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# Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029346
Article Type:	Research
Date Submitted by the Author:	23-Jan-2019
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Keywords:	Tinnitus, Health services evaluation, standard of care, Pan-European, Guidelines, Barriers



# Title page

Title:

Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

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## Abstract:

Tinnitus remains a scientific and clinical problem whereby, in spite of increasing knowledge on effective treatment and management for tinnitus, very little impact on clinical practice has been observed. There is evidence that prolonged, obscure, and indirect referral-trajectories persist in usual tinnitus care.

**Aim:** It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and implementation activities are systematically tailored to the specific determinants of practice. The aim of this study was to administer a health-service evaluation survey to scope current practice- and knowledge of standards in tinnitus care across Europe. The purpose of this survey was to specifically inform the development-process of a European clinical guideline that would be implementable in all European countries.

**Method:** A survey was developed by the study steering group, piloted on clinicians from the TINNET network, and underwent two iterations before being finalized. The survey was then administered to clinicians and policy makers from 24 European countries.

**Results:** Data collected from 625 respondents revealed differences in national healthcare structures, tinnitus-definitions, characteristics of tinnitus -patients, assessment procedures, and particularly in available treatment options. Differences between northern and eastern European countries were most notable.

**Discussion:** Most European countries do not have national clinical guidelines for the management of tinnitus. Reflective of this, clinical practices in tinnitus healthcare vary dramatically across countries. This equates to inequities of care for people with tinnitus across Europe and an opportunity to introduce standards in the form of a European clinical guideline. This survey has highlighted important barriers and facilitators to implementation of such a guideline.

**Keywords:** Tinnitus, health-service evaluation, Standard of care, Pan-European, Guidelines, Barriers, Facilitators

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## **Strengths & Limitations**

# Strengths:

- This is the first and only pan-European health-service evaluation to scope current practiceand knowledge of clinical standards in tinnitus healthcare, which offers valuable information for ongoing endeavors to develop multidisciplinary guidelines and a standard of tinnitus health-care across Europe.
- Results provide health service information and expert opinions on national healthcare structures, reflecting a truly pan-European point of view.
- Based on the results we have succeeded in defining important barriers as well as facilitators to the development and implementation of a guideline that can serve the whole of Europe, by being meaningful and actionable, and offer advice and options for professionals in the field and the patients they care for.

# Limitations:

- From the 24 countries who participated in the survey, some had many more respondents than others. Responses from Lithuania and the Czech Republic might have a strong influence on the eastern region data, because of the large number of respondents from these countries.
- Most respondents were otologists. The large (over)representation of this discipline might indicate that other disciplines are less involved in tinnitus health care and that current reports rely heavily on the clinical views and experiences of otologists and might not reflect views or opinions of professionals of other disciplines.
- Important to note is that the current findings do not necessarily indicate or reflect a right or wrong in the organisation of tinnitus healthcare. Current results are seen in the light of establishing potential facilitators and barriers

#### Introduction

Tinnitus, the perception of a phantom sound, is a widespread auditory symptom [1]. It can occur with several otological disorders, such as sensorineural hearing loss. In rare cases, tinnitus can be traced to an underlying pathology, though uniform aetiology remains undetermined [2]. Epidemiological findings are difficult to pool across studies due to differences in methodologies [3]. Nonetheless, assuming a conservative tinnitus prevalence of 10% (severe tinnitus of 1%), tinnitus affects more than 42 million European Union (EU) adults and is a severe problem by more than four million adults. According to data from two large cohorts from Wisconsin (USA), tinnitus prevalence is increasing over time (on average by 1.4% each 5-year birth cohort) [4]. Assuming this increase is linear and of similar magnitude, prevalence estimates will double by 2050.

Tinnitus is residing within and confined to the individual's subjective perceptual experience, not measurable or quantifiable by objective physical recordings, and furthermore not traceable to disease, injury, or pathology in the brain or elsewhere. Even though knowledge on the pathophysiology of tinnitus has made some progress [5, 6] there is still little evidence for effective curative tinnitus treatments or licensed pharmacological therapy [7]. The Cochrane Library currently includes nine systematic reviews on different tinnitus treatments [8], all of which are reported to have little, if any, quality evidence [9]. Patients report difficulties in concentration, being anxious and distressed, difficulty sleeping, being interrupted in their daily tasks, and feeling helpless and despondent most of the time. Evidence corroborates that cognitive misinterpretations, negative emotional reactivity, and dysfunctional attentional processes are of main importance to the severe tinnitus condition [10-20].

From a scientific and clinical perspective, the increased knowledge on treatment and management for tinnitus has had minimal impact on clinical practice [2]. There is evidence that prolonged, obscure and indirect referral-trajectories persist in usual tinnitus care [21]. Tinnitus is indeed a highly complex condition with a multifactorial origin. Heterogeneous patient-profiles lead to a lack of consensus on standard assessment and treatment approaches, which in turn again lead to increasing complaints, prolonged suffering, and endless referral trajectories, resulting in enormous psychological, societal, and economic burden [22].

In 2014, the EU approved funding for a four-years COST Action (TINNET) to create a pan-European tinnitus research network. TINNET's working group 1 (WG1) consists of clinical

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and academic experts in tinnitus from across Europe whose joint objective is to develop meaningful and actionable clinical guidelines for the assessment and treatment of tinnitus patients, and to provide a consensus-based clinical definition and characterization of tinnitus<sup>1</sup>. Ultimately, a European multidisciplinary clinical guideline would be a first step towards a common minimum standard of care for tinnitus patients across Europe. To ensure from a development perspective that a European guideline would become implementable, it became essential to scope current existence and knowledge of standards in tinnitus care across the continent. Without knowledge on the current 'state of the art' and standards in tinnitus healthcare, a consensus-based, meaningful, and actionable guideline could not be ensured. It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and guidelines for implementation activities are systematically tailored to the specific determinants of practice [23]. As such, a pan-European survey of clinicians and policy makers was carried out to gain service information and expert opinions on national healthcare structures, tinnitus-definition, general characteristics of tinnitus patients, and assessment and treatment options.

#### Methods

The method for scoping current knowledge, opinion, and practices in tinnitus care across Europe, a web-based survey was developed by consensus of members within TINNET WG1. Participation was on a voluntary basis and all data were submitted anonymously.

## Survey development

The survey was developed during three consecutive WG1 meetings. It was agreed that the survey would be developed in the English language, since it was expected that most responders would be able to understand English, irrespective of the country of origin. The development involved two phases. First, based on their shared knowledge of tinnitus, nine members of the WG1 steering group generated a list of domains of interest, formulated a set of questions for each domain, and generated a set of response options for each question. This list of questions was subsequently piloted in a larger group of WG1 members (n=81) via e-mail, and during a WG1 management meeting. Consensus-rounds were used to either include or exclude items. The remaining survey

<sup>&</sup>lt;sup>1</sup> http://tinnet.tinnitusresearch.net/index.php/2015-10-29-10-22-16/wg-1-clinical

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items were then re-disseminated to all WG1 members who had been involved in the development and piloting stages with a request to provide comments on any necessary alterations, changes to wording or response options, and for any general remarks. A final survey was agreed upon and produced for online dissemination using Google-forms. The final survey contained items grouped as (1) Demographics, (2) National healthcare structure, (3) Tinnitus-definitions and characteristics of the tinnitus-patient, and (4) Management, treatment and diagnostics.

