

SEPT. 11 2019 PROGRESS REPORT



# MAASTRICHT WORLD SURVEY ON ANTIPSYCHOTIC DRUG WITHDRAWAL

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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 <u>Dr. Jim van Os</u>.
- 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, and to confronting the climate ecology emergency. So bear with me as the study proceeds as a more modest pace!





### THANKS AND ACKNOWLEDGEMENTS

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:

<b>Study Committee</b>
Jim van Os
Sandra Eschor

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
- View the preliminary results excel chart here
- Request access to the Qualtrics data platform by contacting me directly
  - ▶ Email me will.hall@maastrichtuniversity.nl
  - Phone me +1 413 210 2803
- Link to this progress report is here
- Link the 16 minute video presentation of this progress report is here (private link)





# 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
- Survey Future: Questions moving forward



#### 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-usersurvivor experience:
- Wide success of the <u>Harm Reduction Guide to Coming Off</u>
   <u>Psychiatric Drugs</u> (14 languages) showing existing unmet need
- ▶ <u>UK MIND Coping with Coming Off Study</u>, which included survivor researchers, was an early inspiring precedent, a proof-of-concept for research of this kind







### STUDY BACKGROUND: WILL HALL, LEAD RESEARCHER





Outside Mental Health Voices and Visions of Madness









Portland
Hearing Voices
embrace paper 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 Heaving 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** 

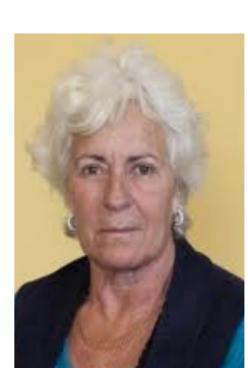
Ongoing community development work around mental health issues

Climate emergency mobilization activist

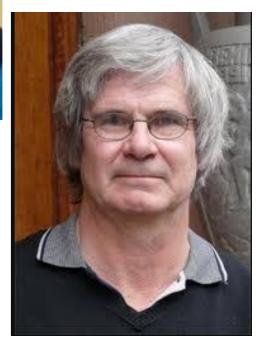


### STUDY BACKGROUND: PHD STUDY COMMITTEE

- 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

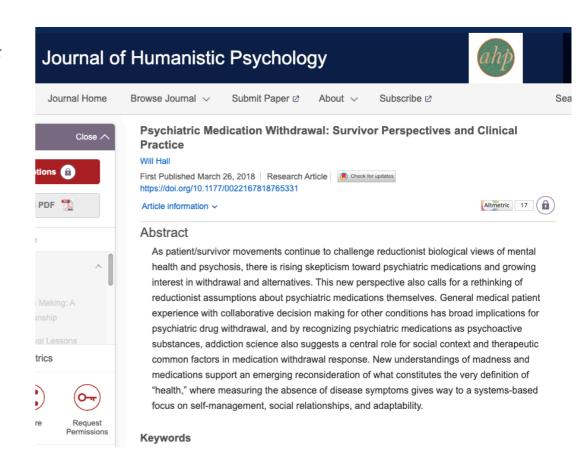
Miriam Larsen-Barr, PhD (special topic advisor) is a clinical psychologist with lived experience from New Zealand who specialises in the study of antipsychotic discontinuation. As a special topic advisor, her role is to support the research committee and provide regular guidance and feedback on survey 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: <a href="https://bit.ly/2m9KHJO">https://bit.ly/2m9KHJO</a>
- 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



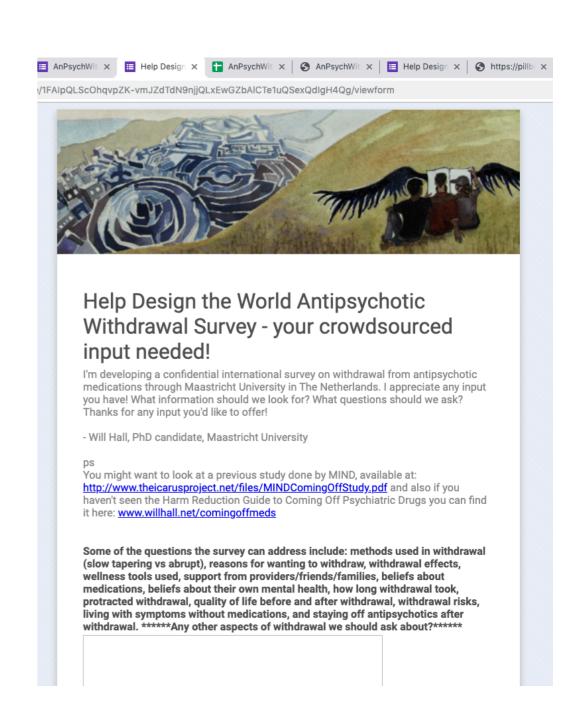
#### Author information

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
- View 89 English Help Design responses here
- View 13 German Help Design responses here





