

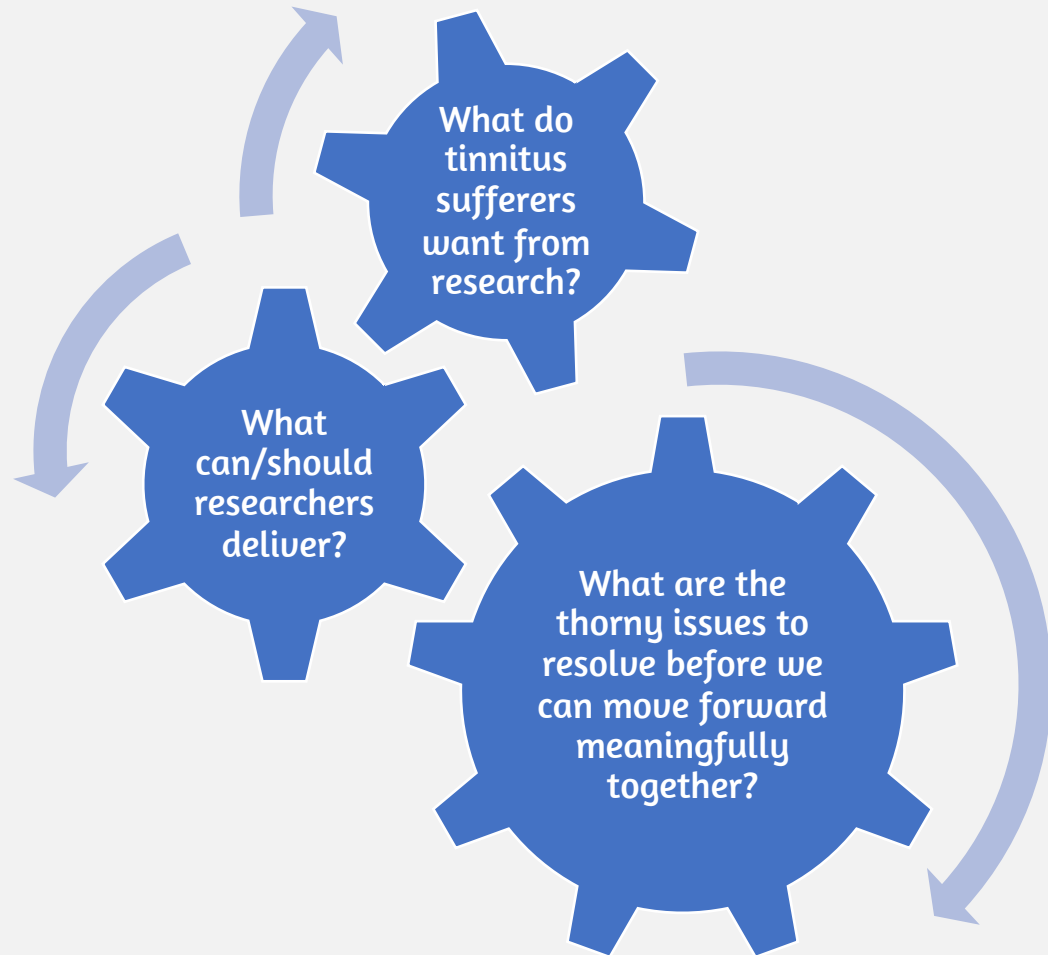
# The Quest for Patient-Led Tinnitus Research



