FND Scientific Registry Surveys

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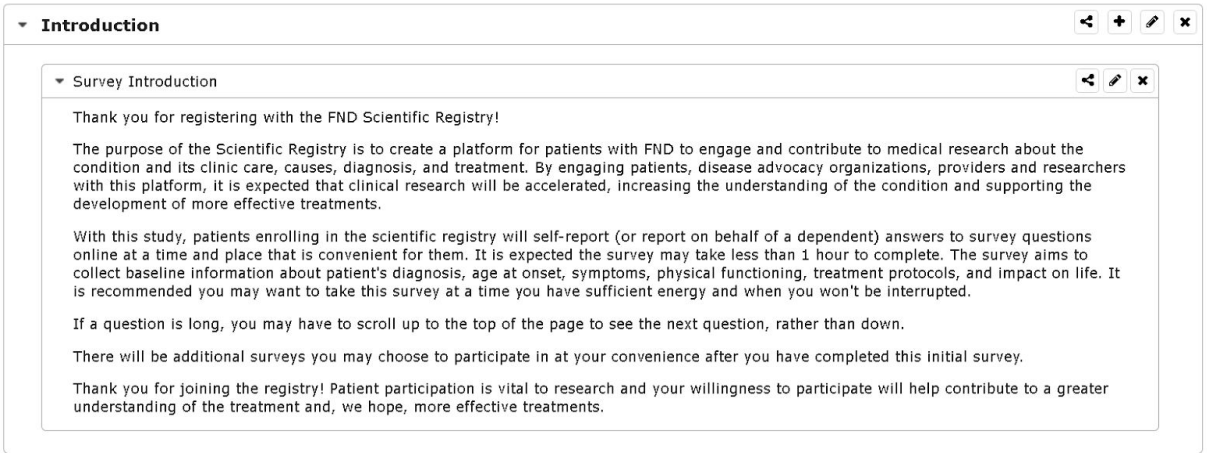
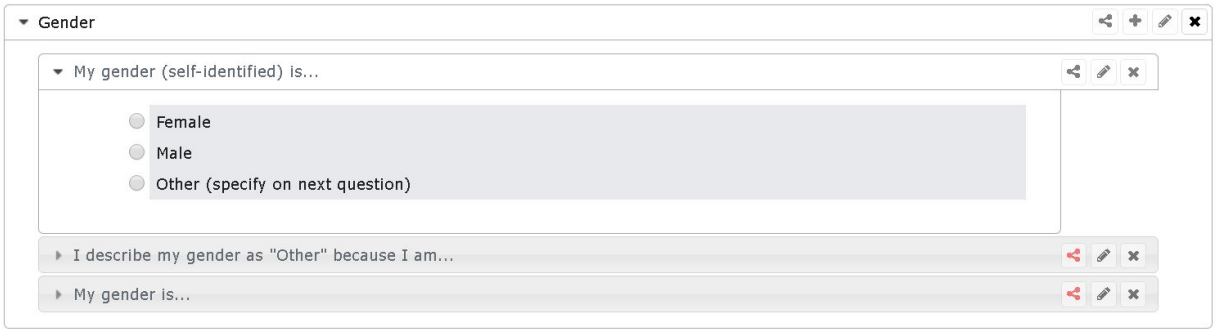
Initial Survey

Introduction

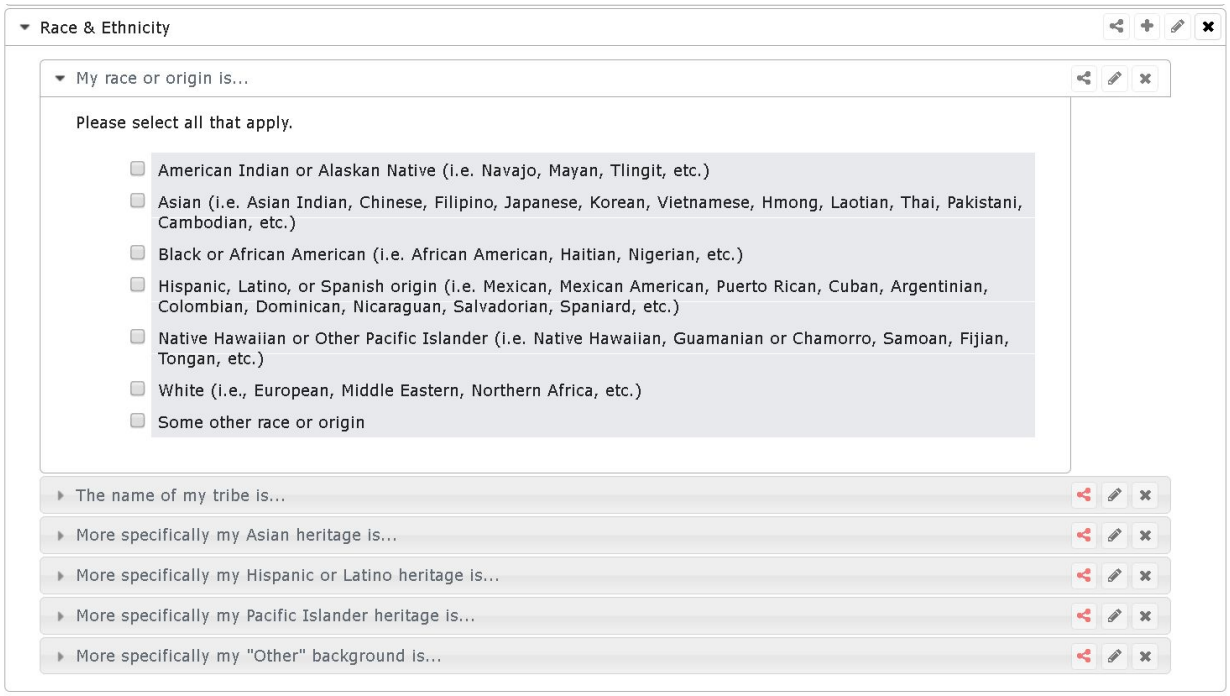


Demographics

Source: Genetic Alliance PEER



Source: Genetic Alliance PEER



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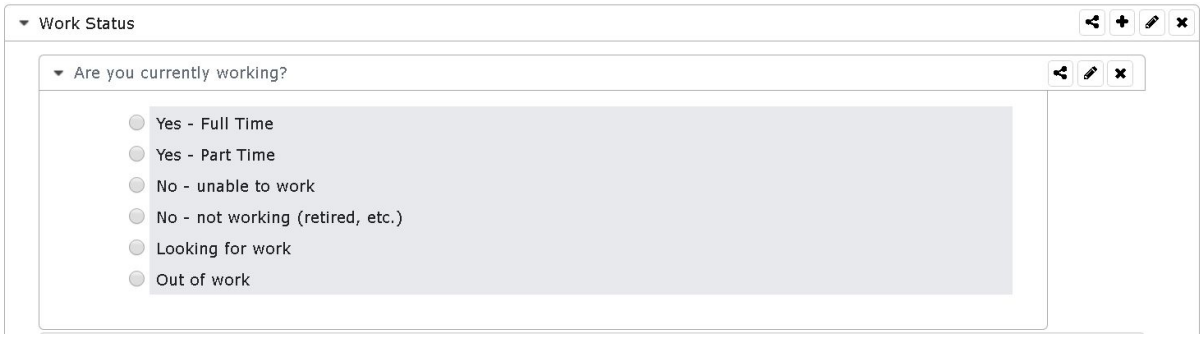

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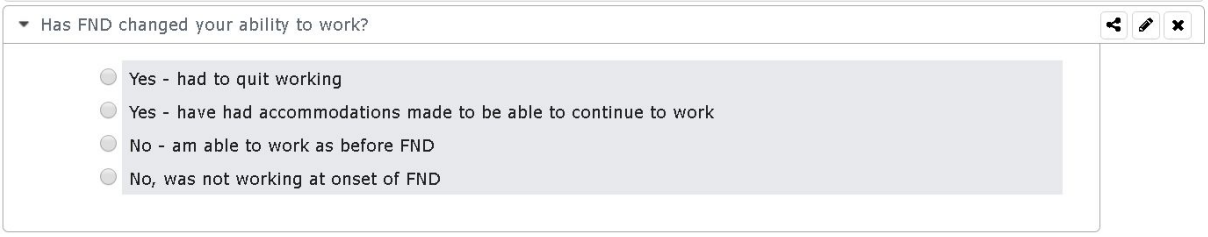

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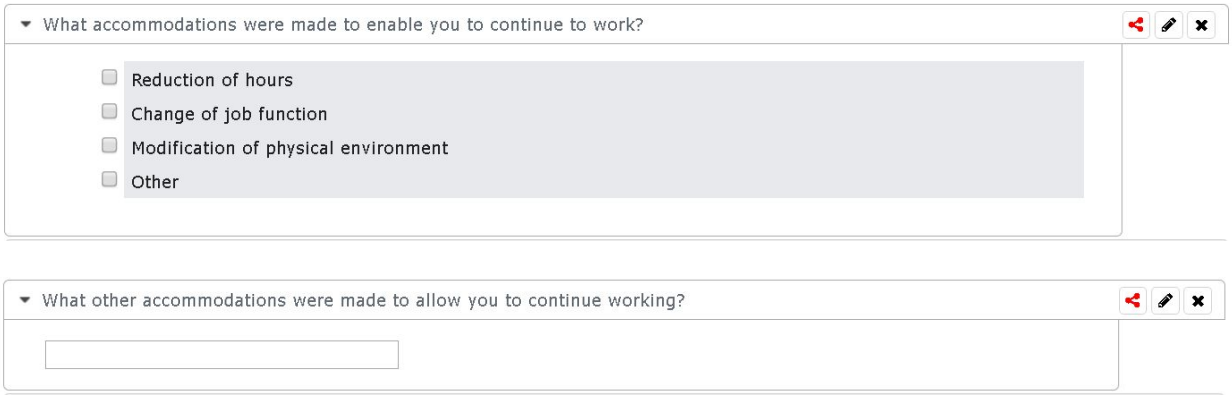

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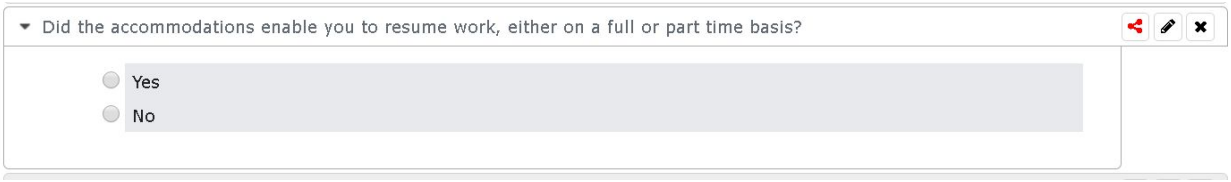

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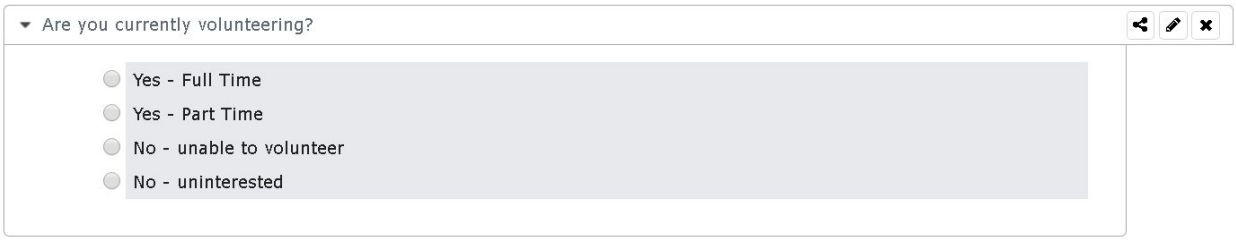

