

Supplementary Data

Survey Questions

Screening Questions

What is your age? _____

<If less than 21 years old: *"Thank you for your interest in our survey. However, you do not currently meet the criteria for this study."*>

What is your relationship to the person with schizophrenia? (select all that apply)

- ☐ I am a parent of an individual with schizophrenia
- ☐ I am a family (non-parent) caregiver of an individual with schizophrenia
- ☐ I am a spouse/partner of an individual with schizophrenia
- ☐ I am a paid caregiver of an individual with schizophrenia
- ☐ I have no relationship to an individual with schizophrenia

<If no relationship: *"Thank you for your interest in our survey. However, you do not currently meet the criteria for this study."*>

How old is the person with schizophrenia? _____ years

Approximately how many years ago did the person with schizophrenia first start having symptoms you now associate with the disease? (If within the last year, please enter "0" years)

Approximately how many years ago was the person formally diagnosed with schizophrenia? (If within the last year, please enter "0" years) _____

Survey Questions

- 1. What type of caregiving support do you provide to the individual with schizophrenia?** (select all that apply)

- ☐ Household tasks (cooking, cleaning, etc.)
- ☐ Shopping
- ☐ Managing finances
- ☐ Driving for errands
- ☐ Participating in recreational activities
- ☐ Taking to medical appointments
- ☐ Medication supervision
- ☐ Coordinating medical care
- ☐ Other: _____

- 2. On a typical week, how many hours do you spend doing caretaking activities for this individual?** ____ hours

- 3. How would you describe the capability of the individual with schizophrenia related to caring for their own activities of daily living (such as eating, bathing, dressing, etc.)?**

1	2	3	4	5
Not at all capable		Somewhat capable		Extremely capable

4. The individual with schizophrenia for whom I provide care has experienced: (select all that apply)

- ☐ Hallucinations (usually involve seeing or hearing things that don't exist, although can be in any of the senses)
- ☐ Delusions (beliefs not based in reality and usually involve misinterpretation of perception or experience)
- ☐ Disorganized behavior (could range from childlike behavior to unpredictable agitation)
- ☐ Thought disorder (difficulty speaking or organizing thoughts, stopping speech midsentence)
- ☐ Agitated body movements
- ☐ Verbal aggression
- ☐ Physical aggression
- ☐ Dull/monotonous voice
- ☐ Lack of emotion
- ☐ Lack of pleasure/interest in everyday life
- ☐ Lack of ability to begin and sustain planned activities
- ☐ Neglect of personal hygiene
- ☐ Social withdrawal
- ☐ Loss of motivation
- ☐ Problems with making sense of information
- ☐ Difficulty paying attention
- ☐ Memory problems
- ☐ Other symptoms: _____

5. When the individual needs to be admitted to the hospital, which schizophrenia symptoms are most worrisome? (choose TOP 3)

- ☐ Hallucinations (usually involve seeing or hearing things that don't exist, although can be in any of the senses)
- ☐ Delusions (beliefs not based in reality and usually involve misinterpretation of perception or experience)
- ☐ Disorganized behavior (could range from childlike behavior to unpredictable agitation)
- ☐ Thought disorder (difficulty speaking or organizing thoughts, stopping speech midsentence)
- ☐ Agitated body movements
- ☐ Verbal aggression
- ☐ Physical aggression
- ☐ Dull/monotonous voice
- ☐ Lack of emotion
- ☐ Lack of pleasure/interest in everyday life
- ☐ Lack of ability to begin and sustain planned activities
- ☐ Neglect of personal hygiene
- ☐ Social withdrawal
- ☐ Loss of motivation
- ☐ Problems with making sense of information
- ☐ Difficulty paying attention
- ☐ Memory problems
- ☐ Other symptoms: _____
- ☐ N/A, the individual has never been admitted to a hospital.

6. When the individual is not in the hospital, which schizophrenia symptoms are most worrisome? (choose TOP 3)

- ☐ Hallucinations (usually involve seeing or hearing things that don't exist, although can be in any of the senses)
- ☐ Delusions (beliefs not based in reality and usually involve misinterpretation of perception or experience)
- ☐ Disorganized behavior (could range from childlike behavior to unpredictable agitation)
- ☐ Thought disorder (difficulty speaking or organizing thoughts, stopping speech midsentence)
- ☐ Agitated body movements
- ☐ Verbal aggression
- ☐ Physical aggression
- ☐ Dull/monotonous voice
- ☐ Lack of emotion
- ☐ Lack of pleasure/interest in everyday life
- ☐ Lack of ability to begin and sustain planned activities
- ☐ Neglect of personal hygiene
- ☐ Social withdrawal
- ☐ Loss of motivation
- ☐ Problems with making sense of information
- ☐ Difficulty paying attention
- ☐ Memory problems
- ☐ Other symptoms: _____

