

Supplementary Materials

Impacts of thyroid eye disease (TED), beyond the signs and symptoms: Results from the ElevaTED patient survey

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Table S1. Table of Inclusion/Exclusion Criteria

Figure S1. Figure of Eligibility and Screening Flow

Table S2. ElevaTED Survey Participants' Self-Reported Symptom Severity (of those having symptoms of TED in the past month)

Figure S2. TED Symptoms experienced by participants at any time or within the prior month for those reporting Mild symptoms (n=44).

Appendix ElevaTED Patient Survey

Table S1. Table of ElevaTED Inclusion/Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Resident of the United States • Of age of majority • Diagnosed by a physician with Thyroid Eye Disease (TED) OR Graves' Disease • Graves' Disease patients must also have been diagnosed by a physician with one of the following: ○ Graves' Eye Disease (GED) ○ Graves' Ophthalmopathy ○ Graves' Orbitopathy / Thyroid-associated orbitopathy • Indicate that TED symptoms (when at their worst) had at least nominal impact on daily life	• Poorly controlled hyper- or hypothyroidism (self-reported) • Poorly controlled glaucoma (self-reported) • Diagnosed by a physician with any of the following: ○ Myasthenia Gravis ○ Sarcoidosis ○ Diabetic retinopathy • No impact of TED symptoms at their worst on daily life

Figure S1. Participant Screening Overview. Number of participants assessed for eligibility, and the number excluded at each stage.

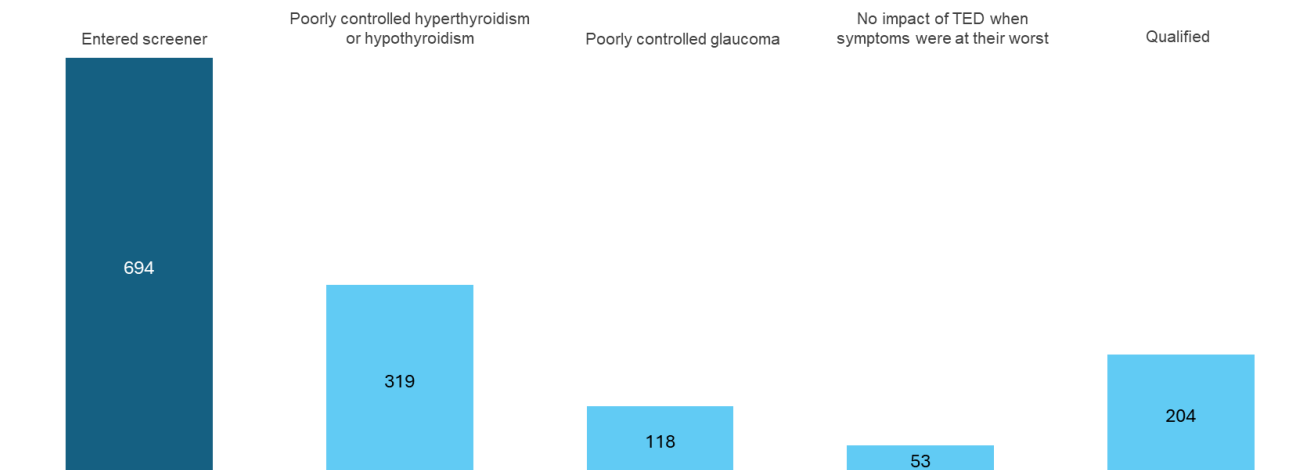
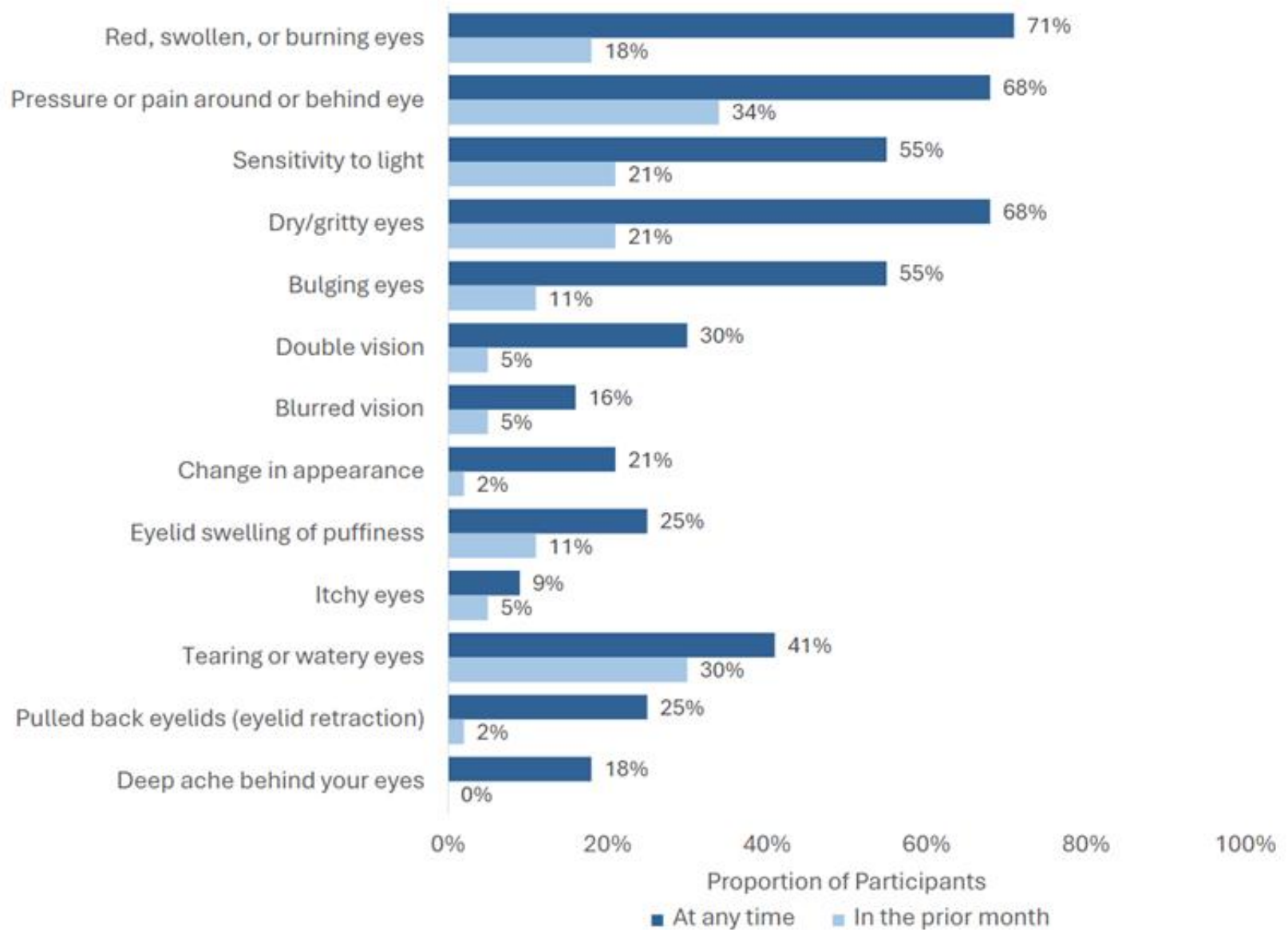


