The purpose of this anonymous survey is to ask you, adults with NF, about your thoughts regarding participation in clinical trials. This research study will help us design clinical trials that are meaningful to you and that you would want to participate in.

Clinical trials are research studies that help determine whether new treatments are safe and improve health outcomes. Psychosocial clinical trials are a type of clinical trial that determines whether particular programs or skills can help patients and/or family members better cope with their stress, symptoms (for example: pain), and feelings to help improve general well-being and quality of life.

For this survey, we are interested in your opinions about psychosocial clinical trials. This is your chance to let us know what is important to you and how we can better serve you.

We also will ask a few questions about how coronavirus (also called COVID-19) pandemic is affecting your psychosocial health.

We value your input and we want to know your ideas!

Instructions and consent for the survey:

Completion of this survey is entirely voluntary. You have the option of not participating. You have the option to stop participating at any time or to not respond to a particular item or items. You may refuse to participate or stop participating at any time without penalty or loss of benefits to which you are otherwise entitled. There are minimal risks associated with doing the survey. These risks may include the time involved to complete the questions as well as the potential for discomfort to arise when answering questions related to social and emotional wellbeing. There are no benefits except for helping researchers design studies to help address the psychosocial concerns of individuals with NF.

THERE IS NO PERSONAL IDENTIFYING INFORMATION DATA BEING COLLECTED SO YOUR RESPONSES ARE COMPLETELY ANONYMOUS.

We will not know who participates and who does not. The responses to these survey questions will be stored in a secure database. We will do our best to make sure that these data are kept private.

If you have questions about this study, please contact Dr. Pam Wolters at waltersp@mail.nih.gov or Dr. Staci Martin at martins@mail.nih.gov. You may also contact them at 240-760-6040 if needed.

There is a total of 67 questions in the survey. It will take about 35 - 50 minutes to complete. Please allow enough time to complete the entire survey at one time because it is not possible to save the responses and then return to complete the rest of the questions later.
<table>
<thead>
<tr>
<th>If you agree to participate in this anonymous research survey, please check the box.</th>
</tr>
</thead>
<tbody>
<tr>
<td>* must provide value</td>
</tr>
</tbody>
</table>

Submit

☐ I agree to participate in this research.
1. Do you read and understand the English language?  
* must provide value

- [ ] Yes
- [ ] No

Submit

End the survey?

You have selected an option that triggers this survey to end right now. To save your responses and end the survey, click the button below to do so. If you have selected the wrong option by accident and do not wish to leave the survey, you may click the other button below to continue, which will also remove the value of the option you just selected to allow you to enter it again and continue the survey.

End the survey now  Continue survey and undo last response

---

1a. Are you 18 years of age or older and have a diagnosis of NF1, NF2, or Schwannomatosis?  
* must provide value

- [ ] Yes
- [ ] No

Submit

---

Please answer the questions in this survey about your experiences as an adult with NF1, NF2, or Schwannomatosis.

If you are a parent of a child with NF, we will have a separate survey for you to complete in the coming months to address the needs you and your child may have.
<table>
<thead>
<tr>
<th><strong>2. What is your age?</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>3. What sex were you assigned at birth on your birth certificate?</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td><strong>4. Do you identify yourself as:</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td><strong>4a. Please specify.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>5. Country of residence:</strong></td>
<td>USA</td>
</tr>
<tr>
<td><strong>5a. State of residence:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>6. What is your race?</strong></td>
<td>American Indian or Alaska Native</td>
</tr>
<tr>
<td><strong>6a. Please specify.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>7. What is your ethnicity?</strong></td>
<td>Hispanic or Latino</td>
</tr>
<tr>
<td><strong>7a. Please specify.</strong></td>
<td></td>
</tr>
</tbody>
</table>

Alternative questions show if select “other” for question #5:
8. What is the highest level of education you have completed?
- Did not complete high school
- High school degree or equivalent (e.g. GED)
- Some college but not degree
- Associate degree (2-year college degree)
- Bachelor’s degree (4-year college degree)
- Graduate degree (completed graduate school after a 4-year college degree)

9. Were you employed right before the coronavirus pandemic?
- Yes
- No

9a. If yes, did you work part-time or full-time?
- Part-time
- Full-time

9b. Did you work primarily at home or outside of the home before the coronavirus pandemic?
- Worked outside the home
- Worked at home

9c. What is your current employment status DURING the coronavirus pandemic?
- Still working
- Laid off
- Furloughed
- Other

9d. Please specify.

