

Survey Research in Wilson Disease Patient Survey

FINAL Version 1.0

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1 CONSENT AND SCREENING

1.1 Electronic consent form

[Consent form text]

1. I consent to take part in this research study. I understand the purpose of this study and what the study entails. I have read all of this consent form. I have been told that I have not given up any legal rights.
☐ Yes
☐ No → *proceed to ineligible page (section 1.4)*
2. What are the first three letters of your last name?
[Open response]

1.2 Electronic screening form

1. Where are you located?
☐ United States
☐ Canada
☐ Other → *proceed to ineligible page (section 1.4)*
2. Are you 18 years of age or older?
☐ Yes
☐ No → *proceed to follow-up page (section 1.3)*
3. How did you learn about the survey?
☐ From my doctor or clinic
☐ From an advocacy organization
☐ I saw the recruitment flyer
☐ From a friend
☐ Someone sent me the survey link → *proceed to follow-up page (section 1.3)*
4. How were you diagnosed with Wilson Disease? Select all that apply.
☐ Blood or urine test
☐ Eye exam (i.e., presence of Kayser-Fleischer rings)
☐ Liver biopsy
☐ Genetic testing
☐ Leipzig score (indicate score if known) [open response]
☐ Other [open response] → *proceed to follow-up page (section 1.3)*
5. Do you experience any of the following due to Wilson Disease?
☐ Liver symptoms (e.g., scarring [cirrhosis] or failure)
☐ Neurologic symptoms (e.g., clumsiness, tremors, difficulty walking, speech problems, impaired thinking ability, depression, anxiety, mood swings, problems with memory, changes in personality)
☐ Bone or muscle symptoms (e.g., arthritis, osteoporosis, frequent bone fractures)
☐ I do not experience any symptoms due to Wilson Disease → *proceed to ineligible page (section 1.4)*

6. Are you able and willing to complete an online survey in English? It should take about 30 minutes to complete.

- ☐ Yes
☐ No → *proceed to ineligible page (section 1.4)*

1.3 Follow-up page

Thank you for your time, based on your responses someone from our research team may need to speak with you to determine if you are eligible to participate in this research. Please provide your phone number so someone can reach out to you. If you have any questions, please feel free to contact WD@endpointoutcomes.com.

[Open response: ###-###-####]

1.4 Ineligible page

Thank you for your time, but unfortunately you are not eligible to participate in this research. If you have any questions, please feel free to contact WD@endpointoutcomes.com.

2 Main Survey

2.1 Introduction

Please answer the following questions about your experience with Wilson Disease. The entire survey will take about 30 minutes and must be completed in one sitting (i.e., you cannot start and stop and come back to the survey). When you have completed all of the questions you will receive a message thanking you for your participation in the survey and someone from our research team will provide you with a \$50 gift card.

2.2 Demographic and health information

1. How old are you?
[Age dropdown: 18 – 85]
2. What is your gender?
☐ Male
☐ Female
3. Where do you live?
☐ United States → *proceed to question 4*
☐ Canada → *proceed to question 5*
4. In what state do you live?
[United States state drop down]
5. In what province do you live?
[Canada province drop down]
6. What is the highest grade you completed in school?
☐ Elementary school or middle or junior high school
☐ High school graduate
☐ Some college (no degree)
☐ Trade school or vocational school
☐ Bachelor's degree
☐ Master's degree
☐ Doctoral degree
☐ Other (please specify): _____
7. Do you have a job?
☐ Yes
☐ No → *proceed to question 9*
8. Do you work full-time or part-time?
☐ Full-time
☐ Part-time
☐ Volunteer

