

Background noise

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Valorisation addendum

Valorisation, in addition to research and teaching, has become an important function of universities in the Netherlands. It can be defined as the process of using academic knowledge to “add value” to society through impact on/in, for example, policy, commerce, and health.

Fundamentally, society can benefit most widely from research if it is freely accessible (Wang, Liu, Mao, & Fang, 2015). It follows that if research articles do not fully present the details of how a study was conducted and what the results were in a transparent and complete way, it makes it very difficult for it to be “consumed” by others (i.e., patients, clinicians, researchers and policy-makers to name a few). Researchers, patients or policy makers cannot act on or use the information if they do not know about it and/or cannot access it. Thus in essence making our research as accessible as possible has been one way we have attempted to *valorise* our findings. In order to make the results as accessible as possible, we have chosen to publish open access and/or make pre-prints available through Researchgate or data repositories; and, provided extensive detailed results and make other materials available as supplementary digital content to accompany publications. In addition to this, we have also registered and/or published study protocols (e.g. Chapters 2 and 3). By doing so, our methods have been peer-reviewed ahead of conducting the studies and thus (hopefully) improving the quality and integrity of results. Lastly, through publishing the protocols and registering the studies, we hope to have minimised the chances of unintended duplication of studies by other research groups, as well as incorporating a safeguard against incomplete or biased reporting of results.

Following, we describe how society can benefit from the results of this dissertation. Specifically, we propose how: people with tinnitus; policy makers; researchers; and, clinicians working with people with tinnitus might use and hopefully benefit from our findings.

We have generated high quality information about the safety, efficacy and effectiveness of CBT for tinnitus

Using the Internet to obtain information about health conditions is convenient and a common practice. Approximately one in 20 of all searches on Google is for health related information (Ennis-O'Connor, 2018). However, when it comes to information available on the Internet about tinnitus, research has consistently found that what exists is highly variable in terms of quality and readability (Kieran, Skinner, Donnelly, & Smyth, 2010; Manchaiah et al., 2019; McKearney, MacKinnon, Smith, & Baker, 2018). Similarly, there is a large number of smartphone applications, also of varying quality, that people with tinnitus use to supplement/complement the information about tinnitus they receive from healthcare providers (Deshpande & Shimunova, 2019). Poor quality information about tinnitus might be misleading, inaccurate, or reflect the commercial interests of the provider of the information. For example, a recent cross-sectional study examining tinnitus related videos on You Tube found that although they were mostly about the personal experience of living with tinnitus, people with tinnitus (who were the majority of people posting videos) were equally likely as companies or clinicians to be selling or

promoting a particular product or service (Basch et al., 2018). The personal or financial interests of the presenter in the video thus might lead tinnitus patients to overestimate the benefits and underestimate the risks of a particular product.

In contrast to this, the methods we used to conduct the systematic review and meta-analysis of CBT generated a (relatively) unbiased account of its efficacy. We conducted the systematic review and meta-analysis (Chapter 3) in collaboration with and according to the strict methodological standards of the Cochrane Organisation. [Cochrane is an international collaboration of researchers, healthcare providers, patients and carers whose mission is to generate high quality, accessible evidence that addresses questions about efficacy and safety of healthcare interventions.] Cochrane does not accept any commercial or “conflicted” funding and employs methods and standards that minimises the influence of biases of researchers conducting systematic reviews and meta-analysis. Because of the enforcement of the highest methodological standards required by Cochrane, Cochrane reviews are considered the benchmark for information about healthcare. Thus, with the production of our systematic review and meta-analysis of CBT for tinnitus, we have generated information, also presented in “plain language”, that can be used by patients, policy-makers and healthcare professionals when considering what treatment options to use, fund or deliver for tinnitus related distress and interference. Indeed, our review has recently been referred to in a parliamentary inquiry into research and service provision for tinnitus sufferers conducted by House of Commons, United Kingdom. Even if, for example, policy makers or patients are prevented by financial constraints from implementing or using CBT, the results demonstrating its safety and efficacy can influence debate around and the demand for the provision of CBT for tinnitus. In other words, by generating evidence that CBT is safe and effective (at least in the short-term), we can shape/influence debate about service provision (Elliott & Popay, 2000).