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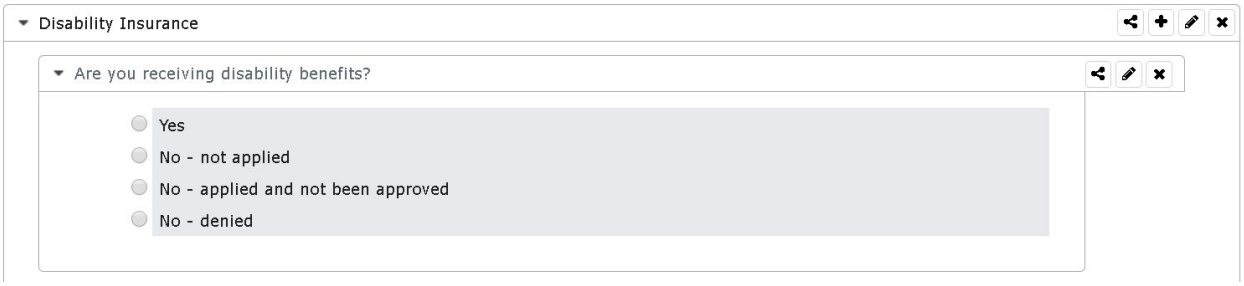
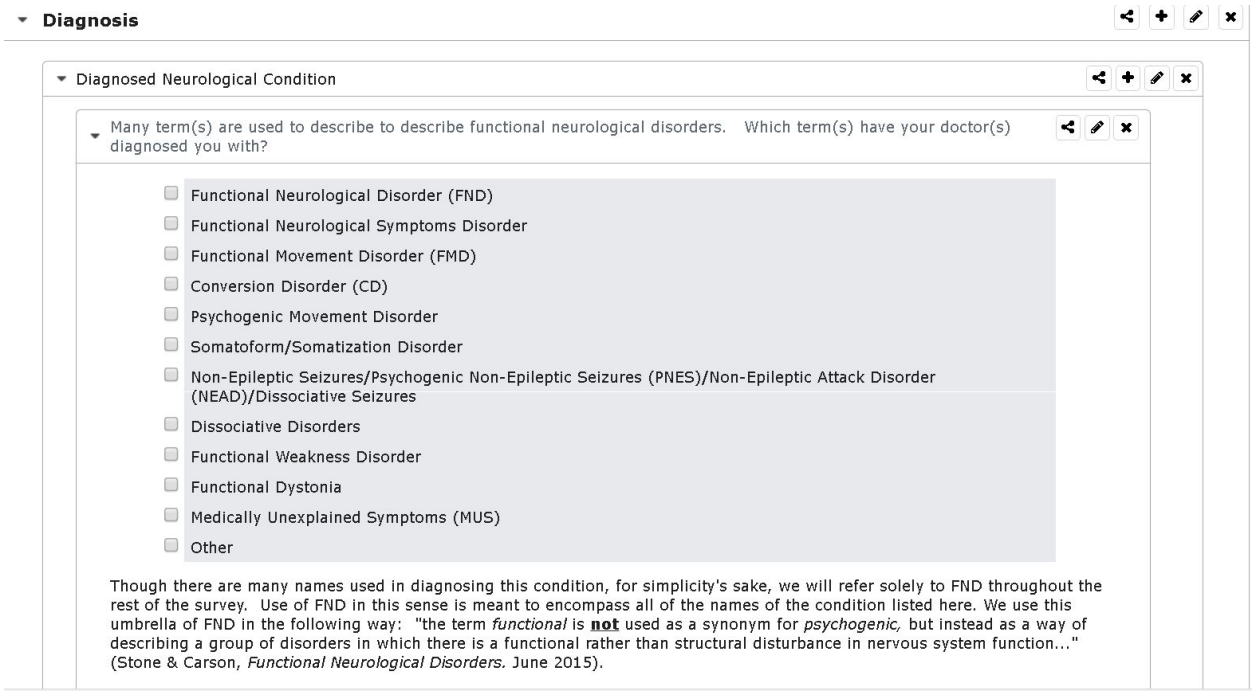
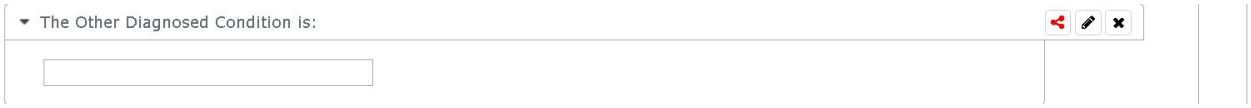


Source: FND Hope

Diagnosis





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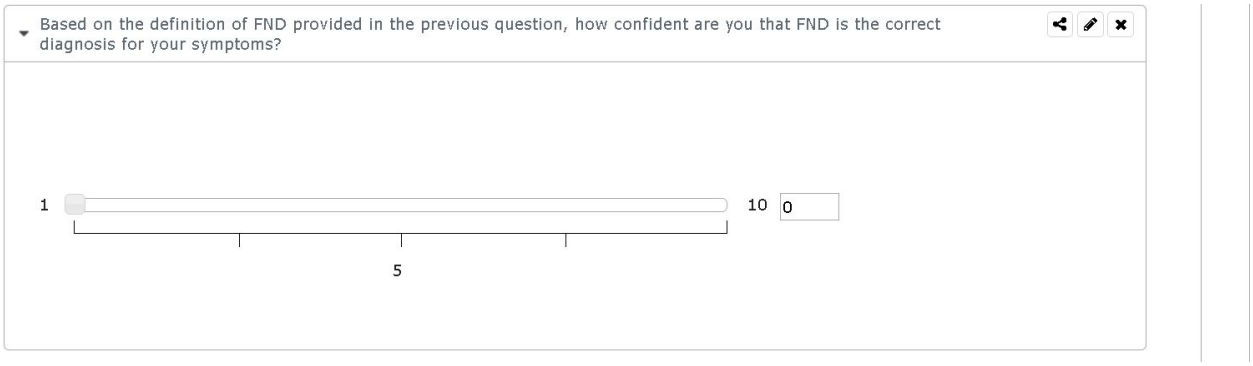

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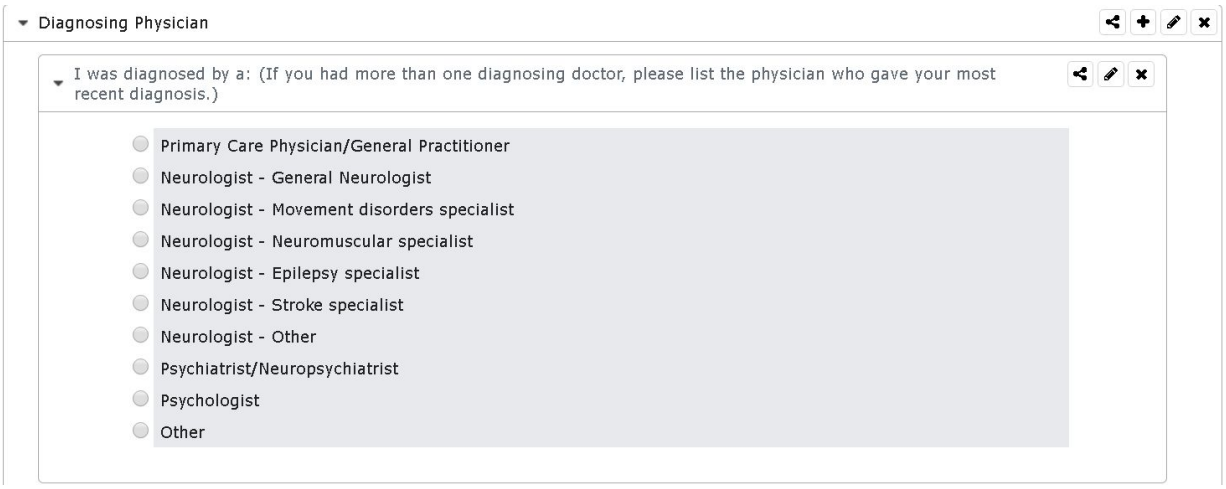

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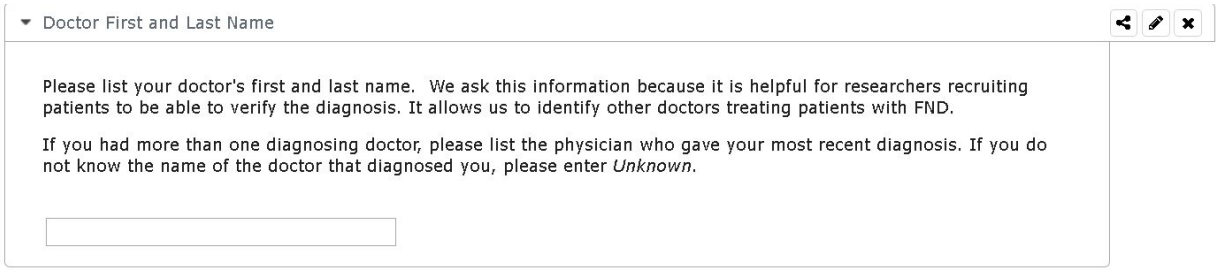

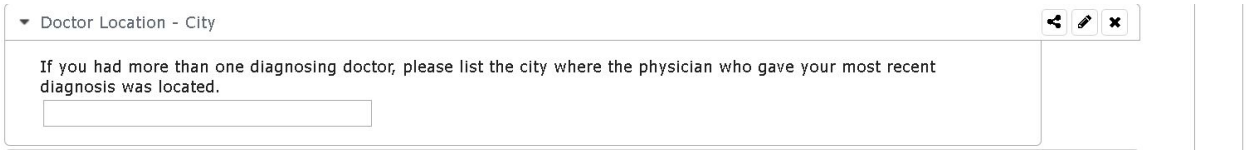

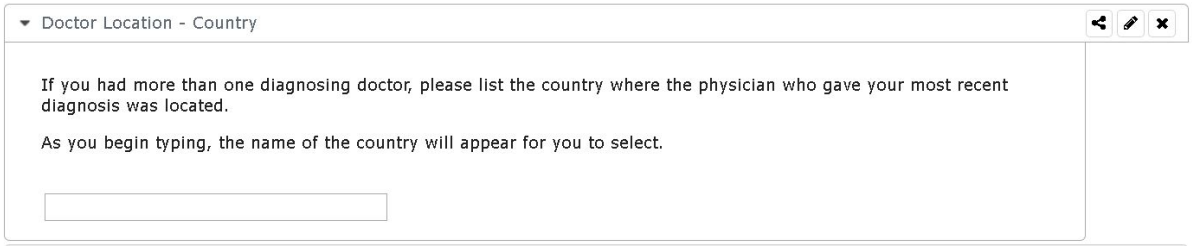

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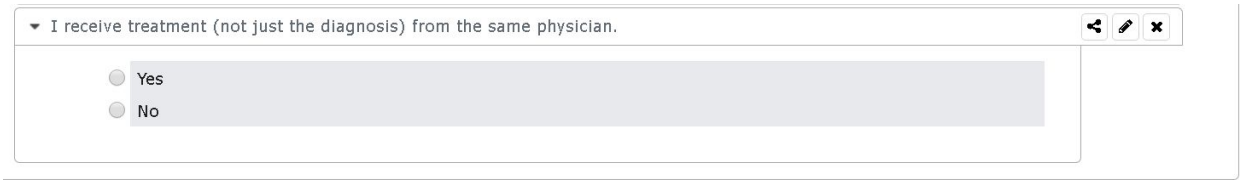

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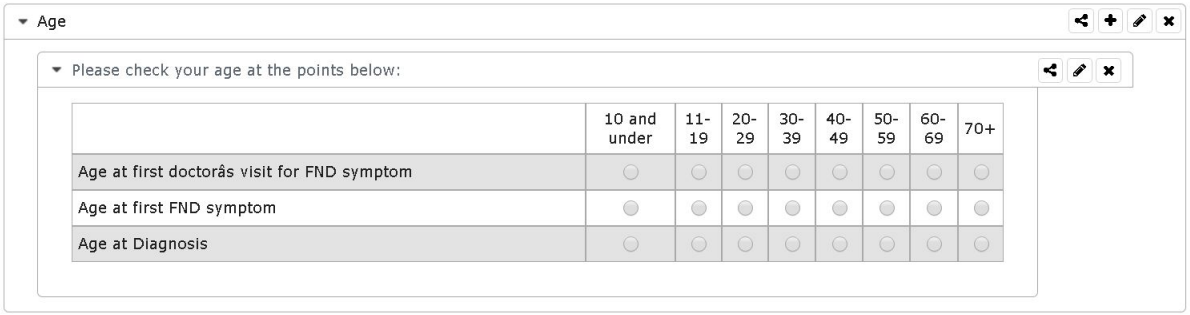

