

WHO mental health guidelines could better capture 'lived experience'

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Mental health patients want mental health diagnostic descriptions to better reflect what it feels like to live with their conditions in the World Health Organisation's global manual of diagnoses—according to a new *Lancet Psychiatry* report.

The study, by UK and US researchers at Norfolk and Suffolk NHS Foundation Trust (NSFT), the University of East Anglia, and Columbia University, in collaboration with the WHO Department of Mental Health and Substance Abuse, is the first to report feedback from service users on such a major [mental health](#) diagnosis guideline.

The WHO's International Classification of Diseases (ICD) is used by 194 countries and is the most influential and widely used classification guide, with around 55,000 unique codes for injuries, diseases and causes of death.

Researchers looked at the latest revision (ICD-11), which will come into effect in 2022, and focused on its chapter on mental, behavioural and [neurodevelopmental disorders](#).

Researchers asked patients with schizophrenia, bipolar disorder, depression, anxiety and [personality disorders](#) in the UK, US and India to compare the WHO descriptions of their diagnoses with their own experiences.

Lead researcher Dr. Corinna Hackman, from UEA's Norwich Medical

School and NSFT, said: "The ICD is the most widely used system to diagnose people with mental health conditions globally. It is extremely influential in framing our understanding of mental illness, and the policy and provision of mental health services.

"Despite this, service users' perspectives have not been included in previous versions of the ICD.

"We wanted to gain feedback from service users internationally on how the WHO intends to classify mental health conditions, and in particular—whether their diagnostic descriptions resonate with the lived experiences of patients.

"We found that the WHO diagnosis descriptions didn't always resonate with people's lived mental health experiences. In particular, the descriptions focused on external symptoms, things that can be seen on the outside, rather than the internal, felt-experience.

"Our findings suggest that this may have potential unintended consequences for service users of feeling alienated and misunderstood.

"People with [bipolar disorder](#) for example thought that the WHO description only reflected negative aspects of the condition, and identified increased levels of creativity, associated with mania, as a positive aspect.

"People with schizophrenia said that the WHO diagnosis wording didn't cover things like difficulties relating to, and communicating with, other people including feelings of isolation and alienation from other people.

"In some cases the wording was confusing or objectionable—for example the use of the word 'retardation' for depression.

"This research offers a unique insight into the views of service users and it really represents an overdue watershed moment in mental [health](#) diagnosis," she added.

Participants also compared the WHO's classification wording with alternate lay translations created by the research team.

Research collaborator Dr. Caitlin Notley, also from UEA's Norwich Medical School, said: "Participants reported that the lay summaries were much more clear, accessible and easier to understand—and consequently they felt that they resonated much better with their own lived experience.

"What we have shown is that patients would benefit from a version of the WHO disease classification system that is easier to understand and includes more information about the felt-experience.

"We hope that the changes we are recommending would also help clinicians better understand and empathise with the felt experience of service users."

The study was undertaken by NSFT, UEA and the London School of Hygiene and Tropical Medicine, in collaboration with Columbia University, NYC, a peer-led service in New Jersey and the All India Institute of Medical Sciences, New Delhi.

It is hoped that the findings will help inform further ICD-11 revisions.

The findings were translated into coproduced recommendations for the WHO, which has established a process of review and consideration of incorporation into revisions of the clinical descriptions and diagnostic guideline for ICD-11 Mental, Behavioural and Neurodevelopmental Disorders.

More information: 'Perspectives on the International Classification of Diseases, 11th Revision (ICD-11); an international qualitative study to Understand and improve mental health Diagnosis using expertise by Experience: INCLUDE Study' is published in *The Lancet Psychiatry* on Monday, July 8, 2019.

Provided by University of East Anglia

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