#### Participants

The recruitment targeted clinical experts, researchers and policy makers involved in national tinnitus healthcare and decision making. A total of 625 participants were recruited using the COST-TINNET network. Firstly, members of the management committee of TINNET were contacted via e-mail with a link to the survey (Supplemental information 1 provides the questions used in the survey) and were requested to forward the invitation to clinical experts, researchers, and tinnitus- organizations in their respective countries (n=24; Table 1). Secondly, another round of targeted dissemination was performed in July 2015, as at that time it was noted that there was a lower response rate from some countries. The low response rate from Italy and Spain was identified as being a language barrier and therefore the survey was translated by native-speaking TINNET members and re-distributed in their national language. The reason for low responses from other countries was not identified. The survey was open from January to October 2015.

#### Patient and Public Involvement

The aim of the current study falls within the framework and main aims of the COST TINNET project<sup>1</sup>. The project and in particular working-package 1 focussed on the objective "Clinical and audiological assessment of tinnitus patients according to common standards". The current study was an essential step in the roadmap towards the aim of the project [24]. In the development and execution of the TINNET project patient-organisations throughout Europe were consulted and we actively involved in several stages. In the current survey, no individual patients were recruited, nor were they involved, since this study involved the evaluation of health-services by clinicians, policy makers, and individual professiobal expert opinions on national healthcare structures. Results of the current study were disseminated to all existing European patient organisations using a Delphi consensus methodology in the development of harmonized and adaptive clinical

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European guidelines for tinnitus entitled "Multidisciplinary European Guideline for Tinnitus: Diagnostics, Assessment and Treatment". These have been presented to the scientific community as well as national patient organisation symposia. The manuscript is currently prepared for peerreviewed publication.

#### Analyses

Results were first described and depicted descriptively. Because the number of responses from each country differed, data were stratified according to whether the country was in northern (higher income), southern (moderate income), or eastern (lower income) Europe (Table 1). (Supplemental information 2 gives the average monthly net income per country and per region). The rationale for this classification was that economic prosperity might lead to differences in health-care for tinnitus patients, since lesser resources indicate lower availability of specialized health-care. One-way ANOVA and regression analyses were performed to assess differences and associations between variables in, northern, southern, and eastern countries. All analyses were performed in IBM-SPSS version 23. N.C.

#### Results

## *Demographics*

Survey responses (n=625) were received from participants across 24 countries (Figure 1) with a large number of participants from Lithuania, Czech Republic, Portugal, and Spain. The mean age of respondents was 43.9 years (SD=12.4), 49.7% were male and 50.3% were female. Respondents were from many disciplines (Figure 2), and worked in public healthcare (n=291), private healthcare (n=199), university (n=89) or other setting (n=48). Some respondents reported more than one workplace (n=213).

# **INSERT FIGURE 1 ABOUT HERE INSERT FIGURE 2 ABOUT HERE**

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Country	Region	n per country	n per region	Pecentage of total
Region 1			216	34.6%
AUSTRIA	1	1		
BELGIUM	1	54		
DENMARK	1	14		
FINLAND	1	1		
FRANCE	1	39		
GERMANY	1	28		
NETHERLANDS	1	41		
SWEDEN	1	23		
SWITZERLAND	1	3		
UK	1	12		
Region 2			225	36.0%
CYPRUS	2	2		
GREECE	2	29		
ITALY	2	50		
ISRAEL	2	12		
MALTA	2	9		
PORTUGAL	2	64		
SPAIN	2	59		
Region 3			184	29.4%
ALBANIA	3	2		
CROATIA	3	2		
CZECH REPUBLIC	3	68		
LITHUANIA	3	82		
POLAND	3	19		
SERBIA	3	8		
SLOVENIA	3	3		
Total		625	625	100

Table 1. Classification and percentage of respondents according to region; 1=North,2=South, 3=East

# National healthcare structure

Across all three regions of Europe, tinnitus healthcare is in most cases financed by national health insurances. This was particularly evident for eastern countries where 90.8% of respondents

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reported that their service is publicly funded. Privately funded treatment is most common in southern Europe (48%) (Supplemental Information 3).

The most common referral pathways as well as the description of services and patients status are given in **Figure 3** and **Table 2** respectively. In taking a regional perspective, difference across Europe became clear. Specialised tinnitus clinics (or teams) are perceived to be most present in the Northern regions (more than 50% of respondents confirmed), where referral by ENT and/or Audiology seems common. Whereas in Southern Europe many people appear to self-refer to specialists, in Eastern Europe referral opinions vary or are less understood by respondents. More northern European respondents reported having and using clinical guidelines (Supplemental information 4) than respondents from southern or eastern Europe.

# **INSERT FIGURE 3 ABOUT HERE**

## *Tinnitus, definitions, and characteristics of the tinnitus-patient*

In all regions, more experts report that, in their opinion, tinnitus is either a peripheral or central auditory symptom (**Table 2**). Still, more than 10% from all regions considered tinnitus a disease, whether auditory or psychological. Differences were found between higher and lower income regions with respect to the perceived emotional status of their 'typical' patients (**Table 2**) and the time spent with individual patients during the first consultation (**Table 3**). The majority of respondents from northern Europe (41.7%) reported spending between 30-60minutes with tinnitus patients on the first appointment, in contrast to 43.9% in the south and 56% in the east spending between 15-30 minutes. Patients in northern Europe were evaluated as being more often "somewhat distressed" in comparison to a more "neutral" status in the south and east (see also Supplemental information 5).

Sign.

n.s.

\*\*

	N	orth	Sc	outh	
What Is Tinnitus?	Ν	%	Ν	%	N
A central auditory disease	8	3,7	9	4,0	17
A central auditory symptom	88	40,7	64	28,4	37
A peripheral auditory disease	11	5,1	17	7,6	12
A peripheral auditory symptom	100	46,3	126	56,0	110
A psychological disease	4	1,9	1	0,4	5
Combination/ Multiple causes/ Other	5	2,3	6	2,7	3
Cannot answer/does not know			2	0,9	
Chronic or acute?					
Chronic (>3months)	123	56,9	144	64,6	104
Acute (<3months)	19	8,8	18	8,1	27
Both	74	34,3	61	27,4	53
Emotional status most patients?		4			
Very positive	1	0,5	0	0	5
Somewhat positive	22	10,2	22	9,9	25
Neutral	56	25,9	102	45,7	96
Somewhat distressed	113	52,3	87	39,0	43
	24	11 1	12	54	15