10. Are you currently enrolled in school/college?
- Yes
- No

10a. If yes, part-time or full-time?
- Part-time
- Full-time
11. Do you have other family members with NF?

- [ ] Yes
- [ ] No
- [ ] Not sure

**NF1 Specific Questions:**

12. Select your primary diagnosis:

- [ ] NF1
- [ ] NF2
- [ ] Schwannomatosis

12a. Do you have optic pathway glioma (brain tumor involving the nerves of the eyes)?

- [ ] Yes
- [ ] No
- [ ] Unsure

If yes, how much does your optic pathway glioma affect your everyday life?

- [ ] Does not affect my everyday life at all
- [ ] Affects my everyday life a little
- [ ] Affects my everyday life somewhat
- [ ] Affects my everyday life a lot

12b. Do you have cutaneous neurofibromas (tumors on or under the skin)?

- [ ] Yes
- [ ] No
- [ ] Unsure

If yes, how much do your cutaneous (skin) neurofibromas affect your everyday life?

- [ ] Does not affect my everyday life at all
- [ ] Affects my everyday life a little
- [ ] Affects my everyday life somewhat
- [ ] Affects my everyday life a lot

12c. Do you have glomus tumors (tumors in the fingers or toes)?

- [ ] Yes
- [ ] No
- [ ] Unsure
If yes, how much do your glomus tumors (in your fingers and toes) affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12d. Do you have plexiform neurofibromas (tumors that grow along the nerves)?

- Yes
- No
- Unsure

If yes, how much do your plexiform neurofibromas (nerve tumors) affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12e. Do you have scoliosis (curving of the spine)?

- Yes
- No
- Unsure

If yes, how much does your scoliosis affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12f. Do you have other orthopedic problems (curving of the leg bones, leg length discrepancy, etc)

- Yes
- No
- Unsure
<table>
<thead>
<tr>
<th>Q: If yes, how much do your orthopedic problems affect your everyday life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Does not affect my everyday life at all, Affects my everyday life a little, Affects my everyday life somewhat, Affects my everyday life a lot</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12g. Do you have learning disabilities and/or attention problems?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Yes, No, Unsure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q: If yes, how much do your learning disabilities or attention problems affect your everyday life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Does not affect my everyday life at all, Affects my everyday life a little, Affects my everyday life somewhat, Affects my everyday life a lot</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12h. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Yes, No, Unsure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q: If yes, how much do your mental health difficulties affect your everyday life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Does not affect my everyday life at all, Affects my everyday life a little, Affects my everyday life somewhat, Affects my everyday life a lot</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>12i. Do you have social skills difficulties?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options: Yes, No, Unsure</td>
</tr>
</tbody>
</table>

<p>| | | |</p>
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<tbody>
<tr>
<td>5/13/2020</td>
<td>[Image]</td>
<td>[Image]</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
</tbody>
</table>
| If yes, how much do your social skills difficulties affect your everyday life? | - Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot |

12j. Do you have vision problems?  
- Yes
- No
- Unsure

If yes, how much do your vision problems affect your everyday life?  
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12k. Do you have any hearing problems?  
- Yes
- No
- Unsure

If yes, how much do your hearing problems affect your everyday life?  
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12l. Do you have café au lait spots?  
- Yes
- No
- Unsure
If yes, how much do your café au lait spots affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12m. Do you have short stature?
- Yes
- No
- Unsure

If yes, how much does your short stature affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12n. Do you have malignant peripheral nerve sheath tumors?
- Yes
- No
- Unsure

If yes, how much do your malignant peripheral nerve sheath tumors affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12o. Do you have seizures?
- Yes
- No
- Unsure
If yes, how much do your seizures affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12p. Do you have headaches?
- Yes
- No
- Unsure

If yes, how much do your headaches affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12q. Do you have tumor-related pain?
- Yes
- No
- Unsure

