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Copy of Informed Consent for download.

Please click on the PDF document below if you wish to download and save to your computer.

[Attachment: "ThyCa COVID Consent 043020.pdf"]

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- 1) By checking this box, I certify that I am at least 18 years old, have read and understand the information above, and I give my consent freely to participate in this study.

I consent

# Thyroid Cancer

Thank you for taking the time to complete our survey.

These first questions will help us learn more about your thyroid cancer and treatment.

Thank you!

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Which of the following best describes you?

- My family member or friend has been diagnosed with thyroid cancer.
- I might have thyroid cancer, but I'm not sure yet.
- I have been diagnosed with thyroid cancer by a physician.

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Which best describes you?

- I have been told I have a thyroid nodule that needs a biopsy, but I have not yet had a biopsy.
- I have had a biopsy of a thyroid nodule, and I am waiting for results.
- I have had a biopsy of a thyroid nodule, but the results weren't definite (for example, not enough tissue for diagnosis, or possible cancer, or suspicious for cancer).

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What were the results of your biopsy?

- I don't know
- Bethesda I, insufficient
- Bethesda II, benign
- Bethesda III, Atypia of Undetermined Significance or Follicular Lesion of Undetermined Significance
- Bethesda IV, Follicular Neoplasm or Suspicious for Follicular Neoplasm
- Bethesda V, Suspicious for Malignancy
- Bethesda VI, Malignant

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How old were you when you were diagnosed with thyroid cancer?

\_\_\_\_\_

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What type of thyroid cancer do you have?

- Papillary
- Follicular
- Medullary
- Hurthle cell
- Non-invasive follicular neoplasm with papillary-like nuclear features (NIFTP)
- Anaplastic
- I'm not sure

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What stage cancer do you have?

- Stage I
- Stage II
- Stage III
- Stage IV
- Unknown, or I haven't been staged

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What types of treatment have you had for your thyroid cancer? (Please check all that apply)

- Surgery
- Radioactive iodine
- Chemotherapy/ Targeted Therapy
- External beam radiation therapy
- Other
- No treatment yet

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Which of the following best describes you?

- I have finished treatment and am not currently waiting for any additional treatment for my thyroid cancer.
- I am waiting to have surgery.
- I have already had surgery, and am waiting to start additional treatment (radioactive iodine, chemotherapy, etc.).
- I have already had surgery, and am in the middle of additional treatment.
- I have already had surgery, and am awaiting additional surgery.
- I am not planning to undergo any treatment.
- Other

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I had surgery in March or April of 2020.

- Yes
- No

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Which of the following best describes you?

- I am waiting to meet with a surgeon.
- I have met with a surgeon and am waiting to have surgery.

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What surgery is planned?

- Thyroid lobectomy (removal of half of the thyroid gland, right or left)
- Total thyroidectomy (removal of the entire thyroid gland)
- Total thyroidectomy with lymph node dissection (removal of lymph nodes in the neck)
- Lymph node dissection only
- Other
- I'm not sure

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What best describes your surgeon?

- Endocrine Surgeon
- Ear, Nose, and Throat Surgeon
- General Surgeon
- Other
- I'm not sure

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What best describes the scheduling of your surgery?

- I have a scheduled date.
- I had a scheduled date, but it was canceled or postponed due to COVID-19.
- I have not yet been given a scheduled date.

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When is your surgery scheduled?

- May, 2020
- June, 2020
- July, 2020
- August, 2020
- September, 2020
- October, 2020
- November, 2020
- December, 2020
- 2021

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How were you notified that your surgery that was canceled or postponed?

- Phone call from your doctor's office staff
- Phone call from your doctor
- Electronic notification (email, electronic medical record notification, etc.)
- Other

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When have you been told your surgery may take place?

- I have not been given an estimate.
- Within the next several weeks
- In approximately 1 month
- In approximately 2 months
- In approximately 3 months
- In approximately 4-6 months
- In approximately 6 months to 1 year
- In more than 1 year

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In this era of COVID-19, how long would you feel comfortable delaying your surgery?