### 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





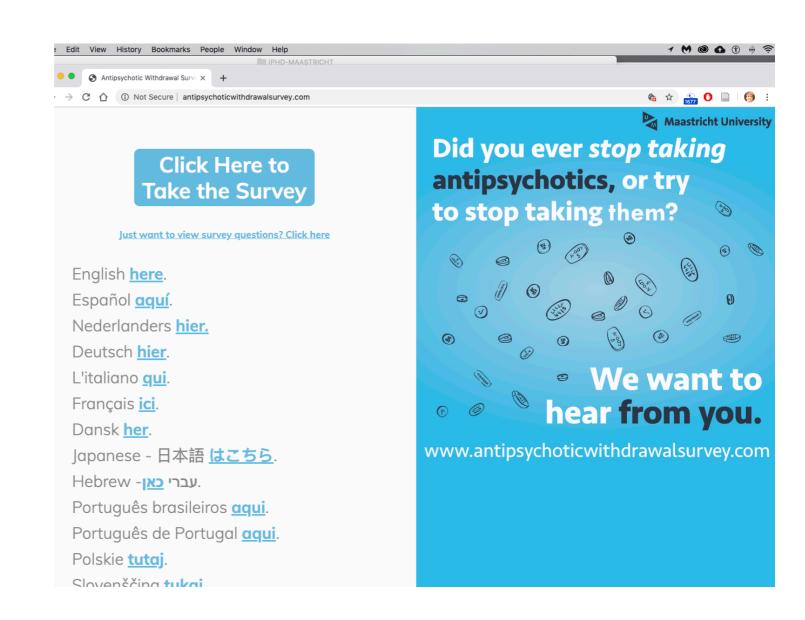
#### Powerful research to power the four core experiences

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 <u>www.antipsychoticwithdra</u> <u>walsurvey.com</u>
- 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: <a href="https://bit.ly/2kHiGsM">https://bit.ly/2kHiGsM</a>



#### **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 <u>www.antipsychoticwithdrawalsurvey.com</u>
- 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=\_

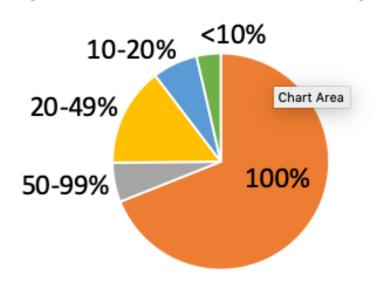
#### ▶ 4733 (valid+invalid) responses:

- 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 <u>■</u> completion rate
2237 100%
480 20-49%
219 10-20%
191 50-99%
117 less than 10%



#### RESULTS: PRELIMINARY DATA CLEANING

- Some irregularities mean this preliminary snapshot reflects rough results: note "=blank" and "=-99" results for example
- Clean nonsensical / inconsistent responses, typos, etc
- Consolidating responses where sensible. So "please specify" into appropriate choice categories, such as, q="ethnicity," answer="none of the above" and please specify = "caucasian" consolidated to choice "European-American/white (original answer retained)
- Cleaning prepares for more nuanced analysis esp. multiple choice rated ranked responses etc., and importing to STATA platform.
- Narrative questions Google translating into intelligible English



### **RESULTS: EXPLORING PRELIMINARY DATA**

- Preliminary results that follow have not been broken down into sub groups of people who came off completely, people who didn't come off completely, etc.
- Review a copy of the survey data in an .xls file here
- Import to google docs if you don't have excel
- Note "sheets" at bottom and arrow to advance list; this is where some data are exported to pivot tables to generate charts:





# RESULTS: 71 COUNTRIES REPRESENTED (N=3142)

USA	1093	
UK	445	
Canada	204	
España	197	
Nederland	189	
Australia	183	
Japan	106	
France	75	
België	69	
Ireland	53	
Norway	50	
Danmark	46	
<b>New Zealand</b>	46	
Deutschland	41	
Chile	40	
Brasil	34	
blank	31	
Sweden	23	
Argentina	21	
India	18	
Slovenija	17	
México	17	
Polska	16	
South Africa	16	
Israel	11	
Italia	11	
Finland	10	

Greece	9
Colombia	7
Switzerland	7
Estonia	5
Czech Republic	5
Perú	5
Turkey	4
Indonesia	4
Portugal	4
UAE	4
Serbia	3
Austria	3
Russia	3
Lithuania	3
Romania	3
Philippines	3
Malaysia	3
Country not list	2
Hungary	2
Iceland	2
Algeria	2
Croatia	2
Uruguay	2
Lebanon	2
Singapore	2
Morocco	1
Costa Rica	1
Cyprus	1