7. What type of treatment is the person with schizophrenia currently taking now? (select all that apply)

- ☐ Oral antipsychotic (pills taken by mouth on daily basis)
- ☐ Long-acting injectable (shot/injections given on longer-term schedule, such as every month)
- ☐ Electroconvulsive therapy (ECT)
- ☐ Psychotherapy (talk therapy)
- ☐ Other: (please describe)
- ☐ None of the above [exclusive option]

8. What type of treatment has the person with schizophrenia taken in the past? (select all that apply)

- ☐ Oral antipsychotic (pills taken by mouth on daily basis)
- ☐ Long-acting injectable (shot/injections given on longer-term schedule, such as every month)
- ☐ Electroconvulsive therapy (ECT)
- ☐ Psychotherapy (talk therapy)
- ☐ Other: (please describe)
- ☐ None of the above [exclusive option]

9. Please rate your agreement with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am confident that if the individual with schizophrenia takes their medication correctly that it will be effective	1	2	3	4	5
I am confident that the individual with schizophrenia takes their medication exactly like the doctors and nurses tell them to	1	2	3	4	5
The individual with schizophrenia is capable of taking their medication exactly like the doctors and nurses tell them to	1	2	3	4	5
I feel that I have to act as a mediator between the medical team and the individual with schizophrenia	1	2	3	4	5
I feel like I am responsible for the individual with schizophrenia's adherence to the treatment	1	2	3	4	5

10. Please rate the significance of the following issues when caring for the individual with

schizophrenia, where 1 represents an issue that is not significant at all and 5 represents an issue that is very significant to you.

	Not at all significant	Slightly significant	Somewhat significant	Significant	Very significant
Disruption of your family life	1	2	3	4	5
Disruption or distraction to your job/career	1	2	3	4	5
Reduction in your ability to have a satisfying personal life	1	2	3	4	5
People with schizophrenia are judged or not approved of by members of the community	1	2	3	4	5
Strain on your physical health	1	2	3	4	5
Strain on your emotional health	1	2	3	4	5
Increased financial burden on you	1	2	3	4	5

QUESTIONS FOR CAREGIVERS NOT YET EXPOSED TO LAI MEDICATIONS <if not currently or previously on LAI in Q7-8>

For the next few questions, we will be referring to long-acting injectable antipsychotic medications. These treatments use the same medicine as oral antipsychotics but are given with a shot/injection so that the patient doesn't have to take a daily oral medication. The goal is to alleviate symptoms of schizophrenia and prevent relapse without the need for a daily oral medication.

11. Have you ever had a conversation with a doctor or other healthcare provider about an injectable medication to help the individual with schizophrenia with their symptoms and prevent relapse without having to take an oral medication every day?

- ☐ Yes
- ☐ No

<If yes> Who initiated this conversation?

- ☐ Me, the caregiver
- ☐ The individual with schizophrenia
- ☐ The doctor/other healthcare provider
- ☐ I can't remember

12. Please rate your agreement with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
A long-acting injectable medication will increase my satisfaction or confidence in the care of the individual with schizophrenia	1	2	3	4	5
In my opinion, the individual with schizophrenia will be open to receiving a long-acting injectable medication rather than oral medication	1	2	3	4	5

13. As the caregiver, please indicate how significant the following potential problems or issues would be to you and to the individual with schizophrenia regarding the use of a long-acting injectable instead of oral medication.

	Not a problem	Slight problem	May be a problem	Probably a problem	Extreme problem
Fear of needles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Higher cost of injectable medication compared to oral medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of control over the medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of information about what the medication does	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

QUESTIONS FOR CAREGIVERS PREVIOUSLY EXPOSED TO LAI MEDICATIONS <if currently or previously on LAI in Q7-8>

For the next few questions, we will be referring to long-acting injectable antipsychotic medications. These treatments use the same medicine as oral antipsychotics but are given with a shot/injection so that the patient doesn't have to take a daily oral medication. The goal is to alleviate symptoms of schizophrenia and prevent relapse without the need for a daily oral medication.

14. Who initiated a conversation regarding using a long-acting injectable medication instead of oral medication?

- ☐ Me, the caregiver
- ☐ The individual with schizophrenia
- ☐ The doctor/other healthcare provider
- ☐ I can't remember

15. Please rate your agreement with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
A long-acting injectable medication increases my satisfaction or confidence in the care of the individual with schizophrenia	1	2	3	4	5
In my opinion, the individual with schizophrenia sees benefits in receiving a long-acting injectable medication rather than oral medication	1	2	3	4	5

16. As the caregiver, please indicate how significant the following potential problems or issues are to you and to the individual with schizophrenia regarding the use of a long-acting injectable instead of oral medication.