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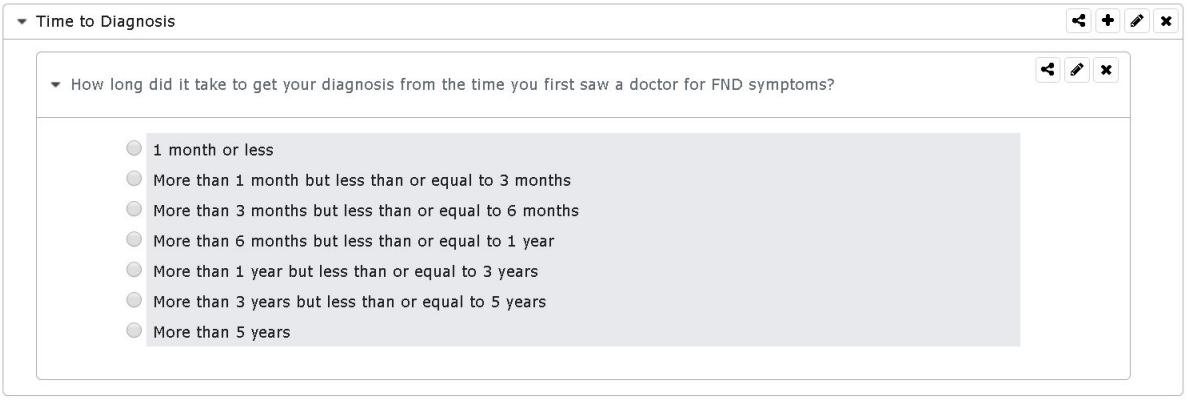

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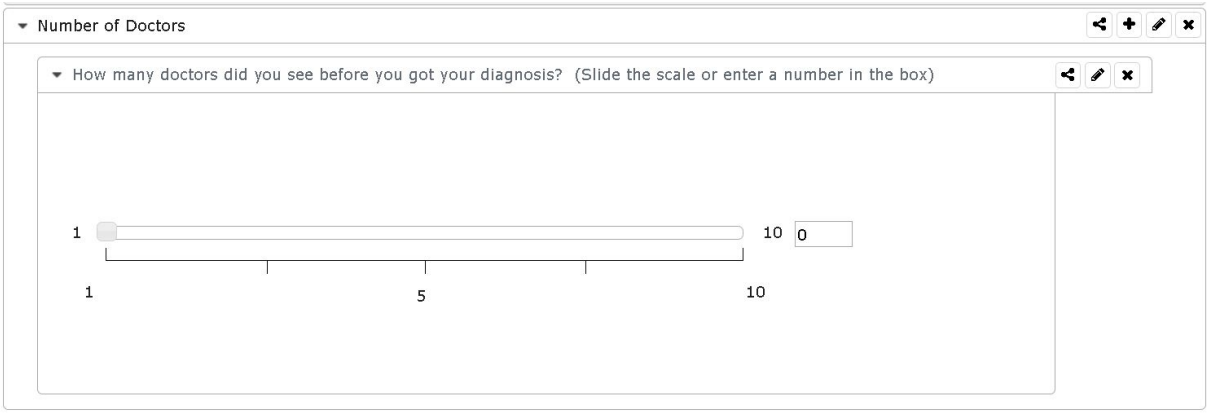


Source: FND Hope

Impact on Life

Physical Functioning (RAND SF-36)

The following items are about activities you might do during a typical day. **Does your health now limit you** in these activities? If so, how much?

Please answer these according to how you feel during a typical day.

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
Lifting or carrying groceries	○	○	○
Climbing several flights of stairs	○	○	○
Climbing one flight of stairs	○	○	○
Bending, kneeling, or stooping	○	○	○
Walking more than a mile	○	○	○
Walking several blocks	○	○	○
Walking one block	○	○	○
Bathing or dressing yourself	○	○	○

Source: Rand 36-Item Short Form Survey (SF-36)[1]

Mental Wellbeing

If you are suffering from depression or anxiety, when did onset of these symptoms occur?

- ○ Before FND
- ○ At the same time as FND onset
- ○ As a result of illness/disability with FND
- ○ No depression or anxiety

Source: FND Hope

[1] As part of the Medical Outcomes Study (MOS), a multi-year, multi-site study to explain variations in patient outcomes, RAND developed the 36-Item Short Form Health Survey (SF-36). SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilized by managed care organizations and by Medicare for routine monitoring and assessment of care outcomes in adult patients.

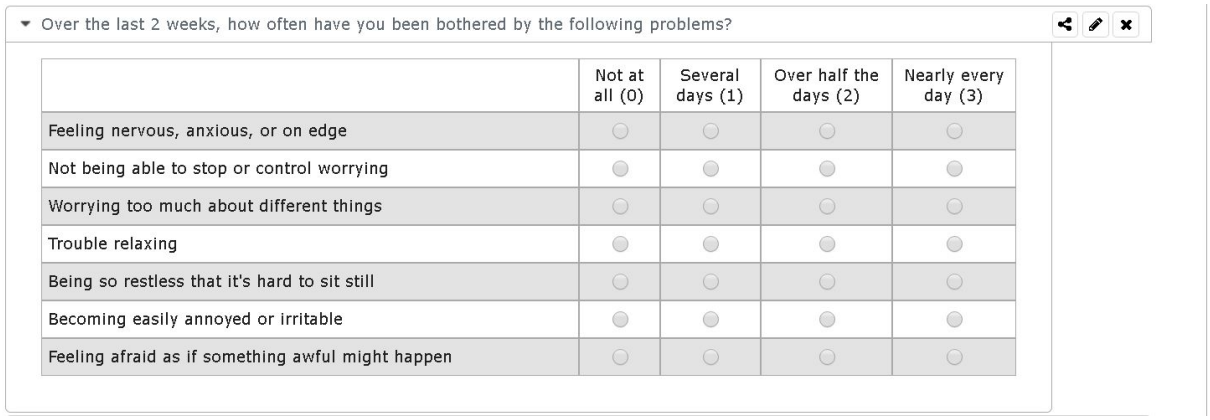
Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	○	○	○	○
Feeling down, depressed, or hopeless	○	○	○	○
Trouble falling or staying asleep or sleeping too much	○	○	○	○
Feeling tired or having little energy	○	○	○	○
Poor appetite or overeating	○	○	○	○
Feeling bad about yourself -- or that you are a failure or have let yourself or your family down	○	○	○	○
Trouble concentrating on things, such as reading the newspaper or watching television	○	○	○	○
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	○	○	○	○
Thoughts that you would be better off dead or of hurting yourself in some way	○	○	○	○

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

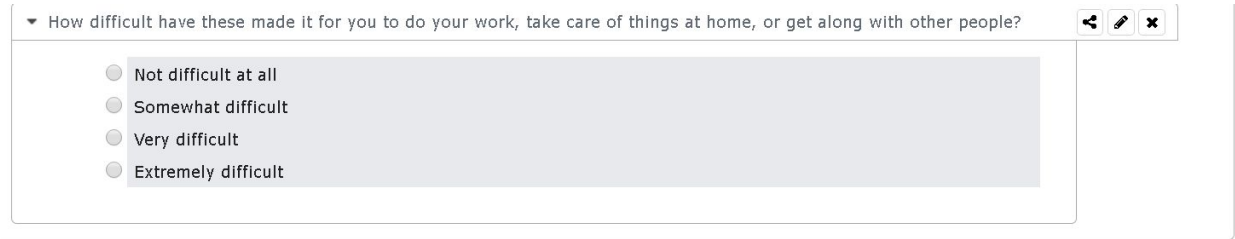
- ○ Not difficult at all
- ○ Somewhat difficult
- ○ Very difficult
- ○ Extremely difficult

Source: Patient Health Questionnaire - 9 (PHQ-9).

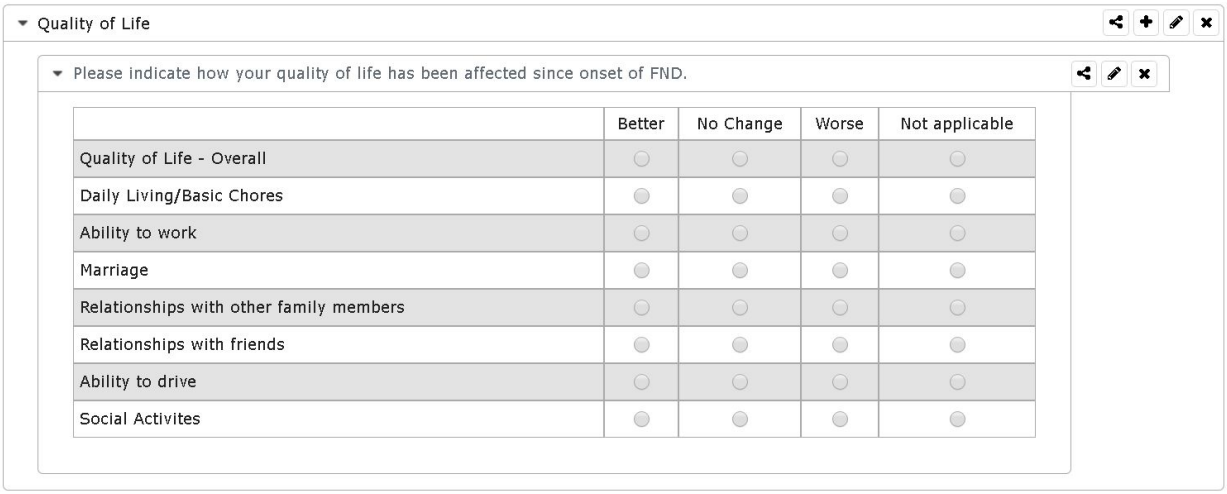


Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all (0)	Several days (1)	Over half the days (2)	Nearly every day (3)
Feeling nervous, anxious, or on edge	○	○	○	○
Not being able to stop or control worrying	○	○	○	○
Worrying too much about different things	○	○	○	○
Trouble relaxing	○	○	○	○
Being so restless that it's hard to sit still	○	○	○	○
Becoming easily annoyed or irritable	○	○	○	○
Feeling afraid as if something awful might happen	○	○	○	○



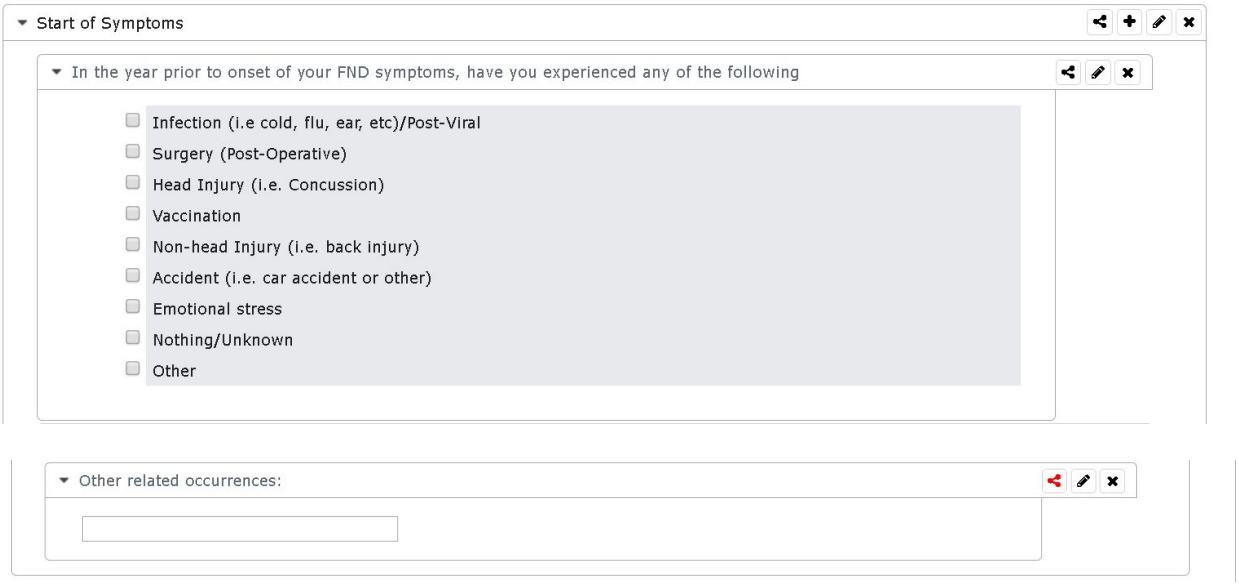
Source: Generalized Anxiety Disorder -7 (GAD-7) Scale[2]



