

SEPT. 11 2019
PROGRESS
REPORT



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



**We want to
hear from you.**

www.antipsychoticwithdrawalsurvey.com

MAASTRICHT WORLD SURVEY ON ANTIPSYCHOTIC DRUG WITHDRAWAL

WILL HALL, MAASTRICHT UNIVERSITY SCHOOL FOR MENTAL HEALTH AND NEUROSCIENCE

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INTRODUCTION

- ▶ Last year I ([Will Hall](#)) launched an online survey for the Maastricht World Study on Antipsychotic Medication Withdrawal. The study is for my PhD research at [Maastricht University School for Mental Health and Neuroscience](#) in the Netherlands, begun in 2016 and supervised by [Dr. Jim van Os](#).
- ▶ Research on antipsychotic withdrawal brings together 15 years of experience working in the field, as well as my personal experiences as a schizophrenia diagnosis survivor, and reflects the collaboration of many user-survivor colleagues and allies over the years.
- ▶ I receive no funding for this research; my income is from my private practice as a therapist and as a training consultant. I also devote considerable time to community development work around mental health. So bear with me as the study proceeds at a more modest pace!



THANKS AND ACKNOWLEDGEMENTS

- This work has been an unpaid part of my PhD studies at Maastricht University. I have greatly benefitted from the assistance and support of many collaborators since inception, and I'm grateful for their contributions and guidance:

Study Committee

Jim van Os
Sandra Escher
John Read

Special Topic Advisor

Miriam Larsen-Barr

Feedback

Laura Cox
James Moore
Monica Cassani
Dina Tyler
Peter Groot

Recruitment

Beth Hazel Faris
Tracy Love
Dana Mccool
Kate de Wolf

Translation

Marian Goldstein
Radoslaw Stupak
Joana Crawford
Masami Glines
Laura van Os
Jade Bertaud
Chiara Forzi
Christian Rauschenberg
Shira Alfiah Burstein
Jan Stensland Holte
Laila Hasmi
Andrea Zwicknagel
Peter Groot

And anyone I may have missed!

INTRODUCTION

- ▶ [Share and take the survey here](#)
- ▶ [Just view the survey questions here](#)
- ▶ Email me will.hall@maastrichtuniversity.nl
- ▶ Phone me +1 413 210 2803



PROGRESS REPORT CONTENTS (CLICK TO SKIP TO SECTION)

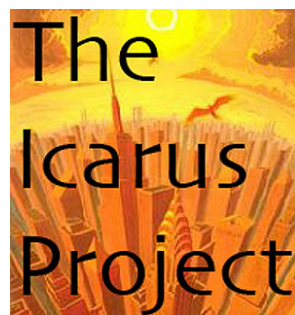
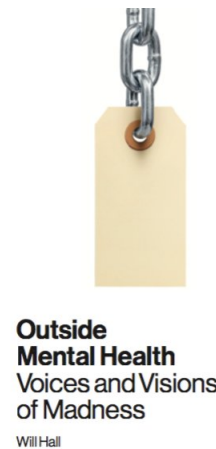
- ▶ [Study Background](#): Will Hall, study committee, *Journal of Humanistic Psychology*
- ▶ [Study Preparation](#): Rationale, crowdsourcing, platform, website, partners
- ▶ [Survey Design](#): Overview, questions, recruitment
- ▶ [Results](#): Rough data collected to date, partial snapshot

STUDY BACKGROUND

- ▶ Ongoing legacy of psychiatric care's failure to adequately meet human rights of patients; controversies in field around medication, diagnosis, and treatment
- ▶ Patient-user-survivor experience of antipsychotic medications goes unrecognized; interest in and experiences of withdrawal unstudied
- ▶ [Freedom Center](#) support groups, [Icarus Project](#) support groups, [Portland Hearing Voices](#) support groups generated many discussions around need for research to include patient-user-survivor experience:
- ▶ Wide success of the [Harm Reduction Guide to Coming Off Psychiatric Drugs](#) (14 languages) showing existing unmet need
- ▶ [UK MIND Coping with Coming Off Study](#), which included survivor researchers, was an early inspiring precedent, a proof-of-concept for research of this kind



STUDY BACKGROUND: WILL HALL, LEAD RESEARCHER



Portland Hearing Voices
embrace *mental* diversity
www.portlandhearingvoices.net

- ▶ Personal experience in the mental health system, schizophrenia diagnosis survivor, disability check for 15 years, past antipsychotics but currently does not take medications
- ▶ PhD Candidate, Maastricht University School for Mental Health and Neuroscience, working with Prof. Jim van Os
- ▶ BA (thesis honors) in Community Studies, MA in Jungian psychology
- ▶ Certificate in Open Dialogue from the Institute for Dialogic Practice
- ▶ Co-founder of Freedom Center, founder of Portland Hearing Voices, co-founder of US Hearing Voices Network, co-founder of WXOJ FM radio, past co-coordinator of Icarus Project
- ▶ Faculty at the International Institute for Psychiatric Medication Withdrawal
- ▶ Support group facilitator in the survivor movement
- ▶ Masters degree therapist working in private practice with psychosis + medication withdrawal
- ▶ Author of *Harm Reduction Guide to Coming Off Psychiatric Drugs*, translated into 14 languages
- ▶ Trainer and educator in more than 15 countries on alternative responses to experiences called psychosis
- ▶ Host of *Madness Radio*
- ▶ Author, *Outside Mental Health: Voices and Visions of Madness*
- ▶ Ongoing community development work around mental health issues
- ▶ Climate emergency mobilization activist

STUDY BACKGROUND: PHD STUDY COMMITTEE

- ▶ **Jim van Os**, MD, PhD (Committee Supervisor) Professor of Psychiatric Epidemiology and Public Mental Health, Head of Neuroscience Division at Utrecht University Medical Centre, member of the Royal Netherlands Academy of Arts and Sciences. Leading innovator in psychiatric research: British Medical Journal *"Schizophrenia Does Not Exist"*
- ▶ **Sandra Escher**, MPhil, PhD, honorary research fellow at the University of Central England in Birmingham, Hearing Voices Movement founder, working to normalize voice hearing and non-ordinary experiences: *"Accepting and Working with Voices"*
- ▶ **John Read**, PhD, Professor at University of East London School of Psychology, Executive Committee, International Society for the Psychological And Social Study of Psychosis. Leading research on child abuse and psychosis: Schizophrenia Bulletin *"Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis"*



STUDY BACKGROUND: SPECIAL TOPIC ADVISOR

- ▶ **Miriam Larsen-Barr**, PhD (special topic advisor) is a clinical psychologist with lived experience from New Zealand who specialises in the study of antipsychotic discontinuation. As a special topic advisor, her role is to support the research committee and provide regular guidance and feedback on survey design, recruitment, data analysis, interpretation of results, and publication of papers. She is the author of [*Experiencing Antipsychotic Medication: From First Prescriptions to Attempted Discontinuation*](#) and lead author of [*Attempting to Discontinue Antipsychotic Medication: Withdrawal Methods, Relapse and Success Attempting to Stop Antipsychotic Medication: Success, Supports, and Efforts to Cope*](#)



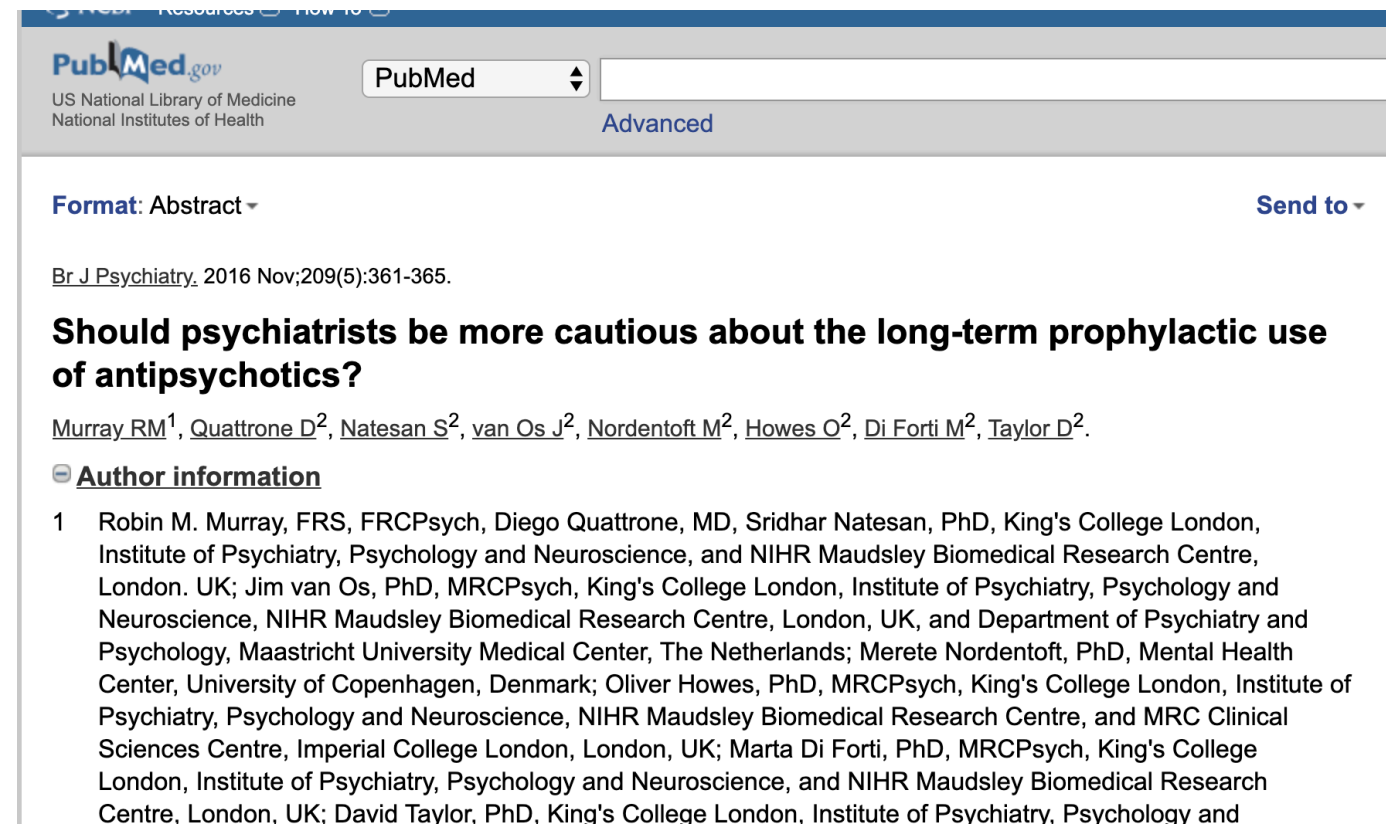
STUDY BACKGROUND: JOURNAL OF HUMANISTIC PSYCHOLOGY

- ▶ “Psychiatric Medication Withdrawal: Survivor Perspectives and Clinical Practice” by Will Hall published March 2018 in *Journal of Humanistic Psychology*. Download here: <https://bit.ly/2m9KHJO>
- ▶ Research agenda for psychiatric medication withdrawal that emphasizes:
 - ▶ psychiatric medications as psychoactive drugs with applicable understandings from addictionology
 - ▶ drug response as individually diverse, relationally embedded, socially constructed, and largely indeterminate
 - ▶ relational common factors in treatment outcomes
 - ▶ patient empowerment patient-doctor collaboration as a larger paradigm of medical practice: “Dr. Google”
 - ▶ common experiences in disease management medications withdrawal across medical domains (asthma, hypertension, epilepsy, diabetes)
 - ▶ individual needs, responses, and approaches, contrasted with applying statistically governed category assessment from the paradigm of “evidence-based medicine”



STUDY PREPARATION: SURVEY RATIONALE

- ▶ Gap in existing literature on antipsychotic withdrawal
- ▶ Antipsychotics seen as medications for life now being questioned
- ▶ Focus on antipsychotics makes analysis more concise; more directly calls into question existing standard of drugs for life
- ▶ Sizable sample, international scope strengthens conclusions
- ▶ Mistaken understanding that psychiatric drug withdrawal can be understood pharmacologically: emergence of relational and adaptation view
- ▶ Importance of patient experiences
- ▶ Rise of survivor led research
- ▶ Complements similar research now emerging; builds redundancy of similar conclusions



PubMed
US National Library of Medicine
National Institutes of Health

PubMed

Format: Abstract

[Br J Psychiatry](#). 2016 Nov;209(5):361-365.