Table S2. ElevaTED Survey Participants' Self-Reported Symptom Severity (of those having symptoms of TED in the past month)

		Question 2: <i>Over the past month, how severe were your TED symptoms? (Select one)</i> 1. Mild 2. Moderate 3. Severe			
	Total (n=190)	Mild (n=44)	Moderate (n=111)	Severe (n=35)	
Question 1: <i>Over the past month, how much did your TED symptoms impact your daily life? Please consider all aspects of your day-to-day personal, social, and professional activities. (Select one)</i>					
1.	No impact	0.5%	-	0.9%	--
2.	Little impact	22.1%	79.5%	6.3%	--
3.	Moderate impact	45.3%	18.2%	69.4%	2.9%
4.	Major impact	26.8%	2.3%	19.8%	80.0%
5.	Severe impact	5.3%	-	3.6%	17.1%

Figure S2. Thyroid Eye Disease (TED) Symptoms experienced by participants at any time or within the prior month for those reporting Mild symptoms (n=44).



Appendix ElevaTED Patient Survey

People with TED: Survey

Thank you. We are pleased to invite you to complete the TED Impact Survey so we may better understand your experiences living with TED.

The survey will give you the opportunity to share your experiences with TED over the past month as well as when your symptoms were at their worst.

Please click the arrow to continue.

Throughout this survey, we will use the abbreviation “**TED**” to describe **thyroid eye disease**. To begin, we will ask you questions about your experiences being diagnosed with TED.

