

# Reflection on Experiences of Alteration of Lived Self and Reality: Development of self-report items to track changes

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Primary objective: The primary objective is to answer the following research question: 1. How do people who transitioned to psychosis describe alterations in their experiences of self and reality prior to the first psychotic episode? 2. Are these...

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Pending
<b>Health condition type</b>	Schizophrenia and other psychotic disorders
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON57160

### Source

ToetsingOnline

### Brief title

REAL

### Condition

- Schizophrenia and other psychotic disorders

### Synonym

psychotic disorder, schizophrenia

### Research involving

Human

### Sponsors and support

**Primary sponsor:** Rijksuniversiteit Groningen

**Source(s) of monetary or material Support:** Ministerie van OC&W

## Intervention

**Keyword:** psychosis, reality, self, subjectivity

## Outcome measures

### Primary outcome

The study's main parameters are the subjective experiences of self and reality, assessed with a qualitative semi-structured interview and translated into self-report items.

### Secondary outcome

Secondary parameters are the recognition and frequency of the experiences described in the self-report items by participants.

## Study description

### Background summary

Psychosis is currently defined as a mental disorder characterized by the presence of distortions in perception (hallucinations), false beliefs (delusions), and disorganization. The high burden associated with psychotic disorders prompted the screening of people who have a high risk of developing psychosis (i.e., UHR) in order to prevent transition to psychosis through early intervention (Nelson et al., 2013). However, predicting psychosis transition remains challenging, partly because UHR criteria predominantly rely on non-specific observable subclinical psychotic symptoms like odd behaviors or perceptual disturbances (Nelson et al., 2013; Nelson & Raballo, 2015). The UHR framework falls short on capturing the subtle and often difficult to describe experiential alterations reported by UHR individuals and people with lived experience of psychosis (Fusar-Poli et al., 2022). Phenomenological researchers challenge the current definition of psychosis as a disturbance of perception and false beliefs, emphasizing the experiential dimension and the active meaning-making process that individuals engage in (Feyaerts et al., 2021a; Feyaerts & Sips, 2023; Ritunnano et al., 2022; Sass 2019). This perspective enables an exploration of alterations in the experience of self and reality that can help to understand psychosis development. Exploring alterations in experiences of self and reality and the contexts within which these experiences occur holds the potential to yield insights into the factors contributing to

the transition into psychosis.

The phenomenological approach to subclinical psychotic symptoms has resulted in a comprehensive model \*the Basic Self-Disturbance (BSD) model\* which describes alterations of pre-reflective consciousness that may predict psychosis onset (Nelson et al., 2012; Sass et al., 2018). This alteration manifests in heightened self-consciousness (hyperreflexivity) and an altered sense of being an engaged and unified subject of awareness and action (Sass et al., 2018; Nelson & Raballo, 2015; Feyaerts & Sass, 2023). Over time, these processes are suggested to result in a blurred boundary between self and world, leading to an altered grip on reality. BSD-processes are typically assessed with the semi-structured interview the Examination of Anomalous Self Experience (EASE, Parnas et al., 2005). However, the EASE is an observer-rated instrument unsuited to assess moment-to-moment fluctuations of pre-reflective self-experiences, given that the scoring of EASE items is too extensive for momentary assessment. Moreover, it explicitly excludes experiences that exhibit temporal instability which potentially contributes to an inflated perception of the temporal stability of these phenomena. Psychosis research may benefit from studying the variability in experiences of self and reality over time and in the natural context of individuals (Nelson et al., 2017), thereby also exploring the influence of the context on these experiences. To gather data on moment-to-moment fluctuations, validated self-report experience-sampling measures of alterations in self and reality experiences are required. However, such items are currently not available.

In the current study, we aim to address this research gap by developing self-report items for self and reality experiences and contextual variables that lend themselves to moment-to-moment assessment. This involves an initial qualitative exploration of subjective experiences of self and reality, the identification of common themes derived from the interview transcripts, the determination of necessary adaptations for their use in quantitative experience sampling methods (ESM), and subsequent development of self-report items assessing alterations in self and reality experiences over time.

We expect that this study will contribute to comprehending the lived experiences of individuals who experienced psychosis and eventually improve current UHR-criteria. The initial qualitative study ensures that the development of ESM-items not only draws on top-down theoretical criteria (e.g., Basic Self Disturbance) but also integrates first-person accounts from individuals with lived experiences in a bottom-up way.