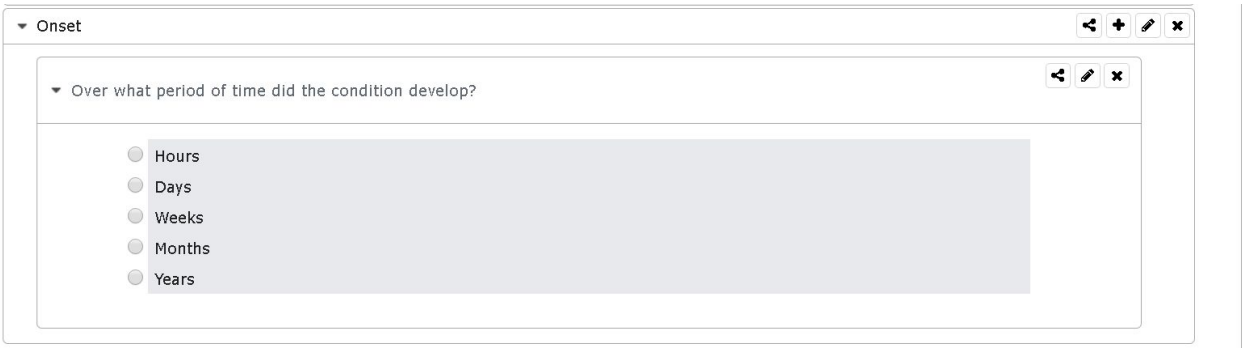
Source: FND Hope

Symptoms

[2] The GAD-7 originates from Spitzer RL, Kroenke K, Williams JB, et al; A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006 May 22;166(10):1092-7. GAD-7 © Pfizer Inc. all rights reserved; used with permission.



Source: FND Hope



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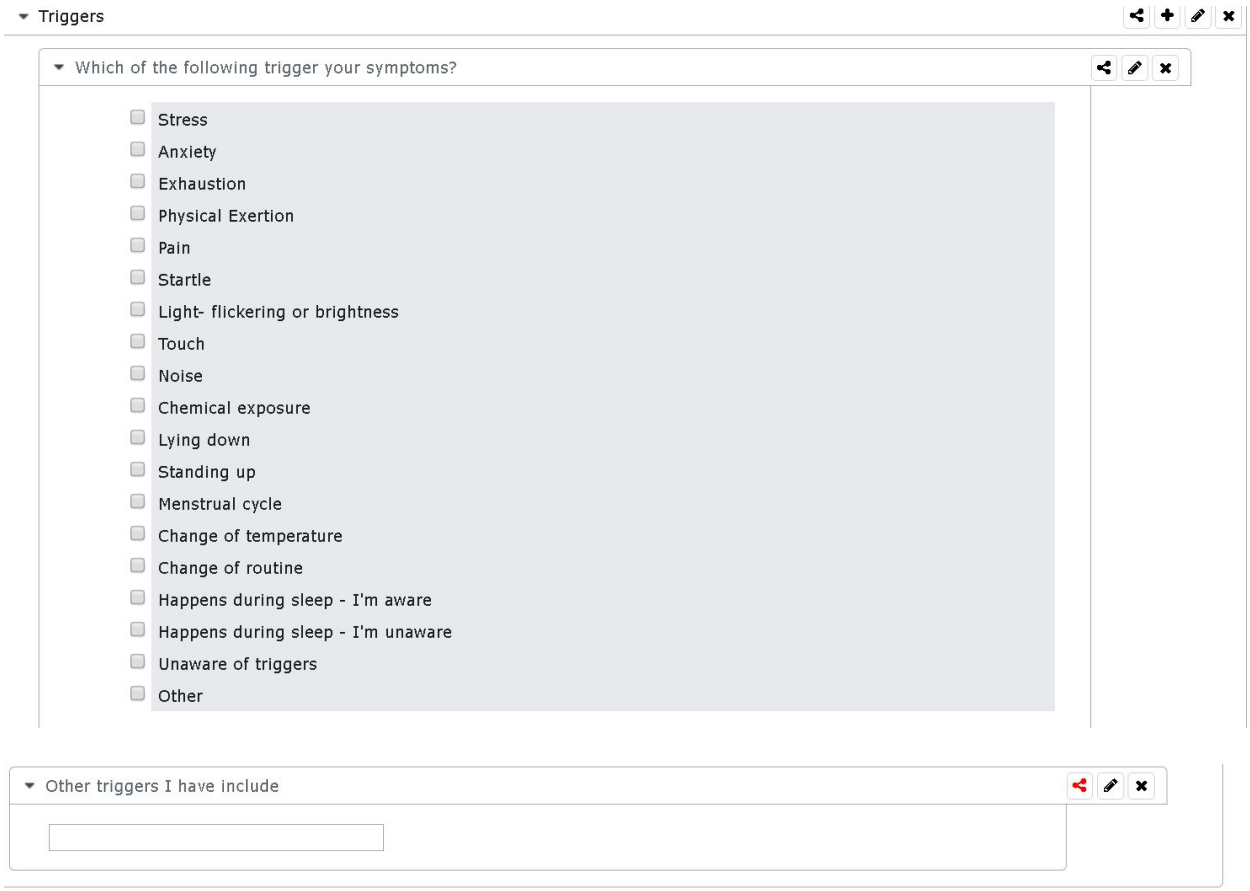

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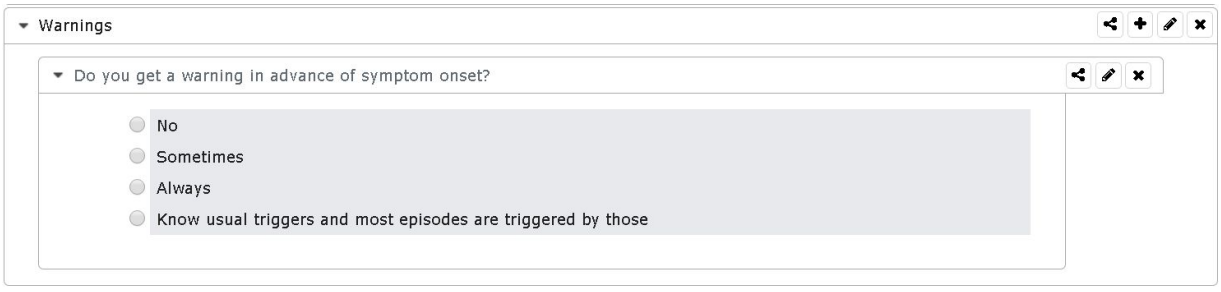

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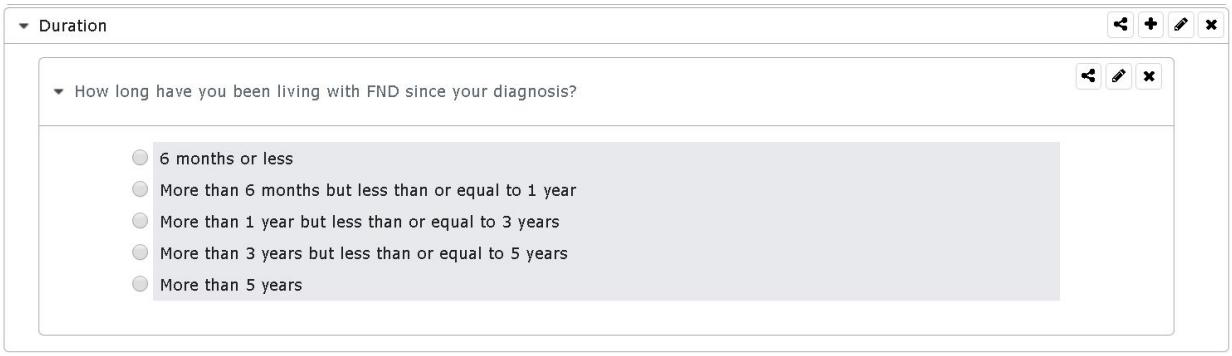
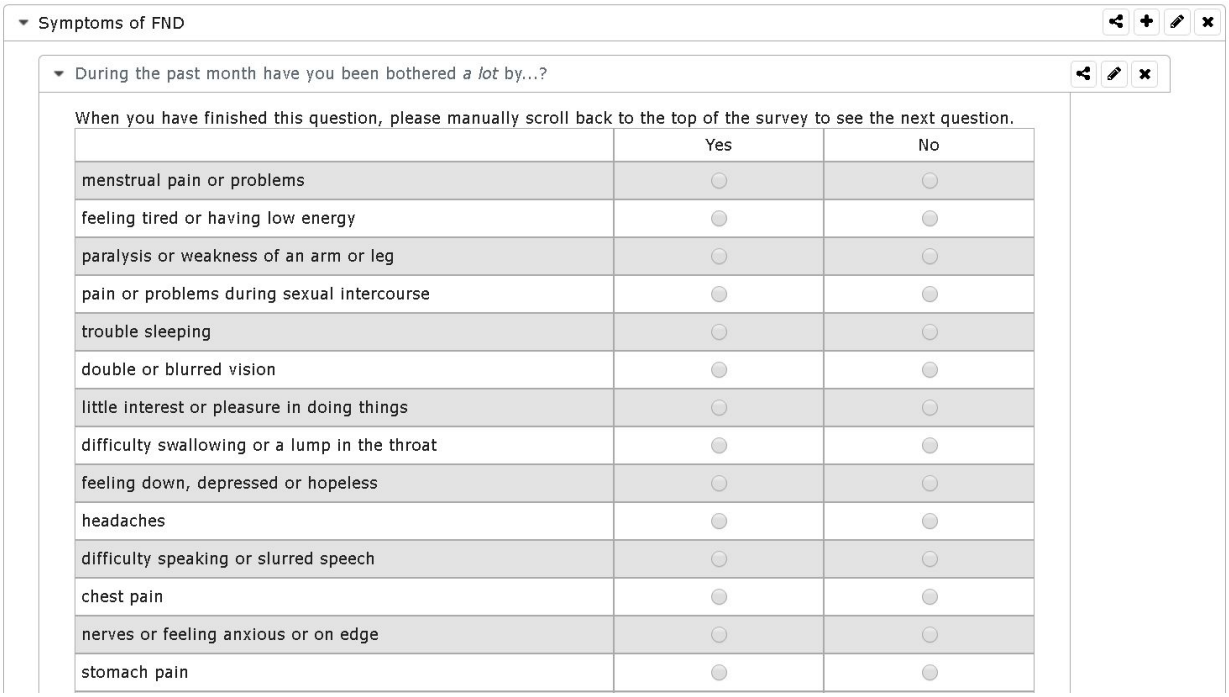