1. How long ago did you **first experience** symptoms of TED? Please answer in either months or years.

If you first experienced symptoms within the last 18 months, please answer in months. (Specify)

1. __ months
 2. __ years
2. Approximately how long ago were you **diagnosed** with TED? Please answer in either months or years. (Specify)
 1. ____ months
 2. __ years
 3. Please think back to the different doctors you saw **from the first time you experienced symptoms of TED until you were correctly diagnosed**.
 1. Approximately how many different doctors did you see before you were diagnosed with TED? Specify)
 2. ____ Which doctors did you see about TED during this time? (Select all that apply)
 - i. Primary care (internal medicine, family practice or general practice)
 - ii. Endocrinologist (specializes in treatment of thyroid disease and hormone-related conditions)
 - iii. Optometrist (performs eye exams to identify any problems in your vision)
 - iv. Ophthalmologist (performs medical and surgical treatments for eye conditions)
 - v. Oculoplastic surgeon (specializes in surgery for eyes, eyelids, and face)
 - vi. Other
 3. Were you ever incorrectly diagnosed with something other than TED before you were correctly diagnosed? (Select one)
 - i. Yes
 - ii. No
 4. How many times were you diagnosed with something else before you were correctly diagnosed with TED? (Specify)
 - i. ____

5. What type of doctor(s) diagnosed you with TED? (Select all that apply)
 - i. Primary care (internal medicine, family practice or general practice)
 - ii. Endocrinologist (specializes in treatment of thyroid disease and hormone-related conditions)
 - iii. Optometrist (performs eye exams to identify any problems in your vision)
 - iv. Ophthalmologist (performs medical and surgical treatments for eye conditions)
 - v. Oculoplastic surgeon (specializes in surgery for eyes, eyelids, and face)
 - vi. Other
4. What doctors are you currently seeing for your TED? (Select all that apply)
 1. Primary care (internal medicine, family practice or general practice)
 2. Endocrinologist (specializes in treatment of thyroid disease and hormone-related conditions)
 3. Optometrist (performs eye exams to identify any problems in your vision)
 4. Ophthalmologist (performs medical and surgical treatments for eye conditions)
 5. Oculoplastic surgeon (specializes in surgery for eyes, eyelids, and face)
 6. Other
5. A TED Specialist is a doctor who is experienced in identifying, diagnosing, and treating TED.
 1. Did a TED Specialist diagnose your TED? (Select one)
 - a) Yes
 - b) No
 2. Are currently being treated by a TED Specialist? (Select one)
 - a) Yes
 - b) No

In this section, we will be exploring the types of symptoms you experience with your TED and how bothersome they may be to you.

6. Which of the following symptoms of TED have you **ever** experienced **at any time**? (Select all that apply)

☐	1	Dry/gritty eyes	☐	10	Blurred vision
☐	2	Itchy eyes	☐	11	Eyelid swelling or puffiness
☐	3	Sensitivity to light	☐	12	Inability to close eyelid
☐	4	Bulging eyes	☐	13	Pulled back eyelids (eyelid retraction)
☐	5	Pressure or pain around or behind eye	☐	14	Eyes that aim different directions or misaligned eyes
☐	6	Tearing or watery eyes	☐	15	Color vision loss
☐	7	Red, swollen, or burning eyes	☐	16	Sense that you can feel your eyes
☐	8	Double vision	☐	17	Deep ache behind your eyes
☐	9	Change in appearance			

7. Have you had any symptoms of TED **in the past month**? (Select one)

1. Yes
2. No

8. Approximately how long ago did your symptoms of TED stop? (Select one)

1. Within the last 3 months
2. Within the last 6 months
3. Within the last year
4. Within the last 1-2 years
5. More than 2 years ago

Although the next set of questions asks about your symptoms and the impact they have had on you during the past month, there will be additional questions later in the survey that ask about the impact of TED when your symptoms were at their worst.

9. Which of the following symptoms of TED did you experience **over the past month**? (Select all that apply)

☐	1	Dry/gritty eyes	☐	10	Blurred vision
☐	2	Itchy eyes	☐	11	Eyelid swelling or puffiness
☐	3	Sensitivity to light	☐	12	Inability to close eyelid
☐	4	Bulging eyes	☐	13	Pulled back eyelids (eyelid retraction)
☐	5	Pressure or pain around or behind eye	☐	14	Eyes that aim different directions or misaligned eyes
☐	6	Tearing or watery eyes	☐	15	Color vision loss
☐	7	Red, swollen, or burning eyes	☐	16	Sense that you can feel your eyes
☐	8	Double vision	☐	17	Deep ache behind your eyes
☐	9	Change in appearance			

10. **In the past month**, how bothersome were each of these symptoms? (Select one per row)

