

Antipsychotic Medication Withdrawal Survey
Launched by Maastricht University

Will Hall MA, Prof. Jim van Os

A world survey on antipsychotic medication withdrawal was launched this June by [Maastricht University School for Mental Health and Neuroscience](#), The Netherlands, co-sponsored by the [International Institute for Psychiatric Drug Withdrawal](#). **People over the age of 18, who have taken antipsychotic medications, and who have stopped taking them or tried to stop can complete the anonymous survey online at www.antipsychoticwithdrawalsurvey.com.** Currently available in English and Spanish, translations into additional languages, including, French, German, Italian, Dutch, and Arabic, are also underway.



Did you ever stop taking antipsychotics, or try to stop taking them?

We want to hear from you.

www.antipsychoticwithdrawalsurvey.com

Commonly prescribed antipsychotics include Abilify, Seroquel, Geodon, Haldol, and Risperdal. (a list of antipsychotics is available here: <https://bit.ly/2JfqVmZ>) Antipsychotics are prescribed primarily to treat psychosis, which affects more than 21 million people globally according to the World Health Organization. In recent years however they have expanded to include anxiety and depression, and antipsychotics are today the third most prescribed class of psychiatric

medication. 1.6% of the US population currently takes antipsychotics, according to a 2017 review in the *Journal of the American Medical Association* (1), and antipsychotics are among the top grossing pharmaceuticals sold in the US.

Patients are frequently told antipsychotics are necessary for symptom management in chronic psychiatric diseases, but growing concerns about adverse effects, consideration of the viability of alternative treatments, and disputes about efficacy evidence in clinical research have fueled interest in withdrawal and discontinuation.

The Maastricht study is an epidemiological approach investigating experiences when patients who have taken antipsychotics come off or attempt to come off. The survey asks not only about medication and withdrawal practices but also social supports, relations with mental health professionals, and personal methods of managing symptoms without antipsychotics.

Dr. Jim van Os, Chair of the Department of Psychiatry and Psychology at Maastricht University Medical Centre and a member of the Royal Netherlands Academy of Arts and Sciences, is sponsoring the research through Maastricht University. "This survey is the first of its kind to compare a large sample of patients' firsthand experiences internationally" said van Os. "Once patients start taking these drugs it can remain unclear if, when, and how to stop. The data from this survey will help fill a gap in the existing research."

Will Hall, lead researcher and PhD candidate at the School for Mental Health and Neuroscience, has himself withdrawn from antipsychotic medication. He has worked for more than 13 years in mutual support and patient movement settings, including around psychiatric medication withdrawal, and his current counseling practice frequently addresses antipsychotic discontinuation. Hall's [Harm Reduction Guide to Coming Off Psychiatric Medications](#) is translated into 14 languages and widely used worldwide as a self-help guide to educate and assist people in their medication withdrawal decisions.

The Maastricht study involved patients with experience of antipsychotics as contributors since its beginning stages. The design of the current survey included a unique crowdsourcing component, where more than 75 English language and 18 German language participants shared their ideas and input of what questions the survey should ask. Additional collaborators include John Read, Sandra Escher, Andrea Zwicknagl, Laura Cox, Miriam Larsen-Barr, Dina Tyler, and Monica Cassani, as well as a team of translators. A previous study, funded by the Foundation for Excellence in Mental Health Care, formed a background of conversations around withdrawal, including with Nev Jones, Laysha Ostrow, and Vanessa Krasinski, and the idea of a study of patient experiences of antipsychotic medication withdrawal first emerged in discussions at patient support groups organized by the Freedom Center, in Western Massachusetts.

Van Os has led prior research into the [prevalence of psychosis in the general population](#), and [questioning the viability of the diagnosis of "schizophrenia" for a widely diverse range of experience](#). Van Os is recognized in The Netherlands for his participation in psychiatric patient led initiatives, and contributed to the innovative Dutch website www.psychosenet.nl, a public

resource for psychosis education that includes information about medication withdrawal and harm reduction.

In addition to investigating the variety of methods used -- such as slow tapering, abrupt withdrawal, or intermittent use of medications -- as well as the reasons for discontinuation -- such as adverse side effects, availability of alternate coping methods, or the desire to return to work or raise children -- the Maastricht study also explores the role of social factors influencing the experience of antipsychotic medication withdrawal. Beliefs about the nature of psychiatric diagnosis, attitudes towards prescribers, and the role of support from family and community are addressed, as well as different social supports, coping mechanisms, and wellness tools. Understanding the impact of medication withdrawal on quality of life and reliance on mental health services is also a central aim of the study.

Research lead Hall poses the hypothesis that antipsychotic medication withdrawal will emerge from the study data as a widely diverse patient experience that has lifestyle changes and social support at its center, which would reinforce other findings from studies on patient withdrawal experiences conducted to date.

The survey is currently open to participants in English and Spanish at www.antipsychoticwithdrawalsurvey.com; and those interested in supporting the project are encouraged to share in their social media, email, and internet networks, including a [Facebook group about the survey](#). Anyone who wants to stay updated on study developments and receive information about study findings can [join the study email list here](#).

People who have taken the survey offered feedback on their experience, including:

The survey was a very powerful process, and actually helped me to integrate even more. Glad I could do it, and that it helps research too.

Brave effort on behalf of the researcher(s) and their motivation behind such an important survey... So different than other surveys. I felt "liberated" and "validated". Very nicely done. I look forward to reading the results.

To take the anonymous survey, go to www.antipsychoticwithdrawalsurvey.com

For more info

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[Will Hall](#) is a therapist, mental health trainer, schizophrenia diagnosis survivor, a blogger at Mad In America and host of the Mad In America affiliate [Madness Radio](#) . He is a PhD Candidate at [Maastricht University School for Mental Health and Neuroscience](#), The Netherlands and lead researcher on Maastricht University's [antipsychotic withdrawal study](#). He is on the Faculty of the International Institute for Psychiatric Drug Withdrawal.

[Dr. Jim van Os](#) is a member of the Royal Netherlands Academy of Arts and Sciences, professor of Psychiatric Epidemiology and Public Mental Health at Utrecht University Medical Centre, and former Chair of the Department of Psychiatry and Psychology at Maastricht University Medical Centre. He is ranked in the top 1% of cited researchers in his field; his TEDx talk Connecting to Madness is here <https://bit.ly/2v8k0H2> and his interview on Madness Radio "New Vision of Psychiatry" is here: <https://bit.ly/1RBHTI3>