

# ***Promoting Misophonia Research Progress***



*A Synthesis of **Research Strategies  
and Emerging Challenges** from the  
2024 MRF Annual Funded  
Investigators Meeting*

# About

The Misophonia Research Fund (MRF) team developed this resource following the Troubleshooting Research Challenges and Learning from Successes Workshop at the 2024 MRF Annual Funded Investigators Meeting.

This guide is intended to increase accessibility to valuable insights and strategies cultivated by the diverse experts within the MRF research community.

The 2024 MRF Annual Funded Investigators Meeting gathered MRF Funded Investigators, trainees, Scientific Advisory Board members, and lived experience community representatives to share research updates, collaboratively problem-solve, and identify next steps for the research field.

The content of this summary was informed by the following dedicated discussion topics:

1. Participant recruitment and retention
2. Data acquisition and analysis pipeline
3. Incorporating the lived experience perspective
4. Developing open data or open science tools
5. Securing external misophonia research funding

Attendees discussed the strategies and challenges faced within each of these topics and then shared key takeaways with the room. Takeaways were packaged into this summary resource to give current and future investigators strategies that can promote the success of their projects.

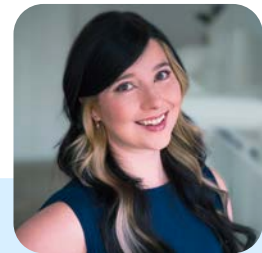
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## *Topic 1*

# ***Participant Recruitment & Retention***



# Securing External Misophonia Research Funding

## Strategies to Promote Success

### Organizational Support

The **MRF** can share recruitment flyers on our website and social media accounts (contact: [info@misophoniasfund.org](mailto:info@misophoniasfund.org)).

The patient advocacy organization **soQuiet** can share recruitment flyers on its community outreach list (contact: [research@soquiet.org](mailto:research@soquiet.org)).



### Proposal Approach

- Online studies, where applicable, have fewer participation barriers.
- The number of on-site visits can impact retention; consider aspects that could be consolidated or completed virtually.
- Studies testing possible therapeutic interventions are often easier to recruit for.
- Promote study information via social media (i.e., targeted ads, Facebook groups).
- Utilize tools like Prolific — an online platform researchers can use to recruit participants, manage data collection, and pay participants for their contributions.
- Network with other misophonia researchers to share research strategies or contact lists.
- Use local, nationwide, and international media where possible; MRF Funded Investigators have found significant recruitment success from discussing their research studies on local news shows or National Public Radio stations.
- Consider reaching out to your university media relations office to access existing communications pipelines and expand your media coverage.

# ***Participant Recruitment & Retention***

## ***Insights on Challenges***



### **Representation & Access**

The prevalence of misophonia and various facets of its epidemiology are still being investigated, increasing the challenge of ensuring that study participants represent the real-world misophonia population. The populations that are most easily accessed for research studies are limited in many important aspects of population diversity. Moving forward, it is important to identify strategies to make studies equally accessible across diverse populations.

### **Limited Male Participants**

Researchers have often found greater response to study recruitment amongst females than males. Strategies to boost recruitment of male participants should be taken into account.

### **Spectrum of Sound Sensitivity**

Self-selected samples can be impacted by individuals with misophonia having a perception of their misophonia that misaligns with the severity as indicated by their clinical misophonia scores. For this, and a variety of other reasons, it can be difficult to recruit individuals across the full range of misophonia severity, including mild, moderate, and severe. For example, individuals with severe misophonia may have limitations to their interest in participating in studies with trigger sound exposure.

### **Centralized Participant List**

A key challenge in misophonia research is the lack of a centralized participant list, making recruitment for studies more difficult. As the field grows, researchers can encourage participants to join the soQuiet participant list, a valuable and growing resource for online studies and future research opportunities.



## *Topic 2*

# ***Data Acquisition & Analysis Pipeline***



# Data Acquisition & Analysis Pipeline

## Strategies to Promote Success

- EEG is a commonly used tool that is relatively accessible to learn and implement. Furthermore, there is a large amount of EEG research and resources across various disorders.
- Participant scheduling can create a bottleneck at various points in data collection. Researchers should consider utilizing tools or apps that reduce logistical hurdles, so long as they are scientifically-sound. An example is the Mimi Hearing Test application to complete basic audiological screening.