Luvemboure	1
Luxembourg	_
Bulgaria	1
Hong Kong	1
Bahrain	1
Guatemala	1
Jordan	1
Senegal	1
Slovakia	1
Martinique	1
Bolivia	1
Fiji	1
Bangladesh	1
Ukraine	1
Malta	1
Nicaragua	1
Pakistan	1
Saudi Arabia	1
(blank)	
<b>Grand Total</b>	3173



# 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
<b>Grand Total</b>	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

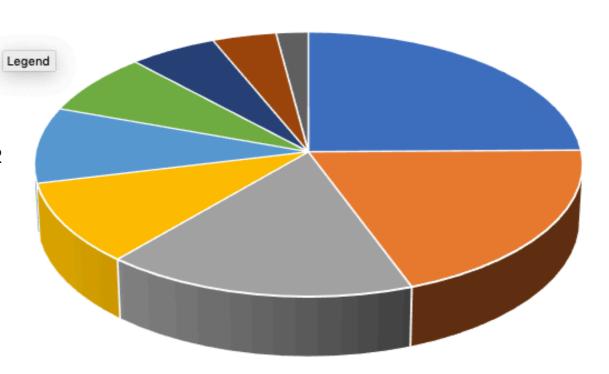
Asian, Mixed race please specify 2

European-White, Black, African-American 2



# RESULTS: EMPLOYMENT STATUS (N=3064)

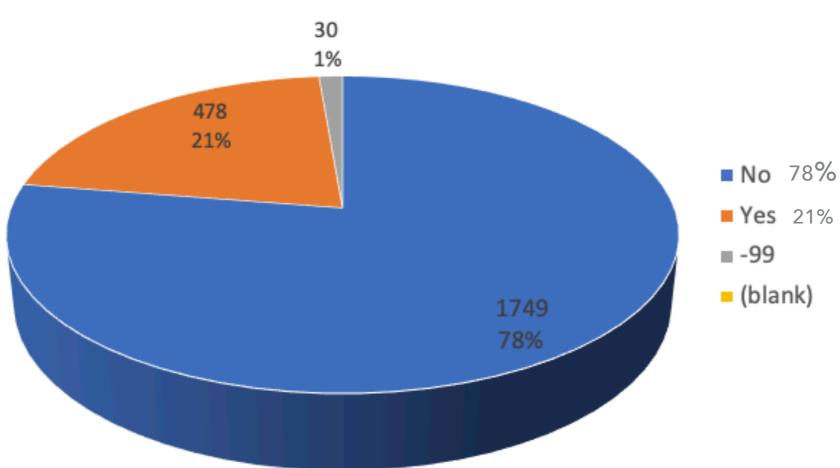
- Disabled 776
- Full time paid 613 employment
- Part time paid 527 employment
- Unemployed and not 312 looking for employment
- Student 291
- Unemployed and looking for employment 238
- Retired 178
- Volunteering or 129 internship





