Psychiatric Medication Discontinuation/Reduction Study: Background and Methods

December 2017

The contents of this report were developed under a contract with Human Services Research Institute from the Foundation for Excellence in Mental Health Care (FEMHC). Laysha Ostrow, PhD served as the Project Director and Yana Jacobs, MFT and Gina Nikkel, PhD served as the Project Officers. The contents of this report do not necessarily represent the position of the FEMHC and you should not assume their endorsement.

For more information please contact Laysha Ostrow at contact@LiveLearnInc.net or visit http://www.LiveLearnInc.net
ABSTRACT


Objective: Individuals undergoing long-term psychiatric treatment frequently choose to stop taking psychiatric medications. To enhance service user choice and prevent undesirable outcomes, this first U.S. survey of a large sample of longer-term users sought to increase knowledge about users’ experience of medication discontinuation.

Methods: A sample of 250 U.S. adults with a diagnosis of serious mental illness and a recent goal to stop up to two prescribed psychiatric medications, which they had taken for at least nine months, completed a web-based survey about experiences, strategies, and supports during discontinuation.

Results: About half (54%) met their goal of completely discontinuing one or more medications; 46% reported another outcome (use was reduced, increased, or stayed the same). Concerns about medications’ effects (for example, long-term effects and side effects) prompted the decision to discontinue for 74% of respondents. They used various strategies to cope with withdrawal symptoms, which 54% rated as severe. Self-education and contact with friends and with others who had discontinued or reduced medications were most frequently cited as helpful. Although more than half rated the initial medication decision with prescribers as largely collaborative, only 45% rated prescribers as helpful during discontinuation. Of respondents who completely discontinued, 82% were satisfied with their decision.

Conclusions: Discontinuing psychiatric medication appears to be a complicated and difficult process, although most respondents reported satisfaction with their decision. Future research should guide health care systems and providers to better support patient choice and self-determination regarding the use and discontinuation of psychiatric medication.
INTRODUCTION

This report presents preliminary findings of the Psychiatric Medication Discontinuation/Reduction study (PMDR), a pilot study funded by the Foundation for Excellence in Mental Health Care. The PMDR study sought to understand first-hand experiences and strategies of individuals with psychiatric diagnoses who initiated discontinuation of psychiatric medications, and either discontinued or reduced (D/R) the use of these medications. There is a need for more research to help guide individuals and providers in the process of discontinuing psychiatric medications, particularly for people who have taken them long-term. Although substantial research describes the effects that follow or result from stopping psychiatric medications, few reports describe why people who took psychiatric medications reduced or stopped them, what factors affected the process, and how they valued the outcomes. All but one of these studies involved data collected 10 to 20 years ago. The PMDR study, led by current and former users of psychiatric medications, represents the first such survey in the US. The PMDR study is an initial, in-depth survey that engaged a self-selected sample; as more representative research is built on these preliminary findings, these kind of findings will have national implications for federal public health systems and large private providers to improve quality of care.

Overall, there has been a gap in knowledge on the self-reported motivations, experiences, processes and outcomes of people who have either attempted to discontinue or have discontinued, treatment with psychiatric medications. Given that research on treatment adherence suggests that many people choose to discontinue medication (Julius, Novitsky Jr, & Dubin, 2009; Samples & Mojtabai, 2015), it is vital to increase understanding of how people might safely and effectively do so. This includes information on withdrawal symptoms, specific resources discontinuers report as being helpful or not, and how their social networks might be supportive and help service users avoid negative outcomes. Such information could assist individuals, their families, and clinicians working with people who choose to discontinue. The overarching aim of the study was to contribute to practice standards for providers and to provide preliminary data to inform more rigorous studies on this topic in the future.

Given the scarcity of nationwide data on this topic from the unique perspective of this pilot study, we focused our initial analyses on describing the sample and their experience. Descriptive research is appropriate for a cross-sectional survey such as this, which aimed to increase our observed understanding of discontinuation in a natural setting.

BACKGROUND

In the mid-1990s, in emerging online forums, mental health service users began to provide direct and unfiltered descriptions of their experiences coming off prescribed medications (Cohen, McCubbin, Collin, & Pérodeau, 2001). At the same time, researchers were describing and defining a previously unexpected syndrome resulting from stopping selective serotonin reuptake inhibitors (SSRIs) (Black, Shea, Dursun, & Kutcher, 2000). Since then, three large, 24-month studies, funded by the National Institute of Mental Health (NIMH), were conducted to evaluate the effectiveness of newer medications for psychiatric disorders: the CATIE study on antipsychotic treatment in psychosis (Lieberman et al., 2005); the STAR*D study on antidepressant treatment in major depression (Trivedi et al., 2006); and the STEP-BD study on multi-drug treatment in bipolar disorders (Perlis et al., 2006). Drug discontinuation
was a common outcome in each of these studies (e.g., reaching an average of 74% of patients on different antipsychotics in CATIE). Despite the relatively large number of patients who discontinued treatment, there was little exploration of why and how participants chose to discontinue and how participants experienced psychiatric medication discontinuation. The lead CATIE article stated, “The majority of patients in each group discontinued their assigned treatment owing to inefficacy or intolerable side effects or other reasons” (Lieberman et al., 2005, p. 1209).

Rarely do trials provide enough information about why participants cease medication (Gartlehner et al., 2005). Overall, trials do not explore discontinuation from the discontinuers’ perspectives. This is because clinical trials are focused on demonstrating efficacy of a given treatment, not factors involved in refusing treatment. Trials also generally recruit samples with exclusion criteria that limit the representation of people with either mild or very serious difficulties. The authors of a comprehensive survey of medication users conducted by the Scottish Mental Health Association (Bradstreet, 2004) stressed that surveys are essential to understand discontinuation. Surveys have the ability to explore discontinuation from the discontinuers’ perspectives. Because different demographic groups may vary in their motivation to discontinue (e.g., women of child bearing age; long term users questioning utility of the treatment over time), it is also important to begin to understand relevant questions that can be sought from more systematic, epidemiologic surveys of psychiatric medication discontinuation.

