

Overview on Global Biobanking Efforts of Tinnitus: Status Quo and Future Needs

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ADMINISTRATIVE INFORMATION**Support** - None.**Review Stage at time of this submission** - Preliminary searches.**Conflicts of interest** - C.R. Cederroth reports being a member of the Tinnitus UK's Professional Advisers' Committee and the American Tinnitus Association's Scientific Advisory Board.

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INPLASY registration number: INPLASY2024110063**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 14 November 2024 and was last updated on 14 November 2024.**INTRODUCTION**

Review question / Objective 1. Present an overview of biobanks currently containing tinnitus-related data. 2. Describe in detail additional data available in the biobanks identified in step 1 that may be relevant to researchers from various disciplines. 3. Discuss findings and establish meaningful guidelines on how to biobank tinnitus data.

Rationale While biobank repositories exist, there is currently no centralized or organized repository or database specifically dedicated to housing tinnitus-related information. This lack of information hampers research efforts in understanding and treating this condition. Currently, tinnitus researchers face the challenge of navigating disparate biobanks to locate relevant data, leading to inefficiencies and potential gaps in knowledge. By mapping and summarizing all biobanks that contain tinnitus-related information, we aim to create a comprehensive resource that

will facilitate findability and utilization of existing data. This endeavor is crucial for advancing tinnitus research, fostering collaboration, and ultimately improving outcomes for individuals affected by this often debilitating condition. With a clear overview of available data sources, researchers can more effectively conduct large-scale studies, identify patterns, and develop targeted therapies.

Condition being studied Tinnitus, defined as the perception of sound without an external stimulus, lacking informational significance for the affected person (Baguley et al., 2013 - PMID: 23827090; Eggermont and Roberts, 2004 - PMID: 15474168), manifests as either intermittent or persistent auditory sensations, potentially becoming chronic within a period of 3 to 6 months (Langguth et al., 2013 - PMID: 23948178). Although commonly characterized by tones or hisses, tinnitus may also manifest in rarer forms such as pulsatile variations, either synchronized with heartbeats or independent of them (Langguth et al., 2013 - PMID: 23948178). De Ridder et al. (2021 - PMID: 33637213) introduced a distinction within the phenomenon, wherein 'tinnitus' denotes the conscious perception of a tone or noise as previously described, while 'tinnitus disorder' encompasses instances where tinnitus is accompanied by emotional and/or cognitive impairments, autonomic arousal, and potential functional disability, leading to behavioral changes. The prevalence of tinnitus tends to increase with age and hearing loss. Nonetheless, tinnitus can onset at any stage of life (Humphriss et al., 2016 - PMID: 26804253). Global estimates of tinnitus prevalence are 14.4% for any tinnitus, and 2.3% for severe tinnitus, (Jarach et al., 2024 - PMID: 35939312) As tinnitus is strongly associated with hearing loss and hyperacusis (sensitivity to sounds), information on these two additional domains will be considered.

METHODS

Search strategy Search dates: from 01.12.2024 to 31.12.2024

Restrictions: no restrictions regarding publication period. In terms of language, it is important that a data showcase is available. If this is not the case, we won't include the biobank because we won't be able to check what tinnitus-related questions it might have.

Searches prior final analysis: yes, a preliminary search was already carried out (PubMed and Google Scholar). But the final search will be more

exhaustive and include more bibliographic databases and also a Google web search.

The search will be carried out by two independent reviewers.

We will adopt a four-step search strategy:

1. Search the electronic bibliographic databases
2. Search the electronic database Google Scholar
3. Web search (Web search will be carried out as systematically as possible according to the principles introduced by Briscoe et al. (2022) - PMID: 36633509)
4. Biobank repositories search

For points 1 and 2, our analysis will entail identifying the biobank referenced in the paper (backward tracking), as well as looking at who cited the paper (forward tracking).

Participant or population These criteria are relevant for the biobanks identified through the literature (journal articles) and web search.