# fied according to region

	North		South		East		Sign.
Duration of the 1st consultation	N	Percent	N	Percent	Ν	Percent	*
less than 15 minutes	23	10,6	37	16,6	55	29,9	
15 to 30 minutes	51	23,6	98	43,9	103	56,0	
30 to 60 minutes	90	41,7	58	26,0	21	11,4	
60 to 120 minutes	44	20,4	25	11,2	5	2,7	
more than 120 minutes	8	3,7	5	2,2	0	0	
Number of patients per month	N	Percent	Ν	Percent	Ν	Percent	*
≤10	73	33,8	117	52,2	101	54,9	
11-30	96	44,4	87	38,8	61	33,2	
31-50	33	15,3	12	5,4	9	4,9	
> 50	14	6,5	8	3,6	13	7,1	

Table 3. Appointment duration and number of patients per month, classified according to region

\* Different between all groups ( $\alpha$ <.05)

\*\*Difference between North compared to South and East ( $\alpha < .05$ )

n.s.: Not significant; Sign: Significant difference

## Management, treatment, and diagnostics

All treatments available within their respective departments were reported (**Table 4**). Where medication was selected as an available option, the respondent were asked to indicate the specific drug in the 'other' free-text space. Here sound therapy is taken to include the use of hearing aids, and TRT includes any reportedly modified version of the treatment.

iley

Medications used in tinnitus treatment included betahistine, steroids, vasodilators, antidepressants, and anxiolytics. 'Other' treatment options reported as available were hyperbaric chamber therapy, laser therapy, transcranial direct current stimulation, Gingko biloba, Vitamin B12, hypnosis, sleep hygiene, osteopathy, cochlear implantation, and music therapy. Differences in treatment availability across regions were striking, particularly between the north and east. Indicative of the general trends, CBT was available from 34.3% of departments in northern Europe, compared to just 4.9% in the east. In contrast, medication was an option in 79.9% of the departments in the east, whereas only 27.3% used medications in the north. While medication

was the most commonly available treatment option in the east, in both the north and south it was sound-based therapy (in 69.9% and 68.4% of departments respectively).

Table 4. Treatments reported as available within respondents departments, reported by region.

	North (n)	%	South (n)	%	East (n)	%
Advice	2	0	0	0	0	0
Alternative therapies	16	7.5	33	14.7	19	10.3
CBT	74	34.3	35	15.6	9	4.9
Counselling	108	50	115	51.1	41	22.3
Coping training	0	0	0	0	0	0
Dental procedure	2	0.9	0	0	0	0
Medication	59	27.3	111	49.3	147	79.9
Mindfulness	5	2.3	0	0	0	0
Neurofeedback	16	7.4	13	5.8	9	4.9
Physiotherapy	52	24.1	27	12	59	32.1
Relaxation	108	50	71	31.6	34	18.5
rTMS	14	6.5	3	1.3	3	1.6
Sound therapy	151	69.9	154	68.4	49	26.6
TRT	1	0.5	69	30.7	29	15.8

Clinicians involved in tinnitus care ranged from just one discipline to a broad multidisciplinary team (**Table 5**). Multidisciplinary treatments (MDT) and having a psychologist in the team was more common in northern countries than in the east and south. In the east, most care appears to be delivered by medical professionals (otolaryngologists or neurologists). Other disciplines involved in tinnitus care, reported by 1-2% of respondents, included prosthetists, social workers, movement therapists, osteopaths, sophrologists, psychosomatic medicine specialists, acupuncturists, hearing therapists, ophthalmologist, dance movement therapists, general practitioners, cardiologists, maxillofacial surgeons, and radiologists. There were single reports of

an arts therapist, counsellor, speech therapist, mindfulness instructor, and hypnotherapist being involved in care.

	North	percent	South	percent	East	percent
ENT	118	54.6	43	19.1	87	47.3
Audiologist	132	61.1	39	17.3	57	31
Psychologist	136	63	32	14.2	24	13
Psychiatrist	33	15.3	39	17.3	39	21.2
Physiotherapist	19	8.8	3	1.3	3	1.6
Neurologist	20	9.3	19	8.4	81	44
Dentist	3	1.4		0.4	0	0

# Table 5. Disciplines involved in tinnitus care

Conditions and or symptoms perceived as being of relevance when assessing and/or treating tinnitus are given in **Table 6**. Most respondents reported hearing loss and dizziness complaints as relevant, irrespective of the region.

Other conditions frequently reported by respondents as of relevance to tinnitus were suicidal tendency, otitis, eustachian tube dysfunction, acoustic neuroma, multiple sclerosis, and coagulation disorder. A minority ( $\leq$ 1%) additionally reported hyperacusis, autoimmune disease, neurovascular conflict, Pendred syndrome, stress, psychosis, nasal septal deformation, vascular disease, facial pain, sensory hypersensitivity, cardiac arrhythmia, arterial stenosis, sleep disorders, hypercholesterolemia, fibromyalgia, apnoea, and rhinosinusitis.

	North	percent	South	percent	East	percent
Hypertension	98	45.4	118	52.4	79	42.9
Diabetes	45	20.8	108	48	55	29.9
Thyroid dysfunction	0	0	1	0.4	0	0
TMJ disorders	92	42.6	125	55.6	28	15.2
Psychological/psychiatric disorders	155	71.8	163	72.4	73	39.7
Hearing loss	212	98.1	221	98.2	159	86.4
Hyperlipidaemia	16	7.4	61	27.1	31	16.8
Dizziness	191	88.4	200	88.9	161	87.5
Cervical disorders	100	46.3	98	43.6	94	51.1
Migraine	72	33.3	83	36.9	41	22.3
Allergy	21	9.7	35	15.6	11	6

Table 6. Opinions on which conditions are taken into consideration in tinnitus diagnostics

There was a general consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice (**Table 7**). Most respondents reported that otoscopy and pure tone audiometry were used. There was some variability in the reported use of other diagnostic tools, e.g. percentage use of audiological assessments such as tympanometry or speech audiometry in the north was twice that in the east. 'Other' responses included clinical interview, Diagnostic and Statistical Manual of Mental Disorders, vestibular evoked myogenic potential, brainstem evoked response audiometry, tone decay, neck vessel ultrasonography, orthopantomography, blood analysis, vestibular testing (calorimetry), blood pressure, and auditory brainstem response, all of which were reported by  $\leq 3\%$  of respondents.

