The part that we at Tinnitus Hub want to play is in bridging the gap between patients and researchers, and in raising the profile of tinnitus. In coordination with our sister site, Tinnitus Talk, we recently conducted a survey to understand more about ourselves and hopefully gain new insights that can help seed future research. The survey link was also hosted by ATA on their website – so to those of you who participated – thank you!

The data presented here is from the two weeks of February 8-22, 2016. During that time, 4,047 respondents took the survey. Of those, less than one percent who took part were under 18 years old, and representation rose with age, peaking at 30 percent from the 55-64 years old category and dropping sharply afterwards. There was an even mixture of people with new onset and long-term tinnitus.

Surprisingly, over 28 percent of people didn’t know the cause of their tinnitus. Of those that did know, the standout group was from noise-induced hearing loss (14 percent), with the greatest numbers outside of this being from acoustic trauma (nine percent), followed by virus (eight percent), stress (five percent) and ototoxic drugs (five percent). Nearly 57 percent of all respondents said they had hyperacusis to some degree (mild, moderate or severe).

We received a lot of information on the myriad treatments people had tried. The most used, and with the most significant improvement, was from self-administered sound therapy, with more than 54 percent improving. The treatments where a “big improvement” was most often indicated were hearing aids (15 percent), Tinnitus Retraining Therapy (13 percent) and CBT (12 percent).

Nine hundred thirty five people had tried supplements as a treatment but over 73 percent of that number found no difference in using them and 22 percent said they only helped a little. Those percentages were almost identical for the 503 respondents that had tried acupuncture. On the whole, very few people were adversely affected by treatments, although antidepressants made more than 12 percent worse, the highest figure of any adverse impact response.
It's well known that tinnitus and stress responses are related, and the answers on health conditions were consistent with that. We found that for 50 percent of respondents, tinnitus causes stress, 47 percent anxiety, 16 percent panic attacks and over 34 percent depression. The reported stress-related impact is far higher for the group in their first year of tinnitus, and then it gradually lowers over time. This highlights the critical need to get the right care early on; to help manage the anxiety response and stop the destructive cycles of worrying that most of us know too well.

Nearly 64 percent of people say they have some degree of hearing loss. Nearly 62 percent perceive their tinnitus in one or both ears, only 7 percent perceive it solely in their head, though just short of 30 percent say it’s in both the ears and the head.

Interestingly, over 32 percent said they could change the volume of their tinnitus with jaw or neck movements (somatic tinnitus), and more than 38 percent report a more general problem with their neck, jaw or both.

Nearly 40 percent of survey takers felt that dietary items affected their tinnitus. The biggest culprits were caffeine, alcohol and salt. Overall, they were perceived to make things worse, though some people identified positive impacts.

Less than 35 percent of people had heard of tinnitus before they got it. It is encouraging to see, however, that the less time people had had tinnitus, the more likely they were to be aware of it beforehand. These findings suggest that the awareness message is spreading, but also underscores the need to do more.

There is some intriguing data so far from this initial survey. We’ve shown that the online community of Tinnitus Hub, Tinnitus Talk, ATA and others can not only help patients but can also play an active part in informing the research community about what it’s really like to live with tinnitus and hyperacusis.

We are inviting researchers to examine the survey data in more depth. The aim is to learn more about ourselves and push the use of online platforms for future research and treatment delivery. Our belief is that together, we can start making some real noise, developing better treatments and collaborate towards really pushing the search for new and better treatments and ultimately cures.

To see the full results of the survey, head over to our friendly support forum at Tinnitustalk.com.