zisman-Ilani Y, Hojlund M, et al. From Idealist to Realist-Designing and Implementing Shared Decision-Making Interventions in the Choice of Antipsychotic Prescription in People Living With Psychosis (SHAPE): A Realist Review (Part 2-Designing SDM Interventions: Optimizing Design and Local Implementation). Schizophr Bull. 2025;51(4):932-48.

201. Spanakis P, Lorimer B, Newbronner E, Wadman R, Crosland S, Gilbody S, et al. Digital health literacy and digital engagement for people with severe mental ill health across the course of the COVID-19 pandemic in England. BMC Med Inform Decis Mak. 2023;23(1):193.

202. Zhang X, Lewis S, Chen X, Berry N, Bucci S. Technology use and attitudes towards digital mental health in people with severe mental health problems: a survey study in China. Front Psychiatry. 2023;14:1261795.

203. Tessier A, Roger K, Gregoire A, Desnavailles P, Misdrahi D. Family psychoeducation to improve outcome in caregivers and patients with schizophrenia: a randomized clinical trial. Front Psychiatry. 2023;14:1171661.

204. RIZIV-INAMI. Eerstelijns psychologische zorg in een netwerk voor geestelijke gezondheid [Web page]. [cited December 22th 2025]. Available from: https://www.riziv.fgov.be/nl/thema-s/verzorging-kosten-en-terugbetaling/wat-het-ziekenfonds-terugbetaalt/geestelijke-gezondheidszorg/eerstelijns-psychologische-zorg-in-een-netwerk-voor-geestelijke-gezondheid

205. NICE. Psychosis and schizophrenia in adults: prevention and management. 2014 Available from: https://www.nice.org.uk/guidance/cg178

206. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. Netherlands: Health system review. 2016. Health Systems in Transition 18

207. Shields GE, Buck D, Elvidge J, Hayhurst KP, Davies LM. Cost-Effectiveness Evaluations of Psychological Therapies for Schizophrenia and Bipolar Disorder: A Systematic Review. Int J Technol Assess Health Care. 2019;35(4):317-26.

208. Mental Health and Work: Belgium. 2013.

209. Matthys F. Staten-Generaal Geestelijke Gezondheidszorg: open brief aan de regering. Geestelijke gezondheidszorg: een haperende ambitie?: Domus Medica; 2025.

210. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med. 2015;45(1):11-27.

211. Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P. "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Med J Aust. 1997;166(4):182-6.

212. Wittevrongel E, Kessels R, Everaert G, Vrijens M, Danckaerts M, van Winkel R. A user perspective on youth mental health services: Increasing help-seeking behaviour requires addressing service preferences and attitudinal barriers. Early Interv Psychiatry. 2025;19(1):e13584.

213. Lloyd-Evans B, Crosby M, Stockton S, Pilling S, Hobbs L, Hinton M, et al. Initiatives to shorten duration of untreated psychosis: systematic review. Br J Psychiatry. 2011;198(4):256-63.

214. Joa I, Johannessen JO, Auestad B, Friis S, McGlashan T, Melle I, et al. The Key to Reducing Duration of Untreated First Psychosis: Information Campaigns. Schizophrenia Bulletin. 2007;34(3):466-72.

APPENDICES

APPENDIX 1. FINAL QUESTIONNAIRE FOR PSYCHOTIC DISORDERS

LimeSurvey

Merci d'avoir accepté de participer à notre enquête.

Notre étude vise à identifier les besoins des patients atteints d'un trouble psychotique afin d'améliorer leur accompagnement.

Ce questionnaire vous concerne si:

Vous êtes atteint d'un trouble psychotique (par exemple schizophrénie, trouble schizo-affectif, ou autre trouble psychotique) Vous avez 18 ans ou plus Vous habitez en Belgique (résidence principale)

Ou

Vous vous exprimez au nom d'une personne adulte atteinte d'un trouble psychotique diagnostiquée dont vous êtes le représentant légal. Cette personne habite en Belgique, et n'est pas en mesure de répondre elle-même.

L'étude vise à mesurer les besoins non-rencontrés des personnes atteintes d'un trouble psychotique. Cela peut aider à améliorer la prise en charge des patients ayant un trouble psychotique. Certaines questions peuvent sembler moins adaptées à votre situation personnelle ou paraître non pertinentes. Néanmoins, elles sont importantes pour pouvoir comparer les besoins de personnes atteintes d'autres maladies. Nous vous prions donc de répondre aux questions aussi précisément que possible afin de bien cerner vos besoins.

Les résultats de cette étude seront publiés sur le site Internet du KCE (www.kce.fgov.be) et sur le site de NEED (www.health-needs.eu) début 2026.

Avant d'accepter de participer à cette enquête, nous vous demandons de lire les informations suivantes sur la confidentialité de vos données, et de donner votre consentement à l'utilisation de vos données.

LimeSurvey

Partie A: Informations générales

A partir de maintenant veuillez répondre à toutes les questions comme si vous étiez la personne atteinte du trouble psychotique. Indiquez "je ne sais pas" si vous ne savez pas comment la personne répondrait.

Merci pour votre participation.

Malheureusement, vous ne rentrez pas dans les conditions pour pouvoir poursuivre cette étude.

Merci pour votre participation.

Malheureusement, vous ne rentrez pas dans les conditions pour pouvoir poursuivre cette étude.

A1. Vous remplissez ce questionnaire

- ☐ Pour vous-même
- ☐ Pour une autre personne dont vous êtes le représentant légal. (La personne que vous représentez n'est pas capable de répondre au questionnaire pour le moment. En cochant cette case, vous participez à cette étude en fonction de sa volonté probable de participer.)

A2. À quel genre vous identifiez-vous ?

- ☐ Homme
- ☐ Femme
- ☐ Autre

A3. Quelle est votre année de naissance ?

☐☐☐☐

A4. Dans quelle province habitez-vous ?

- ☐ Anvers
- ☐ Brabant wallon
- ☐ Bruxelles
- ☐ Hainaut
- ☐ Liège
- ☐ Limbourg
- ☐ Luxembourg
- ☐ Namur
- ☐ Flandre orientale
- ☐ Brabant flamand
- ☐ Flandre occidentale
- ☐ Je n'habite pas en Belgique
- ☐ Je ne sais pas

LimeSurvey

Partie B: Informations générales

B1. Quel est le diplôme ou le niveau d'étude le plus élevé que vous avez obtenu jusqu'à présent?

- [ ] Pas de diplôme ou enseignement primaire
- [ ] Enseignement secondaire inférieur
- [ ] Enseignement secondaire supérieur
- [ ] Enseignement supérieur de type court (p.ex. Bachelier)
- [ ] Enseignement supérieur de type long (p.ex. Master)
- [ ] Doctorat
- [ ] Je ne sais pas
- [ ] Autre diplôme

Autre diplôme

LimeSurvey

B2. Vous vivez …

- [ ] Seul(e)
- [ ] Seul(e) avec enfant(s)
- [ ] En couple (sans enfants)
- [ ] En couple (avec enfants)
- [ ] Avec un ou deux parents
- [ ] En colocation ou habitat partagé
- [ ] En maison de soins psychiatriques
- [ ] En habitation protégée
- [ ] En logement supervisé
- [ ] A l'hôpital (temporairement)
- [ ] En maison de repos
- [ ] Je ne sais pas
- [ ] Autre

Autre

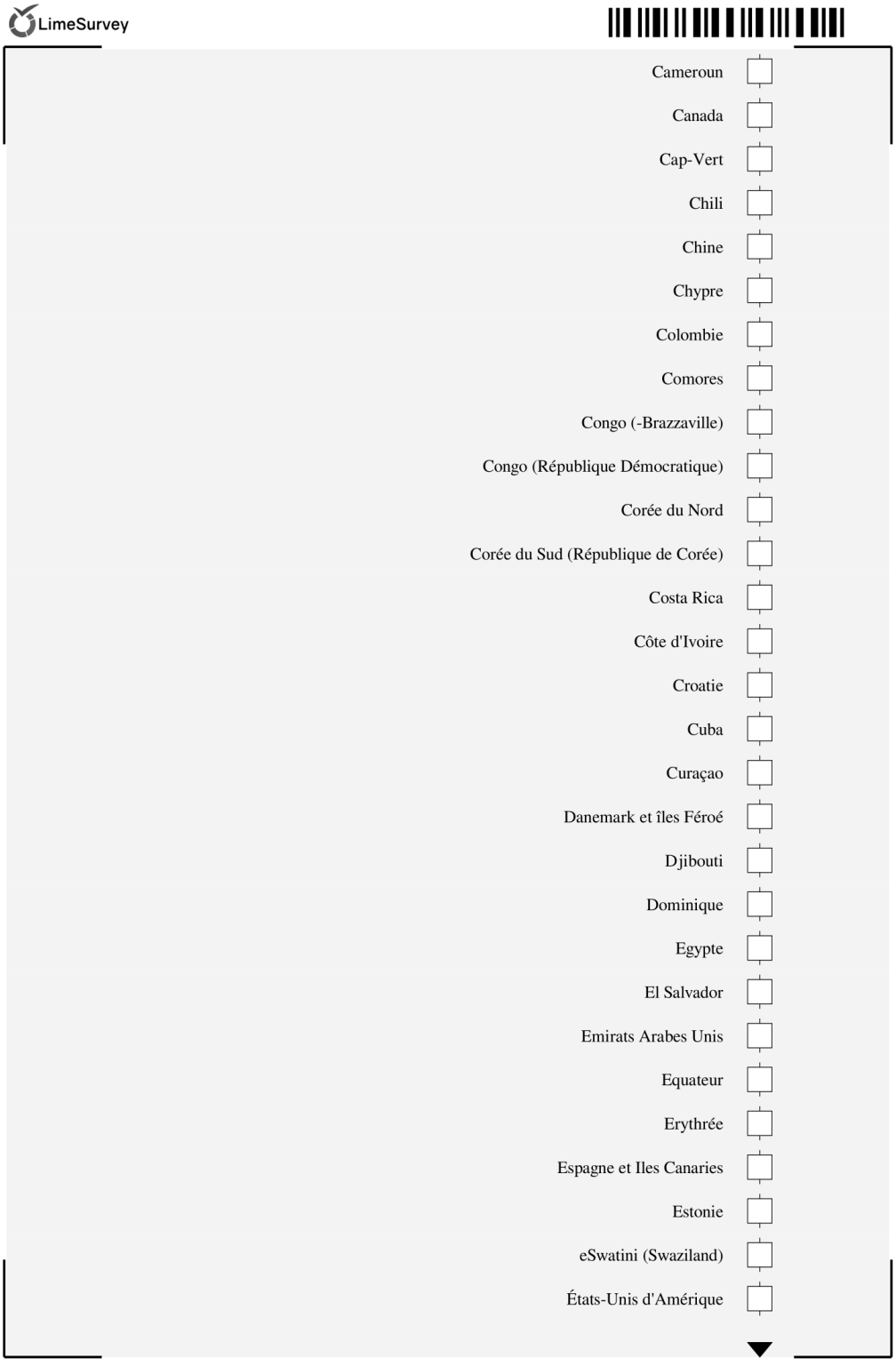
B3. Quel est votre pays de naissance ?

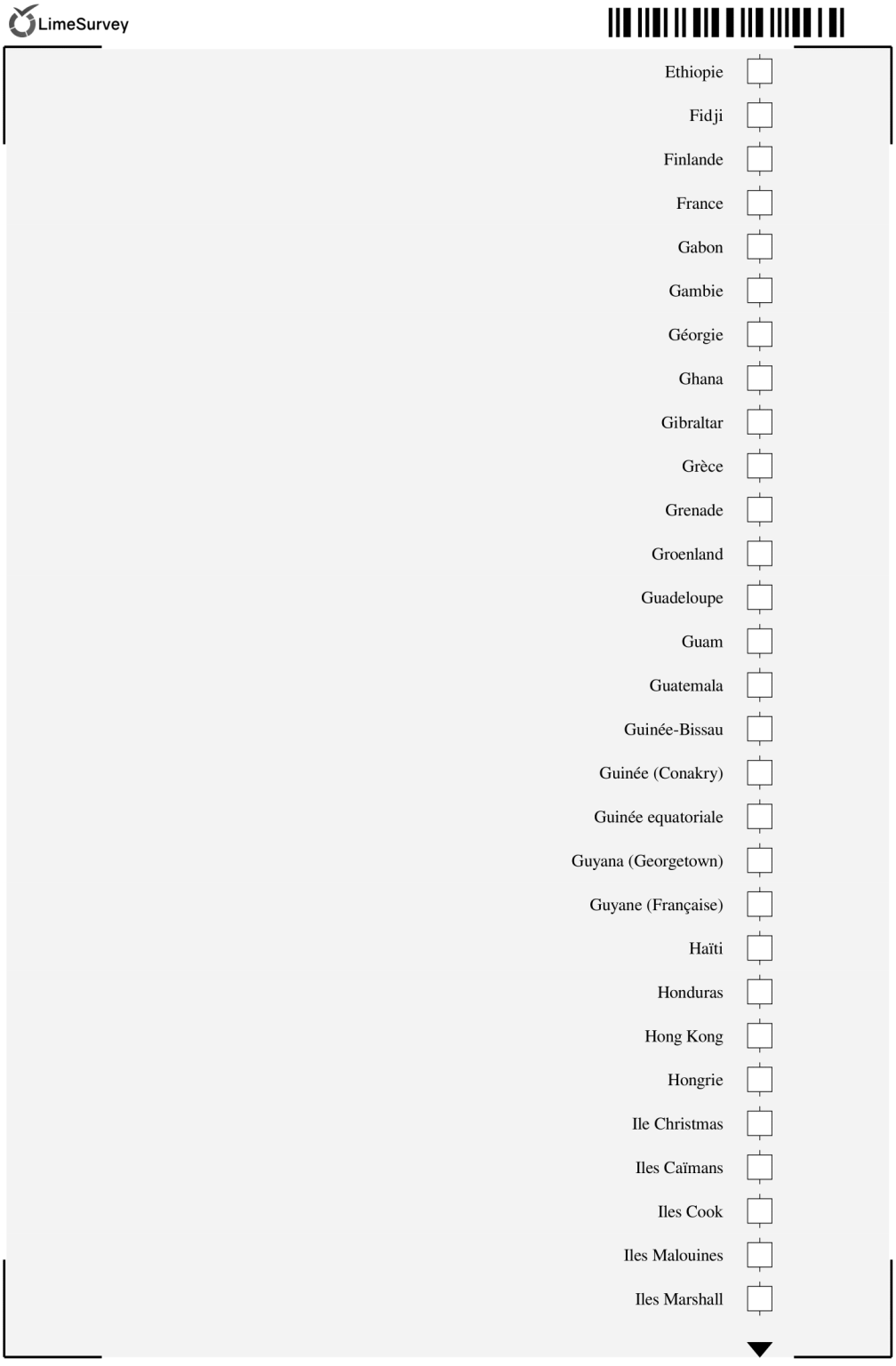
- [ ] Belgique
- [ ] Autre pays
- [ ] Je ne sais pas

B4. Sélectionnez le pays concerné

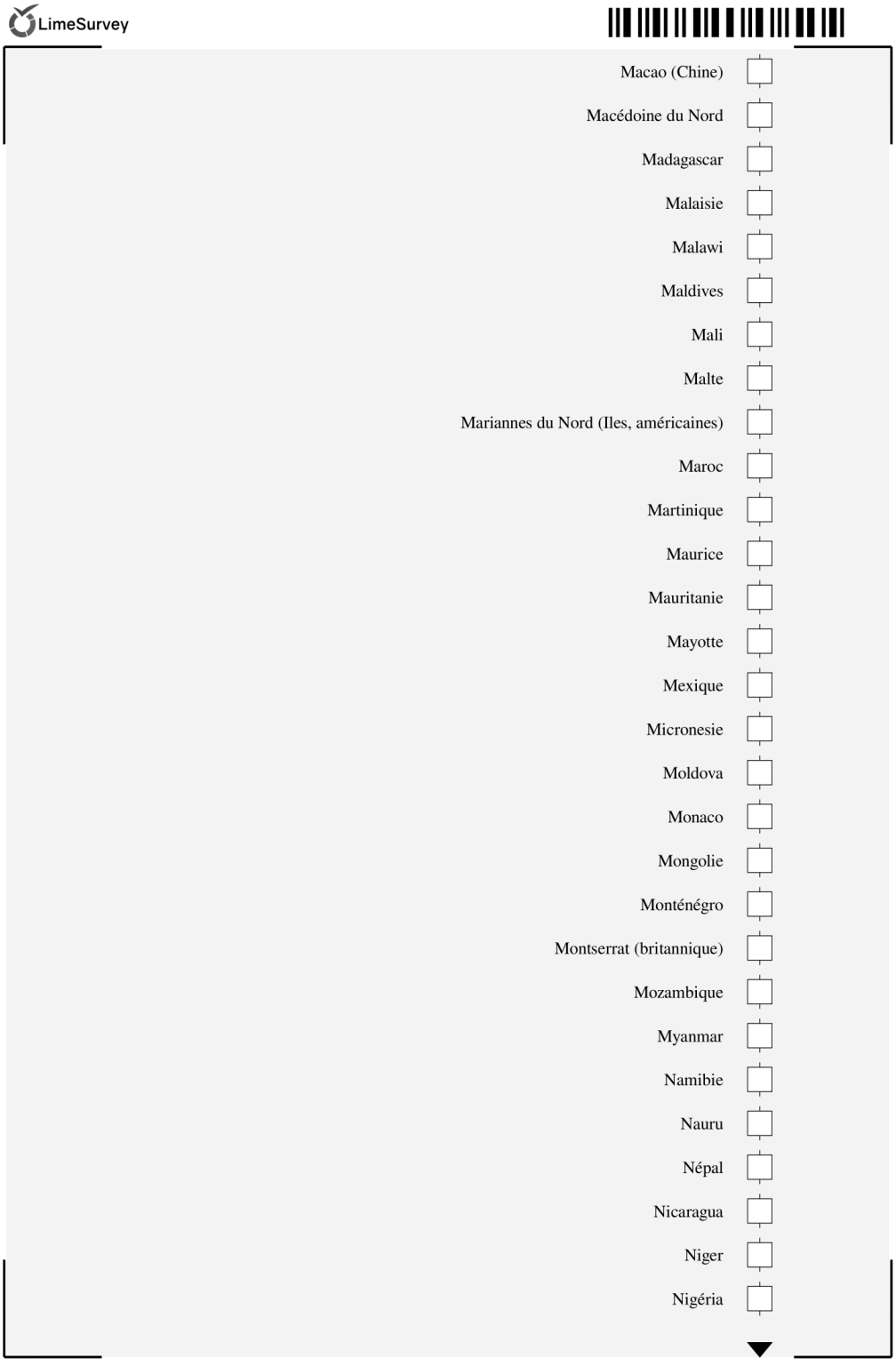
- [ ] Afghanistan
- [ ] Afrique du Sud
- [ ] Albanie
- [ ] Algérie
- [ ] Allemagne
- [ ] Andorre
- [ ] Angola

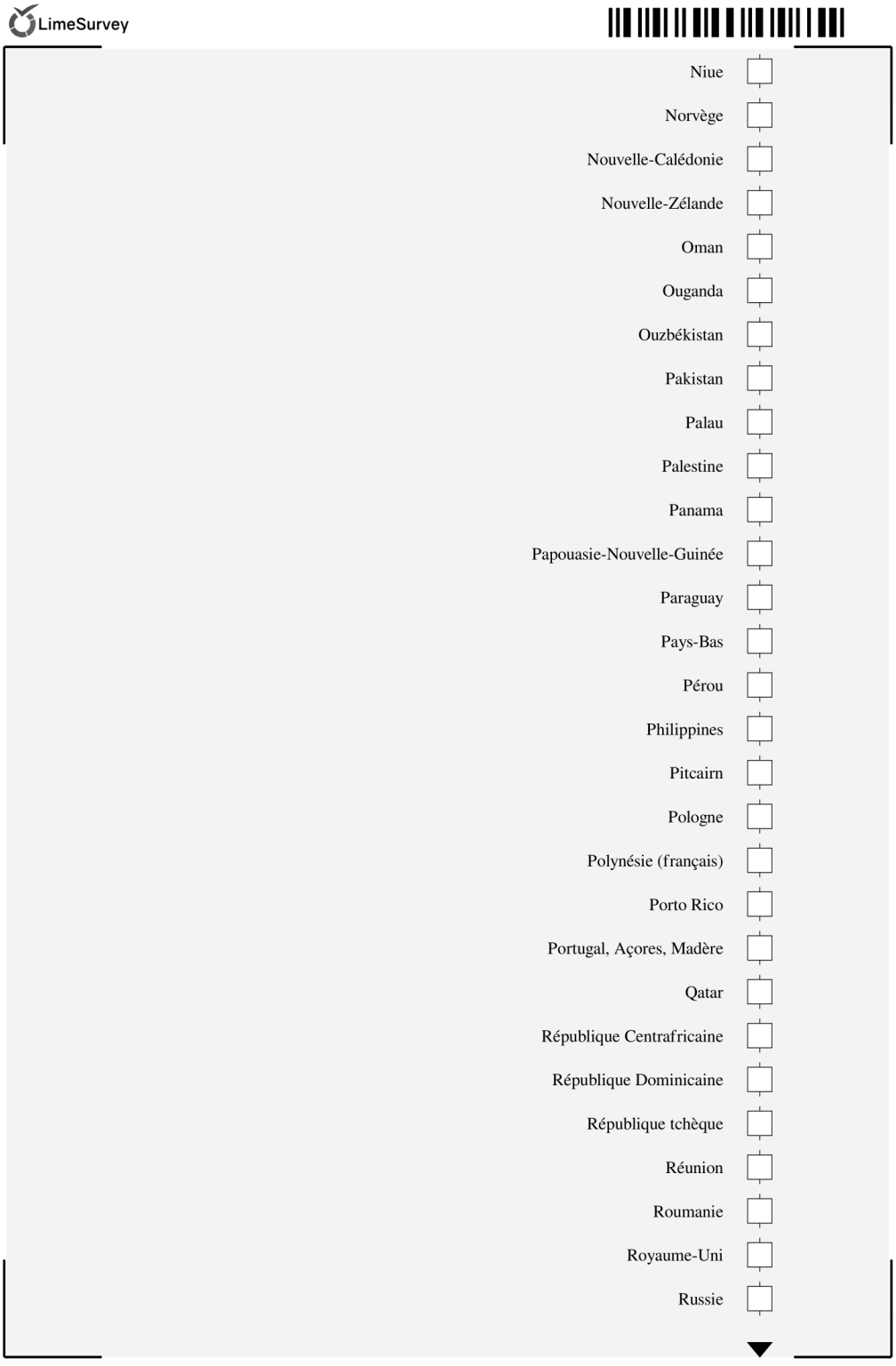

LimeSurvey
Anguilla
Antarctique
Antigua et Barbuda
Arabie Saoudite
Argentine
Arménie
Aruba
Australie
Autriche
Azerbaïdjan
Bahamas
Bahreïn
Bangladesh
Barbade
Bélize
Bénin
Bermudes
Bhoutan
Biélorussie
Bolivie
Bonaire
Bosnie - Herzégovine
Botswana
Brésil
Brunei
Bulgarie
Burkina Faso
Burundi
Cambodge


LimeSurvey
Cameroun
Canada
Cap-Vert
Chili
Chine
Chypre
Colombie
Comores
Congo (-Brazzaville)
Congo (République Démocratique)
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Corée du Sud (République de Corée)
Costa Rica
Côte d'Ivoire
Croatie
Cuba
Curaçao
Danemark et îles Féroé
Djibouti
Dominique
Egypte
El Salvador
Emirats Arabes Unis
Equateur
Erythrée
Espagne et Iles Canaries
Estonie
eSwatini (Swaziland)
États-Unis d'Amérique


LimeSurvey
Ethiopie
Fidji
Finlande
France
Gabon
Gambie
Géorgie
Ghana
Gibraltar
Grèce
Grenade
Groenland
Guadeloupe
Guam
Guatemala
Guinée-Bissau
Guinée (Conakry)
Guinée equatoriale
Guyana (Georgetown)
Guyane (Française)
Haïti
Honduras
Hong Kong
Hongrie
Ile Christmas
Iles Caïmans
Iles Cook
Iles Malouines
Iles Marshall


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Iles Salomon
Iles Vierges (américaines)
Iles Vierges (britanniques)
Inde
Indonésie
Irak
Iran
Irlande
Islande
Israël
Italie
Jamaïque
Japon
Jordanie
Kazakhstan
Kenya
Kirghizistan
Kiribati
Kosovo
Koweït
Laos
Lesotho
Lettonie
Liban
Libéria
Libye
Liechtenstein
Lituanie
Luxembourg


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Macao (Chine)
Macédoine du Nord
Madagascar
Malaisie
Malawi
Maldives
Mali
Malte
Mariannes du Nord (Iles, américaines)
Maroc
Martinique
Maurice
Mauritanie
Mayotte
Mexique
Micronesie
Moldova
Monaco
Mongolie
Monténégro
Montserrat (britannique)
Mozambique
Myanmar
Namibie
Nauru
Népal
Nicaragua
Niger
Nigéria


LimeSurvey
Niue
Norvège
Nouvelle-Calédonie
Nouvelle-Zélande
Oman
Ouganda
Ouzbékistan
Pakistan
Palau
Palestine
Panama
Papouasie-Nouvelle-Guinée
Paraguay
Pays-Bas
Pérou
Philippines
Pitcairn
Pologne
Polynésie (français)
Porto Rico
Portugal, Açores, Madère
Qatar
République Centrafricaine
République Dominicaine
République tchèque
Réunion
Roumanie
Royaume-Uni
Russie


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Rwanda
Sahara occidental
Saint-Barthélemy
Saint-Christophe-et-Niévès
Saint-Eustache et Saba
Saint-Marin
Saint-Martin (France)
Saint-Martin (Pays-Bas)
Saint-Pierre-et-Miquelon
Saint-Vincent-et-les-Grenadines
Sainte-Hélène - Tristan Da Cunha - Ascension
Sainte-Lucie
Samoa
Samoa (Américain)
Sao Tomé et Principe
Sénégal
Serbie
Seychelles
Sierra Leone
Singapour
Slovaquie
Slovénie
Somalie
Soudan
Soudan du Sud
Sri Lanka
Suède
Suisse
Suriname





Syrie ☐
Tadjikistan ☐
Taiwan ☐
Tanzanie ☐
Tchad ☐
Thaïlande ☐
Timor oriental ☐
Togo ☐
Tokelau (Nouvelle-Zélande) ☐
Tonga ☐
Trinité et Tobago ☐
Tunisie ☐
Turkménistan ☐
Turques-et-Caïques (britanniques) ☐
Turquie ☐
Tuvalu ☐
Ukraine ☐
Uruguay ☐
Vanuatu ☐
Venezuela ☐
Vietnam ☐
Wallis-et-Futuna ☐
Yémen ☐
Zambie ☐
Zimbabwe ☐
Je ne sais pas ☐

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Autre ☐

Autre

B5. **Quel était votre <u>principal</u> statut professionnel <u>juste avant le début de votre trouble psychotique</u> ?**

Emploi rémunéré (employé ou indépendant) ☐

Demandeur/demandeuse d'emploi, chômage, CPAS ☐

Homme/femme au foyer, sans revenus ☐

Etudiant(e) ☐

Pensionné(e) ☐

Invalidité ☐

Je ne sais pas ☐

Autre ☐

Autre

B6.

Depuis le début de vos premiers symptômes psychotiques, avez-vous eu un emploi rémunéré?

Considérez comme "premiers symptômes psychotiques" les premières manifestations de votre trouble psychotique, telles qu'entendre des voix ou des bruits qui n'existent pas selon les autres ou de voir des choses que les autres ne voient pas, avoir des pensées qui ne correspondent pas à la réalité perçue par les autres, ou avoir l'idée que quelqu'un cherche volontairement à vous nuire. Si vous ne savez pas quand vos symptômes ont commencé, veuillez à la place considérer le moment de votre premier contact avec les soins psychiatriques.

Oui ☐

Non ☐

Je ne sais pas ☐

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B7. **<u>Actuellement</u>, quel est votre <u>principal</u> statut professionnel?**

- [ ] Emploi rémunéré (employé ou indépendant)
- [ ] Demandeur/demandeuse d'emploi, chômage, CPAS
- [ ] Homme/femme au foyer, sans revenus
- [ ] Etudiant(e)
- [ ] Pensionné(e)
- [ ] Invalidité
- [ ] Je ne sais pas
- [ ] Autre

Autre

B8. **En tenant compte de tous les revenus de votre ménage, dans quelle mesure parvenez-vous à joindre les deux bouts à la fin de chaque mois ?**

C'est à dire, dans quelle mesure est-ce que les revenus de votre ménage suffisent pour couvrir toutes vos dépenses chaque mois?

- [ ] Très facilement
- [ ] Facilement
- [ ] Assez facilement
- [ ] Avec quelque difficulté
- [ ] Avec difficulté
- [ ] Avec grande difficulté
- [ ] Je ne sais pas

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Partie C: Concernant votre problème de santé

Merci pour votre participation.

Malheureusement, vous ne rentrez pas dans les conditions pour pouvoir poursuivre cette étude, car nous n'incluons pas les troubles psychotiques dû à une autre affection médicale.

C1. Depuis combien de temps approximativement avez-vous reçu le diagnostic de trouble psychotique?

- ☐ Moins de 6 mois
- ☐ 6 mois à 2 ans
- ☐ 2 à 5 ans
- ☐ 5 à 10 ans
- ☐ Plus de 10 ans
- ☐ Je ne sais pas

C2. Indiquez approximativement le nombre d'années:

☐☐☐☐☐☐☐☐☐☐

C3. Combien de temps est passé entre vos premiers symptômes psychotiques et le premier contact avec un psychiatre ?

- ☐ Moins de 1 mois
- ☐ Entre 1 mois et 6 mois
- ☐ Entre 6 mois et 1 an
- ☐ Entre 1 an et 2 ans
- ☐ Plus de 2 ans
- ☐ Je ne sais pas

C4. Combien de temps est passé entre votre premier rendez-vous médical pour le trouble psychotique et le diagnostic?

- ☐ Moins de 1 mois
- ☐ Entre 1 mois et 6 mois
- ☐ Entre 6 mois et 1 an
- ☐ Entre 1 an et 2 ans
- ☐ Plus que 2 ans
- ☐ Je ne sais pas

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C5. Quel(s) diagnostic(s) avez-vous reçu(s) ?

- [ ] Schizophrénie
- [ ] Trouble schizo-affectif
- [ ] Trouble schizophréniforme
- [ ] Trouble délirant
- [ ] Trouble psychotique bref
- [ ] Trouble psychotique partagé
- [ ] Trouble psychotique induit par une substance
- [ ] Trouble psychotique dû à une autre affection médicale
- [ ] Trouble psychotique non spécifié
- [ ] Trouble bipolaire avec caractéristiques psychotiques
- [ ] Je ne sais pas
- [ ] Je ne veux pas répondre
- [ ] Autre

Autre

C6. Avez-vous déjà été hospitalisé(e) à cause du trouble psychotique? Considérez uniquement les hospitalisations avec nuitée(s)

- [ ] Oui
- [ ] Non
- [ ] Je ne sais pas

C7.

{if(((is_empty(DSD1_A1.NAOK)) and (is_empty(DSD1_A2.NAOK)) and (is_empty(DSD1_A3.NAOK)) and (is_empty(DSD1_A4.NAOK)) and (is_empty(DSD1_A5.NAOK)) and (is_empty(DSD1_A6.NAOK)) and (is_empty(DSD1_A7.NAOK)) and (is_empty(DSD1_A9.NAOK)) and (is_empty(DSD1_A10.NAOK)) and (is_empty(DSD1_A11.NAOK)) and (is_empty(DSD1_A12.NAOK)) and (is_empty(DSD1_other)) and (DSD1_A8.NAOK == "Y")),'uitgesloten','in')}

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Partie D: Autres problèmes de santé

D1. Avez-vous un ou plusieurs des problèmes de santé suivants pouvant-être associés au trouble psychotique ?

	Oui	Non	Je ne sais pas
Trouble obsessionnel compulsif (TOC)	☐	☐	☐
Dépression	☐	☐	☐
Trouble bipolaire	☐	☐	☐
Trouble de la consommation d'alcool	☐	☐	☐
Trouble lié à l'usage de substances psychoactives / toxicomanie	☐	☐	☐
Trouble anxieux ou trouble de panique	☐	☐	☐
Trouble du stress post-traumatique (TSPT)	☐	☐	☐
Trouble de la personnalité	☐	☐	☐
Trouble du spectre de l'autisme	☐	☐	☐
Trouble déficit de l'attention avec ou sans hyperactivité (TDAH)	☐	☐	☐
Trouble du comportement alimentaire (p.ex. anorexie, boulimie)	☐	☐	☐

D2. Avez-vous également d' autre(s) problème(s) de santé ?

- ☐ Oui
- ☐ Non
- ☐ Je ne sais pas

D3. Quels autres problèmes de santé avez-vous ? <u>Vous pouvez cocher plusieurs cases</u>.

Veuillez également indiquer le nom précis de votre/vos problème(s) de santé si vous le(s) connaissez.

Si vous ne connaissez pas (encore) le diagnostic de votre autre problème de santé, cochez la case "pas de diagnostic connu".

- ☐ Maladie du cœur ou des vaisseaux sanguins (p.ex. hypertension)

Commentaire

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Maladie du système respiratoire (p.ex. asthme) ☐

Commentaire

Maladie de l'appareil digestif (p.ex. syndrôme du colon irritable) ☐

Commentaire

Maladie de la peau ☐

Commentaire

Maladie des os, articulations, ou muscles (p.ex. arthrose, arthrite rhumatoïde) ☐

Commentaire

Autre trouble de santé mentale ou psychologique non mentionné dans la question précédente ☐

Commentaire

Trouble neurodéveloppemental (p.ex. retard de développement) ☐

Commentaire

Maladie du système nerveux (neurologique) (p.ex. démence, sclérose en plaques) ☐

Commentaire

Maladie du sang (hématologique) (p.ex. anémie) ☐

Commentaire

Maladie immunitaire (p.ex. allergies, maladies auto-inflammatoires) ☐

Commentaire

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Maladie endocrinienne, nutritionnelle, ou métabolique (p.ex. diabète, cholestérol élevé, obésité, hypothyroïdisme) ☐

Commentaire

Maladie de l'œil ☐

Commentaire

Maladie de l'oreille ou du système vestibulaire ☐

Commentaire

Maladie des organes reproducteurs ou du système urinaire (p.ex. insuffisance rénale, endométriose) ☐

Commentaire

Troubles du sommeil (p.ex. apnée obstructive du sommeil) ☐

Commentaire

Maladie qui touche plusieurs systèmes (p.ex. psoriasis) ☐

Commentaire

Pas de diagnostic connu ☐

Commentaire

Je ne sais pas ☐

Commentaire

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Autre ☐

Autre

Partie E: Votre état de santé général

Certaines des questions suivantes pourraient ne pas être directement liées à votre situation. Cependant, elles nous aident à mieux comprendre votre contexte. Nous vous remercions de prendre le temps d'y répondre.

Nous aimerions connaître votre état de santé tel que vous le percevez. Veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé juste AVANT l'apparition de vos premiers symptômes psychotiques.

Considérez comme "premiers symptômes psychotiques" les premières manifestations de votre trouble psychotique, telles qu'entendre des voix ou des bruits qui n'existent pas selon les autres ou de voir des choses que les autres ne voient pas, avoir des pensées qui ne correspondent pas à la réalité perçue par les autres, ou avoir l'idée que quelqu'un cherche volontairement à vous nuire. Si vous ne savez pas quand vos symptômes ont commencé, veuillez à la place considérer le moment de votre premier contact avec les soins psychiatriques.

Nous aimerions connaitre votre état de santé actuel, tel que vous le vivez aujourd'hui. Veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé AUJOURD'HUI.

E1. Votre mobilité avant vos premiers symptômes de trouble psychotique

- Je n'avais aucun problème pour me déplacer à pied. ☐
- J'avais des problèmes légers pour me déplacer à pied. ☐
- J'avais des problèmes modérés pour me déplacer à pied. ☐
- J'avais des problèmes sévères pour me déplacer à pied. ☐
- J'étais incapable de me déplacer à pied. ☐
- Je ne sais pas. ☐

E2. Votre autonomie avant vos premiers symptômes de trouble psychotique

- Je n'avais aucun problème pour me laver ou m'habiller tout(e) seul(e). ☐
- J'avais des problèmes légers pour me laver ou m'habiller tout(e) seul(e). ☐
- J'avais des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). ☐
- J'avais des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). ☐
- J'étais incapable de me laver ou de m'habiller tout(e) seul(e). ☐
- Je ne sais pas. ☐

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E3. **Vos activités courantes <u>avant</u> vos premiers symptômes de trouble psychotique (exemples: travail, études, faire des courses, faire le ménage, prendre des transports en commun, activités avec la famille ou voir des amis, loisirs)**

- Je n'avais aucun problème pour accomplir mes activités courantes. ☐
- J'avais des problèmes légers pour accomplir mes activités courantes. ☐
- J'avais des problèmes modérés pour accomplir mes activités courantes. ☐
- J'avais des problèmes sévères pour accomplir mes activités courantes. ☐
- J'étais incapable d'accomplir mes activités courantes. ☐
- Je ne sais pas. ☐

E4. **Votre douleur ou gêne <u>avant</u> vos premiers symptômes de trouble psychotique**

- Je n'avais ni douleur ni gêne. ☐
- J'avais des douleurs ou une gêne légère(s). ☐
- J'avais des douleurs ou une gêne modérée(s). ☐
- J'avais des douleurs ou une gêne sévère(s). ☐
- J'avais des douleurs ou une gêne extrême(s). ☐
- Je ne sais pas. ☐

E5. **Votre anxiété ou dépression <u>avant</u> vos premiers symptômes de trouble psychotique**

- Je n'étais ni anxieux(se), ni déprimé(e). ☐
- J'étais légèrement anxieux(se) ou déprimé(e). ☐
- J'étais modérément anxieux(se) ou déprimé(e). ☐
- J'étais sévèrement anxieux(se) ou déprimé(e). ☐
- J'étais extrêmement anxieux(se) ou déprimé(e). ☐
- Je ne sais pas. ☐

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E6. **Nous aimerions savoir dans quelle mesure votre santé était bonne ou mauvaise AVANT vos premiers symptômes de trouble psychotique sur une échelle de 0 à 100.**

100 correspond à la meilleure santé que vous puissiez imaginer.

0 correspond à la pire santé que vous puissiez imaginer.

Veuillez entrer un nombre entre 0 et 100 afin d'indiquer votre état de santé AVANT vos premiers symptômes de trouble psychotique.

E7. **Votre mobilité aujourd'hui**

- Je n'ai aucun problème pour me déplacer à pied. ☐
- J'ai des problèmes légers pour me déplacer à pied. ☐
- J'ai des problèmes modérés pour me déplacer à pied. ☐
- J'ai des problèmes sévères pour me déplacer à pied. ☐
- Je suis incapable de me déplacer à pied. ☐
- Je ne sais pas. ☐

E8. **Votre autonomie aujourd'hui**

- Je n'ai aucun problème pour me laver ou m'habiller tout(e) seul(e). ☐
- J'ai des problèmes légers pour me laver ou m'habiller tout(e) seul(e). ☐
- J'ai des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). ☐
- J'ai des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). ☐
- Je suis incapable de me laver ou de m'habiller tout(e) seul(e). ☐
- Je ne sais pas. ☐

E9.

Vos activités courantes aujourd'hui (exemples: travail, études, faire des couses, faire le ménage, prendre des transports en commun, activités avec la famille ou voir des amis, loisirs)

- Je n'ai aucun problème pour accomplir mes activités courantes. ☐
- J'ai des problèmes légers pour accomplir mes activités courantes. ☐
- J'ai des problèmes modérés pour accomplir mes activités courantes. ☐
- J'ai des problèmes sévères pour accomplir mes activités courantes. ☐
- Je suis incapable d'accomplir mes activités courantes. ☐
- Je ne sais pas. ☐

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E10. Votre douleur ou gêne aujourd'hui

- Je n'ai ni douleur ni gêne. ☐
- J'ai des douleurs ou une gêne légère(s). ☐
- J'ai des douleurs ou une gêne modérée(s). ☐
- J'ai des douleurs ou une gêne sévère(s). ☐
- J'ai des douleurs ou une gêne extrême(s). ☐
- Je ne sais pas. ☐

E11. Votre anxiété ou dépression aujourd'hui

- Je ne suis ni anxieux(se), ni déprimé(e). ☐
- Je suis légèrement anxieux(se) ou déprimé(e). ☐
- Je suis modérément anxieux(se) ou déprimé(e). ☐
- Je suis sévèrement anxieux(se) ou déprimé(e). ☐
- Je suis extrêmement anxieux(se) ou déprimé(e). ☐
- Je ne sais pas. ☐

E12. Nous aimerions savoir dans quelle mesure votre santé est bonne ou mauvaise AUJOURD'HUI sur une échelle de 0 à 100.

100 correspond à la meilleure santé que vous puissiez imaginer.

0 correspond à la pire santé que vous puissiez imaginer.

Veuillez entrer un nombre entre 0 et 100 afin d'indiquer votre état de santé AUJOURD'HUI.

☐☐☐☐☐☐☐☐☐☐☐

Partie F: Traitements liés au trouble psychotique

F1. Avez-vous reçu un traitement lié à votre trouble psychotique dans les 5 dernières années?

- Oui ☐
- Non ☐
- Je ne sais pas ☐

F2.

Quels traitements avez-vous reçus pour le trouble psychotique dans les 5 dernières années ?