- No delay
- 1 month
- 2 months
- 3 months
- 4 months
- 5 months
- 6 months
- 7 months
- 8 months
- 9 months or more

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Based on your understanding of COVID-19, and your conversation with your surgeon, what are some of the reasons for NOT having surgery during the COVID-19 pandemic? (Check all that apply)

- I could become infected with COVID-19 in the hospital.
- If I have COVID-19 and don't know it, I could infect others in the hospital.
- The hospital needs to make rooms and supplies available for COVID-19 patients.
- The hospital does not have enough staff because of COVID-19.
- Shelter in place means that I should only leave my house for necessities and emergencies.
- If I have COVID-19 and don't know it, anesthesia and surgery could make me very sick.
- No reasons

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What treatment are you in the middle of, or waiting to begin?

- Radioactive iodine
- Chemotherapy/ Targeted therapy
- External beam radiation therapy
- Other therapies

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Has your treatment plan changed due to COVID-19?

- No, I am proceeding as planned with my treatment.
- Yes, the start of my treatment has been delayed
- Yes, the type of treatment I am/will be getting has changed.
- Yes, it has changed in another way.

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25%

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# COVID General

These questions will help us learn more about how the COVID-19 pandemic has affected your life.

Thank you!

I have been diagnosed with COVID-19.

- Yes  
 No

I had symptoms that make me think I may have had COVID-19.

- Yes  
 No

Which best describes what happens when you had symptoms?

- I did not seek testing.  
 I tried to get a test, but could not get one.  
 I was tested, and it came back negative.  
 Other

A family member, close friend, or loved one has been diagnosed with COVID-19.

- Yes  
 No

A family member, close friend, or loved one has died from COVID-19.

- Yes  
 No

Is a "shelter in place" order in effect where you live?

- Yes  No

Approximately how many weeks have you been sheltering in place?

\_\_\_\_\_

Not including you, how many people do you live with at home?

- 0 - I live alone  1 other person  
 2 other people  3 other people  
 4 other people  5 or more

## Please rate how much the COVID-19 pandemic has changed your life in each of the following ways.

Change in family income/employment:

- No change.  
 Small change; I am able to meet all needs and pay bills.  
 Moderate change: I am having to make cuts but still able to meet basic needs and pay bills.  
 Severe change: I am unable to meet basic needs and/or pay bills.

Change in health care access:

- No change.  
 Mild change: My appointments have moved to phone or video chat (telehealth).  
 Moderate change: I've had delays or cancellations in appointments and/or delays in getting prescriptions, but these changes have had a minimal impact on my health.  
 Severe change: I have been unable to access needed care, which has affected my health.

Has your difficulty in obtaining health care been related to a change in your insurance status?

- Yes  
 No

Access to extended family and non-family social supports:

- No change.  
 Mild change. I have continued visits with social distancing and/or regular phone calls, video chats, or social media connections.  
 Moderate change: I have lost in-person and remote contact with a few people, but not all supports.  
 Severe change. I have lost in-person and remote contact with all supports.

### Do you agree with the following statements?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My life is very different now during COVID-19 than it was before.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The way I interact with my doctors is different now than before COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would prefer to visit my doctor as usual, even if it meant a higher risk of being infected with COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would prefer to only "visit" the doctor virtually (phone, video chat, etc.) until the COVID-19 pandemic is over.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My medical provider (doctor/physician's assistant/nurse practitioner/nurse) has discussed with me how the COVID-19 pandemic may affect, or has affected my thyroid cancer treatment plan.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the amount of information I have received from my doctor's office regarding COVID-19 changes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would prefer to stay as far away from doctors and hospitals as I can until the COVID-19 pandemic is over.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am afraid to visit my doctor's office.

○ ○ ○ ○ ○

**For the following questions, please tell us how worried you have been over the past 7 days, on a scale of 0 to 100, where 0 is not at all worried, and 100 is extremely worried.**

How worried are you about catching COVID-19 yourself?

