

Supplementary Materials

THE EXPERIENCES OF ANTIPSYCHOTIC MEDICATION SURVEY



(Please note: This survey was placed on Survey Monkey)

Welcome to *The Experiences of Antipsychotic Medication Survey*. This survey is in 4 parts and usually takes 30 – 45 minutes to complete. Not all questions will be relevant to you, so the time taken to complete the survey will be different for each person. Some questions may seem repetitive. Please answer these questions anyway. If you do not remember something, you can select or write 'I don't remember' and carry on to the next question.

1. I confirm that I fit all of the criteria in the following list:

- a. I have been taking or have previously taken an oral antipsychotic medication continuously for at least three months for any reason (such as Olanzapine, Risperidone, Clozapine, Quetiapine, Haloperidol etc).
- b. I am aged 18 or older
- c. I live in New Zealand
- d. I am not currently experiencing acute symptoms
- e. I am living in the community: i.e. you are not staying in an inpatient unit at the current time

Yes / No

Part 1. CURRENT INFORMATION

The first part of this survey is about your current situation.

2. Gender _____

3. Age _____

4. Ethnicity _____

5. Level of Education (please check one):

- Did not complete high school
- Completed high school
- Diploma/certificate after high school
- University degree

6. Approximate Annual Personal Income

- Under \$10,000
- \$10,001 - \$20,000
- \$20,001 - \$30,000
- \$30,001 - \$50,000
- \$50,001 or more

7. Occupational Status

- Employed part time
- Employed full time
- Student
- Unemployed
- Other:

8. What is your occupation?

9. Brief Multidimensional Life Satisfaction Scale

10. Multidimensional Scale of Perceived Social Support

11. The Brief Cope

12. What additional approaches have you used and how helpful have you found them?

	1. Not Used	2. Used and Not Helpful	3. Used and Slightly Helpful	4. Used and Moderately Helpful	5. Used and Very Helpful	6. Used and Extremely Helpful
Individual therapy or counseling						
Relationship/family therapy						
Drug and/or alcohol counseling						
Support group						
Community support worker						
Cultural support						
Peer Support Worker						
'Green Prescription' / exercise options						
Nutrition and dietary changes						
Vitamins/nutritional supplements						
Herbal remedies						
Meditation practices						
Respite service						
Other (please state)						

13. There are many theories, and lots of debate, about what causes mental-health problems.

What do you think caused the experiences for which you received antipsychotic medication?

Part 2. THE PRESCRIBING PROCESS

1. Have you ever taken an oral antipsychotic medication continuously for longer than 3 months?

Yes/No (No = exit screen)

2. Are you still taking oral antipsychotic medication? Yes/No

3. What experiences were you having that led you to being prescribed antipsychotic medication:

- Hallucinations
- Delusions
- Mania
- Depression
- Other: Please describe:

4. Approximately when did you first start experiencing these things?

Year: _____ or Don't Remember

5. Were you ever given any formal diagnoses? Yes/No

If yes, Q6, if No, Q8

6. What were the diagnoses you were given?

7. In what year did you *first* begin taking anti-psychotic medication? _____

If you were first prescribed antipsychotic medication a long time ago, you might not remember all of the finer details about the initial prescription process, but you might still remember some of your main experiences. If you don't remember, please select or write 'I don't remember' and move on to the next question.

8. Were you under a compulsory treatment order at the time that you were first prescribed antipsychotic medication? Yes/No/Don't Remember

9. Please finish this sentence. For me, the experience of first being prescribed antipsychotic medication was...

10. How well informed of the benefits and risks of antipsychotic medication do you remember being when you were first prescribed them?