- Médicaments antipsychotiques « atypiques » (de 2ème génération) (p.ex. Aripiprazole, Abilify, Sycrest, Reagila, Olanzapine, Zypadhera, Invega, Xeplion, Trevicta, Quétiapine, Risperidone, Serdolect) ☐

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Médicaments antipsychotiques « classiques » (de 1ère génération) (p.ex. Clopixol, Haldol, Nozinan, Fluanxol, Etumine, Deanxit) ☐

Clozapine (p.ex. Clozapine Sandoz, Leponex) ☐

Antidépresseurs utilisés pour traiter la dépression, le trouble obsessionel compulsif, ou trouble de panique (p.ex. Citalopram, Escitalopram, Fluoxetine, Sertraline, Edronax, Redomex, Duloxetine, Venlafaxine) ☐

Tranquillisants (p.ex. Diazepam, Valium, Lormetazepam, Lorazepam) ☐

Psychothérapie (p.ex. thérapie cognitivo-comportementale, psychoéducation, etc) ☐

Electroconvulsivothérapie (ECT) ☐

Autre stimulation cérébrale non invasive : stimulation transcrânienne à courant direct (tDCS), ou la stimulation magnétique transcrânienne répétitive (rTMS). ☐

Stimulation cérébrale profonde ☐

Exercice physique ☐

Soutien par les pairs ☐

Je ne sais pas ☐

Autre ☐

Autre

F3.

Quel(s) effet(s) indésirable(s) avez-vous eu pendant ou après le traitement du trouble psychotique dans les 5 dernières années?

Prise de poids ☐

Hyperglycémie (taux de sucre élevé) ou diabète ☐

Taux élevé de cholestérol (excès de graisses sanguines) ☐

Manque de globules blancs ☐

Troubles du mouvement ☐

Agitation, difficulté à rester immobile, besoin de bouger ☐

Contractions musculaires involontaires, et parfois douloureuses ☐

Tremblements et/ou rigidité faciale ☐

Mouvements involontaires du visage, comme mâchonner, tirer la langue ou cligner des yeux ☐

Fatigue ou somnolence ☐

Vertiges ☐

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Sécheresse de la bouche ou des yeux ☐

Nausées ☐

Constipation ☐

Myocardite (inflammation du muscle cardiaque) ☐

Dysfonction sexuelle (p.ex. baisse de la libido) ☐

Problèmes de mémoire ou "brouillard mental" ☐

Émoussement affectif (manque de motivation, manque d'intérêt) ☐

Aucun effet indésirable ☐

Autre ☐

Autre

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F4. Indiquez dans quelle mesure chacun des effets indésirables était pénible pour vous.

Par pénible nous entendons: désagréable, fatigant ou contraignant, qui cause une gêne ou un inconfort physique ou mental.

	Pas du tout pénible	Légèrement pénible	Modérément pénible	Très pénible	Extrêmement pénible	Je ne sais pas
Prise de poids	☐	☐	☐	☐	☐	☐
Hyperglycémie (taux de sucre élevé) ou diabete	☐	☐	☐	☐	☐	☐
Taux élevé de cholestérol (excès de graisses sanguines)	☐	☐	☐	☐	☐	☐
Manque de globules blancs	☐	☐	☐	☐	☐	☐
Agitation, difficulté à rester immobile, besoin de bouger	☐	☐	☐	☐	☐	☐
Contractions musculaires involontaires et parfois douloureuses	☐	☐	☐	☐	☐	☐
Tremblements et/ou rigidité faciale	☐	☐	☐	☐	☐	☐
Mouvements involontaires du visage, comme mâchonner, tirer la langue ou clinger des yeux	☐	☐	☐	☐	☐	☐
Fatigue ou somnolence	☐	☐	☐	☐	☐	☐
Vertiges	☐	☐	☐	☐	☐	☐
Sécheresse de la bouche ou des yeux	☐	☐	☐	☐	☐	☐
Naussées	☐	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐	☐
Myocardite (inflammation du muscle cardiaque)	☐	☐	☐	☐	☐	☐
Dysfonction sexuelle (p.ex. baisse de la libido)	☐	☐	☐	☐	☐	☐
Problèmes de mémoire ou "brouillard mental"	☐	☐	☐	☐	☐	☐
Emoussement affectif (manque de motivation, manque d'intérêt)	☐	☐	☐	☐	☐	☐
Aucun effet indésirable	☐	☐	☐	☐	☐	☐

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F5. **<u>En dehors des effets indésirables</u>, dans quelle mesure le traitement que vous avez reçu pour le trouble psychotique au cours des 5 dernières années, a-t-il été pénible pour vous? Par exemple, en raison de l'administration par injection, du besoin de se rendre à l'hôpital pour recevoir le traitement, d'un horaire de prise contraignant, de la nécessité de conserver le médicament au frigo, etc.**

- ☐ Pas du tout pénible
- ☐ Légèrement pénible
- ☐ Modérément pénible
- ☐ Très pénible
- ☐ Extrêmement pénible
- ☐ Je ne sais pas

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Partie G: Symptôme(s) lié(s) à votre trouble psychotique

G1. **<u>Depuis que vous êtes suivi(e) ou traité(e) pour le trouble psychotique</u>, quels symptômes parmi les suivants avez-vous ressenti et dans quelle mesure étaient-ils pénibles pour vous ? Ne tenez pas compte des effets indésirables du traitement.**

	Je n'ai pas eu ce symptôme	Pas du tout pénible	Légèrement pénible	Modérément pénible	Très pénible	Extrêmement pénible	Je ne sais pas
L'impression que l'on dise à la télévision ou que l'on écrive dans les journaux des choses spécialement pour vous, l'impression que l'on cherche volontairement à vous nuire, l'impression qu'il y a un complot dirigé contre vous, l'impression d'entendre vos pensées répétées comme par un écho, ou d'autres perceptions altérées de la réalité.	☐	☐	☐	☐	☐	☐	☐
Entendre, voir ou ressentir quelque chose qui n'est pas là. Par exemple, entendre une ou plusieurs voix alors que vous êtes tout(e) seul(e) ; voir des objets, des personnes ou des animaux que les autres personnes ne voient pas.	☐	☐	☐	☐	☐	☐	☐
Sensation d'influence, de contrôle, ou de passivité. Par exemple, l'impression d'avoir dans votre tête des pensées que vous ne reconnaissez pas comme les vôtres. L'impression d'être sous le contrôle d'une force ou d'un pouvoir extérieur à vous-même.	☐	☐	☐	☐	☐	☐	☐
Désorganisation de la pensée, comme le sentiment d'avoir l'esprit vide, ou l'impression que vos pensées ont été enlevées ou extraites de votre tête, ou d'avoir dans votre tête des pensées que vous ne reconnaissez pas comme les vôtres	☐	☐	☐	☐	☐	☐	☐
Désorganisation du comportement. Par exemple, le sentiment que vous négligez votre apparence ou votre hygiène personnelle, ou le sentiment que vous n'arrivez jamais à terminer ce que vous faites.	☐	☐	☐	☐	☐	☐	☐
Incapacité à éprouver de l'intérêt ou du plaisir, manque de motivation ou d'enthousiasme, sentiment que vos émotions sont émoussées.	☐	☐	☐	☐	☐	☐	☐
Isolement social, ou le sentiment que vous n'éprouvez pas d'intérêt à être avec d'autres personnes.	☐	☐	☐	☐	☐	☐	☐
Agitation, ou sentiment de tension	☐	☐	☐	☐	☐	☐	☐
Problèmes de concentration	☐	☐	☐	☐	☐	☐	☐
Fatigue ou épuisement	☐	☐	☐	☐	☐	☐	☐
Peur ou anxiété	☐	☐	☐	☐	☐	☐	☐
Sentiment d'abattement, de déprime, ou de tristesse	☐	☐	☐	☐	☐	☐	☐

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G2. **Dans quelle mesure est-ce que le trouble psychotique a interféré avec votre vie sexuelle ?**

- Pas du tout ☐
- Légèrement ☐
- Modérément ☐
- Beaucoup ☐
- Extrêmement ☐
- Je ne sais pas ☐
- Ne s'applique pas ☐
- Je ne veux pas répondre ☐

G3. **Dans quelle mesure le trouble psychotique a-t-il interféré avec votre vie reproductive, c'est-à-dire avec votre possibilité ou décision de concevoir naturellement des enfants ou de mener à terme une grossesse?**
Par exemple: FIV (Fécondation in Vitro), dépistage génétique, don de sperme/ovocytes, nécessité de retarder une grossesse, ou renoncé à avoir des enfants biologiques à cause du trouble psychotique.

- Pas du tout ☐
- Légèrement ☐
- Modérément ☐
- Beaucoup ☐
- Extrêmement ☐
- Je ne sais pas ☐
- Ne s'applique pas (p.ex. vous n'avez pas encore envisagé d'avoir des enfants, ou vous n'étiez pas touché par le trouble psychotique quand vous étiez en âge d'avoir des enfants) ☐
- Je ne veux pas répondre ☐

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Partie H: Prise en charge médicale du trouble psychotique

Par 'prise en charge' nous entendons l'ensemble des rendez-vous, traitements, et accompagnements proposés par les professionnels de santé pour gérer et améliorer votre état de santé en lien avec le trouble psychotique.

H1. Considérez-vous que votre prise en charge a été bien organisée et planifiée au fil du temps?

- ☐ Toujours
- ☐ Souvent
- ☐ Parfois
- ☐ Rarement
- ☐ Jamais
- ☐ Je ne sais pas

H2. Avez-vous un ou plusieurs professionnels de santé qui sont responsables de la coordination des différents services médicaux dont vous avez besoin ?

Par exemple, un médecin ou une infirmière de référence qui vous suit ou vous oriente, et facilite la communication entre les différents spécialistes ou services que vous consultez.

- ☐ Oui
- ☐ Non
- ☐ Je ne sais pas
- ☐ Ne s'applique pas : le suivi se fait uniquement dans un service, sans besoin de coordination

H3. Dans quelle mesure voyez-vous le(s) même(s) professionnel(s) de santé pendant vos rendez-vous ou examens réguliers ?

- ☐ Toujours
- ☐ Souvent
- ☐ Parfois
- ☐ Rarement
- ☐ Jamais
- ☐ Je ne sais pas

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H4.

Dans quelle mesure recevez-vous suffisamment d'informations utiles et compréhensibles de la part de vos professionnels de santé?

Par utiles, nous entendons des informations à jour et cohérentes qui vous aident à mieux comprendre et gérer votre trouble psychotique.

- ☐ Toujours
- ☐ Souvent
- ☐ Parfois
- ☐ Rarement
- ☐ Jamais
- ☐ Je ne sais pas

H5. **Êtes-vous impliqué(e) autant que vous le souhaitez dans les décisions concernant vos soins ou votre traitement ?**

- ☐ Oui, certainement
- ☐ Oui, dans une certaine mesure
- ☐ Non, pas vraiment
- ☐ Non, certainement pas
- ☐ Non, mais je ne voulais de toute façon pas être impliqué(e)
- ☐ Pas applicable: pas de décisions prises à propos du traitement
- ☐ Je ne sais pas

Partie I: Accès aux soins de santé

I1. **Au cours des 12 derniers mois, y a-t-il des soins pour le trouble psychotique que vous n'avez pas obtenus alors que vous en auriez eu besoin ?**
Il peut s'agir d'une consultation, d'un traitement, d'analyses médicales, de rééducation, ou autre.

- ☐ Oui
- ☐ Non
- ☐ Je ne sais pas

I2.

Pour quelle(s) raison(s) principale(s) n'avez-vous pas reçu les soins dont vous aviez besoin?

- ☐ Distance entre le domicile et le lieu de soins
- ☐ Problème de transport (par exemple pas de transport en commun à proximité, pas de véhicule personnel, impossibilité de conduire votre propre véhicule, personne pour vous emmener sur le lieu de vos soins)

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Manque de personnel compétent pour vous administrer les soins dont vous avez besoin ☐

Délais d'attente très longs ☐

Difficultés pour payer les soins ☐

Peur des examens médicaux, de l'hôpital, ou d'autre chose ☐

Manque de temps à cause du travail, des enfants, ou autre ☐

Manque d'information ☐

Difficultés liées à la langue ☐

Autre raison ☐

Autre raison

Partie J: Impact du trouble psychotique sur l'éducation et sur le travail

La prochaine question concerne les sept derniers jours, sans inclure aujourd'hui.

J1. Dans quelle mesure votre scolarité ou vos études ont-elles été affectées par le trouble psychotique, en termes de présence, de performance, de réussite, ou de choix d'études?

Pas du tout ☐

Légèrement ☐

Modérément ☐

Beaucoup ☐

Extrêmement ☐

Je ne sais pas ☐

Ne s'applique pas: le trouble psychotique est survenu après que la scolarité/les études soient terminées ☐

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J2. **<u>En raison du trouble psychotique</u>, avez-vous diminué votre temps de travail?**

- ☐ Oui, je travaille moins qu'avant en raison de mon trouble psychotique
- ☐ Oui, j'ai arrêté de travailler en raison de mon trouble psychotique
- ☐ Non, le trouble psychotique n'a pas eu d'impact sur mon temps de travail
- ☐ Je ne sais pas
- ☐ Autre

Autre

J3. **Combien de temps, approximativement, avez-vous été en incapacité de travailler en raison de votre trouble psychotique?**

Veuillez donner une estimation approximative du TOTAL de tous les arrêts de travail ou congés maladie, qu'ils soient consécutifs ou non. Par exemple : si vous avez été en arrêt pendant 1 mois, puis, plus tard, pendant 3 mois cocher « pendant 4 mois à 1 an ».

- ☐ Pendant moins de 1 mois
- ☐ Pendant 1 à 3 mois
- ☐ Pendant 4 mois à 1 an
- ☐ Pendant plus de 1 an
- ☐ Je ne sais pas

J4. **Veuillez indiquez approximativement le nombre d'années:**

J5.

<u>Au cours des sept derniers jours</u>, dans quelle mesure le trouble psychotique a-t-il affecté votre productivité <u>pendant que vous travailliez</u> ?

Pensez aux jours où vous avez été limité(e) dans la quantité ou le type de travail que vous pouviez effectuer, aux jours où vous avez accompli moins que vous ne l'auriez souhaité ou aux jours où vous n'avez pas pu faire votre travail avec autant de soin que d'habitude. Si le trouble psychotique n'a que peu affecté votre travail, choisissez un chiffre faible. Choisissez un chiffre élevé si le trouble psychotique a beaucoup affecté votre travail.

Considérez uniquement dans quelle mesure le trouble psychotique a affecté votre productivité pendant que vous travailliez.

Cliquez sur le curseur pour le faire glisser sur la valeur choisie

| 0 = Le trouble psychotique n'a eu aucun effet sur mon travail | 10 = En raison du trouble psychotique, je n'ai pas pu travailler du tout

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Partie K: Conséquences financières

K1. **Dans quelle mesure votre trouble psychotique ou votre traitement médical vous a-t-il causé des difficultés financières?**

- ☐ Pas du tout
- ☐ Légèrement
- ☐ Modérément
- ☐ Beaucoup
- ☐ Extrêmement
- ☐ Je ne sais pas

Partie L: Impact sur les relations sociales et besoins de soutien

L1. **Dans quelle mesure votre trouble psychotique interfère-t-il avec vos relations avec la famille, votre partenaire, vos amis, ou voisins ?**

- ☐ Pas du tout
- ☐ Légèrement
- ☐ Modérément
- ☐ Beaucoup
- ☐ Extrêmement
- ☐ Je ne sais pas

L2.

À cause du trouble psychotique, de quels types de soutien supplémentaire avez-vous eu besoin, sans y être parvenu jusqu'à présent?

- ☐ Aucun soutien supplémentaire
- ☐ Aide logistique (par exemple: nettoyage, cuisine, courses, transport, garde d'enfants)
- ☐ Parler à d'autres patients atteints d'un trouble psychotique
- ☐ Soutien psychologique
- ☐ Soutien médical
- ☐ Aide administrative ou sociale
- ☐ Soutien pour l'adaptation de l'environnement, ou matériel adapté
- ☐ Soutien pour le retour au travail

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Soutien scolaire ou pour les études ☐

Accompagnement spirituel ou religieux ☐

Je ne sais pas ☐

Autre ☐

Autre

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Partie M: Priorité des besoins

M1. Selon vous, quels aspects de votre trouble psychotique ou de sa prise en charge devraient être améliorés en priorité ? Veuillez évaluer chaque aspect selon l'importance que vous lui accordez.

	Pas du tout prioritaire	Légèrement prioritaire	Modérément prioritaire	Très prioritaire	Extrêmement prioritaire	Je ne sais pas
L'impact du trouble psychotique sur la qualité de vie générale (impact sur la mobilité, l'autonomie, la capacité à vous habiller et laver seul, la gêne ou douleur, l'anxiété ou la dépression; années vécues avec une incapacité)	☐	☐	☐	☐	☐	☐
L'impact sur votre santé physique (symptômes physiques, gêne ou douleur liées au à le touble psychotique)	☐	☐	☐	☐	☐	☐
L'impact sur votre santé psychologique (symptômes psychologiques, anxiété, ou dépression liées au à le trouble psychotique)	☐	☐	☐	☐	☐	☐
L'impact sur votre autonomie (impact sur votre mobilité, sur votre capacité à vous laver et habiller seul(e) ; capacité à accomplir vos activités courantes comme le travail, études, travaux ménagers, activités familiales, ou loisirs)	☐	☐	☐	☐	☐	☐
L'impact sur votre vie sexuelle et reproductive	☐	☐	☐	☐	☐	☐
L'impact sur l'espérance de vie	☐	☐	☐	☐	☐	☐
L'impact sur votre scolarité ou vos études	☐	☐	☐	☐	☐	☐
L'impact sur votre travail	☐	☐	☐	☐	☐	☐
L'impact financier	☐	☐	☐	☐	☐	☐
L'impact sur votre vie sociale (relations avec la famille, votre partenaire, ou vos amis ; besoin de soutien supplémentaire- administratif, social, etc)	☐	☐	☐	☐	☐	☐
La qualité de votre prise en charge (la rapidité du diagnostic, la coordination et la continuité des soins, les informations reçues par les professionnels de santé, l'implication dans les décisions concernant vos soins ou traitements)	☐	☐	☐	☐	☐	☐
L'accès aux soins de santé (obtenir des soins lorsque vous en avez besoin, la disponibilité du traitement)	☐	☐	☐	☐	☐	☐
Les connaissances scientifiques (par exemple en termes de diagnostic, de traitement, ou de pronostic)	☐	☐	☐	☐	☐	☐
L'efficacité du traitement (capacité du traitement à contrôler les symptômes et améliorer la qualité de vie)	☐	☐	☐	☐	☐	☐
La pénibilité du traitement (en termes d'effets indésirables ou en termes de logistique/administration du traitement)	☐	☐	☐	☐	☐	☐

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Partie N: Autre besoins importants

N1. **Souhaitez-vous nous faire part d'un ou de plusieurs autres besoins importants que vous n'avez pas pu exprimer dans le questionnaire ?**

Oui ☐

Non ☐

N2. **Quels besoins n'ont pas été abordés dans le questionnaire ?**

Partie O: Impact sur les aidants proches

O1.

En tant que personne remplissant le questionnaire pour quelqu'un atteint d'un trouble psychotique: vous considérez-vous comme « aidant proche » ?

C'est-à-dire venant en aide à cette personne en raison de son trouble psychotique, de manière régulière et à titre non professionnel. Par exemple, un parent aidant son enfant, un membre de la famille ou un ami aidant un proche.

Oui ☐

Non ☐

O2. **Par rapport à la personne que vous aidez, vous êtes :**

Un membre de la famille (par exemple, parent, enfant, grand-parent…) ☐

Une relation proche (par exemple, ami, voisin…) ☐

Autre: ☐

Autre:

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O3. **A quel genre vous identifiez-vous ?**

- Homme ☐
- Femme ☐
- Autre ☐

O4. **Quelle est votre année de naissance ?**

☐☐☐☐☐☐☐☐☐☐☐☐

O5.

La semaine dernière, combien de temps avez-vous passé à aider la personne dans des activités qu'elle aurait normalement faites elle-même si elle était en bonne santé ? Par exemple dans les soins personnels (comme s'habiller/se déshabiller, aller aux toilettes…), les tâches ménagères (comme préparer les repas, nettoyer…) ou le soutien pratique (comme l'accompagner à l'extérieur à des rendez-vous médicaux ou autres…).

☐☐☐☐☐☐☐☐☐☐☐☐

O6. **Selon vous, dans quelle mesure votre santé physique et/ou psychologique est impactée en raison de votre rôle d'aidant proche?**

- Pas du tout ☐
- Légèrement ☐
- Modérément ☐
- Beaucoup ☐
- Extrêmement ☐
- Je ne sais pas ☐

O7. **Selon vous, dans quelle mesure votre vie sociale est impactée en raison de votre rôle d'aidant proche?**

- Pas du tout ☐
- Légèrement ☐
- Modérément ☐
- Beaucoup ☐
- Extrêmement ☐
- Je ne sais pas ☐

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Partie P: Poursuite de l'étude

Merci beaucoup pour votre collaboration!

Un membre de l'équipe de recherche vous recontactera d'ici quelques semaines pour vous tenir informé(e) de votre éventuelle participation à un entretien.

P1.

Nous aimerions en savoir plus sur les besoins et les difficultés que vous rencontrez ou avez rencontrées dans le contexte de votre trouble psychotique. Si vous le souhaitez, vous pouvez participer à un entretien individuel (en ligne ou en face à face avec un chercheur) pour discuter plus en détail de vos expériences et de vos besoins. Cet entretien se déroulera de manière confidentielle et indépendamment des soins que vous recevez des prestataires de soins de santé. Il est prévu que 24 patients soient interrogés. Cet entretien individuel durera environ une heure et demie.

Souhaitez-vous participer à un entretien individuel?

- ☐ Oui
- ☐ Non

P2. **Si vous êtes intéressé(e) par l'entretien individuel, merci de nous indiquer vos coordonnées (numéro de téléphone et adresse mail) afin que nous puissons vous contacter.**

Adresse e-mail

Confirmation de l'adresse e-mail

Numéro de GSM

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Merci pour votre intérêt pour cette étude.

Les résultats de cette étude seront publiés sur le site Internet du KCE (www.kce.fgov.be) et sur le site de NEED (www.health-needs.eu) début 2026.

Veuillez noter que tous les résultats publiés concerneront uniquement des données agrégées, garantissant qu'aucune personne ne pourra être identifiée. La confidentialité et votre vie privée sont ainsi entièrement protégées.

Si remplir ce questionnaire ou réfléchir à votre trouble psychotique a suscité un inconfort ou une détresse émotionnelle, nous vous encourageons à rechercher du soutien. Vous pouvez contacter l'une de nos chercheuses, Margaux Sageot, au numéro 04 73 73 36 06. Vous pouvez également contacter votre médecin généraliste, un psychiatre ou un psychologue.

En cas d'urgence, vous pouvez appeler le 112. Si vous avez besoin de parler à quelqu'un dans l'anonymat et la confidentialité, vous pouvez appeler le 107.

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Hartelijk dank voor uw deelname aan ons onderzoek.

Ons onderzoek heeft als doel de behoeften van patiënten met een psychotische problematiek in kaart te brengen om hun zorg te verbeteren.

Deze vragenlijst is voor u als:

U een psychotische problematiek hebt (bv. schizofrenie, schizoaffectieve stoornis, of een andere psychotische problematiek) U 18 jaar of ouder bent U in België woont (hoofdverblijfplaats)

Of

U spreekt namens een volwassen persoon met een gediagnosticeerde psychotische problematiek, waarvan u de wettelijke vertegenwoordiger bent. Deze persoon woont in België en is niet in staat om voor zichzelf te spreken.

Dit onderzoek heeft als doel om de behoeften van patiënten met een psychotische problematiek te identificeren. Dit kan besluitmakers ondersteunen bij het nemen van beslissingen die de zorg kunnen verbeteren voor patiënten met een psychotische problematiek in het bijzonder en de maatschappij in het algemeen. Sommige vragen kunnen mogelijk minder goed aansluiten bij uw persoonlijke situatie of irrelevant aanvoelen. Deze vragen zijn van belang om de noden van patiënten uit andere ziektedomeinen met elkaar te vergelijken. Daarom verzoeken we u de vragen zo nauwkeurig mogelijk te beantwoorden, zodat we uw behoeften zo goed mogelijk kunnen capteren.

De resultaten van deze studie zullen begin 2026 gepubliceerd worden op de site van het KCE (www.kce.fgov.be) en op de site van NEED (www.health-needs.eu).

Voordat u akkoord gaat met deelname aan dit onderzoek, vragen wij u de volgende informatie over de vertrouwelijkheid van uw gegevens te lezen en toestemming te geven voor het gebruik van uw gegevens.

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Sectie A: Algemene informatie

Gelieve vanaf nu alle vragen te beantwoorden alsof u de persoon met de psychotische problematiek bent. Geef "Ik weet het niet" aan als u niet weet hoe de persoon zou reageren.

Bedankt voor uw deelname.

Helaas voldoet u niet aan de voorwaarden om door te kunnen gaan met deze studie.

Bedankt voor uw deelname.

Helaas voldoet u niet aan de voorwaarden om door te kunnen gaan met deze studie.

A1. U vult deze vragenlijst in

- ☐ Voor uzelf
- ☐ Voor een ander persoon waarvan u de wettelijke vertegenwoordiger bent (De persoon die u vertegenwoordigt is op dit moment niet in staat om de vragenlijst te beantwoorden. Door dit vakje aan te kruisen, neemt u deel aan dit onderzoek op basis van hun waarschijnlijke bereidheid om deel te nemen.)

A2. Met welk geslacht identificeert u zich?

- ☐ Man
- ☐ Vrouw
- ☐ Andere

A3. In welk jaar bent u geboren?

☐☐☐☐

A4. In welke provincie woont u?

- ☐ Antwerpen
- ☐ Waals-Brabant
- ☐ Brussel
- ☐ Henegouwen
- ☐ Luik
- ☐ Limburg
- ☐ Luxemburg
- ☐ Namen
- ☐ Oost-Vlaanderen
- ☐ Vlaams-Brabant
- ☐ West-Vlaanderen
- ☐ Ik woon niet in België
- ☐ Ik weet het niet

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Sectie B: Algemene informatie

B1. Wat is het hoogste diploma of onderwijsniveau dat u tot nu toe hebt behaald?

- [ ] Geen diploma of basisonderwijs
- [ ] Lager secundair onderwijs
- [ ] Hoger secundair onderwijs
- [ ] Hoger onderwijs van het korte type (bv. bachelor)
- [ ] Hoger onderwijs van het lange type (bv. master)
- [ ] Doctoraat
- [ ] Ik weet het niet
- [ ] Andere diploma's

Andere diploma's

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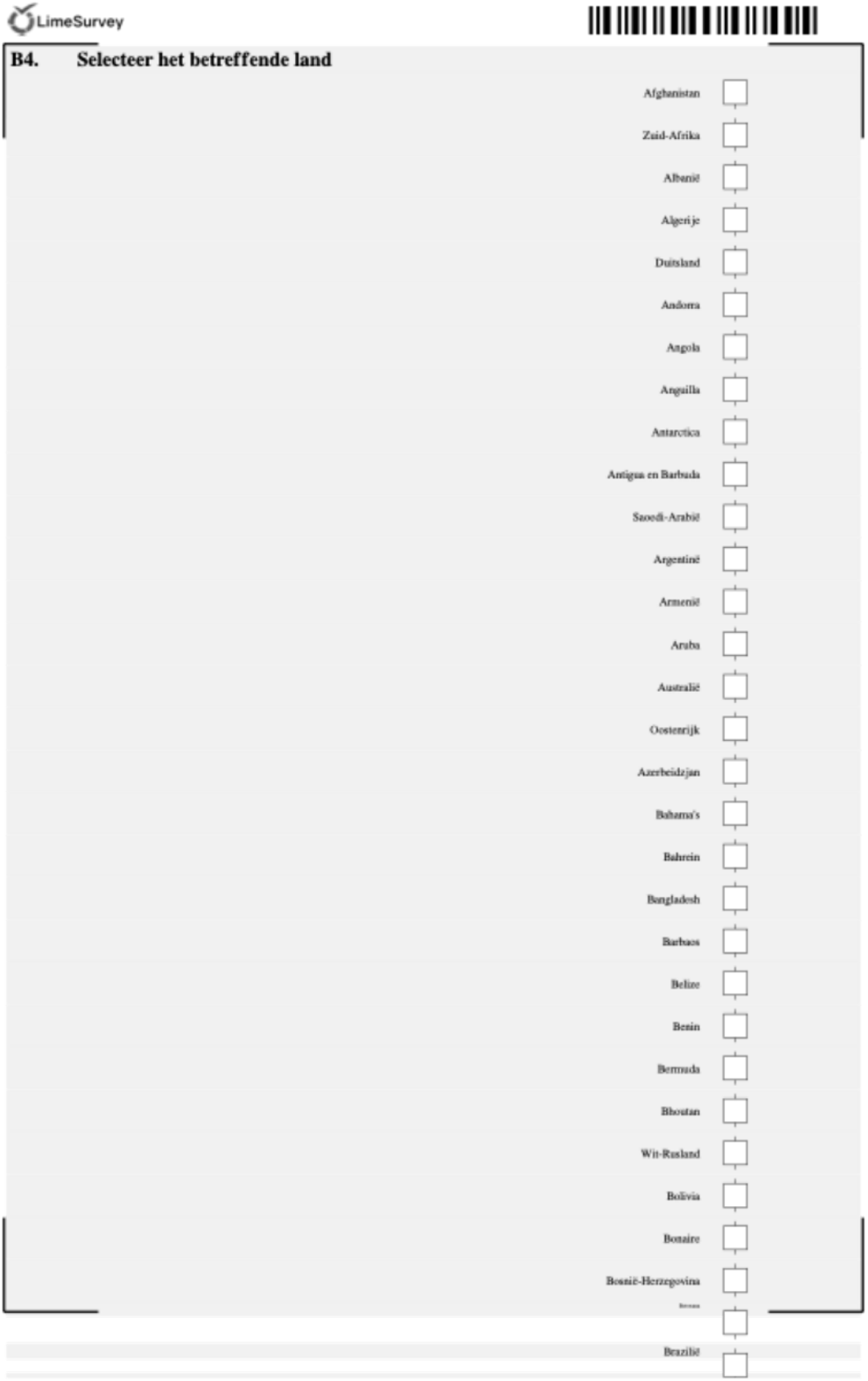
B2. U woont….

- [ ] Alleen
- [ ] Alleen met kinderen
- [ ] Samen (zonder kinderen)
- [ ] Samen (met kinderen)
- [ ] Met één of twee ouders
- [ ] In cohousing (gemeenschappelijk wonen)
- [ ] In een psychiatrisch verzorgingstehuis
- [ ] In beschut wonen
- [ ] In een andere begeleide woonvorm
- [ ] In het ziekenhuis (tijdelijk)
- [ ] In een woonzorgcentrum
- [ ] Ik weet het niet
- [ ] Overige

Overige

B3. In welk land bent u geboren?

- [ ] België
- [ ] Ander land
- [ ] Ik weet het niet


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B4. Selecteer het betreffende land
Afghanistan
Zuid-Afrika
Albanië
Algerije
Duitsland
Andorra
Angola
Anguilla
Antarctica
Antigua en Barbuda
Saoedi-Arabië
Argentinië
Armenië
Aruba
Australië
Oostenrijk
Azerbeidzjan
Bahama's
Bahrein
Bangladesh
Barbaos
Belize
Benin
Bermuda
Bhoutan
Wit-Rusland
Bolivia
Bonaire
Bosnië-Herzegovina
Brazilië

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B5. **Wat was uw voornaamste beroepsstatuut vlak voor het begin van uw psychotische problematiek?**

- [ ] Betaald werk (werknemer of zelfstandige)
- [ ] Werkzoekende, werkloos, ontvanger van een leefloon (OCMW)
- [ ] Huisvrouw of huisman, zonder uitkering
- [ ] Student
- [ ] Gepensioneerde
- [ ] Invaliditeit
- [ ] Ik weet het niet
- [ ] Overige

Overige

B6.

Heeft u betaald werk gedaan sinds het begin van de eerste symptomen van uw psychotische problematiek?

Beschouw als "eerste symptomen van uw psychotische problematiek" de eerste verschijnselen van je aandoening, zoals het horen of zien van dingen waarvan anderen beweren dat ze er niet zijn, het hebben van gedachten die niet overeenkomen met de werkelijkheid die anderen waarnemen, of het idee hebben dat iemand je opzettelijk kwaad wil doen. Als je niet weet wanneer je symptomen begonnen, beschouw dan in plaats daarvan je eerste contact met psychiatrische zorg.

- [ ] Ja
- [ ] Neen
- [ ] Ik weet het niet

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B7. Wat is uw voornaamste beroepsstatuut op dit moment?

- [ ] Betaald werk (werknemer of zelfstandige)
- [ ] Werkzoekende, werkloos, ontvanger van een leefloon (OCMW)
- [ ] Huisvrouw of huisman, zonder uitkering
- [ ] Student
- [ ] Gepensioneerde
- [ ] Invaliditeit
- [ ] Ik weet het niet
- [ ] Overige

Overige

B8. Rekening houdend met alle inkomsten van uw huishouden, in welke mate slaagt u erin om aan het einde van elke maand rond te komen?

Met andere woorden, in welke mate zijn de inkomsten van uw huishouden voldoende om elke maand al uw uitgaven te dekken?

- [ ] Zeer gemakkelijk
- [ ] Gemakkelijk
- [ ] Vrij gemakkelijk
- [ ] Met enige moeite
- [ ] Met moeite
- [ ] Met veel moeite
- [ ] Ik weet het niet

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Sectie C: Met betrekking tot uw gezondheidsprobleem

Bedankt voor uw deelname.

Helaas voldoet u niet aan de voorwaarden om door te kunnen gaan met deze studie aangezien we een psychotische problematiek door een andere medische aandoening niet includeren.

C1. Hoe lang geleden ongeveer kreeg u de diagnose van uw psychotische problematiek?

- ☐ Minder dan 6 maanden
- ☐ 6 maanden tot 2 jaar
- ☐ 2 tot 5 jaar
- ☐ 5 tot 10 jaar
- ☐ Meer dan 10 jaar
- ☐ Ik weet het niet

C2. Geef bij benadering het aantal jaren aan:

☐☐☐☐☐☐☐☐☐☐

C3. Hoeveel tijd zat er tussen de eerste symptomen van uw psychotische problematiek en het eerste contact met een psychiater?

- ☐ Minder dan 1 maand
- ☐ Tussen 1 en 6 maanden
- ☐ Tussen 6 maanden en 1 jaar
- ☐ Tussen 1 en 2 jaar
- ☐ Meer dan 2 jaar
- ☐ Ik weet het niet

C4. Hoeveel tijd zat er tussen uw eerste medische consultatie voor uw psychotische problematiek en de diagnose?

- ☐ Minder dan 1 maand
- ☐ Tussen 1 en 6 maanden
- ☐ Tussen 6 maanden en 1 jaar
- ☐ Tussen 1 en 2 jaar
- ☐ Meer dan 2 jaar
- ☐ Ik weet het niet

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C5. Welke diagnose heeft u gekregen?

- [ ] Schizofrenie
- [ ] Schizoaffectieve stoornis
- [ ] Schizofreniforme stoornis
- [ ] Delirium
- [ ] Korte psychotische stoornis
- [ ] Gedeelde psychotische stoornis
- [ ] Psychotische stoornis door middelen gebruik
- [ ] Psychotische stoornis door een ander medisch probleem
- [ ] Niet gespecifieerde psychotische stoornis
- [ ] Bipolaire stoornis met psychotische kenmerken
- [ ] Ik weet het niet
- [ ] Ik wens hierop niet te antwoorden
- [ ] Overige

Overige

C6. Bent u ooit opgenomen geweest in het ziekenhuis wegens uw psychotische problematiek? Denk alleen aan verblijven met een overnachting in het ziekenhuis.

- [ ] Ja
- [ ] Neen
- [ ] Ik weet het niet

C7. in

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Sectie D: Andere gezondheidsproblemen

D1. Hebt u last van gezondheidsproblemen die geassocieerd kunnen worden met uw psychotische problematiek?

	Ja	Neen	Ik weet het niet
Obsessieve-compulsieve stoornis (OCS)	☐	☐	☐
Depressie	☐	☐	☐
Bipolaire stoornis	☐	☐	☐
Alcoholprobleem	☐	☐	☐
Problematiek gerelateerd aan gebruik van drugs of andere verslavende middelen	☐	☐	☐
Angst- of paniekstoornis	☐	☐	☐
Post-traumatische stress	☐	☐	☐
Persoonlijkheidsstoornis	☐	☐	☐
Autisme spectrum stoornis (ASS)	☐	☐	☐
Aandachtsstoornis met of zonder hyperactiviteit (ADHD)	☐	☐	☐
Eetstoornis (bijv. anorexia, boulemia)	☐	☐	☐

D2. Heeft u ook last van andere gezondheidsproblemen?

- ☐ Ja
- ☐ Neen
- ☐ Ik weet het niet

D3.

Van welke andere gezondheidsproblemen heeft u last? U mag meer dan één vakje aankruisen. Vermeld ook de precieze naam van uw gezondheidsprobleem of -problemen, indien gekend.

Als u de diagnose van uw andere gezondheidsprobleem (nog) niet weet, vink dan het vakje "Ander gezondheidsprobleem zonder gekende diagnose" aan.

- ☐ Hart- en vataandoeningen (bv. hoge bloeddruk)

Opmerking


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Aandoeningen van het ademhalingsstelsel (bv. astma)
Opmerking
Aandoeningen van het spijsverteringsstelsel (bv. prikkelbaredarmsyndroom)
Opmerking
Huidaandoeningen
Opmerking
Aandoeningen van het bewegingsstelsel (beenderen, gewrichten of spieren) (bv. artrose, reumatoïde artritis)
Opmerking
Andere mentale/psychische aandoeningen die niet vermeld werden in de vorige vraag
Opmerking
Neurologische ontwikkelingsstoornis (bv. ontwikkelingsaandoeningen)
Opmerking
Ziekten van het zenuwstelsel (neurologische ziekten) (bv. dementie, multiple sclerose)
Opmerking
Hematologische (bloed) aandoeningen (bv. bloedarmoede)
Opmerking
Immuunziektes (bv. allergieën, auto-inflammatoire ziekten)
Opmerking


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Endocriene, voedings- of stofwisselingsaandoeningen (bv. diabetes, hoge cholesterol, obesitas, onvoldoende werkende schildklier)
Opmerking
Oogaandoeningen
Opmerking
Ooraandoeningen of aandoeningen van het evenwichtsorgaan
Opmerking
Aandoeningen aan het urine- (bv. blaas, nieren) en voortplantingsstelsel (bv. nierfalen, endometriose)
Opmerking
Slaapstoornissen
Opmerking
Aandoeningen die meerdere systemen aantasten (bv. psoriasis
Opmerking
Ander gezondheidsprobleem zonder gekende diagnose
Opmerking
Ik weet het niet
Opmerking

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Overige

Overige

Sectie E: Uw algemene gezondheidstoestand

Sommige van de volgende vragen hebben mogelijk niet direct betrekking op uw situatie. Ze helpen ons echter wel om uw context te begrijpen. Hartelijk dank dat u de tijd neemt om deze vragen te beantwoorden.

We willen graag weten hoe u uw gezondheid ervaart. Kruis het vakje aan naast de verklaring die het beste uw gezondheid beschrijft net VOOR dat de eerste symptomen van uw psychotische problematiek zich voordeden.

Beschouw als "eerste symptomen van uw psychotische problematiek" de eerste verschijnselen van je aandoening, zoals het horen of zien van dingen waarvan anderen beweren dat ze er niet zijn, het hebben van gedachten die niet overeenkomen met de werkelijkheid die anderen waarnemen, of het idee hebben dat iemand je opzettelijk kwaad wil doen. Als je niet weet wanneer je symptomen begonnen, beschouw dan in plaats daarvan je eerste contact met psychiatrische zorg

Met de volgende vragen willen we graag weten hoe het met uw huidige gezondheid is gesteld. Kruis het vakje aan naast de verklaring die het beste beschrijft wat uw gezondheid VANDAAG is.

E1. Uw mobiliteit vóór de eerste symptomen van uw psychotische problematiek.

- Ik had geen problemen met rondwandelen
- Ik had een beetje problemen met rondwandelen
- Ik had matige problemen met rondwandelen
- Ik had ernstige problemen met rondwandelen
- Ik was niet in staat om rond te wandelen
- Ik weet het niet

E2. Uw onafhankelijkheid vóór de eerste symptomen van uw psychotische problematiek.

- Ik had geen problemen om mijzelf te wassen of aan te kleden
- Ik had een beetje problemen met mijzelf te wassen of aan te kleden
- Ik had matige problemen met mijzelf te wassen of aan te kleden
- Ik had ernstige problemen met mijzelf te wassen of aan te kleden
- Ik was niet in staat mijzelf te wassen of aan te kleden
- Ik weet het niet

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E3. **Uw dagelijkse activiteiten vóór de eerste symptomen van uw psychotische problematiek (bijv.: werk, studies, boodschappen doen, schoonmaken, openbaar vervoer nemen, gezinsactiviteiten, vrienden zien of hobby's)**

- Ik had geen problemen met mijn dagelijkse activiteiten ☐
- Ik had een beetje problemen met mijn dagelijkse activiteiten ☐
- Ik had matige problemen mijn dagelijkse activiteiten ☐
- Ik had ernstige problemen met mijn dagelijkse activiteiten ☐
- Ik was niet in staat mijn dagelijkse activiteiten uit te voeren ☐
- Ik weet het niet ☐

E4. **Uw pijn of ongemak vóór de eerste symptomen van uw psychotische problematiek.**

- Ik had geen pijn of ongemak ☐
- Ik had een beetje pijn of ongemak ☐
- Ik had matige pijn of ongemak ☐
- Ik had ernstige pijn of ongemak ☐
- Ik had extreme pijn of ongemak ☐
- Ik weet het niet ☐

E5. **Uw angst of depressie vóór de eerste symptomen van uw psychotische problematiek.**

- Ik was niet angstig of depressief ☐
- Ik was een beetje angstig of depressief ☐
- Ik was matig angstig of depressief ☐
- Ik was erg angstig of depressief ☐
- Ik was extreem angstig of depressief ☐
- Ik weet het niet ☐

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E6. **We willen graag weten hoe goed of slecht uw gezondheid was VÓÓR de eerste symptomen van uw psychotische problematiek op een schaal van 0 tot 100.**

100 komt overeen met de best denkbare gezondheid.