*Hazel Goedhart  
Director, Tinnitus Hub*

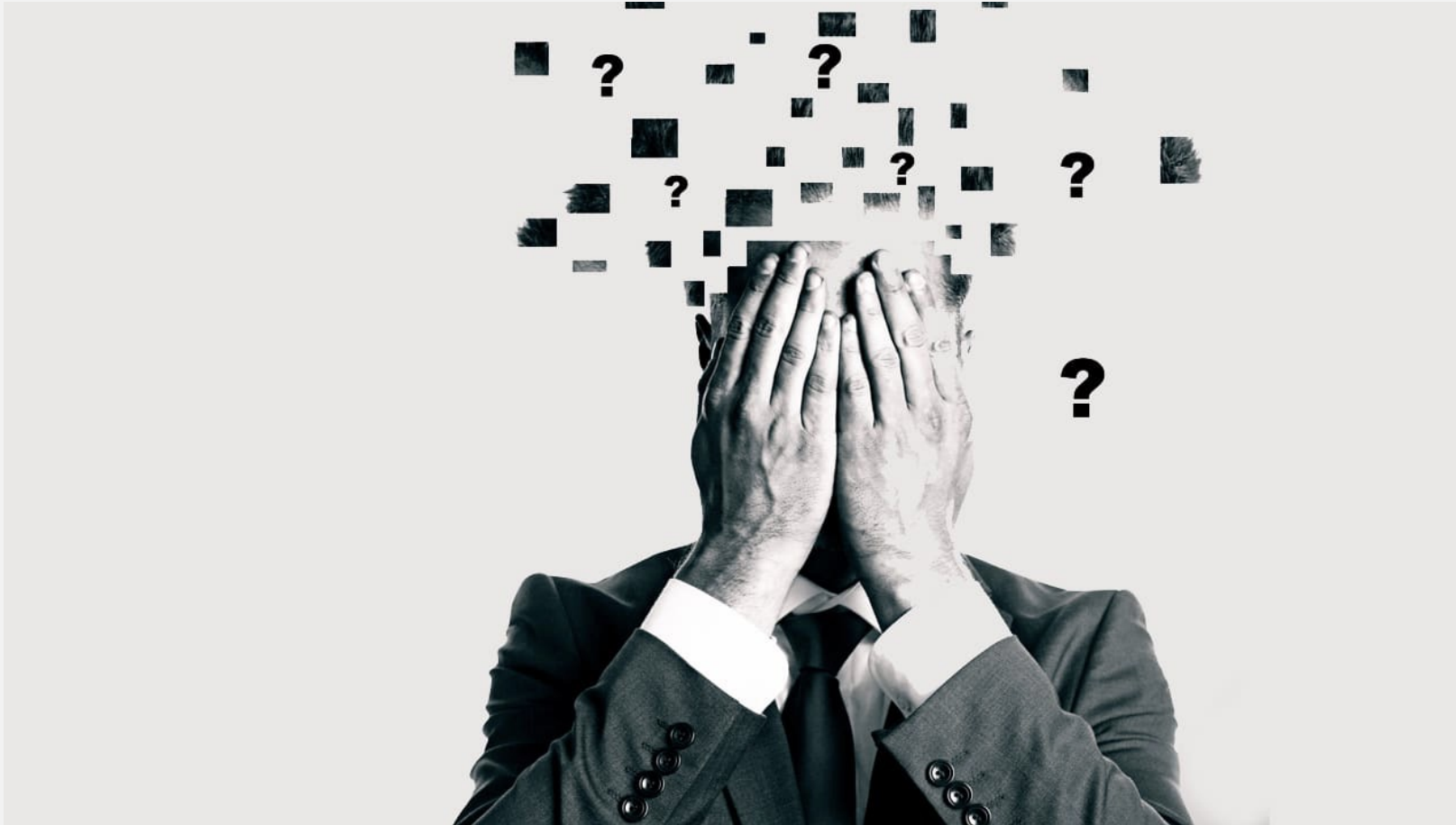
*Markku Vesala,  
Founder, Tinnitus Hub*

