

## Supplementary Online Content

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This supplementary material has been provided by the authors to give readers additional information about their work.

**eFigure. Health State Development and Validation Process**



TED: thyroid eye disease; TTO: time trade-off

**eTable 1. Demographic Characteristics of the Study Population (n=111)**

Characteristics	Study population (n=111)	Percentage	US demographics
<b>Region</b>			
Midwest	19	17.12%	-
North east	34	30.63%	-
South	36	32.43%	-
West	22	19.82%	-
<b>Age (years)</b>			
25–34	6	5.41%	18.15% <sup>1</sup>
35–44	17	15.32%	16.95%
45–54	22	19.82%	16.65%
55–64	47	42.34%	17.15%
65–74	19	17.12%	13.85%
<b>Gender</b>			
Female	75	67.57%	49.5% <sup>1</sup>
Male	36	32.43%	50.5%
<b>Marital status</b>			
Divorced	18	16.22%	10.9% <sup>2</sup>
Married	64	57.66%	47.6%
Single	26	23.42%	33.9%
Widowed	3	2.70%	5.8%
<b>Ethnicity</b>			
Asian	4	3.60%	5.35% <sup>3</sup>
Black/ African American	11	9.91%	12.85%
Hispanic	4	3.60%	17.95%
White	92	82.88%	59.55%
<b>Highest level of education</b>			
Bachelor’s degree	44	39.64%	28.00% <sup>4</sup>
Doctorate degree	4	3.60%	6.80% <sup>5</sup>
Highschool diploma	18	16.22%	33.60% <sup>4</sup>
Master’s degree	27	24.32%	11.90% <sup>5</sup>
Vocational training	18	16.22%	14.00% <sup>6</sup>
<b>Employment status</b>			
Retired	19	17.12%	28.74% <sup>7</sup>
Self employed	11	9.91%	10.34% <sup>8</sup>
Unemployed	18	16.22%	7.84% <sup>9</sup>
Working full time	46	41.44%	41.44% <sup>10</sup>
Working part time	17	15.32%	11.64% <sup>10</sup>
<b>Household income</b>			
\$10,000–\$14,999	6	5.41%	4.8% <sup>11</sup>
\$15,000–\$24,999	4	27.93%	9.1%
\$25,000–\$34,999	6	3.60%	9.2%
\$35,000–\$49,000	14	5.41%	12.7%
\$50,000–\$74,999	32	12.61%	18.3%
\$75,000–\$99,999	18	28.83%	13.6%
\$100,000 and over	31	16.22%	32.3%
<b>Wears glasses or contact lenses</b>			
No	21	18.92%	25% <sup>12</sup>

Characteristics	Study population (n=111)	Percentage	US demographics
Yes	90	81.18%	75%
<b>Vision impairment diagnosis</b>			
No	65	58.56%	96.4% <sup>13</sup>
Yes*	46	41.44%	3.6%
<b>Smoking status</b>			
Current smoker	15	13.51%	NR
Ex-smoker	31	27.93%	NR
Never smoked	65	58.56%	NR

No participants participated in market research the prior past three months or were employed or have family employed in healthcare or market research. NR: not reported.

\*A total of 19 participants (17%) reported vision impairment with long or short sightedness.