If yes, how much does your tumor-related affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12r. Do you have other pain (not related to tumors?)
- Yes
- No
- Unsure
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
<th>Option 4</th>
<th>Option 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, how much does your other pain (not related to your tumors) affect your everyday life?</td>
<td>○ Does not affect my everyday life at all</td>
<td>○ Affects my everyday life a little</td>
<td>○ Affects my everyday life somewhat</td>
<td>○ Affects my everyday life a lot</td>
<td>reset</td>
</tr>
<tr>
<td>12s. Do you have other complications or concerns?</td>
<td>○ Yes</td>
<td>○ No</td>
<td>○ Unsure</td>
<td>reset</td>
<td></td>
</tr>
<tr>
<td>If yes, please list:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, how much do your other complications affect your everyday life?</td>
<td>○ Does not affect my everyday life at all</td>
<td>○ Affects my everyday life a little</td>
<td>○ Affects my everyday life somewhat</td>
<td>○ Affects my everyday life a lot</td>
<td>reset</td>
</tr>
<tr>
<td>13. Check the one statement that best describes how much all of your NF symptoms affect your everyday life:</td>
<td>○ My NF symptoms do not affect my everyday life at all</td>
<td>○ My NF symptoms affect my everyday life a little (mild degree)</td>
<td>○ My NF symptoms affect my everyday life somewhat (moderate degree)</td>
<td>○ My NF symptoms affect my everyday life a lot (severe degree)</td>
<td>reset</td>
</tr>
<tr>
<td>14. In the past year, how often did you visit a doctor for your NF or a symptom related to NF?</td>
<td>○ Not at all in the past year</td>
<td>○ 1 time in the past year</td>
<td>○ 2-3 times in the past year</td>
<td>○ 4-5 times the past year</td>
<td>○ More than 5 times the past year</td>
</tr>
</tbody>
</table>
### 15. How far are you from the nearest NF clinic?
- [ ] Less than 1 hour
- [ ] 1 hour
- [ ] 2 hours
- [ ] 3 hours
- [ ] 4 hours
- [ ] More than 5 hours
- [ ] I don't know

### 16. Have you ever been in a drug clinical trial for NF?
- [ ] Yes
- [ ] No
- [ ] Not sure

### 17. Have you ever been in a psychosocial clinical trial for NF?
- [ ] Yes
- [ ] No
- [ ] Not sure

---

**Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.**

Submit
11. Do you have other family members with NF?
- Yes
- No
- Not sure

**NF2 Specific Questions:**

12. Select your primary diagnosis:
- NF1
- NF2
- Schwannomatosis

**12a. Do you have vestibular schwannoma/acoustic neuroma (brain tumors on the hearing/balance nerve)?**
- Yes
- No
- Unsure

If yes, how much does your vestibular schwannoma(s) affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

**12b. Do you have meningiomas (tumors) in the brain?**
- Yes
- No
- Unsure

If yes, how much does your meningioma(s) affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

**12c. Do you have tumors involving the spinal cord or spinal nerves (including ependymomas, spinal meningiomas, or spinal schwannomas)?**
- Yes
- No
- Unsure
If yes, how much does your spine tumor(s) affect your everyday life?  
- Does not affect my everyday life at all  
- Affects my everyday life a little  
- Affects my everyday life somewhat  
- Affects my everyday life a lot  

12d. Do you have hearing problems?  
- Yes  
- No  
- Unsure  

If yes, how much do your hearing problems affect your everyday life?  
- Does not affect my everyday life at all  
- Affects my everyday life a little  
- Affects my everyday life somewhat  
- Affects my everyday life a lot  

12e. Do you have tinnitus (ringing of the ears)?  
- Yes  
- No  
- Unsure  

If yes, how much does your tinnitus affect your everyday life?  
- Does not affect my everyday life at all  
- Affects my everyday life a little  
- Affects my everyday life somewhat  
- Affects my everyday life a lot  