# RESULTS: HOMELESSNESS (N=2227)



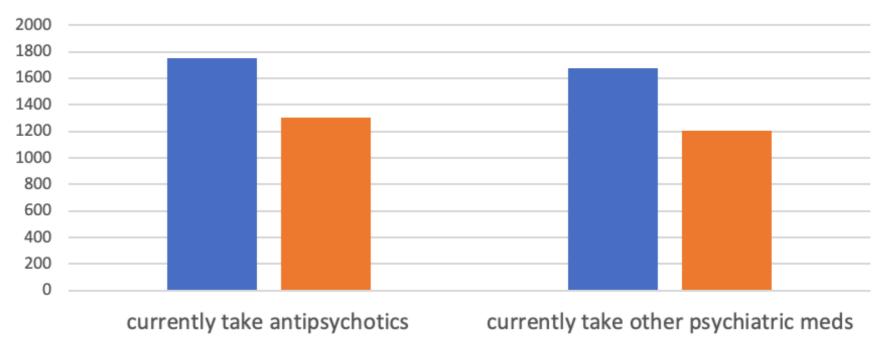




# RESULTS: CURRENT PSYCHIATRIC DRUG USE? (N=3103)

- 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

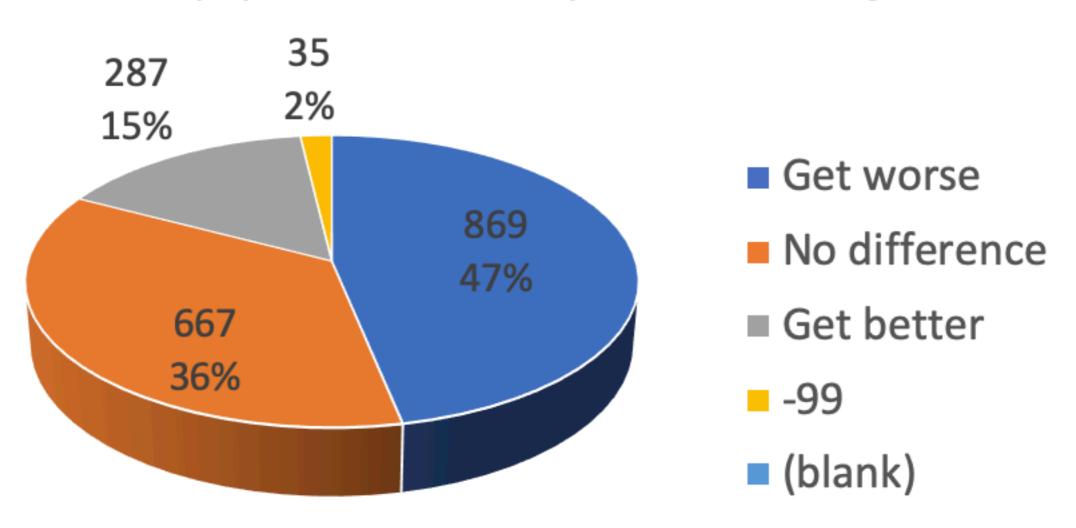
#### Current psych meds use





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

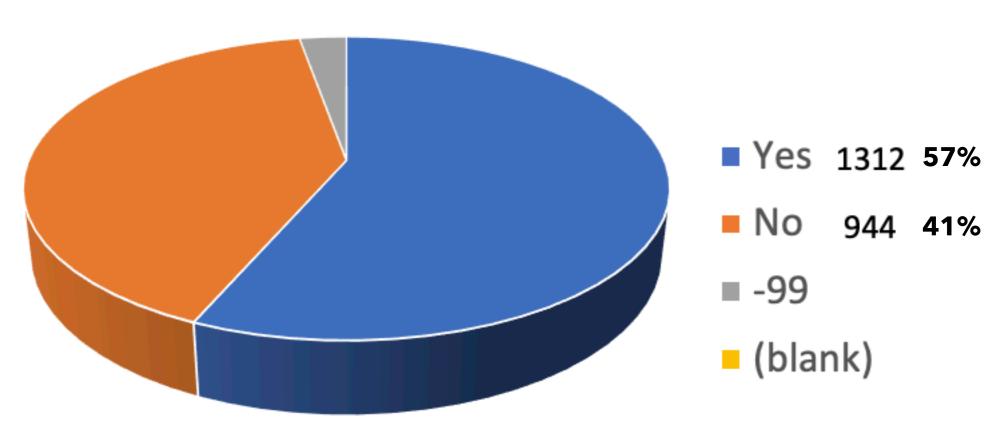
Antipsychotics made my suicidal feelings





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

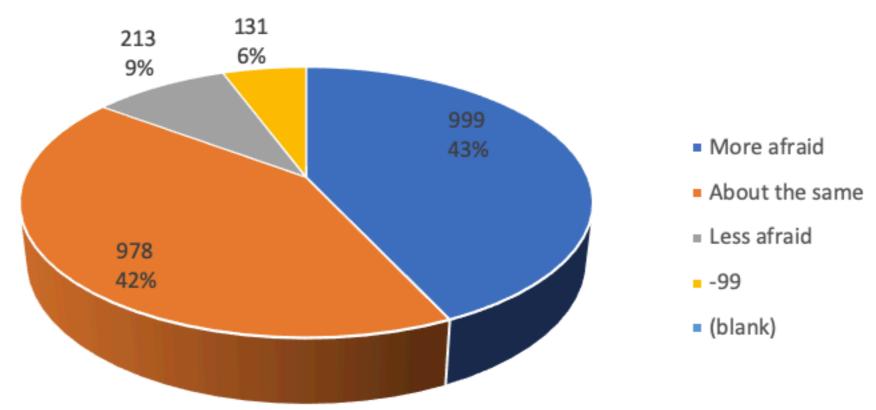
Did a professional ever tell you withdrawal effects were your illness instead?