# Greasing the gears of PPI/citizen science

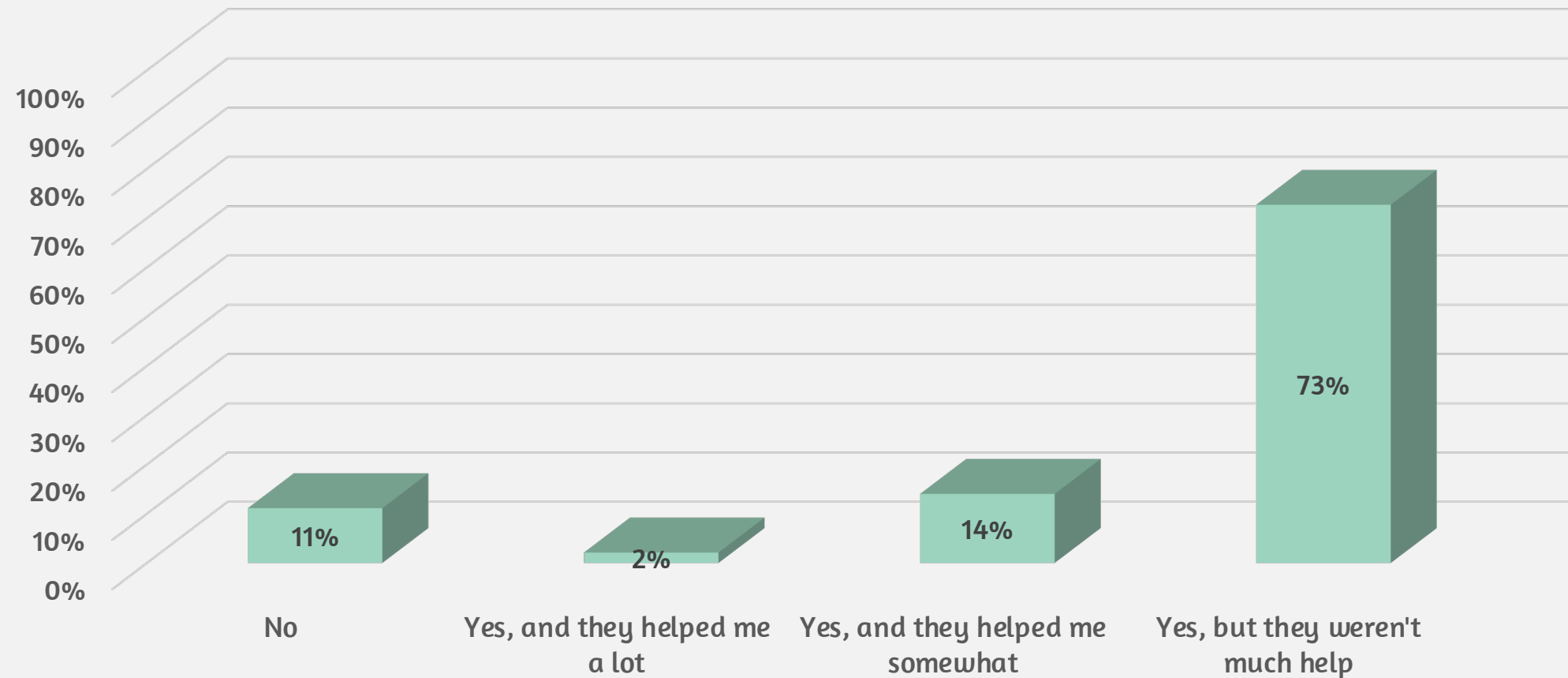


How can Tinnitus Hub help build a bridge between patients and researchers?

To understand patients' research expectations,  
we must first understand their experiences...