0 komt overeen met de slechtst denkbare gezondheid.

Vul een getal in tussen 0 en 100 om uw gezondheidstoestand VÓÓR de eerste symptomen van uw psychotische problematiek weer te geven.

E7. **Uw mobiliteit vandaag**

- Ik heb geen problemen met rondwandelen ☐
- Ik heb een beetje problemen met rondwandelen ☐
- Ik heb matige problemen met rondwandelen ☐
- Ik heb ernstige problemen met rondwandelen ☐
- Ik ben niet in staat om rond te wandelen ☐
- Ik weet het niet ☐

E8. **Uw autonomie vandaag**

- Ik heb geen problemen met mijzelf te wassen of aan te kleden ☐
- Ik heb een beetje problemen met mijzelf te wassen of aan te kleden ☐
- Ik heb matige problemen met mijzelf te wassen of aan te kleden ☐
- Ik heb ernstige problemen met mijzelf te wassen of aan te kleden ☐
- Ik ben niet in staat mijzelf te wassen of aan te kleden ☐
- Ik weet het niet ☐

E9. **Uw huidige activiteiten (bijv. werk, studies, boodschappen doen, schoonmaken, openbaar vervoer nemen, gezinsactiviteiten, vrienden zien of hobby's) vandaag**

- Ik heb geen problemen met mijn dagelijkse activiteiten. ☐
- Ik heb kleine problemen met mijn dagelijkse activiteiten ☐
- Ik heb matige problemen met mijn dagelijkse activiteiten ☐
- Ik heb ernstige problemen met mijn dagelijkse activiteiten ☐
- Ik ben niet in staat mijn dagelijkse activiteiten uit te voeren ☐
- Ik weet het niet ☐

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E10. Uw pijn of ongemak vandaag

- Er is geen pijn of ongemak ☐
- Ik heb een beetje pijn of ongemak ☐
- Ik heb matige pijn of ongemak ☐
- Ik heb ernstige pijn of ongemak ☐
- Ik heb extreme pijn of ongemak ☐
- Ik weet het niet ☐

E11. Uw angst of depressie vandaag

- Ik ben niet angstig of depressief ☐
- Ik ben een beetje angstig of depressief ☐
- Ik ben matig angstig of depressief ☐
- Ik ben erg angstig of depressief ☐
- Ik ben extreem angstig of depressief ☐
- Ik weet het niet ☐

E12. We willen graag weten hoe goed of slecht uw gezondheid VANDAAG is op een schaal van 0 tot 100.

100 komt overeen met de beste gezondheid die u zich kunt voorstellen.

0 komt overeen met de slechtste gezondheid die u zich kunt voorstellen.

Vul een getal in tussen 0 en 100 om uw gezondheidstoestand VANDAAG weer te geven.

Sectie F: Behandelingen gerelateerd aan uw psychotische problematiek

F1. Werd u de afgelopen 5 jaar behandeld voor uw psychotische problematiek?

- Ja ☐
- Neen ☐
- Ik weet het niet ☐

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F2.

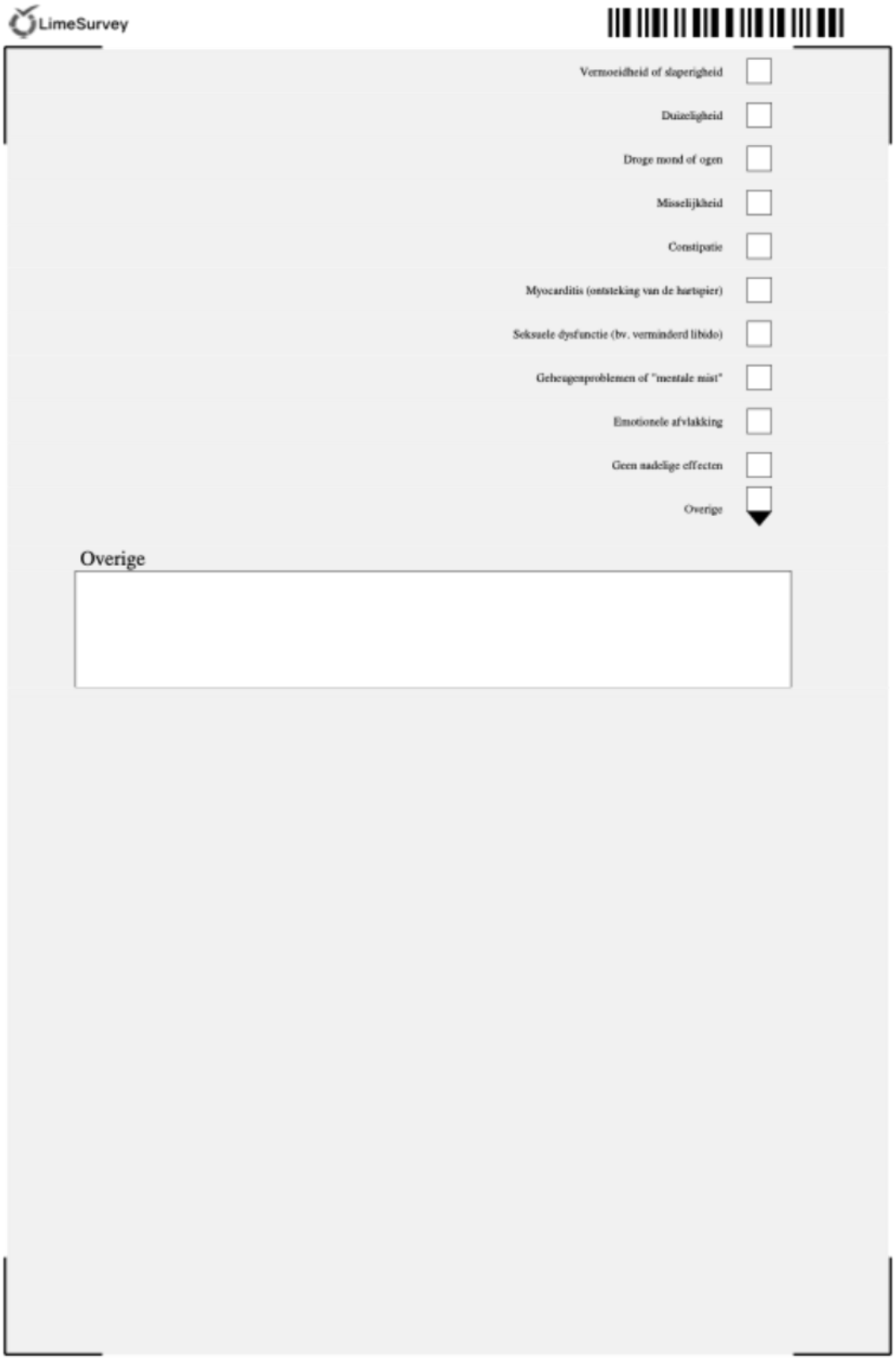
Welke behandelingen heeft u de afgelopen 5 jaar gekregen voor uw psychotische problematiek?

- [ ] Atypische antipsychotica ('tweede generatie' antipsychotica) (bv. Aripiprazole, Abilify, Sycrest, Reagila, Olanzapine, Zypadhera, Invega, Xeplion, Trevicta, Quétiapine, Risperidone, Serdolect)
- [ ] Klassieke antipsychotica ('eerste generatie' antipsychotica) (bv. Clopixol, Haldol, Nozinan, Fluanxol, Etumine, Dessnit)
- [ ] Clozapine (bv. Clozapine Sandoz, Leponex)
- [ ] Antidepressiva gebruikt voor depressie, obsessief-compulsieve stoornis of paniekstoornis (bv. Citalopram, Escitalopram, Fluoxetine, Sertraline, Edronax, Redomex, Duloxetine, Venlafaxine)
- [ ] Kalmeringsmiddelen (bv. Diazepam, Valium, Lormetazepam, Lorazepam)
- [ ] Psychotherapie (bv. cognitieve gedragstherapie, psycho-educatie, etc.)
- [ ] Electroconvulsietherapie (ECT)
- [ ] Andere niet-invasieve hersenstimulatie: transcraniële gelijkstroomstimulatie (tDCS) of repetitieve transcraniële magnetische stimulatie (rTMS)
- [ ] Diepe hersenstimulatie
- [ ] Lichaamsbeweging
- [ ] Ondersteuning van anderen die dezelfde aandoening hebben
- [ ] Ik weet het niet
- [ ] Overige

Overige

F3. **Welke bijwerking(en) heeft u tijdens of na de behandeling voor uw psychotische problematiek gehad in de afgelopen 5 jaar?**

- [ ] Gewichtstoename
- [ ] Hyperglycemie (te veel suiker in het bloed) of diabetes
- [ ] Hoge cholesterol (overtollige vetten in het bloed)
- [ ] Tekort aan witte bloedcellen
- [ ] Bewegingsstoornissen
- [ ] Rusteloosheid, moeite met stilzitten, behoefte om te bewegen
- [ ] Onvrijwillige en soms pijnlijke spiersamentrekkingen
- [ ] Beven en/of gezichtsstijfheid
- [ ] Onwillekeurige gezichtsbewegingen, zoals kauwen, tong uitsteken of knipperen


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Vermoeidheid of slaperigheid
Duizeligheid
Droge mond of ogen
Misselijkheid
Constipatie
Myocarditis (ontsteking van de hartspier)
Seksuele dysfunctie (bv. verminderd libido)
Geheugenproblemen of "mentale mist"
Emotionele afvlakking
Geen nadelige effecten
Overige
Overige

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F4. Geef aan in welke mate elk van de bijwerkingen lastig voor u was

Onder lastig verstaan we: onaangenaam, vermoeiend of beperkend, iets wat hinder veroorzaakt of een fysiek of mentaal ongemak

	Helemaal niet lastig	Licht lastig	Matig lastig	Erg lastig	Extreem lastig	Ik weet het niet
Gewichtstoename	☐	☐	☐	☐	☐	☐
Hyperglycemie (te veel suiker in het bloed) of diabetes	☐	☐	☐	☐	☐	☐
Hoge cholesterol (overtollige vetten in het bloed)	☐	☐	☐	☐	☐	☐
Tekort aan witte bloedcellen	☐	☐	☐	☐	☐	☐
Rusteloosheid, moeite met stilzitten, behoefte om te bewegen	☐	☐	☐	☐	☐	☐
Onvrijwillige en soms pijnlijke spiersamentrekking	☐	☐	☐	☐	☐	☐
Beven en/of gezichtsstijfheid	☐	☐	☐	☐	☐	☐
Onwillekeurige gezichtsbewegingen, zoals kauwen, tong uitsteken of knipperen	☐	☐	☐	☐	☐	☐
Vermoeidheid of slaperigheid	☐	☐	☐	☐	☐	☐
Duizeligheid	☐	☐	☐	☐	☐	☐
Droge mond of ogen	☐	☐	☐	☐	☐	☐
Misselijkheid	☐	☐	☐	☐	☐	☐
Constipatie	☐	☐	☐	☐	☐	☐
Myocarditis (ontsteking van de hartspier)	☐	☐	☐	☐	☐	☐
Seksuele dysfunctie (bv. verminderd libido)	☐	☐	☐	☐	☐	☐
Geheugenproblemen of "mentale mist"	☐	☐	☐	☐	☐	☐
Emotionele afvlakking (gebrek aan motivatie, gebrek aan interesse)	☐	☐	☐	☐	☐	☐
Geen nadelige effecten	☐	☐	☐	☐	☐	☐

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F5. **Hoe lastig is de behandeling die u de afgelopen 5 jaar voor uw psychotische problematiek kreeg voor u geweest, afgezien van de bijwerkingen? Bijvoorbeeld vanwege de toediening via injectie, de noodzaak om naar het ziekenhuis te gaan voor de behandeling, een strikt medicatieschema, de noodzaak om de medicatie in de koelkast te bewaren, etc.?**

- ☐ Helemaal niet lastig
- ☐ Licht lastig
- ☐ Matig lastig
- ☐ Erg lastig
- ☐ Extreem lastig
- ☐ Ik weet het niet

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Sectie G: Sympto(o)m(en) gerelateerd aan uw psychotische problematiek

G1. Sinds u opgevolgd of behandeld wordt voor de psychotische problematiek, welke van de volgende symptomen hebt u ervaren en hoe lastig waren ze voor u? Houd geen rekening met de ongewenste effecten van de behandeling.

	Ik heb dit symptoom niet gehad	Helemaal niet lastig	Licht lastig	Matig lastig	Erg lastig	Extreem lastig	Ik weet het niet
De indruk dat iemand speciaal voor jou iets op de televisie zegt of in de krant schrijft, de indruk dat iemand je opzettelijk kwaad wil doen, de indruk dat er een complot tegen je is, of de indruk dat je gedachten als door een echo worden herhaald.	☐	☐	☐	☐	☐	☐	☐
Iets horen, zien of voelen dat er niet is. Bijvoorbeeld een of meer stemmen horen terwijl je helemaal alleen bent; objecten, mensen of dieren zien die andere mensen niet kunnen zien.	☐	☐	☐	☐	☐	☐	☐
Een gevoel van invloed, controle of passiviteit. Bijvoorbeeld de indruk dat je gedachten in je hoofd hebt die je niet als de jouwe herkent. De indruk onder controle te staan van een kracht of macht buiten jezelf.	☐	☐	☐	☐	☐	☐	☐
Desorganisatie van het denken, zoals het gevoel dat je geest leeg is, of dat je gedachten uit je hoofd zijn gehaald, of dat je gedachten in je hoofd hebt die je niet als de jouwe herkent.	☐	☐	☐	☐	☐	☐	☐
Desorganisatie van het gedrag. Bv. het gevoel dat je je uiterlijk of je persoonlijke hygiëne verwaarloost, of het gevoel dat je nooit afmaakt waar je mee bezig bent.	☐	☐	☐	☐	☐	☐	☐
Onvermogen om interesse of plezier te voelen, gebrek aan motivatie of enthousiasme, het gevoel dat je emoties afgestompt zijn.	☐	☐	☐	☐	☐	☐	☐
Sociaal isolement, of het gevoel dat je geen interesse hebt om met andere mensen om te gaan.	☐	☐	☐	☐	☐	☐	☐
Agitatie of gevoelens van spanning	☐	☐	☐	☐	☐	☐	☐
Concentratieproblemen	☐	☐	☐	☐	☐	☐	☐
Vermoeidheid of uitputting	☐	☐	☐	☐	☐	☐	☐
Angst	☐	☐	☐	☐	☐	☐	☐
Gevoelens van neerslachtigheid, depressie of verdriet	☐	☐	☐	☐	☐	☐	☐
Stress	☐	☐	☐	☐	☐	☐	☐
Gedrag of verlangen om zichzelf pijn te doen of te verwonden	☐	☐	☐	☐	☐	☐	☐
Het gevoel niet meer te willen leven	☐	☐	☐	☐	☐	☐	☐
Stigmatisatie of gevoelens van discriminatie	☐	☐	☐	☐	☐	☐	☐
Verlies van zelfvertrouwen	☐	☐	☐	☐	☐	☐	☐
Andere	☐	☐	☐	☐	☐	☐	☐

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G2. **In welke mate heeft uw psychotische problematiek uw seksleven verstoord?**

- Helemaal niet ☐
- Licht ☐
- Matig ☐
- Zwaar ☐
- Extreem ☐
- Ik weet het niet ☐
- Niet van toepassing ☐
- Ik wil niet antwoorden ☐

G3.

In welke mate heeft uw psychotische problematiek een invloed gehad op uw vruchtbaarheid en voortplanting (d.w.z. op uw vermogen of beslissing om op natuurlijke wijze kinderen te verwekken of een zwangerschap te voltooien)?

Bijvoorbeeld: IVF (In Vitro Fertilisatie), genetische screening, sperma-/eiceldonatie, uitstel van zwangerschap of ervoor kiezen geen biologische kinderen te krijgen vanwege uw psychotische problematiek?

- Helemaal niet ☐
- Licht ☐
- Matig ☐
- Zwaar ☐
- Extreem ☐
- Ik weet het niet ☐
- Niet van toepassing (bijv. Nog niet overwogen om kinderen te krijgen, of niet getroffen door de psychotische problematiek toen ik op de leeftijd was om kinderen te krijgen) ☐
- Ik wil niet antwoorden ☐

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Sectie H: Medische behandeling van de psychotische problematiek

Met 'medische behandeling' of zorg bedoelen we alle afspraken, behandelingen en ondersteuning die door zorgverleners worden aangeboden om uw gezondheidstoestand op vlak van uw psychotische problematiek te beheren en te verbeteren.

H1. Heeft u het gevoel dat uw zorg in de loop van de tijd goed georganiseerd en gepland is?

- [ ] Altijd
- [ ] Vaak
- [ ] Soms
- [ ] Zelden
- [ ] Nooit
- [ ] Ik weet het niet

H2. Hebt u één of meer zorgverleners die verantwoordelijk zijn voor de coördinatie van de verschillende medische diensten waarvan u gebruik maakt?

Bijvoorbeeld een referentie arts of verpleegkundige die u opvolgt of doorverwijst, en die de communicatie vergemakkelijkt tussen de verschillende specialisten of diensten die u raadpleegt.

- [ ] Ja
- [ ] Neen
- [ ] Ik weet het niet
- [ ] Niet van toepassing: de opvolging gebeurt door één dienst, zonder behoefte aan coördinatie

H3. In welke mate bezoekt u dezelfde zorgverlener(s) tijdens uw regelmatige afspraken of controles?

- [ ] Altijd
- [ ] Vaak
- [ ] Soms
- [ ] Zelden
- [ ] Nooit
- [ ] Ik weet het niet

LimeSurvey

H4.

In welke mate krijgt u voldoende nuttige en begrijpelijke informatie van uw zorgverleners?

Met 'nuttig' bedoelen we actuele en coherente informatie die u helpt uw psychotische problematiek beter te begrijpen en aan te pakken.

- ☐ Altijd
- ☐ Vaak
- ☐ Soms
- ☐ Zelden
- ☐ Nooit
- ☐ Ik weet het niet

H5. **Wordt u, zoveel als u wenst, betrokken bij de beslissingen over uw zorg of behandeling?**

- ☐ Ja, helemaal
- ☐ Ja, tot op zekere hoogte
- ☐ Nee, niet echt
- ☐ Nee, helemaal niet
- ☐ Nee, maar ik wilde er toch niet bij betrokken worden
- ☐ Niet van toepassing: er worden geen beslissingen genomen over behandeling
- ☐ Ik weet het niet

Sectie I: Toegang tot gezondheidszorg

I1. **Had u in de afgelopen 12 maanden bepaalde zorg nodig voor uw psychotische problematiek die u niet heeft gekregen?**
Dit kan een consultatie, behandeling, medische test, revalidatie of iets anders zijn.

- ☐ Ja
- ☐ Neen
- ☐ Ik weet het niet

I2.

Om welke reden(en) heeft u zorg die u nodig had niet gekregen?

- ☐ Afstand tussen mijn woonst en de plaats van zorg
- ☐ Vervoersproblemen (bijv.: geen openbaar vervoer in de buurt, geen eigen voertuig, niet in staat om eigen voertuig te besturen, niemand om u naar de plaats van zorg te brengen)
- ☐ Gebrek aan bekwaam personeel om u de zorg te bieden die u nodig had

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Lange wachttijden ☐

Moeilijkheden om de zorg te betalen ☐

Angst voor medische-, ziekenhuis-, of andere onderzoeken ☐

Tijdsgebrek door werk, kinderen of andere ☐

Gebrek aan informatie ☐

Taalproblemen ☐

Andere reden ☐

Andere reden

Sectie J: Impact van de psychotische problematiek op onderwijs en werk

De volgende vraag gaat over de afgelopen zeven dagen, vandaag niet meegerekend.

J1. In welke mate werd uw school- of studietijd beïnvloed door uw psychotische problematiek, in termen van aanwezigheid, prestaties, succes of studiekeuze?

Helemaal niet ☐

Licht ☐

Matig ☐

Zwaar ☐

Extreem ☐

Ik weet het niet ☐

Niet van toepassing: de psychotische problematiek deed zich voor nadat school/studie was afgerond ☐



J2. **Hebt u door uw psychotische problematiek uw werktijd verminderd?**

- Ja, ik werk minder dan vroeger door mijn psychotische problematiek ☐
- Ja, ik ben gestopt met werken vanwege mijn psychotische problematiek ☐
- Nee, de psychotische problematiek heeft geen invloed op mijn werkuren ☐
- Ik weet het niet ☐
- Overige ☐

Overige

J3. **Hoe lang kon u niet werken vanwege uw psychotische problematiek?**

Geef een ruwe schatting van het TOTAAL van alle ziekteverzuimen, al dan niet aaneengesloten.

Bijvoorbeeld: als u eerst 1 maand en daarna 3 maanden niet heeft gewerkt, vink dan « Voor 4 maanden tot 1 jaar » aan.

- Voor minder dan 1 maand ☐
- Voor 1 tot 3 maanden ☐
- Voor 4 maanden tot 1 jaar ☐
- Voor meer dan 1 jaar ☐
- Ik weet het niet ☐

J4. **Geef bij benadering het aantal jaren aan:**

J5. **In welke mate heeft uw psychotische problematiek de afgelopen zeven dagen uw productiviteit op het werk beïnvloed? Denk aan de dagen waarop u beperkt werd in de hoeveelheid of het soort werk dat u kon doen, de dagen waarop u minder bereikte dan u had gewild, of de dagen waarop u uw werk niet zo zorgvuldig kon doen als gewoonlijk. Indien de psychotische problematiek weinig invloed had op uw werk, kies dan een laag cijfer. Kies een hoog cijfer als de ziekte een grote invloed had op uw werk.**

Denk alleen aan de mate waarin de psychotische problematiek uw productiviteit heeft beïnvloed terwijl u werkt. Klik op de cursor om deze tot op de gewenste waarde te schuiven

0 = De psychotische problematiek had geen invloed op mijn werk | 10 = Door de psychotische problematiek kon ik helemaal niet werken.

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Sectie K: Financieel gevolg

K1. **In welke mate heeft uw psychotische problematiek of medische behandeling u financiële problemen bezorgd?**

- ☐ Helemaal niet
- ☐ Licht
- ☐ Matig
- ☐ Zwaar
- ☐ Extreem
- ☐ Ik weet het niet

Sectie L: Impact op sociale relaties en ondersteuningsbehoeften

L1. **In welke mate belemmert uw psychotische problematiek uw relaties met uw familie, partner, vrienden of buren?**

- ☐ Helemaal niet
- ☐ Licht
- ☐ Matig
- ☐ Zwaar
- ☐ Extreem
- ☐ Ik weet het niet

L2.

Welke vormen van extra ondersteuning heeft u nodig omwille van uw psychotische problematiek, maar heeft u tot nu toe nog niet kunnen krijgen?

- ☐ Geen extra ondersteuning
- ☐ Logistieke ondersteuning (bv. schoonmaken, koken, boodschappen doen, vervoer, kinderopvang)
- ☐ Praten met andere patiënten met een psychotische problematiek
- ☐ Psychologische ondersteuning
- ☐ Medische ondersteuning
- ☐ Administratieve of sociale bijstand
- ☐ Ondersteuning bij aanpassen van de omgeving of aangepast materiaal


LimeSurvey
Ondersteuning bij terugkeer naar werk
Bijles en studiebegeleiding
Spirituele of religieuze begeleiding
Ik weet het niet
Overige
Overige

LimeSurvey

Sectie M: Prioritaire behoeften

M1. Welke aspecten van uw psychotische problematiek of de behandeling ervan moeten volgens u prioritair verbeterd worden? Rangschik elk aspect volgens het belang dat u eraan hecht.

	Helemaal geen prioriteit	Lage prioriteit	Matige prioriteit	Hoge prioriteit	Zeer hoge prioriteit	Ik weet het niet
De impact van uw psychotische problematiek op uw algemene levenskwaliteit (impact op mobiliteit, autonomie, uzelf kunnen aankleden en wassen, ongemak of pijn, angst of depressie; jaren geleefd met een handicap)	☐	☐	☐	☐	☐	☐
De impact op uw fysieke gezondheid (fysieke symptomen, ongemak of pijn gerelateerd aan de psychotische problematiek)	☐	☐	☐	☐	☐	☐
De impact op uw psychologische gezondheid (psychologische symptomen, angst of depressie gerelateerd aan de psychotische problematiek)	☐	☐	☐	☐	☐	☐
De invloed op uw onafhankelijkheid (invloed op uw mobiliteit, uw vermogen om u te wassen en aan te kleden; vermogen om dagelijkse activiteiten uit te voeren zoals werk, studie, huishouden, gezinsactiviteiten of vrije tijd)	☐	☐	☐	☐	☐	☐
De invloed op uw seksuele en reproductieve leven	☐	☐	☐	☐	☐	☐
De invloed op uw levensverwachting	☐	☐	☐	☐	☐	☐
De invloed op uw scholing of studie	☐	☐	☐	☐	☐	☐
De invloed op uw werk	☐	☐	☐	☐	☐	☐
De financiële impact	☐	☐	☐	☐	☐	☐
De impact op uw sociale leven (relaties met uw familie, partner of vrienden; behoefte aan extra ondersteuning - administratief, sociaal, enz.).	☐	☐	☐	☐	☐	☐
De kwaliteit van uw zorg (snelheid van diagnose, coördinatie en continuïteit van zorg, informatie ontvangen door zorgverleners, betrokkenheid bij beslissingen over uw zorg of behandeling)	☐	☐	☐	☐	☐	☐
Toegang tot gezondheidszorg (zorg krijgen wanneer u die nodig hebt, beschikbaarheid van behandeling)	☐	☐	☐	☐	☐	☐
Wetenschappelijke kennis (bijv. op het gebied van diagnose, behandeling of prognose)	☐	☐	☐	☐	☐	☐
Effectiviteit van de behandeling (het vermogen van de behandeling om de symptomen of de kwaliteit van leven te verbeteren)	☐	☐	☐	☐	☐	☐
Mogelijkheid van de behandeling (op het gebied van bijwerkingen of logistiek/administratie van de behandeling)	☐	☐	☐	☐	☐	☐

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Sectie N: Andere belangrijke behoeften

N1. **Wilt u ons vertellen over één of meer andere belangrijke behoeften die verband houden met uw psychotische problematiek die niet aan bod kwamen in de vragenlijst?**

- [ ] Ja
- [ ] Nee

N2. **Welke behoeften werden niet behandeld in de vragenlijst?**

Sectie O: Impact op verzorgers

O1.

Als iemand die de vragenlijst invult voor iemand met een psychotische problematiek: beschouwt u zichzelf als een 'mantelzorger'?

Met andere woorden, u helpt deze persoon omwille van zijn/haar psychotische problematiek, op regelmatige basis en in een niet-professionele hoedanigheid. Bijvoorbeeld een ouder die een kind helpt, een gezinslid of een vriend die een naaste helpt.

- [ ] Ja
- [ ] Nee

O2. **In relatie tot de persoon die u helpt, bent u:**

- [ ] Een familielid (bijvoorbeeld: ouder, kind, grootouder, ...)
- [ ] Een nauwe relatie (bijvoorbeeld: vriend, buur, ...)
- [ ] Overige

Overige

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O3. **Met welk geslacht identificeert u zich?**

- Man ☐
- Vrouw ☐
- Andere ☐

O4. **In welk jaar bent u geboren?**

☐☐☐☐☐☐☐☐☐☐

O5.

Hoeveel tijd hebt u tijdens de afgelopen week besteed aan het helpen van de persoon voor activiteiten die hij/zij normaal gesproken zelf zou hebben gedaan als hij/zij in goede gezondheid was?

Bijvoorbeeld voor persoonlijke verzorging (bijvoorbeeld aan- en uitkleden, naar het toilet gaan, ...), huishoudelijke taken (bijvoorbeeld eten klaarmaken, schoonmaken, ...) of praktische ondersteuning (bijvoorbeeld begeleiden naar medische of andere afspraken, ...)

☐☐☐☐☐☐☐☐☐☐

O6. **In welke mate wordt volgens u uw fysieke en/of psychologische gezondheid beïnvloed door uw rol als mantelzorger?**

- Helemaal niet ☐
- Licht ☐
- Matig ☐
- Zwaar ☐
- Extreem ☐
- Ik weet het niet ☐

O7. **In welke mate wordt volgens u uw sociale leven beïnvloed door uw rol als mantelzorger?**

- Helemaal niet ☐
- Licht ☐
- Matig ☐
- Zwaar ☐
- Extreem ☐
- Ik weet het niet ☐

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Sectie P: Vervolg van het onderzoek

Hartelijk dank voor uw deelname.

Iemand van onze onderzoekers zal u binnen een paar weken informeren over een eventueel persoonlijk gesprek met een onderzoeker.

P1.

We willen graag meer weten over de behoeften en moeilijkheden die u ervaart of hebt ervaren in de context van uw psychotische problematiek. Als u dat wilt, kunt u deelnemen aan een één-op-één interview (online of face-to-face met een onderzoeker) om uw ervaringen en behoeften in meer detail te bespreken. Dit interview vindt vertrouwelijk plaats en heeft geen invloed op de zorg die u ontvangt van zorgverleners. Er zullen naar verwachting 24 patiënten worden geïnterviewd. Dit individuele interview zal ongeveer anderhalf uur duren.

Wilt u deelnemen aan een persoonlijk interview?

Ja ☐

Nee ☐

P2. **Als u geïnteresseerd bent in een persoonlijk gesprek, geef ons dan uw contactgegevens (telefoonnummer en e-mailadres) zodat we met u contact kunnen opnemen.**

e-mail adres

Bevestiging e-mail adres

GSM nummer

LimeSurvey

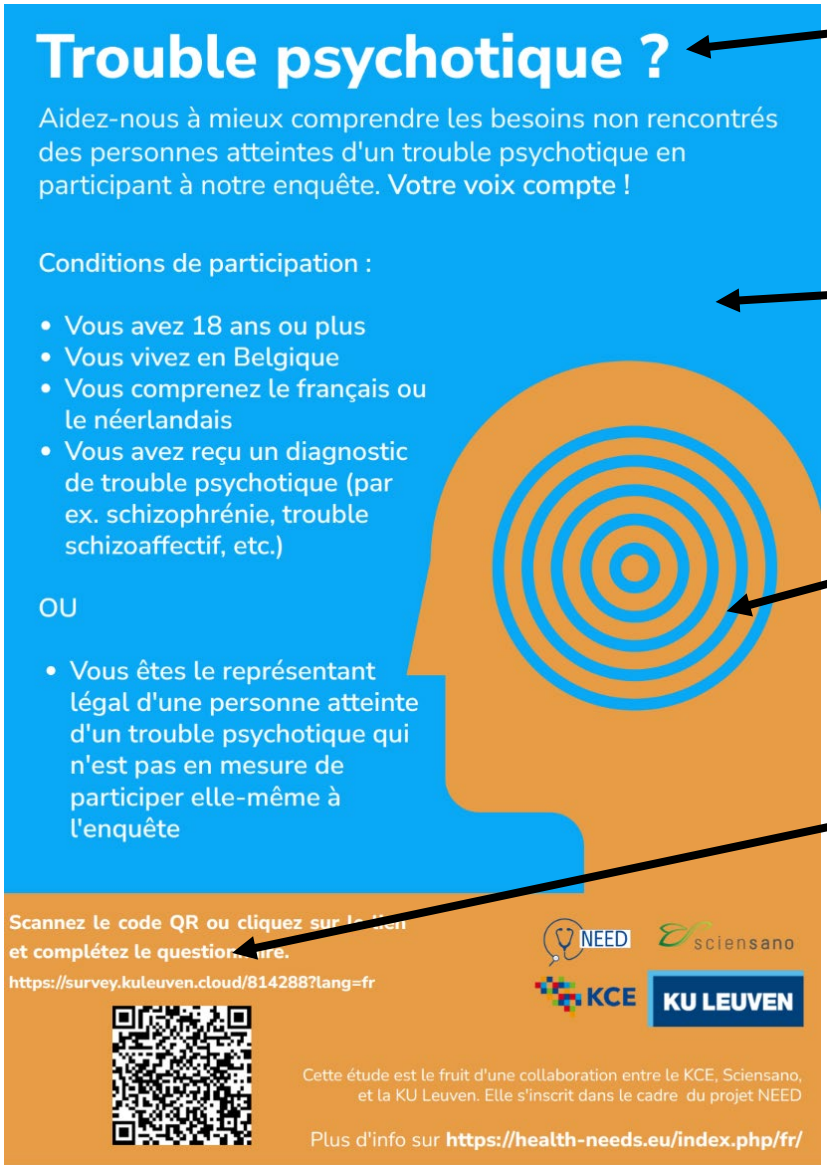
Bedankt voor uw interesse in deze studie.

De resultaten van deze studie zullen begin 2026 gepubliceerd worden op de site van het KCE (www.kce.fgov.be) en op de site van NEED (www.health-needs.eu).

De gegevens van de personen die aan de enquête deelnemen, worden zodanig gegroepeerd dat het onmogelijk is om een individu te identificeren op basis van de gepubliceerde gegevens. Uw privacy en de vertrouwelijkheid van uw antwoorden zijn dus volledig beschermd. Indien het invullen van deze vragenlijst of het nadenken over uw psychotische problematiek ongemak of emotioneel leed heeft veroorzaakt, raden wij u aan om hulp te zoeken. U kan terecht bij één van onze onderzoekers, Margaux Sageot, op het nummer 04 73 73 36 06. U kunt hiervoor ook terecht bij uw huisarts, psychiater of psycholoog.

In geval van dringende nood kunt u 112 bellen. Indien u nood heeft aan een anoniem gesprek kunt u 106 bellen.

APPENDIX 2. CONSIDERATIONS WHEN DEVELOPING RECRUITMENT MATERIALS



Inclusive, stigma-sensitive and patient-friendly terminology while still scientifically correct.

Lively, light colours instead of dark, somber colours to make the posters and flyers more attractive and less negative or heavy.

Appropriate visuals that are not perceived as too negative or somber within the context of PD.

QR-code that directs respondents to the online survey.

APPENDIX 3. OVERVIEW OF SUBGROUP ANALYSIS CONDUCTED PER INDICATOR

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
Health	general health-related quality of life (HRQoL)	Difference EQ-5D before onset of the symptom's vs today	Time since diagnosis	Patients diagnosed more than 10 years ago may report a greater QoL.
			Diagnosis	Individuals with schizophrenia may report lower HRQoL.
			Age	Younger individuals may perceive a lower QoL.
			Financial situation	Beining financially strained may perceive a lower QoL.
			Gender	Gender differences may be associated with a change in QoL.
			Educational level	A lower educational level may be associated with a lower QoL.
	Physical health	Burden of physical symptoms		
		Pain/discomfort	Gender	Gender differences may be associated with a change in pain and discomfort.
			Age	Age differences may be associated with a change in pain and discomfort.
			Educational level	Gender differences may be associated with a change in pain and discomfort.
			Financial situation	Beining financially strained may perceive a greater impact on pain and discomfort. .
	Psychological health	Burden of psychological symptoms	Time since diagnosis	Symptom burden is expected to increase as prolonged exposure to treatment can lead to cumulative side effects or "treatment fatigue," which may exacerbate symptoms and negatively impact overall quality of life.
			Diagnosis	Individuals with schizophrenia may report lower burden, but some may have achieved greater illness acceptance over time, which could moderate the perceived impact.
			Gender	Women may report higher levels of anxiety and depressive symptoms, in line with trends observed in the general population. However, despite the higher prevalence of affective

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
				symptoms, they may exhibit better overall functioning compared to men.
			Age	Age differences may be associated with a change in burden of psychological symptoms.
			Financial situation	Beining financially strained may perceive a higher burden on psychological symptoms, as individuals cannot receive proper care.
			Education level	A lower educational level may be associated with a higher burden on psychological symptoms.
		Anxiety/depression	Gender	Women may report higher levels of anxiety and depressive symptoms, in line with trends observed in the general population. However, despite the higher prevalence of affective symptoms, they may exhibit better overall functioning compared to men.
			Age	Age differences may be associated with a change in anxiety and depression.
			Education level	A lower educational level may be associated with higher levels of anxiety and depression.
			Financial situation	Being financially strained may be associated with higher levels of anxiety and depression.
	Autonomy	Mobility	Gender	Gender differences may be associated with a change in mobility.
			Age	A higher age may be associated with a greater impact on mobility.
			Education level	A lower educational level may be associated with a greater impact on mobility.
			Financial situation	Being financially strained may be associated with a greater impact on mobility.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
		Self-care	Gender	Gender differences may be associated with a change in self-care.
			Age	A higher age may be associated with a greater impact on self-care.
			Educational level	A lower educational level may be associated with a greater impact on self-care.
			Financial situation	Being financially strained may be associated with a greater impact on self-care.
		Usual activities	Gender	Gender differences may be associated with a change in usual activities.
			Age	A higher age may be associated with a greater impact on usual activities.
			Educational level	A lower educational level may be associated with a greater impact on usual activities.
			Financial situation	Being financially strained may be associated with a greater impact on usual activities.
	Reproductive health		Gender	Women may express reproductive health needs more explicitly.
			Financial situation	Being financially strained may be associated with a greater impact on reproductive health.
			Age	A higher age may be associated with a greater impact on reproductive health.
			Educational level	Educational differences may be associated with a change in reproductive health.
	Sexual health		Gender	Men may report more sexual side effects from medication.
			Financial situation	Financial differences may be associated with a change in sexual health.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
			Age	A higher age may be associated with a greater impact on sexual health.
			Educational level	Educational differences may be associated with a change in sexual health.
Healthcare		Treatment use	Time since diagnosis	More chronic patients may have transitioned to long-acting injectables or non-pharmacological strategies.
			Gender	Gender differences may be associated with a change in treatment use.
			Age	Age differences may be associated with a change in treatment use.
			Education level	A lower educational level may be associated with a not knowing what all the treatment possibilities are.
			Diagnosis	Differences in diagnosis may be associated with a change in treatment use, because every diagnosis can be treated differently according to the symptoms.
			Financial situation	Being financially strained may be associated with not being able to afford the most appropriate treatment.
	Effectiveness of the treatment			
	Burden of the treatment	Frequency of side effects	Time since diagnosis	Patients diagnosed longer may report more side effects due to treatment fatigue.
			Involvement in treatment decisions	Greater involvement improves satisfaction and perceived treatment effectiveness.
			Gender	Gender differences may be associated with a change in frequency of the side-effects.
			Age	Age differences may be associated with a change in frequency of the side-effects.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
		Burden of the side-effects	Gender	Gender differences may be associated with a change on the burden of side-effects.
			Age	Age differences may be associated with a change on the burden of side-effects.
			Financial situation	Being financially strained may be associated with a higher burden of the side-effects.
			Time of diagnosis	Time of diagnosis may be associated with a change on the burden of side-effects.
			Education	A lower educational level may be associated with a higher burden on side-effects.
			Diagnosis	Differences in diagnosis may be associated with a change in burden of the side-effects, because every diagnosis can be treated differently, which can lead to different side-effects.
		Burden of the treatment		
	Quality of care	Satisfaction with the organisation of care	Geographical region	Differences in coordination of care and continuity may drive regional disparities in satisfaction.
			Gender	Gender differences may be associated with a change in satisfaction with the organisation of care.
			Age	Age differences may be associated with a change in satisfaction with the organisation of care.
			Educational level	Differences in educational level may be associated with a change in satisfaction with the organisation of care.
			Financial situation	Being financially strained may be associated with a a lower satisfaction on the organisation of care, due to not being to afford proper care.
		Recurrence of same healthcare personnel	Geographical region	Differences in recurrence of the same healthcare personnel may drive regional disparities in satisfaction.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
			Gender	Gender differences may be associated with a change recurrence of the same healthcare personnel.
			Age	Age differences may be associated with a change recurrence of the same healthcare personnel.
			Educational level	Differences in educational level may be associated with a change recurrence of the same healthcare personnel.
			Financial situation	Differences in financial situation may be associated with a change recurrence of the same healthcare personnel.
		Satisfaction with information received from HCPs	Geographical region	Differences in region may be associated with a change in satisfaction of the received information.
			Financial situation	Differences in financial situation may be associated with a change in satisfaction of the received information.
			Gender	Gender differences may be associated with a change in satisfaction of the received information.
			Age	Age differences may be associated with a change in satisfaction of the received information.
			Education	A lower educational level may be associated with a lower satisfaction of the received information.
		Involvement in treatment choice	Geographical region	Differences in region may be associated with a change in involvement of treatment choice.
			Gender	Gender differences may be associated with a change in involvement of treatment choice.
			Age	Age differences may be associated with a change in involvement of treatment choice.
			Educational level	Differences in educational level may be associated with a change in involvement of treatment choice.
			Financial situation	Differences in financial situation may be associated with a change in involvement of treatment choice.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
	Diagnostic timing	Time between first symptoms and decision to search care	Geographical region	Differences in region may be associated with a change in time.
			Gender	Men may delay seeking care more than women due to gender norms and stigma.
		Time between decision and first appointment	Geographical region	Differences in region may be associated with a change in time.
		Time between first appointment and diagnosis	Geographical region	Differences in region may be associated with a change in time.
		Time between diagnosis and treatment	Geographical region	Differences in region may be associated with a change in time.
	Accessibility of treatment	Availability		
		Foregone care	Geographical region	Differences in region may be associated with a change forgone care.
			Gender	Men may delay seeking care more than women due to gender norms and stigma.
Social	Social support needs	Forgone social support	Geographical region	The prevalence of foregone social support could potentially differ by geographical region.
			Gender	Men may delay seeking care more than women due to gender norms and stigma.
			Educational level	Lower educational attainment could be associated with higher levels of foregone social support.
			Financial situation	Respondents with a more difficult financial situation may report higher levels of foregone social support.
			Age	Foregone social support could differ across age groups.
			Living situation	Respondents living alone could perhaps report higher levels of foregone social support than those living with a partner or family.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
	Social connection needs	Impact on personal relations	Gender	Gender norms may influence the way people maintain social bonds during illness.
			Age	Younger people may report greater disruption in friendships and partnerships.
			Educational level	Respondents with lower educational attainment may report a greater negative impact on personal relations.
			Financial situation	Respondents reporting greater financial difficulty could experience a greater negative impact on personal relations.
			Living situation	Respondents living alone may report a greater negative impact on personal relations compared with those living with a partner or family.
	Education	Impact on education	Gender	On average, women receive a diagnosis around the age of 25, while men are typically diagnosed earlier, around 17–18 years old. As a result, women may have had more opportunities to complete their studies and establish a foundation for adult life, contributing to more favorable life prospects and higher recovery rates.
			Age	Younger respondents might report a greater negative impact on education than older respondents
			Educational level	Respondents with lower educational attainment could report a greater negative impact on education.
			Financial situation	Respondents with a more difficult financial situation may experience a greater negative impact on education.
			Living situation	Respondents living alone may report a greater negative impact on education than those living with a partner or family.
	Work	Impact on work intensity	Time since diagnosis	Individuals recently diagnosed may still be employed; impact increases over time.
			Living situation	Those living with others may have more capacity to work due to support structures.