**eTable 2. Utility Values for Each Health State by Ethnicity**  
**Subgroups analyzed with the Kruskal-Wallis test**

Health state	Ethnicity	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	Asian	4	0.34	0.42	0.25	0.00	0.88
	Black or African American	11	0.48	0.42	0.48	0.03	1.00
	Hispanics	4	0.40	0.44	0.30	0.03	0.98
	White	92	0.64	0.31	0.71	0.03	1.00
No diplopia and large proptosis	Asian	4	0.18	0.22	0.14	0.00	0.45
	Black or African American	11	0.46	0.36	0.48	0.03	1.00
	Hispanics	4	0.31	0.36	0.21	0.03	0.78
	White	92	0.48	0.31	0.40	0.00	1.00
Intermittent or inconstant diplopia and small proptosis	Asian	4	0.08	0.16	0.00	0.00	0.33
	Black or African American	11	0.39	0.40	0.38	0.03	1.00
	Hispanics	4	0.12	0.14	0.06	0.03	0.33
	White	92	0.57	0.31	0.59	0.00	1.00
Intermittent or inconstant diplopia and large proptosis	Asian	4	0.06	0.11	0.00	0.00	0.23
	Black or African American	11	0.51	0.38	0.48	0.03	1.00
	Hispanics	4	0.18	0.21	0.11	0.03	0.48
	White	92	0.44	0.32	0.39	0.00	1.00
Constant diplopia and small proptosis	Asian	4	0.22	0.44	0.00	0.00	0.88
	Black or African American	11	0.35	0.40	0.08	0.00	1.00
	Hispanics	4	0.13	0.21	0.03	0.03	0.45
	White	92	0.36	0.29	0.34	0.00	1.00
Constant diplopia and large proptosis	Asian	4	0.17	0.34	0.00	0.00	0.68
	Black or African American	11	0.40	0.45	0.03	0.00	1.00
	Hispanics	4	0.04	0.03	0.03	0.03	0.08
	White	92	0.31	0.29	0.25	0.00	1.00

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**Table 3.** Utility Values for Each Health State by Annual Household Income

Health state	Annual household income	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	\$10,000 to \$14,999	6	0.69	0.37	0.85	0.03	0.98
	\$100,000 and over	31	0.65	0.34	0.78	0.03	1.00
	\$15,000 to \$24,999	4	0.47	0.50	0.44	0.03	1.00
	\$25,000 to \$34,999	6	0.62	0.41	0.69	0.03	1.00
	\$35,000 to \$49,000	14	0.58	0.27	0.61	0.20	0.93
	\$50,000 to \$74,999	32	0.56	0.35	0.53	0.00	1.00
	\$75,000 to \$99,999	18	0.62	0.32	0.70	0.00	1.00
No diplopia and large proptosis	\$10,000 to \$14,999	6	0.60	0.28	0.49	0.35	0.98
	\$100,000 and over	31	0.50	0.31	0.43	0.03	1.00
	\$15,000 to \$24,999	4	0.50	0.52	0.49	0.03	1.00
	\$25,000 to \$34,999	6	0.44	0.33	0.42	0.03	0.90
	\$35,000 to \$49,000	14	0.40	0.26	0.35	0.00	0.88
	\$50,000 to \$74,999	32	0.41	0.33	0.38	0.00	1.00
	\$75,000 to \$99,999	18	0.50	0.31	0.43	0.00	1.00
Intermittent or inconstant diplopia and small proptosis	\$10,000 to \$14,999	6	0.58	0.35	0.55	0.03	0.98
	\$100,000 and over	31	0.57	0.33	0.63	0.03	1.00
	\$15,000 to \$24,999	4	0.52	0.50	0.54	0.03	1.00
	\$25,000 to \$34,999	6	0.51	0.29	0.52	0.03	0.83
	\$35,000 to \$49,000	14	0.43	0.26	0.43	0.01	0.88
	\$50,000 to \$74,999	32	0.48	0.34	0.49	0.00	1.00
	\$75,000 to \$99,999	18	0.53	0.37	0.58	0.00	1.00
Intermittent or inconstant diplopia and large proptosis	\$10,000 to \$14,999	6	0.52	0.36	0.44	0.03	0.98
	\$100,000 and over	31	0.44	0.33	0.35	0.01	1.00
	\$15,000 to \$24,999	4	0.71	0.43	0.89	0.08	1.00
	\$25,000 to \$34,999	6	0.49	0.32	0.53	0.03	0.95
	\$35,000 to \$49,000	14	0.43	0.28	0.36	0.00	0.88
	\$50,000 to \$74,999	32	0.39	0.33	0.38	0.00	1.00
	\$75,000 to \$99,999	18	0.34	0.35	0.29	0.00	1.00
Constant diplopia and small proptosis	\$10,000 to \$14,999	6	0.48	0.38	0.39	0.03	0.98
	\$100,000 and over	31	0.34	0.30	0.20	0.00	0.95
	\$15,000 to \$24,999	4	0.47	0.50	0.44	0.03	1.00
	\$25,000 to \$34,999	6	0.31	0.28	0.32	0.00	0.70
	\$35,000 to \$49,000	14	0.40	0.28	0.39	0.00	0.88
	\$50,000 to \$74,999	32	0.33	0.29	0.29	0.00	1.00
	\$75,000 to \$99,999	18	0.28	0.32	0.14	0.00	1.00
Constant diplopia and large proptosis	\$10,000 to \$14,999	6	0.59	0.40	0.61	0.03	0.98
	\$100,000 and over	31	0.25	0.28	0.18	0.00	0.95
	\$15,000 to \$24,999	4	0.44	0.49	0.36	0.03	1.00
	\$25,000 to \$34,999	6	0.25	0.21	0.28	0.00	0.53
	\$35,000 to \$49,000	14	0.32	0.27	0.28	0.00	0.88
	\$50,000 to \$74,999	32	0.26	0.27	0.21	0.00	1.00
	\$75,000 to \$99,999	18	0.35	0.36	0.25	0.00	1.00