## **Study objective**

Primary objective:

The primary objective is to answer the following research question:

1. How do people who transitioned to psychosis describe alterations in their experiences of self and reality prior to the first psychotic episode?
2. Are these alterations in the experience of self and reality related to

specific contexts, and if so, how?

#### Secondary Objective:

The secondary objective is to develop self-report items based on the experiences of self and reality that participants in the study report. To do so, we aim to answer these research questions:

3. What are valid ESM-questions to investigate the reported alterations in experiences of self and reality?

### **Study design**

This is a qualitative exploratory study in the north of the Netherlands and Belgium (Vlaanderen) with four phases (Figure 1) lasting from summer 2024 to approximately winter 2024: 1) Prior to conducting interviews, discussions will take place with people with lived experience of psychosis (recruited via GGZ Drenthe, UCP Groningen, RGOC) to create an interview guide, ensuring the inclusion of a comprehensive yet non-exhaustive list of relevant experiential alterations in self and reality. 2) Qualitative semi-structured interviews will be conducted to assess which anomalous self and reality experiences are reported by participants with lived experience of psychosis (see section 7.2 study protocol for recruitment). The main focus of the interviews will be to capture how participants describe their experiences in their own words, ensuring that the resulting data aligns as closely as possible with people's lived experiences. The interviews will follow an open style to encourage participants to provide their own examples and explore experiences not covered by the orienting topics. 3) Interviews will be audio-recorded and transcribed to identify codes and common themes through thematic analysis (Braun and Clarke, 2006). Two coding schemes (inductive, deductive) will be developed to relate the reported experiences to phenomenological theory (BSD, EASE, EAWE; Examination of Anomalous World Experience, Sass et al., 2017) while also enabling the inclusion of experiences not mentioned in phenomenological theory. 4) Themes will be translated into self-report items which will be evaluated by researchers and study participants for use in a future ESM study. Study participants will provide feedback on the items.

The qualitative study design is crucial to maintain a phenomenological focus on lived experiences during the constructing of self-report items. After identifying relevant domains of anomalous self and reality experiences, self-report questions for moment-to-moment assessment can be developed.

### **Study burden and risks**

The risks associated with participation in this study can be considered negligible as the target population are patients in out-patient treatment which are not acutely psychotic. Participants are interviewed once about their own experiences (duration 1-2 hours). The interviewing location is determined together with the participant. Participants know beforehand that the aim of

this study is to investigate their subjective experiences. Although reflection on past experiences with psychosis can be considered burdensome, the content of psychotic experiences (e.g., delusionary ideas) are not of primary interest to this study. Rather, this study wishes to explore subjectivity and the form of experiences in participants that are not acutely psychotic. There are no immediate benefits for participants associated with participation in this study. However, participation in this study means that participants support the researchers in their endeavour to better understand psychosis and psychosis development. Furthermore, participants can play an active role in making sure that the development of self-report items of anomalous experiences of self and reality is informed by their experiences. The potential long-term benefits of this include the possibility of future interventions based on the detection of early-warning signals of psychosis. Since the aim of the study is to investigate subjective experiences of self and reality in individuals with FEP-status, this research cannot be conducted with other groups.

## Contacts

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### Scientific

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## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adults (18-64 years)

## Inclusion criteria

- a) Age between 18 and 35.
- b) The subject has recently (< 5 years) experienced a first psychotic episode. This criterion will be confirmed through contact with the participant, and through a conversation before the start of the semi-structured interview.
- c) b) The individual is currently not acutely psychotic to such a degree that participation is not possible. Participants who score higher than 5 on the positive symptom scale of the PANSS (Kay et al., 1987) will be excluded.
- d) Participants will be excluded if their psychotic experiences were solely during substance intoxication.
- e) Ability to speak and read the Dutch language.

## Exclusion criteria

- a) Age outside the range of 18 to 35 years.
- b) The individual has not recently (< 5 years ago) experienced a first psychotic episode.
- c) The individual is currently experiencing acute psychosis to a degree that prohibits participation.
- d) Participants whose psychotic experiences were solely due to substance intoxication will be excluded.
- e) Inability to speak and read the Dutch language.

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

### Recruitment

NL

Recruitment status: Pending

Start date (anticipated): 01-08-2024

Enrollment: 30  
Type: Anticipated

## Ethics review

Approved WMO  
Date: 04-10-2024  
Application type: First submission  
Review commission: METC Universitair Medisch Centrum Groningen (Groningen)

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

### In other registers

Register	ID
CCMO	NL86405.042.24