**Previous Research**

Six surveys and one qualitative study conducted between 1998 and 2012 queried consumers directly and systematically about one or more aspects of discontinuing psychiatric drugs. Two mental health service user studies were conducted in the United Kingdom, two standard (non service-user led) studies were completed in the United States, with additional studies in Australia, New Zealand, and Israel. Three studies looked at discontinuation from all classes of psychiatric medications, two from antidepressants, and two from antipsychotics. All but one (Samples & Mojtabai, 2015) used convenience samples.

**Gaps in Practice and Self-Help Knowledge**

Current literature searches on the process of psychiatric drug discontinuation turn up many suggestions for safe withdrawal, found on websites, in books aimed at consumers, and in peer-reviewed articles. Work in progress by Cohen and Recalt (2016) finds that recommendations directed at clinicians in the peer-reviewed literature vary based on drug class, but typically include recommendations for gradual withdrawal, though what this means remains undefined, and rarely exceeds a few weeks. Recommendations found in books by clinicians and former or current users are more detailed, though they vary in quality, accuracy, and in providing the sources of their conclusions. Many emphasize a three-step process that includes (1) informing oneself about withdrawal effects, (2) setting up a plan and a support network to help one through difficult phases, and (3) reducing dosage gradually rather than abruptly (Hall, 2012). These recommendations appear reasonable, but few have been vetted by empirical support from a focused, sizeable survey of consumers.
METHODS

Data for the PMDR study were collected in June 2016 using an anonymous self-report web survey developed by the PMDR team, based on existing instruments and research. The analytic convenience sample is composed of 250 adults living in the U.S. with a self-reported diagnosis of serious mental illness. This study was approved by the institutional review board (IRB) at Human Services Research Institute (Protocol No. HSRI-IRB-010/2016).

INCLUSION CRITERIA

All participants were: 1) over the age of 18; 2) Diagnosed with a lifetime psychiatric diagnosis of one of the following: schizophrenia, schizoaffective disorder, schizophreniform disorder, psychosis NOS, bipolar disorder I, bipolar disorder II, bipolar disorder NOS, major depressive disorder; 3) attempted to come off medications taken for more than 9 months; and 4) had a goal of completely discontinuing one to two medications within the past five years. The survey instrument and demographic sections below describe the sample in more detail.

SURVEY INSTRUMENT

The PMDR team created a self-report survey instrument based on existing research, instruments, and knowledge of the topic and the field. The survey was designed to understand participants’ experience trying to stop taking psychiatric medications, whether they actually stopped or not.

Survey development

Because no existing instrument could comprehensively address our study aims, the PMDR team developed the instrument based on other research and the team’s collective expertise as clinicians, researchers, and people who have discontinued/reduced psychiatric medications. We reviewed and discussed existing instruments such as:

- MIND UK (Read 2009) Coping with Coming Off Questionnaire
- The Liverpool University Neuroleptic Side Effect Rating Scale (LUNSERS)
- WHO Quality of Life Measure
- Patient Activation Measure-Mental Health (Green et al., 2010)
- Overarching questions for patient surveys: development report for the Care Quality Commission (CQC) Picker Institute Europe
- Decisional Conflict Scale
- Crisis Support Scale

We also reviewed and incorporated clinical tools to inform medical history and experience of medications questions (Carlat, 2005; Doran, 2013; Ferguson, 2001; Stahl, 2008, 2011).

Field test

Following initial development of the instrument, we conducted field testing with 15 members of the target population (6 of whom were determined eligible by the screener). Field testers were instructed to provide the following feedback via text entry boxes in the survey:
- Do you understand the questions?
- Are there any terms or words in the questions that are difficult to understand?
- Are the answer choices a good fit for how you would answer the questions?
- Did you feel motivated to complete the survey or did you want to stop?
- Are there questions that you skipped, or wanted to skip?
- Does the survey work properly on your computer or device?
- Any other problems you ran into.

Following completion of that task, a member of the PMDR team called the field tester to discuss any inconsistencies in their responses and to understand their feedback and experience. We then revised question format, wording, and ordering in the survey and finalized the instrument.¹

**Final Instrument**
The survey included about 90 closed-ended questions (depending on skip patterns) in ten sections, including the initial screener:

1) Initial Screening  
2) Current Medication Status  
3) Motivations, Strategies, Goals for Discontinuation  
4) Withdrawal Effects  
5) Social Supports  
6) Relationship with Prescribing Health Professional and Psychotherapist  
7) Medical History / Labels / Diagnoses  
8) General Health and Wellness  
9) Demographic Information  
10) Socioeconomic Status

Additionally, participants could elect to complete with narrative information six open-ended questions at the end of the survey. Based on our field testing, surveys took approximately 20-30 minutes to complete by eligible participants.