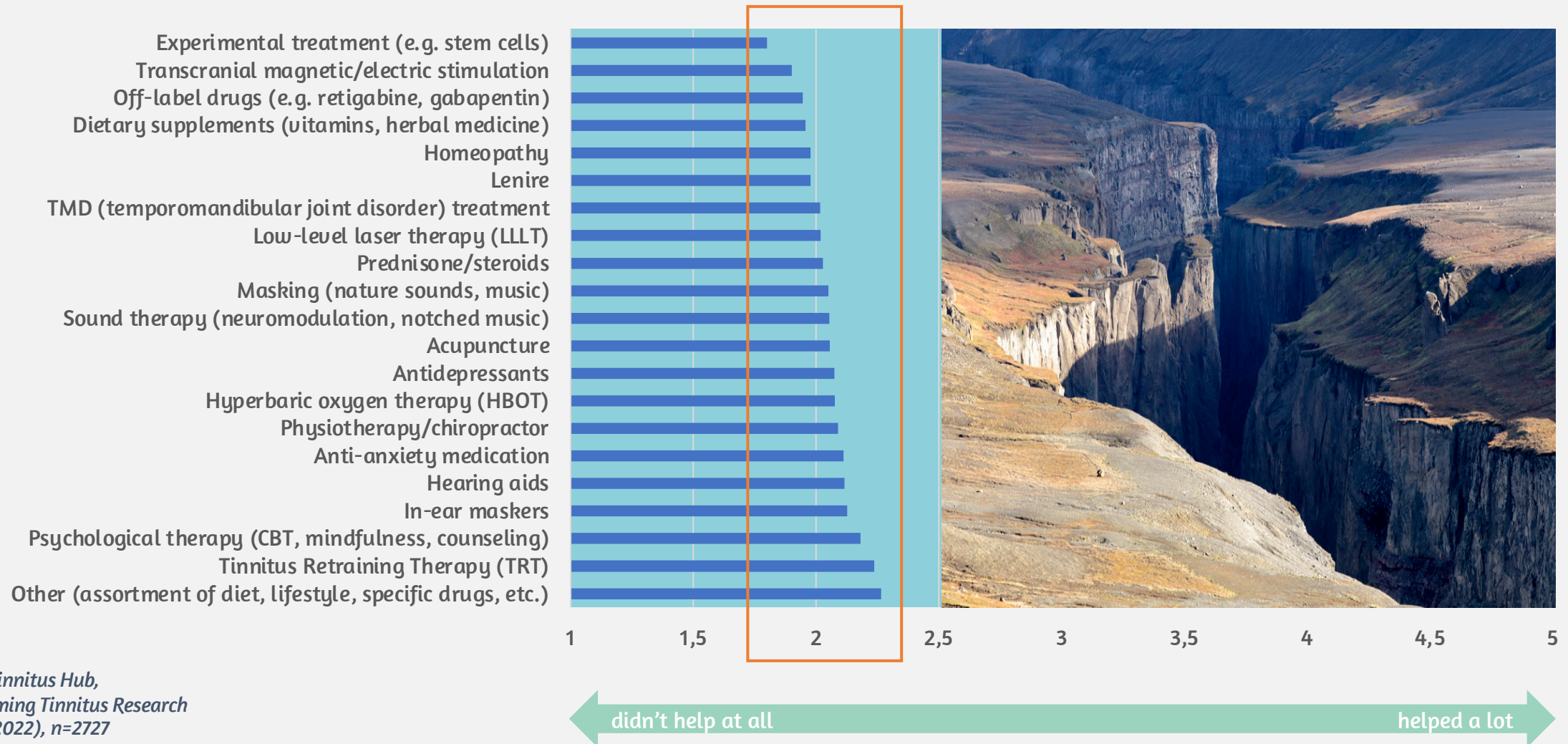


# Did you see a healthcare professional for your tinnitus?



Source: Tinnitus Hub,  
Transforming Tinnitus Research  
Survey (2022), n=2727

# What treatments have you tried to help with your tinnitus? Did these help?



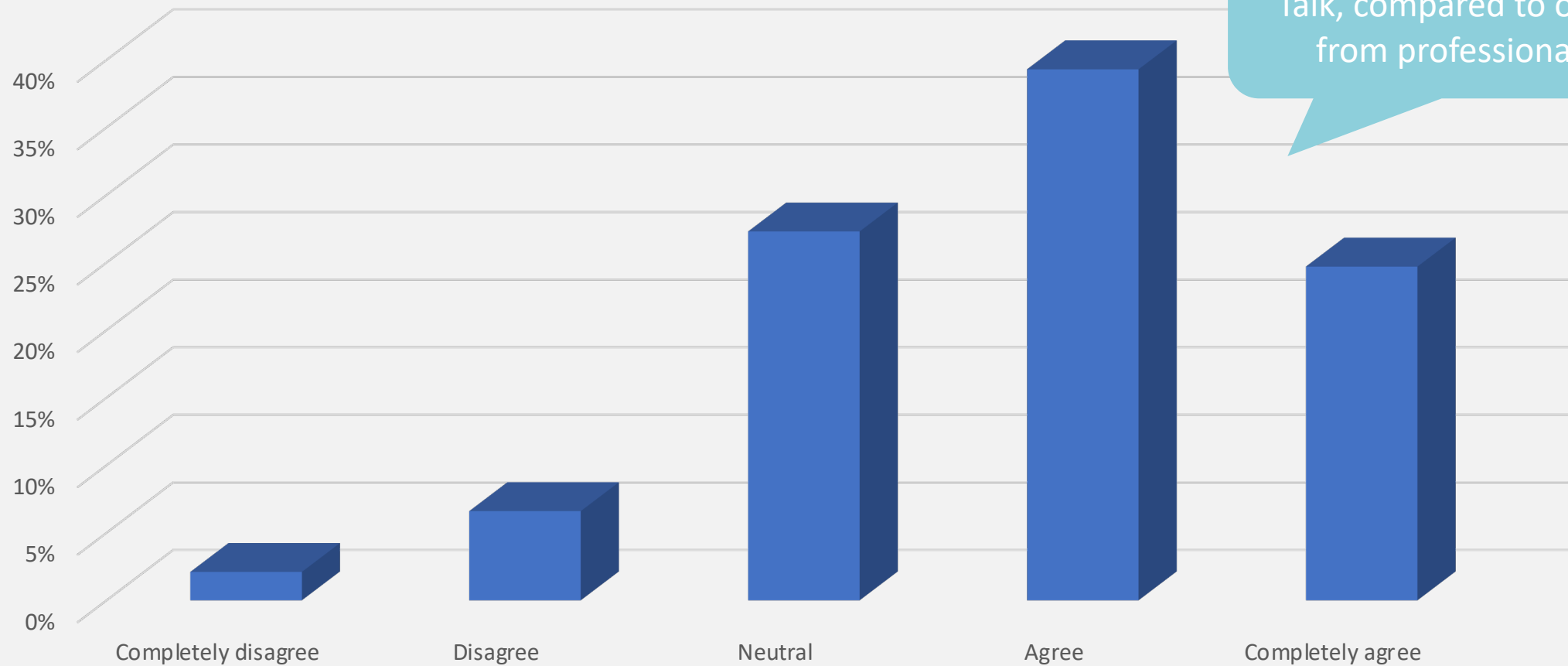
Source: Tinnitus Hub,  
Transforming Tinnitus Research  
Survey (2022), n=2727