## Insights on Challenges

### Facilities and Personnel

Research projects may face a variety of challenges (i.e., facility availability, scheduling, recruiting dedicated project personnel); these challenges often times require troubleshooting or project pivots.

### Stimuli Calibration & Standardization

Calibration of trigger sounds can be difficult depending upon the characteristics of the chosen sound (i.e., length of sound, repetition of sound). Existing open-source databases do not contain standardized sounds and visual stimuli, which can hamper data comparison and replication.

### Data Set Heterogeneity

Heterogeneity in individual responses to sounds can make it difficult to determine the best group data analysis.



# *Topic 3*

## ***Incorporating the lived experience perspective***



# ***Incorporating the lived experience perspective***

## *Strategies to Promote Success*

### **Use Objective Phrasing**

Using subjective terms to describe your study can have a big positive or negative impact on the success of your recruitment and study materials. Subjective phrasing can yield a different result for different people, whereas more objective phrasing or specific descriptors can help to standardize interpretations.

#### **EXAMPLE 1**

Instead of “What sounds **bother** you?” try “Which of the following sounds, if any, **cause you to experience a physical or emotional response such as irritation, discomfort, or distress?**” (Followed by a checklist of misophonic sounds)

#### **EXAMPLE 2**

Instead of “Does sound sensitivity **interfere** with your life?” try “In the past month, how often have sound-related experiences **affected your ability to work, study, or interact socially?**”

#### **EXAMPLE 3**

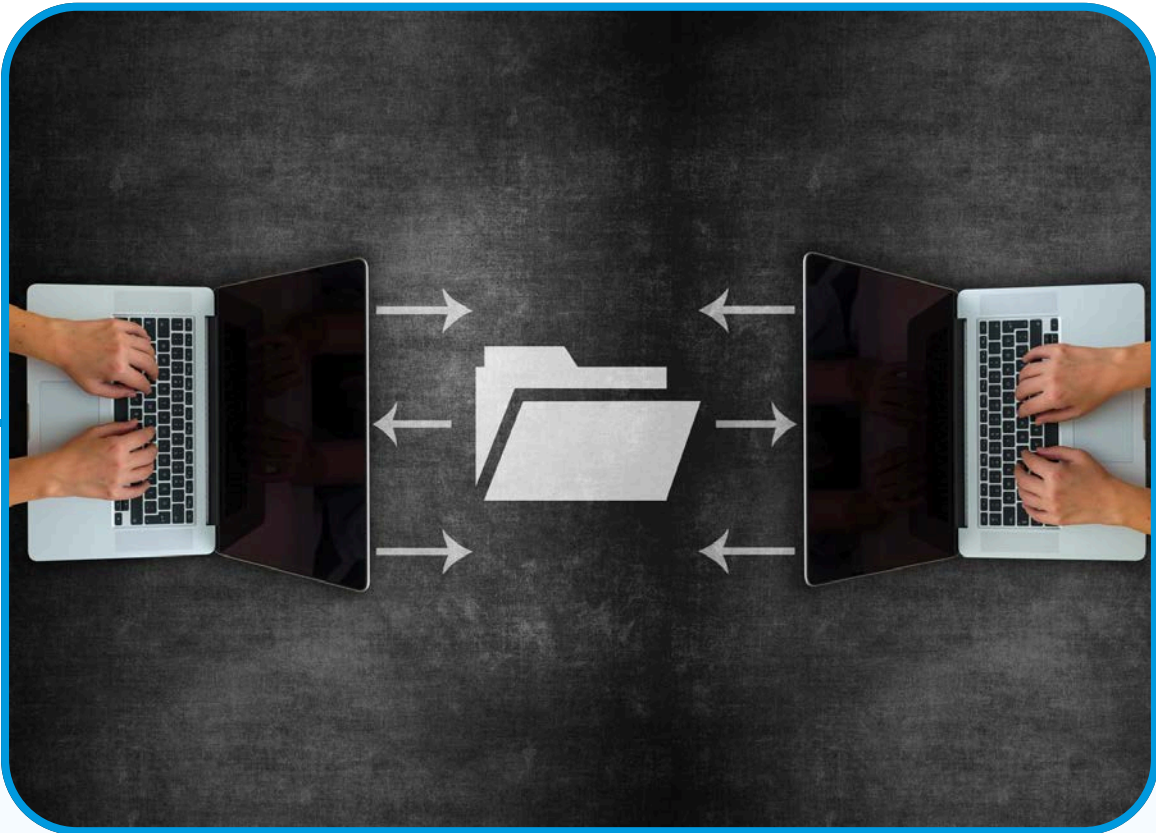
Instead of “Do you have a **strong reaction** to **normal everyday sounds?**” try “Do you **experience physical or emotional discomfort** in response to **specific sounds such as chewing, tapping, or breathing?**”