12f. Do you have balance problems?  
- Yes  
- No  
- Unsure  

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, how much do your balance problems affect your everyday life?</td>
<td>- Does not affect my everyday life at all</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life a little</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life somewhat</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life a lot</td>
</tr>
<tr>
<td>12g. Do you have vision problems?</td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
<tr>
<td></td>
<td>- Unsure</td>
</tr>
<tr>
<td>If yes, how much do your vision problems affect your everyday life?</td>
<td>- Does not affect my everyday life at all</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life a little</td>
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<tr>
<td></td>
<td>- Affects my everyday life somewhat</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life a lot</td>
</tr>
<tr>
<td>12h. Do you have facial weakness/facial nerve damage?</td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
<tr>
<td></td>
<td>- Unsure</td>
</tr>
<tr>
<td>If yes, how much do your facial weakness affect your everyday life?</td>
<td>- Does not affect my everyday life at all</td>
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<tr>
<td></td>
<td>- Affects my everyday life a little</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life somewhat</td>
</tr>
<tr>
<td></td>
<td>- Affects my everyday life a lot</td>
</tr>
<tr>
<td>12i. Do you have speech or swallowing difficulties?</td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
<tr>
<td></td>
<td>- Unsure</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| If yes, how much do your speech or swallowing difficulties affect your everyday life? | - Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot                                        |
| 12j. Do you have pain?                                                  | - Yes
- No
- Unsure                                                                |
| If yes, how much does pain affect your everyday life?                    | - Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot                                        |
| 12k. Do you have muscle wasting?                                        | - Yes
- No
- Not sure                                                              |
| If yes, how much does muscle wasting affect your everyday life?          | - Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot                                        |
| 12l. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)? | - Yes
- No
- Unsure                                                                |
If yes, how much do your mental health difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12m. Do you have social skills difficulties?

- Yes
- No
- Other

If yes, how much do your social skills difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12n. Do you have other complications or concerns?

- Yes
- No
- Unsure

If yes, please list:

13. Check the one statement that best describes how much all of your NF symptoms affect your everyday life:

- My NF symptoms do not affect my everyday life at all
- My NF symptoms affect my everyday life a little (mild degree)
- My NF symptoms affect my everyday life somewhat (moderate degree)
- My NF symptoms affect my everyday life a lot (severe degree)
14. In the past year, how often did you visit a doctor for your NF or a symptom related to NF?
- Not at all in the past year
- 1 time in the past year
- 2-3 times in the past year
- 4-5 times the past year
- More than 5 times the past year

15. How far are you from the nearest NF clinic?
- Less than 1 hour
- 1 hour
- 2 hours
- 3 hours
- 4 hours
- More than 5 hours
- I don’t know

16. Have you ever been in a drug clinical trial for NF?
- Yes
- No
- Not sure

17. Have you ever been in a psychosocial clinical trial for NF?
- Yes
- No
- Not sure

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.

Submit
11. Do you have other family members with NF?
- Yes
- No
- Not sure

**Schwannomatosis Specific Questions:**

12. Select your primary diagnosis:
- NF1
- NF2
- Schwannomatosis

12a. Do you have brain tumors (including vestibular schwannomas/acoustic neuromas, meningiomas, and cranial nerve schwannomas)?
- Yes
- No
- Unsure

If yes, how much does your brain tumor(s) affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12b. Do you have spinal schwannomas (tumors in or near your spine)?
- Yes
- No
- Unsure

If yes, how much does your spine tumor(s) affect your everyday life?
- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12c. Do you have other schwannomas (tumors in the rest of your body, including your neck, chest, abdomen, pelvis, or limbs)
- Yes
- No
- Unsure
If yes, how much do your hearing problems affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12d. Do you have problems with physical functioning (such as difficulty walking, sitting, or grasping objects)?

- Yes
- No
- Unsure

If yes, how much do your problems with physical functioning affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12e. Do you have pain?

- Yes
- No
- Unsure

If yes, how much does pain affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12f. Do you have problems sleeping?

- Yes
- No
- Unsure
If yes, how much do problems sleeping affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12g. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)?

- Yes
- No
- Unsure

If yes, how much do your mental health difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12h. Do you have social skills difficulties?

- Yes
- No
- Other

If yes, how much do your social skills difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

12i. Do you have other complications or concerns?