Not at all worried Extremely worried  


*(Place a mark on the scale above)*

How worried are you about your thyroid cancer?

If you do not have thyroid cancer, please leave blank.

Not at all worried Extremely worried  


*(Place a mark on the scale above)*

How worried are you about pain or side effects related to current or upcoming thyroid cancer treatment?

If you do not have thyroid cancer, please leave blank.

Not at all worried Extremely worried  


*(Place a mark on the scale above)*

How worried are you about COVID-19 delaying treatment for your thyroid cancer?

If you do not have thyroid cancer, please leave blank.

Not at all worried Extremely worried  


*(Place a mark on the scale above)*

How worried are you about a family member or loved one catching COVID-19?

Not at all worried Extremely worried  


*(Place a mark on the scale above)*

How worried are you about the effects of COVID-19 on the economy?

Not at all worried Extremely worried  


*(Place a mark on the scale above)*



**Please respond to each item by clicking one of the responses that reflects how you feel, think, or act toward COVID-19.**

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	I am most afraid of COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2	It makes me uncomfortable to think about COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3	My hands become clammy when I think about COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4	I am afraid of losing my life because of COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5	When I watch news and stories about COVID-19 on social media, I become nervous or anxious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6	I cannot sleep because I'm worrying about getting COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7	My heart races or palpitates when I think about getting COVID-19.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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60%

# PROMIS - 29 Profile v2.0

These questions are part of a validated survey that evaluates and monitors physical, mental, and social health in adults.

Thank you for answering these questions!

## Please respond to each item by choosing one answer per statement.

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
55) 1. Are you able to do chores such as vacuuming or yard work?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56) 2. Are you able to go up and down stairs at a normal pace?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57) 3. Are you able to go for a walk of at least 15 minutes?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58) 4. Are you able to run errands and shop?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## In the past 7 days...

	Never	Rarely	Sometimes	Often	Always
59) 5. I felt fearful....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60) 6. I found it hard to focus on anything other than my anxiety....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61) 7. My worries overwhelmed me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62) 8. I felt uneasy....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## In the past 7 days...

	Never	Rarely	Sometimes	Often	Always
63) 9. I felt worthless....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64) 10. I felt helpless....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65) 11. I felt depressed....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66) 12. I felt hopeless....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**During the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
67) 13. I feel fatigued....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68) 14. I have trouble starting things because I am tired....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69) 15. How run-down did you feel on average?...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70) 16. How fatigued were you on average?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**In the past 7 days...**

	Very poor	Poor	Fair	Good	Very good
71) 17. My sleep quality was....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**In the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
72) 18. My sleep was refreshing....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73) 19. I had a problem with my sleep....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74) 20. I had difficulty falling asleep ....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

  

	Never	Rarely	Sometimes	Usually	Always
75) 21. I have trouble doing all of my regular leisure activities with others....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76) 22. I have trouble doing all of the family activities that I want to do....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77) 23. I have trouble doing all of my usual work (include work at home)....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78) 24. I have trouble doing all of the activities with friends that I want to do....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**In the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
79) 25. How much did pain interfere with your day to day activities?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80) 26. How much did pain interfere with work around the home?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
81) 27. How much did pain interfere with your ability to participate in social activities?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82) 28. How much did pain interfere with your household chores?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**In the past 7 days...**

	No Pain	1	2	3	4	5	6	7	8	9	Worst imaginable pain
83) 29. How would you rate your pain on average?....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

80%

# Participant Info Survey

This portion of the survey will help us get to know you a little better.

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**These questions will help us learn a little about you. Thank you for answering!**

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Please enter your age, in years.

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Which best describes your gender?

- Female
- Male
- Nonbinary/third gender
- Prefer to self-describe
- Prefer not to say

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How do you prefer to self-describe?

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Do you identify as transgender?

- No
- Yes

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Which best describes your ethnicity?

- Hispanic or Latino
- NOT Hispanic or Latino
- Unknown, or would rather not say

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Which best describes the race you identify with?