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
			Gender	Women could potentially be more likely than men to report reduced work intensity.
			Education level	Respondents with lower educational attainment may be more likely to report reduced work intensity compared with those with higher educational levels.
			Financial situation	Respondents reporting financial difficulties may be less likely to experience reduced work intensity or to have stopped working.
		Time of incapacity to work	Time since diagnosis	Individuals recently diagnosed may still be employed; impact increases over time.
			Living situation	Those living with others may have more capacity to work due to support structures.
			Gender	Women could potentially be more likely than men to report incapacity to work.
			Education	Respondents with lower educational attainment may be more likely be incapable to work compared with those with higher educational levels.
			Financial	Respondents reporting financial difficulties may be less likely to being incapable to work.
	Financial consequences	Impact on financial situation	Living situation	Financial strain may be lower for individuals living with family or partners.
			Gender	Gender differences in region may be associated with greater financial consequenses.
	Prioritisation of needs		Age	Age differences may be associated with a change in the prioritisation of needs.
			Financial situation	Differences in financial situation may be associated with a change in the prioritisation of needs
			Time since diagnosis	Differences in time since diagnosis may be associated with a change in the prioritisation of needs

Domain	Criterion	Indicator	Sub-analysis	Hypothesis
			Geographic region	Differences in region may be associated with a change in the prioritisation of needs
			Gender	Gender differences may be associated with a change in the prioritisation of needs
			Living situation	Differences in living situation may be associated with a change in the prioritisation of needs
			Educational level	Differences in educational level may be associated with a change in the prioritisation of needs

APPENDIX 4. INTERVIEW GUIDE FOR INDIVIDUALS AND PROXIES (NL AND FR)

NL - Topic guide voor de individuele interviews

***Goedemiddag**, spreek ik met ….. (contact van de patiënt = de persoon die de vragenlijst heeft ingevuld)? Ik ben …. (uw naam en voornaam). Ik neem contact met u op in het kader van het **NEED-project over** "De evaluatie van de noden van patiënten met een psychotische problematiek", waaraan u onlangs hebt deelgenomen door onze vragenlijst in te vullen. Wij danken u oprecht voor deze bijdrage en uw interesse om deel te nemen aan het interview, en daarom bel ik u vandaag.*

*De **individuele interviews** hebben als doel om de thema's uit de vragenlijst verder te verdiepen, zodat wij uw noden beter kunnen begrijpen. Het interview duurt ongeveer 1,5 uur en kan online of fysiek plaatsvinden, zoals u verkiest. Weet dat de informatie die tijdens dit interview wordt verzameld, vertrouwelijk zal worden behandeld. Het interview vindt plaats tussen u en mij.*

(Disclaimer: als de persoon vraagt om een naaste mee te nemen, is dat mogelijk, maar dan gebruiken we dezelfde interviewgids. De vragen worden in eerste instantie aan de patiënt zelf gesteld, omdat we in de eerste plaats zijn/haar mening willen verzamelen. Er is geen aparte sectie voor mantelzorgers, aangezien het niet gepast lijkt deze vragen in aanwezigheid van de patiënt te stellen.)

Bent u nog steeds bereid om deel te nemen aan het interview? Welke dag en welk uur passen het best voor u? (Afspraak vastleggen.) Verkiest u het interview fysiek te doen (geef de locatie) of online via Teams/Zoom (kiezen)? Het interview kan in het Frans of Nederlands plaatsvinden. In welke taal voelt u zich het meest comfortabel?

U krijgt nog een bevestiging via (kies sms/e-mail), met mijn (onze) contactgegevens zodat u mij (ons) kunt bereiken bij onvoorziene omstandigheden. Ik zal u de dag voordien een sms (of e-mail) sturen om de afspraak te bevestigen.

Nogmaals hartelijk dank voor uw deelname aan dit onderzoeksproject. Uw bijdrage is van grote waarde.

Nota voor de persoon die het interview afneemt:

Structuur van de interviewgids

*De **kolom met vragen** bevat de vragen die de interviewer aan de persoon stelt (zoals ze zijn of aangepast aan de context). De **kolom met follow up** bevat suggesties om de discussie te verdiepen en genoeg informatie te verzamelen om het onderwerp volledig te behandelen. De **kolom "doelstelling"** geeft het doel van de bijbehorende vragen aan. Aantekeningen die **niet** voorgelezen moeten worden aan de geïnterviewde persoon zijn in het document cursief geschreven.*

Aanpassing van de formulering van de vragen

De vragen zijn zo eenvoudig en duidelijk mogelijk geformuleerd. De interviewer past zich echter aan de geïnterviewde persoon aan en kan de vragen in een andere volgorde stellen, afhankelijk van de onderwerpen die de persoon zelf aanhaalt. Het interview volgt zoveel mogelijk een geleid gesprek, met een natuurlijke en spontane toon, terwijl er een professionele en respectvolle houding wordt behouden, vrij van enig oordeel.

Voorbereiding van het interview

Het interview moet worden voorbereid door de antwoorden van de persoon op de NEED-vragenlijst te lezen. Dit is op verschillende momenten tijdens het interview van belang. Zo kan men in de vragenlijst bijvoorbeeld noteren: de gezinssituatie van de persoon, of hij/zij thuis woont of ergens anders, of er comorbiditeiten zijn, of de persoon in het ziekenhuis is opgenomen geweest door de ziekte, en of de ziekte impact heeft gehad op het reproductieve leven. Ook de antwoorden op open vragen kunnen worden genoteerd en later gebruikt worden om door te vragen.

Het doel van dit interview is om de niet-ingevulde noden, die via de vragenlijst werden geïdentificeerd, verder te begrijpen (welke impact precies, welke mogelijke oplossingen…).

*In dit interview geldt: telkens wanneer u de term **[Psychotische problematiek]** ziet, kies het meest passende woord, dus ofwel **"psychotische problematiek"**, of **"de diagnose die de persoon in de vragenlijst heeft vermeld"** (bijvoorbeeld: schizofrenie).*

Begin van het interview met de geïnterviewde persoon (= patiënt of patiënt en proxy)

Hartelijk dank voor uw deelname aan dit interview in het kader van het project "Evaluatie van de behoeften van patiënten met een psychotische problematiek". Deze studie wordt uitgevoerd door het NEED team, een groep onderzoekers van het Federaal Kenniscentrum voor de Gezondheidszorg samen met Sciensano.

Mijn naam is .... en ik ben ....

Het doel van ons project is om uw ervaringen en behoeften gerelateerd aan psychotische problematiek te begrijpen. Dit is nuttig om verbeterpunten voor te stellen indien nodig.

We willen dit interview graag opnemen om het gesprek te vergemakkelijken, om te voorkomen dat uitspraken verkeerd worden begrepen en om het later zorgvuldig te kunnen analyseren.. De opname wordt gewist zodra de notities zijn gemaakt. De inhoud van de interviews wordt geanonimiseerd en er wordt geen informatie gepubliceerd waarmee u zou kunnen worden geïdentificeerd.

Er zijn geen goede of foute antwoorden en u bent vrij om de vragen al dan niet te beantwoorden. Het gaat om uw ervaring en mening.

Ik zal u kort de informatie op het formulier voor geïnformeerde toestemming voorlezen en er u wat uitleg bij geven. Daarna nodig ik u uit om het te ondertekenen en daarna zal ik het zelf ondertekenen.

	Vragen	Follow-up	Doelstelling
	ICE BREAKER		
1	**Hoe voel je je over het algemeen vandaag?**		Mensen aanmoedigen om te spreken Het interview contextualiseren
2	**Wat motiveerde je om deel te nemen aan het online onderzoek en in te stemmen met het interview van vandaag?**		
3	**Als je [psychotische problematiek] aan iemand zou moeten uitleggen die hier niet bekend mee is, hoe zou je dat dan doen?**	• Wist je al iets over [psychtotische problematiek] vooraleer je ze had?	
	We zouden nu graag ingaan op uw persoonlijke ervaring, te beginnen met jouw 'diagnosetraject'		
4	**Hoe ontdekte je dat je een [psychotische problematiek] had?**	• Welke eerste signalen of symptomen deden je denken dat er iets niet in orde was? • Wanneer was de eerste keer dat je besloot je arts te raadplegen? • Hoeveel tijd ging er tussen het eerste moment waarop jij of iemand anders voelde dat er iets niet in orde was met je en het moment waarop een dokter werd gecontacteerd om erover te spreken? • Wie heeft de keuze gemaakt om een dokter te contacteren? • Heb je een diagnose gekregen? • Wie stelde als eerste de diagnose? • Wanneer werd deze diagnose gesteld? • Ben je bij verschillende gezondheidszorgverleners geweest voordat je de diagnose kreeg? • Hoeveel tijd zat er tussen je eerste consultatie en je diagnose? • Was de manier waarop de diagnose werd aangekondigd gepast (werd het je op een gevoelige manier verteld, op een duidelijke manier en met voldoende informatie)?	Behoeften gerelateerd aan de diagnose

		• Na hoeveel tijd ben je begonnen met een behandeling of begeleiding (als dat het geval is)?	
4bis	**Hoe heb je jouw eerste ervaring met de zorg voor jouw [psychotische problematiek] ervaren?**	• Voorgestelde therapie • Voorgestelde medicatie • Zorgkader en zorgomgeving • Relatie met de hulpverleners • Betrokkenheid van de omgeving • Psychologische en emotionele toestand	Behoeften verbonden aan de eerste zorgervaring
5	**Hoe beïnvloedt jouw [psychotische problematiek] je dagelijks leven?**		Contextualiseren, gezondheidsbehoeften
	We gaan nu kijken naar de rol van jouw [psychotische problematiek] in het dagelijks leven en de verschillende moeilijkheden die je mogelijks ervaart als gevolg van je [psychtotische problematiek]. We proberen de moeilijkheden eerst te begrijpen, om daar na te bespreken in hoeverre je suggesties hebt om de situatie te verbeteren.		
6	**Wat voor soort moeilijkheden ervaar je in je dagelijks leven als gevolg van je [psychotische problematiek]?** ***(Als je comorbiditeiten hebt genoteerd in de vragenlijst, stel dan de bijbehorende doorvraagvraag over de comorbiditeiten.)***	In termen van : • Fysieke symptomen? • Psychologische symptomen (zoals je stemming, het beheersen van je emoties) • Impact op je gezinsleven? • Impact op je sociale leven? (zoals uitgaan, vrienden zien,…) • Impact op je school of studies? • Impact op je werk? (zoals kwaliteit van je werk, mogelijkheid te functioneren, verantwoordelijkheden die je kunt opnemen, tijd die je kunt werken, van werk moeten veranderen, relatie met je werkgever) • Financiële gevolgen? • Impact op het uitvoeren van je dagelijkse taken? • Stigmatisering/beoordeling vanwege jouw [psychotische problematiek]? • Interacties met andere gezondheidsproblemen (inclusief tandproblemen…) • Impact op je affectieve en [seksuele leven]?	Vaststellen van **therapeutische en sociale behoeften**

		(Disclaimer: "seksueel leven" alleen als de persoon er zelf over begint.) • Impact op je wens en mogelijkheden om kinderen te krijgen? • Andere moeilijkheden ? ...	
7	**Hoe verzorgt u zichzelf of hoe bent u in het verleden behandeld?**	• Medicijnen op voorschrift • Medicijnen zonder voorschrift • Dieet aanpassingen • Ondersteunend materiaal • Kinesitherapie, ergotherapie, logotherapie, … • Niet-conventionele therapie (acupunctuur, osteopathie, homeopathie...) • Psychologische ondersteuning in groep of inidividueel • Spirituele ondersteuning en/of mindfulness • Projecten rond zingeving en re-integratie	**Identificeren van therapeutische behoeften**
7-	**[INDIEN GEEN BEHANDELING].** **Waarom heb je geen behandeling (medicatie, therapie, of andere)?**	• Keuze om de behandeling niet te volgen *(vraag waarom)* • Stoppen met de behandeling vanwege verbetering van de gezondheidstoestand • Er werd niets voorgesteld/aangeboden • Kosten van de behandeling • Weinig of geen vertrouwen in de voorgestelde behandelingen? • Behandeling gestopt vanwege bijwerkingen of moeilijkheden om de behandeling te blijven volgen? • Geen consultatie? → Obstakels voor de consultatie: • Gebrek aan informatie over wie te raadplegen? • Angst om niet serieus genomen te worden?	Behoeften binnen het **zorgtraject identificeren** (toegang tot zorg, toegang tot behandeling)

		• Angst dat gezondheidswerkers niet genoeg weten over het probleem? • Financiële kosten • Andere redenen ...	
7+	**[INDIEN BEHANDELING].**		
a)	**Hoe ben je ertoe gekomen om deze behandeling(en) te volgen?** ***(aan te passen afhankelijk van het antwoord)***		**Identificeren van therapeutische noden en netwerken**
b)	**Wie heeft deze 'behandelingen' geadviseerd/voorgeschreven?** **Is dit een behandeling die je zelf inneemt, of moet iemand anders die toedienen?**		
c)	**Hoe duidelijk was het voor je wat je moest doen?**	• Arts (huisarts ? specialist ?) • Andere gezondheidsprofessional • Familielid, vriend of collega • Andere patiënten via patiëntengroepen • Internet • Andere • Kreeg je voldoende informatie om een weloverwogen keuze te maken voor behandeling? • Kreeg je voldoende informatie om te weten wanneer en hoe precies je de behandeling kon volgen of nemen ?	Identificeren van de **informatie behoeften**

		• Was de informatie die je kreeg voldoende te begrijpen?	
8	**[INDIEN BEHANDELING]** **Welke moeilijkheden ervaar je in verband met je behandeling(en) (medicatie, therapie, of andere.)?**	In termen van : • Doeltreffendheid? (dat wil zeggen, het vermogen van de behandeling om de ziekte te bestrijden, de symptomen te verminderen en u te helpen beter te worden) • Bijwerkingen? • Informatie rond de bijwerkingen en/of complicaties • Behandellast? (bijvoorbeeld een behandeling die heel vaak moet worden ingenomen, waarvoor u naar het ziekenhuis moet, of die geïnjecteerd moet worden…) • Het volgen van de behandeling zoals werd geadviseerd • Type aanpak (bijv. te gefragmenteerd of te globaal)? • Beschikbaarheid van behandeling? • Basisprijs (prijs die je betaalt vooraleer je een terugbetaling krijgt)? • Terugbetaling? (Tijdspanne/afhandeling) • Beschikbaarheid van de zorg, beschikbaarheid van de gezondheidszorgverleners om behandeling voor te schrijven? • Andere moeilijkheden in verband met de behandeling...	De medische behoeften, informatiebehoeften en financiële impact van de behandeling identificeren
9	**Met welke mogelijke moeilijkheden krijg je te maken bij jouw behandeling?** ***(Als de patiënt nog steeds bezig is met de verschillende behandelingen, zoals medicatie, chirurgie, enzovoort; anders de vraag in de verleden tijd formuleren)***	Bv. • - Afstand/bereikbaarheid van de plaats van zorg; • - Noodzakelijke logistieke hulp • - Taalbarrière • - Angst • - Tijdstekort • - Tekort aan informatie • - Interactie met andere gezondheidsproblemen • - Andere moeilijkheden	Het identificeren van **medische, informatie- en financiële behoeften** met betrekking tot het zorgtraject **(bijv. toegang** tot behandelingen, **acceptatie** van zorg).

10	**Hoe beoordeel je de medische zorg die je gekregen hebt voor de [psychotische problematiek]?**	*Wat ging er voor jou niet goed op het gebied van zorg?* *- organisatie van gezondheidszorg diensten: coördinatie en continuïteit* *- de weg vinden in de zorg, weten bij wie je terechtkunt en wanneer* *- een afspraak kunnen maken wanneer je er één nodig hebt* *- de meest geschikte zorgverlener vinden*	De **therapeutische en ondersteuningsbehoeften** vaststellen
10 bis	**Hoe beoordeel je de opvolging van jouw gezondheidsproblemen tijdens jouw hospitalisatie?** *(Deze vraag wordt alleen gesteld als de persoon voor deze aandoening/dit gezondheidsprobleem in het ziekenhuis is opgenomen – zie informatie vragenlijst.)*		
11	**Welke oplossingen zou je voorstellen om de aanpak voor je [psychotische problematiek] te verbeteren?**	Op het gebied van : • Preventie (indien relevant) • Behandeling • Follow-up en zorgverlening • Informatie • Administratie • Financiën (prijs, terugbetaling) • Ondersteuning, sociaal netwerk • Interactie met andere gezondheidsproblemen • Andere oplossingen…	Het identificeren van **oplossingen** voor **eventuele therapeutische, zorg- en ondersteuningsbehoeften,** evenals **financiële behoeften.**

12	**Hoe zou je je relaties met zorgverleners omschrijven?**	In termen van : • Tijd die de gezondheidszorgverlener besteedt • Luisteren • Voel je je comfortabel om vragen te stellen • Geven ze nuttige en begrijpelijke informatie • Respect • Serieus genomen worden • Betrokken worden bij beslissingen • Taal • Rekening houden met culturele aspecten • Punctualiteit bij afspraken • Overdragen van informatie • Vertrouw je je zorgverlener • Heb je het gevoel dat ze de benodigde expertise hebben	**Het identificeren van behoeften met betrekking tot de relatie met professionals, informatiebehoeften, ondersteuningsbehoeften en financiële behoeften.**
12'	**[INDIEN MOEILIJKHEDEN]** **Hoe kunnen deze moeilijkheden aangepakt worden, naar jouw mening?**	*Wat kan er gedaan worden om de situatie te verbeteren?*	Het identificeren van **oplossingen** voor **zorgbehoeften, de relatie met professionals, therapeutische en sociale behoeften, en informatiebehoeften.**
13	**Welke moeilijkheden ondervind je op administratief vlak of met de administratieve diensten (bijvoorbeeld met administratie, de mutualiteit/ziekenfonds, verzekering…)?**	Bijvoorbeeld : • Erkenning als ziek • Terugbetaling krijgen van je ziekenfonds • Erkenning als beroepsziekte • Verzekeringen • Weten waar men terecht kan voor welke procedure • Andere …	Identificeren van **administratieve behoeften** met betrekking tot het gezondheidszorgsysteem in bredere zin
13'	**[INDIEN MOEILIJKHEDEN WERDEN ONDERVONDEN]** **Hoe kunnen deze administratieve problemen opgelost worden, naar jouw mening?**	*Wat kan er gedaan worden om de situatie te verbeteren?*	Identificeren van **oplossingen** voor **administratieve behoeften**

14	**In welke mate voel je je ondersteund bij je huidige gezondheidstoestand?**	*Welke positieve maatregelen zie je?* *Wat mis je eventueel aan ondersteuning?* Wie zou de ondersteuning kunnen geven die je momenteel mist? *Wie zou je nodig hebben om je ondersteund te voelen?* • Gezondheidszorgverleners • Zorgverleners in de geestelijke gezondheidszorg • Maatschappelijk werkers • Patiëntengroepen • Familie, vrienden, buren, of collega's • Steun vanop het werk (collega's, leidinggevende) • Voor studie (docenten, schoolleiding, medestudenten…) • Andere...	**Ondersteuningsbehoeften** identificeren
15	**Welke andere problemen of niet ingevulde behoeften zou je graag met ons delen?**	*Welke andere aspecten zijn belangrijk en zouden we ons bewust van moeten zijn?*	**Andere niet-erkende behoeften**
	SLOT		
16	**Om te besluiten, van alle behoeften en moeilijkheden die je hebt tegengekomen of die je nog steeds tegenkomt, welke moeten volgens jou prioritair worden aangepakt door wetenschappers en/of politici?**	*Als jij een beleidsmaker (of wetenschapper) was, welke acties zou jij dan prioriteit geven om het dagelijks leven van patiënten met een [psychotische problematiek] te verbeteren?*	**Prioritering van onvervulde behoeften**

Heel erg bedankt voor jouw deelname. Zoals eerder gezegd, zal dit interview worden uitgeschreven, geanonimiseerd en geanalyseerd samen met de interviews met andere personen die deelnemen aan dit onderzoek.

De resultaten zullen opgenomen worden in de NEED database en een rapport van deze studie zal gepubliceerd worden op de websites van het KCE en NEED (https://kce.fgov.be/) (www.health-needs.eu) [wanneer].

De bevindingen uit de interviews worden op zo'n manier gecombineerd dat het niet mogelijk is om een individu te identificeren aan de hand van de gepubliceerde gegevens. De confidentialiteit van je gegevens en je privacy worden zo beschermd.

FR - Guide pour les entretiens individuels

Prise de contact avant l'entretien :

Bonjour, est-ce que je m'adresse bien à .....(contact du patient =personne qui a rempli le questionnaire). Je suis .... (votre nom et prénom). Je vous contacte dans le cadre du projet **NEED sur** « L'Evaluation des besoins de patients avec troubles psychotiques», auquel vous avez participé récemment en répondant à notre questionnaire. Nous vous remercions sincèrement pour cette contribution et votre intérêt à participer à l'entretien, c'est pour ça que je vous appelle aujourd'hui.

Les **entretiens individuels** ont pour but d'approfondir les thèmes du questionnaire pour que nous puissions mieux comprendre vos besoins. L'entretien dure plus ou moins 1H30 et se déroule soit en ligne soit en présentiel, comme vous préférez. Sachez que les informations recueillies lors de cet entretien seront traitées de manière confidentielle. L'entretien se déroule avec vous en duo avec moi. *(Disclaimer: si la personne vous demande de venir avec un proche, cela est possible, vous devrez utilisez le même guide d'entretien. Ainsi vous dirigez vos questions vers le patient en premier car c'est l'avis du patient que nous recueillions en priorité. Il n'y a pas de section "aidants proches" car il n'apparait pas adapté de poser ces questions devant le patient).*uEtes-vous toujours partant(e) pour participer à l'entretien ? Quel jour et quelle heure vous arrangent le mieux ? *(Fixer le rendez-vous)* Préférez-vous le faire en présentiel *(donnez le lieu)* ou en distanciel via teams/zoom *(choisir) ?* L'entretien peut se dérouler en français ou en néerlandais, quelle est la langue dans laquelle vous êtes le plus à l'aise ?

Sachez qu'une confirmation vous sera envoyée par (choisir *sms/ mail)*, avec mon (nos) contact (s) afin que vous puissiez me (nous) joindre en cas d'imprévu. Je vais vous envoyer un sms (ou e-mail) la veille pour confirmer le rendez-vous.

Encore un tout grand merci pour votre participation à ce projet de recherche**.** Votre contribution est précieuse.

Note pour la personne conduisant l'entretien :

Structure du guide d'entretien

*La **colonne des questions** comporte les questions que l'interviewer pose à la personne (telles quelles ou adaptées au contexte), la **colonne des relances** comporte des questions qui permettent d'aider à approfondir et à relancer la discussion pour avoir assez de matière pour couvrir le sujet, la **colonne "objectif"** donne l'objectif des questions associées. Les notes qui ne doivent pas être lues à la personne interviewée sont écrites dans le document en italique.*

Adaptation de la formulation des questions

La formulation des questions a été pensée pour être la plus simple et claire possible. Toutefois, l'interviewer s'adaptera à la personne rencontrée, et les questions pourront être abordées dans un ordre différent, suivant les sujets abordés par la personne. L'entretien suivra autant que possible une conversation dirigée, dans un ton naturel et spontané, tout en maintenant une attitude professionnelle et bienveillante, exempte de tout jugement.

Préparation de l'entretien

Le contenu de l'entretien doit être préparé en lisant les réponses de la personne au questionnaire NEED. Il y a plusieurs endroits dans l'entretien où cela aura de l'importance. On peut par exemple noter dans le questionnaire la situation familiale de la personne, si elle vit à la maison ou ailleurs, si elle a des comorbidités, si elle a été hospitalisée à cause de sa maladie, et si la maladie a eu un impact sur sa vie reproductive. On peut également noter leurs réponses aux questions ouvertes qui peuvent être utilisées comme relance. Le but de cet entretien est d'approfondir la

compréhension des besoins non rencontrés identifiés au travers du questionnaire (quel impact exactement, quelles pistes de solutions...).êDans cet entretien, à chaque fois que vous verrez le terme [Troubles psychotiques], veuillez choisir le terme le plus adapté, donc soit « Trouble psychotique » soit « le diagnostic que la personne a indiqué dans le questionnaire » (par exemple : schizophrénie). Début de l'entretien avec la personne interviewée (= patient ou patient + proxy) êJe vous remercie d'avoir accepté de participer à cet entretien dans le cadre du projet « Evaluation des besoins de personnes avec troubles psychotiques», mené par un groupe de chercheurs du Centre Fédéral d'Expertise des Soins de Santé et de Sciensano*].Je m'appelle …. et je suis ….(l'interviewer se présente).ê L'objectif de ce projet est de comprendre les expériences et les besoins de personnes atteintes de trouble psychotiques. Cela nous sert notamment afin de proposer des pistes d'amélioration de prise en charge pour les personnes ayant [trouble psychotique].Comment se déroule l'entretien ? Je vous poserai des questions sur les expériences que vous avez vécues en lien avec votre maladie, ce que ça implique dans votre quotidien, et je vous demanderai ensuite si vous avez éventuellement des pistes d'amélioration à proposer. C'est donc votre point de vue et vos expériences concrètes qui m'intéresse pour enrichir les différents thèmes abordés dans le questionnaire. Début de l'entretien avec la personne interviewée (= patient ou patient + proxy) êJe vous remercie d'avoir accepté de participer à cet entretien dans le cadre du projet « Evaluation des besoins de personnes avec troubles psychotiques», mené par un groupe de chercheurs du Centre Fédéral d'Expertise des Soins de Santé et de Sciensano*].Je m'appelle …. et je suis ….(l'interviewer se présente).êCet entretien dure plus ou moins 1h30, dites-moi si vous disposez de moins de temps ou si vous avez un impératif de temps. J'aimerai enregistrer cet entretien pour éviter de devoir prendre beaucoup de notes et mieux pouvoir me concentrer sur notre conversation. Cela me permettra aussi de rester fidèles à vos paroles lorsque je ferai une retranscription pour l'analyse. L'enregistrement sera supprimé une fois la transcription réalisée, et ne sera pas partagé en dehors du projet. Le contenu de l'entretien sera anonymisé, c'est à dire qu'aucune information permettant de vous identifier ne sera publiée. Sachiez qu'il n'y a ni bonnes ni mauvaises réponses et que vous êtes entièrement libre de répondre ou non aux questions. Ce qui compte avant tout c'est vos expériences et vos opinions.aJe vais maintenant vous lire et vous expliquer le contenu du formulaire de consentement éclairé. Ensuite, je vous inviterai à le signer, puis je le signerai à mon tour. a a aa aê

Questions		Relances	Objectif
	ICE BREAKER		
1	**Comment allez-vous aujourd'hui ?**		Favoriser la parole Contextualiser l'entretien
2	**Quelles ont été vos motivations pour participer à l'enquête en ligne et pour accepter l'entretien d'aujourd'hui ?**		
3	Comment expliqueriez-vous ce qu'est **[le trouble psychotique] à quelqu'un qui ne le connaît pas ?**	• Connaissiez-vous la **[le trouble psychotique]** auparavant ?	
	Nous allons maintenant nous focaliser sur votre vécu, en commençant par votre « parcours diagnostic ».		
4	**Comment avez-vous découvert que vous aviez le [trouble psychotique]?**	• Quels ont été les premiers signes ou symptômes qui ont fait penser que quelque chose n'allait pas ? • Combien de temps s'est écoulé entre le moment où vous ou quelqu'un d'autre a senti que quelque chose n'allait pas et le moment où un médecin a été contacté pour en parler ? • Qui a pris la décision de contacter un médecin ? • Avez-vous un diagnostic ? • Qui a posé le diagnostic ? • Quand a été posé ce diagnostic? • Avez-vous rencontré plusieurs professionnels de santé avant que le diagnostic ne soit posé ? • Combien de temps s'est écoulé entre votre première consultation et le diagnostic ? • La manière dont a été annoncé le diagnostic était-elle appropriée, c'est-à-dire respectueuse, claire et suffisamment détaillée? • Après combien de temps avez-vous commencé un traitement ou un suivi (si c'est le cas) ?	Besoins liés au diagnostic
4bis	**Comment avez-vous vécu votre première expérience avec les soins proposés pour vos [troubles psychotiques] ?**	Par exemple : • Thérapie proposée • Médication proposée	Besoins liés à la première expérience de soins

		• Cadre et environnement de soin • Relation avec les professionnels • Implication de l'entourage • Etat psychologique et émotionnel	
5	**Comment se manifeste votre [trouble psychotique] au quotidien ?**		Contexte, besoins de santé
	Nous allons maintenant explorer la place de votre [Trouble psychotique]au quotidien et passer en revue toutes sortes de difficultés que vous avez pu éventuellement rencontrer suite à votre état de santé. Nous allons d'abord essayer de les comprendre avant de voir dans quelle mesure vous avez des propositions à faire pour améliorer la situation.		
6	**Quelles difficultés rencontrez-vous par rapport à votre état de santé dû au [trouble psychotique] ?** ***(Si vous avez noté des comorbidités dans le questionnaire, posez la question de relance associée aux comorbidités)***	En termes de : • Symptômes physiques? • Symptômes psychologiques (Humeur, gestion des émotions) ? Conséquences familiales ? • Conséquences sociales ? (par exemple sorties, voir des amis...) • Conséquences sur votre scolarité ou vos études ? • Conséquences professionnelles ? (qualité du travail, fonctionnement, responsabilités, temps de travail, besoin de changer de travail, relation avec l'employeur) • Conséquences financières ? • Fonctionnement au quotidien ? • Stigmatisation/jugement à cause de vos [troubles psychotiques] ? • Interactions avec d'autres problèmes de santé (inclus problème dentaire...) • (Dans votre vie affective [et sexuelle] ? (*Disclaimer: « vie sexuelle » seulement si la personne en parle d'elle-même)* • Dans votre désir/ possibilité d'avoir des enfants ? • Autre type de difficultés ? …	Identifier l'impact sur le patient, les **besoins** de santé, et **besoins sociaux** au sens large
7	**Comment vous soignez-vous ou comment vous êtes-vous soigné(e) dans le passé?**	• Médicaments prescrits • Médicaments non-prescrits • Adaptations du régime alimentaire • Matériel nécessaire • Kinésithérapie, ergothérapie, logopédie...	Identification des **besoins thérapeutiques**

		• Pratiques non conventionnelles (acupuncture, ostéopathie, homéopathie…) • Soutien psychologique en groupe ou individuel • Soutien spirituel et/ou pleine conscience • Projets autour du sens de la vie et de la réintégration • Autre …	
7bis	**[SI AUCUN TRAITEMENT]** **Pourquoi ne prenez-vous aucun traitement (médicament, thérapie, ou autre) ?**	• Choix de ne pas suivre le traitement *(demander pourquoi)* • Arrêt du traitement car amélioration de l'état de santé • Rien n'a été proposé • Coût du traitement • Ne fait pas confiance aux traitements proposés ? • Arrêt du traitement dû aux effets secondaires ou problèmes à suivre le traitement ? • Pas de consultation ? → Obstacles à la consultation : – Manque d'info pour savoir qui consulter ? – Peur de ne pas être pris au sérieux – Peur que les professionnels de la santé n'aient pas assez de connaissances du problème – Coût financier – Autres obstacles… • Autre raison(s) …	Identifier besoins du **parcours thérapeutique (accès aux soins, accès au traitement)**
a)	**[SI TRAITEMENT]** **Comment en êtes-vous arrivé(e) à suivre ce/ces traitements** *(à adapter en fonction de la réponse)***?**		Identifier les **réseaux**
b)	**Qui vous a conseillé/ prescrit ces 'traitements'?**		
c)		• Médecin (généraliste ? spécialiste ?) • Autre professionnel de santé • Proches • Autres malades via groupes • Internet	

d)	**Est-ce que c'est un traitement que vous prenez par vous-même ou est-ce que ça doit être administré par quelqu'un ?** **Dans quelle mesure avez-vous su clairement ce que vous deviez faire ?**	• Autre - Avez-vous reçu suffisamment d'informations pour prendre une décision informée au regard du traitement ? - Avez-vous reçu suffisamment d'informations pour savoir quand et comment exactement prendre le traitement ? - Les informations étaient-elles suffisamment compréhensibles ?	Identifier les besoins **d'information**
8	**[SI TRAITEMENT]** **Quelles difficultés rencontrez-vous par rapport aux différents traitements (médicament, thérapie, etc.) ?**	En termes de : • Efficacité ? (c'est-à-dire, la capacité du traitement à combattre la maladie, à réduire les symptômes et à vous aider à aller mieux) • Effets secondaires ? • Informations concernant les effets secondaires/complications • Lourdeur ? (p.ex. un traitement qu'il faut prendre très souvent, ou pour lequel il faut se rendre à l'hôpital, ou qu'il faut injecter…) • Suivre le traitement tel que conseillé? • Type d'approche (compartimentée par ex ou trop globale…) • Disponibilité du traitement? • Prix de base (le prix que vous payez avant de recevoir un remboursement éventuel)? • Remboursement ? Délai/démarches • Offre de soins disponible ? Disponibilité des professionnels de la santé pour prescrire ou administrer le traitement ? • Autre(s) difficulté(s) liées au traitement…	Identifier les **besoins thérapeutiques**, **d'information** et **financiers** relatifs aux traitements

9	**A quelles difficultés êtes-vous confronté pour vous soigner ?** ***(si le patient est encore concerné par la maladie, sinon formuler la question au passé)***	Ex : • - Distance/accessibilité du lieu de soins ; • - Aide logistique nécessaire • - Langue ou langage • - Peur • - Manque de temps • - Manque d'information • - Interaction avec d'autres problèmes de santé • - Autres difficultés	Identifier les **besoins d'informations** et les besoins du **parcours thérapeutique** (p.ex. **accès** aux soins, **acceptabilité** des soins)
10	**Comment évaluez-vous le suivi de vos problèmes de santé liés au [trouble psychotique]?**	Quels aspects des soins que vous avez reçus ont bien fonctionné pour vous? Quels aspects du soin pourraient être améliorés ? Organisation des services de santé : • coordination des services (y a-t-il un professionnel responsable pour la coordination?) • Continuité des soins (constance dans les professionnels que vous voyez, échange d'information et collaboration entre les différents professionnels) • S'orienter dans les soins, savoir quel professionnel consulter et à quel moment • Pouvoir obtenir un rendez-vous lorsque nécessaire • Prix de base des soins et du traitement • Remboursement	Identifier les **besoins thérapeutiques, d'organisation des soins,** de **soutien, financiers**
10 bis	**Comment évaluez-vous le suivi de vos problèmes de santé au moment de votre hospitalisation?** ***(Question à ne poser que si la personne a été hospitalisé pour ce trouble - information dans le questionnaire)***		

11	**Quelles pistes de solutions verriez-vous pour améliorer la prise en charge de votre [trouble psychotique]?**	En termes : • de prévention (si pertinent) • de traitement • de suivi et offre de soins • d'information • administratifs • financiers (prix, remboursements…) • de soutien, support social • Interaction avec d'autres problèmes de santé • Autres pistes de solutions	Identifier les solutions aux éventuels **besoins thérapeutiques, de soins,** de **soutien, financiers**
12	**Comment décririez-vous vos relations avec les soignants ?**	En termes de : • Temps consacré par le professionnel • Ecoute • Se sentir à l'aise pour poser des questions • réception d'informations claires et compréhensibles • réception d'informations utiles • Respect • Prise au sérieux • Inclusion dans décisions • Langue ou langage • Sensibilité culturelle • Ponctualité • Transmission des informations • Confiance dans les professionnels • Impression que les professionnels de la santé ont l'expertise requise –	Identifier les besoins de **relation avec les professionnels,** besoins **d'information**
12bis	**[SI DIFFICULTÉS ÉPROUVÉES]** **Comment les difficultés que vous venez d'exposer pourraient être surmontées, selon vous ?**	Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?	Identifier des **solutions** aux besoins de **soins**, **relation avec professionnels**, besoins **thérapeutiques**, et besoins **d'information**
13	**Quelles difficultés éventuelles rencontrez-vous d'un point de vue administratif ou avec les services**	Par exemple : • Reconnaissance comme malade • Obtention de remboursements par la mutuelle	Identifier les **besoins administratifs** liés au

	administratifs (par exemple avec une administration, la mutuelle, une assurance, etc.)?	• Reconnaissance comme maladie professionnelle (si pertinent) • Assurances • Savoir où s'adresser pour quelle démarche • Autre : …	système de santé au sens large
13bis	**[SI DIFFICULTÉS RENCONTRÉES]** **Comment ces difficultés administratives pourraient être surmontées ?**	Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?	Identifier les solutions aux besoins de soutien **administratif**
14	**Dans quelle mesure vous sentez-vous soutenu(e) face à votre état de santé actuel ?**	Quelles sont les mesures positives que vous percevez ? Qu'est-ce qui vous manque éventuellement en termes de soutien ? De la part de qui attendez-vous un soutien que vous n'arrivez pas à obtenir ? Quelles sont les personnes dont vous auriez besoin pour vous sentir soutenu ? • Professionnels de santé • Professionnels de la santé mentale • Assistants sociaux • Groupes de patients • Entourage (famille, amis, voisins, collègues) • Au travail (supérieurs, collègues) • Pour les études (enseignants, direction, étudiants...) • Autre : …	Identifier les **besoins de soutien**
15	**De quels autres problèmes ou besoins non satisfaits voudriez-vous nous faire part ?**	Quels autres éléments sont importants et devrions-nous connaitre ?	Autre besoins non rencontrés
	CLOTURE		
16	**Pour conclure, parmi tous les besoins et les difficultés que vous rencontrez quels sont ceux que vous estimez devoir être prioritairement pris en charge par les scientifiques et les politiques ?**	Si vous étiez décideur politique ou scientifique, quelles actions prendriez-vous en priorité pour améliorer le quotidien des patients atteints de [trouble psychotique] ?	Priorisation des besoins non rencontrés

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé et analysé en combinaison avec les entretiens des différentes personnes que nous aurons rencontrées.

Les données relatives aux personnes qui répondent aux entretiens sont combinées entre elles de sorte à rendre impossible l'indentification d'une personne à partir des données publiées. Votre confidentialité et votre vie privée sont ainsi entièrement protégées.

L'ensemble des résultats sera intégré dans la base de données NEED et les résultats de cette étude seront publiés sur le site Internet [du KCE www.kce.fgov.be et le site www.health-needs.eu] [timeline].

Si remplir ce questionnaire ou réfléchir à votre maladie a suscité un inconfort ou une détresse émotionnelle, nous vous encourageons à rechercher du soutien. Vous pouvez contacter votre médecin généraliste, un psychiatre ou un psychologue. En cas d'urgence, vous pouvez appeler le 112.

NL - Topic guide voor de individuele interviews met een wettelijke vertegenwoordiger

Voorafgaand contact met de deelnemer voor het interview

***Goedemiddag**, spreek ik met ….. (contact van de patiënt = de persoon die de vragenlijst heeft ingevuld)? Ik ben …. (uw naam en voornaam). Ik neem contact met u op in het kader van het **NEED-project** **over** "De evaluatie van de noden van patiënten met een psychotische problematiek", waaraan u onlangs hebt deelgenomen door onze vragenlijst in te vullen. Wij danken u oprecht voor deze bijdrage en uw interesse om deel te nemen aan het interview, en daarom bel ik u vandaag. Het **individueel interview** heeft als doel om dieper in te gaan op de thema's uit de vragenlijst, zodat we de noden van patiënten beter kunnen begrijpen. Het interview duurt ongeveer 1,5 uur en kan online of fysiek plaatsvinden, afhankelijk van uw voorkeur. Alle informatie die tijdens dit interview verzameld wordt, wordt uiteraard vertrouwelijk behandeld. Het interview vindt plaats met u en mij samen, tenzij u denkt dat de persoon die u vertegenwoordigt ook actief zou kunnen deelnemen aan het gesprek en dus kan meekomen. U mag dat nu al aangeven of me dat nog laten weten vóór het interview. Voor we de praktische zaken bespreken, zou ik u graag even willen vragen om te bevestigen dat u de **wettelijke vertegenwoordiger** bent én een **naaste** van de persoon voor wie u spreekt, dat u veel tijd met hem/haar doorbrengt en dat u goed op de hoogte bent van zijn/haar situatie, ervaringen en voorkeuren. Klopt dat? (Let op: als de persoon vraagt of een andere naaste kan deelnemen, vraag dan waarom ze dat voorstelt. In deze studie hebben we enkel ethische goedkeuring om een interview af te nemen met een naaste die ook wettelijk vertegenwoordiger is.) Bent u nog steeds bereid om deel te nemen aan het interview? Welke dag en welk uur passen het best voor u? (Afspraak vastleggen). Verkiest u het interview fysiek te doen (geef de locatie) of online via Teams/Zoom (kiezen)? Het interview kan in het Frans of Nederlands plaatsvinden. In welke taal voelt u zich het meest comfortabel?*

U ontvangt nog een bevestiging via (kies sms/e-mail), met mijn (onze) contactgegevens zodat u mij (ons) kunt bereiken bij onvoorziene omstandigheden. De dag voor het interview stuur ik nog een sms (of e-mail) ter bevestiging van de afspraak.

Heel erg bedankt voor uw deelname aan dit onderzoeksproject. Uw bijdrage is van grote waarde.

Nota voor de persoon die het interview afneemt:

Dit interview is bedoeld om afgenomen te worden met de vertegenwoordiger (proxy) alleen.