- Yes
- No
- Unsure

If yes, please list:

Expand
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Check the one statement that best describes how much all of your NF</td>
<td>- My NF symptoms do not affect my everyday life at all</td>
</tr>
<tr>
<td>symptoms affect your everyday life:</td>
<td>- My NF symptoms affect my everyday life a little (mild degree)</td>
</tr>
<tr>
<td></td>
<td>- My NF symptoms affect my everyday life somewhat (moderate degree)</td>
</tr>
<tr>
<td></td>
<td>- My NF symptoms affect my everyday life a lot (severe degree)</td>
</tr>
<tr>
<td>14. In the past year, how often did you visit a doctor for your NF or a</td>
<td>- Not at all in the past year</td>
</tr>
<tr>
<td>symptom related to NF?</td>
<td>- 1 time in the past year</td>
</tr>
<tr>
<td></td>
<td>- 2-3 times in the past year</td>
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<tr>
<td></td>
<td>- 4-5 times the past year</td>
</tr>
<tr>
<td></td>
<td>- More than 5 times the past year</td>
</tr>
<tr>
<td>15. How far are you from the nearest NF clinic?</td>
<td>- Less than 1 hour</td>
</tr>
<tr>
<td></td>
<td>- 1 hour</td>
</tr>
<tr>
<td></td>
<td>- 2 hours</td>
</tr>
<tr>
<td></td>
<td>- 3 hours</td>
</tr>
<tr>
<td></td>
<td>- 4 hours</td>
</tr>
<tr>
<td></td>
<td>- More than 5 hours</td>
</tr>
<tr>
<td></td>
<td>- I don't know</td>
</tr>
<tr>
<td>16. Have you ever been in a drug clinical trial for NF?</td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
<tr>
<td></td>
<td>- Not sure</td>
</tr>
<tr>
<td>17. Have you ever been in a psychosocial clinical trial for NF?</td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
<tr>
<td></td>
<td>- Not sure</td>
</tr>
</tbody>
</table>

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.

Submit
## Specific Questions about Psychosocial Trials

Your answers to the questions below will help us plan psychosocial trials based on your preferences and concerns so that the studies will be more meaningful to you.

### 18. What are the BEST ways for you to learn about psychosocial clinical trials and research opportunities in NF? (Check up to SIX)

- [ ] My NF doctor or nurse
- [ ] My regular doctor or nurse
- [ ] Other specialist doctor
- [ ] Information posted in my NF clinic
- [ ] Information from NF Foundation websites
- [ ] Children's Tumor Foundation registry
- [ ] Clinicaltrials.gov
- [ ] Social media posts
- [ ] Other NF patients
- [ ] Internet searches
- [ ] Email listserv
- [x] Other, please specify:  

### 18a. Other, please specify:  

[Expand](#)
19. What information is the MOST important to you when deciding whether to participate in a psychosocial clinical trial? (Check up to SIX)

- Scientific background of the study
- How the study may help me
- If the study may help others in the future
- Information about the study procedures
- Number of clinic visits required
- Patient involvement in the design of the trial
- Time commitment (in clinic or at home)
- Time away from work
- Accessibility (for example, how much travel is involved)
- Compensation (payment for participating in a study)
- Security of my personal information
- Experience of the participants previously in the study
- Reimbursement of expenses (for example: travel)
- Other, please specify:__________________
- None of the above

19a. Other, please specify:


20. What are the MAIN reasons why you would take part in a psychosocial clinical trial? (Check up to THREE)

- To improve my health and well-being
- To meet and be cared for by NF experts
- To try new interventions for NF symptoms
- To help others with NF based on what is learned in the study
- To meet other patients with NF
- Other, please specify:
- None of the above
### Specific Questions about Psychosocial Trials

#### 20a. Other, please specify:

- [ ]

#### 21. What are the MAIN reasons why you would NOT participate in a psychosocial clinical trial even if you were eligible for it? (Check up to SIX)

- [ ] Time commitment in clinic
- [ ] Time commitment at home
- [ ] Time away from work or school
- [ ] Distance to the clinic/research center if need to attend in person
- [ ] Lack of experience with computers if need to do the study online (for example: using videochat)
- [ ] Costs
- [ ] Not enough compensation (the amount of money given as a thank you to participate)
- [ ] Concern about the privacy and security of my personal information
- [ ] Intervention is not yet proven to be effective in NF
- [ ] I think my NF symptoms are not severe enough
- [ ] I think my NF symptoms are too severe
- [ ] I don't have a mobile phone
- [ ] I don't have a computer
- [ ] I am worried about participating in a psychosocial clinical trial
- [ ] I don't think a psychosocial trial would help me
- [ ] I don't think I need to participate in a psychosocial trial
- [✓] Other, please specify:
- [ ] None of the above

