

Study asked people with mental health disorders to recommend changes to international diagnostic guidelines

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A Rutgers University researcher contributed to the first study to seek input from people with common mental health issues on how their

disorders are described in diagnostic guidelines.

The study, which was conducted by researchers in the United Kingdom and the United States in collaboration with the World Health Organization Department of Mental Health, appears in *The Lancet*.

"Including people's personal experiences with disorders in diagnostic manuals will improve their access to treatment and reduce stigma," said Margaret Swarbrick, an adjunct associate professor and Director of Practice Innovation and Wellness at Rutgers University Behavioral Health Care, who collaborated with Kathleen M. Pike, executive director and scientific co-director of the Global Mental Health Program on the U.S. portion of the study.

The researchers talked to people with five common disorders—schizophrenia, bipolar disorder type 1, depressive episode, personality disorder and generalized anxiety disorder—about how their conditions should be described in the upcoming 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11). The ICD is the most widely used classification system for mental disorders. This is the first time people with diagnosed mental [health](#) disorders who are not health practitioners have been invited to give input on any published mental health diagnostic guidelines.

The project surveyed 157 people diagnosed with these conditions in the United Kingdom, India and the United States. The participants reviewed an initial draft of the ICD-11 chapter on mental, behavioral and neurodevelopmental [disorders](#) and recommended changes to more accurately reflect their experiences and/or remove objectionable language.

Many participants said the draft omitted emotional and psychological experiences they regularly have. People with schizophrenia added

references to anger, fear, memory difficulties, isolation and difficulty communicating internal experiences. People with bipolar disorder added anxiety, anger, nausea and increased creativity. People with generalized anxiety disorder added nausea and anger. People with depression added pain and anxiety. People with personality disorder added distress and vulnerability to exploitation.

The participants also suggested removing confusing or stigmatizing terms such as "retardation," "neuro-vegetative," "bizarre," "disorganized" and "maladaptive."

"We discovered that the current draft reflected an external perspective of these conditions rather than the perspective of the person's lived experience," Swarbrick said. "This is a needed perspective for clinicians and researchers. Participants appreciated the non-technical summaries, which suggest that using such common language would go a long way in bridging the communication gap between the people being diagnosed and clinicians."

More information: Corinna Hackmann et al, Perspectives on ICD-11 to understand and improve mental health diagnosis using expertise by experience (INCLUDE Study): an international qualitative study, *The Lancet Psychiatry* (2019). [DOI: 10.1016/S2215-0366\(19\)30093-8](https://doi.org/10.1016/S2215-0366(19)30093-8)

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