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 4.** Utility Values for Each Health State in Participants With or Without Glasses

Health state	Wears glasses	N	Mean	SD	Median	Lower CI	Upper CI		
No diplopia and small proptosis	No	21	0.57	0.30	0.53	0.03	1.00		
	Yes	90	0.61	0.35	0.70	0.00	1.00		
No diplopia and large proptosis	No	21	0.42	0.27	0.38	0.00	1.00		
	Yes	90	0.47	0.33	0.44	0.00	1.00		
Intermittent or inconstant diplopia and small proptosis	No	21	0.53	0.26	0.53	0.03	1.00		
	Yes	90	0.51	0.35	0.50	0.00	1.00		
Intermittent or inconstant diplopia and large proptosis	No	21	0.43	0.29	0.48	0.00	1.00		
	Yes	90	0.42	0.34	0.35	0.00	1.00		
Constant diplopia and small proptosis	No	21	0.42	0.26	0.43	0.00	1.00		
	Yes	90	0.33	0.32	0.23	0.00	1.00		
Constant diplopia and large proptosis	No	21	0.31	0.25	0.28	0.00	1.00		
	Yes	90	0.30	0.32	0.20	0.00	1.00		

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 5.** Utility Values for Each Health State by Employment Status

Health state	Employment status	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	Retired	19	0.63	0.29	0.70	0.08	1.00
	Self employed	11	0.62	0.40	0.80	0.00	0.98
	Unemployed	18	0.75	0.30	0.89	0.03	1.00
	Working full time	46	0.53	0.34	0.50	0.03	1.00
	Working part time	17	0.61	0.34	0.73	0.03	0.98
No diplopia and large proptosis	Retired	19	0.43	0.37	0.40	0.00	1.00
	Self employed	11	0.49	0.34	0.70	0.00	0.98
	Unemployed	18	0.57	0.33	0.53	0.03	1.00
	Working full time	46	0.42	0.28	0.39	0.01	1.00
	Working part time	17	0.48	0.31	0.38	0.00	0.98
Intermittent or inconstant diplopia and small proptosis	Retired	19	0.48	0.32	0.53	0.00	1.00
	Self employed	11	0.57	0.37	0.73	0.00	0.98
	Unemployed	18	0.61	0.33	0.63	0.00	1.00
	Working full time	46	0.47	0.34	0.43	0.00	1.00
	Working part time	17	0.55	0.31	0.55	0.03	0.98
Intermittent or inconstant diplopia and large proptosis	Retired	19	0.44	0.35	0.40	0.00	1.00
	Self employed	11	0.43	0.33	0.43	0.00	0.98
	Unemployed	18	0.57	0.33	0.48	0.00	1.00
	Working full time	46	0.35	0.32	0.34	0.00	1.00
	Working part time	17	0.47	0.31	0.38	0.00	0.95
Constant diplopia and small proptosis	Retired	19	0.40	0.35	0.28	0.00	1.00
	Self employed	11	0.38	0.30	0.45	0.00	0.98
	Unemployed	18	0.50	0.35	0.45	0.00	1.00
	Working full time	46	0.24	0.24	0.13	0.00	0.93

