Transforming Tinnitus Research

2 727 responses

Are you willing to participate in this survey?

2727 out of 2727 answered

Yes 2,7k resp. 100%

No 0 resp. 0%

What is your gender?

2727 out of 2727 answered

1,7k resp. 63.3%

Female 970 resp. 35.6%

Prefer not to say 18 resp. 0.7%

Other 13 resp. 0.5%

In which	country	do you	live?
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2727 out of 2727 answered

United States of America	1,2k resp.	43.6%
United Kingdom	599 resp.	22%
Canada	145 resp.	5.3%
Australia	104 resp.	3.8%
Netherlands	74 resp.	2.7%
Ireland	52 resp.	1.9%
Germany	50 resp.	1.8%
France	40 resp.	1.5%
Sweden	38 resp.	1.4%
Spain	37 resp.	1.4%

New Zealand	27 resp.	1%
India	24 resp.	0.9%
Italy	23 resp.	0.8%
Belgium	20 resp.	0.7%
South Africa	19 resp.	0.7%
Norway	18 resp.	0.7%
Denmark	17 resp.	0.6%
Denmark Israel	17 resp. 16 resp.	
		0.6%
Israel	16 resp.	0.6%
Israel Portugal	16 resp. 16 resp.	0.6%
Israel Portugal Poland	16 resp. 16 resp.	0.6% 0.6% 0.5%

Brazil	11 resp.	0.4%
Austria	9 resp.	0.3%
Romania	9 resp.	0.3%
Greece	8 resp.	0.3%
Bulgaria	7 resp.	0.3%
Croatia	7 resp.	0.3%
Slovakia	7 resp.	0.3%
Argentina	6 resp.	0.2%
Malaysia	6 resp.	0.2%
Mexico	6 resp.	0.2%
Hungary	5 resp.	0.2%
Lithuania	5 resp.	0.2%
Russia	5 resp.	0.2%

Turkey	5 resp.	0.2%
Colombia	4 resp.	0.1%
Czech Republic	4 resp.	0.1%
Kenya	4 resp.	0.1%
United Arab Emirates	4 resp.	0.1%
Costa Rica	3 resp.	0.1%
Cyprus	3 resp.	0.1%
Egypt	3 resp.	0.1%
Japan	3 resp.	0.1%
Lebanon	3 resp.	0.1%
Peru	3 resp.	0.1%
Philippines	3 resp.	0.1%
Singanore	3 resn.	በ 1%

ompapore.	J. 50p.	0.1 /0
Slovenia	3 resp.	0.1%
Thailand	3 resp.	0.1%
Bosnia and Herzegovina	2 resp.	0.1%
Iceland	2 resp.	0.1%
Indonesia	2 resp.	0.1%
Jamaica	2 resp.	0.1%
Macedonia	2 resp.	0.1%
Malta	2 resp.	0.1%
Malta Nigeria	2 resp. 2 resp.	
		0.1%
Nigeria	2 resp.	0.1%
Nigeria Tunisia	2 resp.	0.1%

Algeria	1 resp.	0%
Angola	1 resp.	0%
Armenia	1 resp.	0%
Barbados	1 resp.	0%
Brunei	1 resp.	0%
Chile	1 resp.	0%
China	1 resp.	0%
Estonia	1 resp.	0%
Ghana	1 resp.	0%
Iran	1 resp.	0%
Korea, South	1 resp.	0%
Malawi	1 resp.	0%
Nepal	1 resp.	0%

Pakistan	1 resp.	0%
Saudi Arabia	1 resp.	0%
Swaziland	1 resp.	0%
Uganda	1 resp.	0%
Uruguay	1 resp.	0%
Uzbekistan	1 resp.	0%
Venezuela	1 resp.	0%
Vietnam	1 resp.	0%
Zimbabwe	1 resp.	0%
Andorra	0 resp.	0%
Antigua and Barbuda	0 resp.	0%
Azerbaijan	0 resp.	0%

Bahrain	0 resp.	0%
Bangladesh	0 resp.	0%
Belarus	0 resp.	0%
Belize	0 resp.	0%
Benin	0 resp.	0%
Bhutan	0 resp.	0%
Bolivia	0 resp.	0%
Botswana	0 resp.	0%
Burkina Faso	0 resp.	0%
Burundi	0 resp.	0%
Cambodia	0 resp.	0%
Cameroon	0 resp.	0%
Cape Verde	0 resp.	0%