Een proxy is een persoon die informatie verstrekt namens de patiënt. In deze studie moet deze persoon een nauwe band hebben met de patiënt (bijvoorbeeld: een familielid, een buur, een vrijwilliger), ÉN veel tijd met hem/haar doorbrengen, ÉN goed op de hoogte zijn van zijn/haar situatie, ervaringen en voorkeuren, ÉN wettelijk vertegenwoordiger zijn.

Professionele zorgverleners — dat wil zeggen personen die betaald worden om zorgdiensten te verlenen (bijvoorbeeld zorgprofessionals) — kunnen niet optreden als proxy. Naasten met een officieel erkend statuut van "mantelzorger" (aidant proche) worden wel als proxy beschouwd.

Indien de proxy vergezeld wordt door de patiënt voor een gezamenlijk interview, raden we aan om de generieke interviewgids voor patiënten te gebruiken.

Structuur van de interviewgids

De **kolom met vragen (links)** bevat de vragen die de interviewer aan de proxy stelt (zoals geformuleerd of aangepast aan de context). De **kolom met follow up (midden)** bevat suggesties om de discussie te verdiepen en genoeg informatie te verzamelen om het onderwerp volledig te behandelen. De **rechterkolom "doelstelling"** geeft het doel van de bijbehorende

vragen aan. Opmerkingen die **niet** voorgelezen moeten worden aan de geïnterviewde persoon staan in cursief in het document.

Voorbereiding van het interview

Het interview moet worden voorbereid door de antwoorden van de persoon op de NEED-vragenlijst zorgvuldig te lezen. Deze informatie is op verschillende momenten tijdens het interview van belang. Zo kan men in de vragenlijst bijvoorbeeld noteren: de gezinssituatie van de persoon, of hij/zij thuis woont of ergens anders, of er sprake is van comorbiditeiten, of de persoon in het ziekenhuis werd opgenomen door zijn/haar psychotische problematiek, en of de ziekte impact heeft gehad op zijn/haar vruchtbaarheid. Ook de antwoorden op **open vragen** zijn interessant en kunnen dienen als inhaakmomenten tijdens het gesprek.

Het doel van dit interview is om de niet-ingevulde noden, die via de vragenlijst werden geïdentificeerd, verder te begrijpen (welke impact precies, welke mogelijke oplossingen…).

Aanpassen van de vraagformuleringen

De formulering van de vragen is ontworpen om **zo eenvoudig en duidelijk mogelijk** te zijn. Toch past de interviewer zich aan aan de gesprekspartner, en mogen de vragen in een **andere volgorde** behandeld worden, afhankelijk van de thema's die spontaan aan bod komen.

Het interview moet zo veel mogelijk een gestuurd gesprek zijn in **een natuurlijke en spontane toon, met een professionele, empathische en niet-oordelende houding**.

Perspectief van de patiënt versus dat van de proxy

In de meeste vragen wordt **verwezen naar het perspectief van de patiënt**; de proxy rapporteert dan wat hij/zij heeft gezien/gehoord/begrepen over het standpunt van de patiënt. Als dat niet mogelijk is, wordt het **standpunt van de proxy** gevraagd; dan deelt de proxy zijn/haar eigen mening of ervaring.

Het is belangrijk om de proxy **duidelijk te begeleiden** in welk perspectief gevraagd wordt, wat ook telkens in de vraag zelf aangegeven wordt.

Gebruikte terminologie

Bij de gebruikte termen willen we enkele aandachtspunten benadrukken: We gebruiken het woord **"proxy"** om de persoon aan te duiden die deelneemt aan het interview. Voor de patiënt gebruiken we de term **"naaste"**, omdat we noch te familiair wilden zijn (alleen voornaam), noch te afstandelijk (voor- én achternaam).

Als de proxy zelf herhaaldelijk een andere term gebruikt, zoals "mijn mama", en dat past goed bij de context, **gebruik dan dat woord** in plaats van "naaste".

Indien de proxy optreedt als "mantelzorger" hebben we ook enkele specifieke vragen over de ervaring van de proxy voorzien aan het einde van het interview. Deze sectie mag **alleen gesteld worden als de proxy zichzelf herkent in de rol van mantelzorger**. Om dat te bepalen, werd hierover al een gerichte vraag gesteld in de vragenlijst en deze zal aan het begin van het interview opnieuw gesteld worden.

Begin van het interview met de geïnterviewde persoon (= Proxy)

Hartelijk dank voor uw deelname aan dit interview in het kader van het project "Evaluatie van de behoeften van patiënten met een psychotische problematiek". Deze studie wordt uitgevoerd door het NEED team, een groep onderzoekers van het Federaal Kenniscentrum voor de Gezondheidszorg samen met Sciensano.

Mijn naam is .... en ik ben ....

Het doel van dit project is om de ervaringen en noden van mensen met een psychotische problematiek beter te begrijpen. Op basis daarvan kunnen we voorstellen doen om de zorg en begeleiding voor deze mensen te verbeteren.

Hoe zal dit interview verlopen?

Eerst stel ik u enkele vragen over uw rol en uw band met de persoon namens wie u vandaag spreekt.

Daarna stel ik u vragen over de ervaringen en de gezondheidstoestand van die persoon. Daarbij vraag ik u om **zijn of haar standpunt in te nemen**, en te antwoorden zoals hij of zij dat zelf zou doen.

Met andere woorden: **u bent vandaag de spreekbuis van zijn of haar ervaring**. Het gaat dus niet om uw eigen gevoelens of meningen, maar om die van uw naaste.

Als het niet mogelijk is om een bepaald antwoord vanuit het perspectief van uw naaste te geven, mag u uiteraard ook uw eigen mening delen. En als u op een vraag niet kunt antwoorden vanuit zijn of haar standpunt, laat het me dan gerust weten.

Dit interview duurt ongeveer **anderhalf uur**. Laat het me zeker weten als u minder tijd heeft of als u op een bepaald tijdstip moet afronden.

Ik zou dit gesprek graag opnemen, zodat ik me beter kan concentreren op ons gesprek.

De opname helpt me ook om bij de transcriptie **trouw te blijven aan wat u gezegd heeft**, zodat we de analyse zo nauwkeurig mogelijk kunnen uitvoeren.

De opname wordt **verwijderd zodra de transcriptie is afgerond**, en wordt **niet gedeeld buiten het project**.

De inhoud van het interview wordt **geanonimiseerd**: dat betekent dat er **geen informatie zal worden gepubliceerd** die u of de persoon die u vertegenwoordigt, kan identificeren.

Weet ook dat er **geen goede of foute antwoorden** zijn, en dat u volledig vrij bent om al dan niet op bepaalde vragen te antwoorden.

U bent zelf niet degene die door de ziekte getroffen is, dus het is heel normaal als u soms moeilijkheden heeft om te antwoorden. Aarzel dan ook niet om dat gewoon te zeggen.

Ik zal u nu de inhoud van het **formulier voor geïnformeerde toestemming** voorlezen en uitleggen. Daarna nodig ik u uit om het te ondertekenen, en vervolgens zal ik het ook ondertekenen.

	Vragen	Follow-up	Doelstelling
	ICE BREAKER		
1	**Hoe voel je je over het algemeen vandaag?**		Mensen aanmoedigen om te spreken Het interview contextualiseren
2	**Wat motiveerde je om deel te nemen aan het online onderzoek en in te stemmen met het interview van vandaag?**		
3	**Wat is jouw relatie met de persoon namens wie je vandaag spreekt?**	**Specificeer alstublieft:** • **Een familielid:** bijvoorbeeld ouder, kind, echtgenoot/echtgenote, partner, grootouder… • **Een nauwe relatie:** bijvoorbeeld een vriend(in), buur • **Andere:** …	
4	**Kan je ons uitleggen waarom jouw naaste vandaag niet zelf aan het interview kan deelnemen?**		
5	**Zou je mij, om een beter beeld te krijgen van jouw interactie met jouw naaste, enkele voorbeelden kunnen geven van de hulp of ondersteuning die je hem/haar biedt?**	**Voorbeelden van soorten hulp:** Bij uw antwoord kunt u denken aan verschillende vormen van ondersteuning, zoals: • **Persoonlijke verzorging** (zoals helpen met aankleden/uitkleden, toiletbezoek… • **Mobiliteitshulp** (bijvoorbeeld hulp bij verplaatsen of vergezellen buitenshuis) • **Huishoudelijke taken** (zoals maaltijden bereiden, schoonmaken…) • **Praktische ondersteuning** (zoals opvolgen van de gezondheid, meegaan naar medische of andere afspraken…) • **Morele of** psychologische **steun** (bijvoorbeeld tijd doorbrengen met de persoon om hem/haar emotioneel te ondersteunen) • **Hulp bij administratieve zaken** (zoals budgetbeheer, contact met de mutualiteit, sociale diensten…)	

5+	**Rekening houdend met wat we zojuist besproken hebben, beschouw je jezelf als een "mantelzorger" of niet?** Een mantelzorger is iemand die een naaste regelmatig helpt en ondersteunt vanwege diens ziekte, zonder hiervoor betaald te worden. (*Opmerking voor de interviewer: als de persoon zichzelf niet spontaan als mantelzorger benoemt, maar wel regelmatig hulp biedt aan zijn/haar naaste omwille van de ziekte en dit op niet-professionele basis doet, dan moet deze persoon toch beschouwd worden als mantelzorger, en dienen de bijhorende vragen uit deze sectie gesteld te worden. In deze context telt de feitelijke situatie van hulp en ondersteuning — het al dan niet bestaan **van een officieel "wettelijk statuut" als mantelzorger speelt geen rol.***)	**Bijvoorbeeld** een ouder die zijn/haar kind met mobiliteitsproblemen dagelijks helpt bij het verplaatsen, of een familielid of vriend die een naaste regelmatig helpt met aankleden en wassen.	
6	**Zijn er nog andere personen die jouw naaste dagelijks helpen?** **Zo ja, welke soort hulp bieden zij?**		
7	**Als je aan iemand zou moeten uitleggen wat de [psychotische problematiek] van jouw naaste inhoudt, wat zou je dan zeggen?**	**Was je al bekend met een [psychotische problematiek] voordat dit zich voordeed?**	
	We gaan ons nu richten op de beleving van jouw naaste, te beginnen met zijn/haar diagnostisch traject. Houd daarbij in gedachten dat het voor ons vooral belangrijk is om de ervaring van jouw naaste zelf goed te begrijpen.		
8	**Hoe heeft jouw naaste ontdekt dat hij/zij een [psychotische problematiek] had?**	• Wat waren de eerste signalen of symptomen die deden vermoeden dat er iets niet in orde was? • Hoeveel tijd zat er tussen het moment waarop hij/zij of iemand anders merkte dat er iets mis was en het moment waarop een arts werd gecontacteerd om erover te praten? • Wie heeft de beslissing genomen om een arts te contacteren? • Wie heeft de diagnose gesteld? • Wanneer werd de diagnose gesteld?	Vaststellen van de diagnostische noden

		• Heeft hij/zij meerdere zorgverleners gezien voordat de diagnose werd gesteld? • Hoeveel tijd zat er tussen het eerste consult en de diagnose? • Was de manier waarop de diagnose werd meegedeeld gepast (dat wil zeggen respectvol, duidelijk en voldoende gedetailleerd?) • Hoeveel tijd verliep er tussen de diagnose en de start van een behandeling of opvolging (indien van toepassing)?	
8bis	**Hoe heeft jouw naaste de eerste ervaring met de aangeboden zorg voor zijn/haar [psychotische problematiek] beleefd?**	Bijvoorbeeld: • Welke therapie werd voorgesteld? • Welke medicatie werd voorgeschreven? • Hoe was de zorgcontext en de omgeving (bijv. ziekenhuis, instelling, thuiszorg)? • Hoe verliep het contact met de zorgverleners? • In welke mate werd de omgeving (familie, vrienden) betrokken? • Hoe was zijn/haar psychologische en emotionele toestand in deze periode?	**Behoeften** verbonden aan de **eerste ervaring met zorg**
9	**Hoe uit zich de [psychotische problematiek] van jouw naaste in het dagelijks leven?**		Context & **gezondheidsbehoeften** in het **dagelijks leven** van iemand met een psychotische problematiek
	We gaan nu samen bekijken welke plaats de [psychotische problematiek] inneemt in het dagelijkse leven van jouw naaste. We zullen daarbij stilstaan bij allerlei moeilijkheden die hij of zij mogelijk ervaren heeft als gevolg van de gezondheidsproblemen. In eerste instantie proberen we deze ervaringen en uitdagingen goed te begrijpen. Later kunnen we samen nadenken over mogelijke pistes om de situatie te verbeteren. **Belangrijk om te onthouden is dat het ons vooral gaat om het begrijpen van de ervaring van jouw naaste, hoe hij of zij het zelf beleeft.**		
10	**Wat voor soort moeilijkheden ervaart jouw naaste in het dagelijks leven als gevolg van [psychotische problematiek]?** ***(Als je comorbiditeiten hebt genoteerd in de vragenlijst, stel dan de bijbehorende doorvraagvraag over de comorbiditeiten.)***	Op het vlak van : • Fysieke symptomen? • Psychologische symptomen (zoals je stemming, het beheersen van je emoties) • Impact op het gezinsleven? • Impact op het sociale leven? (zoals uitgaan, vrienden zien,…) • Impact op school of studies?	Vaststellen van **therapeutische en sociale behoeften**

		• Impact op het werk? (zoals kwaliteit van het werk, functioneren, verantwoordelijkheden, werktijden, noodzaak om van werk te veranderen, relatie met de werkgever) • Financiële gevolgen? • Impact op het uitvoeren van dagelijkse taken? • Stigmatisering/beoordeling vanwege de [psychotische problematiek]? • Interacties met andere gezondheidsproblemen (inclusief tandproblemen…) • Impact op zijn/haar affectieve relaties **[en** seksuele leven**]**? *(Disclaimer: "seksueel leven" alleen als de persoon er zelf over begint.)* • Impact op zijn/haar wens en mogelijkheden om kinderen te krijgen? • Andere moeilijkheden ? ...	
11	**Hoe wordt jouw naaste momenteel behandeld of hoe is hij/zij in het verleden behandeld voor de [psychotische problematiek]?**	• Medicijnen op voorschrift • Medicijnen zonder voorschrift • Dieet aanpassingen • Ondersteunend materiaal • Kinesitherapie, ergotherapie, logotherapie, … • Niet-conventionele therapie (acupunctuur, osteopathie, homeopathie...) • Psychologische ondersteuning in groep of inidividueel • Spirituele ondersteuning en/of mindfulness • Projecten rond zingeving en re-integratie	**Identificeren van therapeutische behoeften**
12	**[INDIEN GEEN BEHANDELING]. Waarom volgt jouw naaste geen behandeling (medicatie, therapie, of andere)?**	• Keuze om de behandeling niet te volgen (vraag waarom) • Stoppen met de behandeling vanwege verbetering van de gezondheidstoestand	Behoeften binnen het **zorgtraject identificeren** (toegang tot zorg, toegang tot behandeling)

12+ *a)* *b)* *c)* *d)*	**[INDIEN BEHANDELING].** **Hoe is jouw naaste ertoe gekomen om deze behandeling(en) te volgen?** ***(aan te passen afhankelijk van het antwoord)*** **Wie heeft deze 'behandelingen' geadviseerd/voorgeschreven?** **Wie is verantwoordelijk voor het beheer of de toediening van de behandeling?** ***Pas de formulering aan afhankelijk van het antwoord op vraag c).*** **In welke mate wist hij/zij duidelijk wat hij/zij moest doen?** **OF** **In welke mate wist de persoon die de behandelingen toedient duidelijk wat hij/zij moest doen?**	• Er werd niets voorgesteld/aangeboden • Kosten van de behandeling • Weinig of geen vertrouwen in de voorgestelde behandelingen? • Behandeling gestopt vanwege bijwerkingen of moeilijkheden om de behandeling te blijven volgen? • Geen consultatie? • → Obstakels voor de consultatie: • Gebrek aan informatie over wie te raadplegen? • Angst om niet serieus genomen te worden? • Angst dat gezondheidswerkers niet genoeg weten over het probleem? • Financiële kosten • Andere redenen ... • Arts (huisarts ? specialist ?) • Andere gezondheidsprofessional • Familielid, vriend of collega • Andere patiënten via patiëntengroepen • Internet • Andere • De persoon die zelf aan de aandoening lijdt	**Identificeren van therapeutische noden en netwerken** Identificeren van de **informatie behoeften**

		• Een naaste • Een zorgverlener • Andere: … • Heeft hij/zij voldoende informatie gekregen om een weloverwogen keuze te maken voor behandeling? • Heeft hij/zij voldoende informatie gekregen om te weten wanneer en hoe precies je de behandeling kon volgen of nemen? • Was de informatie die je kreeg voldoende te begrijpen?	
13	**[INDIEN BEHANDELING]** **Welke moeilijkheden ervaart jouw naaste bij de verschillende behandeling(en) (medicatie, therapie, of andere.)?**	In termen van: • Doeltreffendheid? (dat wil zeggen, het vermogen van de behandeling om de ziekte te bestrijden, de symptomen te verminderen en u te helpen beter te worden) • Bijwerkingen? • Informatie rond de bijwerkingen en/of complicaties • Behandellast? (bijvoorbeeld een behandeling die heel vaak moet worden ingenomen, waarvoor u naar het ziekenhuis moet, of die geïnjecteerd moet worden…) • Het volgen van de behandeling zoals werd geadviseerd • Type aanpak (bijv. te gefragmenteerd of te globaal)? • Beschikbaarheid van behandeling? • Basisprijs (prijs die je betaalt vooraleer je een terugbetaling krijgt)? • Terugbetaling? (Tijdspanne/afhandeling) • Beschikbaarheid van de zorg, beschikbaarheid van de gezondheidszorgverleners om behandeling voor te schrijven?	De medische behoeften, informatiebehoeften en financiële impact van de behandeling identificeren

		• Andere moeilijkheden in verband met de behandeling...	
14	**Met welke mogelijke moeilijkheden krijgt jouw naaste te maken bij het zorgen voor zijn/haar gezondheid?** ***(Als de patiënt nog steeds bezig is met de verschillende behandelingen, zoals medicatie, enzovoort; anders de vraag in de verleden tijd formuleren)***	Bv. • - Afstand/bereikbaarheid van de plaats van zorg; • - Noodzakelijke logistieke hulp • - Taalbarrière • - Angst • - Tijdstekort • - Tekort aan informatie • - Interactie met andere gezondheidsproblemen • - Andere moeilijkheden	Het identificeren van **medische, informatie- en financiële behoeften** met betrekking tot het zorgtraject **(bijv. toegang** tot behandelingen, **acceptatie** van zorg).
15	**Hoe denk je dat jouw naaste het verloop en de opvolging van zijn/haar gezondheidsproblemen in verband met de [psychotische problematiek] evalueert?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*	*Welke aspecten van de zorg die jij of jouw naaste heeft ontvangen, verliepen goed? En welke aspecten zouden verbeterd kunnen worden?* ***Organisatie van de gezondheidszorg:*** • *Hoe verliep de **coördinatie van de zorg**? Was er één zorgverlener die het overzicht hield en de opvolging coördineerde?* • *Hoe was de **continuïteit van de zorg**? Werd jouw naaste steeds door dezelfde professionals opgevolgd? Was er voldoende **informatie-uitwisseling en samenwerking** tussen de betrokken zorgverleners?* • *Was het duidelijk **bij wie men terechtkon**, en op welk moment?* • *Was het mogelijk om **tijdig een afspraak te krijgen** wanneer dat nodig was?* • *Hoe ervaarde je de **kostprijs van de zorg en behandelingen**?* • *Waren de **terugbetalingen** voldoende en correct geregeld?*	De noden identificeren binnen het **therapeutisch traject, de organisatie van de zorg, de ondersteuning en de financiële aspecten.**

16	**Hoe denk je dat jouw naaste de opvolging van zijn/haar gezondheidsproblemen evalueert op het moment van zijn/haar hospitalisatie?** *(Deze vraag wordt alleen gesteld als de persoon voor deze aandoening/dit gezondheidsprobleem in het ziekenhuis is opgenomen – zie informatie vragenlijst.)* *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*		
17	**Welke mogelijke oplossingen denk je dat jouw naaste zou zien om de zorg voor zijn/haar medische problemen te verbeteren?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste.)*	Op het gebied van: • Preventie (indien relevant) • Behandeling • Follow-up en zorgverlening • Informatie • Administratie • Financiën (prijs, terugbetaling) • Ondersteuning, sociaal netwerk • Interactie met andere gezondheidsproblemen • Andere oplossingen…	Het identificeren van **oplossingen** voor **eventuele therapeutische, zorg- en ondersteuningsbehoeften,** evenals **financiële behoeften.**
18	**Hoe denk je dat jouw naaste de relaties met de zorgverleners die hij/zij ziet voor zijn/haar [psychotische problematiek] zou omschrijven?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*	In termen van: • Tijd die de gezondheidszorgverlener besteedt • Luisteren • Zich comfortabel voelen om vragen te stellen • Het krijgen van nuttige en begrijpelijke informatie • Respect • Serieus genomen worden • Betrokken worden bij beslissingen • Taal • Rekening houden met culturele aspecten • Punctualiteit bij afspraken • Overdragen van informatie • Vertrouwen in zijn/haar zorgverlener • Het gevoel hebben dat de zorgverlener de benodigde expertise hebben	Het identificeren van behoeften met betrekking tot de **relatie met professionals, informatiebehoeften, ondersteuningsbehoeften en financiële behoeften.**

19	**[INDIEN MOEILIJKHEDEN]** **Als je je in de plaats van jouw naaste probeert te verplaatsen, hoe zou je de moeilijkheden die je zojuist hebt beschreven kunnen aanpakken?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*	*Wat zou er kunnen worden ingevoerd of georganiseerd om de situatie te verbeteren?*	Het identificeren van **oplossingen** voor **zorgbehoeften, de relatie met professionals, therapeutische en sociale behoeften, en informatiebehoeften.**
20	**Welke moeilijkheden ondervindt jouw naaste op administratief vlak? (bijvoorbeeld met administratie, de mutualiteit/ziekenfonds, verzekering…)?**	Bijvoorbeeld: • Erkenning als ziek • Terugbetaling krijgen van het ziekenfonds • Erkenning als beroepsziekte • Verzekeringen • Weten waar men terecht kan voor welke procedure • Andere …	Identificeren van **administratieve behoeften** met betrekking tot het gezondheidszorgsysteem in bredere zin
20bis	**[INDIEN MOEILIJKHEDEN WERDEN ONDERVONDEN]** **Als je je in de plaats van jouw naaste probeert te verplaatsen, hoe zou je de administratieve moeilijkheden die je hebt beschreven kunnen aanpakken?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*	*Wat kan er gedaan worden om de situatie te verbeteren?*	Identificeren van **oplossingen** voor **administratieve behoeften**
21	**Als je je in de plaats van jouw naaste probeert te verplaatsen, in welke mate voelt hij/zij zich gesteund in zijn/haar huidige gezondheidstoestand?** *(Indien het niet mogelijk is om het standpunt van de patiënt te geven, vragen we naar de mening van de naaste/vervangende gesprekspartner.)*	*Welke positieve maatregelen ziet hij/zij?* *Wat mist hij/zij eventueel nog aan ondersteuning?* Wie zou de ondersteuning kunnen geven die hij/zij momenteel mist? *Wie zou hij/zij nodig hebben om zich ondersteund te voelen?* • Gezondheidszorgverleners • Zorgverleners in de geestelijke gezondheidszorg • Maatschappelijk werkers • Patiëntengroepen • Familie, vrienden, buren, of collega's	**Ondersteuningsbehoeften** identificeren

		• Steun vanop het werk (collega's, leidinggevende) • Voor studie (docenten, schoolleiding, medestudenten…) • Andere...	
22	**Zijn er nog andere problemen of onvervulde noden waar hij/zij met jou over gesproken heeft, of die je belangrijk vindt als je je in zijn/haar plaats verplaatst?**	*Welke andere aspecten zijn belangrijk en zouden we ons bewust van moeten zijn?*	**Andere niet-erkende behoeften**
	OPGELET: stel deze vragen enkel als de geïnterviewde zichzelf ziet (of door jou wordt beschouwd) als mantelzorger. We gaan nu over naar het deel dat over *jou* gaat. In dit gedeelte zijn we benieuwd naar jouw eigen ervaringen en beleving als **mantelzorger of naaste die ondersteuning biedt**.		
23	**Je vertelde me aan het begin van het gesprek dat je … (hulp/ondersteuning zoals beschreven in vraag 5) verleent. Hoeveel tijd neemt dat ongeveer in beslag in jouw dagelijks leven?**		De frequentie van de hulp beschrijven en het verband leggen tussen vraag 5 en vraag 21 bis.
23bis	**Welke mogelijke gevolgen heeft de [psychotische problematiek] van jouw naaste op jouw eigen dagelijks leven?**	Op het gebied van: • Psychologische impact (bijvoorbeeld stress, mentale belasting, of anders) • Fysieke impact (zoals verstoorde slaap, pijn, vermoeidheid…) • Gezinsgevolgen (bijvoorbeeld in de gezinssituatie: spanningen, conflicten, overbelasting…) • Sociale gevolgen (invloed op uw sociale leven, relaties met familie en vrienden) • Gevolgen voor school of studie • Professionele gevolgen (kwaliteit van het werk, functioneren, verantwoordelijkheden, werktijden, noodzaak om van job te veranderen) • Financiële gevolgen • Dagelijks functioneren	De impact op de mantelzorger identificeren en de bredere sociale behoeften.

		• (In het affectieve en seksuele leven?) (alleen als de persoon dit zelf ter sprake brengt) • Invloed op je wens/mogelijkheid om kinderen te krijgen • Andere soorten moeilijkheden? •	
24	**Wat vind je momenteel het moeilijkst in jouw rol als mantelzorger?**	Op het gebied van: • Relatie met zorgprofessionals: bijvoorbeeld het ontvangen van begrijpelijke en volledige informatie van de zorgverleners • Relatie met verzorgers: bijvoorbeeld het erkennen van de niet-medische vaardigheden van de mantelzorger binnen de zorg • Vermogen om bepaalde taken aan professionals over te dragen • Vermogen om een goede balans te vinden tussen de rol van mantelzorger en andere rollen	De informatiebehoeften in kaart brengen en de rol van de mantelzorger erkennen.
25	Van welke vormen van ondersteuning maak je gebruik?	Emotionele ondersteuning (bijvoorbeeld steun bij het nemen van gezondheidsbeslissingen, lotgenotengroepen, …) • Inzet van professionals (bijvoorbeeld thuisverpleegkundige) • Verdeling van taken met andere naasten • Hulp om tijd voor jezelf te maken (respijtzorg, ontmoetingsplekken) • Financiële en administratieve hulp ***Van wie verwacht je steun die je momenteel niet krijgt?*** ***Welke personen zou je nodig hebben om je beter ondersteund te voelen?*** • Zorgprofessionals • Geestelijke gezondheidszorgprofessionals • Mantelzorgverenigingen	De ervaren ondersteuningsbehoeften identificeren.

		• Maatschappelijk werkers • Patiëntengroepen • Lotgenotengroepen • Omgeving (familie, vrienden, buren) • Collega's of leidinggevenden op werk/school • Anders: …	
25bis	**Welke vormen van ondersteuning mis je eventueel nog?**		De niet-erkende of onvervulde ondersteuningsbehoeften identificeren.
	SLOT (Vragen die aan alle geïnterviewden gesteld worden, ongeacht of de persoon zichzelf als "mantelzorger" ziet of niet)		
26	**Om te besluiten, van alle behoeften en moeilijkheden die jouw naaste ervaart, welke moeten volgens jou hem/haar prioritair worden aangepakt door wetenschappers en beleidsmakers?** (Als de patiënt nog steeds te maken heeft met een [psychotische problematiek], anders de vraag in de verleden tijd formuleren)	*Eerst het standpunt van de patiënt peilen.* *Standpunt van de proxy:* *Als jij beleidsmaker (of wetenschapper) zou zijn, welke acties zou jij dan prioriteit geven om het dagelijks leven van **patiënten** met een [psychotische problematiek] te verbeteren?*	**Prioritering van onvervulde behoeften**
27	**Van alle behoeften en moeilijkheden die je als naaste ervaart, welke vind je dat wetenschappers en beleidsmakers met prioriteit moeten aanpakken?**	*Als jij beleidsmaker of wetenschapper zou zijn, welke acties zou je dan prioriteit geven om het dagelijks leven van **naasten** te verbeteren?*	**Prioritering van onvervulde behoeften**

Heel erg bedankt voor jouw deelname. Zoals eerder gezegd, wordt dit interview uitgeschreven, geanonimiseerd en geanalyseerd samen met de interviews die we met andere personen hadden.

De resultaten zullen opgenomen worden in de NEED database en een rapport van deze studie zal gepubliceerd worden op de websites van het KCE en NEED (https://kce.fgov.be/) (www.health-needs.eu) [wanneer].

De bevindingen uit de interviews worden op zo'n manier gecombineerd dat het niet mogelijk is om een individu te identificeren aan de hand van de gepubliceerde gegevens. De confidentialiteit van je gegevens en je privacy worden zo beschermd.

Als het invullen van deze vragenlijst of het nadenken over de situatie van uw naaste ongemak of emotionele stress heeft veroorzaakt, moedigen we u aan om ondersteuning te zoeken. U kunt contact opnemen met uw huisarts, een psychiater of psycholoog, of met de vzw Aidants Proches.

In geval van nood kunt u naar het nummer 112 bellen. Als u anoniem en vertrouwelijk met iemand wilt praten, kunt u bellen naar Tele-Onthaal op het nummer 107.

FR - Guide pour les entretiens individuels avec un PROXY

Prise de contact avant l'entretien :

Bonjour, est-ce que je m'adresse bien à .....(contact du proche qui a rempli le questionnaire). Je suis .... (votre nom et prénom). Je vous contacte dans le cadre du projet **NEED sur** « L'Evaluation des besoins de patients avec troubles psychotiques» , auquel vous avez participé récemment en répondant à notre questionnaire. Nous vous remercions sincèrement pour cette contribution et votre intérêt à participer à l'entretien, c'est pour ça que je vous appelle aujourd'hui.

L'**entretien individuel** a pour but d'approfondir les thèmes du questionnaire pour que nous puissions mieux comprendre les besoins des patients. L'entretien dure plus ou moins 1H30 et se déroule en ligne ou en présentiel, comme vous préférez. Sachez que les informations recueillies lors de cet entretien seront traitées de manière confidentielle. L'entretien se déroule avec vous en duo avec moi sauf si vous pensez que la personne que vous représentez pourrait aussi participer activement à l'entretien et donc vous accompagner. Vous pouvez soit me le dire maintenant soit me le confirmer avant l'entretien.

Avant d'aborder les aspects pratiques, pourriez-vous juste me confirmer que vous êtes bien un représentant légal ET une personne proche de la personne pour lequel vous vous exprimez, que vous passez beaucoup de temps avec lui/elle, que vous connaissez bien son vécu, sa situation et ses préférences. Est-ce bien correct ? *(Disclaimer: si la personne vous demande si un autre proche pourrait participer, demander pour quelle raison elle fait cette proposition. Par contre, dans cette étude nous avons seulement l'accord éthique pour faire un entretien avec un proxy qui est un représentant légal de la personne)*

Etes-vous toujours partant(e) pour participer à l'entretien ? Quel jour et quelle heure vous arrangent le mieux ? *(Fixer le rendez-vous)* Préférez-vous le faire en présentiel *(donnez le lieu)* ou en distanciel via teams/zoom *(choisir)* ? L'entretien peut se dérouler en français ou en néerlandais, quelle est la langue dans laquelle vous êtes le plus à l'aise ?

Sachez qu'une confirmation vous sera envoyée par ... *(choisir sms/e-mail*) avec mon (nos) contact (s) afin que vous puissiez me (nous) joindre en cas d'imprévu. Je vais vous envoyer un sms (ou e-mail) la veille pour confirmer le rendez-vous. Encore un tout grand merci pour votre participation à ce projet de recherche**.** Votre contribution est précieuse.

Note pour la personne conduisant l'entretien :

Cet entretien a été créé pour être mené avec le proxy seul. Un proxy est une personne qui fournit des informations au nom du patient. Dans cette étude, cette personne doit avoir un **lien étroit** avec le patient (par exemple : un membre de la famille, un voisin, un volontaire), **ET** passer un temps significatif avec lui/elle **ET** bien connaître sa situation, ses expériences et ses préférences **ET** être représentant légal. Les aidants professionnels — c'est-à-dire les personnes rémunérées pour fournir des services de soins (par exemple les professionnels de santé) — ne peuvent pas agir en tant que proxy. Les personnes proches ayant un statut légal reconnu "d'aidant proche" sont considérés comme proxy.

Si le proxy est accompagné du patient pour mener un entretien en duo, nous recommandons d'utiliser le guide d'entretien générique patient. Structure du guide d'entretien

La **colonne des questions** comporte les questions que l'interviewer pose au proxy (telles quelles ou adaptées au contexte), la **colonne des relances** comporte des questions (liste non exhaustive) qui permettent d'aider à approfondir et à relancer la discussion pour avoir assez de matière pour couvrir le sujet, la **colonne "objectif"** donne l'objectif des questions associées. Les notes qui ne doivent pas être lues au proxy sont écrites dans le document en italique.

Préparation de l'entretien

Le contenu de l'entretien doit être préparé en lisant les réponses de la personne au questionnaire NEED. Il y a plusieurs endroits dans l'entretien où cela aura de l'importance. On peut par exemple noter dans le questionnaire la situation familiale de la personne, si elle vit à la maison ou ailleurs, si elle a des comorbidités, si elle a été hospitalisée à cause de sa maladie, et si la maladie a eu un impact sur sa vie reproductive. On peut également noter leurs réponses aux questions ouvertes qui peuvent être utilisées comme relance. Le but de cet entretien est d'approfondir la compréhension des besoins non rencontrés identifiés au travers du questionnaire (quel impact exactement, quelles pistes de solutions...).

Dans cet entretien, à chaque fois que vous verrez le terme [Trouble psychotique], veuillez choisir le terme le plus adapté, donc soit « Trouble psychotique » soit « le diagnostic que la personne a indiqué dans le questionnaire » (par exemple : schizophrénie).

Adaptation de la formulation des questions

La formulation des questions a été pensée pour être la plus simple et claire possible. Toutefois, l'interviewer s'adaptera à la personne rencontrée, et les questions pourront être abordées dans un ordre différent, suivant les sujets abordés par la personne. L'entretien suivra autant que possible une conversation dirigée, dans un ton naturel et spontané, tout en maintenant une attitude professionnelle et bienveillante, exempte de tout jugement.

Point de vue du patient versus point de vue du proxy.

Dans la plupart des questions nous faisons référence au point de vue du patient en premier, c'est-à-dire que le proxy rapporte ce qu'il a vu/entendu/compris du point de vue du patient. Si cela n'est pas possible il sera demandé le point de vue du proxy, c'est-à-dire que le proxy donne son propre point de vue sur la question. Il est conseillé d'orienter le proxy clairement dans le point de vue désiré, qui sera indiqué dans la question.

Terminologie employée

Concernant les termes utilisés quelques challenges peuvent être soulignés. Nous avons utilisé le terme « **proxy** » pour désigner la personne qui participe à l'entretien. Nous avons utilisé le terme "**proche**" pour le patient car nous ne voulions pas adopter un ton trop familier en utilisant uniquement son prénom ni induire trop de distance en utilisant son nom et prénom. Toutefois, si le proxy utilise un autre terme de manière récurrente pendant l'entretien, comme "ma maman" et que cela vous parait pertinent utilisez-le au lieu du terme "proche".

Section spécifique sur le vécu du proxy « aidant proche »

Nous avons aussi des questions spécifiques sur le vécu du proxy dans le cas où il/elle agirait en tant qu'« aidant proche » à la fin de l'entretien. Cette section n'est à poser que si le proxy se reconnait comme "aidant proche". Pour savoir cela, une question spécifique a déjà été faite dans le questionnaire et sera reposée ici au début de l'entretien.

Début de l'entretien avec la personne interviewée

Je vous remercie d'avoir accepté de participer à cet entretien dans le cadre du projet « Evaluation des besoins de patients avec **[trouble psychotique]**». Cette recherche est menée par un groupe de chercheurs du Centre Fédéral d'Expertise des Soins de Santé et de Sciensano**]**.

Je m'appelle …. et je suis …. (l'interviewer se présente).

L'objectif de ce projet est de comprendre les expériences et les besoins de personnes atteintes de **[Trouble psychotique]**. Cela nous sert notamment afin de proposer des pistes d'amélioration de prise en charge pour ces personnes.

Comment se déroulera cet entretien ? Tout d'abord, je vous poserai quelques questions sur votre rôle et votre lien avec la personne pour lequel vous vous exprimez aujourd'hui. Ensuite, je vous poserai des questions sur les expériences vécues et l'état de santé de la personne, en vous demandant d'adopter son point de vue et de répondre comme il ou elle l'aurait fait. Dit autrement, vous serez aujourd'hui le ou la porte-parole de son expérience. Il ne s'agira donc pas de votre propre ressentit, mais bien du sien. Cependant, si pour certaines questions cette perspective n'est pas possible, vous pourrez rapporter votre avis personnel sur la question. Si vous ne savez pas répondre en adoptant le point de vue de votre proche veuillez s'il vous plait m'en informer.

Cet entretien dure plus ou moins 1h30, dites-moi si vous disposez de moins de temps ou si vous avez un impératif de temps. Je souhaite enregistrer cet entretien pour éviter de devoir prendre beaucoup de notes et mieux pouvoir me concentrer sur notre conversation. Cela me permettra aussi de rester fidèle à vos paroles lorsque j'effectuerai la transcription pour l'analyse. L'enregistrement sera supprimé une fois la transcription réalisée, et ne sera pas partagé en dehors du projet. Le contenu de l'entretien sera anonymisé, c'est à dire qu'aucune information permettant de vous identifier ou la personne que vous représentez, ne sera publiée. Je vais maintenant vous lire et vous expliquer le contenu du formulaire de consentement éclairé. Ensuite, je vous inviterai à le signer, puis je le signerai à mon tour.