Health state	Employment status	N	Mean	SD	Median	Lower CI	Upper CI
	Working part time	17	0.38	0.31	0.35	0.00	0.89
Constant diplopia and large proptosis	Retired	19	0.31	0.35	0.23	0.00	1.00
	Self employed	11	0.33	0.29	0.35	0.00	0.98
	Unemployed	18	0.49	0.35	0.49	0.00	1.00
	Working full time	46	0.21	0.25	0.12	0.00	0.90
	Working part time	17	0.32	0.28	0.28	0.01	0.90

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 6.** Utility Values for Each Health State by Age

Health state	Age	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	25-34 years old	6	0.56	0.45	0.65	0.03	1.00
	35-44 years old	17	0.52	0.30	0.48	0.03	1.00
	45-54 years old	22	0.62	0.32	0.65	0.03	1.00
	55-64 years old	47	0.65	0.34	0.73	0.00	1.00
	65-74 years old	19	0.56	0.35	0.65	0.00	1.00
No diplopia and large proptosis	25-34 years old	6	0.35	0.26	0.44	0.03	0.60
	35-44 years old	17	0.37	0.26	0.35	0.03	1.00
	45-54 years old	22	0.52	0.28	0.54	0.03	0.95
	55-64 years old	47	0.50	0.33	0.48	0.00	1.00
	65-74 years old	19	0.41	0.37	0.28	0.00	0.95
Intermittent or inconstant diplopia and small proptosis	25-34 years old	6	0.48	0.43	0.48	0.03	1.00
	35-44 years old	17	0.46	0.29	0.45	0.03	1.00
	45-54 years old	22	0.52	0.31	0.55	0.00	1.00
	55-64 years old	47	0.56	0.35	0.63	0.00	1.00
	65-74 years old	19	0.46	0.33	0.53	0.00	0.90
Intermittent or inconstant diplopia and large proptosis	25-34 years old	6	0.36	0.36	0.31	0.03	1.00
	35-44 years old	17	0.36	0.34	0.23	0.00	1.00
	45-54 years old	22	0.37	0.30	0.35	0.00	1.00
	55-64 years old	47	0.46	0.34	0.43	0.00	1.00
	65-74 years old	19	0.47	0.32	0.48	0.00	0.95
Constant diplopia and small proptosis	25-34 years old	6	0.24	0.24	0.20	0.03	0.50
	35-44 years old	17	0.40	0.32	0.38	0.00	1.00
	45-54 years old	22	0.33	0.28	0.35	0.00	0.95
	55-64 years old	47	0.32	0.33	0.20	0.00	1.00
	65-74 years old	19	0.39	0.31	0.40	0.00	0.89
Constant diplopia and large proptosis	25-34 years old	6	0.19	0.20	0.13	0.03	0.50
	35-44 years old	17	0.29	0.29	0.25	0.01	1.00
	45-54 years old	22	0.39	0.33	0.35	0.00	0.95
	55-64 years old	47	0.29	0.32	0.20	0.00	1.00
	65-74 years old	19	0.28	0.28	0.23	0.00	0.90

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 7.** Utility Values for Each Health State by Vision Impairment Diagnosis

Health state	Vision impairment diagnosis	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	No	65	0.61	0.33	0.70	0.00	1.00
	Yes	46	0.59	0.34	0.69	0.00	1.00
No diplopia and large proptosis	No	65	0.49	0.31	0.40	0.00	1.00
	Yes	46	0.43	0.33	0.38	0.00	1.00
Intermittent or inconstant diplopia and small proptosis	No	65	0.55	0.33	0.53	0.00	1.00
	Yes	46	0.47	0.33	0.43	0.00	1.00
Intermittent or inconstant diplopia and large proptosis	No	65	0.46	0.34	0.48	0.00	1.00
	Yes	46	0.37	0.31	0.30	0.00	1.00
Constant diplopia and small proptosis	No	65	0.36	0.31	0.38	0.00	1.00
	Yes	46	0.32	0.31	0.23	0.00	1.00
Constant diplopia and large proptosis	No	65	0.33	0.31	0.28	0.00	1.00
	Yes	46	0.25	0.30	0.16	0.00	1.00

