

Lived experience perspectives essential to reducing global mental health stigma: Study

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Media and anti-stigma activities could help combat mental health stigma and discrimination, but only with lived experience involvement, according to research led by the Institute of Psychiatry, Psychology &

Neuroscience (IoPPN) at King's College London in collaboration with the Global Mental Health Peer Network.

The [study](#), published in *eClinicalMedicine*, is the first to co-produce research with people with lived experience of [mental health conditions](#) to investigate global perspectives of mental health related [stigma](#) and discrimination.

A total of 198 participants from more than 30 countries across Europe, the Americas, Africa, Asia, and Australia/Oceania shared their perspectives on the role that language, media, and societal reactions play in perpetuating stigmatizing views.

Researchers found that insensitive language and misinformation continue to reinforce harmful stereotypes about mental health conditions around the world. Tokenistic involvement of people with lived experience resulted in weak anti-stigma campaigns with little positive impact.

The findings emphasized that people with lived experience play a key role in efforts to reduce stigma and discrimination.

"Superficially including people with lived experience in research is not enough—there must be genuine collaboration. By co-producing our research with people with lived experience, we developed a deeper understanding of global perspectives of stigma, centered around the priorities of those that are impacted by discrimination.

"Our findings highlighted the role of language, media, and societal reactions in perpetuating stigma, and emphasized the importance of involving people with lived experience in the production of anti-stigma activities to maximize impact," says Dr. Petra Gronholm, first author of the study and Research Fellow at King's IoPPN.

This study included people with lived experience as co-authors and collaborators at every stage of the work, from developing methods and [data collection](#) to analysis and conclusions, as well as writing the manuscript for peer-reviewed publication.

The role of language and the media

Participants reported that terms used for mental health conditions, both in informal and health care settings, were often derogatory or insensitive, perpetuating stigma and discrimination. They emphasized that using person-first language was important to avoid feeling defined as a diagnosis, rather than a person.

A participant from Russia said, "Being addressed 'psycho' or 'mental' whenever we even try to articulate our mental health struggle and overthinking we experience, [can] make us feel unsafe to share it [mental distress]... fear of judgment make it hard and unsafe for us to admit we have mental health issues."

The media was identified as a key mechanism for reinforcing harmful stereotypes through language, imagery, and misinformation. Participants felt that media and culture contributed to societal reactions and misunderstandings about mental health. Many participants feared [negative reactions](#) to disclosing conditions from family, friends, workplaces, and health care professionals.

However, person-centered, balanced, and factual media content on mental health difficulties could normalize the topic and educate people.

A participant from Kenya said, "There has been increased media coverage on mental health and a general sense of tolerance has grown."

Lived experience involvement in anti-stigma activities

Although anti-stigma activities such as awareness-raising campaigns and education initiatives were thought to be helpful, participants felt that lived experience involvement was sometimes tokenistic, resulting in reduced effectiveness.

Participants experienced multiple challenges during their involvement in anti-stigma campaigns, including negative reactions from others, the burden of reliving [past experiences](#), and sensing that their involvement was superficial.

However, training and support for people with lived experience to enable them to speak out and share their narratives safely helped overcome some of these challenges, alongside the personal sense of satisfaction that came with involvement. The researchers noted that all participants had taken part in anti-stigma activities, which may have influenced their perspectives.

A participant from Norway said, "[It is] hardest to share a story or deliver a workshop if a safe space is not created first."

The authors emphasized that participation at all stages of anti-stigma program planning, delivery, and evaluation needs to extend beyond a tokenistic role to genuine collaboration to effectively reduce stigma and discrimination.

The study follows The Lancet Commission on Ending Stigma and Discrimination in Mental Health, [published](#) in October 2022, which resulted in a call for radical global action to end stigma and [discrimination](#) against people with mental health conditions. The Commission emphasized the essential role that people with lived experience play in reducing stigma and claiming their rights, a message

that is reinforced by the new findings.

More information: Petra C. Gronholm et al, Exploring perspectives of stigma and discrimination among people with lived experience of mental health conditions: a co-produced qualitative study, *eClinicalMedicine* (2024). [DOI: 10.1016/j.eclinm.2024.102509](https://doi.org/10.1016/j.eclinm.2024.102509)

Provided by King's College London

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