Should psychiatrists be more cautious about the long-term prophylactic use of antipsychotics?

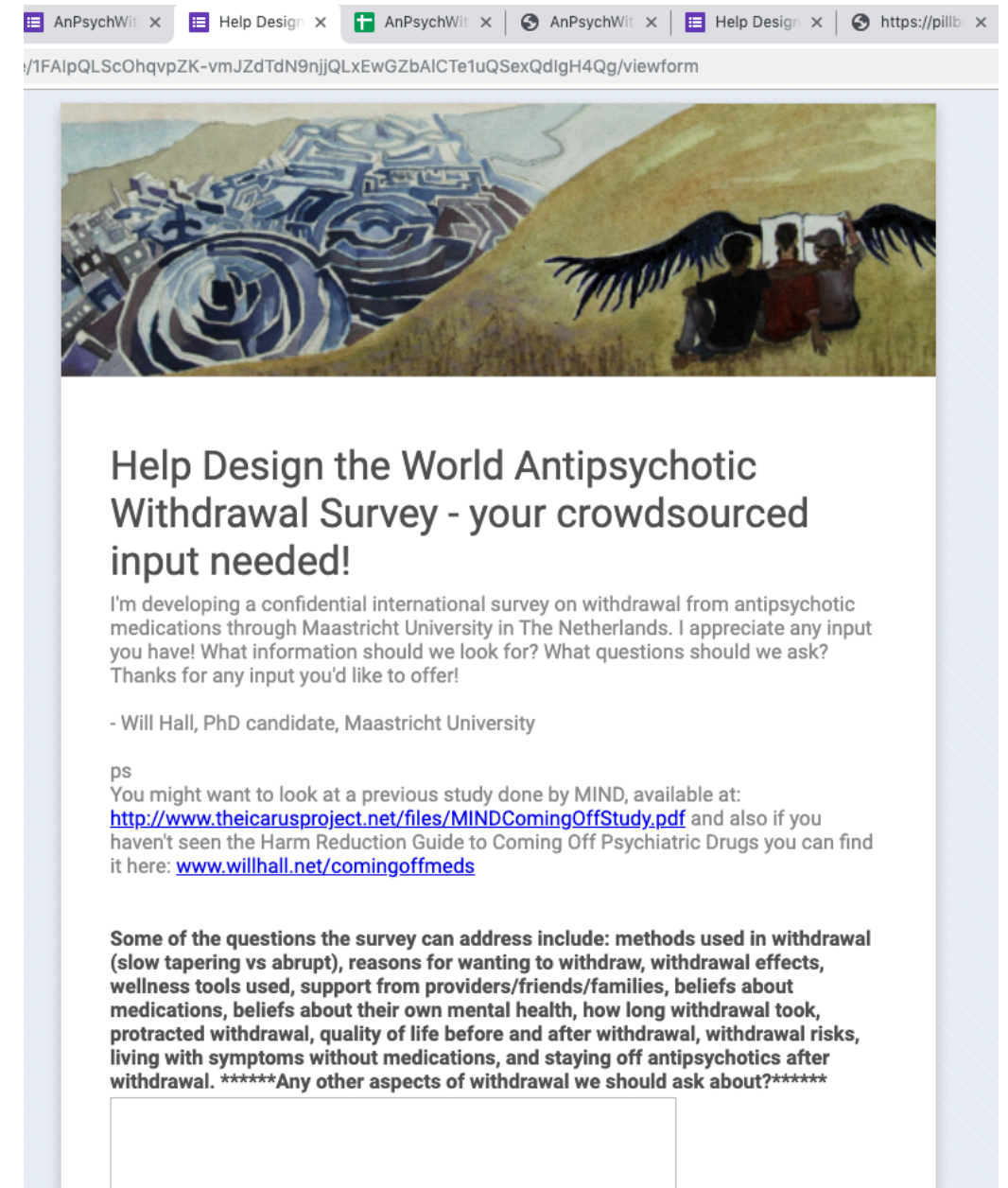
[Murray RM](#)¹, [Quattrone D](#)², [Natesan S](#)², [van Os J](#)², [Nordentoft M](#)², [Howes O](#)², [Di Forti M](#)², [Taylor D](#)².

Author information

1 Robin M. Murray, FRS, FRCPsych, Diego Quattrone, MD, Sridhar Natesan, PhD, King's College London, Institute of Psychiatry, Psychology and Neuroscience, and NIHR Maudsley Biomedical Research Centre, London, UK; Jim van Os, PhD, MRCPsych, King's College London, Institute of Psychiatry, Psychology and Neuroscience, NIHR Maudsley Biomedical Research Centre, London, UK, and Department of Psychiatry and Psychology, Maastricht University Medical Center, The Netherlands; Merete Nordentoft, PhD, Mental Health Center, University of Copenhagen, Denmark; Oliver Howes, PhD, MRCPsych, King's College London, Institute of Psychiatry, Psychology and Neuroscience, NIHR Maudsley Biomedical Research Centre, and MRC Clinical Sciences Centre, Imperial College London, London, UK; Marta Di Forti, PhD, MRCPsych, King's College London, Institute of Psychiatry, Psychology and Neuroscience, and NIHR Maudsley Biomedical Research Centre, London, UK; David Taylor, PhD, King's College London, Institute of Psychiatry, Psychology and

STUDY PREPARATION: CROWDSOURCING SURVEY DESIGN

- ▶ 2016 an internet Help Design the Study survey was shared online in English and German with more than 100 service user-survivors asked for input on the survey questions for the Maastricht Antipsychotic Withdrawal study.
- ▶ Responses were incorporated into survey design: overall conception and questions asked
- ▶ Responses generally coincided with the earlier drafts and ideas about the survey design.
- ▶ [View Help Design survey in English here https://bit.ly/2kchZHB](https://bit.ly/2kchZHB)



STUDY PREPARATION: QUALTRICS SURVEY PLATFORM

- ▶ Industry-standard survey platform for user experience design and data collection
- ▶ Data migration to excel, STATA, and other platforms
- ▶ Exceptional user support

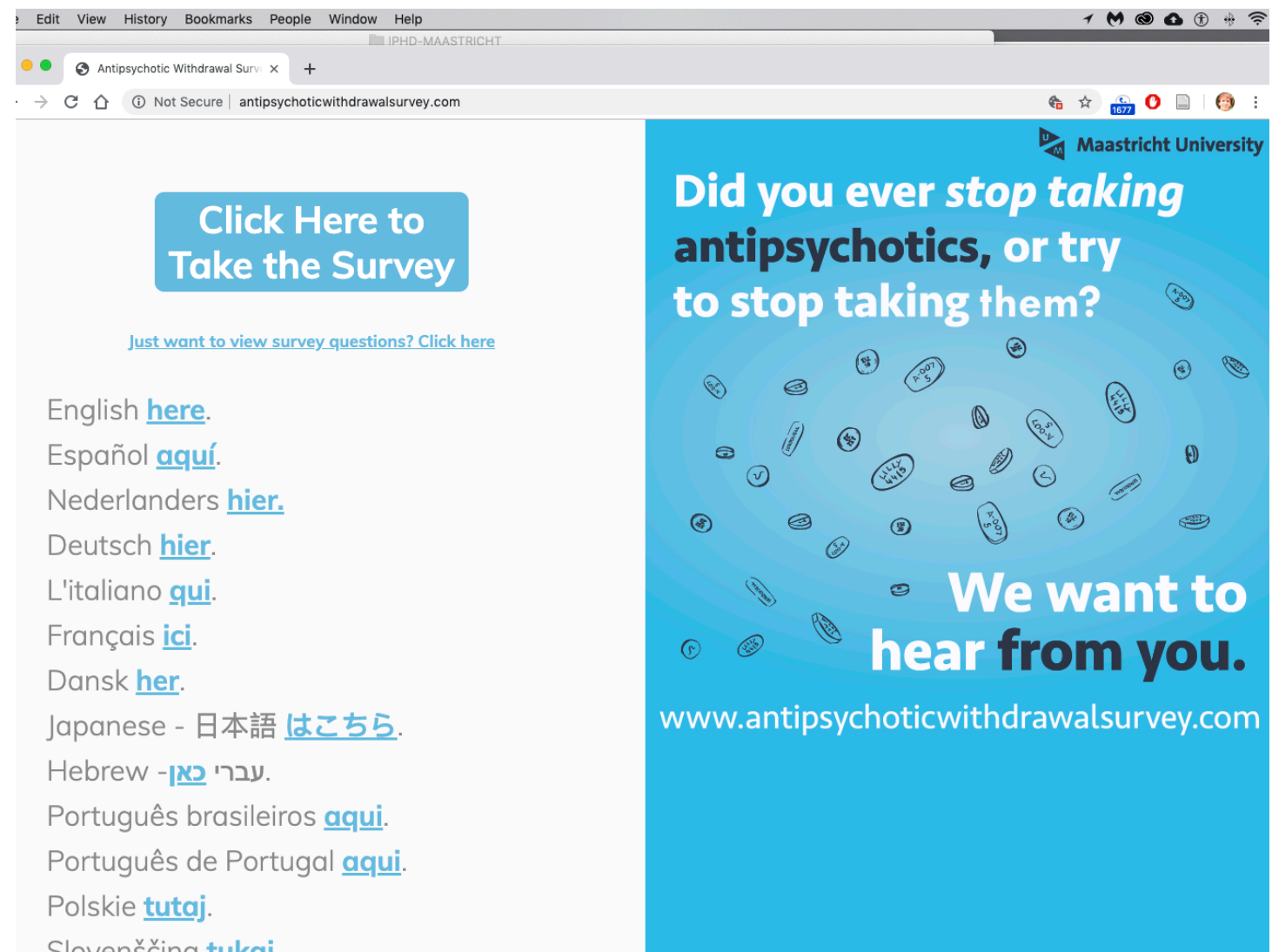


Powerful research to power the four core experiences

Get started with the world's #1 research platform.
Drag-and-drop simplicity. Automated analytics.
Sophisticated research, made simple.

STUDY PREPARATION: WEBSITE AND TRANSLATIONS

- ▶ Easily shared website
www.antipsychoticwithdrawalsurvey.com
- ▶ 10 university paid translators for Spanish, Dutch, German, Italian, French, Danish, Japanese, Hebrew, Portuguese (Portugal and Brazilian)
- ▶ 2 volunteer translations: Polish, Slovenian.