	Questions	Relances	Objectif
	ICE BREAKER		
	Cette première partie vous concerne vous-même et non pas la personne que vous représentez. Rapportez donc votre ressenti personnel.		
1	**Comment allez-vous aujourd'hui ?**		Favoriser la parole Contextualiser l'entretien
2	**Quelles ont été vos motivations pour participer à l'enquête en ligne et pour accepter l'entretien d'aujourd'hui ?**		
3	**Quelle est votre relation avec la personne pour lequel vous vous exprimez aujourd'hui ?**	Spécifiez: • Un membre de la famille: par exemple: parent, enfant, époux/épouse, compagne/compagnon, grand-parent... • Une relation proche: par exemple un ami, un voisin • Autre:	
4	**Pourquoi votre proche ne peut pas participer à l'entretien aujourd'hui ?**		
5	**Pour que je puisse mieux comprendre vos interactions avec votre proche, pourriez-vous me donner des exemples d'aides ou de soutien que vous lui apportez ?**	Type d'aide : Ex: • les soins personnels (comme s'habiller/se déshabiller, aller aux toilettes…) • aide à la mobilité (aide pour se déplacer) • les tâches ménagères (comme préparer les repas, nettoyer…) • soutien pratique (comme le suivi de santé, l'accompagner à l'extérieur à des rendez-vous médicaux ou autres…). • soutien moral ou psychologique (passer du temps avec la personne pour la soutenir moralement) • Soutien dans les démarches administratives (gestion du budget,	

		contact avec la mutuelle, services sociaux...)	
5+	**Compte tenu ce que nous venons de discuter, est-ce vous [vous considérez/vous ne vous considérez pas] comme un "aidant proche" ? Un aidant proche est une personne qui vient en aide à un proche en raison de sa maladie, de manière régulière, et sans être payé pour le faire.** ***(Si la personne ne se définit pas comme aidant proche, mais aide régulièrement la personne en raison de sa maladie et à titre non-professionnel, alors vous devrez la considérer comme aidant proche et lui poser les questions relatives à cette section. Ici nous prenons en compte la situation de vie d'aide et de soutien, quel que soit le "statut légal" de la personne – dans certains pays il existe une reconnaissance légale mais cela n'entre pas en compte ici)***	Par exemple, un parent aidant son enfant ayant des problèmes de mobilité à se déplacer quotidiennement, un membre de la famille ou un ami aidant un proche régulièrement à s'habiller et à se laver.	
6	**Y a t-il d'autres personnes venant en aide à votre proche au quotidien ? Si oui quelles aides apportent ces personnes ?**		
7	**Comment expliqueriez-vous ce qu'est la [trouble psychotique] de votre proche à quelqu'un qui ne la connaît pas ?**	• Connaissiez-vous la [trouble psychotique] auparavant ?	
	Nous allons maintenant nous focaliser sur le vécu de votre proche, en commençant par son « parcours diagnostic ». Gardez à l'esprit que ce qui nous importe est de comprendre l'expérience vécue par votre proche.		
8	**Comment votre proche a t-il/a-t-elle découvert qu'il/elle avait le [trouble psychotique]?**	• Quels ont été les premiers signes ou symptômes qui ont fait penser que quelque chose n'allait pas ? • Combien de temps s'est écoulé entre le moment où il/elle ou quelqu'un d'autre a senti que quelque chose n'allait pas et le moment où un médecin a été contacté pour en parler ? • Qui a pris la décision de contacter un médecin ? • Qui a posé le diagnostic ? • Quand a été posé ce diagnostic? • A t-il/elle rencontré plusieurs professionnels de santé avant que le diagnostic ne soit posé ?	Besoins liés au **diagnostic**

		• Combien de temps s'est écoulé entre la première consultation et le diagnostic ? • La manière dont a été annoncé le diagnostic était-elle appropriée, c'est-à-dire respectueuse, claire et suffisamment détaillée ? • Après combien de temps a t-il/a t-elle commencé un traitement ou un suivi (si c'est le cas) ?	
8bis	**Comment votre proche a t-il vécu sa première expérience avec les soins proposés pour ses [troubles psychotiques] ?**	Par exemple : • Thérapie proposée • Médication proposée • Cadre et environnement de soin • Relation avec les professionnels • Implication de l'entourage • Etat psychologique et émotionnel	Besoins liés à la première expérience de soins
9	**Comment se manifeste [trouble psychotique] de votre proche au quotidien ?**		Contexte, **besoins de santé**
	Nous allons maintenant explorer la place de [trouble psychotique] au quotidien et passer en revue toutes sortes de difficultés que votre proche a pu éventuellement rencontrer suite à son état de santé. Nous allons d'abord essayer de les comprendre avant de voir plus tard dans quelle mesure des propositions pourraient être faites pour améliorer la situation. Gardez à l'esprit que ce qui nous importe est de comprendre l'expérience vécue par votre proche.		
10	**Quelles difficultés rencontre votre proche par rapport à son état de santé dû au [trouble psychotique] ?** ***(Si vous avez noté des comorbidités dans le questionnaire, posez la question de relance associée aux comorbidités)***	En termes de : • Symptômes physiques ? • Symptômes psychologiques (Humeur, gestion des émotions) ? • Conséquences familiales ? • Conséquences sociales ? (p.ex. sorties, voir des amis..) • Conséquences sur sa scolarité ou ses études ? • Conséquences professionnelles ? (qualité du travail, fonctionnement, responsabilités, temps de travail, besoin de changer de travail, relation avec l'employeur) • Conséquences financières ? • Fonctionnement au quotidien ?	Identifier l'impact sur le patient, les **besoins de santé**, et les **besoins sociaux** au sens large

		• Stigmatisation/jugement à cause de vos [troubles psychotiques] ? • Interactions avec d'autres problèmes de santé (inclus problème dentaire...) • (Dans sa vie affective [et sexuelle] (Disclaimer: « et sexuelle » seulement si la personne en parle d'elle-même) • Dans son désir/ possibilité d'avoir des enfants ? • Autre type de difficultés ? …	
11	**Comment votre proche se soigne t-il/t-elle ou s'est il/elle soigné.e dans le passé pour le [trouble psychotique]?**	• Médicaments prescrits • Médicaments non-prescrits • Adaptations du régime alimentaire • Matériel nécessaire • Kinésithérapie, ergothérapie, logopédie… • Pratiques non conventionnelles (acupuncture, ostéopathie, homéopathie…) • Soutien psychologique individuel ou en groupe • Soutien spirituel et/ou pleine conscience • Projets autour du sens de la vie et de la réintégration • Autre …	Identification des **besoins thérapeutiques**
12	**[SI AUCUN TRAITEMENT]** **Pourquoi votre proche ne suit-il/ -elle aucun traitement (médicament, thérapie, ou autre) ?**	• Choix de ne pas suivre le traitement (*demander pourquoi)* • Arrêt du traitement car amélioration de l'état de santé • Rien n'a été proposé • Coût du traitement • Ne fait pas confiance aux traitements proposés ? • Arrêt du traitement dû aux effets secondaires ou problèmes à suivre le traitement ?	Identifier **besoins** du **parcours thérapeutique (accès aux soins, accès au traitement)**

12+ *a)*	**[SI TRAITEMENT]** **Comment votre proche en est-il/elle arrivé(e) à suivre ce/ces traitements *(à adapter en fonction de la réponse)*?**	• **Pas de consultation ?** → Obstacles à la consultation : ○ Manque d'info pour savoir qui consulter ? ○ Peur de ne pas être pris au sérieux ○ Peur que les professionnels de la santé n'aient pas assez de connaissances du problème ○ Coût financier ○ Autres obstacles… ○ Autre raison(s) …	Identifier les **réseaux**
b)	**Qui a conseillé/ prescrit ces 'traitements'?**		
c)	**Qui s'occupe de l'administration du traitement ?**		
d)	***Adapter la formulation en fonction de la réponse à la question c)*** **Dans quelle mesure a-t-il/elle su clairement ce qu'il/elle devait faire ?** **OU Dans quelle mesure la personne qui lui prodigue les traitements a su clairement ce qu'il/elle devait faire ?**	• Médecin (généraliste? spécialiste?) • Autre professionnel de santé • Proches • Autres malades via groupes, association de patients • Internet • Autre • La personne atteinte de la maladie elle-même • Un proche • Un professionnel de la santé • Autre:	Identifier les **besoins d'information**

		• A-t-il/a-t-elle reçu suffisamment d'informations pour prendre une décision informée au regard du traitement ? • A-t-il/a-t-elle reçu suffisamment d'informations pour savoir quand et comment exactement prendre le traitement ? • Les informations étaient-elles suffisamment compréhensibles ?	
13	**[SI TRAITEMENT]** **Quelles difficultés rencontre votre proche par rapport aux différents traitements (médicament, thérapie, etc.) ?**	En termes de : • Efficacité ? (c'est-à-dire, la capacité du traitement à combattre la maladie, réduire les symptômes et à aider la personne à aller mieux) • Effets secondaires ? • Informations concernant les effets secondaires/complications ? • Lourdeur ? (p.ex. un traitement qu'il faut prendre très souvent, ou pour lequel il faut se rendre à l'hôpital, ou qu'il faut injecter…) • Suivre le traitement tel que conseillé? • Type d'approche (compartimentée par ex ou trop globale…) • Disponibilité du traitement? • Prix de base (le prix payé avant de recevoir un remboursement éventuel)? • Remboursement ? Délai / démarches • Offre de soins disponible ? Disponibilité des professionnels de la santé pour prescrire ou administrer le traitement ? • Autre(s) difficulté(s) liées au traitement…	Identifier les **besoins thérapeutiques**, **d'information** et **fin anciers** relatifs aux traitements
14	**A quelles difficultés votre proche est-il confronté pour se soigner ?**	Ex : • Distance/accessibilité des lieux de soins	Identifier les **besoins d'informations** et les **besoins du parcours**

	(si le patient est encore concerné par la maladie, sinon formuler la question au passé)	• Aide logistique nécessaire (mobilité…) • Langue ou langage • Peur • Manque de temps • Manque d'information • Interaction avec d'autres problèmes de santé • Autres difficultés	**thérapeutique** (p.ex. **accès** aux soins, **acceptabilité** des soins)
15	**Comment pensez-vous que votre proche évalue le suivi de ses problèmes de santé lié du [trouble psychotique]?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	Quels aspects des soins que vous avez reçus ont bien fonctionné pour vous? Quels aspects des soins pourraient être améliorés ? Organisation des services de santé : • coordination des services (y a-t-il un professionnel responsable pour la coordination ?) • continuité des soins (constance dans les professionnels qui voient le patient, échange d'information et collaboration entre les différents professionnels) • S'orienter dans les soins, savoir quel professionnel consulter et à quel moment • Pouvoir obtenir un rendez-vous lorsque nécessaire • Prix de base des soins et du traitement • Remboursement	Identifier les **besoins du parcours thérapeutiques, d'organisation des soins,** de **soutien, financiers**
16	**Comment votre proche évalue t-il le suivi de ses problèmes de santé au moment de son hospitalisation?** (***Question à ne poser que si la personne a été hospitalisé pour ce trouble - information dans le questionnaire)*** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***		

17	**Quelles pistes de solutions pensez-vous que votre proche verrait pour améliorer la prise en charge de ses problèmes médicaux ?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	En termes : • de prévention (si pertinent) • de traitement • de suivi et offre de soins • d'information • administratifs • financiers (prix, remboursements…) • de soutien, support social • interactions avec d'autres problèmes de santé) • Autres pistes de solutions	Identifier les solutions aux éventuels **besoins thérapeutiques, d'information, de soins,** de **soutien, financiers**
18	**Comment pensez-vous que votre proche décrirait ses relations avec les soignants qu'il/elle voit pour le [trouble psychotique]?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	En termes de : • Temps consacré par le professionnel • Ecoute • Se sentir à l'aise pour poser des questions • De réception d'informations claires et compréhensibles • De réception d'informations utiles • Respect • Prise au sérieux • Inclusion dans décisions • Langue ou langage • Sensibilité culturelle • Ponctualité • Transmission des informations • Confiance dans les professionnels • Impression que les professionnels de la santé ont l'expertise requise • Autre : …	Identifier les besoins de **relation avec les professionnels,** les **besoins d'information**
19	**[SI DIFFICULTÉS ÉPROUVÉES]** **Si vous vous mettez à la place de votre proche, comment les difficultés que vous venez d'exposer pourraient être surmontées ?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?	Identifier des **solutions** aux éventuels besoins de **soins**, **relation avec professionnels**, besoins **thérapeutiques**, besoins **d'information**

20	**Quelles difficultés rencontre votre proche d'un point de vue administratif (par exemple avec une administration, la mutuelle, une assurance, etc.)?**	Par exemple : • Reconnaissance comme malade • Obtention de remboursements par la mutuelle • Reconnaissance comme maladie professionnelle (si pertinent) • Assurances • Savoir où s'adresser pour quelle démarche • Autre : …	Identifier les **besoins administratifs** liés au système de santé au sens large
20bis	***[SI DIFFICULTÉS RENCONTRÉES]*** **Si vous vous mettez à la place de votre proche, comment ces difficultés administratives pourraient être surmontées ?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?	Identifier les **solutions** aux **besoins de soutien administratif**
21	**Si vous vous mettez à la place de votre proche, dans quelle mesure se sent-il/-elle soutenu(e) face à son état de santé actuel ?** ***(si pas possible de donner l'avis du patient, demander l'avis du proxy)***	Quelles sont les mesures positives qu'il/elle perçoit ? Qu'est-ce qu'il lui manque éventuellement en termes de soutien ? De la part de qui attend-t-il/-t-elle un soutien qu'il/elle n'arrive pas à obtenir ? Quelles sont les personnes dont il/elle aurait besoin pour se sentir soutenu ? • Professionnels de santé • Professionnels de la santé mentale • Assistants sociaux • Groupes de patients • Entourage (famille, amis, voisins) • Au travail (supérieurs, collègues) • Pour ses études (enseignants, direction, étudiants…) • Autre …	Identifier les **besoins de soutien**

22	**Y a-t-il d'autres problèmes ou besoins non satisfaits dont il/elle vous a parlé, ou que vous pensez importants si vous vous mettez à sa place ?**	Quels autres éléments sont importants et devrions-nous connaitre ?	Autres besoins non rencontrés
	Attention ne poser ces questions que si la personne interviewée se définit (ou que vous la définissez) comme aidant proche. **Nous passons maintenant à la partie vous concernant vous. Nous nous intéressons ici à votre vécu et vos expériences personnelles d'aidant proche.**		
23	**Vous m'avez dit en début d'entretien que vous ...(*aide/soutien décrits dans la question 5)*, tout ça vous prend combien de temps au quotidien ?**		Décrire la fréquence de l'aide et de faire le lien entre la question 5 et la 21 bis
23 bis	**Quels sont les éventuels impacts du [trouble psychotique] de votre proche sur votre quotidien à vous ?**	En termes de : • Impact psychologique (p.ex.stress, charge mentale, ou autre) ? • Impact physique (sommeil perturbé, douleur, fatigue…) ? • Conséquences familiales (p.ex. en terme de dynamique familiale : tension, conflit, surcharge…)? • Conséquences sociales (impact sur votre vie sociale, relation avec votre entourage)? • Conséquences sur votre scolarité ou vos études ? • Conséquences professionnelles ? (qualité du travail, fonctionnement, responsabilités, temps de travail, besoin de changer de travail) • Conséquences financières ? • Fonctionnement au quotidien ? • (Dans la vie affective et sexuelle ?) (*Disclaimer: seulement si la personne en parle d'elle-même)* • Dans votre désir/ possibilité d'avoir des enfants ? • Autre type de difficultés ? …	Identifier l'impact sur le proxy et **besoins sociaux** au sens large
24	**Qu'est ce qui est difficile à gérer aujourd'hui dans votre rôle d'aidant?**	En termes de : • Relation avec les professionnels de soin: par exemple réception	

		d'informations compréhensibles et complètes par les professionnels de santé • Relation avec les soignants : par exemple de prise en compte des compétences non-médicales de l'aidant dans le soin • Capacité à déléguer certaines tâches aux professionnels • Capacité à trouver un bon équilibre entre le rôle d'aidant et les autres rôles	Identifier les **besoins d'information et reconnaître le rôle de l'aidant proche**
25	**De quels soutiens bénéficiez-vous ?**	• Soutien émotionnel (soutien à la prise de décisions de santé, , groupe de soutien par les paires,…) • Intervention de professionnels, (p. ex. infirmière t à domicile • Répartition des tâches avec d'autres proches • Aide pour avoir du temps pour soi (services de répit, lieux d'accueil) • Aides financières, administratives De la part de qui attendez-vous un soutien que vous n'arrivez pas à obtenir ? Quelles sont les personnes dont vous auriez besoin pour vous sentir soutenu ? • Professionnels de santé • Professionnels de la santé mentale • Associations pour les aidants proches • Assistants sociaux • Groupes de patients • Groupes de soutien par les pairs • Entourage (famille, amis, voisins) • Collègues ou chefs au travail/à l'école • Autre …	Identifier les besoins de **soutien** "rencontrés"
25bis	**Quels sont les soutiens qui vous manquent éventuellement ?**		Identifier les **besoins de soutien "non rencontrés"**

	CLOTURE ***(questions à poser à toutes les personnes interviewées, que la personne se définisse comme "aidant proche" ou non)***		
26	**Pour conclure, parmi tous les besoins et les difficultés que votre proche rencontre, quels sont ceux que qu'il/elle estimerait devoir être prioritairement pris en charge par les scientifiques et les politiques ?** ***(si le patient est encore concerné par [trouble psychotique], sinon formuler la question au passé)***	*Eliciter d'abord le point de vue du patient.* *Point de vue du proxy :* Si vous étiez décideur politique ou scientifique, quelles actions prendriez-vous en priorité pour améliorer le quotidien des **patients** atteints de [la maladie] ?	**Priorisation** des besoins non rencontrés
27	**Parmi tous les besoins et difficultés que vous rencontrez en tant que proche, quels sont ceux que vous estimez devoir être prioritairement pris en charge par les scientifiques et les politiques ?**	Si vous étiez décideur politique ou scientifique, quelles actions prendriez-vous en priorité pour améliorer le quotidien des **proches** ?	**Priorisation** des besoins non rencontrés

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé, et analysé en combinaison avec les entretiens des différentes personnes que nous aurons rencontrées.

Les données relatives aux personnes qui répondent aux entretiens sont combinées entre elles de sorte à rendre impossible l'identification d'une personne à partir des données publiées. Votre confidentialité et votre vie privée sont ainsi entièrement protégées.

L'ensemble des résultats sera publié dans un rapport sur le site Internet [du KCE www.kce.fgov.be et le site www.health-needs.eu] et intégré dans la base de données NEED [timeline].

Si remplir ce questionnaire ou réfléchir à la maladie de votre proche a suscité un inconfort ou une détresse émotionnelle, nous vous encourageons à rechercher du soutien. Vous pouvez contacter votre médecin généraliste, un psychiatre ou un psychologue, l'ASBL Aidants Proches. En cas d'urgence, vous pouvez appeler le 112. Si vous avez besoin de parler à quelqu'un dans l'anonymat et la confidentialité, vous pouvez appeler le 107.

APPENDIX 5. FINAL CODING TREE FOR QUALITATIVE INTERVIEW ANALYSIS

	Code levels				
General code domain	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
Patient's story					
	Self-definition of the health condition				
	Trigger				
Health	Pre-diagnostic disease course				
		Time of first symptoms			
		Symptoms			
			Disorganisation		
				Delusions	
				Thoughts & behaviour	
				Reduced social behaviour	
			Emotional		
				Emotional dysregulation	
				Lack of motivation	
				Anxiety & depression	
			Sleep-related effects		
				Insomnia	
				Hypersomnia	
			Cognitive effects		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
				Concentration	
				Memory	
				Confusion	
				Difficulty with communication	
			Other somatic symptoms		
		Contact with HCP			
			First contact		
			Follow-up/referrals		
			Experiences with HCP		
	Diagnosis				
		Type of diagnosis			
			Initial clinical assessment		
			Re-assessment		
		Time			
			Time of diagnosis		
			Time between fist consultation and diagnosis		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
			Time between diagnosis and first treatment		
		Communication			
			By who?		
			Experiences with HCP		
			How was the diagnosis communicated?		
			Appropriate way?		
		Other related diagnosis			
	Impact on health status				
		Mobility			
		Sleep-related effects			
			Insomnia		
			Hypersomnia		
		Autonomy			
		Daily life activities			
		Physical wellbeing			
		Sexual wellbeing			
			Libido		
			Reproductivity		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
		Cognitive wellbeing			
			Concentration		
			Memory		
			Confusion		
			Difficulty with communication and speech		
		Emotional wellbeing			
			Anxiety & depression		
			Suicidal thoughts		
			Shame		
			Emotional dysregulation		
			Lack of motivation		
		Disorganisation			
			Delusions		
			Thoughts & behaviour		
			Reduced social behaviour		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
		Other			
Healthcare					
	Treatment				
		Experiences of the treatment			
			Medicinal		
				Oral	
					Satisfaction; Burden; symptom reduction
				Injections	
					Satisfaction; Burden; symptom reduction
				Not specified	
					Satisfaction; Burden; symptom reduction
			Psychotherapy		
				Day therapy	
					Satisfaction; Burden; symptom reduction
				Counselling	

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
					Satisfaction; Burden; symptom reduction
				Peer-to-peer	
					Satisfaction; Burden; symptom reduction
				EDRM	
					Satisfaction; Burden; symptom reduction
				Other	
					Satisfaction; Burden; symptom reduction
			Hospitalisation		
				Satisfaction	
				Burden	
				Symptom reduction	
			Other treatment		
				Physiotherapy	
					Satisfaction; Burden; symptom reduction
				Ergotherapy	

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
					Satisfaction; Burden; symptom reduction
				Self-care strategies and mindfulness	
					Satisfaction; Burden; symptom reduction
				Homeopathy	
					Satisfaction; Burden; symptom reduction
				Brain stimulation	
					Satisfaction; Burden; symptom reduction
				Other	
					Satisfaction; Burden; symptom reduction
		Side-effects			
			General		
				Fatigue	
				Insomnia	
				Lack of energy or motivation	

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
				Sexual dysfunction	
				Excessive salivation	
			Cognition		
			Emotional		
			Metabolic		
				Weight gain	
				Hormonal	
				Cardiovascular	
			Movement disorder		
				Hyperkinesis	
				Rigidity	
			Gastro-intestinal		
				Nausea	
				Constipation	
				Diarrhoea	
	Treatment trajectory				

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
		Organisation & coordination			
			Initiation		
			Follow-up		
			Referral pathway		
		Communication			
			Information		
			Patient involvement		
		Experiences with HCP			
			GP		
			Psychologist		
			Psychiatrist		
			Social worker		
			Mobile intervention team		
			Nurse		
			Other		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
		Modification and (dis)continuation			
	Access to healthcare				
		Treatment availability			
		Pricing and reimbursement			
		Waiting times			
		Staff availability			
		Administration			
		Other			
Socio-economic					
	Impact on work & education				
		Change in time occupation			
		Loss in productivity			
		Discontinuation			
		Voluntary jobs			
		Desire to work/study			

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
	Impact on financial situation				
		Disability allowance			
		Social integration income			
	Impact on social situation				
		Relationships			
			Family & partner		
				Impact	
				Psychoeducation	
			Friends		
				Impact	
				Psychoeducation	
		Social activities			
			Social isolation		
			Engagement in activities		
		Stigma			

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
		Living situation			
			Independent living		
			Co-housing		
			Sheltered housing		
			Nursing home		
			Homeless		
			Therapeutic community center		
Opportunities and proposals					
	Care-related				
		Quality of care			
			HCP availability		
			Care trajectory		
			Disease & treatment information		
			Care coordination		
			Sensibilisation of HCP		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
			Humanity		
		Access to care			
			Availability		
			Affordability		
			Infrastructure		
			Accessibility		
		Treatment			
			Treatment effectiveness		
			Reduction in side-effects		
			Psychotherapy		
			Peer-to-peer support		
	Socio-economic				
		Work & education			
			Integration programs		
			Career coach		

	Code levels				
General code domain	Level 1	Level 2	Level 3	Level 4	Level 5
			Other		
		PW awareness			
			Campaigns		
			Other		
		Other social support			
			Social worker		
			Administrative		
			Other		
Interesting other information					

APPENDIX 6. ORIGINAL TESTIMONIALS

Nr	Quotes
1	*"Ja, als ik als ik psychotische klachten heb, gelijk overlaatst dan ja, dan bepaalt dat wel veel op mijn gezinsleven. Dat kan ik die rol niet meer opnemen, dan kan ik geen taken meer opnemen binnen het huishouden." (N2)*
2	*"De moeilijkheden van een psychose? Ja alles op een rijtje zetten en doen wat dat andere mensen doen bijvoorbeeld gaan werken, naar school gaan, constructief bijdragen, sociale contacten onderhouden, inkopen doen. Voor het huishouden koken, alles wassen. Wat zijn de mogelijkheden? Ja, alles wat dat betreft met het met het leven eigenlijk." (N7)*
3	*"Op het begin was op de tram zitten moeilijk, omdat veel te druk is. Nu lukt dat wel bijvoorbeeld, maar als ik weinig slaap heb en dan op een drukke tram zit, dan gaat dat weer moeilijk." (N5)*
4	*"Ik ben heel erg moe en ik heb mijzelf heel hard afgevraagd van hoe ga ik ooit in het werkveld kunnen staan als ik elke dag zo moe ben en me niet kan concentreren." (N16)*
5	*"Ik slaap dus heel weinig en daarvoor moet ik wel heel goed oppassen… Als je als je heel weinig slaapt dan op een gegeven moment zijn die auditieve hallucinaties zo sterk dat je dan jezelf ook zou aandoen bijvoorbeeld met je hoofd bonken tegen die muur van ik wil dat niet meer horen en dan doe je dat" (N6)*
6	*"Dan heb ik eigenlijk bijna 10 dagen niet geslapen. En dat is een acute trigger geweest voor mijn eerste psychose." (N17)*
7	*"Parfois, j'ai des accès de haine, (...) Quand je vais déjeuner et que j'ouvre la porte et que je tombe sur ma mère. Je lui dis : « Salut maman, comment vas-tu ? » et puis elle me dit quelque chose qui m'énerve et elle finit par me parler d'un type pendant une demi-heure avec une énergie terrible." (F4)*
8	*"Ge schaamt u ook een beetje, want alle ik woon nu toevallig in [stad] hè. En de psychiatrie is hier en dan zie je dat iedereen allemaal vooroordelen heeft." (N18)*
9	*"Ja in het begin na mijn eerste psychose wisten de mensen ook niet hoe dat ze met mij moesten omgaan. Dus ik had met niemand contact en nam niemand contact op met mij. Dan ben ik in een depressie gesukkeld en dan heb ik mij terug laten opnemen. Want dan zat ik mijn zware zelfmoord gedacht." (N18)*
10	*"A un moment donné, c'est le stress qui est tellement fort que le cœur il bat très très fort et le sommeil est très léger et il y a un affaiblissement physique." (F4)*
11	*"Want door de stress krijg ik heel veel van die kwaadaardige stemmen die de stemmen van andere delen overstemmen eigenlijk. En, ja, dan moet ik stoppen met werken" (N14).*
12	*"C'était une amie que je connaissais de longue date, pour laquelle j'avais beaucoup de de de liens et j'avais trop de trop de sentiments pour elle en fait. (…) Donc j'ai eu une, j'ai eu un trouble obsessionnel en fait." (F6)*

13	*"Y a des émotions extrêmement envahissantes qui sont beaucoup plus envahissantes que le sentiment de faim. (…) la sensation de faim est très minime par rapport aux autres sensations qui traversent mon corps, qui sont les sensations de colère immense, qui sont les sensations de de peur immense, ou enfin c'est souvent de la colère, ou ça peut être une sorte de désespoir et de confusion." (F4)*
14	*"Ik weet nog dat er een, dat er een dag is geweest waarin dat ik aan iemand zei van "ik heb vandaag een toertje rond en blok kunnen doen en dat was een overwinning op mezelf". Ik zen uit mijn bed, ik heb mijn pyjama kunnen afdoen, ik heb kunnen douchen, hen kunnen kleren aandoen, kzen naar beneden kunnen gaan, ik heb onbeten en dan zijn ik erin geslaagd om naar buiten te gaan en gewoon een toertje rond de blok te doen. En dat was, dat was een overwinning op mezelf." (N3)*
15	*"Maar ik moet niet overal mee lachen en zo. Het is, het is wat vlakker dan bij iemand anders." (N14)*
16	*"Dus dat maakt het ook heel moeilijk om bijvoorbeeld ergens heel enthousiast over te zijn, ook al weet je dat er iets fantastisch is. Dus of echt goesting te krijgen om een activiteit te ondernemen. Ik heb wel hobby's en ik ga daar met een goed gevoel naartoe, maar toch om om ergens echt enthousiast over te zijn, vind ik heel moeilijk." (N17)*
17	*"Goh, ja, als ik als ik psychotische klachten heb, gelijk overlaatst dan ja, dan bepaalt dat wel veel op mijn gezinsleven. Dat kan ik geen rol niet meer opnemen, dan kan ik geen taken niet meer opnemen binnen het huishouden."(N2)*
18	*"Ik heb er nog altijd veel moeite, zeker na veel psychotische episodes gehad te hebben, heb ik moeite om voor mezelf te zorgen, ja… en ik heb ook ups en downs … maar om te gaan werken of zo is te ver gezocht voor mij." (N7)*
19	*"En dan de vermoeidheid, dat vind ik het ergste. Dat is echt, waar dat ik nu nog altijd ook met sukkel. Met een vast ritme krijgen, met met een beetje alert zijn een beetje, ja, een beetje energie hebben. Zo dat, daar heb ik nog het meeste moeite mee." (N1)*
20	*"C'est possible que je sois tellement confus que j'arrive, que faire ma liste de courses ça pourrait me prendre des heures. Genre je trouverais pas mon BIC, je trouverai pas mon papier, le temps que je cherche le BIC je trouve plus. Puis si je vais d'un coup comme ça au magasin, j'ai tout mon budget, il passe en 2 semaines, je m'en rends pas compte" (F4)*
21	*"Zo simpele dingen gelijk naar een film kijken en dat kunnen we volgen, dan is het heel moeilijk." (N7)*
22	*"J'ai des problèmes pour m'orienter aussi dans l'espace. Voilà pour trouver mon chemin pour certaines villes que je connais, je me trompe encore complètement. Voilà même ma ville natale, je voilà dans les transports à Bruxelles. C'est très difficile de coordonner les transports, prendre tel bus et puis tel tram, savoir les arrêts, les trucs, … je me perds, voilà à chaque déplacement pratiquement je me perds, je suis en retard, je rate mon rendez-vous, …" (F3)*
23	*"Maar ik moest altijd naar [stad] rijden met de auto en ik werd gewaar dat dat eigenlijk toch te belastend werd met al die medicatie, eigenlijk dus. En ook doordat ik soms een keer in de auto dissocieerde, was dan de druppel." (N14)*
24	*"Au niveau de ma vie intime, j'ai plein de de désordre aussi, de dysfonctionnement, un truc que qui … ça ne fonctionne pas bien que ce soit avec une femme ou même tout seul." (F3)*
25	*"Troubles de la libido, oui. Disons que je suis avec une compagne, mais (…) Il y a un problème aussi de de désir sans doute." (F6)*

26	*“Mijn libido is verlaagd, alez tijdens een psychose verhoogt dat heel fel. Dan heb je eigenlijk precies altijd zin in in seksuele betrekkingen, maar nu door de medicatie en door het alez zo terug beter worden stillekes aan, dan is dat juist minder.” (N1)*
27	*“Ik merk daar op het vlak van partnerrelaties en zo, dat we zelfs vergeten dat gemeenschap een behoefte kan zijn. Ik maak zo een onderscheid tussen wat je verlangt en wat je behoeften zijn. Maar dus de vertaling van verlangen naar een behoefte is eigenlijk belangrijk. Enfin, een behoefte, dat is iets waar je aan moet voldoen, terwijl een verlangen iets is wat open blijft en onvervuld kan blijven. Maar een behoefte kan niet onvervuld blijven en het is die vertaling van verlangen naar behoefte dat soms heel moeilijk loopt, vooral dan op relationeel vlak." (N13)*
28	*“Mijn mama was bijvoorbeeld ook psychisch kwetsbaar. Ik zag haar graag, maar ik denk dat dat misschien beter was... Ja, ik weet het niet, dat is een beetje raar gezegd eigenlijk hè. Ik denk wel dat mijn moeder was een goede moeder, maar ja… voor dat doorgeven te doorbreken denk ik dat het beter is dat je misschien geen kinderen hebt.” (N10)*
29	*"Toen ik jong was wou ik heel graag kinderen. Maar nu is ook wel die vraag van OK, stel dat de diagnose juist is van bipolariteit type I. Dat is wel erfelijk, ik ben nu vergeten met welk percentage, maar dat was toch een significant percentage dan. Dan deed mij dat wel twijfelen van, is dat wel een goed idee?” (N17)*
30	*“Disons j'ai été anéanti pendant une dizaine d'années, donc je me suis retrouvé relativement seul durant cette période. Enfin, j'habitais chez mes parents, j'avais quelques amis mais je n'ai pas envisagé d'avoir d'enfants, quoi. Du fait que les symptômes durant 10 ans étaient étaient fort marqués.” (F6)*
31	*“Ja, die kinderenwens is altijd wel gebleven en ja, we zijn er op een bepaalde moment toch voor gegaan. Maar ik moest wel … ik nam nog geen antidepressiva of nog geen bipolaire medicatie, dus ik moest in de zwangerschap mijn abilify afbouwen. Maar ik moest wel direct na de bevalling, mijn [medication name] terugnemen. Ik mocht geen borstvoeding geven, want dat de abilify zou in de moedermelk terecht gekomen zijn en zo aan de baby doorgeven zijn". (N2)*
32	*“Ik weet ook wel dat die medicatie, ik heb in het verleden ook wel eens gestopt met de medicatie of geminderd. En dan kreeg ik na een tijdje toch weer een psychose, dus de medicatie is ook wel effectief.” (N11)*
33	*“Je trouve que c'est pas très efficace. Non mais bon je pense que si je les prenais pas, je serais peut-être encore beaucoup plus mal hein,… on n’en sait rien mais moi je pense que je n'ai pas besoin des médicaments et je pense que je me porterais beaucoup mieux sans traitement. Mais bon ça c'est un avis qui est tout à fait personnel et qui peut être modifié par la maladie elle-même et qui est peut-être pas vrai hein ! Peut-être que c'est une illusion et que j'ai besoin de médicaments !. En tout cas, si j'arrête du jour au lendemain, là c'est sûr que je vais décompenser gravement.” (F3)*
34	*“Mijn eerste opname denk ik, en en en behandelplan in de dagkliniek en dan verdere uitloop naar naar ambulante zorgen is zeker goed geweest. Kwestie alez van behandeling op zich vind ik dat wel oké.” (N1)*
35	*“Op die PAAZ afdeling in (stad) was eigenlijk echt geen zorg. Gewoon aan ja, gewoon heel veel medicatie en lieten u aan hun lot over. Dus dat heb ik niet als goed ervaren.” (N11)*
36	*“Ik denk dat de zorg die ik heb gekregen, en heel de afwikkelingen uiteindelijk nadien. En vooral de opname alleszins, die is vermengd met die psychose hè, dat die… Ik ben eigenlijk gewoon getraumatiseerd alleszins door wat ik heb meegemaakt in de instelling.” (N5)*

37	*"Alors à l'hôpital, c'est quand même enfin, ça manque quand même un peu d'humanité quoi. Donc bon avec mon caractère bah je me Enfin je aux uns et aux autres mais je trouvais quand même que les personnes qui étaient présentes parce que j'en avais vu quand même bah déambulaient pas mal donc il y avait un manque de d'activité. Les enfermer comme ça sur une unité où on tourne en ronde pense qu'il y a moyen de faire mieux je pense je sais qu'il y a moyen de faire mieux." (F5, proxy)*
38	*"Je vois une psychologue (…) toutes les 3 semaines, en plus de ma psychiatre. Et ça aussi c'est ça a fait du bien d'aller à mon rythme et de mettre des mots sur certaines choses, de déconstruire certains trucs, ... " (F1)*
39	*"Dus sessies bij de therapeut zijn… Dat werkt stressverlagend ja. En dat is uiteindelijk de bedoeling he." (N12)*
40	*"J'ai déjà eu de temps en temps, oui, des suivis psychologiques, mais ça n'a jamais fonctionné beaucoup, ça n'a jamais aidé beaucoup et donc j'ai arrêté principalement ou j'ai été voir quelqu'un d'autre mais ça a toujours été des petits suivis d'une dizaine de séances où voilà je n'ai jamais trouvé mon compte là-dedans (…) ils n'ont jamais réussi vraiment à m'aider et là c'est pour ça que (…) c'est moi qui ai [mis fin]… parce que ça ne servait à rien et quand ça sert à rien on va pas, on va pas continuer à payer 60€ chaque semaine pour des trucs qui ne sont pas utiles quoi ." (F3)*
41	*"J'ai vraiment trouvé la psychologue qui me correspond parfaitement parce qu'on aborde tant l'aspect psychologie clinicienne, (…) donc un aspect très terre à terre. Mais c'est aussi quelqu'un de spirituel, donc c'est quelqu'un avec qui je peux aborder ces sujets-là. Et ça, ça me manquait dans le réseau d'avant." (F2)*
42	*"Ik ben bij een lotgenoten contactgroep terechtgekomen die praten organiseert, en dat heeft mij wel uit mijnn isolement gehaald. Omdat ik merk van "oké een psychose is iets heel bijzonder om mee te maken" en zelfs mijn mijn beste vrienden, ge kunt dat niet uitleggen, wat dat dat is. Ge kunt ook niet uitleggen wat dat dat me je doet. Je kunt ook de zwaarte, je kunt er wel even over praten, maar op het einde van de dag heeft iedereen zijn eigen problemen en ik voelde dat ik wel deugd had aan meer ondersteuning, dus dat heeft mij wel geholpen om een stukje op verhaal te komen, om een stukje de woorden te vinden en een stukje de kracht terug te vinden om om daar om daar in te gaan staan." (N3)*
43	*"Ik weeg heel wat meer dan dat ik zo mogen wegen volgens mijn BMI. En ja, dat bepaalt wel ja, dat is onrechtstreeks een gevolg van mijn psychotische problematiek. En dat bepaald wel mijn leven momenteel. Dus ja, ik ben een beetje onzekerder over mijn uiterlijk en zo. Als ge da ook als bepalend kunt omschrijven, dat bepaalt wel mijn leven." (N2)*
44	*"Ma prise de poids, boulimie. J'ai mangé à me faire exploser la panse j'arrivais plus à contrôler je veux, dire bon sang ! j'avais jamais perdu autant le contrôle de mon comportement de toute ma vie ! De toute ma vie, j'avais jamais vécu ça ! Je bouffais et je sentais mon ventre qui était en train de craquer, qui avait plus la place et j'arrivais pas à empêcher de me mettre des trucs dans ma bouche et de les avaler. C'est quoi ce truc ?" (F4)*
45	*"Op een gegeven moment woog ik 87 kg. Waar dat voor mij voor iedere keer gezaag was aan de dokter van ok, waardoor je op den duur ook medicatie ontrouw bent, waar dat dat dan terug opflakkert want ja je zelfbeeld gaat ook naar beneden." (N6)*
46	*"Die zorgt dat je eigenlijk moe bent, dood moe. Motivatie verminderd, bijvoorbeeld ik kan een hele voormiddag in de zetel zitten niets doen." (N6)*
47	*"Mijn denken wordt afgevlakt. Mijn emoties worden afgevlakt." (N12)*

48	*"De moeilijkheid van van heel de zaak is dat dat dat ik dus kwetsbaar blijf voor de rest van mijn leven. En dat ik er nooit meer vanaf ga. Alé dat ik daarmee mee zit he." (N12)*
49	*"ça commence à aller mieux maintenant, mais je… je reste encore quelqu'un à un moment donné, j'oubliais tout. J'oubliais tout, c'était tellement grave. Je veux dire, ça me pourrissait la vie au quotidien. … on me disait quelque chose, Je ne retenais pas et ça allait jusqu'à-je pour la petite anecdote, un ami qui m'annonce que son père qui était fort malade, est mort le mardi et le samedi je lui demande comment va son père. Enfin, ça allait loin, quoi." (F2)*
50	*"Et puis après je suis devenu stupide. J'arrivais plus bien à réfléchir, j'arrivais plus bien à raisonner, j'arrivais plus bien à avoir un jugement, et puis j'arrivais plus bien à interagir, j'arrivais plus à rentrer en opposition avec les gens. Donc je subissais, j'étais handicapé à 50% [en raison de mes troubles psychotiques] et je suis devenu handicapé à 300% [à cause des médicaments]." (F4)*
51	*"Donc sur 5 ans il a été changé très très très souvent. Donc à ça d'un moment ils ont essayé de réduire le neuroleptique et puis à chaque fois il y avait une manifestation du trouble du comportement. Enfin je n'aime pas ces troubles du comportement à un moment donné ben « il était un peu plus lui-même » entre guillemets donc dans l'opposition." (F5, proxy)*
52	*"Dan van allerhande medicatie probeert op een gegeven moment dikke voeten, benen, barstende koppijn. Dat ik zei van kijk dat neem ik niet meer, waardoor dat je op den duur in de weerstand zit tegen de psychiater omdat je het gewoonweg niet meer vertrouwt." (N6)*
53	*Ja, ik heb soms het gevoel dat ik gewoon een beetje uitgepraat ben of zo. Dat ik zo, bijvoorbeeld bij (organisatie) heb ik soms het gevoel van, wij kennen elkaar al zo lang en je bent door heel dat proces mee geweest me mij, iedere week zag je elkaar 2-3 keer, je weet wat er allemaal is gebeurd. En soms voel ik dan een soort van schaamte om of schuld om daar nu nog steeds over te praten. Omdat ik denk van 'jij weet dat al en ik heb dat al gezegd'." (N4)*
54	*"Psychiaters die niet onderling met elkaar afspreken wat welke medicatie helpt wel, welke medicatie helpt niet." (N6)*
55	*"De gezondheidszorg landschap is uhm veel te versnipperd. Ik heb hier een psychiater, daar een huisarts en daar een uhm en die zijn niet, er is geen samenwerking van tussen al die instanties." (N7)*
56	*"Ik heb soms het gevoel dat er zoveel tijd gaat naar administratie. Euhm da ze eigenlijk een beetje de mensen, de echte connectie met de mensen een beetje verliezen. euhm dat er zoveel mensen zijn waardoor dat ze eigenlijk ni echt me iemand aan de slag kunnen gaan, en me iedereen maar een beetje." (N4)*
57	*"Allee de opvolging valt dan precies weg en dan heb je gewoon een psychiater, maar dat is enkel voor de medicatie eigenlijk. Alleen, ge kunt dan wel een keer iets bespreken, maar dat is veel te kort. Dus en als je zelf dan verder hulp wil, dan moet je daar gelijk precies op je eigen houtje uitzoeken heb ik zo de indruk." (N10)*
58	*"Pour savoir les modalités, pour savoir qui contacter, pour savoir où aller, pour savoir comment on fait. Oui tout ça j'ai eu des problèmes." (F3)*
59	*"Enfin moi en tout cas, quand je suis en crise, je ne suis pas toujours en état de demander de l'aide… par exemple le service de santé mentale où je vais du jour au lendemain, j'ai cessé d'y aller. Il n'y a pas une personne qui m'a appelé pour me demander ce qui se passe ou quoi. Je me rends compte que il faut aller chercher les choses. Euh… Je trouve que le suivi à domicile, c'est vraiment extrêmement bien. Mais en dehors des équipes mobiles d'urgence qui comme je vous dis les 2 dernières fois ne m'ont même pas été accessibles…" (F2)*