Central African Republic	0 resp.	0%
Chad	0 resp.	0%
Comoros	0 resp.	0%
Congo, Democratic Republic of the	0 resp.	0%
Congo, Republic of the	0 resp.	0%
Cote d'Ivoire	0 resp.	0%
Cuba	0 resp.	0%
Djibouti	0 resp.	0%
Dominican Republic	0 resp.	0%
Dominica	0 resp.	0%
East Timor (Timor-Leste)	0 resp.	0%
Ecuador	0 resp.	0%
El Salvador	0 resp.	0%

Equatorial Guinea	0 resp.	0%
Eritrea	0 resp.	0%
Ethiopia	0 resp.	0%
Fiji	0 resp.	0%
Gabon	0 resp.	0%
Georgia	0 resp.	0%
Grenada	0 resp.	0%
Grenada	0 resp.	0%
Guatemala	0 resp.	0%
Guatemala	0 resp.	0%
Guinea Guinea-Bissau	0 resp. 0 resp.	0%

Honduras	0 resp.	0%
Iraq	0 resp.	0%
Jordan	0 resp.	0%
Kazakhstan	0 resp.	0%
Kiribati	0 resp.	0%
Korea, North	0 resp.	0%
Kosovo	0 resp.	0%
Kuwait	0 resp.	0%
Kyrgyzstan	0 resp.	0%
Laos	0 resp.	0%
Latvia	0 resp.	0%
Lesotho	0 resp.	0%
Liberia	0 resp.	0%

28.5.2023, 13.11

Libya	0 resp.	0%
Liechtenstein	0 resp.	0%
Luxembourg	0 resp.	0%
Madagascar	0 resp.	0%
Maldives	0 resp.	0%
Mali	0 resp.	0%
Marshall Islands	0 resp.	0%
Mauritania	0 resp.	0%
Mauritius	0 resp.	0%
Micronesia, Federated States of	0 resp.	0%
Moldova	0 resp.	0%
Monaco	0 resp.	0%
Mongolia	0 resp.	0%

Montenegro	0 resp.	0%
Morocco	0 resp.	0%
Mozambique	0 resp.	0%
Myanmar (Burma)	0 resp.	0%
Namibia	0 resp.	0%
Nauru	0 resp.	0%
Nicaragua	0 resp.	0%
Niger	0 resp.	0%
Oman	0 resp.	0%
Palau	0 resp.	0%
	·	
Panama		0%
	0 resp.	0%

Paraguay	0 resp.	0%
Qatar	0 resp.	0%
Rwanda	0 resp.	0%
Saint Kitts and Nevis	0 resp.	0%
Saint Lucia	0 resp.	0%
Saint Vincent and the Grenadines	0 resp.	0%
Samoa	0 resp.	0%
San Marino	0 resp.	0%
Sao Tome and Principe	0 resp.	0%
Senegal	0 resp.	0%
Serbia	0 resp.	0%
Seychelles	0 resp.	0%
Sierra Leone	0 resp.	0%

Solomon Islands	0 resp.	0%
Somalia	0 resp.	0%
South Sudan	0 resp.	0%
Sri Lanka	0 resp.	0%
Sudan	0 resp.	0%
Suriname	0 resp.	0%
Syria	0 resp.	0%
Taiwan	0 resp.	0%
Tajikistan	0 resp.	0%
Tanzania	0 resp.	0%
The Bahamas	0 resp.	0%
The Gambia	0 resp.	0%
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годо	u resp.	U%0
Tonga	0 resp.	0%
Trinidad and Tobago	0 resp.	0%
Turkmenistan	0 resp.	0%
Tuvalu	0 resp.	0%
Ukraine	0 resp.	0%
Vanuatu	0 resp.	0%
Vatican City (Holy See)	0 resp.	0%
Yemen	0 resp.	0%
Zambia	0 resp.	0%

Which of the following conditions do you have?

2727 out of 2727 answered

Tinnitus - ringing or buzzing in the ears	2,7k resp.	98.8%
Hearing loss - reduced ability to hear speech in noisy environments	1k resp.	37.5%
Loudness Hyperacusis - sounds seem louder than normal	646 resp.	23.7%
Hearing loss - reduced perception of loudness	605 resp.	22.2%
Phonophobia - fear/avoidance of loud sounds	445 resp.	16.3%
Pain Hyperacusis - sounds can cause pain	408 resp.	15%
Misophonia - human sounds trigger anger/annoyance	265 resp.	9.7%
A non-hearing related chronic condition	178 resp.	6.5%

How many years have you had tinnitus for?