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 8.** Utility Values for Each Health State by Smoking Status

Health state	Smoking status	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	Current smoker	15	0.60	0.34	0.65	0.03	1.00
	Ex-smoker	31	0.61	0.32	0.70	0.00	1.00
	Never smoked	65	0.60	0.35	0.68	0.00	1.00
No diplopia and large proptosis	Current smoker	15	0.33	0.28	0.35	0.00	1.00
	Ex-smoker	31	0.44	0.31	0.40	0.00	1.00
	Never smoked	65	0.51	0.32	0.48	0.00	1.00
Intermittent or inconstant diplopia and small proptosis	Current smoker	15	0.42	0.28	0.43	0.00	1.00
	Ex-smoker	31	0.49	0.33	0.48	0.00	1.00
	Never smoked	65	0.55	0.34	0.60	0.00	1.00
Intermittent or inconstant diplopia and large proptosis	Current smoker	15	0.34	0.27	0.35	0.00	1.00
	Ex-smoker	31	0.37	0.30	0.31	0.00	1.00
	Never smoked	65	0.47	0.35	0.43	0.00	1.00
Constant diplopia and small proptosis	Current smoker	15	0.26	0.27	0.20	0.00	1.00
	Ex-smoker	31	0.28	0.30	0.20	0.00	1.00
	Never smoked	65	0.39	0.31	0.38	0.00	1.00
Constant diplopia and large proptosis	Current smoker	15	0.28	0.32	0.20	0.00	1.00
	Ex-smoker	31	0.25	0.28	0.20	0.00	1.00
	Never smoked	65	0.33	0.31	0.28	0.00	1.00

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.



**eTable 9.** Utility Values for Each Health State by Gender

Health state	Gender	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	Female	75	0.61	0.34	0.73	0.00	1.00
	Male	36	0.59	0.34	0.66	0.03	1.00
No diplopia and large proptosis	Female	75	0.45	0.31	0.4	0	1
	Male	36	0.48	0.32	0.46	0	1
Intermittent or inconstant diplopia and small proptosis	Female	75	0.51	0.33	0.5	0	1
	Male	36	0.53	0.33	0.53	0	1
Intermittent or inconstant diplopia and large proptosis	Female	75	0.40	0.33	0.35	0	1
	Male	36	0.48	0.33	0.43	0	1
Constant diplopia and small proptosis	Female	75	0.32	0.31	0.28	0	1
	Male	36	0.39	0.30	0.39	0	1
Constant diplopia and large proptosis	Female	75	0.29	0.31	0.23	0	1
	Male	36	0.33	0.31	0.23	0	1

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 10.** Utility Values for Each Health State by Education Level

Health state	Education level	N	Mean	SD	Median	Lower CI	Upper CI
No diplopia and small proptosis	Bachelor's degree	44	0.67	0.32	0.80	0.03	1.00
	Doctorate degree	4	0.85	0.23	0.96	0.50	0.98
	High school diploma	18	0.58	0.33	0.61	0.03	1.00
	Master's degree	27	0.43	0.35	0.43	0.00	1.00
	Vocational training	18	0.67	0.31	0.69	0.03	1.00
No diplopia and large proptosis	Bachelor's degree	44	0.46	0.30	0.40	0.00	1.00
	Doctorate degree	4	0.83	0.25	0.95	0.45	0.95
	High school diploma	18	0.43	0.31	0.34	0.03	1.00
	Master's degree	27	0.38	0.32	0.38	0.00	0.95
	Vocational training	18	0.54	0.31	0.48	0.00	1.00
Intermittent or inconstant diplopia and small proptosis	Bachelor's degree	44	0.54	0.31	0.61	0.00	1.00
	Doctorate degree	4	0.70	0.47	0.91	0.00	0.98
	High school diploma	18	0.48	0.28	0.45	0.03	1.00
	Master's degree	27	0.44	0.35	0.38	0.00	1.00
	Vocational training	18	0.56	0.37	0.51	0.01	1.00
Intermittent or inconstant diplopia and large proptosis	Bachelor's degree	44	0.41	0.34	0.33	0.00	1.00
	Doctorate degree	4	0.72	0.48	0.95	0.00	0.98
	High school diploma	18	0.49	0.32	0.44	0.00	1.00
	Master's degree	27	0.32	0.29	0.31	0.00	0.93
	Vocational training	18	0.49	0.30	0.48	0.00	1.00
Constant diplopia and small proptosis	Bachelor's degree	44	0.32	0.28	0.28	0.00	1.00
	Doctorate degree	4	0.69	0.46	0.91	0.00	0.95
	High school diploma	18	0.36	0.31	0.29	0.00	1.00
	Master's degree	27	0.30	0.28	0.20	0.00	0.80
	Vocational training	18	0.39	0.35	0.39	0.00	1.00
Constant diplopia and large proptosis	Bachelor's degree	44	0.28	0.27	0.26	0.00	1.00
	Doctorate degree	4	0.69	0.46	0.90	0.00	0.95
	High school diploma	18	0.35	0.29	0.28	0.00	1.00
	Master's degree	27	0.18	0.23	0.05	0.00	0.80
	Vocational training	18	0.41	0.38	0.29	0.00	1.00