Source: FND Hope



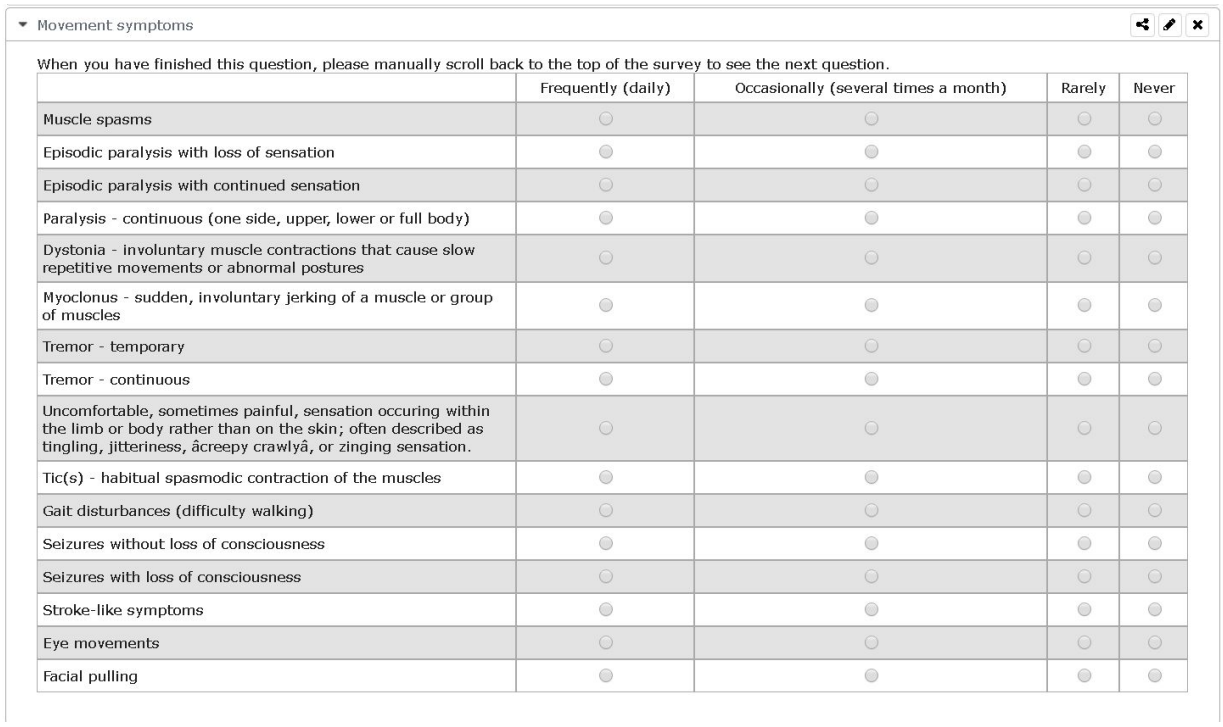
dizziness	○	○
worrying about a lot of different things	○	○
back pain	○	○
fainting spells	○	○
feeling your heart pound or race	○	○
lack of coordination or balance	○	○
pain in your arms, legs, or joints	○	○
loss of sensation, numbness or tingling	○	○
problems with your memory or concentration	○	○
partial or total loss of vision	○	○
partial or total loss of hearing	○	○
shortness of breath	○	○
constipation, loose bowels or diarrhoea	○	○
nausea, gas or indigestion	○	○

Source: FND Hope

▾ During the past month have you experienced...?

	Yes	No
A seizure or fit	○	○
an axiety attack (suddenly feeling fear or panic)	○	○

Source: FND Hope

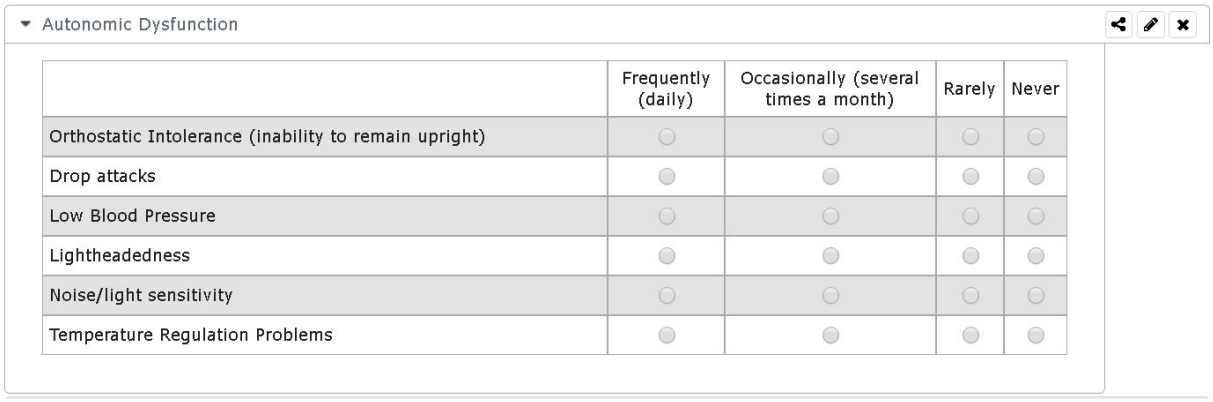


Movement symptoms

When you have finished this question, please manually scroll back to the top of the survey to see the next question.

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Muscle spasms				
Episodic paralysis with loss of sensation				
Episodic paralysis with continued sensation				
Paralysis - continuous (one side, upper, lower or full body)				
Dystonia - involuntary muscle contractions that cause slow repetitive movements or abnormal postures				
Myoclonus - sudden, involuntary jerking of a muscle or group of muscles				
Tremor - temporary				
Tremor - continuous				
Uncomfortable, sometimes painful, sensation occuring within the limb or body rather than on the skin; often described as tingling, jitteriness, âcreepy crawlyâ, or zinging sensation.				
Tic(s) - habitual spasmodic contraction of the muscles				
Gait disturbances (difficulty walking)				
Seizures without loss of consciousness				
Seizures with loss of consciousness				
Stroke-like symptoms				
Eye movements				
Facial pulling				

Source: FND Hope



Autonomic Dysfunction

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Orthostatic Intolerance (inability to remain upright)				
Drop attacks				
Low Blood Pressure				
Lightheadedness				
Noise/light sensitivity				
Temperature Regulation Problems				

Source: FND Hope

Other Symptoms

When you have finished this question, please manually scroll back to the top of the survey to see the next question.

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Incontinence				
Frequent Urination				
Urinary retention				
Numbness/neuropathy				
Sensation of electrical shocks or pin pricks				
Aches in joints				
Aches in muscles				
Changes in taste				
Dry eye				
Dry mouth				
Multiple Chemical Sensitivity (MCS)				
Smelling strange smells				
Sleep apnea				
Excessive yawning				
Insomia				

Excessive Fatigue				
Exercise Intolerance				
Foreign Accent Syndrome				
Difficulty having blood drawn				

Source: FND Hope

Do you experience any other symptoms of FND that were not listed previously?

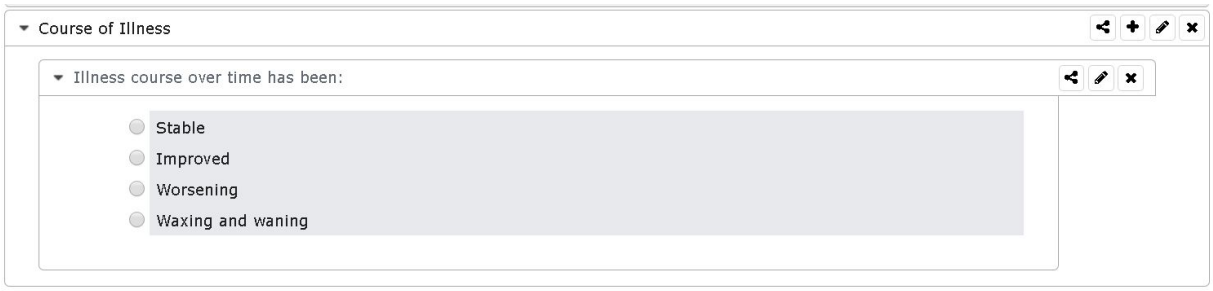
Please note that any symptoms of conditions that are not FND will be covered in a subsequent section on Comoribd Conditions.

- Yes
- No

What other symptoms of FND that were not listed previously do you experience?

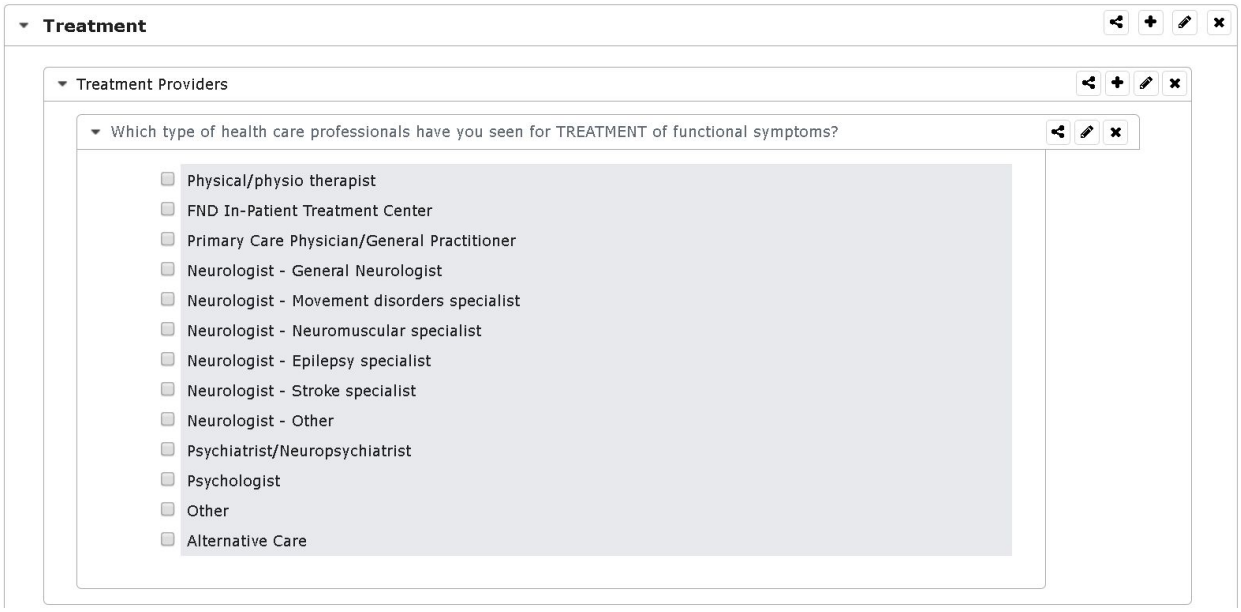
Please list the symptom(s), followed by the frequency (frequently, occasionally, rarely, never) in parentheses.

Source: FND Hope



Source: FND Hope

Treatment



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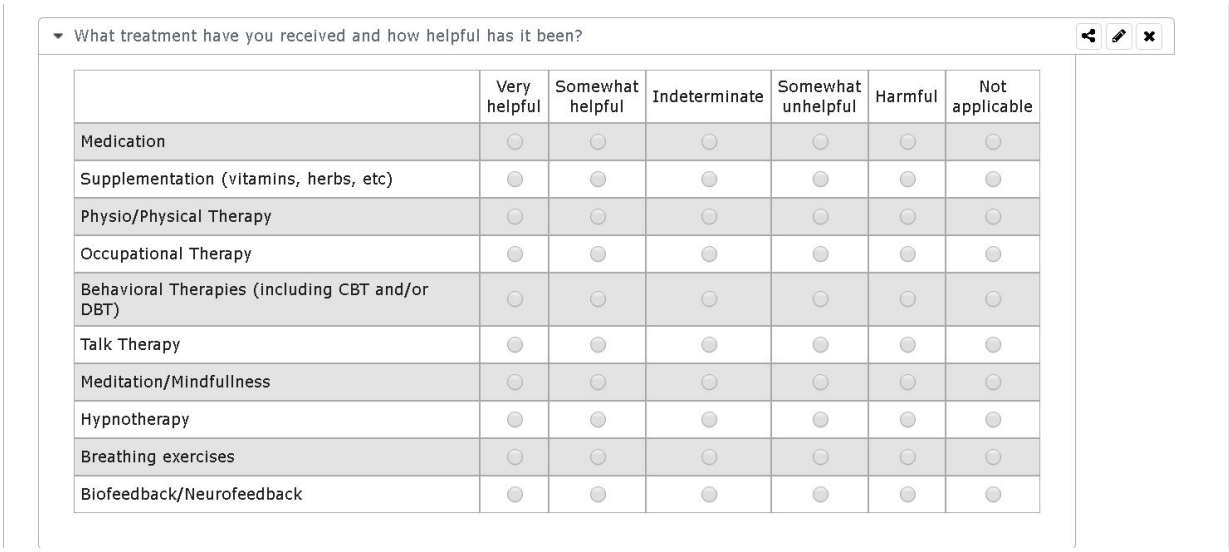