	North	percent	South	percent	East	percent
Otoscopy	169	78.2	211	93.8	135	73.4
Tympanometry	142	65.7	172	76.4	56	30.4
Nasal endoscopy	37	17.1	87	38.7	147	79.9
Pure tone audiometry	162	75	186	82.7	151	82.1
High frequency audiometry	64	29.6	48	21.3	27	14.7
Speech audiometry	119	55.1	93	41.3	44	23.9
Tinnitus pitch and	95	44	86	38.2	46	25
loudness						
LDL	2	0.9	1	0.4	0	0
LMM	1	0.5	0	0	0	0
IR	1	0.5	0	0	0	0
Broadband noise EP	0	0	0	0	0	0
Pure tone EP	0	0	0	0	0	0
(DP)OAE	68	31.5	54	24	35	19
AC-ASSR	9	4.2	18	8	4	2.2
EEG	14	6.5	3	1.3	16	8.7
СТ	17	7.9	34	15.1	44	23.9
MRI	76	35.2	119	52.9	100	54.3
Angio-MRI	28	13	37	16.4	19	10.3

Table 7. Diagnostic tools used with tinnitus patients

Most respondents from northern and southern countries reported using some form of multi-item questionnaire, in comparison with only about one in five respondents from eastern European countries (**Figure 4**). In eastern countries, the use of these measures is much less common. The most frequently used questionnaire, irrespective of region was the Tinnitus Handicap Inventory (THI) [25]. Interestingly, the only anxiety/depression questionnaire used was the Hospital Anxiety and Depression Scale (HADS) [26] and this in Eastern countries. The Tinnitus Questionnaire (TQ) [27] was mentioned frequently in northern and southern regions. The more recently developed Tinnitus Functional Index (TFI) [28] was only mentioned in the North. Additionally, respondents from all regions specified to use visual analogue scales (though unspecified which) as well. Questionnaires reported as 'other' were unspecified.

## **INSERT FIGURE 4 ABOUT HERE**

Finally, regarding the satisfaction rate on the service provided by their health care unit, 81.7% respondents from the north, 38.5% from the South, and 35.0% from the east reported they were.

In northern Europe professionals were largely satisfied, whereas in southern and eastern Europe opinions were more divided, and less than half of respondents claimed to be satisfied.

# Regression analyses

Regression analyses were conducted to establish whether there were statistically significant associations between average net income of the country of origin of respondents and the presence of specialised tinnitus-clinics, time for tinnitus-patients per consult, satisfaction of the respondent with their service, number of patients seen per month, the requirement of a referral by GP in their country, and whether or not clinical guidelines exist. Significant associations were found between net income per month and all variables in the model (**Table 8**). In summary, higher income was associated with more specialised clinics, longer appointment times, greater satisfaction with health-care options, fewer patients per month, more referral-necessity by GP, and more knowledge and use of clinical guidelines.

**Table 8.** Associations between income and tinnitus care. Regressions summary: Dependent = income, Independents = Specialised clinics present, time per consult, Satisfaction of respondent with healthcare, Patients seen per month, Necessity of referral by GP, Existence of clinical guidelines, controlled for age and gender.

	1					
	Change Statistics					
	R Square			6		Sig. F
Model	Change	F Change	df1	df2	Beta	Change
Age / gender	0,007	1,989	2	605	-0,033	0,138
Specialised clinic	0,266	220,407	1	604	-0,516	0,000
Time per consult	0,106	102,780	1	603	0,334	0,000
Satisfaction healthcare	0,048	50,505	1	602	-0,235	0,000
Patients per month	0,015	15,728	1	601	0,124	0,000
GP necesary	0,010	10,507	1	600	-0,106	0,001
Clinical guidelines	0,008	9,272	1	599	0,094	0,002

Dummy coding: Specialised clinic: Yes=0, No=1; Time per consult: 1=< 15 min, 2=15-30min, 3=30-60min,4=60-12min, 5=>120min; Satisfaction healthcare: Yes=0, No=1; GP necesary: Yes=0, No=1; Clinical guidelines: Yes=0, No=1. Dependent: income

# Discussion

This survey sought to collate details and opinions on healthcare structure and clinical practices for tinnitus across Europe. The first interesting result from the survey was the difference between regions of Europe in terms of whether specialist tinnitus clinics are present. In the northern countries of Europe, most respondents confirmed the presence of specialised tinnitus clinics, in the South about half confirmed having specialist centres, and in the East most respondents reported not having specialised clinics. That there seems to be discord in knowledge or opinions in the rest of Europe is interesting. Where there are indeed specialised clinics, which professionals are aware of, they might more easily refer patients to these clinics without the need for a GP. On the other hand, when fewer clinics are present or known, tinnitus care more often falls to the GP, who might refer to a specialist, but not necessarily to a specialised centre. Opinions differ on whether a referral from a GP is necessary; the majority of respondents from Eastern Europe reported that it is indeed the case, whereas in northern and southern Europe less than half of respondents thought so. These findings indicate the importance of knowing the referral path. The lack of knowledge of existing specialised clinics also makes it difficult for tinnitus patients to identify the most appropriate professionals in their country. Addressing the lack of clinician's knowledge is key in the development of meaningful and actionable European guidelines.

In terms of national healthcare structure, the typical pathways differ by region. In the north they most commonly include specialised audiologists and otolaryngologists, who can presumably refer onto specialist centres where available. In southern Europe it was more common that people self-refer for tinnitus care. In Eastern Europe referral pathways were either less understood or less well-defined.

When asked which disciplines usually 'handle' tinnitus patients, the mix of disciplines reported was more evenly distributed across the counselling and medical professions in northern countries than other regions, i.e. tinnitus care was not more associated with one type of healthcare professional than another. In contrast, in southern and eastern countries it is reported that medical and technical professionals are most commonly involved. Interestingly this indicates a tendency towards a 'psychological' approach in the north compared to a more curative approach in tinnitus

treatment in the other regions. Since there is ample evidence that psychological therapy is beneficial in any tinnitus treatment approach, and that there are regions in Europe where this is not provided, these findings highlight a *second barrier* in to the adoption and implementation of a Europe wide practice guideline.

In all regions, opinions varied on whether tinnitus is a peripheral or central auditory symptom or condition. This data will be useful in achieving a consensus definition of tinnitus within a European guideline. Interestingly, respondents from northern countries more often reported their average patients to be distressed, whereas most respondents from the south and east judged their patients to be neither distressed nor 'positive' but to be of a 'neutral' emotional status. This could indicate that in the north, the range of patients that are seen by experts is broader, i.e. patients with milder as well as more severe tinnitus are assessed by specialists. It is also possible that since northern countries dedicate more time per patient, physicians are more able to assess levels of distress. It might also reflect a greater awareness of the emotional distress of patients since in the north, a psychological assessment including clinical questionnaires is more often conducted. This is of interest because the level of distress of tinnitus patients is an important indicator of the need for onward referral for subsequent treatment options. A third barrier to the implementation of a European guideline may therefore be that in most regions of Europe, professionals responsible for tinnitus patients do not have a sufficient amount of time to adequately assess the level of distress of their patients.

The presence of a multidisciplinary treatment teams for tinnitus in northern regions was reported in most cases, including a psychologist working in most teams. By region however, it is noted that in the south many respondents report that there are no multidisciplinary treatment teams, and in the east there was almost no psychologists involved in treatment. These findings represent a major fourth barrier in developing the development of meaningful and actionable European guidelines, if the guideline is to include evidence-based healthcare.