- Not at all informed
- Slightly informed
- Moderately informed
- Well informed

11. What possible positive effects or benefits do you remember being told about?

12. What possible side effects or risks do you remember being told about?

13. Were you offered any other treatment options to consider as alternatives or additions to antipsychotic medication? Yes/No/Don't Remember

If yes, Q14, what options; If No/Don't Remember, Q15, expected duration

14. What other options were you offered?

15. When you started taking antipsychotic medication, how long were you told you could expect to take it for?

- A. About a month
- B. 1 – 3 months
- C. 4 - 6 months
- D. 7 - 12 months
- E. more than a year
- F. the rest of your life
- G. until you felt better
- H. other

16. Were you informed of how you would know when to stop taking antipsychotics medication?

Yes/No/Don't Remember

17. If yes, what were you told?

18. Overall, how satisfactory was the *initial* prescribing process for you?

1. Not at all satisfactory
2. Not satisfactory
3. Not sure
4. Satisfactory
5. Very satisfactory

19. What was the *ongoing* prescribing process like for you?

20. Have you ever received an antipsychotic medication *injection* on a regular basis? Yes/No

If No, go to Part 3, Experiences of Taking Antipsychotic Medication.

21. Do you currently receive an antipsychotic medication *injection* on a regular basis?

Yes/No

22. Did you receive the antipsychotic injection *at the same time* as taking an oral antipsychotic medication? Yes/No

23. In your experience, was the antipsychotic injection more or less helpful than the pills?

- More helpful than the pills
- No more or less helpful than the pills
- Less helpful than the pills

Part 3. YOUR EXPERIENCE OF ANTIPSYCHOTIC MEDICATION

The following section is interested in your most recent or current experiences of taking antipsychotic medication.

1. When were you most recently taking oral antipsychotic medication on a regular basis?

- Taking at the current time
- In the last year
- 2 years ago
- 3 – 5 years ago
- More than 5 years ago

When answering the questions in this section, please think about your most recent experiences of taking the medication. If you were taking antipsychotic medication a long time ago, you might not remember all of the finer details, but you might still remember some of your main experiences. If you don't remember, please select or write 'I don't remember' and move on to the next question.

2. What is the name of your current or most recent anti-psychotic medication (if you know)

_____ | I Don't Know | I Don't Remember

3. What dose were you / are you on? _____ | I Don't Know | I Don't Remember

4. What other medications for mental health (tablets and injections) were you or are you taking at the same time? _____ | I Don't Know | I Don't Remember

5. Please complete this sentence or paragraph. In my life, antipsychotics have been ...

6. How helpful would you say the antipsychotic medication was?

- 1. Very unhelpful
- 2. Somewhat unhelpful
- 3. Unsure
- 4. Somewhat helpful
- 5. Very helpful

7. While taking anti-psychotic medication my quality of life was/is:

- 1. A lot worse
- 2. Slightly worse

3. Unchanged
4. Slightly improved
5. Greatly improved

8. What were the benefits of taking antipsychotic medication for you?

9. What were the disadvantages of taking antipsychotic medication for you? Please use the 'other' option to describe any disadvantages that are not included in the list of options.

- Drowsiness, feeling tired, sedation
- Dizziness
- Loss of motivation
- Feeling not like myself
- Emotional numbing
- Hypertension
- Increased appetite
- Weight gain
- Dry mouth
- Tremors
- Loss of sex drive
- Diabetes
- Suicidality
- Withdrawal effects
- Health problems: Please state
- Other: (please state)

10. How much is your everyday life affected by the problems you experience as a result of the antipsychotic medication you take?

0. Not at all
1. Mildly
2. Moderately
3. Severely

11. When taking antipsychotic medication do you or did you always take the antipsychotic medication exactly as prescribed? Yes/No/ I Don't Remember

If yes, or don't remember, please go to Q14 other comments. If No, go to Q12, type of changes.

12. What kinds of changes do/did you make? Select as many as apply.

- Taking medication less often or in smaller doses than prescribed
- Taking medication more often or in larger doses than prescribed
- Taking the same amount but at a different time than prescribed
- I don't remember

13. What are the main reasons why you don't/didn't always take the medication exactly as prescribed?

14. Is there anything else you would like to say, or emphasise, about your experiences with anti-psychotics?

15. Have you ever thought about stopping your antipsychotic medication altogether?

Yes/No

If yes, go to Q16, if No, go to completion screen.