9. Are you on disability?
- ☐ Yes
 - ☐ No → *proceed to question 10*
10. Are you on disability because of your Wilson Disease?
- ☐ Yes
 - ☐ No
11. Where do you live?
- ☐ In an apartment, house, or college dorm by myself
 - ☐ At home with family or parents/guardians
 - ☐ In an apartment, house, or college dorm with roommate(s), girlfriend/boyfriend, husband/wife
 - ☐ At a residential facility
12. How old were you when you were diagnosed with Wilson Disease?
[Age dropdown: 0 – 100]
13. How old were you when you began experiencing symptoms of Wilson Disease?
[Age dropdown: 0 – 100]
14. Who diagnosed you with Wilson Disease?
- ☐ Geneticist
 - ☐ Pediatrician
 - ☐ Gastroenterologist
 - ☐ General Practitioner/Family doctor
 - ☐ Urologist
 - ☐ Ophthalmologist
 - ☐ Psychiatrist
 - ☐ Neurologist
 - ☐ Hepatologist
 - ☐ Other (please specify): [open response]
15. Where do you go for the management of your Wilson Disease? Please specify the location in the space provided below. Select all that apply.
- ☐ Doctor's office/clinic: [open response]
 - ☐ Specialist's office: [open response]
 - ☐ Hospital: [open response]
 - ☐ Other (please specify): [open response]
16. How were you diagnosed with Wilson Disease?
- ☐ Blood or urine test
 - ☐ Eye exam
 - ☐ Liver biopsy
 - ☐ Genetic testing
 - ☐ Leipzig Score (indicate score if known) [open response]
 - ☐ Other (please specify): [open response]

17. Were Kayser-Fleischer rings (green-to-brownish ring that surrounds the colored part of the eye) seen in your eye exam?

- ☐ Yes
- ☐ No
- ☐ I don't know

18. Were you misdiagnosed with a psychiatric, liver, neurologic, or other condition before being diagnosed with Wilson Disease? Select all that apply.

- ☐ Psychiatric condition: [open response]
- ☐ Liver condition: [open response]
- ☐ Neurologic condition: [open response]
- ☐ Other: [open response]

19. Have you had a liver transplant?

- ☐ Yes
- ☐ No

2.3 Signs and symptoms

2.3.1. Neurologic symptoms

20. Do you ever experience any of the following? Select all that apply.

- ☐ Stiffness or inflexibility
- ☐ Involuntary muscle contractions (spasms)
- ☐ Involuntary muscle movements, tremor (dyskinesia)
- ☐ Uncontrollable muscle contraction that causes body parts to twist involuntarily in repetitive movements or abnormal postures, tremor (dystonia)
- ☐ Slurred speech, stumbling, falling, and lack of coordination (ataxia)
- ☐ Abnormal involuntary movements that range from minor fidgeting to more major uncontrolled arm and leg movements (chorea)
- ☐ Speech issues from muscle weakness (dysarthria)
- ☐ Difficulty swallowing foods or liquids (dysphagia)
- ☐ Abnormalities in eye movements, such as restricted ability to gaze upwards
- ☐ Seizures
- ☐ None of the above

21. *[Symptoms selected in question 20 appear]* How old were you when *[symptom]* first appeared?
[Age dropdown <1-50]

22. Have you ever experienced any of the following? Select all that apply.

- ☐ Difficulty with concentration
- ☐ Difficulty paying attention (e.g., attentional deficit disorder)
- ☐ Trouble remembering things
- ☐ Altered personality (e.g., irritability, aggression)
- ☐ Depression
- ☐ Anxiety

- ☐ Seeing, hearing, or believing things that aren't real (psychosis)
- ☐ None of the above

23. *[Symptoms selected in question 22 appear]* How old were you when *[symptom]* first appeared?
[Age dropdown <1-50]

2.3.2. Social cognition symptoms

24. Have you ever experienced any of the following? Select all that apply.

- ☐ Difficulty recognizing emotions through facial expressions
- ☐ Difficulty interpreting positive emotions (e.g., joy) in other people
- ☐ Difficulty interpreting negative emotions (e.g., anger, sadness) in other people
- ☐ Impulsive behavior
- ☐ Responding to situations with more than normal aggression or irritability
- ☐ None of the above

2.3.3. Musculoskeletal symptoms

25. Have you ever been diagnosed with any of the following? Select all that apply.

- ☐ Premature weak or brittle bones (osteoporosis)
- ☐ Premature arthritis
- ☐ Skeletal or joint deformities
- ☐ Joint pain (arthralgia)
- ☐ Frequent bone fractures
- ☐ None of the above

2.3.4. Liver symptoms

26. Have you been diagnosed with any of the following? Select all that apply.

- ☐ Elevated liver enzymes
- ☐ Liver scarring (cirrhosis)
- ☐ Liver failure
- ☐ None of the above