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



Source: Tinnitus Hub,  
Transforming Tinnitus Research  
Survey (2022), n=2727

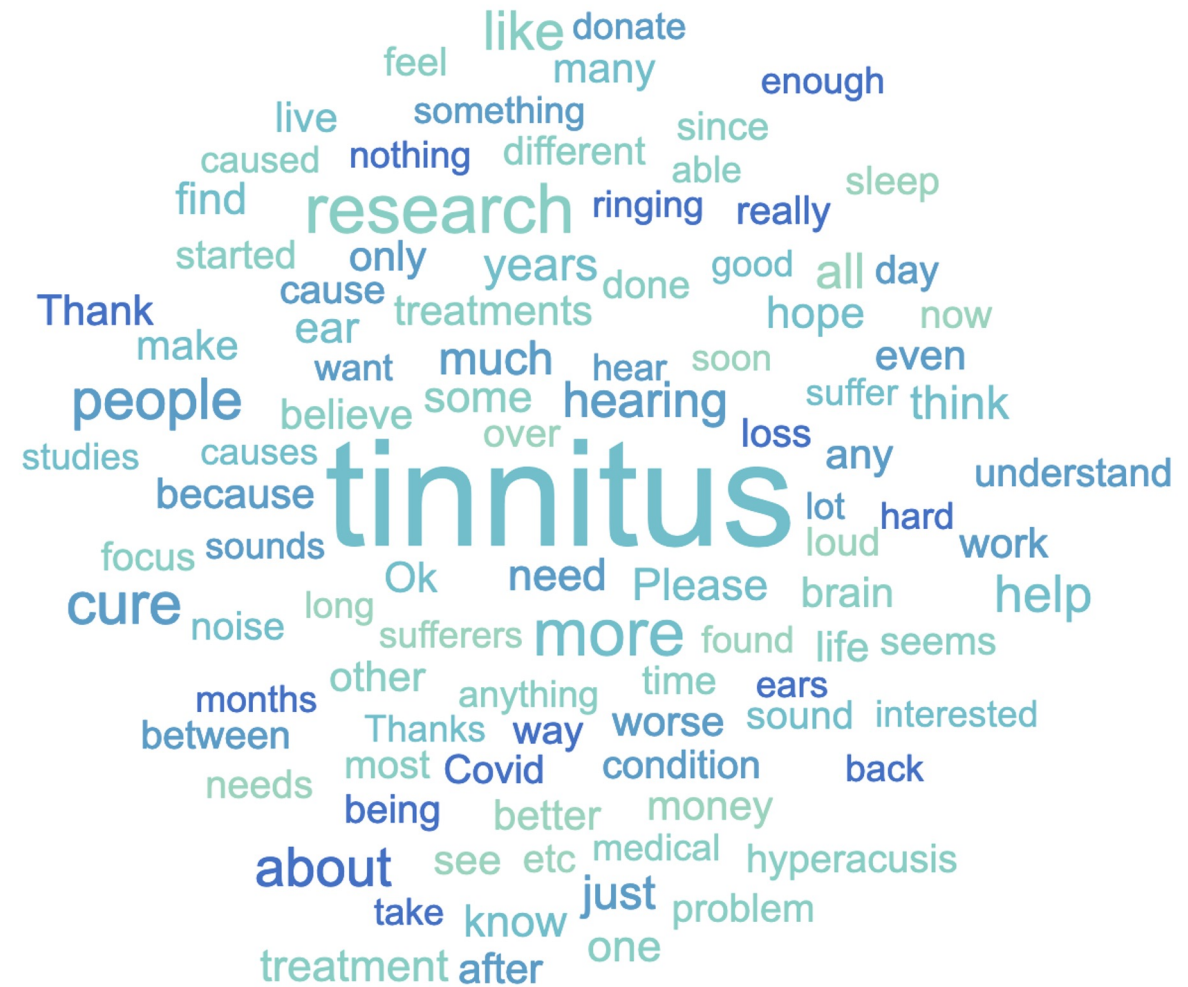
# Do you agree/disagree with: The information and advice posted by others on Tinnitus Talk has helped me?