To determine eligibility, participants were first shown a six-question screening questionnaire requiring completion in order to proceed to the full survey. The PMDR team used this technique to minimize participant burden, since our inclusion criteria were fairly restrictive. The following table shows the screener for exclusion of non-eligible participants, with required responses for inclusion underlined and in bold:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you 18 years old or over?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>
| Have you been given any of the following psychiatric diagnoses? (Check all that apply). | Schizophrenia  
Schizoaffective disorder  
Schizophreniform disorder  
Psychosis NOS  
Bipolar disorder I  
Bipolar disorder II |

¹ Appendix III contains the survey instrument
### Bipolar disorder NOS
- Major depressive disorder
- None of the above

In the last five years, were you prescribed medications in any of these classes? (Check all that apply).
- Antipsychotics
- Antidepressants
- Mood stabilizers
- Anti-anxiety
- Stimulant
- None of the above

In the last five years, did you stop or attempt to stop taking psychiatric medications completely?
- Yes
- No

If yes, how many different psychiatric medications did you stop or attempt to stop taking most recently?
- One medication
- Two medications
- More than two medications
- Does not apply

Did you take at least one of the medications that you stopped or attempted to stop most recently for nine months or more?
- Yes
- No

### Recruitment and Data Collection
Data were collected using Qualtrics, a commonly used online survey software. Participants were recruited using non-random sampling that deliberately targeted members of the target population (Kelley, Clark, Brown, & Sitzia, 2003). Since most researchers on the team identified as members of the target population, we were able to reach a large number of current and former service users through our pre-existing networks. These networks included former and current service users, service providers, mental health organizations, and advocacy groups.

Recruitment flyers, listservs, and social media –involving mental health agencies, university-based counseling and wellness centers, and advocacy organizations – were used to identify and recruit members of the target population. Our use of social media in our recruitment efforts allowed potential participants to easily share the study information with friends and acquaintances, thus spreading study information through word of mouth.

Data were collected in June 2016. In addition to individuals who shared the recruitment notice via Facebook, Twitter, and LinkedIn, email, and word-of-mouth, the following organizations supported our recruitment efforts:

- National Empowerment Center
- Peerlink Technical Assistance
- Doors to Wellbeing (Copeland Center)
- National Mental Health Consumer Self-Help Clearinghouse
- National Alliance on Mental Illness (NAMI) STAR Center
- International Association of Peer Supporters
- NAMI national
- New York University

---

2 Appendix II contains the recruitment flyer
Table 1 shows where respondents in our analytic sample reported hearing about the survey:

**Table 1: Reported recruitment source**

<table>
<thead>
<tr>
<th>Recruitment Source</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social media site</td>
<td>139</td>
<td>56%</td>
</tr>
<tr>
<td>Email list</td>
<td>46</td>
<td>18%</td>
</tr>
<tr>
<td>Professional website</td>
<td>33</td>
<td>13%</td>
</tr>
<tr>
<td>Friend/family</td>
<td>15</td>
<td>6%</td>
</tr>
<tr>
<td>Personal website</td>
<td>11</td>
<td>4.6%</td>
</tr>
<tr>
<td>Provider</td>
<td>3</td>
<td>1.2%</td>
</tr>
<tr>
<td>Counselor</td>
<td>2</td>
<td>0.8%</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>0.4%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>250</td>
<td>100%</td>
</tr>
</tbody>
</table>

The survey link first connected participants with informed consent information and notified them that their participation was completely voluntary and confidential. Consenting participants were then screened for eligibility. Eligible participants were brought to the full survey. Participants did not receive monetary compensation for completing the survey. Figure 1 shows the flow of participants into the screener, eligibility, and final participation.
The most common reason for not qualifying for the study was attempting to discontinue more than two medications (N=248). Additionally, several respondents to the screener contacted the research team during the recruitment period to note that their experience did not satisfy this criterion.

**Data analysis procedures**

**Key medication status variables**

In order to understand the continuum of discontinuation and reduction, we created post-hoc categories of medication status to begin to explore how the spectrum of discontinuation may be related to other experiences. We categorized respondents by their current medication status with respect to the index medications: Complete discontinuation; Moderate discontinuation; Partial discontinuation. The index medications were the one or two medications as reported by respondents. Participants were asked to specify which medication(s) they had reported having a goal of discontinuing.

*Please list the one or two medication(s) you attempted to come off most recently.*

- Name of Medication #1: (1)
- Name of Medication #2: (2)

These answers were automatically auto-filled into questions about the medications in the survey.

Following data collection, two research team members who are Psychiatric-Mental Health Nurse Practitioners (PMHNP) independently translated the write-in names to a set of consistent generic names.
for medications. The two PMHNPs were asked to then discuss and flag any discrepancies that could not be resolved between them so that a third PMHNP could help resolve them if needed. However, no discrepancies were flagged. A third PMHNP then worked with a social worker on the team to code the generic medication names into the five different medication classes (antipsychotics, antidepressants, mood stabilizers, anti-anxiety, and stimulants) which were part of our inclusion criteria. Only two respondents were removed from the analytic sample for reporting on a non-eligible medication.

One key measure was determining the change in participants’ medication usage. Participants were asked the following question about current medication use:

*Please indicate how much [auto-filled with medication name] you take now compared to when you started the process of coming off it.*

- I have stopped taking this medication completely
- I am still taking this medication, but at a lower dose
- I am taking the same dose of this medication
- I am taking a higher dose of this medication

The “complete discontinuation” group consists of those who discontinued both medications (n=83), or discontinued one medication and were not taking a second medication (n=52). The “moderate discontinuation” group consists of those who discontinued one medication and reduced the other (n=23), reduced both medications (n=7), reduced one medication and were not on a second (n=39), or reduced one and are on the same dose of the other (n=7). The third group is any “partial discontinuation” (n=39), made up mostly of people who remained on the same dose or higher of both drugs (n=28), and less than a third of whom (n=11) discontinued one drug, but were on the same or higher dose of the other. This study’s grouping by discontinuation status mirrors Read’s (2009) MIND study, although the present categories relate to self-reported medication outcomes rather than respondents’ broader subjective experiences.

The three groups are as shown in Table 2.