- American Indian/Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White
- More Than One Race
- Unknown or would rather not report

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Do you live in the United States?

- Yes
- No

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Which state or territory?

- AL
- AK
- AZ
- AR
- CA
- CO
- CT
- DE
- FL
- GA
- HI
- ID
- IL
- IN
- IA
- KS
- KY
- LA
- ME
- MD
- MA
- MI
- MN
- MS
- MO
- MT
- NE
- NV
- NH
- NJ
- NM
- NY
- NC
- ND
- OH
- OK
- OR
- PA
- RI
- SC
- SD
- TN
- TX
- UT
- VT
- VA
- WA
- Washington, D.C.
- WV
- WI
- WY
- Puerto Rico
- American Samoa
- U.S. Virgin Islands
- Other
- Prefer not to say

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Where do you live?

- Afghanistan
- Albania
- Algeria
- Andorra
- Angola
- Antigua and Barbuda
- Argentina
- Armenia
- Australia
- Austria
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bhutan
- Bolivia
- Bosnia and Herzegovina
- Botswana
- Brazil
- Brunei
- Bulgaria
- Burkina Faso
- Burundi
- Côte d'Ivoire
- Cabo Verde
- Cambodia
- Cameroon
- Canada
- Central African Republic
- Chad
- Chile
- China
- Colombia
- Comoros
- Congo (Congo-Brazzaville)
- Costa Rica
- Croatia
- Cuba
- Cyprus
- Czechia (Czech Republic)
- Democratic Republic of the Congo
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini (fmr. "Swaziland")
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Gambia
- Georgia
- Germany
- Ghana
- Greece
- Grenada
- Guatemala

- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Holy See
- Honduras
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Mauritania
- Mauritius
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Morocco
- Mozambique
- Myanmar (formerly Burma)
- Namibia
- Nauru
- Nepal
- Netherlands
- New Zealand
- Nicaragua
- Niger
- Nigeria
- North Korea
- North Macedonia
- Norway
- Oman
- Pakistan
- Palau
- Palestine State
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Poland



- Portugal
- Qatar
- Romania
- Russia
- Rwanda
- Saint Kitts and Nevis
- Saint Lucia
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Sweden
- Switzerland
- Syria
- Tajikistan
- Tanzania
- Thailand
- Timor-Leste
- Togo
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States of America
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela
- Vietnam
- Yemen
- Zambia
- Zimbabwe
- Other
- Prefer not to say

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The following best describes the area where I live:

- Urban area (more than 50,000 people)
- Urban cluster (between 2,500 and 50,000 people)
- Small town or rural area (less than 2,500 people)

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How far do you typically travel to get treatment for your thyroid cancer?

- Less than 25 miles
- Between 25 and 50 miles
- Between 50 and 100 miles
- Between 100 and 300 miles
- Greater than 300 miles

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What is the highest degree or level of school you have completed?  
(If you're currently enrolled in school, please indicate the highest degree you have received.)

- Less than a high school diploma
- High school degree or equivalent
- Some college, no degree
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree or doctorate

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Which best describes your current employment status?

- Employed full time (40+ hours per week)
- Employed part time (less than 40 hours per week)
- Unemployed and currently looking for work
- Student
- Retired
- Homemaker
- Unable to work
- Other

---

Which best describes your health insurance status?  
(Can check more than one, if applicable)

- No insurance
- Insured through my or a family member's employer
- Affordable Care Act plan
- Other private health insurance (not through an employer)
- Medicaid
- Medicare (includes plans such as Medicare Advantage, etc.)
- Veterans Health Administration (VA)
- Other
- Not sure

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Have you been diagnosed with any of the following conditions?  
(Please check all that apply. If none, please leave blank.)

- High blood pressure
- High cholesterol
- Diabetes
- Heart disease or history of heart attack
- Liver disease
- Kidney disease
- History of stroke
- Lung disease
- Fibromyalgia
- Depression
- Anxiety
- Severe obesity

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Do you take any medications for anxiety or depression?

- Yes
- No

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100%

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