There is consensus across the regions on which conditions are important in tinnitus. Most respondents, irrespective of region, reported hearing loss, acoustic trauma, and vertigo as the

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most relevant conditions to consider in the assessment of tinnitus. This consensus represents a second facilitator in discussions on and implementation of European guidelines,

The treatment options reported by respondents also showed clear trends according to region. This finding can be classified as a *fifth barrier*, in that it might be difficult to get consensus on what works for whom when many treatment avenues are preferentially made available. When developing a guideline it is of importance to provide clear indications on which treatments are recommended, which are not recommended, and which have insufficient evidence to make a recommendation in either direction [29].

There was consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice. Although some small differences in procedures were reported, most experts use otoscopy and pure tone audiometry. There is some variability in the use of other diagnostic tools suggesting a potential third facilitator to discussions, on the inclusion of standardised diagnostic procedure in the guidelines.

A sixth barrier to standardised practice emerging from our data may be the limited use of clinical questionnaires in eastern and southern countries. Yet consensus exists that in research as well as the clinic questionnaires are key in assessment, both for screening and monitoring treatment progress [2, 30]. The most commonly used questionnaire however, irrespective of region, was the Tinnitus Handicap Inventory (THI). This finding is consistent with a previous study [31]. This might offer a fourth facilitator to discussions, on primary outcome measures to recommend within a guideline.

When asked how patients pay for treatment, respondents from southern and eastern Europe reported fewer patients pay privately for their tinnitus healthcare. Nonetheless, in all regions, tinnitus treatments were financed by national health insurance schemes. This may become restrictive if health insurance companies have a strong influence on what tinnitus treatment options are made available within a country. When patients pay for treatment privately, more treatment options might be on offer, even without adequate evidence of effectiveness. That there are differences in how patients pay for treatment is a seventh barrier to standard care across

Europe, and a difficult one. In cases where the regulatory bodies in health care in a country are unwilling or unable to hold to the restrictions or recommendations stated in a guideline, the chances of implementation of this guideline drastically decrease.

Less than half of respondents from the south and east of Europe reported they were satisfied with current tinnitus healthcare in their country. This dis-satisfaction may represent a fifth facilitator in that professionals are likely to be positive about progressive guidelines and towards changes in healthcare for tinnitus.

Finally, economic prosperity in a country often defines healthcare organization and healthcare satisfaction [32]. In the current study, it was hypothesized that the economic resources available to individuals in a country might dictate the view of professionals on levels of advancement in healthcare for tinnitus. This was indeed the case. Lower average net income in the country of origin of respondents was associated with reports of fewer specialized tinnitus healthcare; fewer specialised tinnitus-clinics, less time for tinnitus-patients per consult, and more often a lack (or use) of guidelines. Lower average income was also associated with lower satisfaction of the respondent with healthcare, and more necessity of referral by a GP. Interestingly, higher average net income in a country was associated with seeing more patients per month. This might be because the problem is better understood, patients are better recognised, or suffering is taken more seriously.

Some additional points are worthy of discussion. First, from the 24 countries who participated in the survey, some had many more respondents than others. This issue was presently solved by stratifying the countries according to region of Europe to yield similar respondent numbers per region. Nevertheless, responses from Lithuania and the Czech Republic might have a strong influence on the eastern region data, because of the large number of respondents from these countries. Second, most respondents were otologists. The large (over)representation of this discipline might indicate that other disciplines are less involved in tinnitus health care, and that current reports rely heavily on the clinical views and experiences of otologists and might not reflect views or opinions of professionals of other disciplines. Third, it is important to note that the current findings do not necessarily indicate or reflect a right or wrong in the organisation of

tinnitus healthcare, the available assessment and treatment options for tinnitus in a country, or the advancement of specialised healthcare in a country. It is important that the current results are seen in the light of establishing potential facilitators and barriers (see Box 1 below for summary) to the development and implementation of a guideline that can serve the whole of Europe, by being meaningful and actionable, and offer advice and options for professionals in the field, and the patients they care for.

## **BOX 1: Summary of Barriers and Facilitators** Barriers

- Lack of knowledge about or non-existence of specialised tinnitus clinics or teams makes it difficult for tinnitus patients to find their way to the most appropriate professionals in a country.
- 2 Lack of time or other resources for adequate counselling
- **3** Lack of time or other resources for professionals responsible for tinnitus patients to be able to adequately assess the distress-level of tinnitus patients
- 4 Lack of multidisciplinary teams, and/or availability of psychologists in southern and eastern European countries
- 5 High variation in available treatment options; more medical-pharmacological treatment in southern and eastern countries. psychological-rehabilitative approaches more available in northern countries. When many treatment avenues are considered viable it may be difficult to reach consensus on what works for whom
- 6 The use of self-report instruments is much less common in southern and eastern countries
- 7 There are differences in how patients pay for treatment. If regulatory bodies in healthcare in a country are unwilling or unable to hold to the restrictions or recommendations stated in a guideline, the likelihood of implementation of this guideline is lower.

#### **Facilitators**

- 1 Common ground in expert-opinion that tinnitus is a central auditory symptom. This offers options for discussions on the definition of tinnitus in a European guideline
- 2 Consensus across regions on what conditions are relevant or associated with tinnitus. Harmonies such as these are to be highlighted where possible to facilitate implementation of a standard guideline
- Though some small differences in procedures were reported, most experts use otoscopy and pure tone audiometry. Findings will facilitate discussions on diagnostics to include in the guidelines
- 4 The most commonly used questionnaire irrespective of region is the Tinnitus Handicap Inventory. This may facilitate discussions on assessment methods to recommend within a guideline
- 5 The percentage of respondents satisfied with current tinnitus healthcare in their country in southern and eastern Europe was low; less than half of respondents reported they were satisfied. Healthcare professionals are likely to be positive towards progressive guidelines and towards changes in health care for tinnitus.

# Acknowledgements & Funding Statements

The current investigation was funded by the European Commission by under the COST program; Project TINNET with Action number BM1306, a European tinnitus research network funded from April 11, 2014 to April 10, 2018.

RFFC is funded through The Netherlands Organisation for Scientific Research (NWO); Innovational Research Incentives Scheme Veni

DJH is funded through the National Institute for Health Research (NIHR) Biomedical Research Centre programme. The opinions expressed are those of the authors and not necessarily those of the NIHR, the NHS, or the Department of Health and Social Care.