STUDY PREPARATION: PARTNERS

- ▶ Maastricht University School for Mental Health And Neuroscience - Netherlands
- ▶ International Institute for Psychiatric Drug Withdrawal - US and Sweden
- ▶ FIOCRUZ - Brazil



SURVEY DESIGN: OVERVIEW

- ▶ **18+, taken antipsychotics, withdrawn, or tried to withdraw**
- ▶ **Anonymous web survey** completed online with an internet browser desktop and mobile compatible
- ▶ **167 questions**, multiple choice with 15 opportunities for text and narrative replies and 3 open-ended questions.
- ▶ **~30 mins to complete** entire survey, but key questions front loaded so meaningful data collected even from partial completion

SURVEY DESIGN: GENERAL QUESTION AREAS

- ▶ **Demographic** information: *employment, homelessness, education, ethnicity, gender*
- ▶ **Medication use** current and past: *people off antipsychotics completely, people taking other psych meds*
- ▶ **Reasons** for withdrawal: *side effects, perceived usefulness of medication, education, life circumstances*
- ▶ **Methods** of withdrawal: *gradual vs. abrupt, intermittent use, pill cutters*
- ▶ **Attitudes** towards and relationship with prescribers and mental health professionals
- ▶ **Strategies** for coping with withdrawal: *role of professionals and family, role of medication use, sleep*
- ▶ **Diagnosis**, hospital history, and other psychiatric information: *history of trauma, attitudes towards diagnosis*
- ▶ **Side effects** and withdrawal effects, including persistent effects
- ▶ **Support** sources during the withdrawal process: *family, professionals, peer/user-survivor movement, community*
- ▶ **Experiences** of withdrawal: *disclosure to others, severity of withdrawal effects, crisis and hospitalization,*
- ▶ **Medical** information: *diseases, current health, disability status, role of medications*
- ▶ **Suicidal and psychotic** currently experiences and coping strategies
- ▶ **Open ended** questions: *What did you learn? What would you want professionals to do differently?*
- ▶ **View the survey questions here:** <https://bit.ly/2kHiGsM>

SURVEY DESIGN: RECRUITMENT

- ▶ Social media sharing of survey website
www.antipsychoticwithdrawalsurvey.com
- ▶ 2 part-time research assistants Beth Farris and Dana Mccool; recruitment to African-Americans assistant Tracy Love. Contracted by Maastricht University
- ▶ Presentations to mental health groups internationally (German Association for Social Psychiatry)
- ▶ Mental health newsletters
- ▶ Blog posts / social media promotion: English, Dutch, Spanish, Portuguese
- ▶ Facebook page, Twitter account, email lists
- ▶ Collected email list of people interested in the survey: 1,208 subscribers

SURVEY RESULTS: SNAPSHOT OVERVIEW SO FAR 8-26-2019

- ▶ Data collection ongoing at www.antipsychoticwithdrawalsurvey.com
- ▶ To-date data analysis begun on responses received before 8/26/19, some basic results shown in this report
- ▶ Export of data from Qualtrics to Excel; cleaning raw data
- ▶ Preparation of data for import into STATA for analysis
- ▶ Data collected after 8/26/19 can still be added to analysis

RESULTS: RESPONSES AND N=_

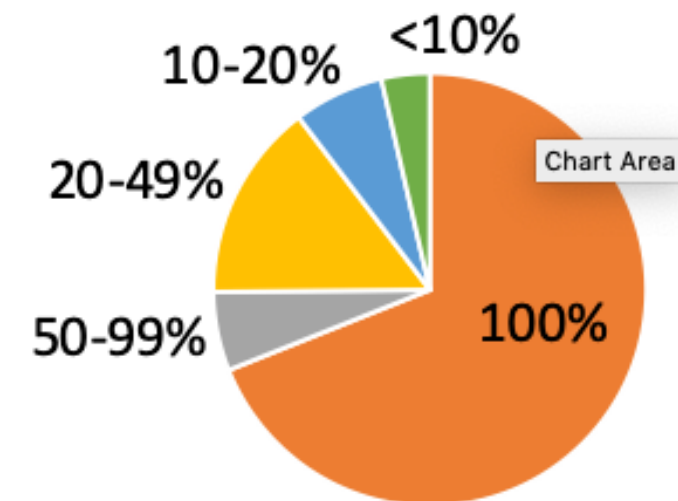
▶ 4733 (valid+invalid) responses:

- ▶ Includes null, spam etc responses
- ▶ Includes 1089 "Do you agree to take?"="No"
- ▶ Includes 243 "Are you 18+ yrs old?"="No"
- ▶ Includes 57 "Have you ever taken antipsychotics?"="No"
- ▶ Includes 84 "Ever stopped or tried to stop?"="No"

▶ 3244 valid responses:

- ▶ 2237 100% completed all questions to end, others varied
 - ▶ ("completed" = if end reached, skipped/incomplete ok)
- ▶ Includes 333 responses of 17% or fewer questions
- ▶ Survey design was unsure if a long survey would have enough completions.
- ▶ **Each question was optional and so has a varying n=** number showing its number of responses
- ▶ **Most questions tend to be around n=2200**

completion rate of valid respondents



respondents completion rate	
2237	100%
480	20-49%
219	10-20%
191	50-99%
117	less than 10%

RESULTS: 71 COUNTRIES REPRESENTED (N=3142)

USA	1093	Greece	9	Luxembourg	1
UK	445	Colombia	7	Bulgaria	1
Canada	204	Switzerland	7	Hong Kong	1
España	197	Estonia	5	Bahrain	1
Nederland	189	Czech Republic	5	Guatemala	1
Australia	183	Perú	5	Jordan	1
Japan	106	Turkey	4	Senegal	1
France	75	Indonesia	4	Slovakia	1
België	69	Portugal	4	Martinique	1
Ireland	53	UAE	4	Bolivia	1
Norway	50	Serbia	3	Fiji	1
Danmark	46	Austria	3	Bangladesh	1
New Zealand	46	Russia	3	Ukraine	1
Deutschland	41	Lithuania	3	Malta	1
Chile	40	Romania	3	Nicaragua	1
Brasil	34	Philippines	3	Pakistan	1
blank	31	Malaysia	3	Saudi Arabia	1
Sweden	23	Country not list	2	(blank)	
Argentina	21	Hungary	2	Grand Total	3173
India	18	Iceland	2		
Slovenija	17	Algeria	2		
México	17	Croatia	2		
Polska	16	Uruguay	2		
South Africa	16	Lebanon	2		
Israel	11	Singapore	2		
Italia	11	Morocco	1		
Finland	10	Costa Rica	1		
		Cyprus	1		

RESULTS: 12 LANGUAGES REPRESENTED (N=3244)

EN (English)	2274
ES-ES (Spanish)	278
DE (German)	235
NL (Dutch)	172
JA (Japanese)	116
FR (French)	89
PT-BR (Portuguese-Brazil)	28
DA (Danish)	24
PL (Polish)	10
IT (Italian)	9
HE (Hebrew)	4
ES (Spanish)	3
PT (Portuguese-Portugal)	2
Grand Total	3244

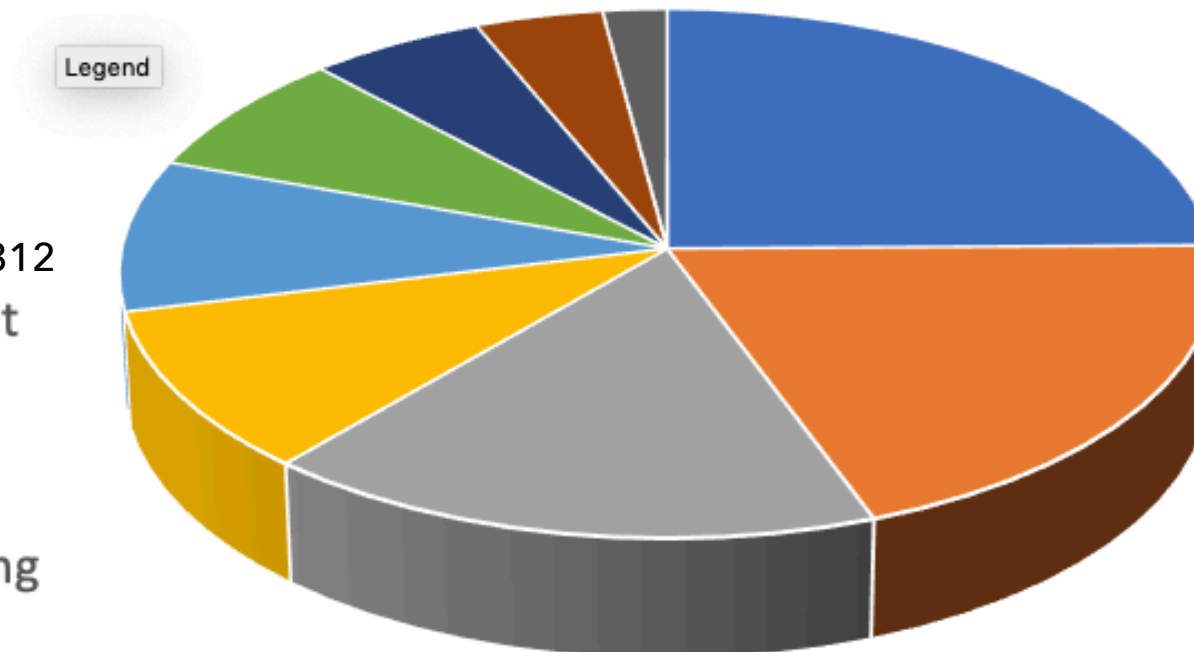
RESULTS: ETHNICITY (N= 3173)

European-White 2522
 Latino/Hispanic 133
 East Asian 113
 -99 85
 South Asian 40
 Middle Eastern 31
 European-White,Not listed, please specify 30
 Black, African-American 21
 Indigenous, American Indian, Aboriginal or Maori 19
 Mixed race please specify 19
 East Asian,Mixed race please specify 15
 Middle Eastern,Mixed race please specify 11
 European-White,Indigenous, American Indian, Aboriginal or Maori 11
 European-White,Latino/Hispanic 10
 Not listed, please specify 10
 Black African-American,Mixed race please specify 8
 European-White,Middle Eastern 7
 South Asian,Mixed race please specify 7