2727 out of 2727 answered

10+ years 910 resp. 33.4% 5-10 years 547 resp. 20.1%

3-5 years	407 resp.	14.9%
2-3 years	295 resp.	10.8%
1-2 years	277 resp.	10.2%
6-12 months	157 resp.	5.8%
Less than 6 months	134 resp.	4.9%

How much of a problem is your tinnitus?

2727 out of 2727 answered

3.6 Average rating

2.2%	13.2%	32.2%	28.6%	23.7%
61	361	879	780	646
resp.	resp.	resp.	resp.	resp.

 1
 2
 3
 4
 5

 Not a proble...
 A very big p...

Do you worry that your tinnitus will get worse?

2727 out of 2727 answered

4.0 Average rating

3.6%	7.1%	18.7%	27.3%	43.3%
99	193	510	744	1,2k
resp.	resp.	resp.	resp.	resp.

1 2 3 4 5
Not worried Very worried

Is your tinnitus...

2727 out of 2727 answered

Always there, with slight fluctuations in volume and/or pitch 1,4k resp. 51.8%

Always there, with strong fluctuations in volume and/or pitch 752 resp. 27.6%

Always there, and always at the same volume and pitch 363 resp. 13.3%

Sometimes there, sometimes not	200 resp. 7.3%
Have you - in the past year - followed tinnitus research?	
2727 out of 2727 answered	
A little bit	1,6k resp. 57.6 %
No	671 resp. 24.6 %
Very closely	485 resp. 17.8 %

What sources have you used to follow tinnitus research?

2056 out of 2727 answered

Tinnitus Talk/Tinnitus Hub	1,6k resp.	78.1%
Social media	937 resp.	45.6%
Other tinnitus organizations	647 resp.	31.5%
Academic journals	514 resp.	25%
Conventional media	498 resp.	24.2%
Other	40 resp.	1.9%

How would you rate your knowledge of tinnitus science?

2727 out of 2727 answered

2.7 Average rating

5%

550 resp. 20.2%

16.9%

13.1%

358 resp.	710 resp.	1,1k resp.	461 resp.	137 resp.	

38.9%

1 2 3 4 5

Which fields of tinnitus research are you interested in?

26%

2727 out of 2727 answered

Interdisciplinary

Neurology	1,5k resp. 56.5%
Audiology	1,3k resp. 47.6 %
I don't know	884 resp. 32.4%
Pharmacology	825 resp. 30.3%
Psychology	790 resp. 29 %
Otolaryngology	654 resp. 24 %

Genetics	476 resp.	17.5%
Endocrinology	288 resp.	10.6%
Epidemiology	246 resp.	9%
Other	18 resp.	0.7%

The critical objective should be to completely eliminate tinnitus

2727 out of 2727 answered

4.4 Average rating

1.7%	3.5%	10.5%	18.3%	66.1%
46	96	285	498	1,8k
resp.	resp.	resp.	resp.	resp.

1 2 3 4 5

5

The critical objective should be to substantially reduce tinnitus loudness, even if the sounds do not completely disappear

2727 out of 2727 answered

4.6 Average rating

1.1%	1.6%	5.9%	22.4%	69.1%
30	43	160	611	1,9k
resp.	resp.	resp.	resp.	resp.

The critical objective should be to reduce the emotional distress caused by tinnitus, even if the sounds can still be heard

3

2727 out of 2727 answered

1

2

3.8 Average rating

6.8%	10.1%	21.5%	18.3%	43.3%
185	275	585	500	1,2k
resp.	resp.	resp.	resp.	resp.

1 2 3 4 5

The critical objective should be to enable people to carry on with their everyday life as normal, even if the sounds can still be heard

2727 out of 2727 answered

3.9 Average rating

6.9%	10.4%	18.8%	17.1%	46.8%	
189	284	513	466	1,3k	
resp.	resp.	resp.	resp.	resp.	
1	2	3	4	5	

Tinnitus research mostly focusses on the right topics of investigation.

10%

16.1%

2727 out of 2727 answered

3.2 Average rating

7.3%

3.9%

106	200	1,7k	439	274
resp.	resp.	resp.	resp.	resp.

62.6%

1 2 3 4 5

Strongly dis... Neutral Strongly agr...

The amount of funding for tinnitus research, in comparison with other health conditions, is sufficient.

2727 out of 2727 answered

1.8 Average rating

649 resp. 23.8%

53.1%	20.4%	20.7%	1.8%	4%
1,4k	555	565	50	110
resp.	resp.	resp.	resp.	resp.