60	*"Ik heb nu ook geen echte afspraak. Ik moet zelf een afspraak maken als ik een afspraak wil. Maar ja, ik heb de indruk ze geven medicatie en ze laten het zo allemaal op hun beloop zo een beetje, allee mijn hulpverlening, denk ik." (N10)*
61	*"Het hiërarchisch model, daarvan moet men van afstappen. Dat er bijvoorbeeld open dialogue gesprekken moeten kunnen plaatsvinden. Als dat opgestart is thuis, dat dat verder moet kunnen gaan in het ziekenhuis en dat de medewerkers in het ziekenhuis daar ook moeten aan deelnemen en dat dat niet zo is van ja maar ja, dat dat is hier gestart thuis, wij werken daar niet meer aan mee." (N6)*
62	*"Het gezondheidszorg landschap is uhm veel te versnipperd. Ik heb hier een psychiater, daar een huisarts en daar een uhm en die zijn niet, er is geen samenwerking van tussen al die instanties." (N7)*
63	*"Genoeg mensen ter beschikking stellen om de mensen op te vangen en te luisteren en een concreet plan op te stellen van kijk mensen met een psychotische kwetsbaarheid. Daar moet zus en zo op gereageerd worden." (N12)*
64	*"Iemand die echt, ja echt één op één. Niet zomaar in de groeps, als dat u een eerste keer is. Later maakt dat allemaal niet meer uit. Maar uw eerste keer als die nog nooit een symptoom heeft gehad, en die nieuw is, die gaat bij de huisarts en die huisarts ziet goed dat is hier precies een psychose. Dan moet die één op één kunnen begeleid worden, niet zomaar in een groep smijten." (N18)*
65	*"Tu m'aides à organiser mon temps, tu m'aides à organiser, tu m'aides pour tout et je veux un être humain qui est qui qui m'aide et voilà, je veux des êtres humains qui m'aident avec amour, j'ai besoin de rien d'autre et d'ailleurs je pense qu'il n'y a pas beaucoup, je n'ai pas vu." (F4)*
66	*"Ik ben niet genoeg geïnformeerd. Dus op gegeven moment hebben ze dat dus mij verteld van ja, de psychose of je zit in een psychose. Maar wat precies dat dat is? Hebben ze mij niet uitgelegd. Dat ik daar voor de rest van mijn leven vatbaar zou voor zijn, hebben ze mij niet uitgelegd." (N12)*
67	*"Oh aucune information, j'ai pas du tout été informé, d'ailleurs je comprends toujours pas grand-chose à un médicament, j'ai changé plein de fois de médication, je n'ai jamais eu aucune information sur les produits que je prenais !. Alors quand je lis un petit peu la notice, voilà évidemment j'ai attrapé une crise cardiaque, presque, mais voilà, quand j'en ai parlé aux psychiatres, ils commencent à s'énerver, ils disent « ouais mais bon, vous revenez toujours avec les effets secondaires, avec ceci, il faut pas lire les notices des médicaments, C'est pas c'est pas fait pour lire, lire les notices !». Bon je me demande pourquoi on les fait alors voilà !, non non !c'est à ce moment-là j'ai une information vraiment très incomplète et enfin absent je vais dire j'ai pas eu d'information, j'ai aucune information." (F3)*
68	*"Dus als ze medicatie geven aan iemand dan ook zeggen waarom dat ze dat doen. In het begin bedoel ik, als we in het begin opgenomen zijn of zo. Ge weet niet wat u overkomt he, als je wordt opgenomen met psychose de eerste keer." (N8)*
69	*"Ik ben niet geïnformeerd geweest dat de medicatie ervoor zou zorgen da ik zou verzwaren. Wat dat uiteindelijk een nieuw probleem creëerde, want ik heb een verleden met een eetstoornis en da was gewoon. Dar is, tot op de dag van vandaag struggle ik daarmee, dus dat vind ik moeilijk." (N4)*
70	*"Dat ziekteinzicht is pas later gekomen, zoals ik net zei om dat ook, ook al was het al uitgelegd. Ik geloofde dat niet. Ik dacht, nee bij mij is het anders, en ik heb dat wel in de hand. En ik wou eerst voor mij een positief verhaal van maken en ondertussen is dat wel gelukt. Maar toen was dat echt nog niet aan de orde." (N17)*
71	*"Context, het is zo belangrijk van de context daarin mee te betrekken. En dan niet alleen de context van van thuis, mijn netwerk zijn vooral mijn vrienden die dat mee opgevangen heeft. Omdat de thuissituatie niet weten hoe dat men daarmee moet omgaan." (N6)*
72	*"Ze hebben ook op een gegeven moment op het einde van de van het traject hebben die een netwerk bijeenkomst gezorgd met mijn beste vrienden en familie. En dan hebben we eigenlijk daarover gepraat zo over wat het is om een psychose te hebben en hoe we daar best mee kunt omgaan enzo ja." (N11)*

73	*"Dat is zeker wel gecommuniceerd naar mijn partner, daar is het woord psychose uitgesproken naar mijn partner, maar niet naar de rest van de familie, hè. Niet naar mijn ouders, niet naar andere mensen en ook niet wat dat de medicatie dat ik toen kreeg, welke nevenwerkingen dat dat had. Want dat is wel wat fout gelopen ook in de opname in (stad) dan." (N1)*
74	*"Bij de huisarts en in de wachtzaal zie je heel weinig documentatie over over mentale gezondheid. Wat is dat, er kan daar perfect brochures liggen: wat is schizofrenie, wat is borderline? Waarom ligt dat niet? Er ligt vanalles rond rond zalfjes voor een huid, acné, rond de griep maar dat mentaal welzijn? Voor mij is dat onbegrijpelijk dat dat tot op heden vandaag nog niet is." (N6)*
75	*"Het enige dat ik hun wel wat verwijt, is dat ze dat ze de familie zelfs geen folderke ofzo hebben meegegeven van over wat er met mij aan de hand was. Dus dus dat had op zijn minst wel gekunnen, vind ik." (N1)*
76	*"Nu als er bijvoorbeeld in school, weet ik het, als het tijdens biologie of zo ook gegeven wordt naast seksuele voorlichting ook mentale gezondheidsvoorlichting of iets in die stijl, dan zou dat veel logischer geweest zijn om die die link te maken. Ja en dan had ik daar misschien al eerder naar gehandeld of had die kunnen inzien in een aanloop van oei dit gaat mis, ik moet eigenlijk al hulp zoeken voordat dat uitloopt." (N17)*
77	*"Ja dat team besliste, was zo en en ge werd er misschien wel van op de hoogte gesteld, maar weinig weinig inspraak." (N2)*
78	*"En toen heb ik op een gegeven moment zei van kijk ik neem dat niet meer, dan dreigde mijn psychiater en die heeft dat ook wel gedaan, dan ga ik u inspuitingen geven, dan kom ik aan huis om u inspuitingen te geven waardoor dat ik ja, ik voelde me echt tegen die die de muren zitten iedere keer van, ik heb hier geen eindspraak." (N6)*
79	*"Ik wou dus afbouwen samen met die psychiater die die er akkoord mee was om af te bouwen. En dus ik had dan ook eerst een depot om ja, ik weet niet waarom. Dat was de psychiater die dat voorstelde en eigenlijk volgde ik blindelings, moet ik zeggen, ja." (N10)*
80	*"Na een paar goede gesprekken met de psychiater die mij ook al jaren kent, hebben we beslist dat het eigenlijk wel heel snel kan afgebouwd worden, omdat mijn problematiek nu een heel andere achtergrond of omkadering heeft dan de voorgaande. Ook ja, het zijn speciale ja gebeurtenissen, maar dat is voor nu denk ik niet zo belangrijk. Dus dan kan er ook heel snel terug af doen, dus nu zit ik al terug op 10mg en dan is de het idee om, als het goed gaat, na twee weken na 5mg. En als het dan nog goed gaat na twee weken naar niks." (N17)*
81	*"Het is eigenlijk een soort realiteitsverlies, dat eigenlijk niet meer strookt met de werkelijkheid zoals andere mensen die waarnemen. Dus dat je eigenlijk overtuigd bent dat jouw werkelijkheid klopt, terwijl dat de werkelijkheid die anderen waarnemen heel verschillend is eigenlijk." (N10)*
82	*"Ja het is eerder een beetje jouw zintuigen die dingen in de omgeving anders gaan interpreteren, bijvoorbeeld bepaalde boodschappen die er eigenlijk niet zijn en waardoor dat je wel in een soort van andere realiteit leeft. Want jouw waarnemingen kloppen niet, de dingen dat je denkt kloppen niet en je kan uzelf niet meer vertrouwen." (N16)*
83	*"Les premiers signes, c'est difficile à dire, mais en tout cas, ce qui a mené à l'hospitalisation, c'était d'abord une disparition, un comportement totalement déplacé dans l'espace public.". (F5)*
84	*"De diagnose is pas gesteld na mijn tweede psychose omdat ik daartussen een depressie heb gehad, hebben ze eigenlijk gezegd dat dat toch een soort, dat het daarmee te maken had. De echte diagnose van schizoaffectief, daar is zeker twee jaar over gegaan." (N9)*
85	*"De eerste uitbraak was toen ik 18 jaar was in mijn puberteit. Toen zat ik nog op school. En dat was de meest ernstige ervaring dat ik ook heb gehad. En toen heeft het maar een paar dagen geduurd en toen was ik al rap in de psychiatrie beland." (N7)*

86	*"Stel da ik zo wa psychotische dingen, ben beginnen meemaken, was bijvoorbeeld rond november december. Maar het moment dat ik me haar heb gebeld en dat ik zei van "dit loopt echt uit de hand" was augustus, september." (N4)*
87	*"En u problemen die komen voort uit trauma, je hebt dingen meegemaakt in uw kindertijd en uw jeugd en daardoor zijt ge psychotisch geworden." (N11)*
88	*"Dat wordt getriggerd door stress maar over- overweldigende stress." (N12)*
89	*"Het enige waar dat ik rekening denk ik mee wel mee houd sowieso is dat ik genoeg slaap heb en een goed ritme heb. Omdat ja slaapgebrek kan wel een trigger zijn of dat kan dat wel soort van in de hand werken." (N16)*
90	*"In 2013, je vais divorcer et le choc émotionnel du divorce va me plonger dans une crise épouvantable, qui va durer des mois." (F2)*
91	*"La prise en charge d'une personne délirante, elle se fait souvent par exemple par la police ou des choses comme ça et je pense que ça vaudrait la peine que les gens soient plus formés ou je ne sais pas quoi. (…) et je pense que très souvent, quand on arrive aux urgences, et cetera, il y a en fait il n'y a pas le temps. Les gens, les soignants n'ont pas le temps de s'asseoir une demi-heure ou 1h avec vous parce que vous êtes agité pour discuter avec vous ou pour vous, ils n'ont pas le temps, donc on vous. Ou on vous enferme dans un coin." (F2)*
92	*"Ik was daar heel wantrouwig in en ik geloofde daar niet echt in dat dat er iets met mij scheelde en het is door mijn ouders dat ze constant erop hamerden dat ze er waren om met de helpen en niet om niet om niet het omgekeerde, niet om mij kwaad doen. En het was een harde les om te leren dat, dat het zo was. Dus ja, maar ik ik stond daar in het begin heel wantrouwig in, maar dat heeft de tijd doen omkeren." (N7)*
93	*"Quand même quelques années où j'étais de moins en moins bien. Et je dirais pendant 2, 3 ans, ça s'est aggravé. C'est une démarche de mes parents qui ont décidé d'aller me faire voir par une psychiatre (…) pour voir un peu ce qui se passait." (F3)*
94	*"Omdat ik dan antipsychotica medicatie kreeg en ik las daarop de diagnose van schizofrenie enzo. En ik was dan eigenlijk geschrokken, omdat ja, omdat ik al hoorde dat dat dan niet zo positief was. En ik heb dan mijn psychiatrie vraagt of ik dat had." (N10)*
95	*"Ik ben dan op de psychische eenheid terecht gekomen en ik ben daar 6 weken in opname geweest en... Ja, daar was de diagnose snel gesteld. Van ja, jij hebt een psychose." (N12)*
96	*"Dat heb ik echt wel het gevoel van... Het wordt je niet in de schoot geworpen. Als je wil, als je wel beter worden, dan moet je er zelf naar op zoek." (N12)*
97	*"Op het einde van de rit wordt er over heel veel nagedacht, maar in essentie moet het gaan over wie zit er hier voor mij en hoe kunnen we die persoon terug terug op de rails krijgen? En ik heb het gevoel, in de grote instituten dat die te groot zijn geworden, en dat dat meer managers zijn geworden, hè die die vooral managementprocessen aan het besturen zijn. De essentie van wat is goede zorg, dat die soms vergeten wordt." (N3)*
98	*"Omdat de psycholoog die heeft een wachtlijst van meerdere maanden, terwijl ik al ja toch heel lang met dat problemen rondliep voor ikzelf die hulpvraag stelde, of voor ik doorhad dat er een hulpvraag was om te stellen. En dan zet je eindelijk die stap en dan moet je nog maanden wachten." (N17)*
99	*"Er zijn daar zoveel revalidanten, ieder met hun eigen verhaal, iedereen met een eigen programma en eigen team. En je merkt gewoon dat ze gewoon, in mijn ogen, niet voldoende tijd hebben om echt bezig te zijn met de mensen, dat je daar ergens ook maar gewoon doet wat het programma zegt maar, ja." (N4)*
100	*"Vroeger was dat vlakbij, maar nu moet ik 3 kwartier stappen." (N8)*

101	*"Psychotherapie, dat is iets wat dan meer zou mogen, ja toegankelijker, dat mensen u daar makkelijker naartoe brengen, maar dat er meer ruimte voor gemaakt wordt na zo een opname." (N10)*
102	*"Vooral het administratieve. Dat je daar inderdaad, zeker de eerste 3 maand ofzo hulp bij hebt, ook al word je niet opgenomen, ook al dat dat daar dat daar ergens iemand is die dat bepaalde dingen kan overnemen." (N1)*
103	*"Eigenlijk moeten er een buddy zijn die dat 24 op 24 uur paraat staat om, dat die op alles op punt van informatie kan geven." (N7)*
104	*"Een individuele begeleider of een coördinator die een soort zorgtraject maakt voor dingen te doen buiten de instelling." (N17)*
105	*"Dat er iemand kan komen om je huishouden te doen, dat er iemand kan komen om te koken voor jou. Da zo'n dingen heel gemakkelijk voor een korte periode kunnen opgestart worden, omdat ik gewoon daar totaal niet meer toe in staat was om zo'n dingen te doen." (N4)*
106	*"Wat dat ik moeilijk vind, is da niemand echt begrijpt wat je doorgaat. Ook al vertel je dingen, als je nooit een psychose hebt meegemaakt, dan weet je gewoon echt niet, wat het is in mijn ogen." (N4)*
107	*"In het begin van mijn hospitalisatie, waren het vooral mijn ouders die mij kwamen bezoeken. Ik denk dat mijn broers en mijn zus niet goed wisten wat dat ik had en zo dus." (N8)*
108	*"Ensuite au niveau de l'entourage, tout le milieu de la musique dans lequel j'étais, j'ai perdu tout contact avec ces gens-là. Ça a été très difficile à vivre parce que je me suis rendu compte que personne, à part deux personnes, personne n'est venu vers moi. (…) Je suis simplement sortie des radars et je me suis retrouvée très très seule." (F2)*
109	*"Ma mère, à comprendre la schizophrénie. Elle pensait vraiment que j'allais la tuer dans son sommeil, par exemple. Et elle pensait que j'étais possédée parce qu'elle est fort croyante(…) En fait le psychiatre lui a expliqué, et après ça, ça allait mieux et mon père il connaissait pas trop la schizophrénie, il connaît pas trop la santé mentale tout ça, mais après il a compris quoi !" (F1)*
110	*"Mijn mama is veel meer betrokken bij dat gegeven psychose, mijn zus ook, en mijn partner. Dat zijn de 3 die dat dichtst bij mij staan, die dat ook zich inlezen over wat is een psychose, hoe komt dan nu juist?" (N1)*
111	*"Aujourd'hui ça va. Mais je suis chez ma mère quoi, c'est elle qui fait les courses et grâce à cette aide. (...) Mais les années avant de revenir chez ma mère. Donc de mes 25 à 30 ans, là j'étais tout seul, plus ou moins. Je veux dire, j'ai vécu un moment donné, j'avais pas de rideau, j'avais pas de couverture et je m'en rendais même pas compte tellement les sensations physiques sont difficiles à gérer. "(F4)*
112	*"Ik heb bijna elke dag bezoek gehad daar in die 40 dagen, er zijn maar een paar dagen waarin niemand is komen opdagen. Mijn planten zijn water gegeven en zo, dus ik heb steun vanuit mijn vrienden, dus het is wel herschikt alleszins je merkt dat er, dat er minder zijn bijvoorbeeld, maar dat is, dat er heel veel steun is." (N5)*
113	*"Tijdens mijn depressie ben ik met opzet, heb ik eigenlijk niet echt hulp gezocht omdat ik daar schrik van had. Toen ik wou geen hulp en ik ben mijn ouders gaan wonen omdat het niet meer ging en dan heb ik opnieuw een psychose gedaan." (N9)*
114	*"Il y a eu beaucoup de stigmatisation de la part de mon entourage. .(…) Parce que comme j'ai tenu des propos délirants, ça a fait peur aux gens. Pourtant, ce n'étaient pas des propos agressifs ou quoi, mais il y a certaines personnes qui ont eu peur et qui du coup ont complètement coupé les liens." (F2)*
115	*"Mijn nicht die gaat het onderwerp niet uit de weg, maar begrijpt het niet zo goed. En mijn vader gaat het onderwerp uit de weg, omdat dit gewoon niet begrijpt en omdat hij er ook niet mee om kan dat zijn dochter psychisch ziek is. Dat is onbespreekbaar bij ons in in in mijn familie." (N12)*

116	*"Bijvoorbeeld met mijn broer, hij heeft mij meegemaakt op een moment dat ik echt in een psychotische crisis was. En hij heeft daaruit afgeleid dat ik eigenlijk voor niks voor hem kan doen. Of nu, dat mijn manier van in de wereld staan, voor hem eigenlijk op niets slaat. En dat ik kansen mis vanwege mijn manier van denken." (N13)*
117	*"Je sais que ça angoisse ma mère. (…), ils m'ont recherché, ils ont lancé un avis de recherche pendant 2 semaines (…) Alors voilà, ça devait être compliqué pour les parents j'imagine." (F1)*
118	*"Je vois bien que pour eux voir quelqu'un qu'on aime disparaître comme ça dans une sorte de folie, des incohérences et ne pas pouvoir l'aider, c'est tellement insupportable qu'ils préfèrent eux souffrir beaucoup à essayer de m'aider sans y arriver." (F4)*
119	*"Mais c'est surtout que parfois j'ai des bouffées de haine, (…) quand je vais prendre mon déjeuner et donc j'ouvre la porte et je tombe sur ma mère. Je dis 'Bonjour maman et tout', puis elle me parle d'un truc qui m'énerve et elle se retrouve avec un type qui va faire un monologue pendant une demi-heure avec une énergie abominable. Voyez. Et ma pauvre maman, elle a septante ans et franchement, ça me fait vraiment chier!" (F4)*
120	*"Nu heb ik wel het gevoel dat ik maatschappelijk wel geëngageerd ben. Ik heb ook wel een vriendenkring opgebouwd. En soms volg ik wel een keer een cursus, of ik ga op zoek naar een hobby. Dus ik ben daarin wel veel gegroeid." (N4)*
121	*"Une vie sociale depuis 2 ans à peu près et mes nouveaux amis. Enfin il y a certains anciens amis et des nouveaux amis. Mon réseau, je les ai… ils sont totalement au courant de ma maladie parce que je ne peux pas faire autrement et ils sont très soutenants. Oui et c'est mon filet de sécurité maintenant." (F2)*
122	*"Il y a aussi ses 3 enfants mais pour les enfants c'est compliqué. Donc le lien n'est pas rompu mais il le voit pas très souvent.." (F5, proxy)*
123	*"Ik heb de laatste jaren wel een aantal psychoses gehad en dan voel ik wel dat de kinderen ja, die zijn nu 31 en 28 dat die meer naar mijn man zich richtte als iets moeten hebben of iets willen vertellen. Maar ik voel zo dat... ja dat ze mij wel een beetje ...mij ontzien, ik weet het niet, maar dat ik dan minder goed contact heb met de kinderen eigenlijk." (N11)*
124	*"Ik vraag mij af wat dat dat me mijn kinderen gedaan heeft? Dat is een vraag waar dat ik ook geen antwoord op heb. Want die hebben ook een aantal dingen meegemaakt. Ja, die waren toen nog klein. We hebben daar ook al over een beetje over gepraat van "weet je nog toen dat papa een beetje ziek was in zijn hoofd en een beetje gekke dingen deed?" (N3)*
125	*"Awel ik had heel lang, lang gedacht van dat dat een belemmering was op onze relatie, dat het de volgende dag ging uit zijn. Maar maar nu lijkt hij zo altijd te beklemtonen van 'dat is niet erg, dat is goed voor u dat gij opgenomen zijt' en zo dus." (N14)*
126	*"Dat heeft een hele zware impact gehad, hoor wij, dat heeft geen haar gescheeld of wij waren niet meer samen." (N3)*
127	*"Mannen hebben daar gewoon schrik van als ze dat horen. Ik vind dat ook een heel moeilijke hoe dat ik daarmee moet omgaan. Het gewone daten, online, dat gaat gewoon niet. Ze vragen dan 'Wat is uw werk?' en daar begint het al. Dus ge kunt enkel mensen leren kennen op een occasionele manier die daar uiteindelijk willen doorkijken, maar dat is heel moeilijk." (N9)*
128	*"Ik denk dat ik vooral bang ben om te tonen wie dat ik ben en wat mijn levensgeschiedenis is. Bang om mijn kwetsbaarheden te tonen en daarin afgerekend te worden." (N4)*

129	*"Dus sindsdien heb ik geen relatie meer gehad, dus dat is wel even geleden. Niet per se omdat ik dat niet wil, maar ook omdat ik me daar niet altijd klaar voor voel. Eerst moeten mijn klachten onder controle zijn voor dat ik iemand anders in mijn leven toelaat, en zelf in iemand anders zijn leven stap." (N17)*
130	*"Quand j'ai fait la crise et que je lui ai dit que j'ai besoin d'aide, elle s'est mise à pleurer en disant qu'elle tombe tout le temps sur des fous. Et moi en ce moment, je me dis, là, je vais mettre en place un truc pour être stable sans avoir besoin de demander de l'aide à la personne qui partage ma vie, puisque les gens qui sinon les gens qui partagent ma vie, ça devient des infirmiers ou des infirmières donc c'est des gens qui sont en train de se faire arnaquer par le système eux aussi ! Et j'ai pas envie d'arnaquer mes proches !" (F4)*
131	*"Ik heb zo de indruk dat ik enkel nog, nog partners kan vinden in de psychiatrie omdat die mensen, omdat wij een zelfde achtergrond hebben." (N10)*
132	*"Maar dat is gemakkelijker om met iemand een relatie aan te gaan dat dezelfde ziekte heeft. Dan weten ze waar dat het over gaat en die begrijpen dat beter natuurlijk. En bij andere mensen, ik heb niet veel relaties gehad, maar zo van die flirt momenten van een paar dagen of een paar weken of een maand of zo, maar dan was dat altijd dat ik dat verzwegen heb." (N15)*
133	*"Tijdens mijn tweede psychose had ik wel een relatie, maar dat is ook een totaal foute persoon, want ik ben er achteraf achter gekomen dat ze in een borderline persoonlijkheidsstoornis zat. Dus dat was al zeker niet de meest stabiele relatie om mee te beginnen. En het is eigenlijk die relatie dat mij in die tweede psychose geduwd heeft." (N17)*
134	*"Au niveau social ? Ben oui, j'ai très peu de contacts. Y a pas vraiment personne qui m'appelle, je n'appelle personne. Parce que je n'ai quoi ? j'ai vraiment personne sur qui je peux compter, j'ai pas mes parents que j'ai pas de cercle social, j'ai pas d'amis, j'ai pas de copain, j'ai pas de copine, j'ai pas de compagne, de petite amie quoi, j'ai pas créé de famille, …" (F3)*
135	*"Die periode toen ik op de VUB studeerde, toen ik terugkwam van mijn opname, was ik heel gesloten. Ja, ik was onzeker, in shock, getraumatiseerd, al die dingen en ik. Ik ging nog met hun om, maar er was veel minder initiatief langs mijn kant van om gewoon om te praten eigenlijk al. Gewoon omdat ik echt zo onzeker was en zo slecht in mijn vel zat." (N16)*
136	*"Ik was gewoon volledig geïsoleerd. Ja, ik had op dat moment misschien 1 vriend of zo, denk ik. Maar ik weet niet of dat echt door mijn psychoses is. Ik denk dat dat ook gewoon een beetje is door zo in psychiatrie te zitten en zo, da ik sowieso mezelf zo isoleerde en zo wat bang was van de wereld. Maar ja, ik heb wel echt maanden niemand gezien." (N4)*
137	*"Ik ben verhuisd naar [stad], ik kende hier niemand en ik had echt nood om mensen te leren kennen en ik vind dat echt geen evidente. Dat is nog altijd niet evident. En ik dacht, ik ga vrijwilligerswerk doen in een sociaal gegeven dat ik mensen leer kennen. Maar ik heb dat ook zelf gezocht, zelf gedaan." (N9)*
138	*"Het feit dat ik bij een een vrijwilligersorganisatie ben terechtgekomen, heeft ook wel mijn sociaal leven stukje anders vormgegeven. In die zin, dat ik een ander soort relaties ook ben beginnen opzoeken met mensen, waarin dat authenticiteit veel centraler is beginnen komen te staan, dus naar naar netwerk en naar sociaal leven heeft dat ook wel wat gevolgen." (N3)*
139	*"Ik merk dat er nog wel een aantal zusters zijn, ook buiten in ander congregaties die er eigenlijk op stoten van 'ja je hebt een psychose, dus wij gaan alles overnemen. Ge moogt geen verantwoordelijkheid niet meer nemen.' Zo dat betuttelend. Ja dat is ik weet niet hoe moeilijk." (N6)*

140	*"Sommige mensen zijn nieuwsgierig en dingen dat ze wel weten, kloppen niet. Ofwel denken mensen dat wij gevaarlijk zijn, wat dat soms het geval kan zijn, maar het is voornamelijk dat ze dat niet begrijpen wat het effectief is. Maar dat is stigmatisering, hè, dat is een enorme inpact. Want ik ken zo veel patiënten die dat, dat gewoon verzwijgen, die daar zich voor schamen, dat ze in in het ziekenhuis zitten, in de psychiatrie zitten." (N7)*
141	*"Mais quand on a le statut de handicapé, disons que pour moi, c'était embarrassant. C'était stigmatisant parce que les gens ne comprennent pas pourquoi on ne travaille plus, pourquoi on reste au lit? Pourquoi on ne fait rien?" (F6)*
142	*"Ik doe nu vrijwilligerswerk bijvoorbeeld en daar durf ik ook niet zeggen wat dat mijn kwetsbaarheid is. Ik zeg dat liever niet. Vroeger was ik daar heel open over, maar ik ben daar steeds meer terughoudend in geworden omdat ge toch voelt van dat ze u anders bekijken en anders behandelen en dat wil ik niet." (N9)*
143	*"Il y a que les gens qui me connaissent depuis avant la maladie, qui acceptent de prendre le temps de se dire 'le pauvre, mais qu'est ce qui lui arrive?' Les autres ils ils me discriminent immédiatement. ça prend 10 min quoi. En gros ça va très vite quoi, je suis très vite discriminé, c'est hyper pénible." (F4)*
144	*"J'ai fait ma première année réussie, ma 2e année en en 2 ans. J'ai demandé une dérogation pour trisser ma 3e année, que la décompensation a eu lieu. Avec là une hospitalisation dans un hôpital psychiatrique. (…) Bon, j'ai réussi en juin tous mes examens, donc quand j'étais en 3e année. Et puis en 4e année, j'ai fait ma 4e année malgré tout, mais ça ne fonctionnait plus quoi, je n'étais plus à même d'étudier. J'avais des problèmes cognitifs, donc j'avais des problèmes liés à la maladie quoi." (F6)*
145	*"Dat is continu puzzelen geweest van "kijk, nu ben ik ziek, ma ik moet wel aan zoveel studiepunten geraken voor een studietoelage te krijgen, dus ik ga nu enkel theoretische vakken opnemen, in combinatie met therapie." (…) "En dan ja, een bepaald moment mezelf dan ook een beetje geforceerd van "oké om ook maar eindelijk een beetje die opleiding te kunnen afronden, dan is het ook wel belangrijk dat ik nog een keer stage doe, maar dan bijvoorbeeld in minder uren of meer gespreid." (N4)*
146	*"Dat was voor mij erg dat ik niet meer goed kon studeren met al die Haldol en zo. Ik vond dat ik daar eigenlijk in (ziekenhuis) dat dat allemaal te lang duurde enzo. Ja, ik wou gewoon terug gaan studeren, maar ja, kon dat toch niet met al die Haldol." (N8)*
147	*"Awel ik heb nog 5 jaar proberen werken na mijn eerste psychose en dat is altijd mislukt. Ik ben dan ook ontslagen wegens medische redenen. Ik wou dat ook, want ik durfde niet meer terug te gaan werken omdat ik daar ook dingen had gedaan in een nieuwe psychose." (N9)*
148	*"Het enigste van, het enigste wat dat ik door had, is dat ik moest rusten. Dat ik moest thuisblijven en rusten en niet kunnen gaan werken." (N12)*
149	*"Ik was net veranderd van job ook, toen dat ik die tweede psychose doorgemaakt heb. En dan langdurig ziek geweest wat dat ertoe geleid heeft dat mijn werkgever op een bepaald moment zoiets had van "ja, dat gaat hier ook niet lukken", dus op een of andere manier is ne weg gevonden mij op een zijspoor te zetten. Dus ik heb mij ook professioneel moeten heroriënteren." (N3)*
150	*"Et alors entre 2013 où j'ai démissionné de tous mes boulots et 2017, je vais chaque fois retrouver du travail, puis délirer, donc ne pas être reconduite en fin de période d'essai, et cetera. Et je vais faire ping-pong, comme ça, entre délire, retrouver du travail, délire, retrouver du travail." (F2)*
151	*"Ik heb nog eens geprobeerd via een jobcoach een werk te doen. Dat was een werk dat ik ooit al gedaan had en ik vond dat heel leuk. En ik dacht, ik ga dat terug doen want dat is het enige dat ik mij nog zie doen. Maar dan denk ik ook psychotisch geworden op het werk en zo en dan heb ik daarmee gestopt." (N18)*

152	*“Daarenboven ook gewoon, ook het volume hè. Op het moment dat ik begon progressief te werken, was een halftijdse job. Dat was zo uitdagend dat ik echt de rest van de week ook nodig had om bij te rusten, of om wandelingskes te gaan doen of of die energie op een of andere manier weer wat aan te vullen.” (N3)*
153	*“Ik werk trager eigenlijk dan een doorsnee iemand. Veel trager, omdat ik dat nu terug op de evaluatie heb, gekregen heb ook in een maatwerkbedrijf.” (N10)*
154	*“Dat is een beetje een probleem, de brug naar de wereld, bijvoorbeeld de reguliere arbeidsmarkt of zo, dat dat dat veel moeilijker. Maar ik heb eigenlijk altijd heel veel proberen te doen om contact te houden met met wereld van het werk en waar ik hoop dat ik nog iets kan betekenen.” (N13)*
155	*“Door te gaan werken is mijn gevoel veel verbeterd, dus mijn eigenwaarde veel verbeterd.” (N12)*
156	*“Ben du coup je ne sais pas travailler, j'aimerais bien travailler pourtant, mais la mutuelle me refuse de travailler parce qu'elle ne veut pas me donner les autorisations et les formulaires adhoc alors que je pourrais travailler. Je pense que je pourrais quand même travailler à mi-temps.” (F3)*
157	*“ Mais je prends l'exemple aux Pays-Bas, dès qu'une personne tombe dans la la, la psychose ou la schizophrénie, il y a tout de suite une cellule qui la prend en charge de façon à la réintégrer dans dans une occupation soit professionnelle, soit autre.” (F6)*
158	*“Awel ja, met het werk ook was onder mijn, als ge dat moogt zeggen, onder mijn niveau, want ik moest altijd beschutte werkplaatsen doen.” (N15)*
159	*“Ja, ik moet gewoon oppassen dat ik niet teveel stress heb. Dus die twee dagen in de week werken dat gaat. Maar daarvoor werkte ik in het onderwijs en dan werk ik eigenlijk 4/5 of fulltime en dat was te zwaar.” (N11)*
160	*“Alle zieken controleren dat er tenminste aangepast werk moet zijn. En met aangepast werk bedoel ik weinig uren, ja ook toegankelijk werk hé, dat er rekening wordt gehouden met uw kwetsbaarheid en dat is volgens mij onbestaande, tenzij vrijwilligerswerk.” (N9)*
161	*“Er was een een functie vrij voor ervaringswerker en ik mocht zelf eigenlijk zeggen hoeveel uur ik wou werken en toen ben ik daar aangenomen. Dus ik ben eigenlijk de maand nadat op vervroegd pensioen ben gezet ben ik daar ook kunnen beginnen. Dus ik heb eigenlijk ook niet het gevoel gehad dat ik zonder werk heb gezeten.” (N11)*
162	*“Ik zou heel graag opnieuw aan de slag gaan in een rol die me ook ligt. En dat is altijd nog zoeken en dat is misschien nog extra zoeken als je met een gevoeligheid zit en zo. Maar dat er gewoon meer, dat er tijd voor nodig is om om jezelf daarin te vinden en zo, maar ook niet te veel tijd dat je, dat je blijft hangen of zo.” (N13)*
163	*“Dan heb ik besloten van "oké, kga gewoon zelf terug de hulpverlening in” en mijn eerste diploma is, ik ben psycholoog van opleiding, dacht ik van “oké, dan kan ik maar proberen met mijn eigen ervaring en mijn euhm ervaring een stukje kijken dat ik anderen op hun op hun weg of op hun pad of op hun dingen dat ze meemaken kan, kan proberen te ondersteunen.” (N3)*
164	*“Omdat ik een beetje vrijwilligerswerk doe bij een vereniging, zo een denkvergaderingen van een netwerkgroep om toch iets bij te dragen aan de gezondheidszorg.” (N7)*
165	*“Ik ben eigenlijk ervaringsdeskundige en ik zit in de werking van patiënten-vertegenwoordiging. (…) Dus de patiëntenvertegenwoordiging is zo van: hoe kunnen we de eerstelijns psychologische zorg beter doen aansluiten bij onze maatschappij. Want men is nog altijd aan het onderzoeken van ja eerstelijns psychologische zorg moet niet altijd een op een zijn, moest men al beginnen met groep rond wat is angst, psycho-educatie geven ja ja die zaken.” (N6)*

166	*"Er is altijd toch nog je eigen gedeelte dat je moet betalen. Awel ja en ik heb nu dus mijn therapie, omdat ik dus nog verhoogde tegemoetkoming heb via het ziekenfonds heb ik dus mijn therapie aan een mindere prijs. Maar als je de gewone sessies moet betalen, dat is € 75. Dat is serieuze hap uit je budget." (N12)*
167	*"En van psychotherapie wordt er, denk ik 10 sessies 10 euro van terugbetaald of zo van het ziekenfonds. En osteopathie, dat valt dan onder alternatieve behandelingen en daar wordt ook iets van terugbetaald, maar ook echt heel weinig." (N17)*
168	*"De relaxatie betaal ik echt niet veel, da wordt echt grotendeels terugbetaald. Ik denk voor 10 sessies, dat ik misschien € 20 betaal of zo. Mijn psychiaters zijn denk ik € 8 per sessie, wat ook oké is. En mijn psycholoog is € 4 denk ik, dus ja. Das wel oké." (N4)*
169	*"Als ik 8 maanden niet kon gaan werken, dan kreeg ik mijn uitkering van het ziekenfonds en dat is niet evenveel als dat je gaat gaan werken. Plus dat je nog een keer op belast ga worden, dus dat is wel even slikken. En ik ben ook nog een alleenstaande moeder." (N12)*
170	*"Ja, ik verdien niet zoveel eigenlijk hèvan mijn vervangingsinkomen en mijn man heeft zo wat crisisjaren achter terug op het werk, dus dan zijn wij nu wel aan het ploeteren met onze reserves, dus ons onze spaarrekening." (N14)*
171	*"C'est que comme je n'allais pas bien les mois qui précèdent l'arrêt maladie, j'ai travaillé moins d'heures. D'un commun accord avec ma patronne, j'ai diminué mes heures. Mais ça a une conséquence très délétère, c'est que la mutuelle vous donne votre revenu en fonction des 3 derniers mois de salaire moyen. Mais donc comme je ne travaillais plus temps plein parce que j'avais diminué mes heures, je me suis retrouvée avec 800 et quelques euros de mutuelle par mois." (F2)*
172	*"J'ai eu des pertes de revenus énormes évidemment, j'ai eu plein de frais de médicaments, plein de frais de de soins de santé. J'ai eu plein de revenus en moins puisque j'ai une allocation sociale comme je n'ai pas de travail donc je n'ai pas de revenu professionnel. J'ai eu plein de déboires, j'ai été arnaqué plein de fois, c'était dû à mes maladies, à mes fragilités et tout ça oui j'ai eu plein de soucis. pécuniers dûs à tout ça." (F3)*
173	*"J'ai démissionné de tous mes boulots parce que je pensais que l'univers allait pourvoir à mes besoins. Donc je me suis retrouvée dans une situation financière et personnelle catastrophique. Parce que mes délires m'ont poussé à démissionner de tous mes boulots. Et je n'ai pas fait de démarches auprès des institutions pour avoir un revenu de remplacement... Donc je suis restée des mois à errer comme ça." (F2)*
174	*"Ik heb eigenlijk wel nood aan misschien meer zoals lichaamswerk of zelfs een psychotherapeut dat ik zelf zou kunnen kiezen, maar financieel is dat gewoon niet haalbaar." (N9)*
175	*"Ik heb de chance gehad dat mijn vorige job goed betaald was, dus ik kreeg de maximale uitkering. Maar eigenlijk voor een goed leven te hebben en uw eigen therapie te voorzien is dat onvoldoende, zeker als je weet dat nu in het laatste jaar dat ik het buiten mijn psychiater twee andere therapeuten heb aangesteld, maar dat kost wel meer dan € 200 per maand om die therapie te volgen. En iemand die gewoon van de uitkering moet leven en geen spaargeld heeft, dan komt ge er niet mee toe." (N17)*
176	*"J'ai candidaté pour l'habitat protégé et le CPAS et j'ai expliqué ma situation, que pour le moment je pouvais pas être totalement indépendante. Et ils ont accepté ma demande." (F1)*
177	*"En de wachtlijsten van de sociale woningen en appartementen enzo. Ik heb 11 jaar moeten wachten op een appartement ongeveer." (N15)*

178	*"En wij zijn een lening gaan vragen bij de bank en dan moet je zo een vragenlijst invullen, wat dat er gepolst wordt naar zowel lichamelijke als psychische antecedenten. Ik heb die in alle eerlijkheid ingevuld waar dat ik heb aan geleden, van oké, ik heb een psychose meegemaakt, dan is der daar een vervolg euhm vragenlijst op gekomen, die ik ook heel eerlijk heb ingevuld. En dan kreeg ik op dat moment een offerte in de bus die 5 keer zo hoog was als wat dat er initieel wordt voorgesteld. Dus dat is ook een hele strijd geweest." (N3)*
179	*"Ja niet goed dus dat sommige sommige verpleegkundigen waren wel goed. Sommigen waren minder goed. Maar ik voelde dat het beleid gewoon was, macht uitoefenen en ja u zo rustig mogelijk te houden door met veel, heel veel medicatie te geven, door u op te sluiten in de isoleercel dan ook zo soms het gevoel gehad dat ze mij uitlachten. Omdat als ze niet als ze u niet goed behandelen, dan gaat je ook gekke dingen doen. Je voelt je niet begrepen. En dan angst, uit onveiligheidsgevoel gaat ge dingen doen en die je normaxal niet zou doen. En dan begonnen ze moesten ze lachen. Dat vond ik eigenlijk ook heel, heel erg." (N11)*
180	*"Die mensen zijn zo hard voor jou daar. En geen empathie gelijk. Ik weet niet die, ik heb ook bepaalde ervaringen, met verpleegkundigen dat zij bepaalde dingen zeiden tegen mij dat ik echt dat dat ik achteraf zeg van maar ale wat er met jullie dat nu gezegd, want voor meerwaarde heeft dan nu." (N12)*
181	*"Dan zeker niet fixeren, hè? Dat dat lijkt mij inderdaad in een psychose de hel hè? Dwang is eigenlijk, dwang is iets dat ze eigenlijk zo weinig mogelijk mogen gebruiken denk ik. Ook dwang om medicatie in te nemen is heel, alez ge hebt wanen, je bent achterdochtig en dan dwingen ze u om iets te nemen of een spuit te krijgen of dingen, dat lijkt mij niet oké. Natuurlijk als je echt heel ver in die wanen bent, kan je zelf niet beslissen oké, ik neem dat pilletje wel in, want dan word ik beter. Dat kan je op dat op het moment niet." (N1)*
182	*"Lotgenoten heeft heel hard geholpen, maar dat daar toch wel zo wat meer info mag zijn van 'kijk, dit is hoe dat je lotgenoten kunt bereiken' uhm omdat gewoon ja zo dat ge een goed gevoel dat je niet alleen bent en dat er toch een community soort van is. Ik denk dat dat voor heel veel mensen wel deugd kan doen, uhm dus dat is toch echt wel iets dat ik. (N16)*
183	*"Ja en toch denk ik dat er wel heel waardevolle initiatieven zijn die meer bekendmaking zouden verdienen. Als je kijkt wat dat de psychose net betekent voor mensen die op zoek zijn, dat dat is een zeer waardevol platform waarin dat mensen delen van "dat heb ik geprobeerd en dat heeft voor mij gewerkt". Dus daar heb ik wel veel veel euhm, veel steun aan gehad." (N3)*
184	*"Terwijl dat ik nood had toen aan inhoudelijk, wat is er gebeurd? Uhm vanwaar komt dat? En dat werd absoluut niet behandeld dus en dat is ook niet langdurig, hè? Terwijl Ik denk met een psychotische kwetsbaarheid hebt ge misschien wel langer nood aan psychologische hulp, dus ik heb dat helemaal niet. Ik kan dat ook niet betalen, dus." (N9)*
185	*"Ja tijdens de opname meer betekenis geven aan uw, allee goh, niet echt betekenis geven aan uw wanen, maar met u daarover in gesprek gaan van 'welke gedachten had je en welke, hoe heb je dat ervaren'? Want daar hebben ze wel niet over gesproken. Het was eerder zo van 'ja, hoe ben je hier terechtgekomen en wat voor soort persoon ben jij?' En Dat is ook allemaal heel positief, maar zo meer ingaan op hoe dat voor mij was, mijn ervaring of ja." (N16)*
186	*"Met de ziekenkas al was dat heel moeilijk in het begin de communicatie. Ze waren helemaal niet open, want er waren fouten gebeurd, want financieel mijn uitkering, dat was veel te weinig. En er was helemaal, ze hebben daar helemaal, allee ik heb echt wel hemel en aarde moeten bewegen eer dat ze openlijk zeiden hoe dat dat berekend werd waarna dat rechtgezet is kunnen worden." (N9)*

187	*“Ook op administratief niveau, heb ik ook wel heel wat problemen gehad. Zo papierwerk, ik was de enige thuis die altijd alle papierwerk opvolgde en de facturen betaalde en die ook wist van wat moet er allemaal gebeuren? Ook da, kon ik, ik kon dat niet meer. Dat was ene chaos van papier en ik wist ik niet goed “wat betekent dat hier en, wat moet ik hier mee doen?”.” (N3)*
188	*“Ben ça c'est vraiment compliqué parce que les démarches sont vraiment très compliquées. On ne comprend pas comment ça fonctionne, on comprend pas ce à quoi on peut avoir accès, la personne à qui s'adresser, les horaires d'ouverture, les manières de renvoyer les papiers…, c'est vraiment fait exprès pour ne pas obtenir les trucs ! On dirait que c'est vraiment pour coincer la personne. Et voilà, c'est très difficile de communiquer avec les administrations.” (F3)*
189	*“Doordat je in een kloostergemeenschap zit, ben je al bescherm dat met dat overneemt, omdat er een centraal administratie is waar alles gebeurt voor u. Maar ik merk bij andere patiënten dat dat wel moeilijk is.” (N6)*
190	*“Ik heb een boekhoudkunde opleiding gedaan en ik ben redelijk stipt in de administratie. Dus papieren invullen, dat is zo een beetje mijn ding, dat doe ik, dat volg ik wel goed op eigenlijk.” (N10)*
191	*“Mijn zus, die werkt op de ziekenkas en zij helpt mij daar altijd mee met mijn papieren in te vullen enzo. Ik denk als ik mijn zus niet had dan, want het is toch allemaal niet zo simpel wat je altijd moet invullen.” (N11)*
192	*“Il y a des assistantes sociales ou assistance sociales qui aident pour les certaines démarches administratives, et cetera. Et ça c'est précieux parce que mais encore une fois, il faut aller chercher, demander.” (F2)*
193	*“Par les molécules adaptées aux personnes. Enfin, en fonction du des différents profils, ça je pense qu'il faut vraiment être à l'écoute des patients par rapport à ce qu'ils veulent dire et aussi par le. Moi j'ai eu l'impression au début qu'on m'a imposé quelque chose. Mais ça fait peut être partie de la schizophrénie aussi hein.” (F1)*
194	*“a pas eu de trajet de soins en tout cas voilà y a pas eu de trajet de soins à proposer par rapport aux troubles psychotiques. C'est vraiment uniquement focalisé sur le traitement et le schéma médicamenteux. Parce que justement c'était parce que le psychiatre qu'on m'expliquait à l'époque, c'est que voilà, c'était quand même des médicaments qui étaient qui n'étaient pas anodins Et donc il fallait absolument un suivi par une psychiatre qui a été fait. Mais ça s'est vraiment résumé à ça.” (F5)*
195	*“Dus ja, allee, ik merk wel als er iets, ja vrij emotioneel gebeurt bij mij is dat door emotionele stress dat ik het nog altijd soms moeilijk heb *lacht*, dat ik zo de neiging heb om daar toch wel in te glijden en dat ik dat echt moet counteren.” (N9)*
196	*“Dat psychotherapie iets is wat dan meer zou mogen uhm ja toegankelijker maken, dat mensen u daar makkelijker naartoe brengen, maar dat je het ook uhm dat er meer ruimte voor gemaakt wordt na zo een opname.” (N10)*

APPENDIX 7. SUBGROUP ANALYSES RESULTS

Appendix 7.1. Subgroup analysis with a statistically significant overall difference

Table 22 – Association (p-values) between burden of symptoms and respondent characteristics.

