



UC Irvine Health

UC Irvine Acoustic Neuroma Decision Making Survey

We are asking you to take part in a study conducted by researchers at the University of California, Irvine. The intended use of this data is to better understand decision making and treatment from the perspective of the patient. We hope to use this data to improve care offered by physicians.

Participating in this study is optional. If you choose to participate, please complete this anonymous survey which will take approximately 15 minutes. You must have a diagnosis of acoustic neuroma to be eligible for this study.

Please email us at UCIAcousticNeuroma@gmail.com if you have any additional questions and issues regarding this study or survey.

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Have you been diagnosed with an acoustic neuroma (or vestibular schwannoma)?

- No, I am a caregiver or family member filling out this survey on the patients behalf
- Yes

reset

Do you have neurofibromatosis type II?

- No
- Yes
- I do not know

reset

What was your age at diagnosis?

How many years ago were you diagnosed?

What was the approximate initial size of the tumor (in cm)?

After diagnosis, how long did you take (in days) to decide on how to manage your tumor?

What caused the delay between initial diagnosis to treatment?

- Getting second opinions
- Initial observation of the tumor
- Scheduling of procedure
- There was no delay, I received treatment immediately
- Other

reset

Which physician played the most important role in discussing treatment options with you?

- Primary care physician
- General ear, nose and throat (ENT) physician
- Neurotologist (ear specialist or skull base surgeon)
- Neurosurgeon
- Radiation Oncologist
- Other

reset

How many minutes total did you spend with the physician that played the most important role in the management of your acoustic neuroma?

What is your final decision on which course of management to undergo?

- Surgery
- Radiation
- Observation
- Surgery and Radiation
- Undecided at the moment

reset

Did you (or your physician) decide to change the management of your tumor after the initial management decision was made?

- No
- Yes

reset

In deciding which treatment to undergo, what was the single most important factor for your decision:

In deciding which treatment to undergo, what was the second most important factor for your decision:

In deciding which treatment to undergo, what was the third most important factor for your decision:

In deciding which treatment to undergo, how informed did you feel about making your decision?

- Not informed- I did not understand all the possible treatment options
- Moderately informed
- Very informed- I understood all the possible treatment options for my condition

reset

Which treatment did your doctor recommend?

- Surgery
- Radiation (GammaKnife, Cyberknife, etc.)
- Doctor left it up to me
- Other

After diagnosis, who made the decision for treatment?

- I made the decision
- My doctor and I made the decision together
- My doctor made the decision for me

reset

Did your acoustic neuroma recur/grow after treatment?

- No
- Yes

reset

After treatment, how frequently is your provider requesting MRIs to evaluate for residual tumor?

- Once every six months
- Once every year
- Once every two years
- More than every three years
- My doctor does not use MRI surveillance for my acoustic neuroma

reset

Do you regret your treatment choice?

- No
- Yes

reset

How satisfied were you with your treatment decision?

- Extremely Dissatisfied
- Very Dissatisfied
- Satisfied
- Very Satisfied
- Extremely Satisfied

reset

How satisfied are you with your quality of life?

- Extremely Dissatisfied
- Very Dissatisfied
- Satisfied
- Very Satisfied
- Extremely Satisfied

reset

How much stress or anxiety does the presence of your acoustic neuroma cause in your life?

- Extreme stress/ anxiety
- A considerable amount of stress/ anxiety
- A moderate amount of stress/ anxiety
- Very little stress/ anxiety
- No stress/ anxiety

reset

Did you experience any complications with treatment? (check all that apply)

- I experienced no complications
- Balance issues
- Cognitive issues
- CSF leaks
- Inability to close eye
- Dry eyes
- Double vision
- Facial pain
- Partial facial weakness
- Complete facial weakness
- Synkinesis (eyes move with mouth motion or vice versa)
- Need for botox treatments
- Headaches
- Hydrocephalus
- Meningitis
- Regrowth of tumor
- Seizures
- Strokes
- Taste problems
- Voice or swallowing problems
- Tinnitus
- Eye droop
- Other

If you had any of the complications above, did you undergo surgery to correct any of the complications?

- No
 Yes
 Experienced no complications

reset

Is the medical center you received treatment at an academic or private institution?