64% find benefit from Tinnitus Talk, compared to only 18% from professional care

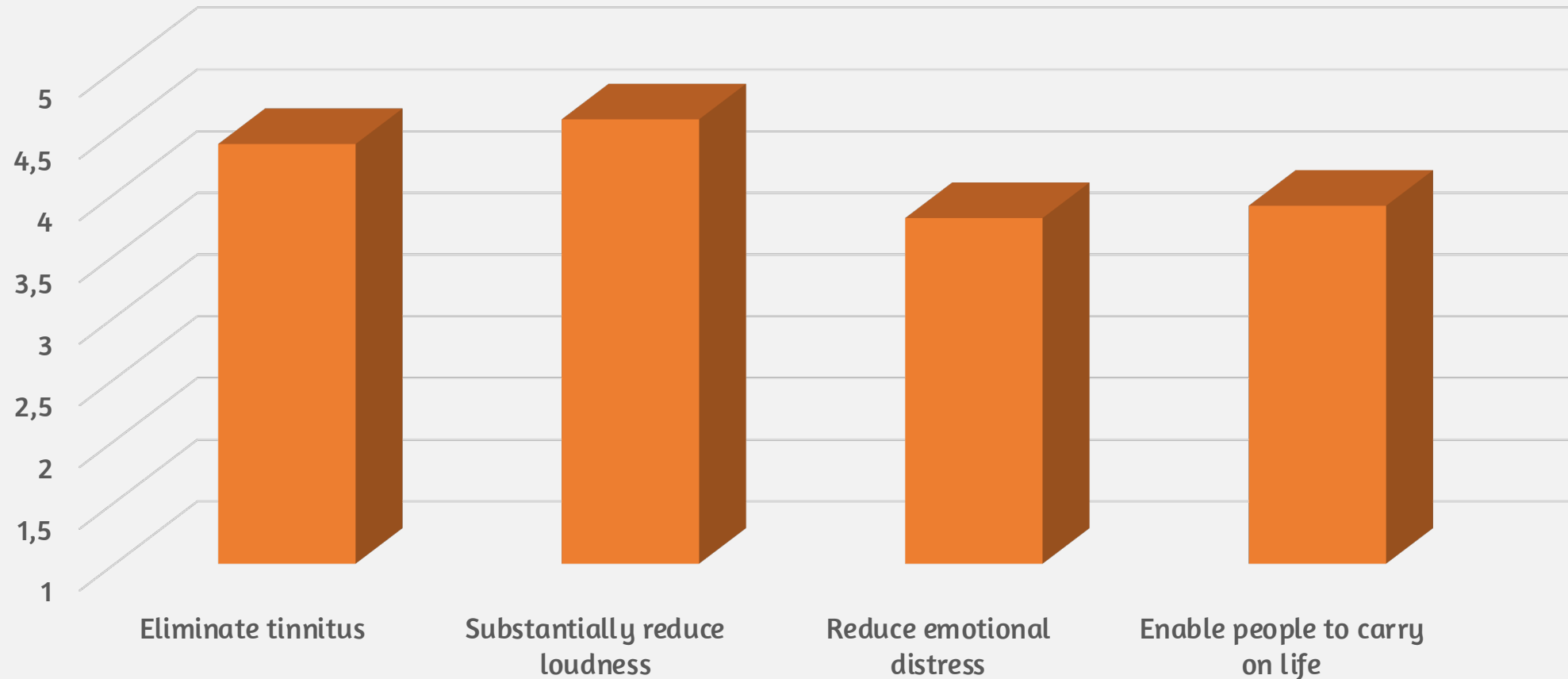
So, what DO  
tinnitus  
sufferers  
want from  
research?

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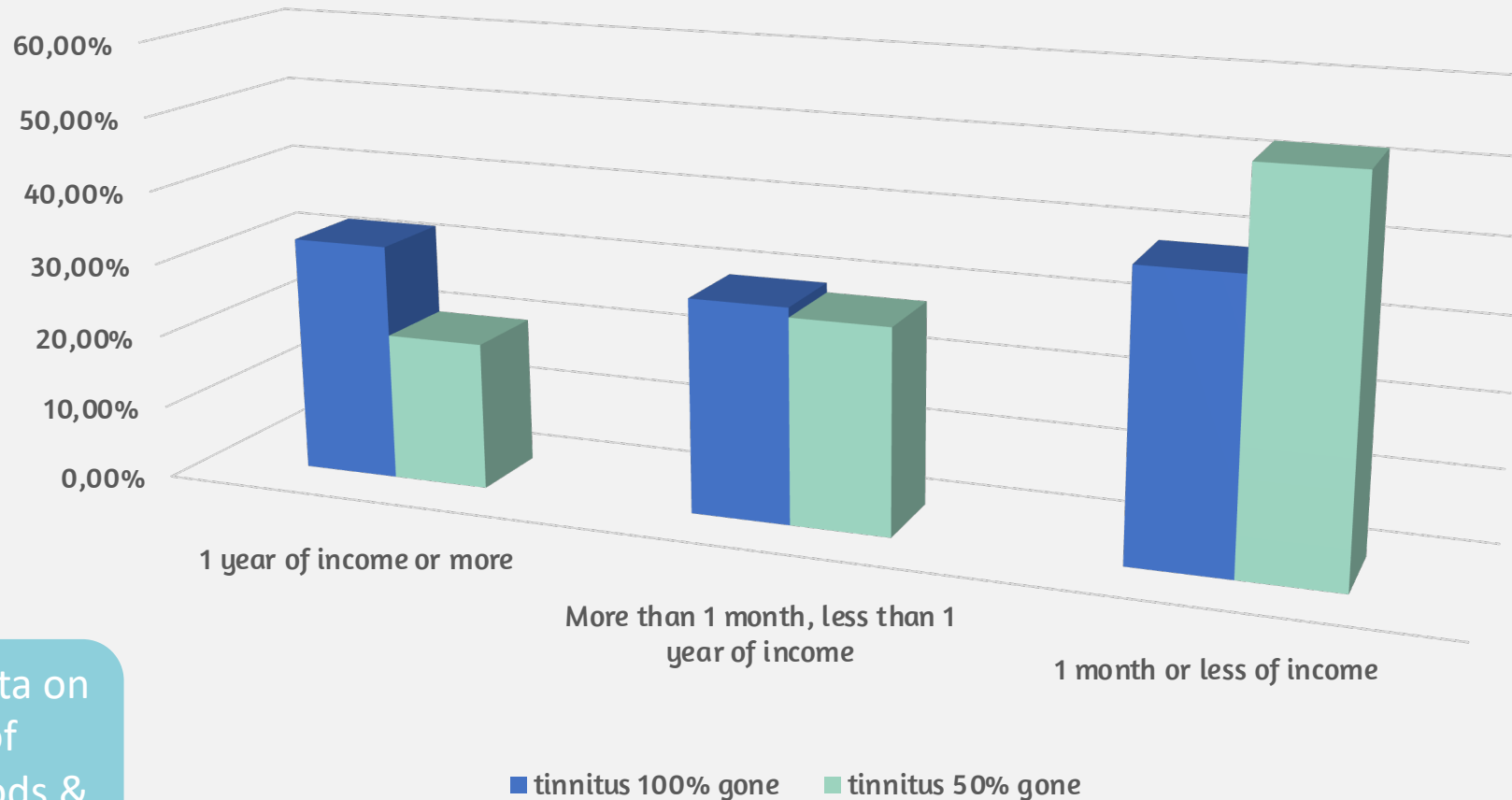