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

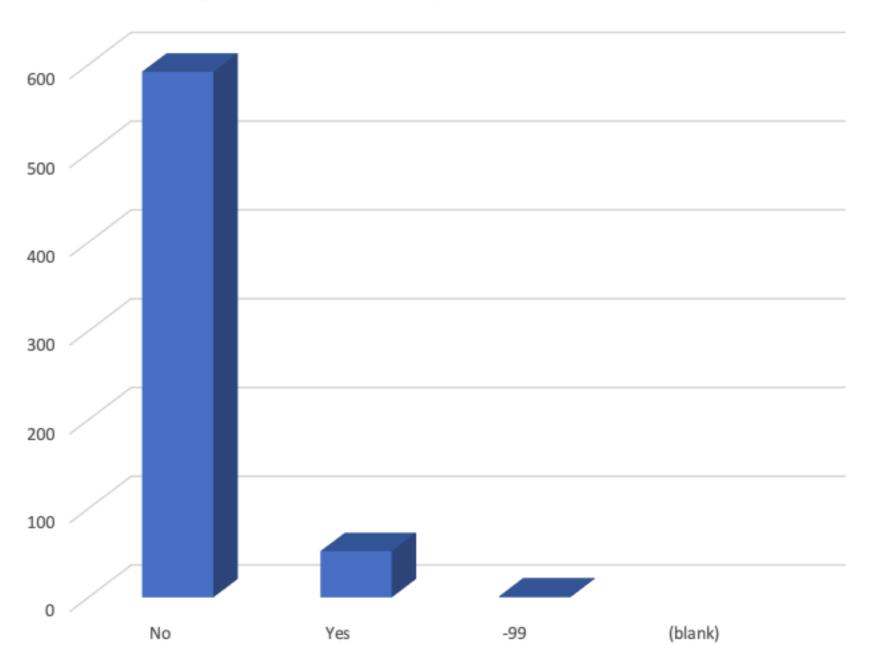
Overall how did prescribers make you feel about the process of withdrawal?





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

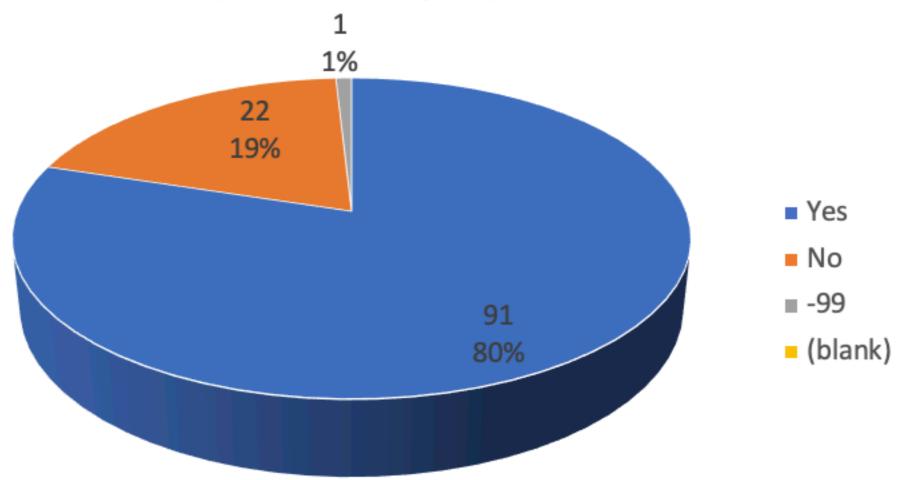
Did your prescriber tell you how you would know when you no longer need to take antipsychotics and should come off?





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

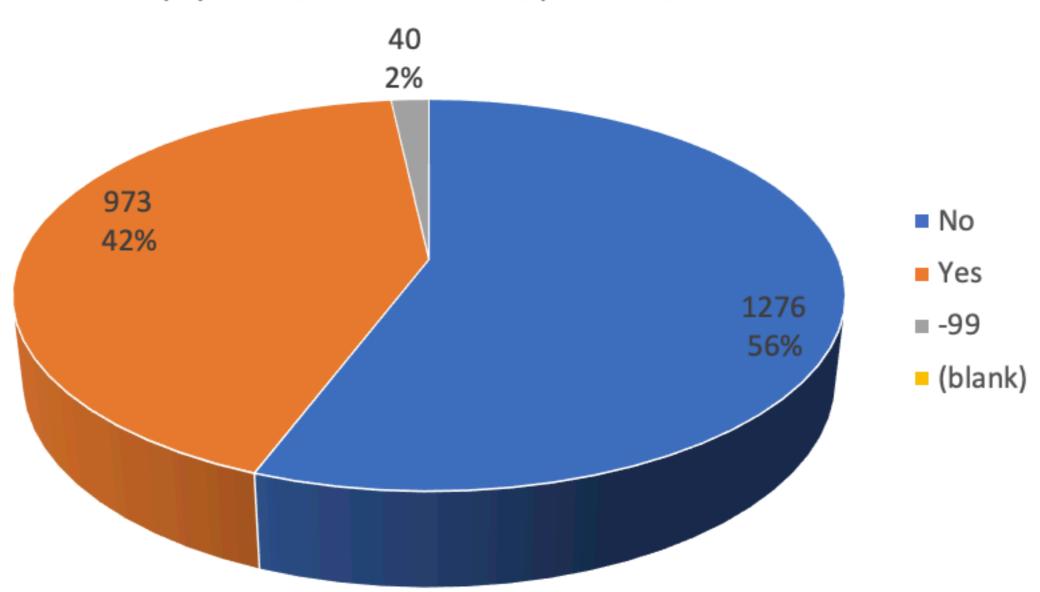
If you were diagnosed with diabetes, was it diagnosed after you started taking antipsychotics?