	Not a problem	Slight problem	May be a problem	Probably a problem	Extreme problem
Fear of needles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Higher cost of injectable medication compared to oral medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of control over the medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of information about what the medication does	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ALL RESPOND TO THESE QUESTIONS:

17. Please rate your agreement with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Long-acting injectable antipsychotics are as safe as other medications for schizophrenia management	1	2	3	4	5
Long-acting injectable antipsychotics are only used for patients with more severe symptoms	1	2	3	4	5
Society stigmatizes people with schizophrenia	1	2	3	4	5
The societal stigma is worse for people who receive injections for schizophrenia than those on oral medication	1	2	3	4	5
Injectable medications are only for patients who aren't taking their medication as directed	1	2	3	4	5

18. Please rate your agreement with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I would benefit from more information about schizophrenia symptoms	1	2	3	4	5
I would benefit from more information about treatment options for schizophrenia	1	2	3	4	5
I would benefit from more information on how to provide quality supportive care for an individual with schizophrenia	1	2	3	4	5
I regularly use local community caregiver support resources	1	2	3	4	5
I regularly use online caregiver support resources	1	2	3	4	5
Local community caregiver support resources are inadequate sources of help or encouragement for me	1	2	3	4	5
Online caregiver support resources are inadequate sources of help or encouragement for me	1	2	3	4	5

19. What types of resources do you currently use to learn more about schizophrenia? (select all that apply)

- ☐ Online, or Internet-based
- ☐ Printed materials received from healthcare professional
- ☐ Printed materials not received from healthcare professional
- ☐ Information from healthcare professional provided during office visit
- ☐ Local community-based resources
- ☐ Other (please specify): _____
- ☐ None, I do not use any resources to learn more about schizophrenia

20. <If selected online in Q16> Which websites do you most often visit to find information regarding schizophrenia? _____

21. Please rate your interest in learning more about schizophrenia and its treatment.

1	2	3	4	5
Not interested at all		Somewhat interested		Extremely interested

22. What informational or educational topic(s) related to schizophrenia and its treatment would be most valuable to you? _____

23. Please rate your interest in learning more about providing care for individuals with schizophrenia.

1	2	3	4	5
Not interested at all		Somewhat interested		Extremely interested

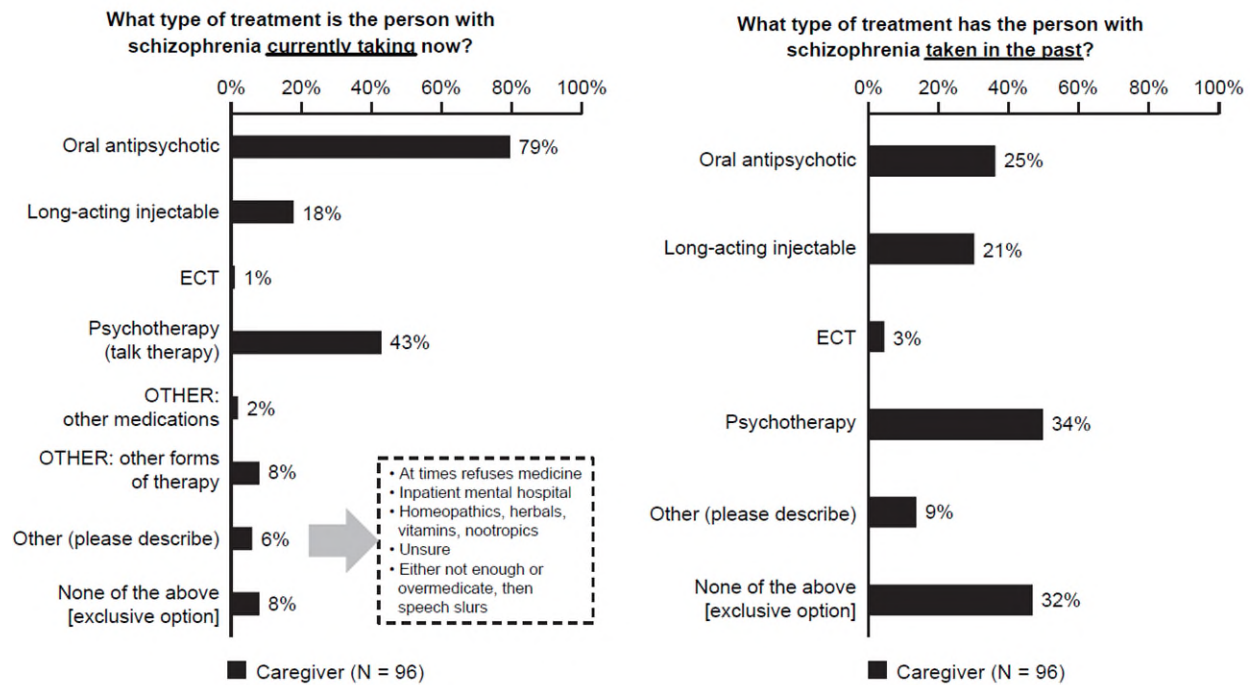
24. What informational or educational topic(s) related to providing care for individuals with schizophrenia would be most valuable to you? _____