# The critical objective of tinnitus research should be to... *(assess each on 1-5 scale)*



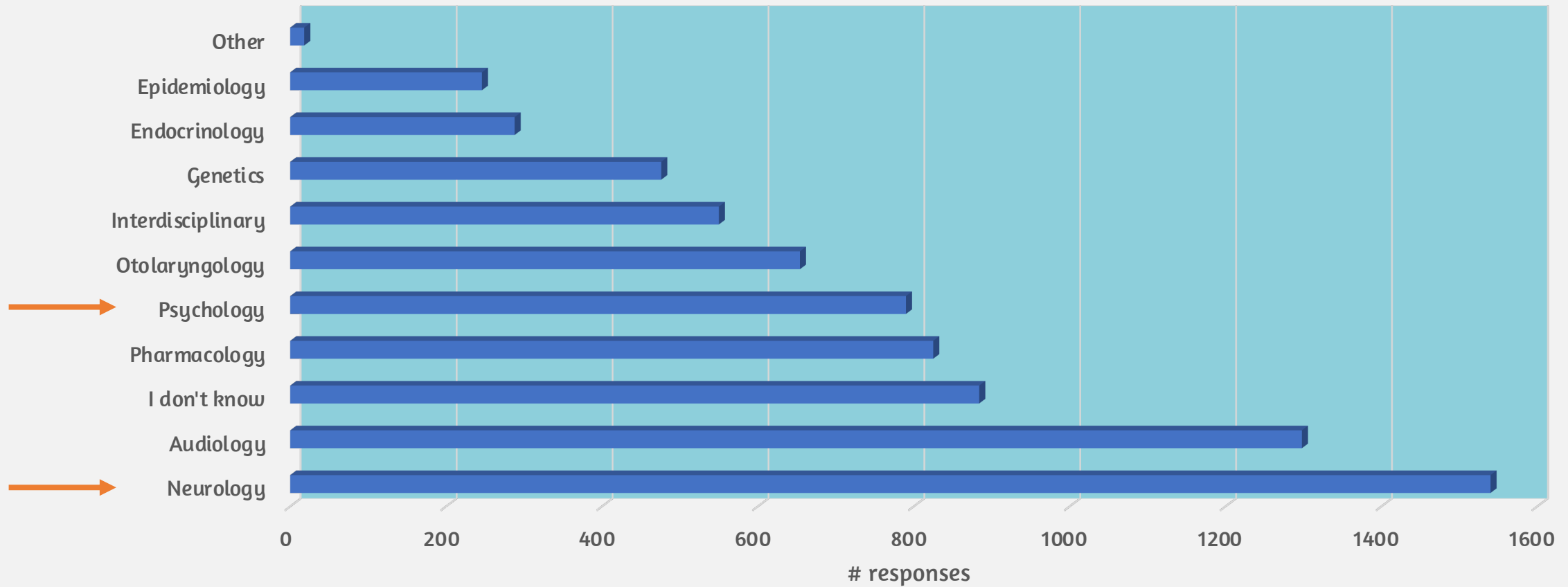
Source: Tinnitus Hub,  
Transforming Tinnitus Research  
Survey (2022), n=2727