# **Competing Interests**

All authors have declared that there are no competing interests

# Figure captions & Legends

- FIGURE 1. Responses from each participating country
- FIGURE 2. Discipline of respondents
- FIGURE 3: Most common referrals according to region
- FIGURE 4. Main questionnaire used per region

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Participating Country



90x72mm (300 x 300 DPI)





90x72mm (300 x 300 DPI)

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#### Self-referral most common



#### Referral by ENT most common



## Referral by Audiology most common



Figure 3. Most common referrals according to region

90x172mm (300 x 300 DPI)



DEMOGRAPHICS
1. Age
2. Gender
3. In which country do you reside?
4. What is your profession? (Multiple choice). Options: GP, ENT, psychologist, psychiatrist, neurologist,
audiologist, other, namely
5. Where do you work? (Multiple choice). Options: Public hospital, private hospital, university, university
hospital, private office/practice, other, namely
NATIONAL HEALTH-CARE STRUCTURE
6. Are there specialized tinnitus healthcare-units in your country? (yes/no)
7. What referral pathways for tinnitus patients are typically used in your country? (Multiple choice)
Options: GP, ENT, Internet, directly, hospital, psychologist, dentist, community services, other
namely
8. Is a consultation with GP necessary to go to a tinnitus unit/clinic/ENT/Audiological centre? (yes/no)
STATUS OF THE PATIENT
9. Do you consider tinnitus to be? (Multiple choice). Options: Symptom, disease, audiological problem,
psychological problem, none of the above, other, namely
10. What is on average the emotional status of your patient at the moment of first consultation? (5-point
Likert). Options: Very positive, somewhat positive, neutral, distressed, very distressed
11. Do you see predominantly? (Multiple choice). Options: Chronic tinnitus (more than 3 months), acute
tinnitus (less than 3 months), both
12. How much time can you allocate to an individual tinnitus patient in one consultation? (Multiple choice).
Options: 1-10 min, 10-30 min, 30-60 min, More than 60 min
13. How many tinnitus patients do you see in one week? (Multiple choice). Options: Less than 1, 1-5, 6-10.
More than 10
MANAGEMENT OF THE PATIENT
14. Is there a protocol for tinnitus management in your country? (yes/no)
b. If yes, how often do you use it? (5-point Likert). Options: Always, almost always, sometimes, almost
never, never
15. What disciplines most often handle tinnitus patients in your country? (Multiple choice). Options: ENT
audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely

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16	Is there a multidisciplinary approach to treat the tinnitus patient? ( $ves/no$ )
10	b. If ves which professionals are included? (Multiple choice). Options: ENT, audiologist, psychologist,
	psychiatrist, physiotherapist, neurologist, dentist, other, namely
17.	. Which medical/psychiatric conditions are taken into consideration when examining tinnitus patients?
	(Multiple choice). Options: Hypertension, diabetes, thyroid dysfunction, TMJ disorders,
	psychological/psychiatric disorders, hearing loss, hyperlipidaemia, dizziness, cervical disorders, migraine,
	allergy, other
TR	REATMENT AND DIAGNOSTICS
18.	. What kind of clinical department in your country treats tinnitus patients? (Multiple choice). Options:
	ENT, audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely
19.	. What are the treatments options for tinnitus patients in your center? (Multiple choice). Options: TRT,
	CBT, mindfulness, relaxation, coping training, counselling, medication, advise/counselling, alternative
20	What diagnostic tools do you use on a tinnitus patient? (Multiple choice) Options: Questionnaires
20	micro-otoscopy tympanometry nasal endoscopy pure tone audiometry high frequency audiometry (12
	16. 20 kHz), speech audiometry (hearing loss), tinnitus pitch and loudness – LDL – LMM – IR, broad
	band noise EP, pure tone EP, (DP)OAE, air-conduction auditory steady-state responses (AC-ASSR),
	EEG, CT, MRI, angio-MRI.
21	. Which questionnaires do you use to assess tinnitus severity? (Multiple choice). Options: TQ, TRQ, TFI,
	THI, TFI, TSCH, HADS, BDI, STAI, VAS scales, Grade from 1 to 10, other, namely
22.	. How do your patients pay for treatment? (Multiple choice). Options: Public health, health insurance,
	privately, other, namely
23.	. Are you satisfied with the current service provided by your healthcare-unit? (yes/no)
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	2	AUSTRIA	1	1	0,2	2009	
	3	BELGIUM	1	54	8,6	2091	
	4	CROATIA	3	2	0,3	754	
	5	CYPRUS	2	2	0,3	1658	
		CZECH					
	6	REPUBLIC	3	68	10,9	772	
	7	DENMARK	1	14	2,2	3095	
	8	FINLAND	1	1	0,2	2509	
	9	FRANCE	1	39	6,2	2157	
	10	GERMANY	1	28	4,5	2265	
	11	GREECE	2	29	4,6	947	
	12	ISRAEL	2	12	1,9	1924	
	13	ITALY	2	50	8	1725	
	14	LITHUANIA	3	82	13,1	616	
	15	MALTA	2	9	1,4	1021	
	16	NETHERLANDS	1	41	6,6	2263	
	17	POLAND	3	19	3	677	
	18	PORTUGAL	2	64	10,2	984	
	19	SERBIA	3	8	1,3	377	
	20	SLOVENIA	3	3	0,5	692	
	21	SPAIN	2	59	9,4	1718	
	22	SWEDEN	1	23	3,7	2465	
	23	SWITZERLAND	1	3	0,5	4760	
	24	UK	1	12	1,9	2120	
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# \*Average net monthly income

Region	total	mean	n	
1	25734	2573,40	10	
2	9977	1425,29	7	
3	4258	608,29	7	

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# Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029346.R1
Article Type:	Original research
Date Submitted by the Author:	09-Aug-2019
Complete List of Authors:	Cima, Rilana FF ; Universiteit Maastricht Faculteit der Psychologie en Neurowetenschappen, Clinical Psychological Science; Adelante , Centre of knowledge and expertise Kikidis, Dimitris; National and Kapodistrian University of Athens Mazurek, Birgit; University Medicine Berlin Haider, Haúla; Hospital Cuf Infante Santo, ENT department Cederroth, Chistopher; Karolinska Institutet Norena, Arnaud; Universite de Provence Lapira, Alec; University of Malta, Otolaryngology Bibas, Athanasios; National and Kapodistrian University of Athens Hoare, Derek; University of Nottingham, NIHR Nottingham Hearing Biomedical Research Unit
<b>Primary Subject Heading</b> :	Health services research
Secondary Subject Heading:	Health policy, Ear, nose and throat/otolaryngology
Keywords:	Tinnitus, Health services evaluation, standard of care, Pan-European, Guidelines, Barriers
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Title:

Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

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# Abstract:

Tinnitus remains a scientific and clinical problem whereby, in spite of increasing knowledge on effective treatment and management for tinnitus, very little impact on clinical practice has been observed. There is evidence that prolonged, obscure, and indirect referral-trajectories persist in usual tinnitus care.

**Objective:** It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and implementation activities are systematically tailored to the specific determinants of practice. The aim of this study was to administer a health-service evaluation survey to scope current practice- and knowledge of standards in tinnitus care across Europe. The purpose of this survey was to specifically inform the development-process of a European clinical guideline that would be implementable in all European countries.

Design: A health-services evaluation survey was carried out

Setting: The survey was carried out online across Europe

**Participants:** Clinical experts, researchers and policy makers involved in national tinnitus healthcare and decision making

**Outcome measures:** A survey was developed by the study steering group, piloted on clinicians from the TINNET network, and underwent two iterations before being finalized. The survey was then administered to clinicians and policy makers from 24 European countries.

**Results:** Data collected from 625 respondents revealed significant differences in national healthcare structures, use of tinnitus-definitions, opinions on characteristics of tinnitus-patients, assessment procedures, and particularly in available treatment options. Differences between northern and eastern European countries were most notable.