# RESULTS: CURRENT EXPERIENCE OF PSYCHOSIS (N=2249)

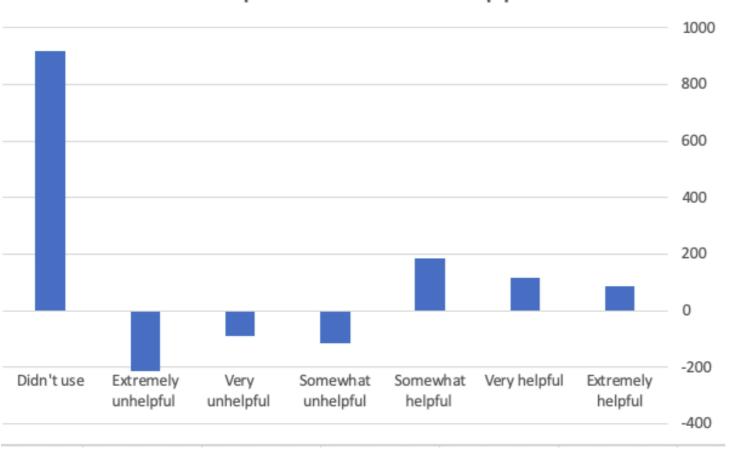
Do you currently experience anything doctors might consider psychosis, such as voices, paranoia, unusual beliefs...?





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

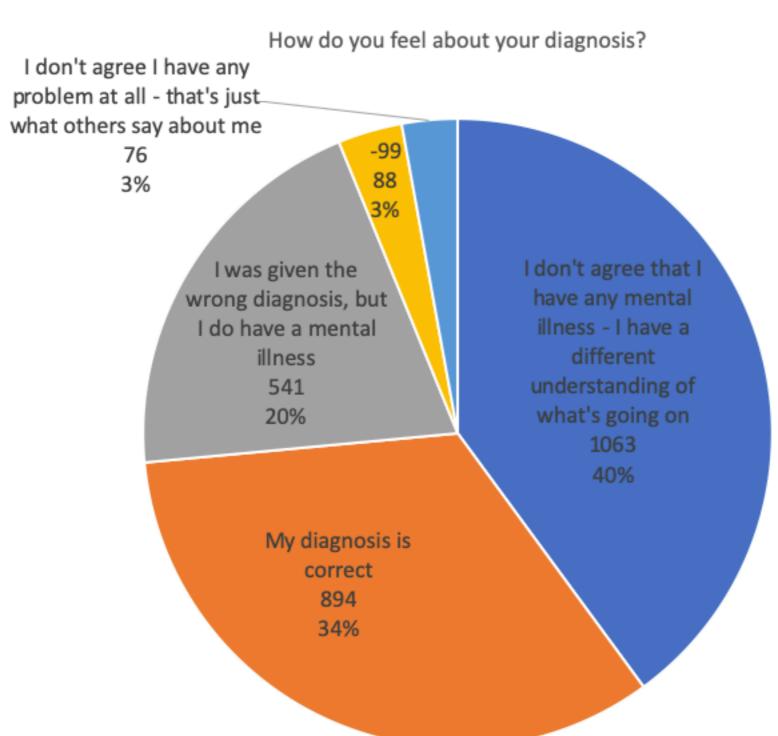
#### How helpful was doctor support?



Didn't use	920
-99	732
Extremely unhelpful	214
Somewhat helpful	185
Neither helpful nor unhelpful	141
Somewhat unhelpful	117
Very helpful	116
Very unhelpful	90
Extremely helpful	87