In addition to patients and policymakers, other tinnitus researchers can use the results of the review to guide future studies they conduct. For example, the review can inform their choice of outcome measure, type of treatment/CBT component, comparator intervention and follow-up duration. In particular, establishing the longer-term effectiveness of CBT for tinnitus should be considered a research priority.

Improving access to treatment for tinnitus patients in the Netherlands

In the course of conducting the systematic review and meta-analysis of randomised controlled trials of CBT for tinnitus it became clear that pragmatic trials of CBT were rare. Given that, policy-makers and clinicians experience uncertainty about how the interventions would actually work in practice. Chapter 4 addresses this issue by demonstrating that it is indeed possible to provide specialised stepped-care CBT for tinnitus (Cima et al., 2012) in settings and under conditions more readily found in everyday care in the Netherlands.

The results have already had an impact on the treatment of tinnitus in the Netherlands. Specifically, and in conjunction with Chapter 3, the preliminary results contributed to the evidence base underpinning the Dutch clinical guidelines for the assessment and treatment of tinnitus that were published in December 2016 (Dutch Association for Ear

Nose Throat and Head surgery [Nederlandse Vereniging voor Keel – Neus – Oor heel kunde en Heelkunde van het Hoofd – Halsgebied], 2016). Furthermore, from 2019 specialised CBT for tinnitus was included in the standard health insurance package, thereby allowing greater numbers of people to access treatment, albeit with the caveat that currently there are only a limited number of services accredited to deliver the intervention. The current challenge is thus to build workforce capacity to deliver the intervention.

The results from the study can also be used as a reference point for future evaluations of treatment effectiveness in the Netherlands.

Helping inform assessment and treatment of tinnitus across Europe and beyond ...*gathering comprehensive data is a time-consuming process. When time is limited, it can be far too convenient to form policy recommendations based on common sense or intuition, authority, habit, status quo, or tradition.* (p. 5; Umphrey & Miraglia, 2017)

This quote further highlights the importance of making research findings as accessible and consumable as possible in order to be used. If policy makers cannot interpret the results easily or if consumers/patients do not understand whether one intervention is better than another, decisions they make about preferences, cannot be considered to be *informed*.

The pathways to access assessments and interventions for tinnitus have long been recognised as fragmented and inconsistent. Fragmented and variable assessment and treatment strategies for tinnitus can produce inequalities between patients within the healthcare system as well as exacerbating distress and disability as people either cannot access help or can only do so after delays. As part of the Tinnnet initiative (<https://tinnnet.tinnitusresearch.net/>), we undertook the systematic review of clinical guidelines (Chapter 2) to inform the development of the European clinical guideline for assessment and treatment of tinnitus. The review confirmed the assumption held by clinicians and researchers that there was a lack of existing clinical guidelines, but also highlighted that there were more similarities than differences between the recommendations of particular assessment and treatment strategies. Not only did the review contribute to the development of the European clinical guideline, but it has been viewed nearly 30,000 times, has an Altmetric score of 55 (in the top 5% of research articles), and already been cited 20 times. While the value of such metrics might be debatable, they provide a crude indication of its interest and relevance to a wide audience.

An assessment tool for psychologists, audiologists, ENTs and other clinicians working with people with tinnitus

Tinnitus related fear, as measured by the Fear of Tinnitus Questionnaire has been shown to be associated with quality of life (Cima, Crombez, & Vlaeyen, 2011) and mediate improvements in patients level of distress (Cima, van Breukelen, & Vlaeyen, 2017). However, the actual psychometric properties of the questionnaire had, until now, not been examined. A lack of data about a questionnaire conceivably affects the level of confidence one has in results and thus potentially limits/reduces its uptake. With the publication of Chapter 5, we have shown that tinnitus researchers can use the FTQ as an outcome measures and clinical psychologists can use a three-factor version to inform discussions within therapy.