**Table 2: Combined Discontinuation Status**

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete discontinuation</td>
<td>135</td>
<td>54.0%</td>
</tr>
<tr>
<td>Moderate discontinuation</td>
<td>76</td>
<td>30.4%</td>
</tr>
<tr>
<td>Partial discontination</td>
<td>39</td>
<td>15.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>250</td>
<td>100%</td>
</tr>
</tbody>
</table>

The goal of the study was to understand the experiences of those who attempted to completely discontinue and our recruitment was designed to reach that population.

We report the frequency of key variables\(^3\) in total and in the three discontinuation groups to give a sense of the distribution of other variables across medication status, using the percentage of each variable in each of the three groups along with the statistical significance of their association with discontinuation group (using \(\chi^2\)). Statistical significance at the 0.05 level is denoted in the table with an

---

\(^3\) Appendix I contains more extensive data tables.
*. These medication status groups are interesting as they provide us a closer look at where participants are in the discontinuation process, and whether certain experiences and activities are potentially associated with achieving that status. However, it is important to consider the distribution of variables across the medication status groups exploratory, and remember that statistically significant associations in this context may appear by chance. The study is cross-sectional, and therefore causality cannot be inferred. Some measures have missing data; in particular, because the demographic and socioeconomic status sections were near the end, those have a greater proportion of missing data than prior sections. Data were analyzed in Stata 13 (StataCorp, 2014).
Have you come off, or tried to come off, psychiatric medications in the past nine months? We want to know about your experience!

The goal of this project is to understand the process of coming off psychiatric medications. What helps or prevents people from stopping their psychiatric medications?

Sometimes people who take psychiatric medications choose to stop taking it. When people choose to come off medications, they may struggle to find the information or support they need. Providers who want to help often lack evidence to guide people. Your responses to this survey will help better support people coming off psychiatric medications. We will share the results in public reports and presentations, as well as academic journals.

Who can participate?
Adults ages 18+ in the United States who meet the following criteria:
- Labeled with a psychiatric diagnosis.
- In the last five years, took prescribed psychiatric medications for at least nine months before trying to come off them.
- Had a goal to completely stop taking one or two medications in the past five years.

If you would like to participate:
The survey can be accessed at: [hyperlink]
First, you will complete a screening questionnaire. If you are eligible, you will continue to the survey. It will take you about 25 to 45 minutes to complete the survey. You can start the survey and come back to it later. Your answers will be anonymous. Your answers will be combined with others’ when we report results.
The survey will ask you about:
- Your motivation for stopping medications.
- Supports you used.
- How you feel about stopping medication.

You can help move the science forward!
We are particularly interested in hearing from people of color and people who have experienced poverty. Please share this announcement widely!

Contact:
Laysha Ostrow, PhD
Project Director
contact@livelearninc.net

About the PMDR Project and Team:
All of the people working on this project have personal experience with psychiatric treatment and coming off psychiatric medications.
The project is funded by the Foundation for Excellence in Mental Health Care. You can read more: http://www.LiveLearnInc.net/projects/
Thank you for your interest in our survey. The following questions will determine if you are eligible to participate.

Are you 18 years or older?
- Yes
- No

Have you been given any of the following psychiatric diagnoses? (Check all that apply).
- Schizophrenia
- Schizoaffective Disorder
- Schizophreniform Disorder
- Psychosis NOS
- Bipolar I
- Bipolar II
- Bipolar Disorder NOS
- Major Depressive Disorder
- None of the above

In the last five years, were you prescribed medications in any of these classes? (Check all that apply).
Please hover your mouse over the answer choices to view examples of each kind of medication.
- Anti-psychotics
- Anti-depressants
- Mood Stabilizers
- Anti-Anxiety
- Stimulants
- None of the above

In the last five years, did you stop or attempt to stop taking psychiatric medications completely?
- Yes
- No

If yes, how many different psychiatric medications did you stop or attempt to stop taking most recently?
These are the medications we will ask you to report on in this survey.
- One medication
- Two medications
- More than two medications
- Does not apply

Did you take at least one of the medications that you stopped or attempted to stop most recently for nine months or more?
- Yes
- No
Please tell us where you heard about this survey?

- Social Media (e.g. Facebook, Twitter.)
- Email Listserv
- Personal Website
- Professional Website
- Friend or Family Member
- Health Care Provider
- Counselor / Coach

Medication Status
Please list the one or two medication(s) you attempted to come off most recently.

Name of Medication #1:
Name of Medication #2:

Please indicate your total daily dose of ${q://QID221/ChoiceTextEntryValue/1} in milligrams (mgs) before beginning the process of coming off it:

How long had you taken ${q://QID221/ChoiceTextEntryValue/1} when you decided to come off it?

- 9 months to one year
- One to two years
- Two to four years
- Four to ten years
- Ten or more years

Please indicate your total daily dose of ${q://QID221/ChoiceTextEntryValue/1} in milligrams (mgs) today (Enter 0 if you have stopped completely):

Please indicate how much ${q://QID221/ChoiceTextEntryValue/1} you take now compared to when you started the process of coming off it.

- I have stopped taking this medication completely
- I am still taking this medication, but at a lower dose
- I am taking the same dose of this medication
- I am taking a higher dose of this medication

Display This Question:
If Please indicate how much of you take ${q://QID221/ChoiceTextEntryValue/1} now compared to when you... I have stopped taking this medication completely Is Selected

If you stopped ${q://QID221/ChoiceTextEntryValue/1} completely, how long ago did you stop?

<table>
<thead>
<tr>
<th>Years</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
On a scale of 1 to 10, with 1 being very unhelpful and 10 being very helpful...