Not at all	Slightly bothersome	Moderately bothersome	Very bothersome	Extremely bothersome
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐

11. **In the past month**, which of these symptoms was the **most bothersome**? (Select one)

☐	1	Dry/gritty eyes	☐	10	Blurred vision
☐	2	Itchy eyes	☐	11	Eyelid swelling or puffiness
☐	3	Sensitivity to light	☐	12	Inability to close eyelid
☐	4	Bulging eyes	☐	13	Pulled back eyelids (eyelid retraction)
☐	5	Pressure or pain around or behind eye	☐	14	Eyes that aim different directions or misaligned eyes
☐	6	Tearing or watery eyes	☐	15	Color vision loss
☐	7	Red, swollen, or burning eyes	☐	16	Sense that you can feel your eyes
☐	8	Double vision	☐	17	Deep ache behind your eyes
☐	9	Change in appearance			

12. **Over the past month**, how much did your TED symptoms impact your daily life? Please consider all aspects of your day-to-day personal, social, and professional activities. (Select one)

1. No impact
2. Little impact
3. Moderate impact
4. Major impact
5. Severe impact

13. **Over the past month**, how severe were your TED symptoms? (Select one)

1. Mild
2. Moderate
3. Severe

We next want to better understand the impact that TED has on your life and your day-to-day activities.

14. Please think about your TED **today**. (Select one per row)

	Does not interfere 										Completely Interferes 
1. How is your TED currently interfering with your overall quality of life?	0	1	2	3	4	5	6	7	8	9	10
2. How is your TED currently affecting your ability to carry out daily activities?	0	1	2	3	4	5	6	7	8	9	10
3. How is your TED currently affecting your satisfaction with your appearance?	0	1	2	3	4	5	6	7	8	9	10

15. **During the past month**, were you limited in carrying out the following activities, because of your TED? (Select one per row)

	No, not at all limited	Yes, a little limited	Yes, seriously limited	
1. Bicycling	☐	☐	☐	☐ Never learned to ride bike
2. Driving	☐	☐	☐	☐ No driver's license
3. Moving around the house	☐	☐	☐	
4. Walking outdoors	☐	☐	☐	
5. Reading	☐	☐	☐	
6. Watching TV	☐	☐	☐	
7. Hobby or pastime	☐	☐	☐	
8. Being outside or doing activities outside	☐	☐	☐	
9. Taking care of yourself	☐	☐	☐	
10. Caring for family members	☐	☐	☐	
11. Doing household chores	☐	☐	☐	
12. Exercising	☐	☐	☐	
13. Using electronic devices (e.g., cell phone, iPad/tablet, computer)	☐	☐	☐	

16. **During the past month**, did you feel hindered from something that you wanted to do because of your TED? (Select one)

No, not at all hindered	Yes, a little hindered	Yes, severely hindered
☐	☐	☐

17. The next set of questions deal with your TED **over the past month**.

	No, not at all	Yes, a little	Yes, very much so	
1. Do you feel that your appearance has changed because of your TED?	☐	☐	☐	
2. Do you feel that you are stared at in the streets because of TED?	☐	☐	☐	
3. Do you feel that people react unpleasantly because of your TED?	☐	☐	☐	
4. Do you feel that your TED has an influence on your self-confidence?	☐	☐	☐	
5. Do you feel socially isolated because of your TED?	☐	☐	☐	
6. Do you feel that your TED has an influence on making friends?	☐	☐	☐	
7. Do you feel that you appear less often in photos than before you had TED?	☐	☐	☐	
8. Do you try to mask changes in appearance caused by your TED?	☐	☐	☐	
9. Do you try to avoid professional interactions because of your TED?	☐	☐	☐	
10. Do you avoid your family because of your TED?	☐	☐	☐	
11. Do you avoid your friends because of your TED?	☐	☐	☐	
12. Do you avoid intimacy because of your TED?	☐	☐	☐	
13. Do you feel that your TED keeps you from being the parent you want to be?	☐	☐	☐	☐ I do not have children

17a. **Over the past month**, how often did you have sensitivity to light?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

17b. **Over the past month**, what were the sources of your sensitivity to light? (Select all that apply)

1. Sunlight
2. Glare
3. Bright colors
4. Phone or tablet screens
5. Computer monitors or TV screens
6. Interior lights (e.g., overhead lighting, lamps, fluorescent lights)
7. Street lights
8. Car headlights
9. Other types of light

17c. **Over the past month**, how much impact did sensitivity to light have on your daily activities?

No impact	Little impact	Moderate impact	Major impact	Severe impact
☐	☐	☐	☐	☐

17d. Please rate the severity of your sensitivity to light at its worst **over the past month**.