27. Have you ever experienced any of the following due to liver disease?

- ☐ Yellow skin or eyes (jaundice)
- ☐ Fatigue
- ☐ Loss of appetite
- ☐ Abdominal swelling
- ☐ None of the above

2.3.5. Other organ symptoms

28. Have you ever been diagnosed with any of the following? Select all that apply.

- ☐ A disease that occurs when kidneys don't properly excrete acids into the urine, making a person's blood too acidic (renal tubular acidosis)
- ☐ Kidney stones
- ☐ A disease of the heart muscle that makes it harder for your heart to pump blood to the rest of your body (cardiomyopathy)

- ☐ Decreased secretion of the parathyroid hormone (PTH) leading to decreased levels of calcium and increased levels of phosphorous in the blood (hypoparathyroidism)
- ☐ A disease in which the pancreas becomes inflamed (pancreatitis)
- ☐ None of the above

[Question 29 only appears to female participants]

29. Have you ever experienced any of the following? Select all that apply.

- ☐ Loss of periods (amenorrhea)
- ☐ Irregular periods
- ☐ A miscarriage
- ☐ Infertility
- ☐ None of the above

2.3.6. Most important symptom to improve

30. Given that a new drug will be unlikely to cure Wilson Disease, of the things listed below, which **three** would be most important for you to see improvement on after treatment?

- ☐ Stiffness or inflexibility
- ☐ Fatigue
- ☐ Lack of appetite or abdominal pain
- ☐ Yellowing of skin and whites of eyes (jaundice)
- ☐ Golden-brown eye discoloration (Kayser-Fleishcher rings)
- ☐ Build up of fluid in legs or abdomen
- ☐ Involuntary muscle contractions
- ☐ Involuntary muscle movements tremor (dyskinesia)
- ☐ Uncontrollable muscle contraction that causes body parts to twist involuntarily in repetitive movements or abnormal postures (dystonia)
- ☐ Slurred speech, stumbling, falling, and lack of coordination (ataxia)
- ☐ Abnormal involuntary movements that range from minor fidgeting to more major uncontrolled arm and leg movements (chorea)?
- ☐ speech issues from muscle weakness (dysarthria)
- ☐ difficulty swallowing foods or liquids (dysphagia)
- ☐ Seizures
- ☐ Abnormalities in eye movements, such as restricted ability to gaze upwards
- ☐ Difficulty with concentration
- ☐ Attentional disorders (e.g., attentional deficit disorder)
- ☐ Trouble remembering things
- ☐ Altered personality
- ☐ Depression
- ☐ Anxiety
- ☐ Seeing, hearing, or believing things that aren't real (psychosis)
- ☐ Difficulty recognizing emotions through facial expressions
- ☐ Difficulty interpreting positive emotions (e.g., joy) in other people
- ☐ Difficulty interpreting negative emotions (e.g., anger, sadness) in other people
- ☐ Impulsive social behavior
- ☐ Responding to situations with more than normal aggression or irritability
- ☐ None of the above

2.3.7. Additional symptoms

31. Do you experience any other symptoms not yet mentioned due to your Wilson Disease?

- ☐ No
☐ Yes: [open response]

2.4 Impacts

2.4.1. Activities of daily living impacts

32. Please rate how difficult the following activities of daily life are because of your Wilson Disease:

	Not at all difficult	A little bit difficult	Somewhat difficult	Very difficult	Extremely difficult
Getting ready in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swallowing foods and/or liquids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Running errands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing housework or chores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical activity or exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.4.2. Emotional impacts

33. Please indicate how often you experience the following emotional impacts because of your Wilson Disease:

	Never	Rarely	Occasionally	Most of the time	All of the time
Feeling sad or depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious or worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling frustrated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling self-conscious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling embarrassed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling overwhelmed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling dependent on others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling aggression towards others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling concerned about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.4.3. Social impacts

34. Please indicate how often you experience the following social impacts because of your Wilson Disease:

	Never	Rarely	Occasionally	Most of the time	All of the time
Avoid spending time with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Avoid conversations with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty making friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble dating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receiving unwanted attention from strangers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relying on family for help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.4.4. Executive function impacts

35. Please indicate how often you experience the following impacts because of your Wilson disease:

	Never	Rarely	Occasionally	Most of the time	All of the time
Difficulty planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty remembering instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty juggling multiple tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty moving from one activity or situation to another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty checking work or assessing personal performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty anticipating, future events, setting goals, and grasping main ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty independently beginning an activity, generating ideas, and solving problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. Do you think Wilson Disease negatively affects your quality of life?