<table>
<thead>
<tr>
<th>How would you rate</th>
<th>1= very unhelpful</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10= very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>[q://QID221/ChoiceTextEntryValue/1]</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Display This Question:
If Please identify the one or two medication(s) you decided to come off most recently. Name of Medication #2: Is Not Empty

Please indicate your total daily dose of \[q://QID221/ChoiceTextEntryValue/2\] in milligrams (mgs) before beginning the process of coming off it:

Display This Question:
If Please identify the one or two medication(s) you decided to come off most recently. Name of Medication #2: Is Not Empty

About how long had you taken \[q://QID221/ChoiceTextEntryValue/2\] when you decided to come off it?
○ 9 months to one year
○ One to two years
○ Two to four years
○ Four to ten years
○ Ten or more years

Display This Question:
If Please identify the one or two medication(s) you decided to come off most recently. Name of Medication #2: Is Not Empty

Please indicate your total daily dose of \[q://QID221/ChoiceTextEntryValue/2\] in milligrams (mgs) today (enter 0 if you have stopped completely):

Display This Question:
If Please identify the one or two medication(s) you decided to come off most recently. Name of Medication #2: Is Not Empty

Please indicate how much \[q://QID221/ChoiceTextEntryValue/2\] you take now compared to when you started the process of coming off it:
○ I have stopped taking the medication completely
○ I am still taking this medication, but at a lower dose
○ I am taking the same dose of this medication
○ I am taking a higher dose of this medication
Display This Question:
If Please indicate how much of ${q://QID221/ChoiceTextEntryValue/2} you take now compared to when you... I have stopped taking the medication completely Is Selected

If you stopped ${q://QID221/ChoiceTextEntryValue/2} completely, how long ago did you stop?

<table>
<thead>
<tr>
<th>Years</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Display This Question:
If Please identify the one or two medication(s) you decided to come off most recently. Name of Medication #2: Is Not Empty

On a scale of 1 to 10, with 1 being very unhelpful and 10 being very helpful...

<table>
<thead>
<tr>
<th>How would you rate ${q://QID221/ChoiceTextEntryValue/2}?</th>
<th>1= very unhelpful</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10= very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

Have you started taking a different psychiatric medication since beginning the process of coming off the medication(s) you just told us about?
☐ Yes
☐ No

Display This Question:
If Have you started taking a different medication since beginning the process of coming off ... Yes Is Selected
If yes, please list the medication(s)?
Medication #1
Medication #2

Did you consider the timing of your decision come off medications, such as impact on school or work functioning, impending decisions or changes, anniversaries, or how the season affects you?
☐ I carefully considered the timing
☐ I somewhat considered the timing
☐ I did not consider the timing

Over what time period did you stop your medication(s)?
☐ All at once, immediately
☐ In less than one month
☐ One to six months
☐ More than six months

Motivations, Strategies, Goals Please remember that all of these questions refer to the last time you came off or attempted to come off medication.
Why did you choose to come off psychiatric medication? (Select all that apply)

☐ I didn't like the adverse effects of the drugs
☐ I was concerned about the long-term effects
☐ I felt better or things were better in my life and I didn’t need them
☐ I learned about an alternative approach to medication that I preferred
☐ I did not have access to medications anymore (for financial or other reasons)
☐ The drugs were not useful
☐ The drugs did not work anymore
☐ I had only expected to be on them for a limited time
☐ I wanted to know who I am without medications
☐ I was advised to come off them by a prescriber
☐ I was advised to come off them by a health care or other professional (who was not a prescriber)
☐ Someone in my personal life asked me to stop taking them
☐ I was concerned about my reproductive health and/or wanted to become pregnant or breastfeed
☐ Other (please specify) ____________________

Did you take time off from school or work activities while you were coming off your medication?

☐ Yes, and taking time off was helpful
☐ Yes, but taking time off was not helpful
☐ No, I did not need to take time off
☐ No, I could have benefited from taking time off but didn't
Thinking about any self-care practices you may have used, please indicate which practices listed below you tried and how helpful they were. Questions about relationships and social support are in the next section; you do not need to report them here.

<table>
<thead>
<tr>
<th>Strategies to get sleep / rest</th>
<th>Helpful</th>
<th>Not helpful</th>
<th>Did not use this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical exercise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being outdoors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being with pets or other animals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking baths, being in water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Journaling / writing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying and expressing feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mindfulness / Meditation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prayer / Chanting / Mantra</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food, diet, or nutritional changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over-the-counter medications, vitamins, minerals, or supplements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entertainment / TV, Movies, Reading</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strategies to reduce stimulation (e.g. limiting screen time, wearing ear plugs, reducing light exposure)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-education (e.g. internet research, listening to stories of people who had come off, reading blogs or books on the topic)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hobbies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other; please specify</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other; please specify</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medication Outcomes
Please remember that all of these questions refer to the LAST time you came off or attempted to come off medication.
Please comment on the changes you have experienced since you began the process of coming off psychiatric medications most recently.

If you have reduced your medication, do you plan on discontinuing it?

- Yes
- No
- N/A, I have discontinued it completely

Have you been admitted to a psychiatric hospital since beginning the process of coming off psychiatric medications?

- Yes
- No

Overall, how satisfied or dissatisfied are you with your decision to come off psychiatric medications?

- Very dissatisfied
- Dissatisfied
- Neither satisfied nor dissatisfied
- Satisfied
- Very Satisfied

If you knew before starting medication what you know today, would you have taken medication to begin with?

- Yes
- No
- Unsure

Did your prescriber give you enough information about psychiatric medication for you to make an informed decision about taking them?

- Yes
- No
- Unsure

Do you feel you learned something important in the process of coming off psychiatric medication?