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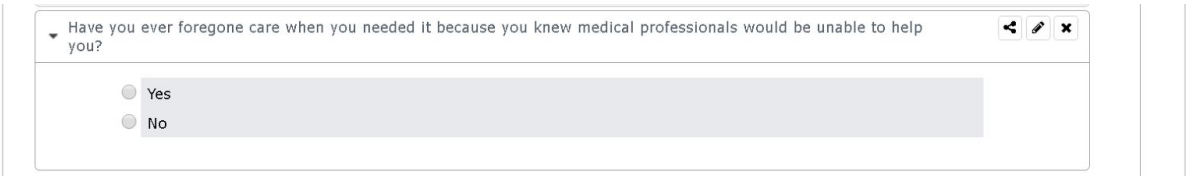

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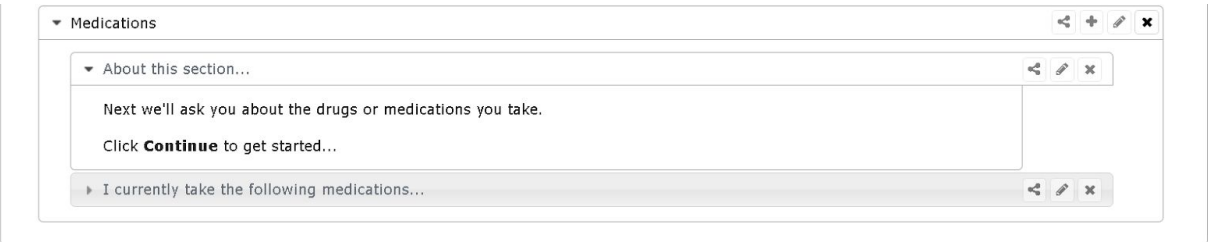
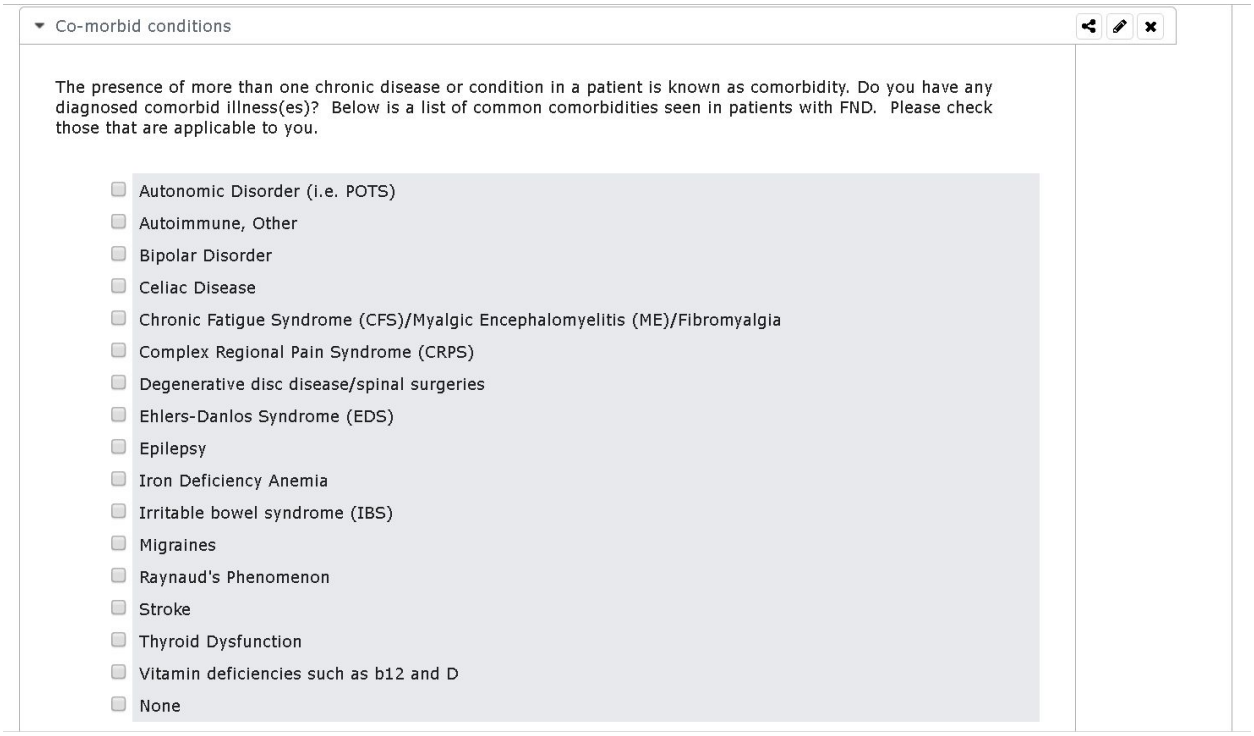


Source: Genetic Alliance PEER

Comorbid Conditions



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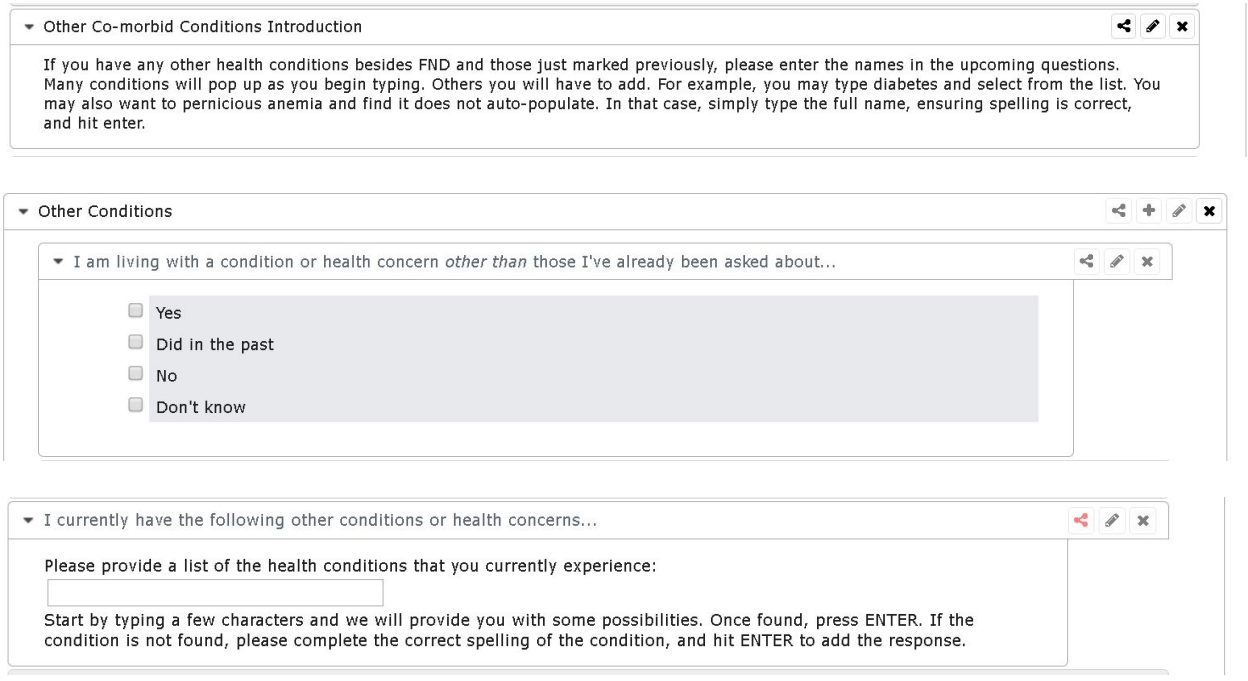
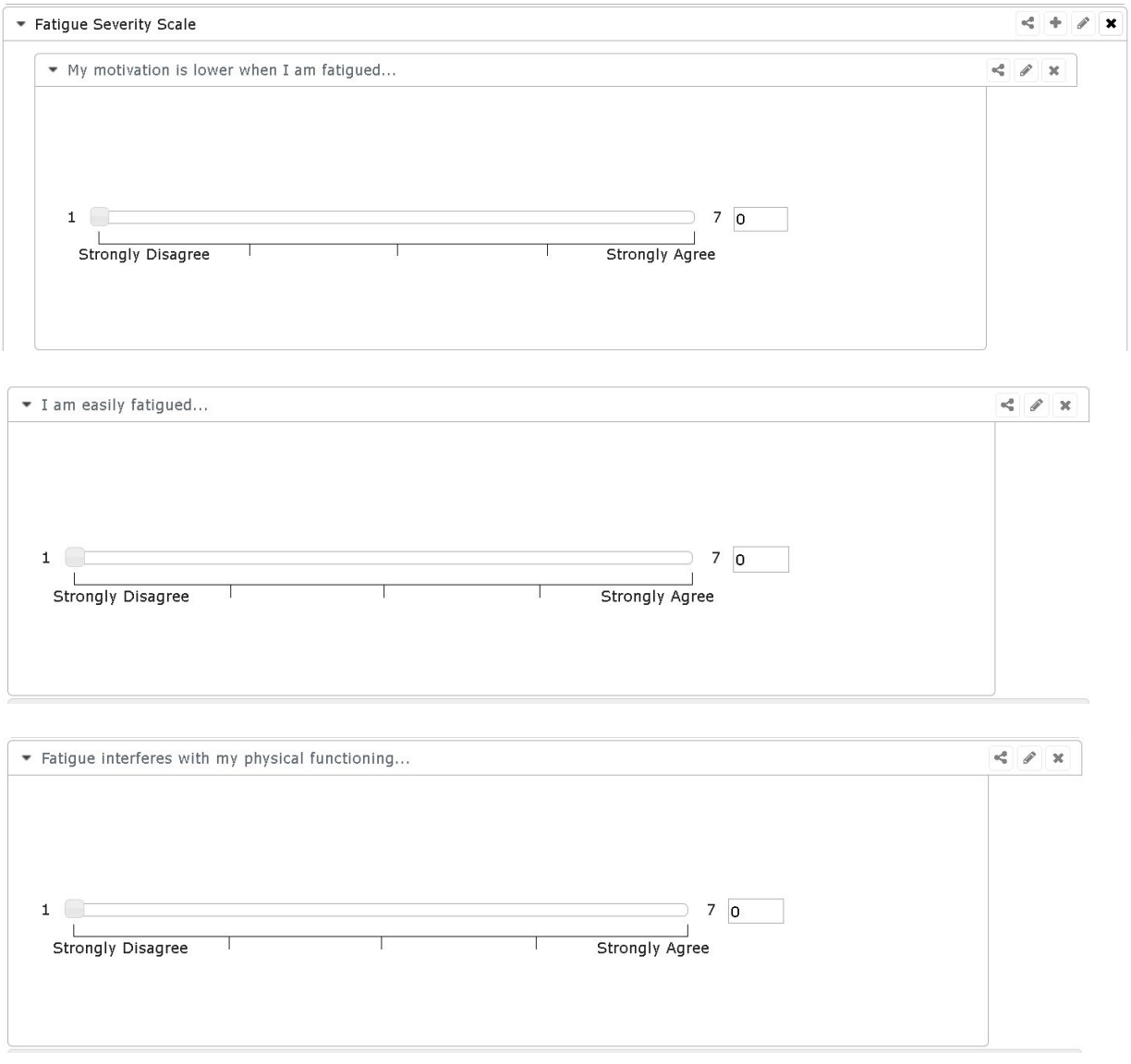


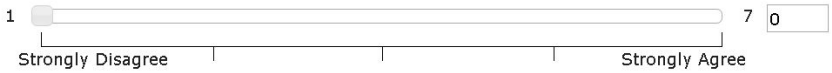
Source: Genetic Alliance PEER

Follow-Up Survey

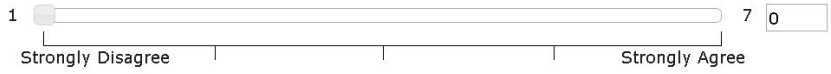
Fatigue Severity Scale



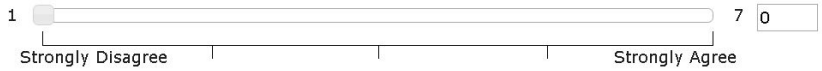
Fatigue causes frequent problems for me...