#### 21a. Other, please specify:

- [ ]
### Specific Questions about Psychosocial Trials

**22. What kind of computer or mobile device do you have regular access to?**

- desktop or laptop computer (PC or Mac)
- smartphone (like an iPhone or Android)
- regular cell phone
- electronic tablet (like an iPad or Microsoft)
- none of the above

**23. Does your computer have a camera in it or do you own a separate webcam (for doing video chats)?**

- Yes
- No
- Not sure

**24. Do you have access to the internet?**

- Yes
- No
- Not sure

**25. Do you require captioning/CART (Communication Access Real-time) Translation?**

- Yes
- No
- Not sure

**26. Do you have concerns about the privacy of your information?**

- Yes
- No
- Not sure

**27. Would getting some compensation to pay for travel, parking, or meals make you more likely to participate in a psychosocial trial?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Fairly</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**28. Would getting a small compensation (such as $20 per visit) as a thank you make you more likely to participate in a psychosocial trial?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Fairly</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*A RANDOMIZED CONTROLLED TRIAL is a clinical trial where participants are randomized (like flipping a coin) between one intervention and no intervention (control group) or between two different types of interventions. This type of trial is important to prove a new intervention is effective.*
29. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you might not get the intervention?  
- Yes  
- No  
- Not sure

30. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you might not know which intervention you will be getting?  
- Yes  
- No  
- Not sure

31. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you could get the intervention after a short waiting period?  
- Yes  
- No  
- Not sure

32. How important is it for participants to receive results of the study?  
- Not at all  
- A little  
- Somewhat  
- Fairly  
- Very

33. What are the BEST ways to communicate the results of a psychosocial trial to the participants? (Choose up to FOUR)  
(One selection allowed per column)  
- First choice  
- Second choice  
- Third choice  
- Fourth choice

- Letter summarizing the results  
- Email summarizing the results  
- Summary article in NF foundation newsletters  
- Summary article posted on NF foundation websites  
- Copy of the scientific article  
- Other, please specify:

34. How would you PREFER that the study investigators communicate with patients while at home during a psychosocial trial? Please rank the following from first to third.  
(One selection allowed per column)  
- First choice  
- Second choice  
- Third choice

- Text messages  
- Emails  
- Phone Calls  
- Other, please specify:

35. What would you be willing to do to help clinical researchers plan specific psychosocial trials to make them more relevant to patients with NF? (Choose up to FOUR)
<table>
<thead>
<tr>
<th>(One selection allowed per column)</th>
<th>First choice</th>
<th>Second choice</th>
<th>Third choice</th>
<th>Fourth choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete surveys like this (both before and after the trial)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Participate in focus groups in person</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Participate in interviews in person</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Participate in focus groups over video on the computer</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Participate in individual interviews over the phone or video on the computer</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Have patient representatives involved in the design of the trial</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Other, please specify:</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
</tbody>
</table>

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.
### Specific Questions about Psychosocial Trials Continued

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>36. How much does NF affect your PHYSICAL well-being?</td>
<td>Not at all</td>
</tr>
<tr>
<td>37. How much does NF affect your EMOTIONAL well-being?</td>
<td>Not at all</td>
</tr>
<tr>
<td>38. How much does NF affect your SOCIAL well-being?</td>
<td>Not at all</td>
</tr>
<tr>
<td>39. How much does NF affect your functioning at WORK or SCHOOL?</td>
<td>Not at all</td>
</tr>
<tr>
<td>40. How much does NF affect your functioning at HOME?</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

Please answer questions 41 - 43 about your mental health (UNRELATED TO THE CORONAVIRUS PANDEMIC AND QUARANTINE).

<table>
<thead>
<tr>
<th>Question</th>
<th>Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. Have you been diagnosed with anxiety, depression, or other mental health problems?</td>
<td>Yes</td>
</tr>
<tr>
<td>41a. If you have not been diagnosed, do you think you have anxiety, depression, or other mental health problems?</td>
<td>Yes</td>
</tr>
<tr>
<td>42. Have you taken medicine recently for anxiety, depression, or other mental health problems?</td>
<td>Yes</td>
</tr>
<tr>
<td>43. Have you seen a mental health professional recently for anxiety, depression, or other mental health problems?</td>
<td>Yes</td>
</tr>
</tbody>
</table>
### 44. If you experience NF-related pain, please check the ways you currently treat your pain. (Check all that apply)