Psychological symptoms	Age[1] (n = 145)	Financial situation[2] (n = 141)	Education level[1] (n = 132)	Time since diagnosis[2] (n = 144)
Feeling down, depressed, or sad	**0.005***	0.12	0.2	0.3
Fear or anxiety	**0.01***	**0.016***	**0.04***	0.1
Problems with concentration	0.2	0.1	0.5	0.6
Stress	0.075	0.06	0.7	0.4
Loss of self-confidence	0.072	**0.007***	0.05	0.2
Inability to feel interested or pleasure, lack of motivation or enthusiasm, emotional blunting	0.13	**0.035***	0.4	0.5
Social isolation, or feeling no interest in being with other people	0.077	**0.02***	**0.03***	0.4
Agitation or feeling tense	0.3	**<0.001***	**0.02***	**0.039***
Stigma or feeling discriminated	0.6	0.2	0.05	0.3
Disorganised behaviour	0.051	0.7	0.2	0.11
Disorganised thinking or intrusive thoughts	0.4	0.5	0.3	**0.039***
Hallucinations (hearing, seeing or feeling something, that others don't)	0.7	0.6	0.9	0.8
Feeling that you no longer want to live	0.2	0.7	0.3	0.5
Feelings of external control or influence	**0.01***	0.5	0.3	0.2
Self-harm behaviour or urges	0.4	0.4	0.3	0.4

*1Kruskal-Wallis rank sum test for comparisons between more than 2 groups; 2Wilcoxon rank sum test for comparisons between two groups; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

Table 23 – Association (p-value) of the burden of self-reported treatment-related side effects by respondents' individual characteristics.

Treatment-related side effects	Gender[1] (n = 136)	Age[2] (n = 139)	Financial situation[1] (n = 136)
Weight gain	**0.030***	0.4	**0.012***
Fatigue or drowsiness	0.8	**0.017***	**0.003***
Affective bunting (lack of motivation, lack of interest)	0.6	0.7	0.12
Memory problems or "brain fog"	0.7	0.2	**<0.001**
Sexual dysfunction (e.g., decreased libido)	0.092	0.8	0.15
Agitation, difficulty staying still, urge to move	>0.9	0.077	0.5
Dry mouth or eyes	**0.039***	0.3	0.5
High cholesterol (excess blood lipids)	0.8	0.1	0.3
Tremors and/or facial rigidity	0.6	0.061	0.8
Dizziness	>0.9	0.7	0.7
Constipation	0.4	0.8	0.3
Involuntary and sometimes painful muscle contractions	>0.9	0.7	0.9
Nausea	0.7	0.7	>0.9
Involuntary facial movements, such as chewing, sticking out the tongue, or blinking	>0.9	0.14	**0.016***
Hyperglycaemia (high blood sugar or diabetes)	0.3	0.4	>0.9
Low white blood cell count	0.3	0.4	NA

*[1]Wilcoxon rank sum test; [2]Kruskal-Wallis rank sum test; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

Table 24 – Association (p-value) between self-reported treatment and respondent characteristics.

Treatments[1]	Gender (n = 149)	Age (n = 152)	Education level (n = 139)	Diagnosis (n = 147)
Prescription drugs				
Atypical antipsychotics (SGAs)	0.5	0.1	0.3	0.6
Typical antipsychotics (FGAs)	**0.009***	0.4	0.3	0.12
Clozapine	0.2	0.6	>0.9	**0.009***
Antidepressants	0.15	**0.03***	0.4	>0.9
Tranquilizers/ Benzodiazepines	0.8	**0.008***	0.4	0.9
Non-prescription therapies				
Psychotherapy	0.8	0.15	0.2	**0.022***
Electro convulsion therapy (ECT)	0.3	0.074	**0.037***	>0.9
Other non-invasive brain stimulation techniques	>0.9	>0.9	>0.9	>0.9
Deep brain stimulation (DBS)	>0.9	0.3	>0.9	0.5
Physical exercise	0.3	0.3	0.2	0.7
Peer support	>0.9	0.8	0.6	0.8

*[1]Pearson's Chi-squared test; Fisher's exact test; *Bolded p-values indicate statistically significant group differences (p < 0.05).*

Table 25 – Association (p-value) between priority of needs and respondent's characteristics

Priority of needs	Age[2] (n = 139)	Financial situation[1] (n = 135)	Time since diagnosis[1] (n = 138)	Geographical region (n = 139)
Treatment effectiveness	0.3	0.066	0.3	0.2
Impact on psychological health	**0.007***	0.064	0.7	0.8
Access to healthcare	0.13	0.3	0.8	0.3
Financial impact	0.051	**<0.001***	0.9	0.7
Scientific knowledge	0.5	0.2	**0.045***	**0.046***
Quality of care	**0.008***	0.6	0.2	0.3
Impact on work	**0.009***	0.13	0.2	0.2
Impact on social life	0.14	0.2	0.5	0.6
Impact on quality of life	**0.031***	0.072	0.7	0.3
Impact on physical health	0.4	0.2	**0.037***	0.4
Impact on independence	0.5	0.9	0.4	0.2
Treatment burden	0.5	**0.038***	>0.9	0.4
Impact on life expectancy	0.2	**0.034***	**0.008***	0.072
Impact on school	**0.035***	0.14	>0.9	0.5
Impact on sexual and reproductive life	0.3	**0.032***	0.10	0.4

*[1]Wilcoxon rank sum test; [2]Kruskal-Wallis rank sum test; *Bolded p-values indicate statistically significant group differences (p < 0.05)*



Appendix 7.2. Subgroup analysis with no statistically significant overall difference

Table 26 – Difference EQ-5D-5L (general score) before onset of the symptoms vs today by age (n = 158)

EQ-5D-5L health score difference	Age (years)			p-value1
	<30 n = 20	30 – 50 n = 88	>50 n = 50	0.10
Median (Q1, Q3)	-0.2 (-0.6, 0.0)	0.0 (-0.2, 0.1)	0.0 (-0.2, 0.1)	
Min, Max	-1.0, 0.3	-1.1, 0.8	-0.5, 0.7	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the general median EQ5D5L scores for today and before symptom onset. A negative score reflects a decrease in health score over time.

Table 27 – Difference EQ-5D-5L (general score) before onset of the symptoms vs today by time since diagnosis (n = 156)

EQ-5D-5L health score difference	Time since diagnosis (years)		p-value[1]
	<10 years n = 62	10+ years n = 94	0.2
Median (Q1, Q3)	0.0 (-0.2, 0.1)	-0.1 (-0.3, 0.1)	
Min, Max	-1.1, 0.8	-1.1, 0.8	

[1] Wilcoxon rank sum test; The scores reflect the difference between the general median EQ5D5L scores for today and before symptom onset. A negative score reflects a decrease in health score over time.

Table 28 – Difference EQ-5D-5L (general score) before onset of the symptoms vs today by gender (n = 155)

EQ-5D-5L health score difference	Gender		p-value[1]
	Male n = 68	Female n = 87	0.12
Median (Q1, Q3)	-0.1 (-0.3, 0.0)	0.0 (-0.2, 0.1)	
Min, Max	-1.1, 0.7	-1.0, 0.8	

[1] Wilcoxon rank sum test; The scores reflect the difference between the general median EQ5D5L scores for today and before symptom onset. A negative score reflects a decrease in health score over time.

Table 29 – Difference EQ-5D-5L (general score) before onset of the symptoms vs today by education level (n = 145)

EQ-5D-5L health score difference	Education level			p-value[1]
	Basic n = 8	Secondary n = 67	Higher n = 70	0.069
Median (Q1, Q3)	-0.2 (-0.5, 0.0)	-0.1 (-0.4, 0.0)	0.0 (-0.2, 0.1)	
Min, Max	-1.1, 0.0	-1.1, 0.8	-0.7, 0.8	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the general median EQ5D5L scores for today and before symptom onset. A negative score reflects a decrease in health score over time.

Table 30 – Difference EQ-5D-5L (general score) before onset of the symptoms vs today by diagnosis (n = 152)

EQ-5D-5L health score difference	Diagnosis		p-value[1]
	Schizophrenia n = 52	Other n = 100	0.3
Median (Q1, Q3)	-0.1 (-0.3, 0.0)	0.0 (-0.2, 0.1)	
Min, Max	-1.1, 0.7	-1.1, 0.8	

[1] Wilcoxon rank sum test; The scores reflect the difference between the general median EQ5D5L scores for today and before symptom onset. A negative score reflects a decrease in health score over time.

Table 31 – Median difference between today vs. before symptom onset, in EQ-5D-5L scores for pain/discomfort, by gender (n = 144)

EQ-5D-5L health score difference	Gender		p-value[1]
	Male n = 63	Female n = 81	0.10
Median (Q1, Q3)	+1.0 (0.0, 2.0)	0.0 (0.0, 1.0)	
Min, Max	-4.0, 4.0	-2.0, 3.0	

[1] Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for pain/discomfort for today and before symptom onset. A positive score reflects an increase in pain/discomfort over time.

Table 32 – Median difference between today vs. before symptom onset, in EQ-5D-5L scores for pain/discomfort, by age (n = 147)

EQ-5D-5L health score difference	Age (years)			p-value[1]
	<30 n = 18	30 – 50 n = 84	>50 n = 45	>0.9
Median (Q1, Q3)	+0.5 (0.0, 1.0)	0.0 (0.0, 1.5)	0.0 (0.0, 1.0)	
Min, Max	-2.0, 2.0	-4.0, 4.0	-3.0, 3.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for pain/discomfort for today and before symptom onset. A positive score reflects an increase in pain/discomfort over time.

Table 33 – Median difference between today vs. before symptom onset, in EQ-5D-5L scores for pain/discomfort, by educational level (n = 136)

EQ-5D-5L health score difference	Education level			p-value[1]
	Basic n = 8	Secondary n = 60	Higher n = 68	0.11
Median (Q1, Q3)	+1.5 (0.5, 2.0)	0.0 (0.0, 1.0)	0.0 (0.0, 1.0)	
Min, Max	0.0, 4.0	-4.0, 3.0	-3.0, 4.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for pain/discomfort for today and before symptom onset. A positive score reflects an increase in pain/discomfort over time.

Table 34 – Median differences between today vs. before symptom onset, in EQ-5D-5L scores for pain/discomfort, by financial situation (n=143)

EQ-5D-5L health score difference	Financial situation		p-value[1]
	Comfortable n = 60	Strained n = 83	0.081
Median (Q1, Q3)	0.0 (0.0, 1.0)	+1.0 (0.0, 1.0)	
Min, Max	-4.0, 3.0	-3.0, 4.0	

[1]Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for pain/discomfort for today and before symptom onset. A positive score reflects an increase in pain/discomfort over time.

Table 35 – Association (p-values) between burden of psychological symptoms and respondent characteristics

Psychological symptoms	Gender [1] (n = 142)	Diagnosis[1] (n = 140)
Feeling down, depressed, or sad	0.7	>0.9
Fear or anxiety	>0.9	0.7
Problems with concentration	0.8	0.059
Stress	0.7	>0.9
Loss of self-confidence	0.6	0.9
Inability to feel interested or pleasure, lack of motivation or enthusiasm, emotional blunting	0.8	0.7
Social isolation, or feeling no interest in being with other people	0.4	0.3
Agitation or feeling tense	0.5	0.6
Stigma or feeling discriminated	0.6	0.2
Disorganised behaviour	0.3	0.2
Disorganised thinking or instrusive thoughts	>0.9	0.4
Hallucinations (hearing, seeing or feeling something, that others don't)	0.7	0.07
Feeling that you no longer want to live	0.7	0.3
Feelings of external control or influence	0.07	0.12
Self-harm behaviours or urges	0.3	0.3

[1]Wilcoxon rank sum test

Table 36 – Median difference between today vs. before symptom onset, in EQ-5D-5L scores for anxiety/depression, by financial situation (n = 141)

EQ-5D-5L health score difference	Financial situation		p-value[1]
	Comfortable n = 60	Strained n = 81	0.12
Median (Q1, Q3)	0.0 (-1.0, 0.5)	0.0 (-1.0, 1.0)	
Min, Max	-3.0, 4.0	-4.0, 3.0	

[1]Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for anxiety/depression for today and before symptom onset. A positive score reflects an increase in anxiety/depression over time.

Table 37 – Median difference EQ-5D-5L (general score) in problems with mobility by gender (n = 148)

EQ-5D-5L health score difference	Gender		p-value[1]
	Male n = 67	Female n = 81	0.4
Median (Q1, Q3)	0.0 (0.0, 2.0)	0.0 (0.0, 1.0)	
Min, Max	-1.0, 4.0	-1.0, 4.0	

[1] Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for problems with mobility for today and before symptom onset. A positive score reflects an increase in mobility problems over time.

Table 38 – Median difference EQ-5D-5L (general score) in problems with mobility by age (n = 151)

EQ-5D-5L health score difference	Age (years)			p-value[1]
	<30 n = 19	30 – 50 n = 84	>50 n = 48	0.6
Median (Q1, Q3)	0.0 (0.0, 1.0)	0.0 (0.0, 1.0)	0.0 (0.0, 1.0)	
Min, Max	0.0, 2.0	-1.0, 4.0	-1.0, 3.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for problems with mobility for today and before symptom onset. A positive score reflects an increase in mobility problems over time.

Table 39 – Median difference EQ-5D-5L (general score) in problems with mobility by education level (n = 139)

EQ-5D-5L health score difference	Education level			p-value[1]
	Basic n = 8	Secondary n = 63	Higher n = 68	0.4
Median (Q1, Q3)	0.0 (-0.5, 3.0)	0.0 (0.0, 1.0)	0.0 (0.0, 1.0)	
Min, Max	-1.0, 3.0	-1.0, 4.0	-1.0, 4.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for problems with mobility for today and before symptom onset. A positive score reflects an increase in mobility problems over time.

Table 40 – Median difference EQ-5D-5L (general score) in problems with mobility by financial situation (n = 148)

EQ-5D-5L health score difference	Financial situation		p-value[1]
	Comfortable n = 61	Strained n = 87	0.9
Median (Q1, Q3)	0.0 (0.0, 1.0)	0.0 (0.0, 1.0)	
Min, Max	-1.0, 4.0	-1.0, 3.0	

[1] Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for problems with mobility for today and before symptom onset. A positive score reflects an increase in mobility problems over time.

Table 41 – Median difference EQ-5D-5L (general score) in problems with self-care by gender (n = 150)

EQ-5D-5L health score difference	Gender		p-value[1]
	Male n = 68	Female n = 82	0.13
Median (Q1, Q3)	0.0 (0.0, 1.0)	0.0 (0.0, 0.0)	
Min, Max	-3.0, 4.0	-3.0, 4.0	

[1] Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for self-care for today and before symptom onset. A positive score reflects an increase in self-care issues over time.

Table 42 – Median difference EQ-5D-5L (general score) in problems with self-care by age (n = 152)

EQ-5D-5L health score difference	Age (years)			p-value[1]
	<30 n = 18	30 – 50 n = 84	>50 n = 50	0.7
Median (Q1, Q3)	0.0 (0.0, 1.0)	0.0 (0.0, 0.0)	0.0 (0.0, 1.0)	
Min, Max	0.0, 3.0	-3.0, 4.0	-2.0, 4.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for self-care for today and before symptom onset. A positive score reflects an increase in self-care issues over time.

Table 43 – Median difference EQ-5D-5L (general score) in problems with self-care by education level (n = 140)

EQ-5D-5L health score difference	Education level			p-value[1]
	Basic n = 8	Secondary n = 64	Higher n = 68	0.077
Median (Q1, Q3)	0.5 (0.0, 1.5)	0.0 (0.0, 1.0)	0.0 (0.0, 0.0)	
Min, Max	0.0, 3.0	-3.0, 3.0	-2.0, 4.0	

[1] Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for self-care for today and before symptom onset. A positive score reflects an increase in self-care issues over time.

Table 44 – Median difference EQ-5D-5L (general score) in problems with self-care by financial situation (n = 148)

EQ-5D-5L health score difference	Financial situation		p-value[1]
	Comfortable n = 63	Strained n = 85	>0.9
Median (Q1, Q3)	0.0 (0.0, 0.0)	0.0 (0.0, 1.0)	
Min, Max	-2.0, 4.0	-3.0, 3.0	

[1] *Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for self-care for today and before symptom onset. A positive score reflects an increase in self-care issues over time.*

Table 45 – Median difference EQ-5D-5L (general score) in problems with usual activities by gender (n = 149)

EQ-5D-5L health score difference	Gender		p-value[1]
	Male n = 67	Female n = 82	0.2
Median (Q1, Q3)	1.0 (0.0, 2.0)	0.0 (0.0, 2.0)	
Min, Max	-2.0, 4.0	-4.0, 4.0	

[1] *Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for usual care for today and before symptom onset. A positive score reflects an increase in usual care problems over time.*

Table 46 – Median difference EQ-5D-5L (general score) in problems with usual activities by age (n = 152)

EQ-5D-5L health score difference	Age (years)			p-value[1]
	<30 n = 19	30-50 n = 84	>50 n = 49	0.2
Median (Q1, Q3)	1.0 (0.0, 2.0)	0.0 (0.0, 2.0)	0.0 (0.0, 1.0)	
Min, Max	-1.0, 4.0	-4.0, 3.0	-2.0, 4.0	

[1] *Kruskal-Wallis rank sum test; The scores reflect the difference between the median change EQ5D5L scores for usual care for today and before symptom onset. A positive score reflects an increase in usual care problems over time.*

Table 47 – Impact of PD on sexual health and gender of respondents (n = 112)

Characteristic	Gender		p-value[1]
	Male n = 52	Female n = 60	0.4
Median (Q1, Q3)	3.5 (2.0, 5.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 48 – Impact of PD on sexual health and age of respondents (n = 114)

Characteristic	Age (years)			p-value[1]
	<30 n = 12	30 – 50 n = 65	>50 n = 37	0.7
Median (Q1, Q3)	4.0 (2.5, 4.0)	3.0 (2.0, 5.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 49 – Impact of PD on sexual health and education of respondents (n = 103)

Characteristic	Education level			p-value[1]
	Basic n = 4	Secondary n = 44	Higher n = 55	0.9
Median (Q1, Q3)	3.5 (2.0, 4.5)	4.0 (2.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 50 – Impact of PD on reproductive health and gender of respondents (n = 80)

Characteristic	Gender		p-value[1]
	Male n = 35	Female n = 45	0.3
Median (Q1, Q3)	3.0 (1.0, 5.0)	2.0 (1.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 51 – Impact of PD on reproductive health and age of respondents (n=81)

Characteristic	Age (years)			p-value[1]
	<30 n = 8	30 – 50 n = 47	>50 n = 26	0.4
Median (Q1, Q3)	3.5 (1.0, 5.0)	2.0 (1.0, 5.0)	1.0 (1.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 52 – Impact of PD on reproductive health and education level of respondents (n = 73)

Characteristic	Education level			p-value[1]
	Basic n = 4	Secondary n = 31	Higher n = 38	0.8
Median (Q1, Q3)	2.5 (1.0, 4.5)	3.0 (1.0, 5.0)	2.0 (1.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test;*

Table 53 – Impact of PD on reproductive health and financial situation of respondents (n = 79)

Characteristic	Financial situation		p-value[1]
	Comfortable n = 32	Strained n = 47	0.2
Median (Q1, Q3)	1.0 (1.0, 4.0)	3.0 (1.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for reproductive health for today and before symptom onset.*

Table 54 – Association (p-value) between self-reported treatment use by time since diagnosis and financial situation

Treatments	Time since diagnosis (n = 151)	Financial situation[1] (n = 148)
Prescription drugs		
Atypical antipsychotics (SGAs)	0.5	0.5
Typical antipsychotics (FGAs)	0.5	0.2
Clozapine	0.6	0.2
Antidepressants	0.054	0.6
Tranquilizers/ Benzodiazepines	0.2	0.3
Non-prescription therapies		
Psychotherapy	0.5	0.7
Electro convulsion therapy (ECT)	0.3	0.6
Other non-invasive brain stimulation techniques	>0.9	>0.9
Deep brain stimulation (DBS)	>0.9	0.2
Physical exercise	0.3	0.8
Peer support	>0.9	0.7

[1] *Pearson's Chi-squared test; Fisher's exact test*

Table 55 – Frequency of self-reported treatment-related side effects by respondents' individual characteristics

Treatment-related side effects[1]	Gender[2] (n = 145)	Age[2] (n = 148)	Time since diagnosis[2] (n = 147)
Weight gain	0.7	>0.9	>0.9
Fatigue or drowsiness	0.7	0.2	0.5
Affective bunting (lack of motivation, lack of interest)	>0.9	0.9	0.5
Memory problems or "brain fog"	0.5	0.067	0.3
Sexual dysfunction (e.g., decreased libido)	0.6	0.6	0.3
Agitation, difficulty staying still, urge to move	0.5	0.094	0.2
Dry mouth or eyes	0.3	0.5	0.2
High cholesterol (excess blood lipids)	0.070	0.5	0.3
Tremors and/or facial rigidity	0.5	0.6	0.068
Dizziness	0.2	0.2	>0.9
Constipation	0.2	0.4	0.7
Involuntary and sometimes painful muscle contractions	0.6	0.8	0.8
Nausea	0.6	0.5	0.11
Involuntary facial movements, such as chewing, sticking out the tongue, or blinking	>0.9	0.7	0.8

Hyperglycaemia (high blood sugar or diabetes)	0.6	0.5	0.053
Low white blood cell count	0.5	>0.9	>0.9

[1]*n(%)*
[2]*Pearson's Chi-squared test; Fisher's exact test*

Table 56 – Association (p-value) between burden of self-reported treatment-related side effects by respondents' individual characteristics

Treatment-related side effects	Time since diagnosis[1] (n = 138)	Education level[2] (n = 128)	Diagnosis[1] (n=135)
Weight gain	>0.9	>0.9	>0.9
Fatigue or drowsiness	0.11	0.4	0.7
Affective bunting (lack of motivation, lack of interest)	0.2	0.085	0.4
Memory problems or "brain fog"	>0.9	0.5	0.2
Sexual dysfunction (e.g., decreased libido)	0.13	0.5	0.7
Agitation, difficulty staying still, urge to move	0.4	0.7	0.7
Dry mouth or eyes	0.13	0.2	0.11
High cholesterol (excess blood lipids)	>0.9	0.7	0.6
Tremors and/or facial rigidity	0.9	0.5	0.8
Dizziness	0.7	>0.9	0.2
Constipation	0.7	0.3	0.6
Involuntary and sometimes painful muscle contractions	0.6	0.6	0.10
Nausea	0.3	0.13	>0.9
Involuntary facial movements, such as chewing, sticking out the tongue, or blinking	0.4	0.7	0.9
Hyperglycaemia (high blood sugar or diabetes)	0.5	>0.9	0.6
Low white blood cell count	0.3	0.7	>0.9

[1]*Wilcoxon rank sum test;* [2]*Kruskal-Wallis rank sum test*

Table 57 – Experienced treatment burden, other than treatment related side-effects, by time since diagnosis (n = 144)

Characteristic	Time since diagnosis		p-value[1]
	< 10 years n = 58	**10+ years** n = 86	0.7
Median (Q1, Q3)	3.0 (2.0, 4.0)	2.0 (2.0, 3.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 58 – Experienced treatment burden, other than treatment related side-effects, by gender (n = 142)

Characteristic	Gender		p-value[1]
	Male n = 61	Female n = 81	0.089
Median (Q1, Q3)	3.0 (2.0, 4.0)	2.0 (1.0, 3.0)	
Min, Max	2.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 59 – Experienced treatment burden, other than treatment related side-effects, by education level (n = 133)

Characteristic	Education level			p-value[1]
	Basic n = 7	Secondary n = 61	Higher n = 65	0.5
Median (Q1, Q3)	3.0 (1.0, 4.0)	3.0 (2.0, 4.0)	2.0 (2.0, 3.0)	
Min, Max	2.0, 4.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 60 – Experienced treatment burden, other than treatment related side-effects, by diagnosis (n = 141)

Characteristic	Diagnostic group		p-value[1]
	Schizophrenia n = 48	Other n = 93	0.8
Median (Q1, Q3)	3.0 (1.5, 3.0)	2.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 61 – Experienced treatment burden, other than treatment related side-effects, by age (n = 145)

Characteristic	Age (years)			p-value[1]
	<30 n = 20	30 – 50 n = 80	>50 n = 45	0.3
Median (Q1, Q3)	3.0 (2.0, 4.0)	2.0 (2.0, 3.5)	2.0 (1.0, 3.0)	
Min, Max	2.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 62 – Respondent satisfaction with organisation of care by gender (n = 137)

Characteristic	Gender		p-value[1]
	Male n = 58	Female n = 79	0.4
Median (Q1, Q3)	3.0 (3.0, 4.0)	3.0 (3.0, 4.0)	
Min, Max	2.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 63 – Respondent satisfaction with organisation of care by age (n = 139)

Characteristic	Age (years)			p-value[1]
	<30 n = 18	30 – 50 n = 75	>50 n = 46	0.080
Median (Q1, Q3)	3.5 (3.0, 5.0)	3.0 (3.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	2.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 64 – Respondent satisfaction with organisation of care by education level (n = 127)

Characteristic	Education level			p-value[1]
	Basic n = 6	Secondary n = 58	Higher n = 63	0.5
Median (Q1, Q3)	3.0 (2.0, 4.0)	3.0 (3.0, 4.0)	3.0 (3.0, 4.0)	
Min, Max	2.0, 4.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 65 – Respondent satisfaction with organisation of care by financial situation (n = 134)

Characteristic	Financial situation		p-value[1]
	Comfortable n = 58	Strained n = 76	0.1
Median (Q1, Q3)	3.0 (2.0, 4.0)	3.0 (3.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 66 – Recurrence of the same healthcare personnel by geographical region (n = 140)

Characteristic	Geographical region			p-value[1]
	Flanders n = 77	Brussels n = 20	Wallonia n = 43	0.8
Median (Q1, Q3)	3.0 (2.0, 3.0)	2.0 (2.0, 3.0)	3.0 (2.0, 3.0)	
Min, Max	1.0, 5.0	1.0, 4.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 67 – Recurrence of the same healthcare personnel by gender (n = 137)

Characteristic	Gender		p-value[1]
	Male n = 58	Female n = 79	0.3
Median (Q1, Q3)	2.0 (2.0, 3.0)	3.0 (2.0, 3.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 68 – Recurrence of the same healthcare personnel by age (n = 140)

Characteristic	Age (years)			p-value[1]
	<30 n = 19	30 – 50 n = 75	>50 n = 46	0.4
Median (Q1, Q3)	3.0 (2.0, 3.0)	3.0 (2.0, 3.0)	2.0 (2.0, 3.0)	
Min, Max	2.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 69 – Recurrence of the same healthcare personnel by education level (n = 128)

Characteristic	Education level			p-value[1]
	Basic n = 6	Secondary n = 60	Higher n = 62	
Median (Q1, Q3)	2.0 (2.0, 3.0)	2.5 (2.0, 3.0)	3.0 (2.0, 3.0)	0.7
Min, Max	2.0, 3.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 70 – Recurrence of the same healthcare personnel by financial situation (n = 135)

Characteristic	Financial situation		p-value[1]
	Comfortable n = 57	Strained n = 78	
Median (Q1, Q3)	2.0 (2.0, 3.0)	3.0 (2.0, 3.0)	0.12
Min, Max	2.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 71 – Respondent satisfaction with information received from healthcare personnel by geographical region (n = 139)

Characteristic	Geographical region			p-value[1]
	Flanders n = 75	Brussels n = 21	Wallonia n = 43	
Median (Q1, Q3)	2.0 (2.0, 3.0)	2.0 (1.0, 3.0)	2.0 (1.0, 4.0)	0.6
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 72 – Respondent satisfaction with information received from healthcare personnel by gender (n = 136)

Characteristic	Gender		p-value[1]
	Male n = 57	Female n = 79	
Median (Q1, Q3)	2.0 (1.0, 4.0)	2.0 (2.0, 3.0)	0.3
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 73 – Respondent satisfaction with information received from healthcare personnel by age (n = 139)

Characteristic	Age (years)			p-value[1]
	<30 n = 19	30 – 50 n = 75	>50 n = 45	0.9
Median (Q1, Q3)	2.0 (1.0, 3.0)	2.0 (2.0, 3.0)	2.0 (1.0, 3.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 74 – Respondent satisfaction with information received from healthcare personnel by education level (n = 128)

Characteristic	Education level			p-value[1]
	Basic n = 6	Secondary n = 61	Higher n = 61	0.3
Median (Q1, Q3)	2.0 (1.0, 2.0)	3.0 (1.0, 3.0)	2.0 (2.0, 3.0)	
Min, Max	1.0, 3.0	1.0, 5.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 75 – Involvement in treatment choice by geographical region (n = 137)

Characteristic	Geographical region			p-value[1]
	Flanders n = 75	Brussels n = 20	Wallonia n = 42	0.2
Median (Q1, Q3)	2.0 (1.0, 2.0)	2.0 (2.0, 3.0)	2.0 (2.0, 3.0)	
Min, Max	1.0, 4.0	1.0, 4.0	1.0, 5.0	

[1] *Kruskal-Wallis rank sum test*

Table 76 – Involvement in treatment choice by gender (n = 134)

Characteristic	Gender		p-value[1]
	Male n = 56	Female n = 78	0.3
Median (Q1, Q3)	2.0 (1.0, 3.0)	2.0 (1.0, 2.0)	
Min, Max	1.0, 5.0	1.0, 4.0	

[1] *Wilcoxon rank sum test*

Table 77 – Involvement in treatment choice by age (n = 137)

Characteristic	Age (years)			p-value[1]
	<30 n = 19	30 – 50 n = 73	>50 n = 45	0.3
Median (Q1, Q3)	2.0 (2.0, 3.0)	2.0 (2.0, 3.0)	2.0 (1.0, 2.0)	
Min, Max	1.0, 4.0	1.0, 5.0	1.0, 4.0	

[1] *Kruskal-Wallis rank sum test*

Table 78 – Involvement in treatment choice by education level (n = 126)

Characteristic	Education level			p-value[1]
	Basic n = 6	Secondary n = 59	Higher n = 61	0.2
Median (Q1, Q3)	2.5 (1.0, 3.0)	2.0 (2.0, 3.0)	2.0 (1.0, 2.0)	
Min, Max	1.0, 4.0	1.0, 5.0	1.0, 4.0	

[1] *Kruskal-Wallis rank sum test*

Table 79 – Involvement in treatment choice by financial situation (n = 134)

Characteristic	Financial situation		p-value[1]
	Comfortable n = 64	Strained n = 90	0.3
Median (Q1, Q3)	2.0 (1.0, 2.0)	2.0 (2.0, 3.0)	
Min, Max	1.0, 4.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 80 – Time of first symptoms and decision to seek care by gender (n = 142)

Time between first symptoms and decision to seek care[1]	Gender		p-value[2]
	Male n = 64	Female n = 88	
< 1 month	17 (27%)	32 (41%)	0.3
1-6 months	17 (27%)	12 (15%)	
6-12 months	7 (11%)	9 (12%)	
1-2 years	7 (11%)	7 (9.0%)	
> 2 years	16 (25%)	18 (23%)	

[1]*n(%)*
[2]*Fisher's Exact Test for Count Data with simulated p-value (based on 2000 replicates)*

Table 81 – Foregone care and geographical region (n = 42)

Reasons for forgone care[1]	Geographical region			p-value[2]
	Flanders n = 18	Brussels n = 6	Wallonia n = 18	
Waiting times	12 (67%)	1 (17%)	9 (50%)	0.13
Fear for medical intervention	8 (44%)	1 (17%)	6 (33%)	0.5
Lack of time	1 (5.6%)	0 (0%)	1 (5.6%)	>0.9
Lack of information	5 (28%)	2 (33%)	5 (28%)	>0.9
Distance between house and health facility	4 (22%)	0 (0%)	6 (33%)	0.4
Lack of qualified staff	6 (33%)	3 (50%)	8 (44%)	0.8
Transport problem	3 (17%)	2 (33%)	3 (17%)	0.7
Difficulty paying	6 (33%)	3 (50%)	6 (33%)	0.8

[1]*n (%)*
[2]*Fisher's Exact Test*

Table 82 – Respondents' social support needs by age (n = 118)

Characteristic[1]	Age (years)			p-value[2]
	<30 n = 18	30 – 50 n = 64	>50 n = 36	
No support needs	2 (11%)	12 (19%)	10 (28%)	0.4
Talking to peers	8 (44%)	16 (25%)	9 (25%)	0.2
Return-to-work	3 (17%)	18 (28%)	4 (11%)	0. 13
Spiritual and religious	3 (17%)	13 (20%)	7 (19%)	>0.9
Psychological	7 (39%)	21 (33%)	15 (42%)	0.7
Practical	5 (28%)	16 (25%)	9 (25%)	>0.9
Administrative and social	7 (39%)	17 (27%)	9 (25%)	0.5
Medical	7 (39%)	15 (23%)	10 (28%)	0.4
Environmental adaptations	3 (17%)	3 (4.7%)	4 (11%)	0.14
School and study	4 (22%)	10 (16%)	2 (5.6%)	0.2

[1] *n (%)*
[2]*Fisher's exact test; Pearson's Chi-squared test*

Table 83 – Impact of PD on personal relations by gender (n = 137)

Characteristic	Gender		p-value[1]
	Male n = 58	Female n = 79	0.2
Median (Q1, Q3)	4.0 (3.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] Wilcoxon rank sum test; The scores reflect the difference between the median change EQ5D5L scores for reproductive health for today and before symptom onset. A positive score reflects an increase in reproductive health over time.

Table 84 – Impact of PD on personal relations by age (n = 140)

Characteristic	Age (years)			p-value[1]
	<30 n = 19	30 – 50 n = 77	>50 n = 44	0.092
Median (Q1, Q3)	4.0 (3.0, 4.0)	4.0 (2.0, 4.0)	3.0 (2.5, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1]Kruskal-Wallis rank sum test

Table 85 – Impact of PD on personal relations by education level (n = 129)

Characteristic	Education level			p-value[1]
	Basic n = 6	Secondary n = 60	Higher n = 63	0.067
Median (Q1, Q3)	4.0 (1.0, 5.0)	4.0 (3.0, 5.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	1.0, 5.0	

[1] Kruskal-Wallis rank sum test

Table 86 – Impact of PD on personal relations by living situation (n = 137)

Characteristic	Living situation		p-value[1]
	Alone n = 67	With others n = 70	0.5
Median (Q1, Q3)	4.0 (3.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] Wilcoxon rank sum test

Table 87 – Impact of PD on education by living situation (n = 106)

Characteristic	Living situation		p-value[1]
	Alone n = 51	With others n = 55	0.5
Median (Q1, Q3)	3.0 (1.0, 5.0)	4.0 (1.0, 5.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] Wilcoxon rank sum test

Table 88 – Impact of PD on work intensity by time since diagnosis (n = 82)

Impact on work intensity[1]	Time since diagnosis (years)		p-value[2]
	<10 years n = 27	10+ years n = 55	0.4
Work less	10 (33%)	18 (32%)	
Stopped working	15 (50%)	31 (55%)	
No impact	2 (6.7%)	6 (11%)	

[1]n(%)
[2]Fisher's Exact Test

Table 89 – Impact of PD on work intensity by gender (n = 81)

Characteristic[1]	Gender		p-value[2]
	Male n = 28	Female n = 53	0.2
Worked less	7 (25%)	21 (37%)	
Stopped working	19 (68%)	26 (46%)	
No impact	2 (7.1%)	6 (11%)	

[1]n(%)
[2]Fisher's Exact Test

Table 90 – Impact of PD on work intensity by financial situation (n = 81)

Characteristic[1]	Financial situation		p-value[2]
	Comfortable n = 35	Strained n = 46	0.14
Worked less	13 (36%)	14 (29%)	
Stopped working	16 (44%)	30 (61%)	
No impact	6 (17%)	2 (4.1%)	

[1]n(%)
[2]Fisher's Exact Test

Table 91 – Impact of PD on work intensity by education level (n = 78)

Characteristic[1]	Education level			p-value[2]
	Basic n = 2	Secondary n = 31	Higher n = 45	0.7
Worked less	0 (0%)	12 (36%)	13 (28%)	
Stopped working	2 (100%)	17 (52%)	27 (59%)	
No impact	0 (0%)	2 (6.1%)	5 (11%)	

[1]n(%)
[2]Fisher's Exact Test

Table 92 – Impact of PD on work intensity by living situation (n = 81)

Characteristic[1]	Living situation		p-value[2]
	Alone n = 45	With others n = 36	0.6
Worked less	17 (37%)	11 (28%)	
Stopped working	23 (50%)	22 (56%)	
No impact	5 (11%)	3 (7.7%)	

[1]n(%)
[2]Fisher's Exact Test

Table 93 – Impact of PD on incapacity to work intensity by living situation (n = 138)

Characteristic[1]	Living situation		p-value[2]
	Alone n = 67	With others n = 71	0.5
< 1 month	2 (3.0%)	15 (21%)	
1-3 months	2 (3.0%)	1 (1.4%)	
4-12 months	6 (9.0%)	4 (5.6%)	
1-5 years	18 (27%)	1 (1.4%)	
6-10 years	11 (16%)	25 (35%)	
11-20 years	7 (10%)	10 (14%)	
20+ years	6 (9.0%)	7 (9.9%)	

[1]*n(%)*
[2]*Fisher's Exact Test*

Table 94 – Impact of PD on incapacity to work intensity by financial situation (n = 136)

Characteristic[1]	Financial situation		p-value[2]
	Comfortable n = 58	Strained n = 78	0.072
< 1 month	3 (5.2%)	0 (0%)	
1-3 months	4 (6.9%)	2 (2.6%)	
4-12 months	5 (8.6%)	2 (2.6%)	
1-5 years	20 (34%)	21 (27%)	
6-10 years	7 (12%)	14 (18%)	
11-20 years	7 (12%)	8 (10%)	
20+ years	5 (8.6%)	10 (13%)	

[1]*n(%)*
[2]*Fisher's Exact Test*

Table 95 – Impact of PD and financial consequences by living situation (n = 134)

Characteristic	Living situation		p-value[1]
	Alone n = 64	With others n = 70	0.7
Median (Q1, Q3)	3.0 (2.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 96 – Impact of PD and financial consequences by gender (n = 133)

Characteristic	Gender		p-value[1]
	Male n = 58	Female n = 75	0.4
Median (Q1, Q3)	3.0 (2.0, 4.0)	3.0 (2.0, 4.0)	
Min, Max	1.0, 5.0	1.0, 5.0	

[1] *Wilcoxon rank sum test*

Table 97 – Association (p-value) between prioritisation of needs and respondents' characteristics

Priority of needs[1]	Gender[2] (n = 136)	Education level[3] (n = 128)	Living situation[2] (n = 136)
Treatment effectiveness	0.2	>0.9	>0.9
Impact on psychological health	>0.9	>0.9	>0.9
Access to healthcare	0.3	0.6	>0.9
Financial impact	0.6	0.3	0.2
Scientific knowledge	0.6	0.8	0.2
Quality of care	>0.9	0.6	0.2
Impact on work	0.7	0.8	0.4
Impact on social life	0.6	0.6	0.090
Impact on quality of life	0.2	0.2	0.5
Impact on physical health	0.3	0.6	0.12
Impact on independence	0.7	0.7	0.2
Treatment burden	0.6	0.4	0.9
Impact on life expectancy	0.5	0.3	0.5
Impact on school	0.5	0.058	0.15
Impact on sexual and reproductive life	0.4	0.4	>0.9

[1]n(%); [2]Wilcoxon rank sum test; [3]Kruskal-Wallis rank sum test.