1 2 3 4 5
Strongly dis... Neutral Strongly agr...

What treatments have you tried to help with your tinnitus?

Psychological therapy (CBT, mindfulness, counseling)

2727 out of 2727 answered

Masking (nature sounds, music)

1,7k resp. 63%

Dietary supplements (vitamins, herbal medicine)

1,3k resp. 49%

Hearing aids

747 resp. 27.4%

Anti-anxiety medication

733 resp. 26.9%

Sound therapy (neuromodulation, notched music)

680 resp. 24.9%

Antidepressants	573 resp. 21%
Acupuncture	541 resp. 19.8%
In-ear maskers	506 resp. 18.6 %
Prednisone/steroids	470 resp. 17.2%
Physiotherapy/chiropractor	397 resp. 14.6 %
None	321 resp. 11.8%
TMD (temporomandibular joint disorder) treatment	242 resp. 8.9 %
Tinnitus Retraining Therapy (TRT)	234 resp. 8.6 %
Off-label drugs (e.g. retigabine, gabapentin)	222 resp. 8.1 %
Homeopathy	215 resp. 7.9 %
Transcranial magnetic/electric stimulation	72 resp. 2.6 %
Hyperbaric oxygen therapy (HBOT)	53 resp. 1.9 %
Low-level laser therapy (LLLT)	53 resp. 1.9 %

Lenire	43 resp.	1.6%
Experimental treatment (e.g. stem cells)	20 resp.	0.7%
Other	35 resp.	1.3%

Did any of the treatments you tried help with your tinnitus?

2406 out of 2727 answered

2.1 Average rating

39.7%	27.9%	22.2%	7.2%	3.1%
954	672	533	173	74
resp.	resp.	resp.	resp.	resp.
1	2	3	4	5

How satisfied are you with the tinnitus treatment options currently available to you?

2727 out of 2727 answered

1.5 Average rating

64.8%	22.2%	10.4%	1.5%	1.1%
1,8k	606	284	40	31
resp.	resp.	resp.	resp.	resp.

1 2 3 4 5

Did you see a healthcare professional for your tinnitus?

2716 out of 2727 answered

Yes, but they weren't much help

2k resp. 72.7%

Yes, and they helped me somewhat

381 resp. 14%

No

302 resp. 11.1%

Yes, and they helped me a lot

58 resp. 2.1%

What do v	ou think is needed to develop better tinnitus treatments?	
vviiat uo y	ou tilling is needed to develop better tilling a leatineins:	

2727 out of 2727 answered

More funding for research	1,9k resp.	69%
More knowledge on how tinnitus works	1,7k resp.	61.6%
More awareness of how bad tinnitus can be	1,2k resp.	45.6%
More research collaboration	1,2k resp.	45.6%
Focus on loudness reduction rather than coping	1,2k resp.	44.7%
More/better clinical trials	1,2k resp.	43.5%
A way to measure tinnitus objectively (scan, blood test)	1,1k resp.	38.8%
Focus on tinnitus sub-types	612 resp.	22.4%
I don't know	239 resp.	8.8%
Data on the economic burden of tinnitus	221 resp.	8.1%
Other	14 resp.	0.5%

A one-	time	pill
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2727 out of 2727 answered

Acceptable 2,6k resp. 96.5%

Not acceptable 95 resp. 3.5%

A pill every day for a few months

2727 out of 2727 answered

Acceptable 2,6k resp. 96.6%

Not acceptable 94 resp. 3.4%

A pill every day for the rest of your life

2727 out of 2727 answered

Acceptable 2,3k resp. 83%

ne-time injection through the eardrum 17 out of 2727 answered eptable 2 acceptable ozen injections through the eardrum 17 out of 2727 answered	2,2k resp. 518 resp.	81%
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c acceptable ozen injections through the eardrum		
ozen injections through the eardrum	518 resp.	19%
ozen injections through the eardrum	518 resp.	19%
7 out of 2727 answered		
	1.61	EO 40
eptable	1,6k resp.	58.49
t acceptable	1,1k resp.	41 60
. deceptable	±,±κ τεσμ.	71.07

A monthly injection through the eardrum for the rest of your life

2727 out of 2727 answered

66
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0% 2%

A device to be used at h	ama ayarı day farth	a root of vour life
A device to be used at r	iome every day for it	ie resi oi vour ille.