- Yes
- No
- Unsure

Display This Question:
If Do you feel you learned something important in the process? Yes Is Selected

If yes, please comment on what you learned:

Overall, would you recommend others consider the option of coming off medication, even if they have a different experience than you?

- Yes
- No
- Unsure
Withdrawal Effects Please remember that all of these questions refer to the LAST time you came off or attempted to come off medication.

Some people have experienced the withdrawal effects or discontinuation syndrome. Did you experience any of the following effects listed below...?

<table>
<thead>
<tr>
<th>Effect</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flu-like symptoms (e.g. body aches, sweats, nausea, headaches, fever and/or chills)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Diarrhea or constipation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Increased anxiety</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Sadness or tearfulness</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Fatigue</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Difficulty with emotions</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Difficulty interacting with others</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Difficulty with your thinking (e.g. planning, organizing, problem-solving)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Difficulty with memory or concentration</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Hearing or seeing things other people do not (sometimes called &quot;psychosis&quot;)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Thoughts of harming yourself or others</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Increasing thoughts of suicide</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Neurological symptoms (e.g. numbness, tingling, burning, &quot;brain zaps,&quot; or other new sensations)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
On a scale of 1 to 10, with 1 indicating that these withdrawal effects did not interfere with your daily activities and 10 indicating that they had a severe impact, how much of an impact did the withdrawal effects have on your daily activities?

<table>
<thead>
<tr>
<th>How much of an impact did the withdrawal effects have on your daily activities?</th>
<th>1= No impact</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10= Severe impact</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

What about these withdrawal effects was the most challenging?

Did you experience any changes in sleep patterns when coming off psychiatric medication?

- Yes
- No

Display This Question:

If you experienced problems with sleep when coming off psychiatric medication? Yes Is Selected

If you experienced problems with sleep, which of the following best describes your experience(s) (Select all that apply)

- Difficulty falling asleep
- Difficulty staying asleep
- Sleeping more than usual
- Waking early
- Vivid dreaming
- Frequent nightmares
If did you experience problems with sleep when coming off psychiatric medication? Yes Is Selected

On a scale of 1 to 10, with 1 indicating that these problems with sleep did not interfere with my daily activities and 10 indicating that they had a severe impact, how much of an impact did these problems with sleep have on your daily activities?

<table>
<thead>
<tr>
<th>1= No impact</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10= Severe impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much of an impact did these sleep problems have on your daily activities?</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
</tbody>
</table>

Please indicate whether or not you tried any of the following substances to support you in coming off medications.

- Vitamins, supplements, or herbal remedies
- Over-the-counter medicines (e.g. Benadryl, Tylenol, or other cold/pain medicine)
- Recreational substances (e.g. alcohol, marijuana, cigarettes, or other drugs)
- Psychiatric medication specifically prescribed to ease your coming off
- Psychiatric medication taken as needed and not daily, such as a medication to help you sleep
- Other (please specify): ____________________

Please indicate whether vitamins, supplements, or herbal remedies were helpful in coming off medications.

- This was helpful
- This was unhelpful
- Unsure

Please indicate whether over-the-counter medicines (e.g. Benadryl, Tylenol, or other cold/pain medicine) was helpful in coming off medications.

- This was helpful
- This was unhelpful
- Unsure
Display This Question:
If You indicate whether or not you tried any of the following substances to support you in coming... Recreational substances (e.g. alcohol, marijuana, cigarettes, or other drugs) Is Selected
Please indicate whether recreational substances (e.g. alcohol, marijuana, cigarettes, or other drugs) were helpful in coming off medications.
○ This was helpful
○ This was unhelpful
○ Unsure

Display This Question:
If You indicate whether or not you tried any of the following substances to support you in coming... Psychiatric medication specifically prescribed to ease your coming off Is Selected
Please indicate whether psychiatric medication specifically prescribed to ease your coming off was helpful in coming off medications.
○ This was helpful
○ This was unhelpful
○ Unsure

Display This Question:
If You indicate whether or not you tried any of the following substances to support you in coming... Psychiatric medication taken <strong>as needed </strong>and<strong> not daily</strong>, such as a medication to help you sleep Is Selected
Please indicate whether psychiatric medication prescribed as needed and not daily was helpful in coming off medications.
○ This was helpful
○ This was unhelpful
○ Unsure

Display This Question:
If You indicate whether or not you tried any of the following substances to support you in coming... Other (please specify): Is Selected
Please indicate whether ${q://QID202/ChoiceTextEntryValue/3} was helpful in coming off medications.
○ This was helpful
○ This was unhelpful
○ Unsure

Display This Question:
If You indicate whether or not you tried any of the following substances to support you in coming... Other (please specify): Is Selected
Please indicate whether ${q://QID202/ChoiceTextEntryValue/4} was helpful in coming off medications.
○ This was helpful
○ This was unhelpful
○ Unsure

Social Supports Please remember that all of these questions refer to the LAST time you came off or attempted to come off medication.
How supportive was your family in your decision to come off medication?
- Very supportive
- Somewhat supportive
- Neutral
- Somewhat unsupportive
- Very unsupportive
- My family was not aware of my decision
- Does not apply

How supportive were your friends in your decision to come off medication?
- Very supportive
- Somewhat supportive
- Neutral
- Somewhat unsupportive
- Very unsupportive
- My friends were not aware of my decision
- Does not apply

What was your living situation when you decided to come off medication?
- I lived alone
- I lived with family (children, parents, siblings, etc.)
- I lived with a partner or spouse
- I lived with roommates
- I lived in a supportive housing program / group home / other residential care facility
- I did not have stable housing

Display This Question:
If What was your living situation when you decided to come off medication?  I lived alone Is Not Selected

If you lived with other people, how supportive were these people in your decision to come off medication?
- They were not aware of my decision
- Very supportive
- Somewhat supportive
- Neutral
- Somewhat unsupportive
- Unsupportive

Did you have contact with others who had come off psychiatric medication during your process of coming off?
- Yes
- No
Display This Question:
If Did you have contact with others who had come off psychiatric medication during your process of c... Yes Is Selected

If yes, did you feel that having contact with people who had come off medication was helpful?
- Yes
- No
- Unsure

How helpful were the following people when coming off psychiatric medication(s)?