**Conclusions:** Most European countries do not have national clinical guidelines for the management of tinnitus. Reflective of this, clinical practices in tinnitus healthcare vary dramatically across countries. This equates to inequities of care for people with tinnitus across Europe and an opportunity to introduce standards in the form of a European clinical guideline. This survey has highlighted important barriers and facilitators to implementation of such a guideline.

**Keywords:** Tinnitus, health-service evaluation, Standard of care, Pan-European, Guidelines, Barriers, Facilitators

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# Article Summary Strengths & Limitations of this study

# Strengths:

- This is the first and only pan-European health-service evaluation to scope current practiceand knowledge of clinical standards in tinnitus healthcare, which offers valuable information for ongoing endeavors to develop multidisciplinary guidelines and a standard of tinnitus health-care across Europe.
- Results provide health service information and expert opinions on national healthcare structures, reflecting a truly pan-European point of view and based on the results we have succeeded in defining important barriers as well as facilitators to the development and implementation of a guideline that can serve the whole of Europe, by being meaningful and actionable, and offer advice and options for professionals in the field and the patients they care for.

# Limitations:

- From the 24 countries who participated in the survey, some had many more respondents than others. Responses from Lithuania and the Czech Republic might have a strong influence on the eastern region data, because of the large number of respondents from these countries.
- Most respondents were otologists. The large (over)representation of this discipline might indicate that other disciplines are less involved in tinnitus health care and that current reports rely heavily on the clinical views and experiences of otologists and might not reflect views or opinions of professionals of other disciplines.
- Important to note is that the current findings do not necessarily indicate or reflect a right or wrong in the organisation of tinnitus healthcare. Current results are seen in the light of establishing potential facilitators and barriers

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# Introduction

Tinnitus, the perception of a phantom sound, is a widespread auditory symptom [1]. It can occur with several audiological and/or otological disorders, such as sensorineural hearing loss. In rare cases, tinnitus can be traced to an underlying pathology, though uniform aetiology remains undetermined [2]. Epidemiological findings are difficult to pool across studies due to differences in methodologies [3]. Nonetheless, assuming a conservative tinnitus prevalence of 10% (severe tinnitus of 1%), tinnitus affects more than 42 million European Union (EU) adults and is a severe problem by more than four million adults. According to data from two large cohorts from Wisconsin (USA), tinnitus prevalence is increasing over time (on average by 1.4% each 5-year birth cohort) [4]. Assuming this increase is linear and of similar magnitude, prevalence estimates will double by 2050.

Tinnitus is residing within and confined to the individual's subjective perceptual experience, not measurable or quantifiable by objective physical recordings, and furthermore very rarely traceable to disease, injury, or pathology in the brain or elsewhere. Even though knowledge on the pathophysiology of tinnitus has made some progress [5, 6] there is still little evidence for effective curative tinnitus treatments or licensed pharmacological therapy [7]. The Cochrane Library currently includes nine systematic reviews on different tinnitus treatments [8], all of which are reported to have little, if any, quality evidence [9]. Patients report difficulties in concentration, being anxious and distressed, difficulty sleeping, being interrupted in their daily tasks, and feeling helpless and despondent most of the time. A wide range of evidence corroborates the theory that cognitive misinterpretations, negative emotional reactivity, and dysfunctional attentional processes are of main importance to the severe tinnitus condition [10-20].

From a scientific and clinical perspective, the increased knowledge on treatment and management for tinnitus has had minimal impact on clinical practice [2]. There is evidence that prolonged, obscure and indirect referral-trajectories persist in usual tinnitus care [21]. Tinnitus is indeed a highly complex condition with a multifactorial origin. Heterogeneous patient-profiles lead to a lack of consensus on standard assessment and treatment approaches, which in turn again lead to increasing complaints, prolonged suffering, and endless referral trajectories, resulting in enormous psychological, societal, and economic burden [22].

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In 2014, the EU approved funding for a four-years COST Action (TINNET) to create a pan-European tinnitus research network. TINNET's working group 1 (WG1) consists of clinical and academic experts in tinnitus from across Europe whose joint objective is to develop meaningful and actionable clinical guidelines for the assessment and treatment of tinnitus patients, and to provide a consensus-based clinical definition and characterization of tinnitus<sup>1</sup>. Ultimately, a European multidisciplinary clinical guideline would be a first step towards a common minimum standard of care for tinnitus patients across Europe [23]. To ensure from a development perspective that a European guideline would become implementable, it became essential to scope current existence and knowledge of standards in tinnitus care across the continent. Without knowledge on the current 'state of the art' and standards in tinnitus healthcare, a consensus-based, meaningful, and actionable guideline could not be ensured. It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and guidelines for implementation activities are systematically tailored to the specific determinants of practice [24]. As such, a pan-European survey of clinicians and policy makers was carried out to gain service information and expert opinions on national healthcare structures, tinnitus-definition, general characteristics of tinnitus patients, and assessment and treatment options.

## Methods

The method for scoping current knowledge, opinion, and practices in tinnitus care across Europe, a web-based survey was developed by consensus of members within TINNET WG1. Participation was on a voluntary basis and all data were submitted anonymously.

#### Survey development

The survey was developed during three consecutive WG1 meetings. It was agreed that the survey would be developed in the English language, since it was expected that most responders would be able to understand English, irrespective of the country of origin. The development involved two phases. First, based on their shared knowledge of tinnitus, nine members of the WG1 steering group generated a list of domains of interest, formulated a set of questions for each domain, and generated a set of response options for each question. This list of questions was subsequently

<sup>&</sup>lt;sup>1</sup> http://tinnet.tinnitusresearch.net/index.php/2015-10-29-10-22-16/wg-1-clinical

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piloted in a larger group of WG1 members (n=81) via e-mail, and during a WG1 management meeting. Consensus-rounds were used to either include or exclude items. The remaining survey items were then re-disseminated to all WG1 members who had been involved in the development and piloting stages with a request to provide comments on any necessary alterations, changes to wording or response options, and for any general remarks. A final survey was agreed upon and produced for online dissemination using Google-forms. The final survey contained items grouped as (1) Demographics, (2) National healthcare structure, (3) Tinnitus-definitions and characteristics of the tinnitus-patient, and (4) Management, treatment and diagnostics.

# Participants

The recruitment targeted clinical experts, researchers and policy makers involved in national tinnitus healthcare and decision making. A total of 625 participants were recruited using the COST-TINNET network. Firstly, members of the management committee of TINNET were contacted via e-mail with a link to the survey (Supplemental information 1 provides the questions used in the survey) and were requested to forward the invitation to clinical experts, researchers, and tinnitus- organizations in their respective countries (n=24; Table 1). Secondly, another round of targeted dissemination was performed in July 2015, as at that time it was noted that there was a lower response rate from some countries. The low response rate from Italy and Spain was identified as being a language barrier and therefore the survey was translated by native-speaking TINNET members and re-distributed in their national language. The reason for low responses from other countries was not identified. The survey was open from January to October 2015.