Mild	Moderate	Severe	Very severe
☐	☐	☐	☐

18. Please think about your eye pain from TED. **Over the past month** ... (Select one per row)

	Had no pain	Mild	Moderate	Severe	Very severe
1. How intense was your eye pain on average?	☐	☐	☐	☐	☐
2. How intense was your eye pain at its worst?	☐	☐	☐	☐	☐

	No pain	Mild	Moderate	Severe	Very severe
3. What is your eye pain level right now?	☐	☐	☐	☐	☐

19. **Over the past month**, did you experience eye pain when you moved your eyes to look at different things? (Select one)

1. Yes
2. No

20. **Over the past month**, did you experience eye pain when you were not moving your eyes? For example, when your eyes were focused on one thing? (Select one)

1. Yes
2. No

The next set of questions focuses on the impact your TED may have on your sleep.

21. Please think back to the **majority of nights over the past month**. Please think about the quality of your sleep overall, such as how many hours of sleep you got, how easily you fell asleep, how often you woke up during the night (except to go to the bathroom), how often you woke up earlier than you had to in the morning, and how refreshing your sleep was. (Select one)

Terrible	Poor			Fair			Good			Excellent
0	1	2	3	4	5	6	7	8	9	10

22. How often **in the past month** did you: (Select one)

	Never	1-day per week	2 days per week	3-4 days per week	5-6 days per week	Every day
1. Have trouble falling asleep?	☐	☐	☐	☐	☐	☐
2. Wake up several times per night?	☐	☐	☐	☐	☐	☐
3. Have trouble staying asleep (including waking far too early)?	☐	☐	☐	☐	☐	☐

4. Wake up after your usual amount of sleep feeling tired or worn out?	☐	☐	☐	☐	☐	☐
5. Have trouble closing your eyes to sleep?	☐	☐	☐	☐	☐	☐

Please answer the next section of questions to help us appreciate how mood and emotions may be impacted by TED.

23. **Over the past month**, how often have you been bothered by any of the following problems?
(Select one per row)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	☐	☐	☐	☐
2. Feeling down, depressed, or hopeless	☐	☐	☐	☐
3. Trouble falling or staying asleep, or sleeping too much	☐	☐	☐	☐
4. Feeling tired or having little energy	☐	☐	☐	☐
5. Poor appetite or overeating	☐	☐	☐	☐
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	☐	☐	☐	☐
7. Trouble concentrating on things, such as reading the newspaper or watching television	☐	☐	☐	☐
8. 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	☐	☐	☐	☐
9. Thoughts that you would be better off dead or of hurting yourself in some way	☐	☐	☐	☐

The 988 Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals in the United States. Call or text 988.



24. **Over the past month**, 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
☐	☐	☐	☐

25. How often have you been bothered by the following problems **over the past month**? (Select one per row).

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	☐	☐	☐	☐
2. Not being able to stop or control worrying	☐	☐	☐	☐
3. Worrying too much about different things	☐	☐	☐	☐
4. Trouble relaxing	☐	☐	☐	☐
5. Being so restless that it is hard to sit still	☐	☐	☐	☐
6. Becoming easily annoyed or irritable	☐	☐	☐	☐
7. Feeling afraid, as if something awful might happen	☐	☐	☐	☐

26. **Over the past month**, 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
☐	☐	☐	☐

Now, we have some questions about how TED affects your health.

27. Please think about your overall health **over the past month** and select the option in each category that best describes it. (Select one in each section)

Mobility	
☐	I had no problems in walking
☐	I had slight problems in walking
☐	I had moderate problems in walking
☐	I had severe problems in walking
☐	I was unable to walk

Self-Care	
☐	I had no problems washing or dressing myself

☐	I had slight problems washing or dressing myself
☐	I had moderate problems washing or dressing myself
☐	I had severe problems washing or dressing myself
☐	I was unable to wash or dress myself

Usual Activities (e.g., work, study, housework, family, or leisure activities)	
☐	I had no problems doing my usual activities
☐	I had slight problems doing my usual activities
☐	I had moderate problems doing my usual activities
☐	I had severe problems doing my usual activities
☐	I was unable to do my usual activities

Pain/Discomfort	
☐	I had no pain or discomfort
☐	I had slight pain or discomfort
☐	I had moderate pain or discomfort
☐	I had severe pain or discomfort
☐	I had extreme pain or discomfort

Anxiety / Depression	
☐	I was not anxious or depressed
☐	I was slightly anxious or depressed
☐	I was moderately anxious or depressed
☐	I was severely anxious or depressed
☐	I was extremely anxious or depressed

28. We would like to know how good or bad your health has been **over the past month**. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Please click on the scale to indicate your health over the past month.