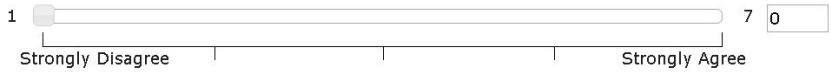
My fatigue prevents sustained physical functioning...

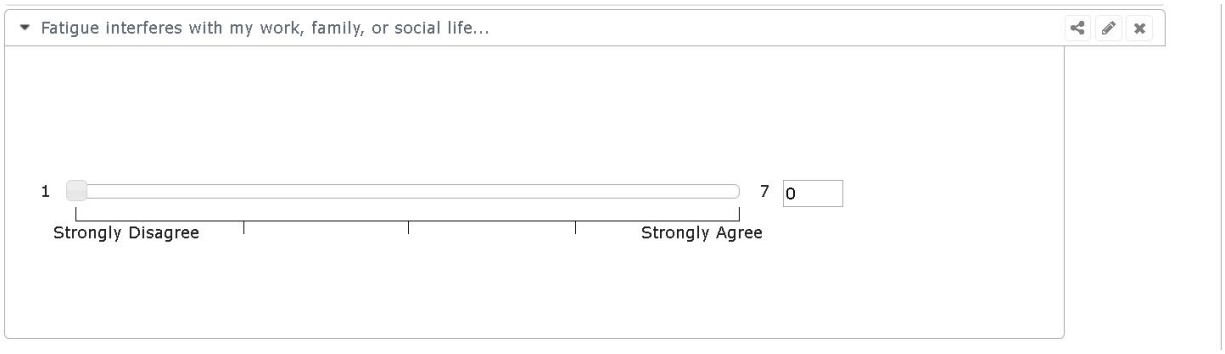


Fatigue interferes with carrying out certain duties and responsibilities...



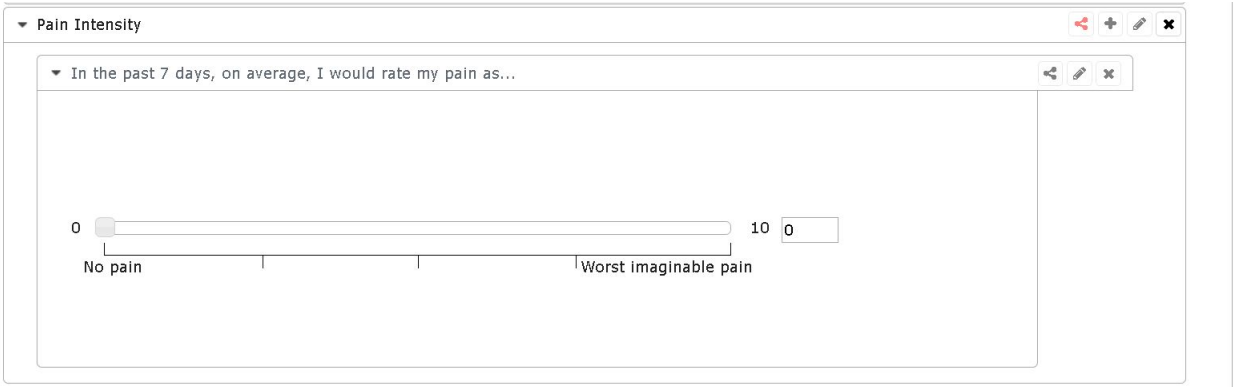
Fatigue is among my most disabling symptoms...

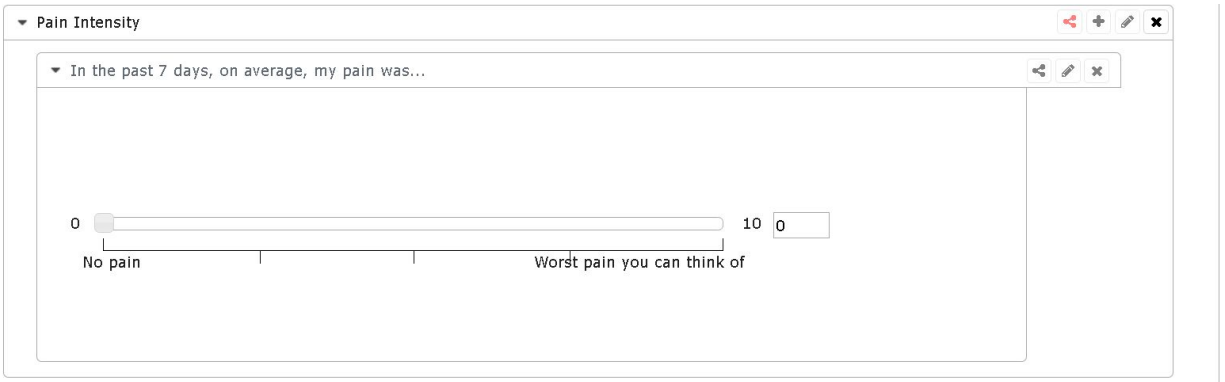




Source: Fatigue Severity Scale (FSS)[3]

Pain Intensity





Source: Genetic Alliance PEER - PROMIS(r) Pain Intensity instrument Short Form

Pain Interference

[3] Developers were Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. Contact Lauren B. Krupp, Department of Neurology, School of Medicine, Health Sciences Center, State University of New York at Stony Brook, Stony Brook, NY 11794-8121. E-mail: Lauren.krupp@sunysb.edu.

Pain Interference

In the past 7 days, pain interfered with my...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Day to day activities	○	○	○	○	○
Work around the home	○	○	○	○	○
Ability to participate in social activities	○	○	○	○	○
Household chores	○	○	○	○	○

Pain Interference

In the past 7 days, I felt angry when I had pain...

- ○ Never
- ○ Almost Never
- ○ Sometimes
- ○ Often
- ○ Almost Always

In the past 7 days, I had trouble doing schoolwork when I had pain...

- ○ Never
- ○ Almost Never
- ○ Sometimes
- ○ Often
- ○ Almost Always

In the past 7 days, I had trouble sleeping when I had pain...

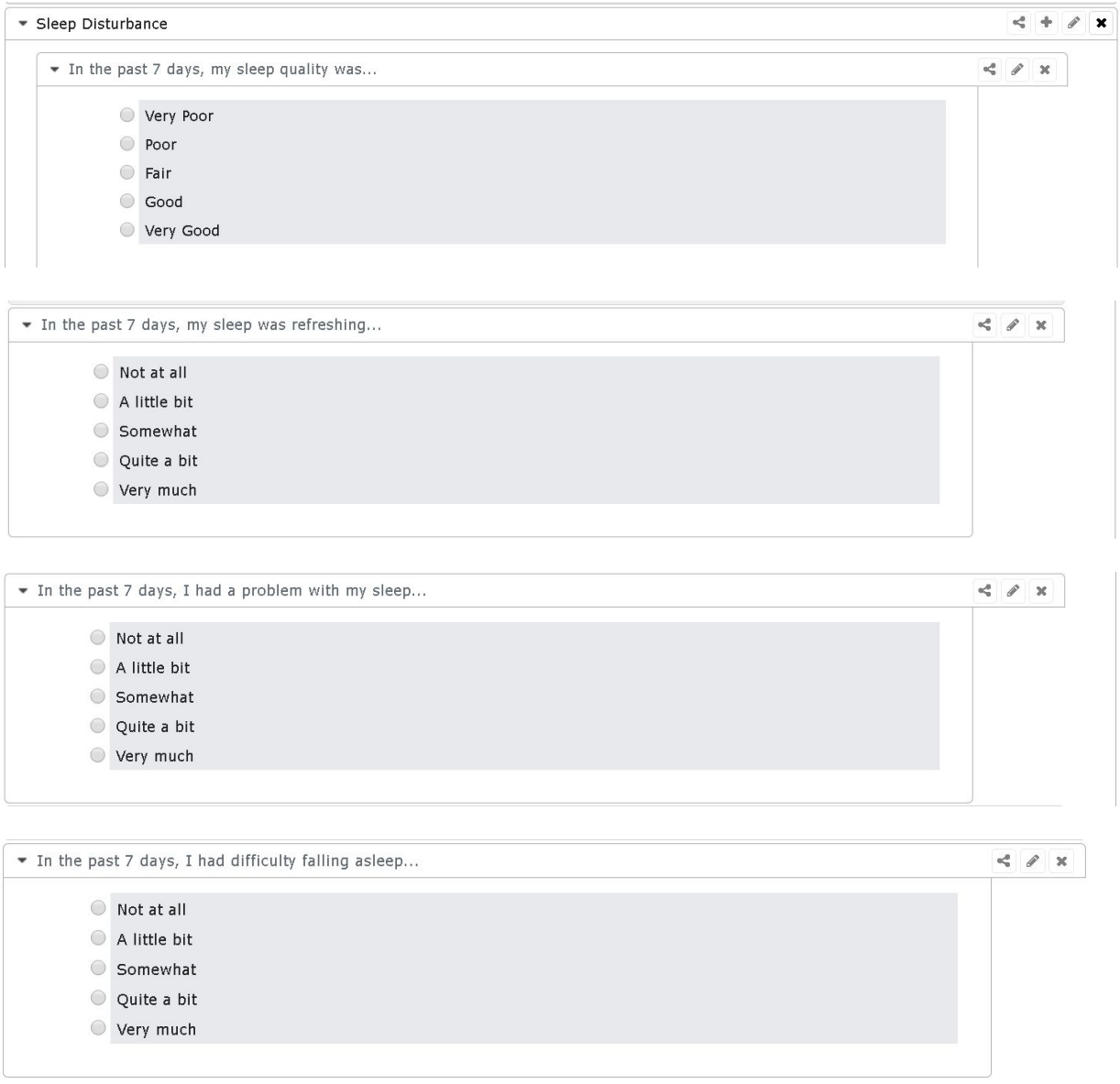
- ○ Never
- ○ Almost Never
- ○ Sometimes
- ○ Often
- ○ Almost Always

In the past 7 days, when I felt pain, it was hard for me to...

	Never	Almost never	Sometimes	Often	Almost always
Pay attention	○	○	○	○	○
Run	○	○	○	○	○
Walk one block	○	○	○	○	○
Have fun	○	○	○	○	○
Stay standing	○	○	○	○	○

Source: Genetic Alliance - PROMIS Pain Interference Short Form[4]

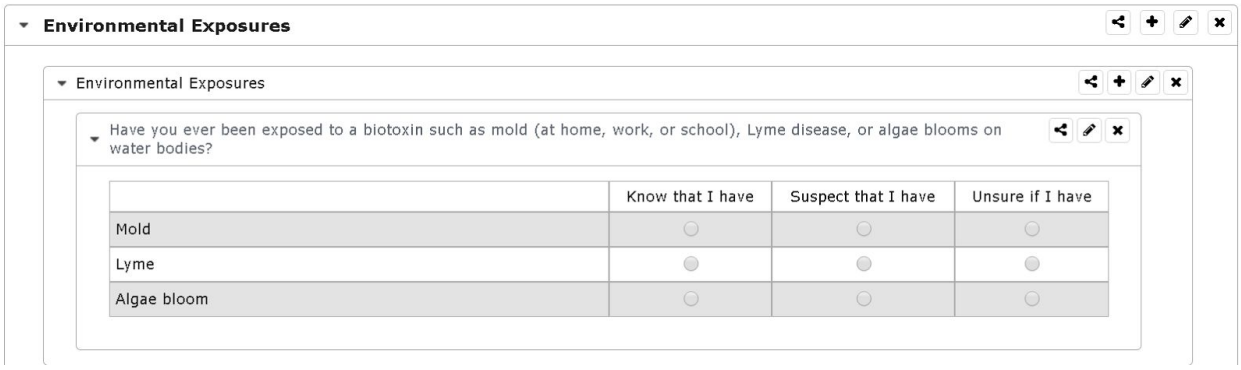
Sleep Disturbance



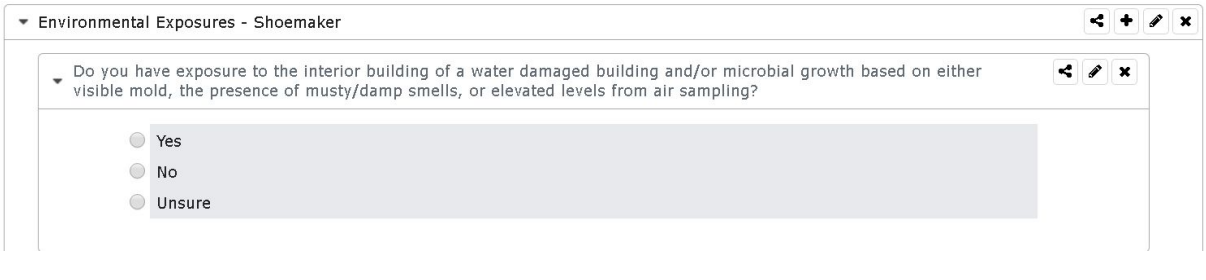
[4] Pain Interference - This instrument has been validated by PROMIS as a "stand-alone" measure of pain interference (it's one of their adult short forms). There's also a stand-alone pediatric version of the short form, which has been included. Depending on age of participant, adult or child version is used.