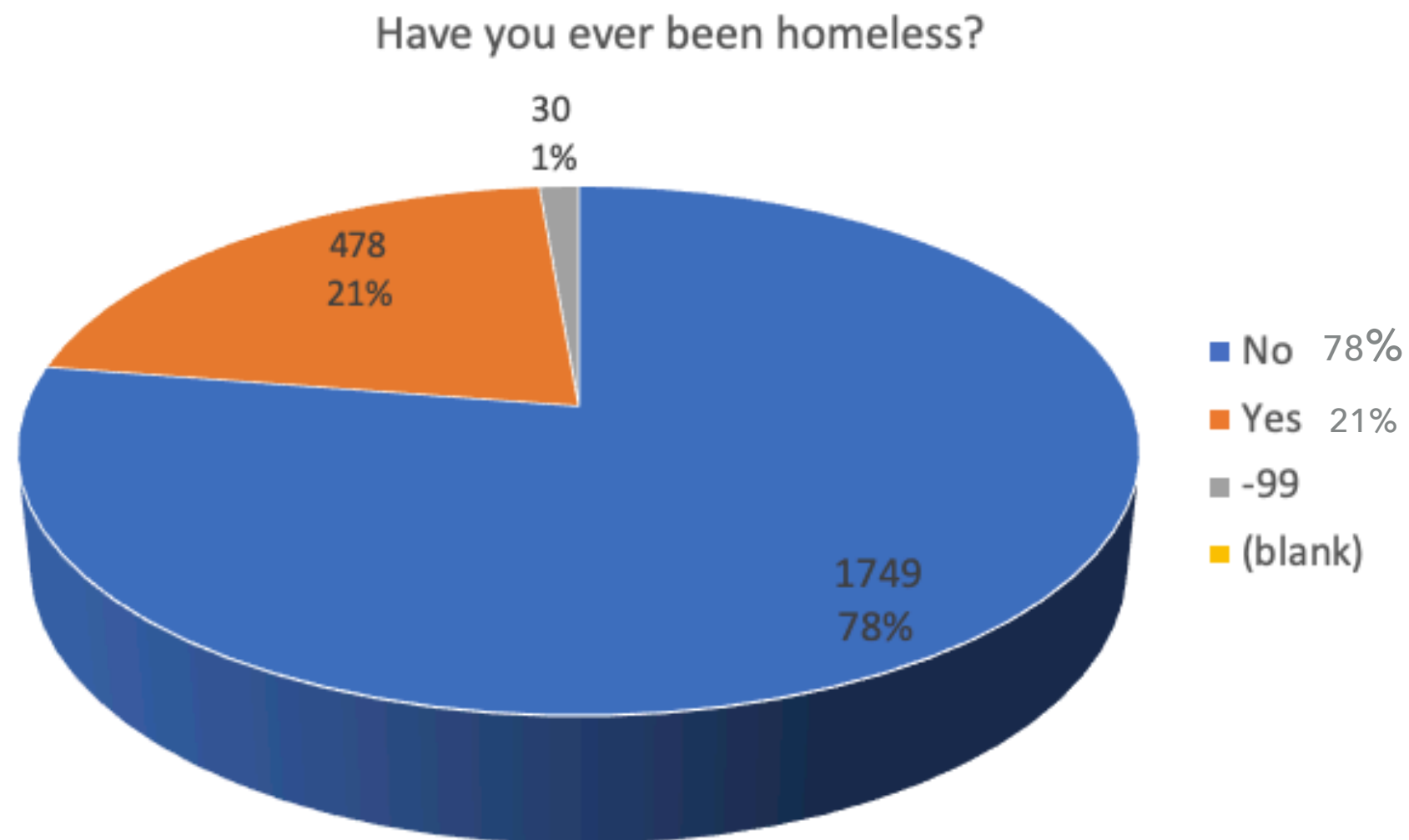
Latino/Hispanic,Mixed race please specify 6
 Indigenous, American Indian, Aboriginal or Maori,Mixed race please specify 6
 East Asian,Not listed, please specify 6
 South Asian,Not listed, please specify 5
 Black, African-American,Caribbean,Mixed race please specify 5
 Caribbean 3
 European-White,East Asian,Mixed race please specify 3
 Latino/Hispanic, Mixed race please specify 3
 Black, African-American, Mixed race please specify 3
 European-White,Indigenous, American Indian, Aboriginal or Maori,Mixed race please specify 3
 Mixed race please specify,Not listed, please specify 2
 European-White,Mixed race please specify 2
 African 2
 Latino/Hispanic,not listed, please specify 2
 Black, African-American, Indigenous, American Indian, Aboriginal or Maori 2
 Indigenous, American Indian, Aboriginal or Maori, Mixed race please specify 2
 Asian, Mixed race please specify 2
 European-White,Black, African-American 2

RESULTS: EMPLOYMENT STATUS (N=3064)

- Disabled 776
- Full time paid employment 613
- Part time paid employment 527
- Unemployed and not looking for employment 312
- Student 291
- Unemployed and looking for employment 238
- Retired 178
- Volunteering or internship 129

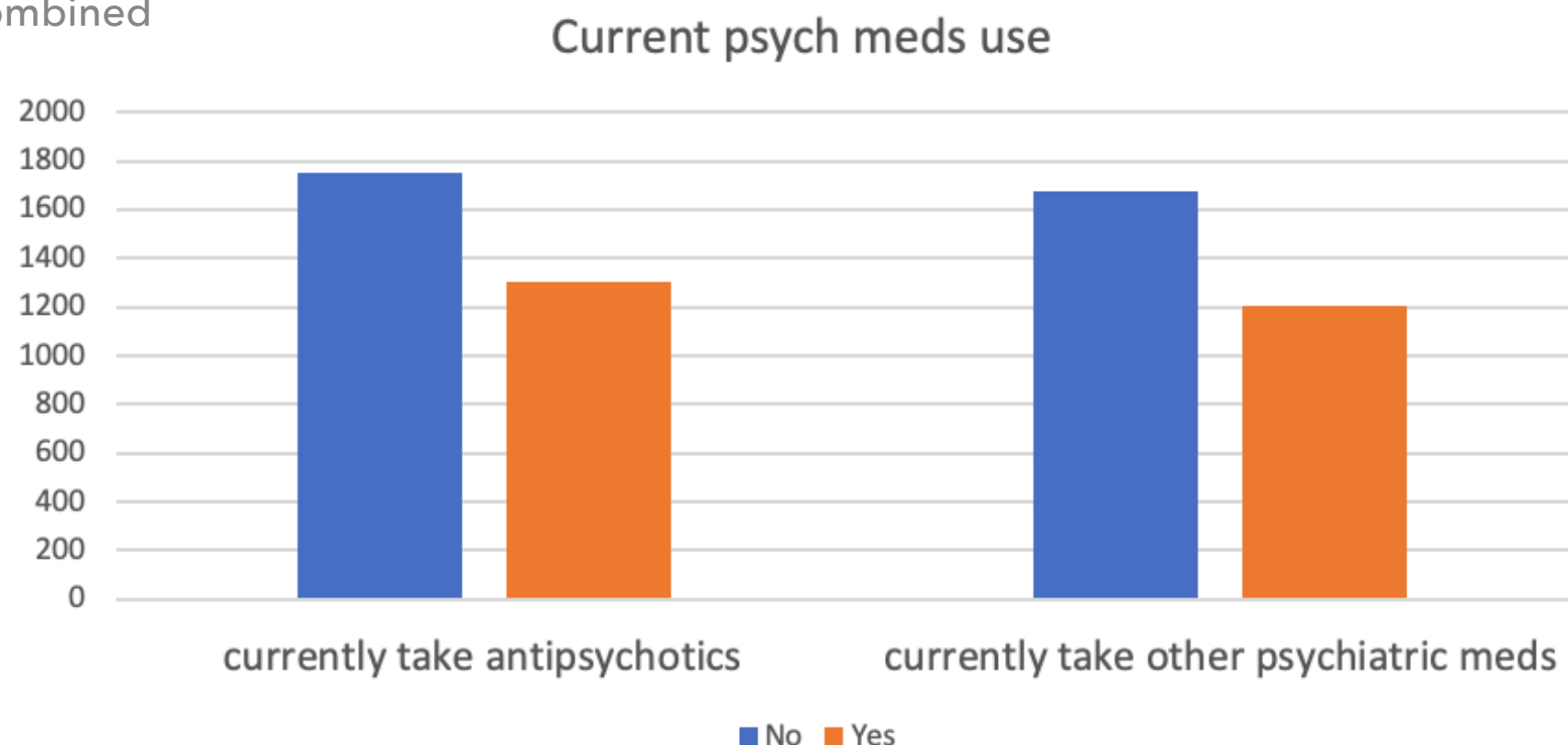


RESULTS: HOMELESSNESS (N=2227)



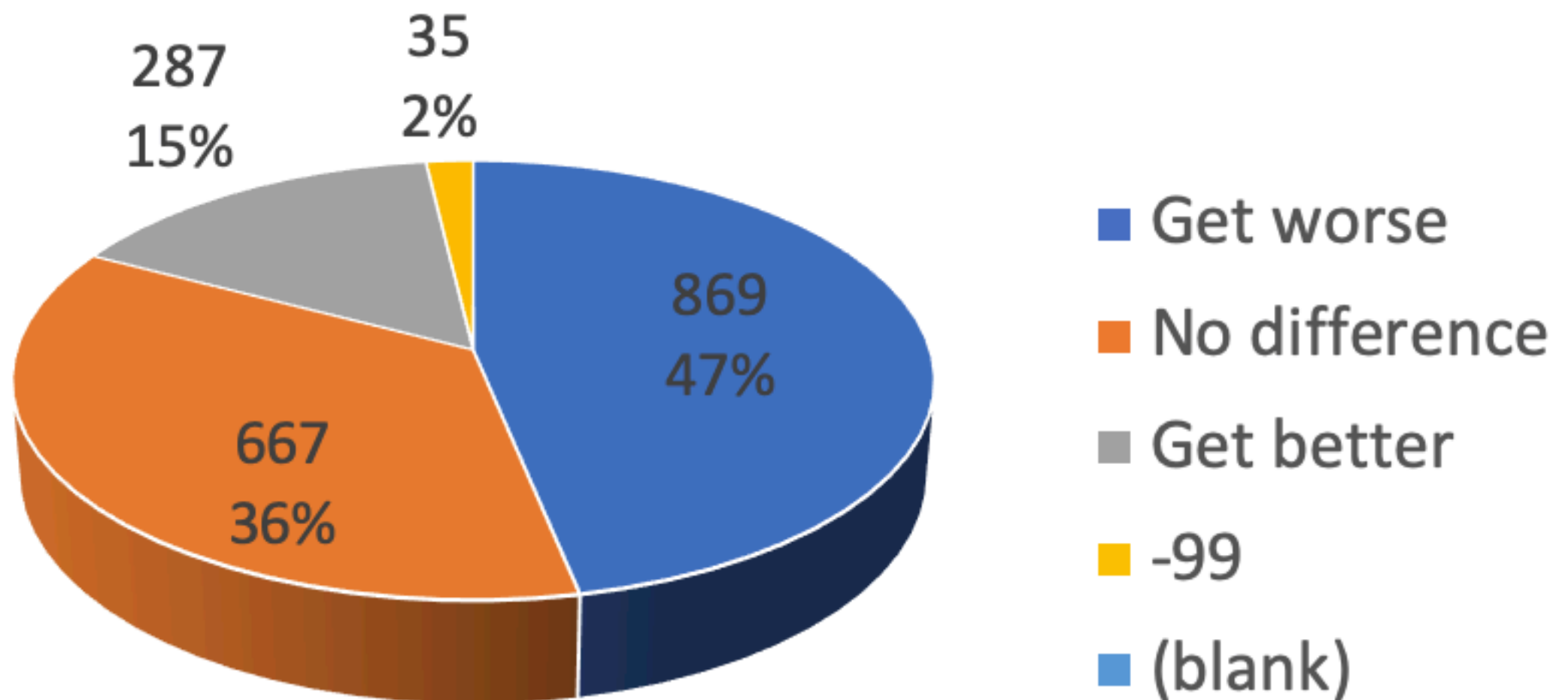
RESULTS: CURRENT PSYCHIATRIC DRUG USE? (N=3103)

- ▶ Currently not taking antipsychotics=1751, of 3103 responding
- ▶ Currently taking antipsychotics=1306, of 3103 responding
- ▶ Currently not taking other psychiatric meds= 1672, of 2910 responding
- ▶ Currently taking other psychiatric meds=1203, of of 2910 responding
- ▶ Note - charts not combined