- [ ] I do not have NF related pain
- [ ] I do nothing to treat my pain
- [ ] I take over the counter medicine (for example, Tylenol, motrin)
- [ ] I take prescription medicine (for example, Neurontin or Oxycodone)
- [ ] I do alternative therapies (for example, acupuncture or biofeedback)
- [ ] I do talk therapy (for example, cognitive behavioral therapy)
- [ ] Other (please specify):

### 44a. Other, please specify:

[ ]

---

### To help us better understand the psychosocial challenges that children with NF might face growing up, please answer the following questions:

### 45. Did you ever experience any learning difficulties when you were growing up?

- [ ] Yes
- [ ] No
- [ ] Don't remember

### 45a. If yes, about what age were you when you first noticed you had learning difficulties?

[ ]

### 45b. If yes, did you receive any intervention or assistance with these learning difficulties?

- [ ] Yes
- [ ] No
- [ ] Not sure

### 46. Did you ever experience any difficulties with social interactions with peers (bullying, limited friends, etc.) when you were growing up?

- [ ] Yes
- [ ] No
- [ ] Don't remember

### 46a. If yes, about what age were you when you first noticed you had these social difficulties?

[ ]

---

[https://redcap.partners.org/redcap/surveys/?s=aQTxxF68DM](https://redcap.partners.org/redcap/surveys/?s=aQTxxF68DM)
46b. If yes, did you receive any intervention or assistance with these social difficulties?
- Yes
- No
- Not sure

47. Did you ever experience any difficulties with your mood (anxiety, depression, etc.) when you were growing up?
- Yes
- No
- Don't remember

47a. If yes, about what age were you when you first noticed you had these mood difficulties?

47b. If yes, did you receive any intervention or assistance with these mood difficulties?
- Yes
- No
- Not sure

48. What types of psychosocial trials would you be MOST interested in participating in? (Check up to SIX)
- To help increase my social interaction with others
- To help me with anxiety
- To help me with depression
- To learn ways to cope with pain
- To learn ways to cope with daily stress
- To help me cope with trauma related to NF (for example: surgery, medical procedures)
- To help develop a healthier lifestyle (like nutrition, physical activity)
- To help me with family planning issues
- To help me with parenting issues (with or without a child who has NF)
- To cope with current or increasing physical difficulties from NF
- To help me reach my full potential
- To help me with cognitive and learning difficulties

☑️ Other (please specify):
- None of the above
48a. Other (please specify):

49. How willing would you be to participate in a psychosocial trial if it targeted an important concern that you have about your NF?

- I definitely would want to participate
- I probably would want to participate
- I might want to participate
- I'm not sure
- I might not want to participate
- I probably would not want to participate
- I definitely would not want to participate

49a. If you do not think you would participate in a psychosocial trial, what are the reasons why you would not want to participate? (open-ended)

50. What would you be willing to do to participate in a psychosocial trial? (Check ALL that apply)

- Come into the nearest NF clinic 2 to 4 times a month for several months to participate in most of the study in person
- Combination of coming into the nearest NF clinic (1 to 2 times over the course of a 6 months study) but doing most of the program from home (using secure videochats, emails, videos)
- Not come into the clinic at all and do all of the program from home on the computer (use secure videochats, emails, videos, internet support group)
- Other (please specify):
51. What type of program would you MOST prefer? (Check up to TWO)

- Individual sessions led by a clinician
- Group sessions led by a clinician
- Group sessions led by a trained peer facilitator
- Combination of group and individual sessions led by a clinician

52. What time of day would you MOST prefer to do the sessions for the psychosocial trial?

(One selection allowed per column)

<table>
<thead>
<tr>
<th>Time Period</th>
<th>First choice</th>
<th>Second choice</th>
<th>Third choice</th>
<th>Fourth choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekdays early in the evening (5 pm - 7 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekdays later in the evening (7 pm - 9 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekdays during lunch time (11 am - 2 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekday mornings (9 am - 11 am)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekday afternoons (2 pm - 5 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekends mornings (9 am - 12 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Weekends afternoons (12 pm - 4 pm)</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
<tr>
<td>Other suggestions:</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
<td>reset</td>
</tr>
</tbody>
</table>
53. What outcomes would be MOST important to measure in a psychosocial trial? (Check up to SEVEN)