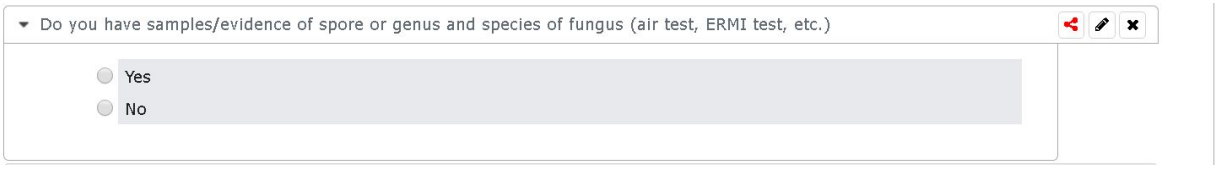
Source: Genetic Alliance - PROMIS Sleep Disturbance Short Form[5]

Environmental Exposures



Source: abridged from survey at survivingmold.com, developed by Dr. Ritchie Shoemaker as Assessment of Chronic Inflammatory Response Syndrome (CIRS)





[5] The National Institutes of Health (NIH) implemented the Patient Reported Outcomes Measurement Information System (PROMIS) more than 10 years ago. NIH created PROMIS to develop and evaluate measures to target important health outcomes across various chronic diseases.

Was/is there visible microbial growth (mold)?

- Yes
- No

Is there a presence of musty smells?

- Yes
- No

Do you remember a tick bite occurring before your illness beginning?

- Yes
- No

Did you have an unexplained rash after the bite?

- Yes
- No

Did you experience flu-like illness after the bite?

- Yes
- No

Have you had a brown recluse or other poisonous spider bite?

- Yes
- No
- Unknown

Did you experience flu-like illness after the bite?

- Yes
- No

Did you become ill after eating fish?

- Yes
- No

Source: survey at survivingmold.com, developed by Dr. Ritchie Shoemaker as Assessment of Chronic Inflammatory Response Syndrome (CIRS)

Family History

What was the relationship to you of the family member(s) with a neurological disorder?

- [ ] Father
- [ ] Mother
- [ ] Brother
- [ ] Sister
- [ ] Son
- [ ] Daughter
- [ ] Grandchild(ren)
- [ ] Paternal Grandfather
- [ ] Paternal Grandmother
- [ ] Maternal Grandfather
- [ ] Maternal Grandmother
- [ ] Paternal Uncle(s)
- [ ] Paternal Aunt(s)
- [ ] Maternal Uncle(s)
- [ ] Maternal Aunt(s)
- [ ] First Cousins (Fatherâs Side)
- [ ] First Cousins (Motherâs Side)

What neurological diagnosis did the family member receive?

Is there a family history of autoimmune disease?

- ( ) Yes
- ( ) No
- ( ) Unsure

What was the relationship to you of the family member(s) with autoimmune disorder(s)?

- [ ] Father
- [ ] Mother
- [ ] Brother
- [ ] Sister
- [ ] Son
- [ ] Daughter
- [ ] Grandchild(ren)
- [ ] Paternal Grandfather
- [ ] Paternal Grandmother
- [ ] Maternal Grandfather
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- [ ] Paternal Uncle(s)
- [ ] Paternal Aunt(s)
- [ ] Maternal Uncle(s)
- [ ] Maternal Aunt(s)
- [ ] First Cousins (Fatherâs Side)
- [ ] First Cousins (Motherâs Side)

What autoimmune diagnosis did the family member receive?

Is there a family history of major psychiatric disorders?

- ( ) Yes
- ( ) No
- ( ) Unsure

What was the relationship to you of the family member(s) with a major psychiatric disorder?

- [ ] Father
- [ ] Mother
- [ ] Brother
- [ ] Sister
- [ ] Son
- [ ] Daughter
- [ ] Grandchild(ren)
- [ ] Paternal Grandfather
- [ ] Paternal Grandmother
- [ ] Maternal Grandfather
- [ ] Maternal Grandmother
- [ ] Paternal Uncle(s)
- [ ] Paternal Aunt(s)
- [ ] Maternal Uncle(s)
- [ ] Maternal Aunt(s)
- [ ] First Cousins (Fatherâs Side)
- [ ] First Cousins (Motherâs Side)

What psychiatric diagnosis did your family member receive?

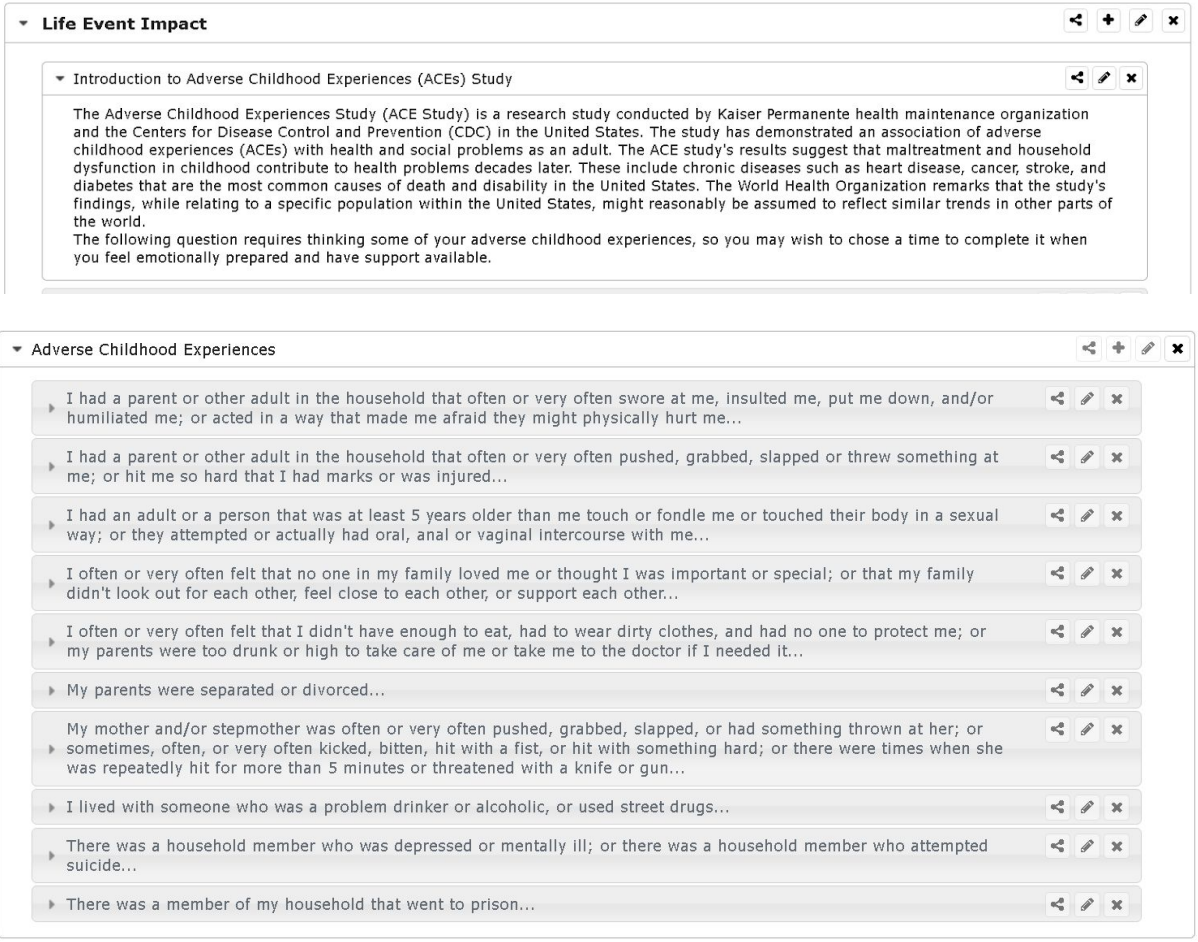
Is there a family history of medically unexplained symptoms?

- ( ) Yes
- ( ) No
- ( ) Unsure

Source: FND Hope with list of family members from Genetic Alliance PEER

Life Event Impact Survey

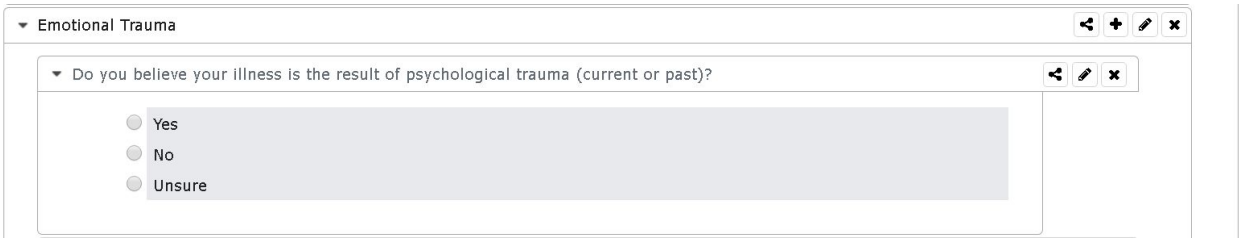
Adverse Childhood Experiences (ACEs)



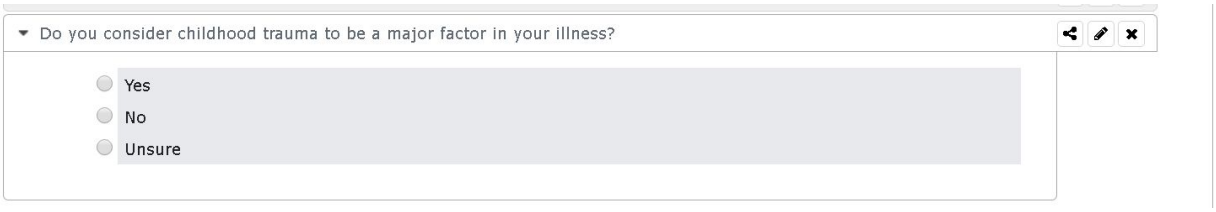
Source: Adverse Childhood Experiences (ACEs) Study[6]

[6] The CDC-Kaiser Permanente Adverse Childhood Experiences (ACE) Study is one of the largest investigations of childhood abuse and neglect and later-life health and well-being.
The original ACE Study was conducted at Kaiser Permanente from 1995 to 1997 with two waves of data collection. Over 17,000 Health Maintenance Organization members from Southern California receiving physical exams completed confidential surveys regarding their childhood experiences and current health status and behaviors.

Trauma



Source: FND Hope



Source: FND Hope

The CDC continues ongoing surveillance of ACEs by assessing the medical status of the study participants via periodic updates of morbidity and mortality data.