Demographic Questions

25. How would you describe the location of your main residence? (select only one)

- ☐ Urban
- ☐ Suburban
- ☐ Rural

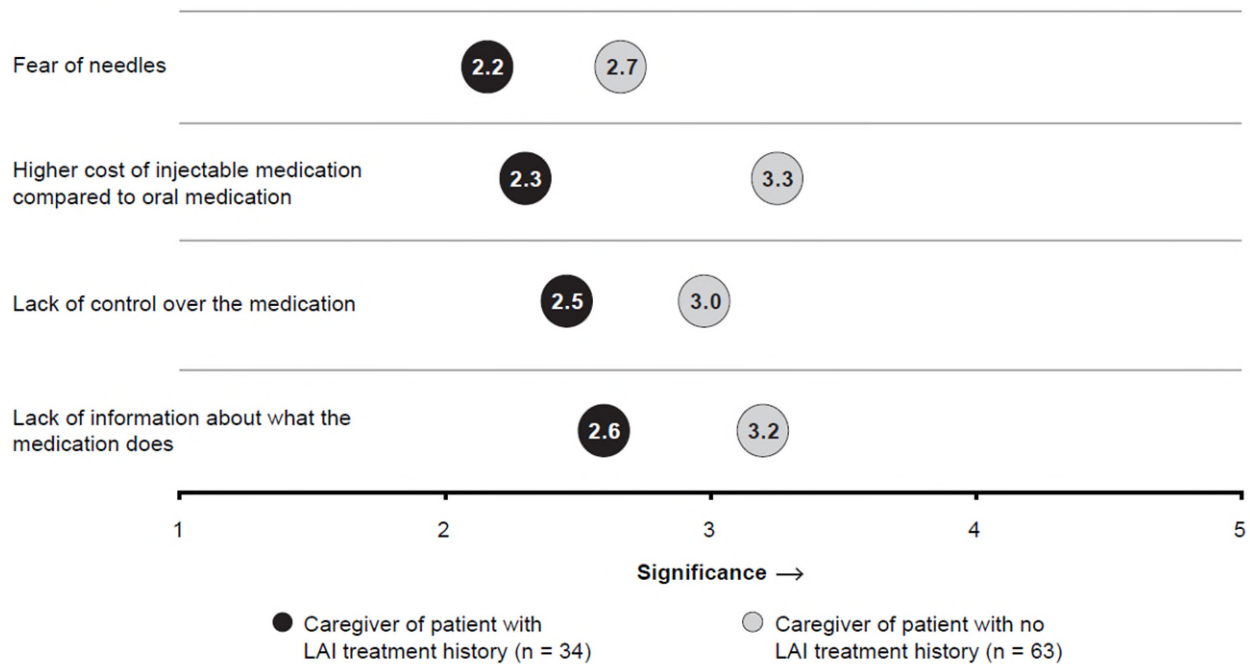
Supplemental Figure 1 Current treatment options.



Abbreviation: ECT, electroconvulsive therapy.

Supplemental Figure 2 Issues and barriers with LAI antipsychotic medications.

As the caregiver, please indicate how significant the following potential problems or issues would be (are) to you and to the individual with schizophrenia regarding the use of a long-acting injectable instead of oral medication.



Abbreviation: LAI, long-acting injectable.

Supplemental Figure 3 Perceptions with LAI antipsychotic medications.

Please rate your agreement with the following statements:

Long-acting injectable antipsychotics
are as safe as other medications for
schizophrenia management

3.1

3.6

Long-acting injectable antipsychotics
are only used for patients with more
severe symptoms

2.7

3.0

Society stigmatizes people
with schizophrenia

4.3

4.5

The societal stigma is worse for people
who receive injections for schizophrenia
than those on oral medication

2.1

2.6

Injectable medications are only for
patients who aren't taking their
medication as directed

2.4

2.8

1

2

3

4

5

Agreement →

● Caregiver of patient with previous
LAI exposure (n = 37)

○ Caregiver of patient with no
LAI exposure (n = 59)

Abbreviation: LAI, long-acting injectable.