Scores rounded to 2 decimal places. CI: confidence interval; N: total number of respondents; SD: standard deviation.

**eTable 11.** Comparison of VAS Scores for Each Health State vs US General Population VAS

State	Mean VAS (n = 111)	US general population VAS (n = 1134)	Difference to US general population	Lower CI-upper CI	P value
No diplopia and small proptosis (<3 mm)	51.71	80.4	28.69	47.67-55.74	<.001
No diplopia and large proptosis (≥3 mm)	38.95		41.45	35.64-42.27	<.001
Intermittent or inconstant diplopia and small proptosis (<3 mm)	45.38		35.02	42.04-48.71	<.001
Intermittent or inconstant diplopia and large proptosis (≥3 mm)	36.52		43.88	33.11-39.94	<.001
Constant diplopia and small proptosis (<3 mm)	30.56		49.84	27.20-33.91	<.001
Constant diplopia and large proptosis (≥3 mm)	27.42		52.98	24.40-30.44	<.001

Abbreviation: VAS, Visual Analog Scales.

Scores rounded to 2 decimal places. 0: worst health; 100: perfect health.

## eAppendix 1. Interview Guide Example Questions

### General Questions about TED

#### 1. How did you first get diagnosed with thyroid eye disease?

- > *When did you get diagnosed?*
- > *What symptoms led you to seeing a doctor?*
- > *How long did you experience the symptoms prior to a formal diagnosis?*
- > *How many doctors did you visit about your symptoms prior to receiving a formal diagnosis?*
- > *What type of doctor diagnosed you, and what types of tests were performed?*
- > *How did you feel about the diagnosis?*

### Impact of proptosis on patients QoL

#### 2. How would you describe proptosis to someone who has never experienced it?

#### 3. How would your doctor/HCP describe the degree or size of your proptosis?

- > *Do they describe it as large or small?*
- > *How do you perceive it?*

#### 4. What symptom or sign of proptosis do you feel most influences the severity of your disease?

- > *How bothersome would you consider this would be at its worst?*
- > *How bothersome would you consider this would be at its best?*

- > *How bothersome would you consider this would be on average?*

### **Impact of Diplopia on patient's QoL**

- 5. Are there any other words or terms you would use to describe diplopia?**
- 6. How would you describe diplopia to someone who has never experienced it?**
- 7. How would your doctor/HCP describe the degree of your diplopia?**
  - > *How do you perceive it?*
- 8. What symptom or sign of diplopia do you feel most influences the severity of your disease?**
  - > *How bothersome would you consider this would be at its worst?*
  - > *How bothersome would you consider this would be at its best?*
  - > *How bothersome would you consider this would be on average?*

### **Impact of proptosis and diplopia combined on patients QoL**

- 9. How much does both proptosis and diplopia play a role in your experience of thyroid eye disease?**
  - > *Would you consider both proptosis and diplopia to be “Not at all important,” “A little important,” “Somewhat important,” or “Extremely important” to your thyroid eye disease experience? **Probe to explain why.***
  - > *Is the burden greater when both of these symptoms are experienced together?*