References

- Basch, C. H., Yin, J., Kollia, B., Adedokun, A., Trusty, S., Yeboah, F., & Fung, I. C.-H. (2018). Public online information about tinnitus: A cross-sectional study of YouTube videos. *Noise Health, 20*(92), 1-8. doi:10.4103/nah.NAH_32_17
- Cima, R. F. F., Crombez, G., & Vlaeyen, J. W. (2011). Catastrophizing and fear of tinnitus predict quality of life in patients with chronic tinnitus. *Ear Hear, 32*(5), 634-641. doi:10.1097/AUD.0b013e31821106dd
- Cima, R. F. F., Maes, I. H., Joore, M. A., Scheyen, D. J., El Refaie, A., Baguley, D. M., . . . Vlaeyen, J. W. (2012). Specialised treatment based on cognitive behaviour therapy versus usual care for tinnitus: a randomised controlled trial. *Lancet, 379*(9830), 1951-1959. doi:10.1016/s0140-6736(12)60469-3
- Cima, R. F. F., van Breukelen, G., & Vlaeyen, J. W. S. (2017). Tinnitus-related fear: Mediating the effects of a cognitive behavioural specialised tinnitus treatment. *Hear Res. doi:10.1016/j.heares.2017.10.003*
- Deshpande, A. K., & Shimunova, T. (2019). A Comprehensive Evaluation of Tinnitus Apps. *Am J Audiol, 1*-12. doi:10.1044/2019_aja-18-0135
- Dutch Association for Ear Nose Throat and Head surgery [Nederlandse Vereniging voor Keel – Neus – Oor heel kunde en Heelkunde van het Hoofd –Halsgebied]. (2016). *Guideline Tinnitus [Richtlijn Tinnitus]*. Retrieved from Utrecht, Netherlands: https://richtlijndatabase.nl/richtlijn/tinnitus/tinnitus_-_startpagina.html
- Elliott, H., & Popay, J. (2000). How are policy makers using evidence? Models of research utilisation and local NHS policy making. *Journal of Epidemiology and Community Health, 54*(6), 461. doi:10.1136/jech.54.6.461
- Ennis-O'Connor, M. (2018). As Google Turns 20, What's Next For Health Information Searching Online? Retrieved from <https://hcsmonitor.com/2018/09/27/as-dr-google-turns-20-whats-next-for-health-information-searching-online/>
- Kieran, S. M., Skinner, L. J., Donnelly, M., & Smyth, D. A. (2010). A critical evaluation of Web sites offering patient information on tinnitus. *Ear Nose Throat J, 89*(1), E11-14.
- Manchaiah, V., Dockens, A. L., Flagge, A., Bellon-Harn, M., Azios, J. H., Kelly-Campbell, R. J., & Andersson, G. (2019). Quality and Readability of English-Language Internet Information for Tinnitus. *J Am Acad Audiol, 30*(1), 31-40. doi:10.3766/jaaa.17070
- McKearney, R. M., MacKinnon, R. C., Smith, M., & Baker, R. (2018). Tinnitus information online - does it ring true? *J Laryngol Otol, 132*(11), 984-989. doi:10.1017/s0022215118001792
- Umphrey, L. R., & Miraglia, P. R. (2017). Evidence-Based Policy Making. In M. Allen (Ed.), *The SAGE Encyclopedia of Communication Research Methods*. Thousand Oaks, California: SAGE.
- Wang, X., Liu, C., Mao, W., & Fang, Z. (2015). The open access advantage considering citation, article usage and social media attention. *Scientometrics, 103*(2), 555-564. doi:10.1007/s11192-015-1547-0