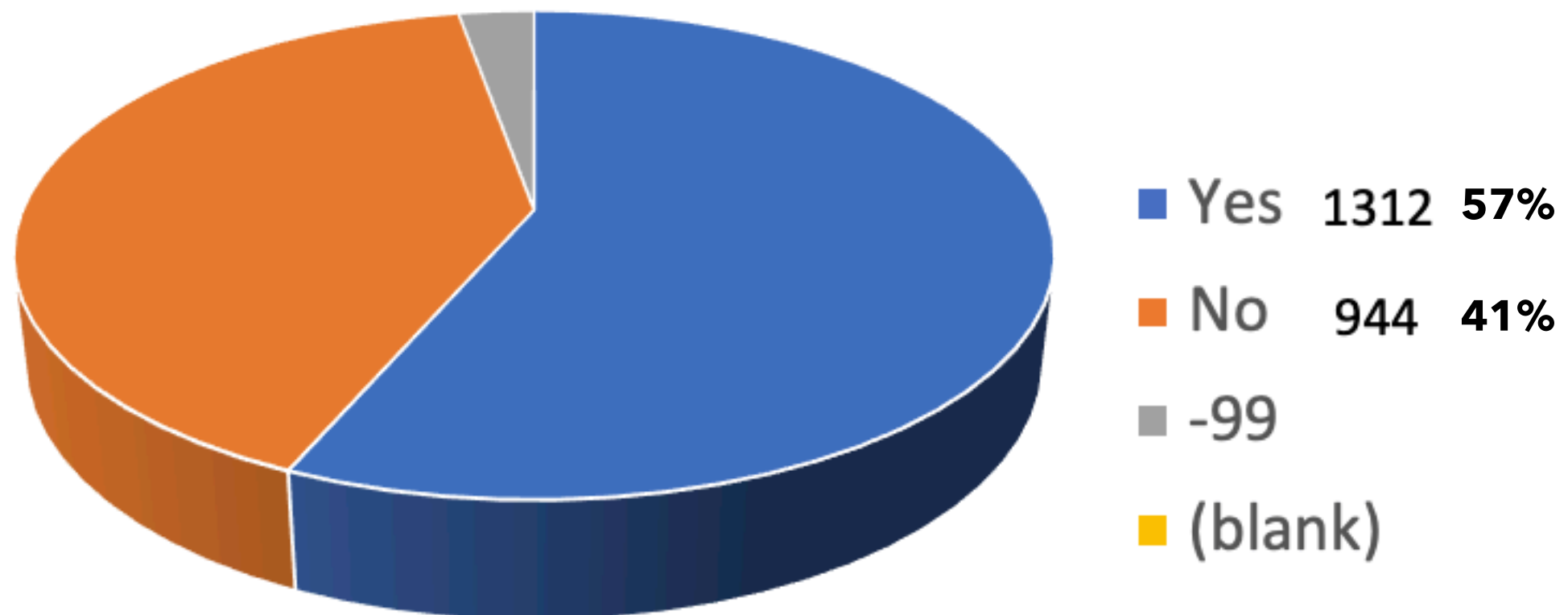
RESULTS: EFFECT ON SUICIDAL FEELINGS? (N=1856)

Antipsychotics made my suicidal feelings



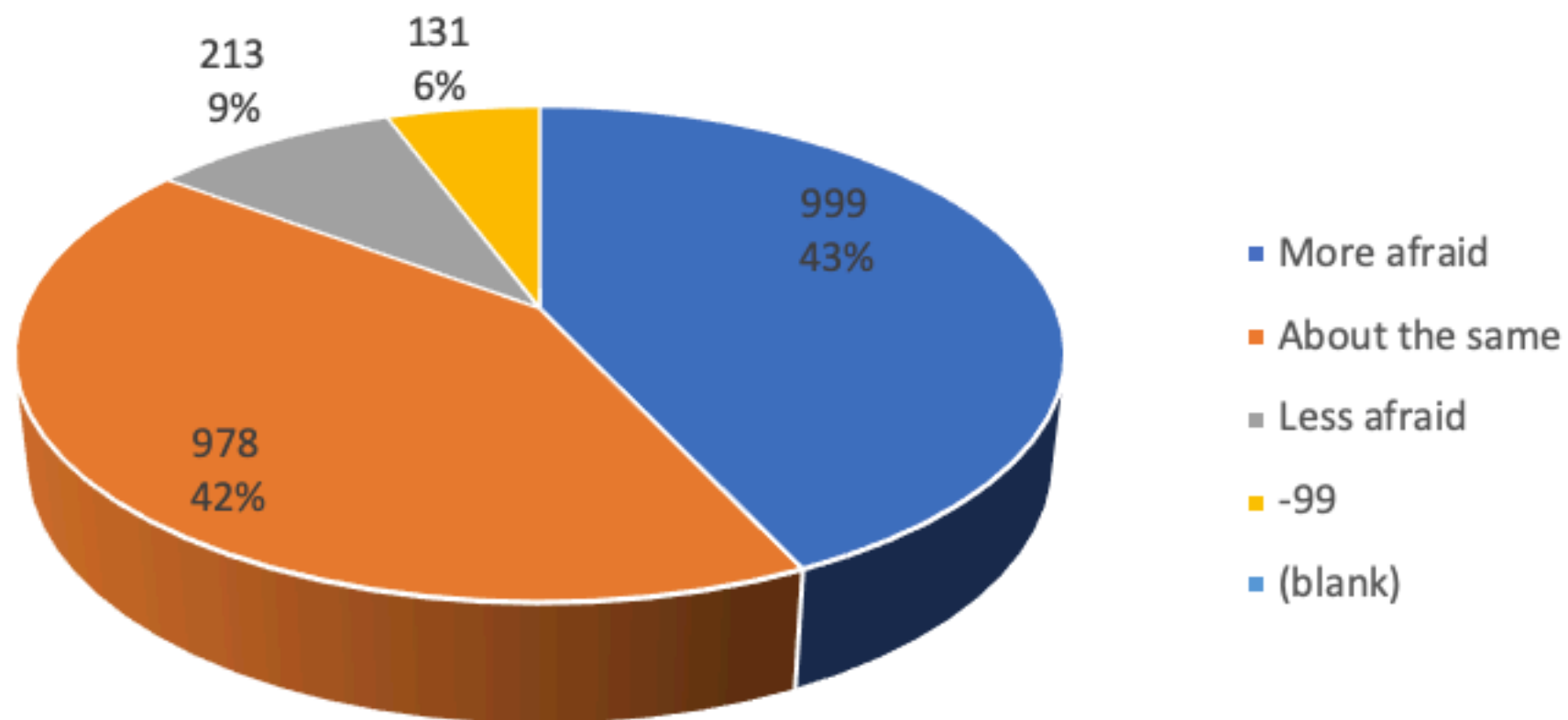
RESULTS: BLAMED WITHDRAWAL ON DISORDER? (N=2256)

Did a professional ever tell you withdrawal effects were your illness instead?

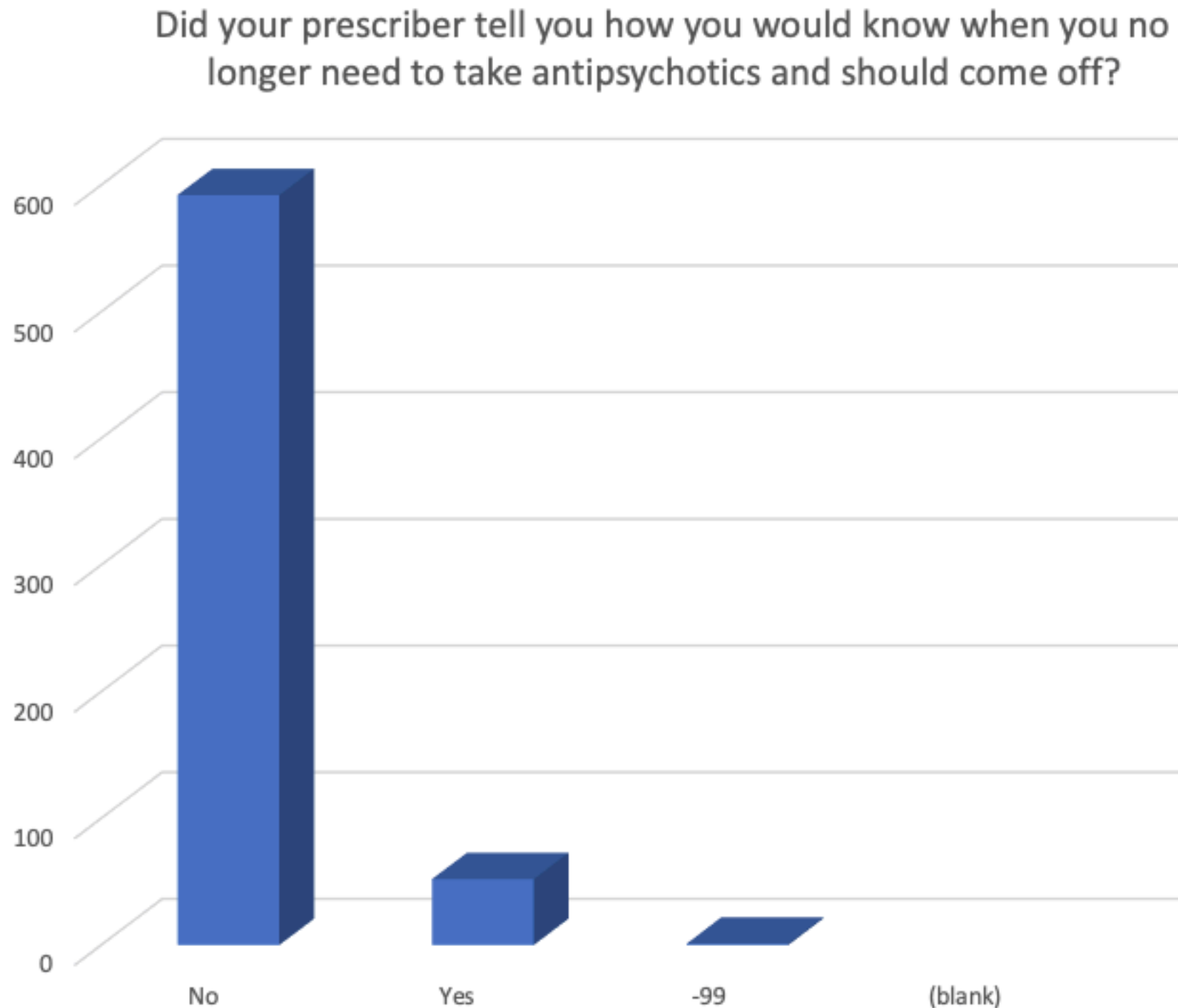


RESULTS: HOW DID PROVIDERS MAKE YOU FEEL? (N=2190)

Overall how did prescribers make you feel about the process of withdrawal?