2727 out of 2727 answered

Acce	otable	1,9k resp.	69%
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Not acceptable 846 resp. 31%

A 10% risk of your tinnitus/hyperacusis getting worse

2727 out of 2727 answered

Intolerable 1,	1,5k resp.	56.1%
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Tolerable 1,2k resp. 43.9%

A 10% risk of your hearing getting worse

2727 out of 2727 answered

Intolerable 1,4k resp. 52.9%

Tolerable 1,3k resp. 47.1%

A 10% risk of	osychologica	l effects (e.g.	anxiety, de	pression)

2727 out of 2727 answered

Intolerable	1,4k resp. 51.3%
Intolerable	1,4K resp. 51.3%

Tolerable	1,3k resp.	48.7%
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A 10% risk of chronic pain

2727 out of 2727 answered

Intolerable	2,1k resp. 75.8 %
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Tolerable	659 resp.	24.29	%
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How much would you be willing to pay to be completely rid of your tinnitus, as a one-time payment?

2727 out of 2727 answered

Two years of income or more 550 resp. 20.2%

A full month of income	462 resp.	16.9%
Less than half my monthly income	378 resp.	13.9%
A year of income	333 resp.	12.2%
3-5 months of income	330 resp.	12.1%
Two months of income	315 resp.	11.6%
Half my monthly income	210 resp.	7.7%
6-11 months of income	149 resp.	5.5%

How much would you be willing to pay for a 50% reduction in your tinnitus, as a one-time payment?

2727 out of 2727 answered

Less than half my monthly income	573 resp.	21%
A full month of income	494 resp.	18.1%
Half my monthly income	353 resp.	12.9%

3-5 months of income	290 resp.	10.6%
Two years of income or more	288 resp.	10.6%
Two months of income	282 resp.	10.3%
A year of income	259 resp.	9.5%
6-11 months of income	188 resp.	6.9%

Do you want to be informed about tinnitus research?

2727 out of 2727 answered

I only want to get the highlights	1,4k resp. 52.5%
I am interested in in-depth information	1,1k resp. 40.7%
No, I'm not interested	184 resp. 6.7 %

What should tinnitus researchers do to better inform the community about their research?

2543 out of 2727 answered

Write easy-to-read summaries of their work	2,1k resp.	80.9%
Interact directly with communities like Tinnitus Talk	1,4k resp.	55.7%
Create educational videos	1,3k resp.	52.3%
Provide free access to academic publications	1,2k resp.	48.1%
Take part in the Tinnitus Talk Podcast	1k resp.	40%
Take part in webinars	742 resp.	29.2%
Other	24 resp.	0.9%

When do you want to be informed/updated about a tinnitus study that interests you?

2543 out of 2727 answered

I want to get updates while the study is ongoing, even if there are no hard results yet, AND learn about the final results at the end

1,4k resp. **54.4**%

Only at the end – I just want to know the final results	1,2k resp. 45.6 %
Would you like to directly interact with tinnitus researchers?	
2727 out of 2727 answered	
Yes	1,8k resp. 64.9 %
No	956 resp. 35.1%
What kind of interaction with tinnitus researchers are you interested in? 1771 out of 2727 answered	
Participating in a trial to test a new treatment	1,2k resp. 65%
Participating in data collection (filling in surveys)	1k resp. 56.5%
Choosing/voting which project should get funded	484 resp. 27.3%
Interpreting/discussing study results	475 resp. 26.8 %

1,8k resp. 65.1%

Setting research priorities and objectives	465 resp.	26.3%
I don't know	358 resp.	20.2%
Public outreach	330 resp.	18.6%
Conducting data analysis	291 resp.	16.4%
Co-designing a study	189 resp.	10.7%
Other	4 resp.	0.2%

Have you ever donated money to tinnitus research?

2727 out of 2727 answered

No

I donated to an organization that supports tinnitus research	430 resp. 15.8 %
I don't remember/prefer not to say	346 resp. 12.7 %
I donated to a specific research project	91 resp. 3.3 %

tinnitus research	84 resp.	3.1%
Which of the following are you at least 50% likely to do in the coming year to support tinni 2727 out of 2727 answered	itus research?	
Volunteer as a research subject, if the opportunity arises	1,3k resp.	47%
Donate money to research that I value	905 resp. 3	33.2%
Donate money to a tinnitus organization	684 resp. 2	25.1%
Nothing	661 resp. 2	24.2%
Volunteer for a tinnitus organization	400 resp. <u>1</u>	14.7%
Fundraise for research that I value	180 resp.	6.6%
Start my own campaign/project	86 resp.	3.2%

I donated BOTH to a specific research project AND an organisation that supports