<table>
<thead>
<tr>
<th>Role</th>
<th>Helpful</th>
<th>Neutral</th>
<th>Unhelpful</th>
<th>Didn’t ask for support</th>
<th>Do not have someone in this role in my life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coworkers / colleagues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other service user(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Licensed Psychologist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Licensed Social Worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer Support Worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Care Provider or General Practitioner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric Nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative healing practitioners (e.g. Acupuncturist, body or energy worker, yoga instructor)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clergy, religious leader, or spiritual provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lay members of my spiritual/religious community/congregation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-person mutual support group for people coming off</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet mutual support group for people coming off</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addiction and other recovery programs (e.g. AA, SMART, ACA)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Relationship with Prescribing Health Professional Please remember that all of these questions refer to the LAST time you came off or attempted to come off medication.

Did you see a prescriber (e.g psychiatrist, primary doctor, nurse practitioner) about your medication while you were coming off?

- Yes
- No

If No Is Selected, Then Skip To Did you see a licensed therapist (e.g...

How would you rate your relationship with your current or most recent psychiatric medication prescriber?

- Very helpful
- Somewhat helpful
- Neutral
- Somewhat unhelpful
- Very unhelpful

How long had you been seeing this prescriber before you started the coming off process?

- Only once
- For less than 6 months
- 6 months to one year
- More than one year

About how frequently were you seeing your prescriber for management of psychiatric medication?

- Weekly
- Monthly
- Every three months
- Every six months
- Once a year or less often

Did this frequency change when you started the coming off process?

- Increased
- Decreased
- No change

How was your prescriber involved in the decision to come off your medication?

- I decided to try coming off against the advice of my prescriber
- I decided without telling my prescriber
- I changed prescribers to find someone who would support me
- I stopped seeing a prescriber
- I decided and my prescriber accepted this
- It was a joint decision between me and my prescriber
- My prescriber decided and I accepted
Please think about your relationship with your prescriber(s) when coming off medication. Your prescriber...
<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Slightly Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Slightly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understood your reasons for wanting to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Believed it was possible for you to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Was willing to support your decision to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Listened to your ideas when thinking through what might help when coming off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Shared stories of people who had come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Shared alternatives to medications or other options that you could try</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Was open to learning about your experiences and preferences related to coming off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Made you feel like your feelings and experiences coming off medication were important</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Knew how to support you during challenging times when coming off medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discouraged you or warned you about coming off medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actively undermined your efforts to come off medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please describe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Did you see a licensed therapist (e.g. social worker, psychologist, etc) while coming off medications?  
○ Yes  
○ No
Display This Question:

If Did you also see a licensed therapist (e.g. social worker, psychologist, etc) while coming off me... Yes Is Selected

Now please think about your relationship with your licensed therapist(s) when coming off medication. Your therapist...
<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Slightly Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Slightly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understood your reasons for wanting to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Believed it was possible for you to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Was willing to support your decision to come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Listened to your ideas when thinking through what might help when coming off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Shared stories of people who had come off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Shared alternatives to medications or other options that you could try</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Was open to learning about your experiences and preferences related to coming off medication</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Made you feel like your feelings and experiences coming off medication were important</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Knew how to support you during challenging times when coming off medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Discouraged you or warned you about coming off medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actively undermined your efforts to come off medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please describe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Medical History / Labels / Diagnoses

At what age were you given your first psychiatric diagnosis?
- 0-4 years
- 5-10 years
- 11-17 years
- 18-25 years
- 26-35 years
- 36-45 years
- 46-55 years
- 55-65 years
- 65+ years

At what age were you first prescribed psychiatric medication?
- 0-4 years
- 5-10 years
- 11-17 years
- 18-25 years
- 26-35 years
- 36-45 years
- 46-55 years
- 55-65 years
- 65+ years
Think back to the first psychiatric medication you were prescribed. What kind of medication was it? (Select all that apply if you were initially prescribed more than one medication). Please hover your mouse over the answer choices to view examples of each kind of medication.

- Anti-psychotics
- Anti-depressants
- Mood Stabilizers
- Anti-Anxiety
- Stimulants
- None of the above

Please select the degree of choice that you feel you had in taking psychiatric medication for the first time:

- I was compelled to take them under court order
- I felt that if I did not comply, I would be forced
- I had no choice because I was in the hospital
- I felt pressured to take them
- I felt passive about taking them
- I felt I had a free choice about taking them
- I had another experience not listed

Have you ever been admitted to a psychiatric hospital?

- Yes
- No

Display This Question:

If Have you ever been admitted to a psychiatric hospital? Yes Is Selected

If yes, how many times have you been admitted to a psychiatric hospital (not including emergency room visits for which you were not admitted)? (If unsure, please estimate)

(Tables Truncated)

Have you ever been admitted to a psychiatric hospital under a doctor’s or court order?

- Yes
- No

Display This Question:

If Have you ever been admitted to a psychiatric hospital? Yes Is Selected

Thinking back, what came first?