Your health over the past month

The best health you can imagine

100
95
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
The worst health you can imagine

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = 77

For example this response should be coded as 77

This next set of questions asks about the effect TED has had on your ability to work.

29. Are you currently working either full-time or part-time? (Select one)

1. Yes
2. No

30. Prior to having TED symptoms, were you working (full-time or part-time)? (Select one)

1. Yes
2. No

31. Did you stop working because of your TED symptoms? (Select one)

1. Yes
2. No

32. **During the past 7 days**, how many hours did you miss from work because of your TED? Include hours you missed on sick days, times you went in late, left early, etc. because of your TED (Specify)
1. _____ hours
33. **During the past 7 days**, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off? (Specify)
1. _____ hours
34. **During the past 7 days**, how many hours did you actually work? (Specify)
1. _____ hours
35. **During the past 7 days**, how much did your TED affect your productivity while you were working? (Select one)

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If your TED affected your work only a little, choose a low number. Choose a high number if TED affected your work a great deal.

TED had no effect on my work										TED completely prevented me from working
0	1	2	3	4	5	6	7	8	9	10

36. **During the past 7 days**, how much did your TED affect your ability to do your regular daily activities, other than work at a job? (Select one)

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If your TED affected your activities only a little, choose a low number. Choose a high number if TED affected your activities a great deal.

TED had no effect on my regular daily activities										TED completely prevented me from doing my regular daily activities
0	1	2	3	4	5	6	7	8	9	10

36a. When were your TED symptoms at their worst?

1. Over the past month
2. Prior to the past month

We would like to ask a set of questions about the impact of TED on your life when your symptoms were at their worst. This is an optional section of the survey, and you will receive your full honorarium even if you choose to skip it.

37. Would you like to answer this set of questions about the impact of TED on your life when your symptoms were at their worst? (Select one)

1. Yes
2. No

38. How severe were your TED symptoms when they were **at their worst**? (Select one)

1. Mild
2. Moderate
3. Severe

39. Earlier in the survey, you indicated you had experienced the following symptoms of TED. **At their worst**, how bothersome were each of these symptoms? (Select one per row)

Not at all	Slightly bothersome	Moderately bothersome	Very bothersome	Extremely bothersome
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐

40. **When your TED symptoms were at their worst**, to what extent were you limited in carrying out the following activities, because of your TED? (Select one per row)

	No, not at all limited	Yes, a little limited	Yes, seriously limited	
1. Bicycling	☐	☐	☐	☐ Never learned to ride bike
2. Driving	☐	☐	☐	☐ No driver's license
3. Moving around the house	☐	☐	☐	
4. Walking outdoors	☐	☐	☐	
5. Reading	☐	☐	☐	
6. Watching TV	☐	☐	☐	
7. Hobby or pastime	☐	☐	☐	
8. Being outside or doing activities outside	☐	☐	☐	
9. Taking care of yourself	☐	☐	☐	
10. Caring for family members	☐	☐	☐	
11. Doing household chores	☐	☐	☐	
12. Exercising	☐	☐	☐	
13. Using electronic devices (e.g., cell phone, iPad/tablet, computer)	☐	☐	☐	

41. **When your TED symptoms were at their worst**, did you feel hindered from something that you wanted to do because of your TED? (Select one)

No, not at all hindered	Yes, a little hindered	Yes, severely hindered
☐	☐	☐

42. The next set of questions deal with your TED **when your symptoms were at their worst**.

	No, not at all	Yes, a little	Yes, very much so	
1. Did you feel that your appearance had changed because of your TED?	☐	☐	☐	
2. Did you feel that you were stared at in the streets because of TED?	☐	☐	☐	
3. Did you feel that people reacted unpleasantly because of your TED?	☐	☐	☐	
4. Did you feel that your TED had an influence on your self-confidence?	☐	☐	☐	
5. Did you feel socially isolated because of your TED?	☐	☐	☐	
6. Did you feel that your TED had an influence on making friends	☐	☐	☐	
7. Did you feel that you appeared less often on photos than before you had TED?	☐	☐	☐	
8. Did you try to mask changes in appearance caused by your TED?	☐	☐	☐	
9. Did you try to avoid professional interactions because of your TED?	☐	☐	☐	
10. Did you avoid your family because of your TED?	☐	☐	☐	
11. Did you avoid your friends because of your TED?	☐	☐	☐	
12. Did you avoid intimacy because of your TED?	☐	☐	☐	
13. Did you feel that your TED kept you from being the parent you want to be?	☐	☐	☐	☐ I do not have children