## **eAppendix 2. Large Proptosis and Constant Diplopia Description With Pictures<sup>14</sup>**

### **Description of Health State of Large Proptosis with Constant Diplopia**

- > Your eyes are **sore and painful, red, itchy and irritated.**
- > You **continuously see two images instead of one.** This can be side by side, up and down, diagonal, or the images can blur together.
- > You **constantly experience double vision throughout the day,** mostly but also at night. This makes you **feel nauseous and dizzy all the time.** You also experience **constant headaches.**
- > You always feel your eyes are stuck looking in the wrong direction, so you have to rub your eyes to try and get them in line.
- > You are **constantly aware** of how your double vision impairs your life. When double vision constantly occurs, it **disrupts you from what you are doing or thinking.** It takes away your vision and your sense of where you are. You are exhausted from trying to think about what you're actually seeing. For example, when you are surrounded by people picking up a glass

of drink, you can't figure out whether you are really touching the glass or to the left or the right of it. As a result, you feel uncomfortable leaving your home or going new places.

- > You find it's **difficult to use your phone every time** due to the bright lights and seeing double images of words and numbers.
- > At home, you are finding it **difficult to do basic things**. You can't keep track of words when reading, measure water for cooking, do laundry, handle the TV remote or walk without hitting obstacles. As a result, you feel you can no longer take care of yourself or loved ones and your family has to step in to help you. You feel angry and depressed at **losing your independence, identity and sense of control**.
- > You **frequently have to depend on others** to take you where you need to go because you find it extremely difficult to drive or walk safely (e.g. doctor's appointments).
- > With constant double vision, **your depth perception is vastly different**. You can no longer tell what lane cars are coming in and everything looks out of focus. You are **afraid** that you may get yourself or others into an **accident** as a result of driving, so you **hardly or do not drive anymore and rely on others for transportation** instead.
- > You are **unable to take part in leisure activities**, such as exercising, playing games or watching movies. You feel sad because the constant double vision **stops you from doing what you love**, as well as activities that are important for you to spend time with your friends and family.
- > As double vision is associated with the eyes not lining up properly, people may react differently to you because they're not sure which eye you're looking at them with.
- > You are worried **you cannot do your job properly** because you're unable to focus and keep up with the tasks. You **find it is difficult** to read your computer screen or documents, so you must take regular breaks and rest your eyes. You **think about taking time off from work**, but you are aware your job is important for you to earn your living, so you continue to work even if you feel unwell. You think about **quitting and changing jobs**, but it bothers you since

you worked so hard and enjoyed what you're doing, and your income is likely to drop. You also consider **retiring early**, but you feel restricted as you are not able to go and do things. You will likely have to stop working altogether without surgery.

- > You **often blink or close your eyes** to try and reduce the double vision. You rely on eye patches to cover one of your eye or corrective glasses with prisms, but these are not always effective.
- > The white part of your eyes between the top of your iris (colored part of the eyes) and your upper eyelid is **largely visible**.
- > Your eyes bulge **noticeably** forward because of the **considerable swelling** in and behind your eyes. It feels like you are suffering from a migraine with pressure in your eyes, face and temples. You **feel very uncomfortable** along with the **persistent pain** inside or around your eyes.
- > Since your eyes largely bulge out, your eyelids do not close completely, leaving a **considerable part of your eyes exposed to the environment**. **Because of this, your eyes lack moisture and become dry**. As a result, you experience a **dry or gritty/sandy feeling in your eyes on a daily basis**, especially in the morning after you wake up.
- > You **struggle to sleep at night** because you are unable to close your eyelids. Therefore, you use eye covers at night or tape down your eyelids to keep your eyes closed and stop them from becoming dry while you sleep. Even with these measures, sleeping is very difficult. You may even have surgery (stitching your eyelids together) to partially close your eyelids in order to protect your eyes better
- > Due to lack of sleep, you feel like as though every day you stayed up all night and then drank too much coffee.
- > Because your eyes are so red and irritated, you constantly apply eye drops. Otherwise, you experience **excessive tearing or watery eyes** and you always have to wipe your eyes like you are crying all the time.