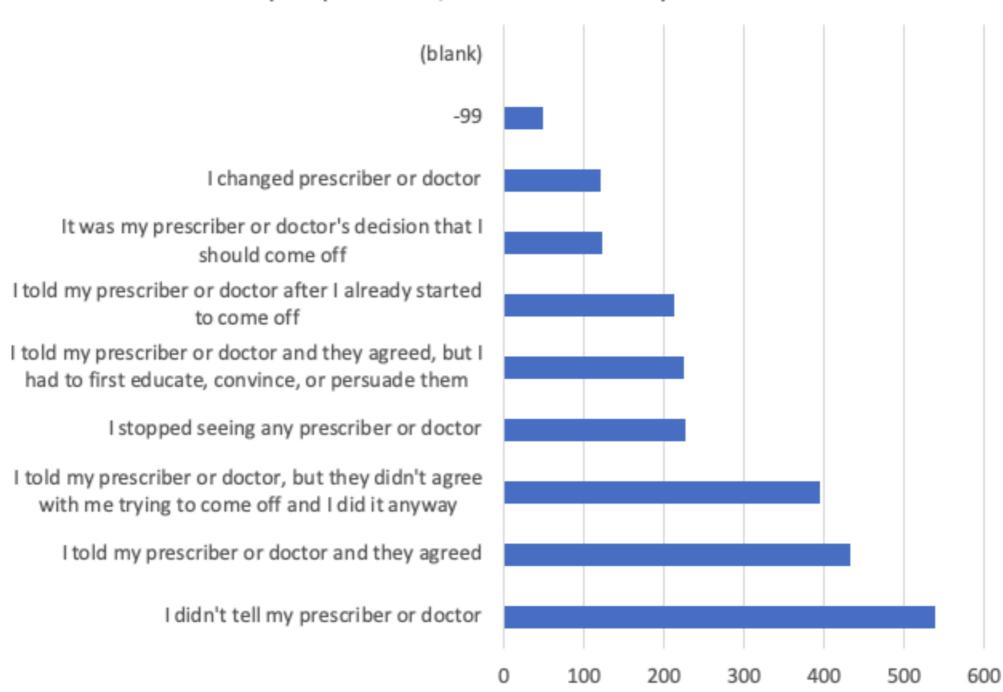
# RESULTS: HOW DO YOU FEEL ABOUT YOUR DIAGNOSIS? (N=2574)





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

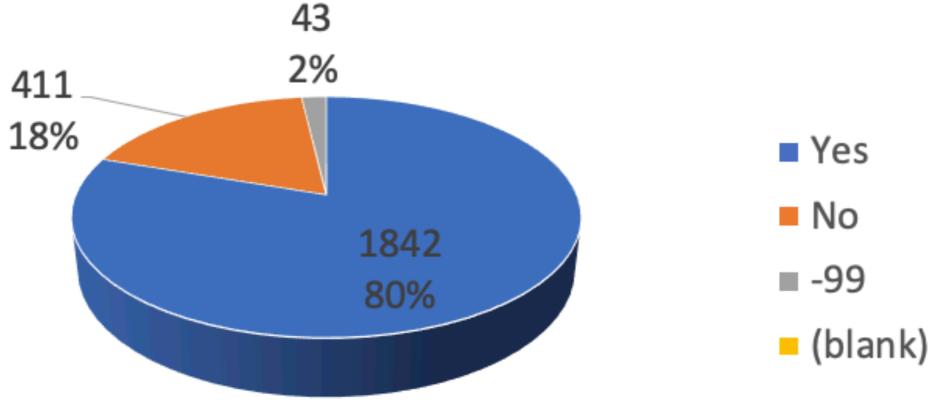
How was your prescriber / doctor involved in your decision to come off?





# RESULTS: ANGER TOWARDS PROFESSIONALS? (N=2253)

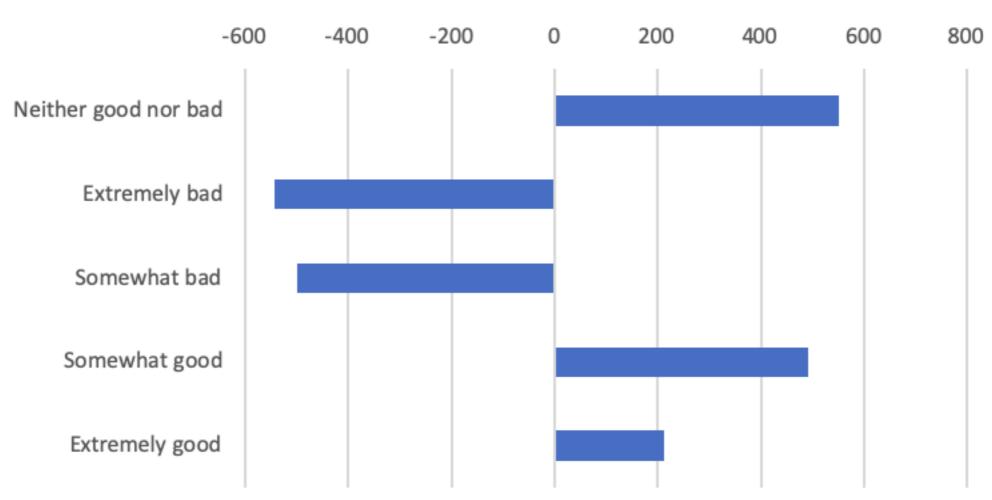
Were you ever angry at doctors or professionals about your treatment related to antipsychotics?