43. How intense was your eye pain **when your TED symptoms were at their worst**? Select one)

Had no pain	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐

44. Please think back to the **majority of nights when your TED symptoms were at their worst.**

Please think about the **quality of your sleep** overall, such as how many hours of sleep you got, how easily you fell asleep, how often you woke up during the night (except to go to the bathroom), how often you woke up earlier than you had to in the morning, and how refreshing your sleep was. (Select one)

Terrible	Poor			Fair			Good			Excellent
0	1	2	3	4	5	6	7	8	9	10

45. **When your TED symptoms were at their worst**, how often did you: (Select one)

	Never	1-day per week	2 days per week	3-4 days per week	5-6 days per week	Every day
1. Have trouble falling asleep?	☐	☐	☐	☐	☐	☐
2. Wake up several times per night?	☐	☐	☐	☐	☐	☐
3. Have trouble staying asleep (including waking far too early)?	☐	☐	☐	☐	☐	☐
4. Wake up after your usual amount of sleep feeling tired or worn out?	☐	☐	☐	☐	☐	☐
5. Have trouble closing your eyes to sleep?	☐	☐	☐	☐	☐	☐

46. Please think about your overall health **when your TED symptoms were at their worst** and select the option in each category that best describes it. (Select one in each section)

Mobility	
☐	I had no problems in walking
☐	I had slight problems in walking
☐	I had moderate problems in walking
☐	I had severe problems in walking
☐	I was unable to walk

Self-Care	
☐	I had no problems washing or dressing myself
☐	I had slight problems washing or dressing myself
☐	I had moderate problems washing or dressing myself
☐	I had severe problems washing or dressing myself
☐	I was unable to wash or dress myself

Usual Activities (e.g., work, study, housework, family, or leisure activities)	
☐	I had no problems doing my usual activities
☐	I had slight problems doing my usual activities
☐	I had moderate problems doing my usual activities
☐	I had severe problems doing my usual activities
☐	I was unable to do my usual activities

Pain/Discomfort	
☐	I had no pain or discomfort
☐	I had slight pain or discomfort
☐	I had moderate pain or discomfort
☐	I had severe pain or discomfort
☐	I had extreme pain or discomfort

Anxiety / Depression	
☐	I was not anxious or depressed
☐	I was slightly anxious or depressed
☐	I was moderately anxious or depressed
☐	I was severely anxious or depressed
☐	I was extremely anxious or depressed

47. We would like to know how good or bad your health was **when your TED symptoms were at their worst**. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Please click on the scale to indicate your health **when your TED symptoms were at their worst**.

____ Your health when your TED symptoms were at their worst

The best health you can imagine

100
95
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
The worst health you can imagine

For example this response should be coded as 77

YOUR HEALTH TODAY = 77

Now, we are going to ask you questions about your treatment goals and the way you treat your TED today.

48. What are your most important treatment goals for your TED? Please rank up to 5 goals with 1 = Most important and 5=Least important.
1. Improve your appearance
 2. Improve how your eyes feel
 3. Improve your vision
 4. Improve your sleep
 5. Improve your ability to do daily activities
 6. Improve your sensitivity to light
 7. Improve your social relationships
 8. Improve your intimate relationships
49. Which of the following treatments are you **currently taking** for your TED? (Select all that apply)
1. Over-the-counter lubricating eye drops
 2. Prescription lubricating eye drops
 3. Steroid eye drops
 4. Oral steroids
 5. IV steroids

6. Subconjunctival steroids
7. Actemra® (tocilizumab)
8. Cyclosporine/azathioprine
9. Mycophenolate
10. Rituxan® (rituximab)
11. Selenium
12. Tepezza® (teprotumumab)
13. Other therapy
14. No treatment

50. Which of the following treatments have you **previously taken for your TED, but no longer take?** (Select all that apply)

1. Over-the-counter lubricating eye drops
2. Prescription lubricating eye drops
3. Steroid eye drops
4. Oral steroids
5. IV steroids
6. Subconjunctival steroids
7. Actemra® (tocilizumab)
8. Cyclosporine/azathioprine
9. Mycophenolate
10. Rituxan® (rituximab)
11. Selenium
12. Tepezza® (teprotumumab)
13. Other therapy
14. I have not stopped taking any TED treatments