- ☐ Yes
☐ No → *proceed to question 38*

37. Are there any other aspects of Wilson Disease not previously asked about in this survey that negatively impact your quality of life?

- ☐ No
☐ Yes: [open response]

38. Please rank which aspect of your life is most negatively affected by Wilson disease (1 being the most negatively affected and 6 being the least negatively affected):

- ☐ Activities of daily living (e.g., getting ready in the morning, running errands, household chores)
☐ Emotional state (e.g., feeling sad/depressed, anxious/worried, frustrated, angry)
☐ Social life (e.g., relationships with family/friends)
☐ Ability to perform physical activity or exercise
☐ Work or school

39. What concerns you most about your future health due to your Wilson Disease?
 [Open response]

2.5 Most bothersome aspect

40. What bothers you most about living with Wilson Disease?
 [Open response]

2.6 Treatment side effects

41. Do you or have you ever used any of the following to help manage your Wilson Disease? Select all that apply.

	Took in the past	Currently takes	N/A – Never taken
D-penicillamine (Cuprimine, Depen) → <i>proceed to question 42</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trientine dihydrochloride (Syprine) → <i>proceed to question 43</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Zinc acetate (Galzin) in the past → <i>proceed to question 44</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Took in
the pastCurrently
takesN/A –
Never
takenTetrathiomolybdate (TTM) → *proceed to question 43*☐☐☐Other: [open response] → *proceed to question 45*☐☐☐

42. While using D-penicillamine (Cuprimine, Depen), did you ever experience any of the following side effects? Select all that apply.

- ☐ An increase in any neurological symptoms you previously had
- ☐ Fever
- ☐ Enlarged lymph nodes
- ☐ Kidney toxicity or failure
- ☐ Abnormal blood cell counts
- ☐ Skin rash
- ☐ No side effects
- ☐ Other (please specify): [open response]

43. While using Trientine (Syprine) and/or TTM, did you ever experience any of the following side effects? Select all that apply.

- ☐ Any of the following signs of bone marrow toxicity: easy bruising, bleeding of the nose, gums, or mouth, tiny red spots on the skin, or blood in the urine
- ☐ Skin rash
- ☐ Loss of taste
- ☐ Dizziness
- ☐ Vomiting
- ☐ Viral hepatitis
- ☐ Seizures
- ☐ No side effects
- ☐ Other (please specify): [open response]

44. While using Zinc acetate (Galzin), did you ever experience an upset stomach (gastrointestinal discomfort) or any other side-effects? Select all that apply.

- ☐ An increase in any neurological symptoms you previously had
- ☐ Upset stomach (gastrointestinal discomfort)
- ☐ Low red blood cell count (anemia)
- ☐ No side effects
- ☐ Other (please specify): [open response]

45. While undergoing any form of treatment did you experience irreversible liver scarring (cirrhosis)?

- ☐ Yes

☐ No

46. Have you used any of the following treatments for symptoms of Wilson Disease? Select all that apply.

- ☐ OnabotulinumtoxinA (Botox®) (e.g., for spasms or tremors)
- ☐ Electrical stimulation for spasms of the voice box
- ☐ Deep brain stimulation for tremors
- ☐ Feeding tube
- ☐ Beta blockers (e.g., propranolol [Inderal], metoprolol [Toprol], primidone [Mysoline], topiramate [Topamax], pregabalin [Lyrica], benzodiazepines [Diazepam], clonazepam [Klonopin]) for tremors or anxiety
- ☐ Speech therapy
- ☐ Consultation with a nutritionist
- ☐ Medication for psychiatric symptoms like psychosis (e.g., quetiapine [Seroquel], olanzapine [Zyprexa], clozapine [Versacloz, Clozaril])
- ☐ None of the above