# RESULTS: RELATIONS TO PROFESSIONALS? (N=294)

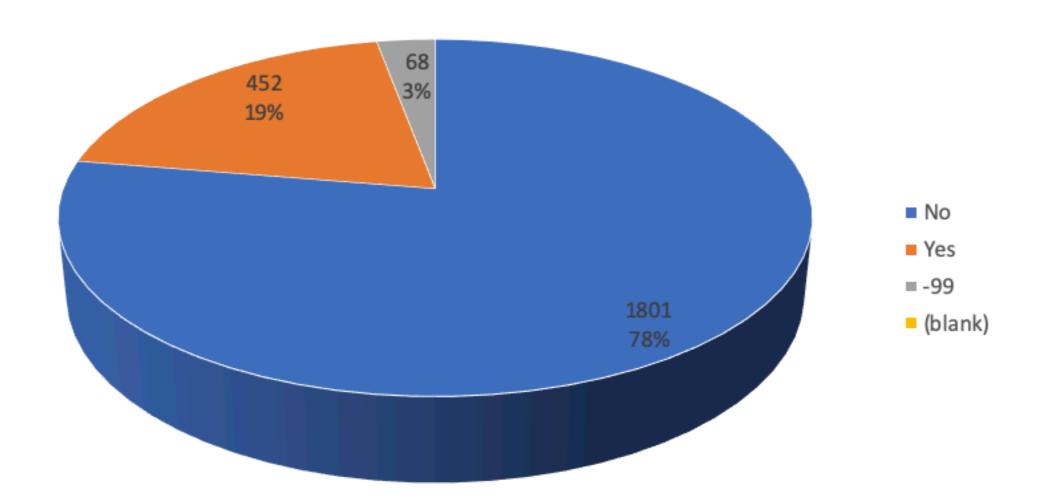
Overall, how would you rate your relationship with all your past prescribing doctors or professionals?





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

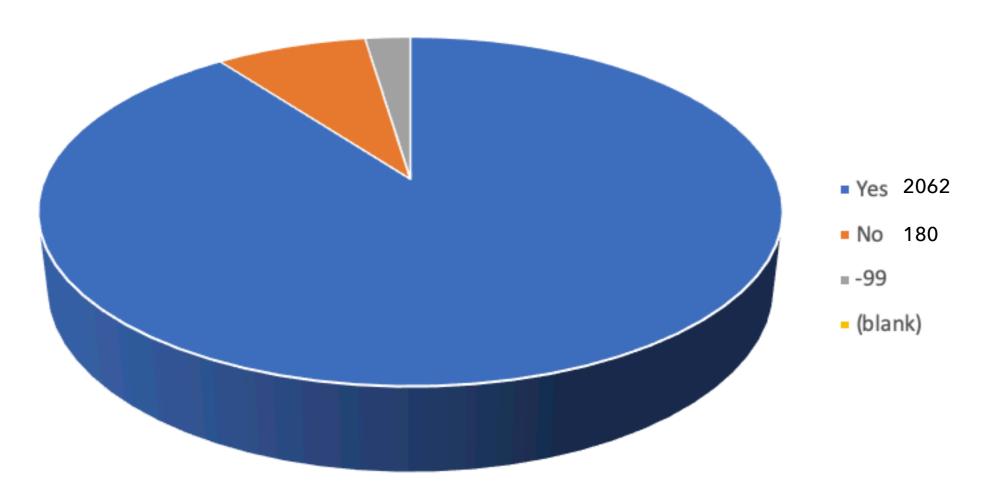
Overall did prescribers give you hope that one day you could possibly be free of your problems and recover?





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

#### Are you glad you tried to come off?





### SURVEY NEXT STEPS: QUESTIONS AND TASKS PENDING

- ▶ K eep data collection open? When/how to make dataset public/open source? Publishing all data on a website dashboard as a public resource
- Wait to collect more data before proceed to publication?
  - Sample size and diversity strong enough?
  - New wave of recruitment?
  - Underrepresented countries, languages, ethnicities
- Time to think about paper/publication?
  - Where to focus data analysis?
    - Detailed data analysis with filtering, comparison, use of STATA for publication preparation
  - Literature review
  - Other elements to work on for publication
- Next steps?
- will.hall.maastrichtuniversity.nl +1 (413) 210-2803
- Please join climate emergency mobilizations worldwide!