51. Have you ever had the following procedures for your TED? (Select one per row)

	Yes	No
1. Orbital radiotherapy	☐	☐
2. Other eye surgeries or procedures	☐	☐

52. Overall, how satisfied have you been with each of these **treatments** for your TED? (Select one)

Not at all	Slightly	Moderately	Very	Extremely
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐
☐	☐	☐	☐	☐

53. How worried are you, if at all, about your TED symptoms returning or getting worse? (Select one)

Not at all	Slightly	Moderately	Very	Extremely
☐	☐	☐	☐	☐

54. Overall, how satisfied are you with the care you are receiving from your current doctors for your TED? (Select one)

Not at all	Slightly	Moderately	Very	Extremely
☐	☐	☐	☐	☐

55. Which of the following would you like to discuss more with your doctors? (Select all that apply)

1. TED symptoms
2. Your overall quality of life
3. Your overall ability to do the day-to-day things you want to do
4. Your ability to be outdoors
5. Your satisfaction with your appearance
6. Your self-confidence
7. The quality of your family relationships
8. The quality of your social relationships
9. The quality of your professional relationships
10. Your sex life
11. Your eye pain
12. The quality of your sleep
13. Feelings of depression
14. Feelings of anxiety
15. Your productivity
16. Other (Specify)
17. None of the above

Please imagine there are new treatments for your TED in the future.

56. What are the most important symptoms for a new treatment for TED to address? Please rank order up to 5 symptoms with "1" being most important. (Select up to 5)

☐	1	Dry/gritty eyes	☐	10	Blurred vision
☐	2	Itchy eyes	☐	11	Eyelid swelling or puffiness
☐	3	Sensitivity to light	☐	12	Inability to close eyelid
☐	4	Bulging eyes	☐	13	Pulled back eyelids (eyelid retraction)
☐	5	Pressure or pain around or behind eye	☐	14	Eyes that aim different directions or misaligned eyes
☐	6	Tearing or watery eyes	☐	15	Color vision loss
☐	7	Red, swollen, or burning eyes	☐	16	Sense that you can feel your eyes
☐	8	Double vision	☐	17	Deep ache behind your eyes
☐	9	Change in appearance*			

57. How would you prefer to take a new treatment for your TED? Please rank order the following options with 1 being your most preferred and 3 being your least preferred option. (Rank order up to 3)

1. Oral pill taken twice per day for 6 months
2. 4-8 **self-administered** subcutaneous injections (under the skin) over the course of 6 months
3. 4-8 **doctor-administered** subcutaneous injections (under the skin) over the course of 6 months
4. 4-8 intravenous infusions (into a vein) over the course of 6 months

58. For a new treatment given subcutaneously (under the skin), would you prefer to administer it at home or in your doctor's office?

1. At home by yourself
2. Physician's office with the help of a healthcare provider
3. No preference
4. I would not take a subcutaneous treatment

59. How familiar are you with the following pharmaceutical companies? (Select one per row)

	Not at all	Slightly	Moderately	Very	Extremely
1. Horizon	☐	☐	☐	☐	☐
2. Sling	☐	☐	☐	☐	☐
3. Viridian	☐	☐	☐	☐	☐
4. Roche	☐	☐	☐	☐	☐
5. Amgen	☐	☐	☐	☐	☐
6. Acelyrin	☐	☐	☐	☐	☐
7. Immunovant	☐	☐	☐	☐	☐
8. Tourmaline	☐	☐	☐	☐	☐
9. Argenx	☐	☐	☐	☐	☐

In closing, we have a few demographic questions.

60. How would you describe the area where you live? (Select one)

1. Urban
2. Suburban
3. Rural

61. How far (in minutes) do you have to travel to see the physician who treats your TED? (Specify)

1. ____ minutes

62. What type of health insurance do you have? (Select all that apply)

1. Medicare
 - i. Do you have one of these types of Medicare? (Select one)
 1. Medicare Advantage
 2. Original Medicare (Fee for service Medicare)
 - a. Do you have Medicare Supplement Insurance or a MediGap plan?
 - i. Yes
 - ii. No
 - b. Do you have Medicare Part D (prescription drug coverage)?
 - i. Yes
 - ii. No
 3. Don't know
 2. Private or commercial health insurance
 3. Military/VA/DoD (Tricare)
 4. Medicaid
 5. Uninsured
 6. Other (specify)
 7. Prefer not to respond

63. What is your household income before taxes? (Select one)

1. Less than \$50,000
2. \$50,000 \$99,999
3. \$100,000 to \$199,999
4. \$200,000 or more
5. Prefer not to respond