# How much would you be willing to pay (once) to be 100%/50% rid of your tinnitus?



Also gathered data on acceptance of treatment methods & risk tolerance

# Which fields of tinnitus research are you interested in? *(unlimited choice)*



Source: Tinnitus Hub,  
Transforming Tinnitus Research  
Survey (2022), n=2727

Community voting on  
the 'best research  
paper of the month'

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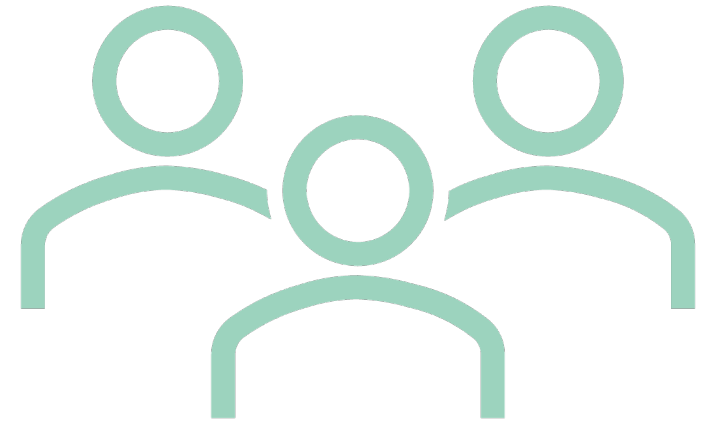
*results from 6 months  
of polling (2021)*



- Six monthly winners (Jan-Jun 2021)
  - Won often by a large margin
  - ALL were related to **treatment efficacy testing** (non-psychological treatments)
- Runner-ups:
  - Investigating **neural correlates of tinnitus**
  - Various **meta-analyses**
- No clear patterns in studies with least # votes

## “Web-based discussion forums reveal the person-centred relevance and importance of tinnitus” (2021), Hall et al.

- Five major themes emerged from discussion threads:
  - **diversity** of tinnitus experiences
  - **severity** of complaints for the unfortunate few
  - short-term **fluctuations** in tinnitus experience
  - life’s long-term **journey** in living with tinnitus
  - feeling **misunderstood** by others
- Reference to “**suffering**” rather than “bothersomeness” or “distress”
- **Patient empowerment** as the defining feature of the web discussion forum contributing to the therapeutic benefit of participation expressed by some discussants



- Psychological research alone is not the answer
- Greatest interest in neurology and audiology
  - Tinnitus models exploration, bottom-up & top-down
- Easier to see relevance of applied vs fundamental research
  - Need to connect the dots between the two
- An individualised approach is needed
- But ... no clear research agenda can emerge from the patient community alone, this requires engagement with researchers

A white computer keyboard is partially visible in the upper left corner. A silver stethoscope with a black chest piece and earbuds is positioned diagonally across the center of the image. The background is a plain white surface.

**What are the implications for research?**

# Hot topics for debate



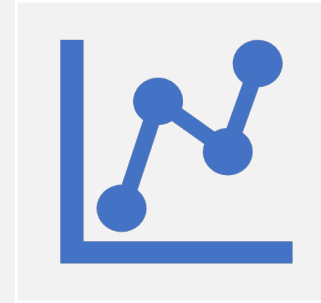
## Loudness versus distress

What does it mean to target one v the other?

Be clear on which is the target

Disentangle lack of loudness/distress correlation within populations from significance within an individual

Question the usefulness of the concept “tinnitus disorder”



## Outcome measures

“Clinically significant improvement” is not meaningful (enough) for patients

Frameworks developed with patient input (i.e. COMiT study) are not being used, why?

Consider general wellbeing and quality of life

Tinnitus characteristics and comorbidities matter, not just distress

# Clinical study design & reporting

- **Patient selection**
  - Whom is the target: acute onset, severe sufferers, etc.?
  - Why do treatments work for some but not others?
- Create **conditions for high-quality research**, by agreeing on:
  - Minimum data to be collected
  - Involving the right competencies
  - For treatments, only RCTs!
- Report on **dropouts and adverse event**



# Our experiences with research collaboration

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**Co-authored 9 papers in academic journals**

Patient empowerment  
Treatment outcomes  
Somatosensory tinnitus



**Some amazing PPI ambassadors in the research community**



**However, significant room for improvement**

Criticism is not well taken, generally  
Occasional patronising attitude  
Invited late to the party  
Seen as channel for distribution, not participation

# How Tinnitus Hub can add value = *call for partnerships*



- Immense potential for data collection (biggest survey = 8k+ responses)
- Direct access to large online community
- Over a decade of experience working with researchers & tinnitus sufferers

Visit us at:

[www.tinnitushub.com](http://www.tinnitushub.com)

Engage with the community at:

[www.tinnitustalk.com](http://www.tinnitustalk.com)

# Thank You!

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Please get in touch for  
collaboration opportunities:

[info@tinnitushub.com](mailto:info@tinnitushub.com)