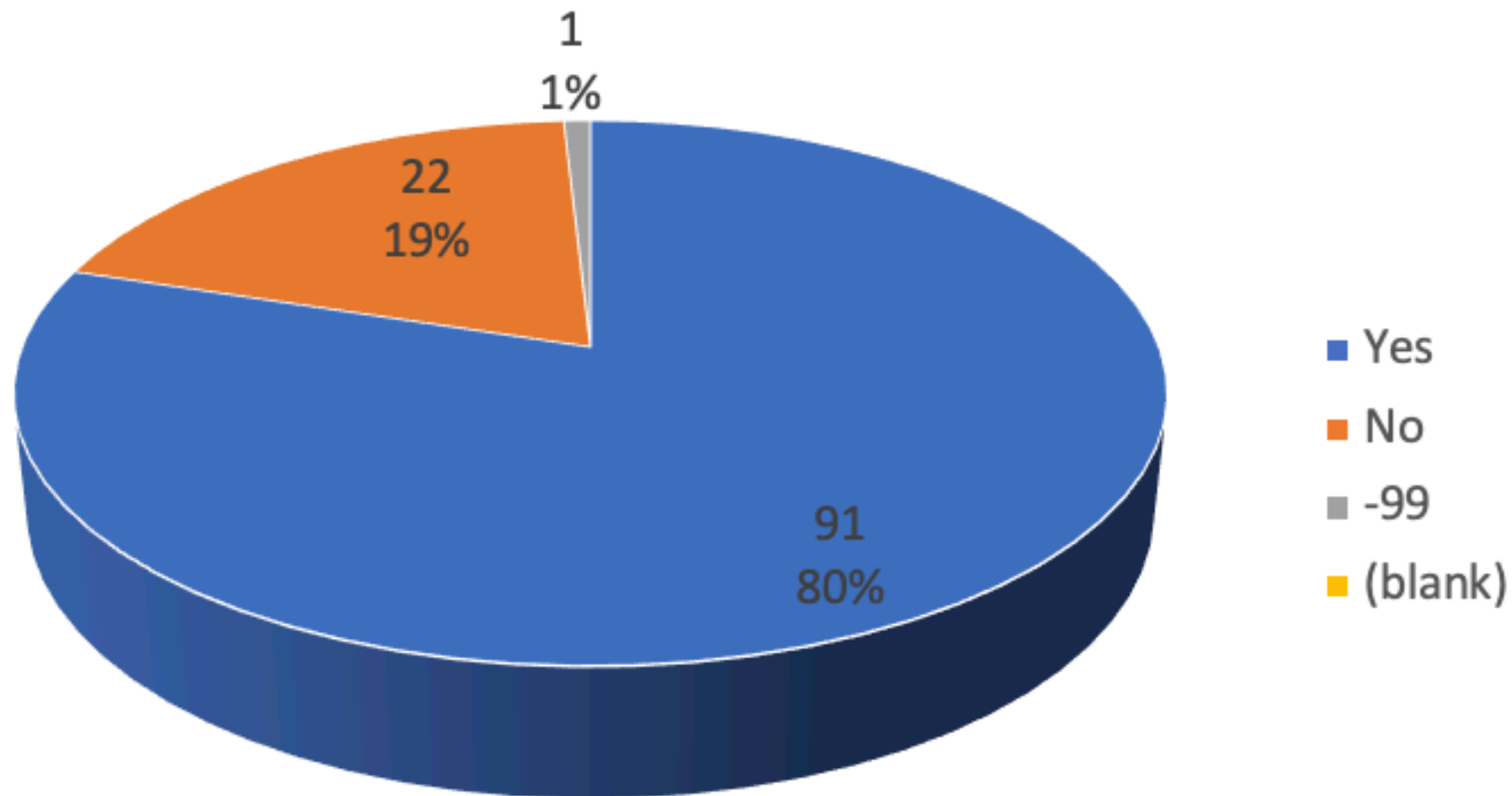


RESULTS: TOLD WHEN MEDICATION UNNEEDED? (N= 644)



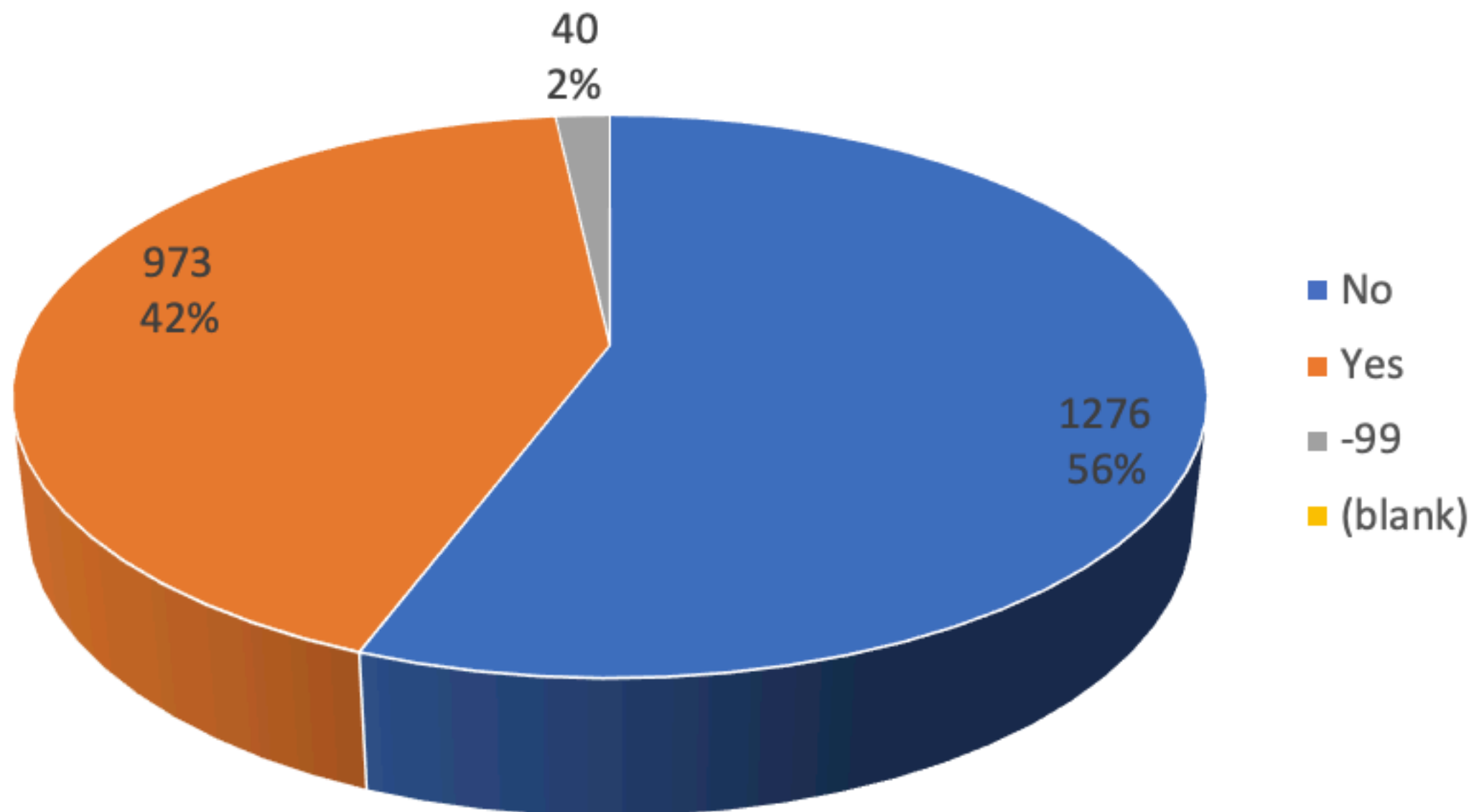
RESULTS: WHEN DID DIABETES START? (N=113)

If you were diagnosed with diabetes, was it diagnosed after you started taking antipsychotics?

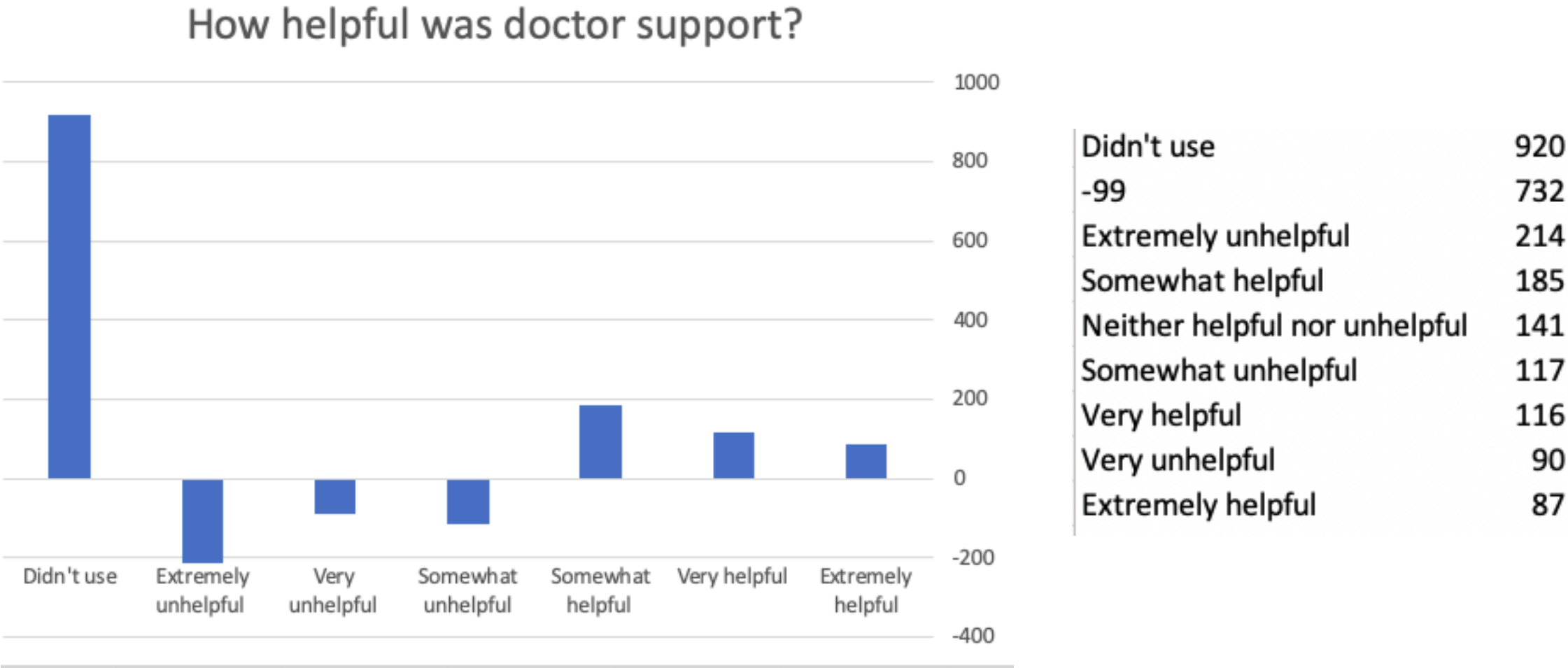


RESULTS: CURRENT EXPERIENCE OF PSYCHOSIS (N=2249)