47. Have you ever stopped taking a medication for their Wilson Disease for any reason?

- ☐ Yes (please indicate medication and reasons for stopping [open response])
- ☐ No

2.7 Treatment satisfaction

48. How satisfied are you with current treatment options for Wilson Disease?

- ☐ Not at all satisfied
- ☐ A little satisfied
- ☐ Moderately Satisfied
- ☐ Quite a bit satisfied
- ☐ Extremely satisfied

[Questions 50-52 only appears to participants who took D-penicillamine (Cuprimine, Depen)]

49. Based on your experience with D-penicillamine (Cuprimine, Depen), how would you rate its effectiveness?

- ☐ Not at all effective
- ☐ A little effective
- ☐ Moderately effective
- ☐ Quite a bit effective
- ☐ Extremely effective

50. What do you like best about D-penicillamine (Cuprimine, Depen)?

[open response]

51. What do you like least about D-penicillamine (Cuprimine, Depen)?

[open response]

[Questions 53-55 only appears to participants who took Trientine dihydrochloride (Syprine) or Ammonium tetrathiomolybdate (TTM)]

52. Based on your experience with Trientine dihydrochloride (Syprine) or Ammonium tetrathiomolybdate (TTM), how would you rate its effectiveness?

- ☐ Not at all effective
- ☐ A little effective
- ☐ Moderately effective
- ☐ Quite a bit effective
- ☐ Extremely effective

53. What do you like best about Trientine dihydrochloride (Syprine) or Ammonium tetrathiomolybdate (TTM)?

[open response]

54. What do you like least about Trientine dihydrochloride (Syprine) or Ammonium tetrathiomolybdate (TTM)?

[open response]

[Questions 56-58 only appears to participants who took Zinc acetate (Galzin)]

55. Based on your experience with Zinc acetate (Galzin), how would you rate its effectiveness?

- ☐ Not at all effective
- ☐ A little effective
- ☐ Moderately effective
- ☐ Quite a bit effective
- ☐ Extremely effective

56. What do you like best about Zinc acetate (Galzin)?

[open response]

57. What do you like least about Zinc acetate (Galzin)?

[open response]

58. Based on your current experience with your treatments would you like to see more treatment options?

- ☐ Yes
- ☐ No

2.8 Future clinical trial participation

59. Are you currently participating in a Wilson Disease clinical trial?

- ☐ No
- ☐ Yes [open response]

60. Have you ever participated in a clinical trial of a new drug or treatment for Wilson Disease?

- ☐ Yes → *proceed to question 62*
- ☐ No → *proceed to question 63*

61. What clinical trial did you participate in and what treatment did you receive?

[open response]

62. What might prevent you from participating in a clinical trial? Rank the following options from 1-6 (1 being most likely to prevent you from participating and 6 being least likely to prevent you from participating).

- ☐ Distance to the clinical trial site for routine visits
- ☐ Amount of time spent at the clinical trial site
- ☐ Number of times needed to visit the clinical trial site
- ☐ Length of the trial
- ☐ Information about the benefits and risks of participating in the trial
- ☐ Fear of not being eligible to participate in the trial

63. Please rate how likely you would be to participate in a clinical trial if the main site you had to go to was:

	Not at all likely	Somewhat unlikely	Neutral	Somewhat likely	Extremely likely
10 miles away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30 miles away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60 miles away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
More than 120 miles away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

64. Please rate how likely you would be to use a treatment if the effects of the treatment lasted:

	Not at all likely	Somewhat unlikely	Neutral	Somewhat likely	Extremely likely	N/A – depends on what the treatment does
Less than 6 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 months to 1 year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 – 2 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 – 5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
More than 5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.9 Advocacy involvement

65. Are you part of any formal patient advocacy organization for Wilson Disease?

- ☐ Yes → *proceed to question 67*
☐ No → *proceed to question 68*

66. Which formal patient advocacy organizations do you belong to?

[Open response]

2.10 Contact information

67. Would you like to be contacted about future research opportunities?

- ☐ Yes → *proceed to question 69*
☐ No

68. Please provide an e-mail address where you can be reached. [Open response]