- I took psychiatric medication before I was hospitalized for the first time
- I took psychiatric medication for the first time during or following my first hospitalization

How many different psychiatric medications have you taken in total? If you don’t know exactly, please make your best estimate:
About how many years in total have you taken any psychiatric medication? (If you have not taken medications continuously, please provide the total number of years you have taken medication(s).

- Less than one year
- 1-5 years
- 5-9 years
- 9+ years

Many people have been given more than one psychiatric diagnosis. Have you ever been diagnosed with one or more of the following? (Select all that apply)

- None
- Substance use disorder
- Eating disorder (e.g. anorexia, bulimia, or binge eating)
- Obsessive Compulsive Disorder
- PTSD
- Autism Spectrum Disorder
- Personality Disorder
- Generalized Anxiety Disorder
- Attention Deficit / Hyperactivity Disorder
- Other (Specify) ____________________

People ascribe different causes to psychiatric problems or serious emotional problems (mental illness, mental disorder, etc.). From the list below, please select two factors you consider most important in causing or bringing about such problems:

- Disease or dysfunction of the brain, such as a chemical imbalance
- Genetic inheritance
- Difficult early life
- Physical or other forms of abuse
- Drug or alcohol misuse
- Frequent stress
- Traumatic event or shock
- Poverty
- Spiritual emergence or awakening
- Oppression
- Possession by evil spirits
- God's punishment
- Creative maladjustment

General Health and Wellness

In your current social network, how many people do you trust and can you count on in general?

<table>
<thead>
<tr>
<th>Number of people in your social network</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>10+</th>
</tr>
</thead>
</table>

Click to write the question text

<table>
<thead>
<tr>
<th>How do you feel about your life in general?</th>
<th>Terrible</th>
<th>Unhappy</th>
<th>Mostly Dissatisfied</th>
<th>Mixed</th>
<th>Mostly Satisfied</th>
<th>Pleased</th>
<th>Delighted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Compared to other people your age, would you say your health is:
- Excellent
- Very good
- Good
- Fair
- Poor

Has your sex drive and/or sexual activity increased, stayed the same, or decreased since you tried coming off psychiatric medication?
- Increased a lot
- Increased a little
- Stayed the same
- Decreased a little
- Decreased a lot

Demographic Information

In what year were you born?

What is your race?
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

Are you of Hispanic origin?
- Yes
- No

What is your gender?
- Male
- Female
- Transgender
- If not listed, please self-identify: ____________________
How would you describe your sexual orientation?
- Heterosexual/Straight
- Homosexual/Gay/Lesbian
- Bisexual
- Queer
- If not listed, please self-identify: ____________________

Are you a veteran / have you served in the armed forces?
- Yes
- No

Display This Question:
If Are you a veteran/have you served in the armed forces? Yes Is Selected

If yes, were you in active duty?
- Yes
- No

What state do you live in?

Socioeconomic Status

Describe the setting in which you live
- Urban/City
- Suburb/outskirts of city
- Rural/Countryside

What is your present employment status?
- Employed full time
- Employed part time
- Unemployed looking for work
- Unemployed not looking for work
- Volunteering
- Retired
- Student

What is your approximate total household income today?
- less that $12,000
- $12,000-$24,999
- $25,000-$39,999
- $40,000-$69,999
- $70,000-$149,000
- $150,000-$349,999
- $350,000+
Describe your partnership status:
- Never married
- Partnered but not married
- Married
- Widowed
- Divorced
- Separated

What is the highest level of education you have completed?
- Less than high school
- High school degree or GED
- Some college, associates or vocational degree
- College
- Graduate or professional school

Growing up, were your material needs adequately met? By material needs we mean, for example, food, housing, clothing, healthcare, and education.
- Extremely adequate
- Moderately adequate
- Slightly adequate
- Neither adequate nor inadequate
- Slightly inadequate
- Moderately inadequate
- Extremely inadequate

What kind of health insurance do you have? (Check all that apply)
- Medicaid
- Medicare
- Insurance through work
- Insurance through a family member
- Self-pay private insurance (including through the health insurance exchange)
- I do not have health insurance
- I don't know

Display This Question:
If What kind of health insurance do you have? (Check all that apply) Medicaid Is Selected
Or What kind of health insurance do you have? (Check all that apply) Medicare Is Selected

Are you on Medicaid or Medicare for a disability?
- Yes
- No
Display This Question:
If What kind of health insurance do you have? (Check all that apply) Medicaid Is Selected
And What kind of health insurance do you have? (Check all that apply) Medicare Is Selected
Are you qualified for Medicaid or Medicare for the following:
- Qualified on the basis of a psychiatric disability
- Qualified on the basis of a physical or sensory disability
- Qualified because I am a TANF/ welfare recipient or an older adult

Do you receive any kind of public assistance? (Check all that apply)
- Food stamps
- Housing subsidy/Section 8
- SSI or SSDI
- Workers compensation
- Unemployment insurance
- Other, please specify ____________________
- None

Do you receive any other regular financial assistance from others? (Check all that apply)
- Alimony from a divorce
- Child support payments
- Financial support from a family member, partner or friend
- Other, please specify ____________________

Do you financially support someone else?
- Yes
- No

Display This Question:
If Do you financially support someone else? Yes Is Selected
If yes, please specify who you financially support (check all that apply)
- Child
- Parent
- Partner
- Other family member
- Friend

Open Ended Questions

What helped you the most during the process of coming off medication?

What was the most challenging part of your process of coming off medication?

What was the most surprising thing you learned in your process of coming off medication?

Is there anything you wish you had done differently? If so, what?

What advice would you share with someone who is considering coming off psychiatric medication?
Do you have any other comments related to reducing or coming off psychiatric medication that you would like to share?

This is the end of the questionnaire. When you click the arrow your responses will be recorded.