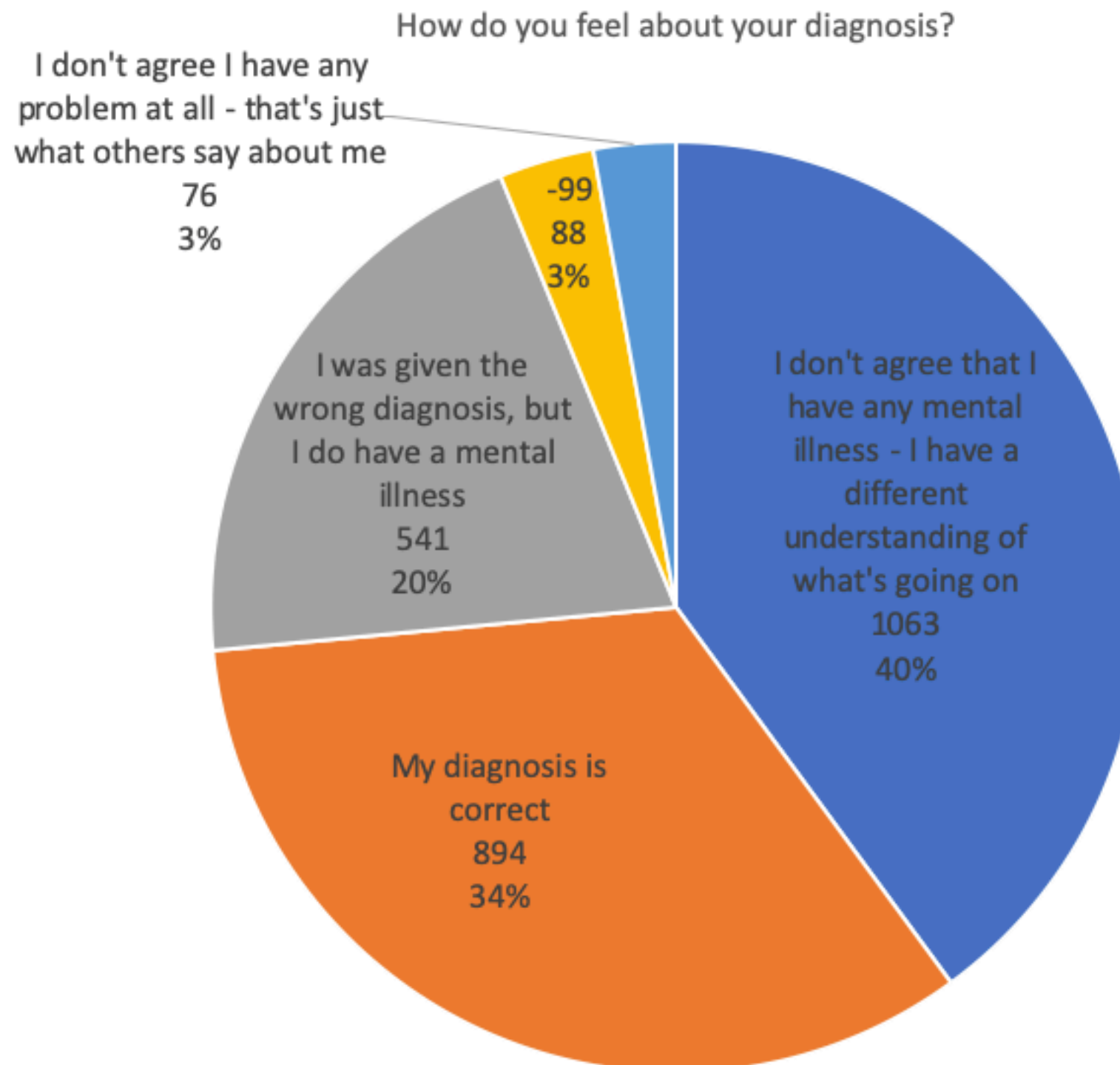
Do you currently experience anything doctors might consider psychosis, such as voices, paranoia, unusual beliefs...?



RESULTS: HOW HELPFUL WAS A DOCTOR’S SUPPORT? (N=1729)

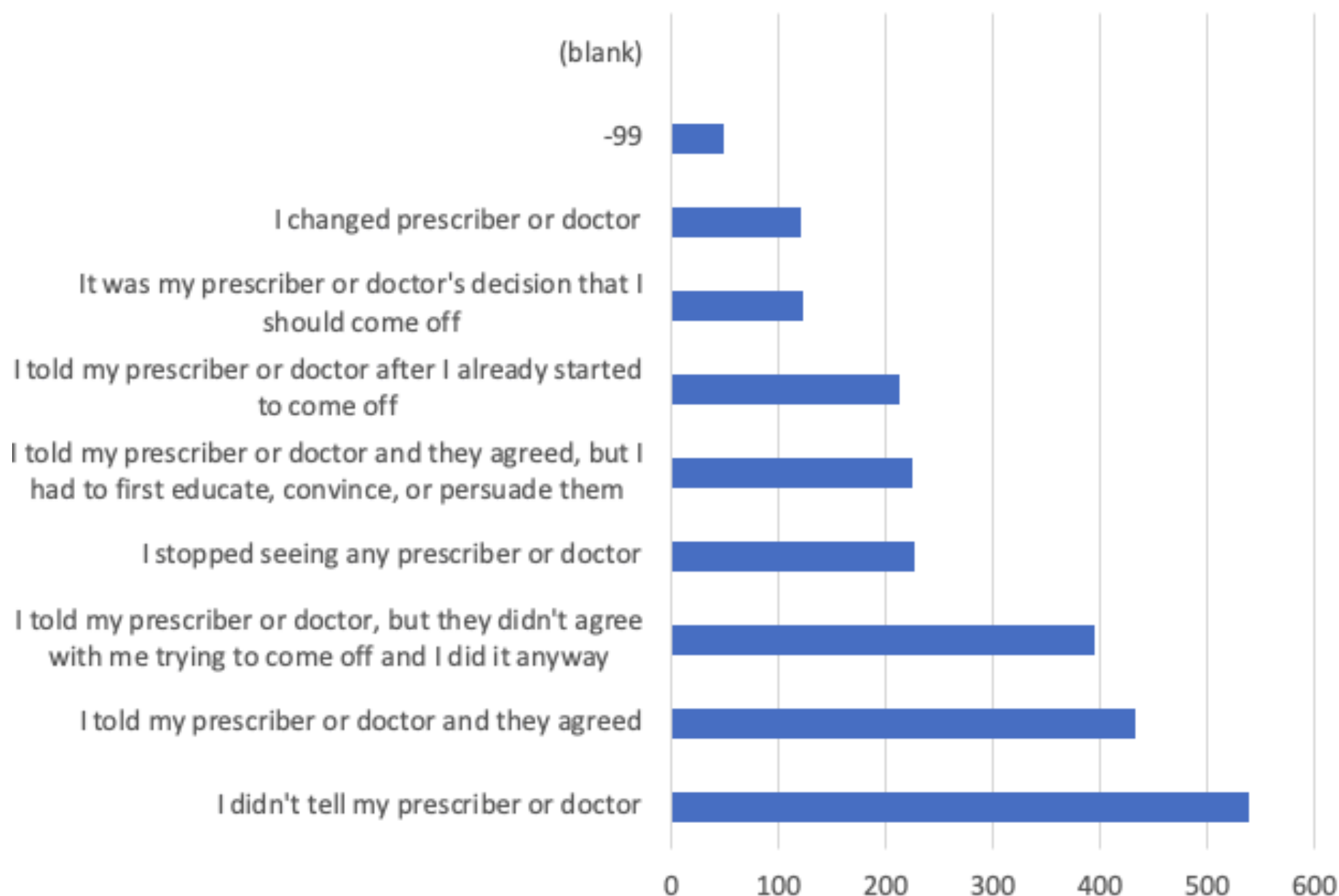


RESULTS: HOW DO YOU FEEL ABOUT YOUR DIAGNOSIS? (N=2574)



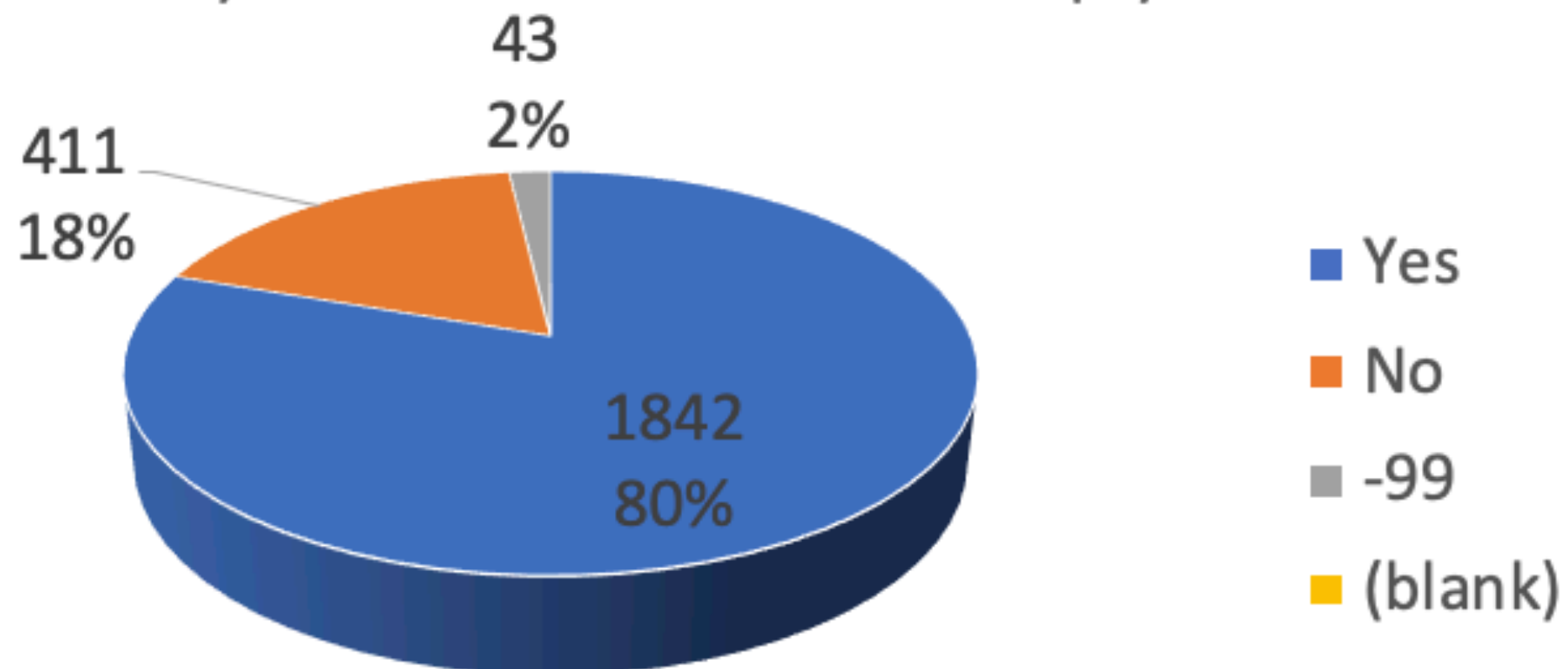
RESULTS: HOW WAS YOUR PRESCRIBER INVOLVED? (N=2273)

How was your prescriber / doctor involved in your decision to come off?