Inclusion:

- The biobank contains tinnitus-related data (e.g., tinnitus-specific questionnaires or questions, clinical diagnosis)
- At least 500 cases
- Human samples
- Should contain genetic material
- Participants: Adults (≥ 18)
- FAIR principles: Findable, Accessible, Interoperable, and Reusable
- A website with the data showcase is available
- A common data format should be used
- Access should be guaranteed for researchers that want to use the data for research (even if there is a fee).

Intervention Not applicable.

Comparator Not applicable.

Study designs to be included We will include studies mentioning or using data from biobanks which contain tinnitus-related information. The focus is on the biobanks and the inclusion criteria of these are listed above.

Eligibility criteria Inclusion criteria are defined in 12 (Participant or population).

Information sources Embase, PsycINFO, PubMed, Cochrane Library, Web of Science, Scopus databanks, CINAHL, Google Scholar, Google web search, Biobank repositories (e.g. Biobank resource centre: <https://biobanking.org/>).

Main outcome(s) Our study aims to achieve three key outcomes. First, we will provide an overview of biobanks currently containing tinnitus-related data, offering a valuable resource for researchers. Second, we will detail the additional relevant data available in these biobanks, highlighting interdisciplinary research opportunities. Finally, we will synthesize our findings to establish guidelines for biobanking tinnitus data, promoting standardized practices for data collection, storage, and sharing. These outcomes will enhance data accessibility and usability, fostering advancements in tinnitus research and treatment.

Data management Study selection:

- Number of reviewers: Two independent reviewers will screen records for inclusion. The reviewers will be blinded to each other's decision during the selection process.
- Disagreements: In case of disagreements a third reviewer will be involved.
- Software: "CADIMA" software will be used to aid study selection and CSV spreadsheets will be used for storage. For the search through google scholar the software "Publish or Perish" will be employed.

Data extraction:

- Extracted data from study documents: Title, full abstract, authors, year of publication, publication type.
- Extracting data: Two individuals will extract and check extracted data (search string predefined).
- Disagreements: In case of disagreements a third reviewer will be involved.
- Missing data: if there is reason to believe that the biobank contains tinnitus-related information, but this cannot be found, biobank data managers will be contacted.
- Recording data: "CADIMA" software will be used to aid study selection and CSV spreadsheets will be used for storage. "Publish or Perish" will be used as a data extraction tool for the google scholar search.

Experts determine which parameters are of importance.

Which data will be synthesized including outcomes and summary effect measures:

Biobank

- Location, Country, Application, Fees, Population, Number of Tinnitus Cases, Number of Control Subjects, Longitudinal Data, Twins data, Onset of Data Collection, Ongoing Data Collection

Sample of Biobank

- Epidemiology: Age, Education, Employment, Socioeconomic Status/Household Income, Exercise, Smoking, Diet.
- Psychological Variables: Cognitive Tests, Psychological Data (Personality, Psychopathology, Coping, etc)
- Comorbidities: Headache, Anxiety, Depression, Insomnia, Psychiatric Diagnosis, Cardiometabolic Disease, Neurological Disorders, Otolological Disorders, Cervical Spine Dysfunction, Temporomandibular Disorder.
- Hearing: Self-Report with Questionnaires, Professional Hearing Test, App-Based Hearing Test, Hearing Aids, Hyperacusis
- Health Markers: Body Measures, Physiological Information, Other Health Conditions
- Genetics: Genotyping Array, Genotyping Resolution, NGS
- Biological Samples: DNA, Blood, Urine, Stool, Saliva
- Neuroimaging: MRI, PET, CT, M/EEG.

Quality assessment / Risk of bias analysis Not applicable.

Strategy of data synthesis Not applicable. Review on biobanks containing tinnitus-related information.

Subgroup analysis Not applicable.

Sensitivity analysis Not applicable.

Country(ies) involved Switzerland.

Keywords Tinnitus; biobank; systematic review; repository; database; registry; tinnitus-biobank-repository.

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