- Academic institution (such as a university affiliated hospital)
 Private institution
 Government institution (i.e. Veterans Administration hospital)
 Unsure

reset

What is the name of the medical center you received treatment at?

Which of the following acoustic neuroma specialists have you seen? (check all that apply)

- Neurotologist
 Neurosurgeon
 Radiation therapist
 None
 Other

Within this list, which specialist did you see first?

- Neurotologist
 Neurosurgeon
 Radiation therapist
 None

reset

Who made the acoustic neuroma diagnosis?

- Primary care physician
 General ear, nose and throat (ENT) physician
 Neurotologist
 Neurosurgeon
 Radiation Oncologist
 Other

reset

Did your acoustic neuroma cause you to have symptoms prompting an MRI?

- Yes- I had symptoms
 No- I had no symptoms, the tumor was found incidentally on imaging

reset

What were your initial symptoms that prompted you to get a magnetic resonance image (MRI)?

- Headaches
- Balance difficulties/ Dizziness
- Tinnitus
- Vertigo
- Hearing loss
- Facial numbness
- Change in smell or taste
- Depression
- Difficulty concentrating
- Difficulty swallowing
- Eye problems
- Facial paralysis
- Facial twitching
- Fatigue
- Fullness in ear
- Memory difficulties
- Sinusitis
- None of the above
- Other

Which doctor ordered your MRI?

- Primary care physician
- General ear, nose and throat (ENT) physician
- Neurotologist
- Neurosurgeon
- Radiation Oncologist
- Other

reset

How many different neurosurgeons did you see before making a decision?

How many different neurotologists did you see before making a decision?

How many different radiation oncologists did you see before making a decision?

If you went to more than one physician before making a decision on your treatment, did the opinions of the doctors differ?

- No
- Yes
- N/A, only went to one physician

reset

What city and state do you reside in?	<input type="text"/>	
In which part of the United States do you live?	<input type="radio"/> West <input type="radio"/> Mid West <input type="radio"/> South <input type="radio"/> North East	reset
If you received treatment, what city and state did you receive it?	<input type="text"/>	
Approximately how far apart (in miles) is your home from the treatment center?	<input type="text"/>	
Did you travel outside your state to receive treatment?	<input type="radio"/> No <input type="radio"/> Yes	reset
What type of health insurance did you have at the time of your diagnosis?	<input type="radio"/> HMO <input type="radio"/> PPO <input type="radio"/> Medicare <input type="radio"/> Medicaid <input type="radio"/> N/A, do not have health insurance	reset
Did you change health insurance plans to get treatment?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> N/A, did not have health insurance	reset
Did you go outside your health insurance for preferred provider or HMO?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> N/A, did not have health insurance	reset
Did you have to pay out of pocket for your surgery because your surgeon did not accept your insurance or was out of network?	<input type="radio"/> No <input type="radio"/> Yes	reset
Were you or have you been involved with litigation with your doctors for your acoustic neuroma (sued your doctor or hospital)?	<input type="radio"/> No <input type="radio"/> Yes	reset

Which gender do you identify with?

- Male
- Female

reset

What is your ethnicity?

- Caucasian
- Asian/Pacific Islander
- Hispanic/Latino
- African/African American/W. Indian
- Native American
- Other

reset

What is your primary language spoken?

- English
- Mandarin
- Spanish
- Hindi
- Arabic
- Bengali
- Russian
- Portuguese
- Japanese
- Punjabi
- Farsi
- Korean
- Vietnamese
- Other

reset

What was your education level at the time of your diagnosis?

- None
- High school diploma
- Some college
- Technical school
- College degree
- Graduate degree (MA, MS, PhD, MD, JD, MBA, etc.)

reset

What was your income level at the time of your diagnosis?

- Less than \$25,000
- \$25,000 to \$50,000 per year
- \$51,000-\$100,000 per year
- \$101,000-\$200,000 per year
- \$201,000 or more per year
- Prefer not to say

reset

If there was something you could change about the decision making process on what treatment you would choose, what would it be?

Expand

Is there anything else you would like to add about your experience with acoustic neuroma.

Expand

Submit