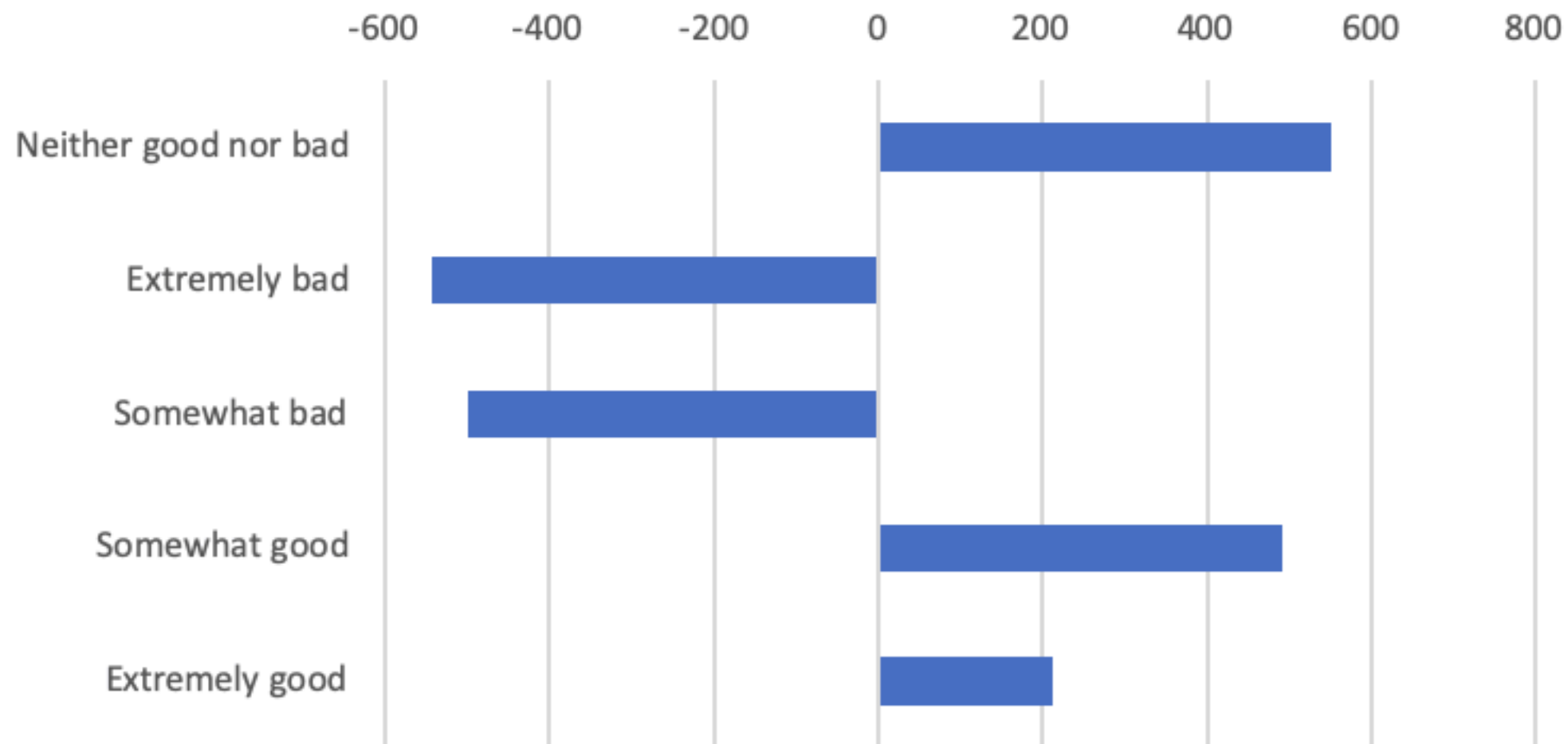
RESULTS: ANGER TOWARDS PROFESSIONALS? (N=2253)

Were you ever angry at doctors or professionals about your treatment related to antipsychotics?



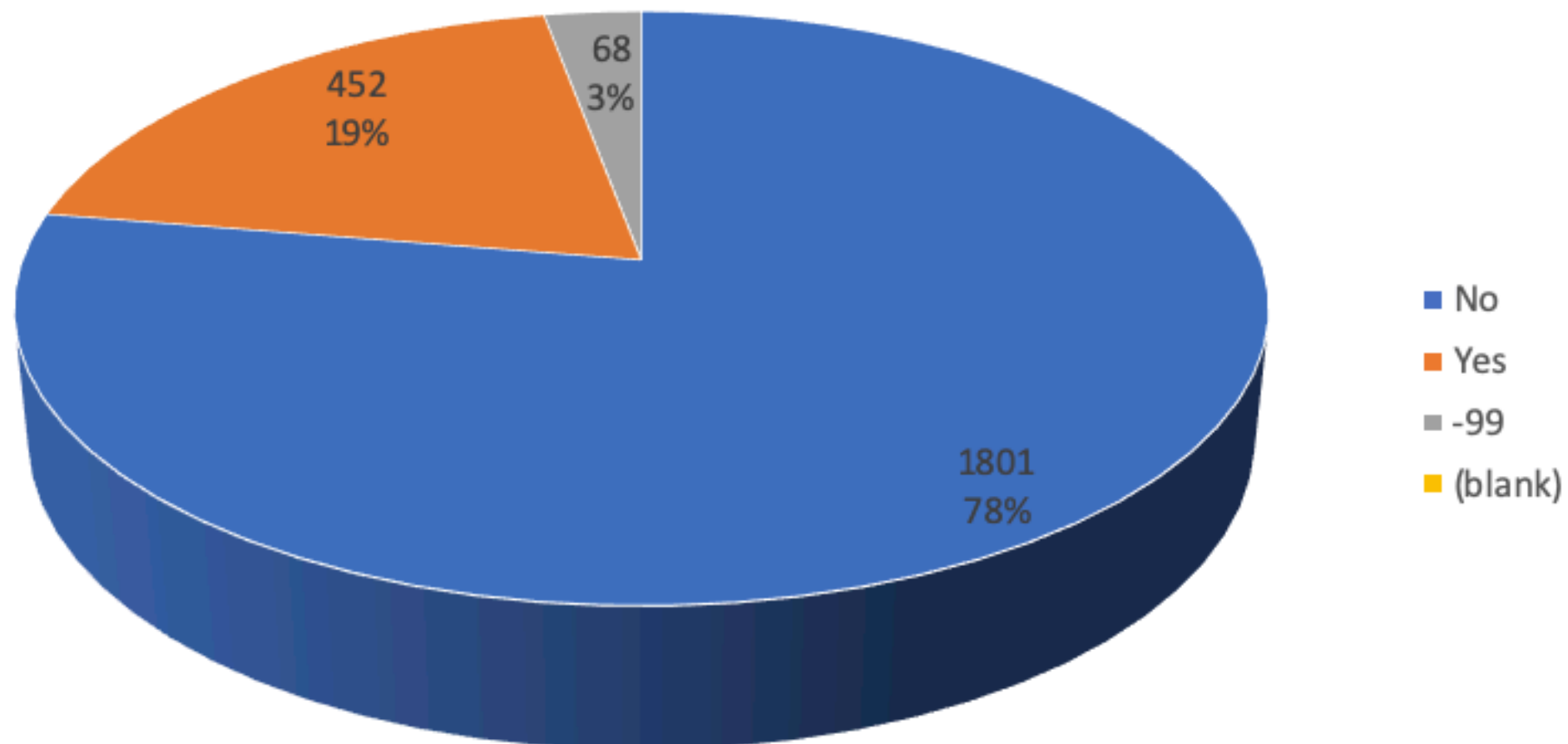
RESULTS: RELATIONS TO PROFESSIONALS? (N=294)

Overall, how would you rate your relationship with all your past prescribing doctors or professionals?



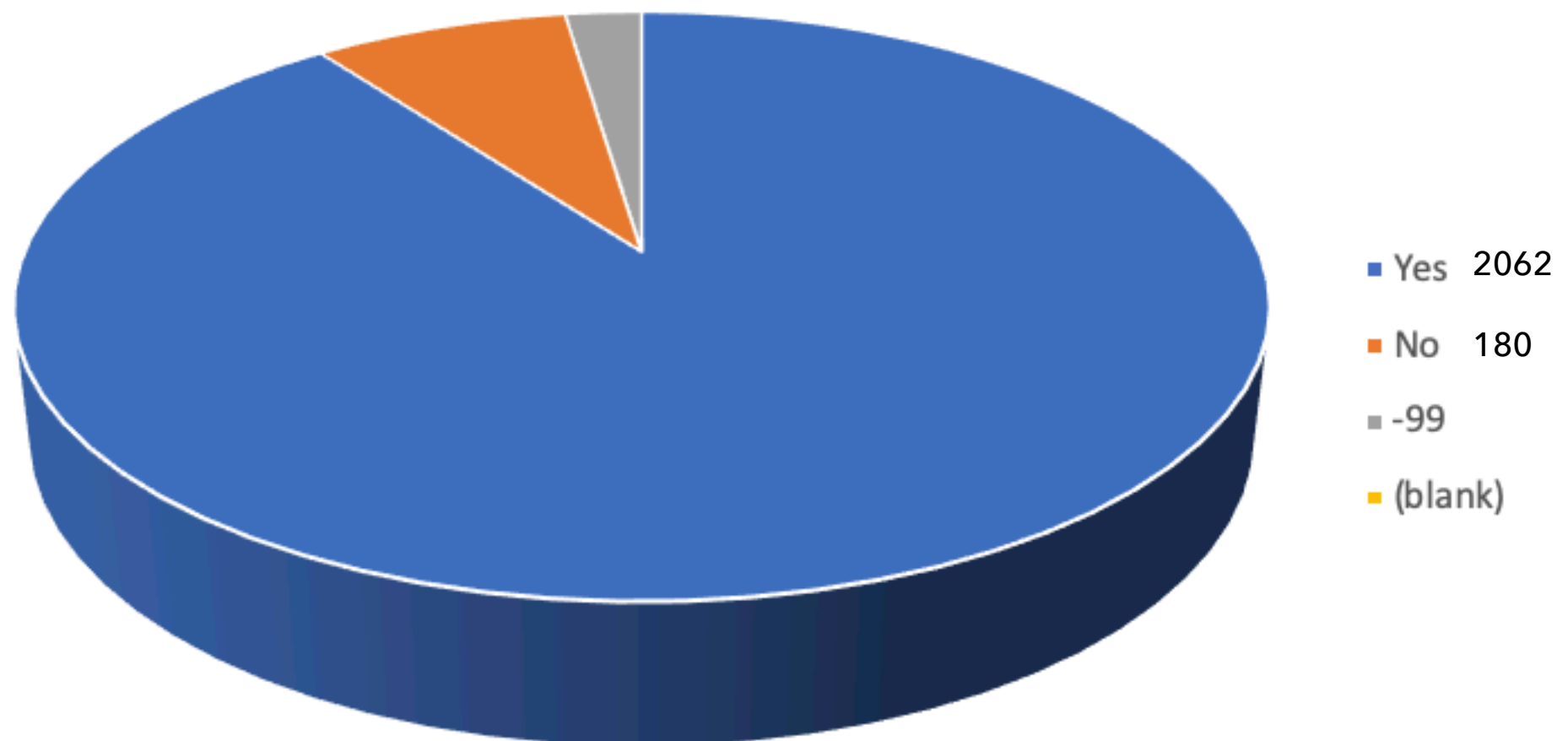
RESULTS: DID PROFESSIONALS GIVE YOU HOPE? (N=2253)

Overall did prescribers give you hope that one day you could possibly be free of your problems and recover?



RESULTS: GLAD YOU TRIED WITHDRAWAL? (N=2242)

Are you glad you tried to come off?



SURVEY NEXT STEPS

- ▶ Continuing to prepare and analyze data using STATA
- ▶ Consolidate into publication
- ▶ Questions? will.hall.maastrichtuniversity.nl +1 (413) 210-2803
- ▶ **Thanks to everyone for your involvement and support!**