### **Helpful Reminders**

- To avoid biased recruitment or study data, it is important to consider cultural differences and societal gender norms around affective responses.
- Utilize the Lived Experience Advisory Panel (LEAP) available through soQuiet and other community resources.
- Avoid communicating research findings to participants as advice for misophonia management because the data is simply not concrete enough yet.

## Topic 4

# ***Developing Open Data and Open Science Tools***





# Developing Open Data and Open Science Tools

## Strategies to Promote Success

### Collaborative Research Climate



- The misophonia research community is interested furthering the emphasis on open data and open science practices as well as proactively discussing methods to reduce the duplication of research efforts, increase ease in reproducibility, and accelerate scientific progress.
- Metadata analysis, where/when applicable, can help leverage already-existing data towards discovery. Many investigators emphasized that there is enough research being done on brain imaging to begin doing interesting meta analyses.
- Utilize the MRF listserv for funded investigators to discuss various aspects of research.

### Utilize Open Source Tools

- **Zenodo:** an open-access research data repository. Zenodo can also be used to store software, preprints, reports, posters, presentations, and more.
- **Open Science Framework (OSF):** an open science platform that allows researchers to preregister their study plans, team info, protocols, preliminary findings, and preprints. OSF can also serve as a centralized project hub for all collaborators to store and share materials.
- **OpenNeuro:** a free, open science platform for sharing and validating Brain Imaging Data Structure (BIDS)-compliant neuroimaging data, promoting open science and reproducibility in neuroscience research.
- The “**FOAMS**” database (aka Free Open-Access Misophonia Stimuli database): publicly available sound bank on Zenodo, accompanied by pilot discomfort ratings for 32 of these sounds.

# ***Developing Open Data and Open Science Tools***

## *Strategies to Promote Success*

### **Standardization is Key**

- Establishing a consensus on how to standardize and upload raw fMRI data would be beneficial for improving data sharing and collaboration.
- Ensuring consistency in the metadata provided would help promote standardization and make datasets more useful across studies.
- Providing accurate descriptions of the data is essential for transparency—for example, including details about preprocessing protocols, data cleaning methods, and the extent to which the shared data has been processed.
- Standardizing data collection methods would increase the usability of data for other research groups, facilitating replication and broader analysis.
- Developing and adopting common scales to measure misophonia symptoms would support comparability across studies and advance the field.

## **Insights on Challenges**

- The costs associated with these efforts—such as data hosting—can be substantial, posing a barrier to widespread data sharing.
- The timeline for making data available to the research community is often influenced by whether investigators believe their data still holds potential for additional findings, which can delay open access.



## *Topic 5*

# ***Securing External Misophonia Research Funding***



# Securing External Misophonia Research Funding

## Strategies to Promote Success

### CONGRATULATIONS!

Two junior investigators on MRF-funded projects have received external funding through the NIH and National Sciences and Engineering Research Council of Canada (NSERC)

Misophonia is still considered rare. Having a better idea of prevalence through expanded epidemiological research will help the misophonia community advocate at a policy level, promoting congressional acts to incentivize governmental funding for misophonia.



### Hurdles

#### Proposal Approach

- **Leverage Other Projects/Funding:** collect misophonia data by leveraging a separate grant (e.g., add a misophonia control group to a study on a comorbidity (e.g., autism, hyperacusis).
- **Consider Training Grants:** Take advantage of training grant opportunities through graduate or postdoctoral programs or departments. These grants are typically internally reviewed and focus on trainee development, allowing for more flexibility in the project subject matter.
- **Strategic Framing:** Being a relatively newly recognized disorder, funding for a misophonia-specific proposal may be harder to come by. However, to get around this funding bottleneck, try framing misophonia research in terms of fundamental, basic or translational research aimed at understanding the mechanisms between sensory inputs, perception, and behavior in the general population.
- Building a meaningful and clear impact statement that expands beyond the value of the work for the misophonia community can be helpful.

# THANK YOU!



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