16. Have you ever tried to stop taking antipsychotic medication?

Yes/No

If Yes, go to Part 4. If No, go to completion screen.

Part 4. YOUR EXPERIENCE OF ATTEMPTED DISCONTINUATION

Part 4 of The Experiences of Antipsychotic Medication Survey is for people who have previously tried to stop taking antipsychotic medication. There are 20 questions in this section.

1. How many times have you tried to stop taking antipsychotic medication altogether?

2. Approximately how old were you when you FIRST attempted to stop taking medication?

3. Approximately how old were you when you MOST RECENTLY attempted to stop taking medication?

If you have made more than one attempt to stop taking antipsychotic medication, please think about your most recent attempt when answering the following questions. If your most recent discontinuation experience was a long time ago, you might not remember the finer details. Just do your best and if you don't remember, select 'I Don't Remember' and move on to the next question.

4. What were your main reasons for wanting to stop taking antipsychotic medication? Select all that apply. Please use the 'other' option to describe any of your main reasons that are not included in the list of options.

- Felt better and thought I didn't need it
- The medication was not helping
- Wanted to solve the problem without medication
- Medication caused unpleasant side effects
- Afraid that would get dependent on the medication
- I worried about the long-term effect on my physical health
- I don't remember
- Other reasons; please describe

5. What else do you have to say about your reasons for wanting to stop taking antipsychotic medication?

6. How did you go about withdrawing from antipsychotic medication?

- A: I slowly reduced my dose over a period of time before stopping entirely*
- B: I stopped taking the medication abruptly all in one go
- C: I don't remember
- D: Other

If A, go to Q7, if B/C/D, go to Q8.

7. Approximately how long did it take you to reduce to no medication?

8. Did you make any preparations for your attempt to stop taking antipsychotic medication?

Yes/No

If yes, go to Q9, if No, go to Q10

9. What, if any, preparations did you make for your attempt to stop taking antipsychotic medication? Please select all that apply.

- I tried to gather information about coming off antipsychotic medication
- I made a plan for gradual withdrawal before making any changes
- I informed friends of my plans and what to expect
- I informed my family, partner or spouse of my intentions and/or how I wanted them to support me.
- I stopped or reduced taking drugs
- I stopped or reduced drinking alcohol
- I arranged a safe, quiet place to go in case the need arose
- I got into a regular sleeping pattern
- I reduced the stress in my environment
- I took time off work or away from study
- I created an advanced directive with a plan for how I wanted to handle relapse if it happened
- I learned meditation
- I started seeing a counsellor, psychologist or psychotherapist to help me manage my experiences during withdrawal
- I joined a support group
- I made sure I had a stable, regular routine
- I don't remember
- Other...

10. Did you consult with a doctor before stopping your medication regime?

Yes/No/I Don't Remember

11. What advice or information do you remember finding or being given about coming off antipsychotic medication? _____ | I Don't Remember

12. What were the effects of withdrawing from the medication?

- 13. What did you do to cope with the unwanted effects of withdrawing from the medication?**
- 14. Did you ever briefly resume taking the antipsychotic medication or increase the dose again to control the side effects of coming off the medication? Yes/No**
- 15. What support did you have for your attempt to stop taking antipsychotic medication?**
- 16. What strategies and supports did you find most helpful in your attempt to stop taking antipsychotic medication and why?**
- 17. What strategies and supports did you find unhelpful in your attempt to stop taking antipsychotic medication and why?**
- 18. What was the outcome of your attempt to stop taking antipsychotic medication?**
- 19. What else would you like to share about the experience of coming off antipsychotics?**
- 20. How long did you stay off antipsychotic medication for, the last time you attempted to discontinue?**
- A: Less than a month
 - B: 1 – 6 months
 - C: 6 – 12 months
 - D: More than a year*

ENDS

Completion Message

*Respondents who select option D on Question 20 are shown the alternate completion message inviting expressions of interest in Study Two.