- Improvement in symptoms of anxiety
- Improvement in symptoms of depression
- Less symptoms of stress
- Improved coping skills
- Better self-esteem
- How much my pain hurts
- How much pain interferes with my daily activities
- Greater involvement in social activities
- Improved interpersonal relationships
- Less feelings of loneliness and social isolation
- Improved ability to manage NF symptoms
- Better physical functioning
- Improved cognitive and learning skills
- Improved performance at work or school
- Better overall quality of life

53a. Other, please specify:

54. How would you PREFER that we administer questionnaires to assess changes from participating in psychosocial trials?

<table>
<thead>
<tr>
<th>Questionnaire Method</th>
<th>Not at all</th>
<th>A little</th>
<th>Some</th>
<th>Pretty much</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online questionnaires completed on the computer from your home</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Online questionnaires completed on your mobile phone</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Paper and pencil questionnaires mailed to you at home</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Question</td>
<td>Options</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>Paper and pencil questionnaires completed in person at a medical clinic</td>
<td>reset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questions completed in an interview over the phone</td>
<td>reset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questions completed in an interview in person at a medical clinic</td>
<td>reset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaires completed on a computer or mobile tablet in person at a medical clinic</td>
<td>reset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55. In addition to questionnaires, to what extent would you be willing to also use direct objective measures to assess change, such as activity trackers (like a Fit Bit), physiological measures (like heart rate), or stress biomarkers (like from saliva) in psychosocial trials?</td>
<td>Very willing, Somewhat willing, Not very willing, Not at all willing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56. Please tell us if there is anything else you would like us to know about how NF affects your social and emotional functioning.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>57. Please tell us if there is anything else you would like us to know to help us plan psychosocial intervention trials for people with NF1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.
Impact of Coronavirus

Please answer the following questions related to the coronavirus (also called COVID-19) pandemic:

A. During the worst of the coronavirus pandemic in your area, how worried were you about:

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. .... being infected with coronavirus?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. ... friends or family being infected with coronavirus?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. ... your physical health being influenced by coronavirus?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. ... your emotional health being influenced by coronavirus?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B. How stressful has the coronavirus pandemic been for you?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
</table>

Which of the following events have you experienced as a result of the coronavirus pandemic? (For questions about coronavirus illness, please include instances of both suspected and confirmed cases).
C. (Select all that apply)

☐ Unemployment of self
☐ Unemployment of spouse/partner
☐ Significant reduction in/loss of main source of income
☐ Loss of health insurance coverage
☐ Experienced difficulties registering for unemployment benefits
☐ Tried to register for unemployment benefits but did not qualify
☐ Exposed to coronavirus
☐ Fell ill with coronavirus
☐ Family member fell ill with coronavirus
☐ Caring for a family member with coronavirus
☐ Death of family member due to coronavirus
☐ Death of a close friend due to coronavirus
☐ Work in healthcare setting with coronavirus patients
☐ Unable to quarantine due to work deemed "essential"
☐ Live with "essential" worker at high risk of contracting coronavirus
☐ Other
☐ NONE OF THE ABOVE

Please specify:

D. Please answer the following questions about your NF care during the coronavirus pandemic:

1. Was an in-person doctor's appointment for your NF care cancelled or delayed because of the coronavirus pandemic?

   ☭ Yes
   ☐ No
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, how much did missing that in-person doctor's appointment concern you?</td>
<td>Not at all, Slightly, Moderately, Very Much, Extremely</td>
</tr>
<tr>
<td>2. Was an in-person treatment for your NF cancelled or delayed because of the coronavirus pandemic?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>If yes, how much did missing that in-person treatment concern you?</td>
<td>Not at all, Slightly, Moderately, Very Much, Extremely</td>
</tr>
<tr>
<td>3. Did you use telehealth instead of an in-person doctor's appointment for your NF care because of the coronavirus pandemic?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>If yes, how much did the telehealth appointment meet your needs?</td>
<td>Not at all, Slightly, Moderately, Very Much, Extremely</td>
</tr>
<tr>
<td>E. Please let us know any other ways the coronavirus pandemic and the stay-at-home order has affected you.</td>
<td>Expand</td>
</tr>
</tbody>
</table>

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.
Thank you for taking the survey.

Have a nice day!