- > You feel and look **disfigured** as a result of your large bulging eyes combined with constant bloodshot eyes which appear like frog eyes. You feel sad when looking at old pictures because you no longer recognize who you are, and you miss how you looked before.
- > In social situations, you feel **very emotional and embarrassed** because you know **your eyes are very noticeable to others**. Your **self-confidence has dropped to an all-time low**.
- > Your friends and family **frequently comment about your eyes bulging or looking sore and swollen and being “puffy”**. You feel **self-conscious** when some people ask you “What’s the matter with your eyes?”, “Are you tired?” or “Are you angry”, while other people will just stare at you and young children may be scared.
- > The intensity of your bulging eyes can appear as if you were **constantly staring like a statue and that you are angry**. Both adults and children feel intimidated or afraid of you or even appear angry. Some strangers may question whether you are intoxicated or mad and refuse to interact with you.
- > You avoid people you don’t know and often look away or down at the floor. It bothers you when you feel like you are being stared at or when other people give shocked or surprised looks at you.
- > You **avoid social interactions or having your picture taken as much as possible**. You **always wear sunglasses or a cap to hide, and protect**, your eyes. This often gives people the wrong impression about you.
- > Your eyes are **sensitive to bright lights**. You wear sunglasses even inside to block the light and to hide them from people, work in dark places or keep your home dark **at all times**. You rarely want to go outside in the sunshine.
- > You are tired of explaining your eye condition each time you meet someone to avoid being misunderstood. For example, when you wear sunglasses indoors, you have to explain to the someone your eyes are sensitive to bright lights and that you are not purposely trying to hide from anyone.

- > With your eyes being problematic, you **isolate yourself** and don't want to engage in social interaction or get more involved in social or personal activities.
- > Due to the swelling, you **frequently tilt your head** back to expand what you can see at different angles, which becomes **tiresome and stressful**.
- > You are uncomfortable talking to healthcare professionals about the distressing and emotional impact of the disease because you don't want to be dismissed as being vain. You **feel alone** and that no one is able to understand your concerns or help you.
- > Your doctor has suggested **multiple surgeries may be required** to remove bone and/or fat from behind your eyes to reduce the bulging eye appearance, and to repair the eye muscles and correct double vision. But these are not 100% effective. As with all surgery, there is a risk of complications, which can include a decline in or worsening of vision, double vision and/or a change in the height or position of your eyelids. You will have to wait to have the major surgeries for potentially two years or more, meaning you will be living with these symptoms for quite a while.
- > With having both constant double vision and large bulging eyes, you are always reminded that you are struggling with the disease. It is consuming having to deal and worry about it every day. You ask yourself questions like, "is it ever going to go away on its own?" or "is it something I have to be used to for the rest of my life?" and "how much worse is it going to get?"

### **eAppendix 3. Literature Search**

"The authors conducted a targeted literature search in Medline and Embase to assess whether there were existing utility values for TED, proptosis or diplopia. The following search strategy was employed in Medline and was adapted for the Embase database.

In total 58 publications were identified across both databases', based upon a review of the abstracts, no studies were identified which presented utility values for TED with the exception of an abstract presented by the study authors at the American Thyroid Association Annual Meeting.

<b>1</b>	<b>exp Graves Ophthalmopathy/</b>
<b>2</b>	<b>thyroid eye disease.mp.</b>
<b>3</b>	<b>exp Diplopia/ or diplopia.mp.</b>
<b>4</b>	<b>exp exophthalmos/ or proptosis.mp.</b>



5	4 or 1 or 2 or 3
6	health state utilit\$.mp.
7	health utilit\$.mp.
8	(health utility ind\$ or hui or hui\$ or hui2 or hui3).mp.
9	(euroqol or euro qol or eq 5d or eq5d).mp.
10	(sf6d or sf 6d or shortform sixD or short form 6d or sf sixD).mp.
11	(TTO or time trade off).mp.
12	(SG or standard gamble).mp.
13	health stat\$ preference.mp.
14	preference based.mp.
15	preference score.mp.
16	preference measure.mp.
17	or/6-16
18	17 and 5

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