# Patient and Public Involvement

The aim of the current study falls within the framework and main aims of the COST TINNET project<sup>1</sup>. The project, and in particular working-package 1, focussed on the objective "Clinical and audiological assessment of tinnitus patients according to common standards". The current study was an essential step in the roadmap towards the aim of the project [25]. In the development and execution of the TINNET project, patient-organisations throughout Europe were consulted and were actively involved in several stages. In the current survey, no individual patients were recruited, nor were they involved, since this study involved the evaluation of health-services by clinicians, policy makers, and individual professional expert opinions on

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national healthcare structures. Results of the current study were disseminated to all existing European patient organisations using a Delphi consensus methodology in the development of harmonized and adaptive clinical European guidelines for tinnitus entitled "Multidisciplinary European Guideline for Tinnitus: Diagnostics, Assessment and Treatment"[23]. These have been presented to the scientific community as well as national patient organisation symposia.

# Analyses

Results were first described and depicted descriptively. Because the number of responses from each country differed, data were stratified according to whether the country was in northern (higher income), southern (moderate income), or eastern (lower income) Europe (Table 1). (Supplemental information 2 gives the average monthly net income per country and per region). The rationale for this classification was that economic prosperity might lead to differences in health-care for tinnitus patients, since lesser resources indicate lower availability of specialized health-care. One-way ANOVA and regression analyses were performed to assess differences and associations between variables in, northern, southern, and eastern countries. All analyses were performed in IBM-SPSS version 23. er.e.

# Results

#### *Demographics*

Survey responses (n=625) were received from participants across 24 countries (Figure 1) with a large number of participants from Lithuania, Czech Republic, Portugal, and Spain. The mean age of respondents was 43.9 years (SD=12.4), 49.7% were male and 50.3% were female. Respondents were from many disciplines (Figure 2) and worked in public healthcare (n=291), private healthcare (n=199), university (n=89) or other setting (n=48). Some respondents reported more than one workplace (n=213).

# **INSERT FIGURE 1 ABOUT HERE INSERT FIGURE 2 ABOUT HERE**

# Table 1. Classification and percentage of respondents according to region; 1=North,2=South, 3=East

Country	Region	n per country	n per region	Pecentage of total
Region 1		•	216	34.6%
AUSTRIA	1	1		
BELGIUM	1	54		
DENMARK	1	14		
FINLAND	1	1		
FRANCE	1	39		
GERMANY	1	28		
NETHERLANDS	1	41		
SWEDEN	1	23		
SWITZERLAND	1	3		
UK	1	12		
Region 2			225	36.0%
CYPRUS	2	2		
GREECE	2	29		
ITALY	2	50		
ISRAEL	2	12		
MALTA	2	9		
PORTUGAL	2	64		
SPAIN	2	59		
<b>Region 3</b>			184	29.4%
ALBANIA	3	2		
CROATIA	3	2		
CZECH REPUBLIC	3	68		
LITHUANIA	3	82		
POLAND	3	19		
SERBIA	3	8		
SLOVENIA	3	3		
Total		625	625	100

# National healthcare structure

Across all three regions of Europe, tinnitus healthcare is in most cases financed by national health insurances. This was particularly evident for eastern countries where 90.8% of respondents

reported that their service is publicly funded. Privately funded treatment is most common in southern Europe (48%) (Supplemental Information 3).

The most common referral pathways as well as the description of services and patients status are given in **Figure 3** and **Table 2** respectively. In taking a regional perspective, difference across Europe became clear. Specialised tinnitus clinics (or teams) are perceived to be most present in the Northern regions (more than 50% of respondents confirmed), where referral by ENT and/or Audiology seems common. Whereas in Southern Europe many people appear to self-refer to specialists, in Eastern Europe referral opinions vary or are less understood by respondents. More northern European respondents reported having and using clinical guidelines (Supplemental information 4) than respondents from southern or eastern Europe.

# **INSERT FIGURE 3 ABOUT HERE**

# Tinnitus, definitions, and characteristics of the tinnitus-patient

In all regions, more experts report that, in their opinion, tinnitus is either a peripheral or central auditory symptom (**Table 2**). Still, more than 10% from all regions considered tinnitus a disease, whether auditory or psychological. Differences were found between higher and lower income regions with respect to the perceived emotional status of their 'typical' patients (**Table 2**) and the time spent with individual patients during the first consultation (**Table 3**). The majority of respondents from northern Europe (41.7%) reported spending between 30-60minutes with tinnitus patients on the first appointment, in contrast to 43.9% in the south and 56% in the east spending between 15-30 minutes. Patients in northern Europe were evaluated as being more often "somewhat distressed" in comparison to a more "neutral" status in the south and east (see also Supplemental information 5).

	N	orth	Sc	outh	Е	ast	Sign.
What Is Tinnitus?	N	%	Ν	%	Ν	%	
A central auditory disease	8	3,7	9	4,0	17	9,2	
A central auditory symptom	88	40,7	64	28,4	37	20,1	
A peripheral auditory disease	11	5,1	17	7,6	12	6,5	
A peripheral auditory symptom	100	46,3	126	56,0	110	59,8	
A psychological disease	4	1,9	1	0,4	5	2,7	
Combination/ Multiple causes/ Other	5	2,3	6	2,7	3	1,6	
Cannot answer/does not know			2	0,9			
Chronic or acute?							n.s
Chronic (>3months)	123	56,9	144	64,6	104	56,5	
Acute (<3months)	19	8,8	18	8,1	27	14,7	
Both	74	34,3	61	27,4	53	28,8	
Emotional status most patients?							**
Very positive	1	0,5	0	0	5	2,7	
Somewhat positive	22	10,2	22	9,9	25	13,6	
Neutral	56	25,9	102	45,7	96	52,2	
Somewhat distressed	113	52,3	87	39,0	43	23,4	
Very distressed	24	11,1	12	5,4	15	8,2	

# Table 2. View of 'Tinnitus' and emotional status of patients, classified according to region

\*\*Difference between North compared to South and East ( $\alpha$ <.05)

n.s.: Not significant; Sign: Significant difference

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			North		South		East	Sign.
	Duration of the 1st consultation	Ν	Percent	Ν	Percent	Ν	Percent	*
-	less than 15 minutes	23	10,6	37	16,6	55	29,9	
	15 to 30 minutes	51	23,6	98	43,9	103	56,0	
	30 to 60 minutes	90	41,7	58	26,0	21	11,4	
	60 to 120 minutes	44	20,4	25	11,2	5	2,7	
	more than 120 minutes	8	3,7	5	2,2	0	0	
	Number of patients per month	Ν	Percent	Ν	Percent	Ν	Percent	*
	≤10	73	33,8	117	52,2	101	54,9	
	11-30	96	44,4	87	38,8	61	33,2	
	31-50	33	15,3	12	5,4	9	4,9	
	> 50	14	6,5	8	3,6	13	7,1	

Table 3. Appointment duration and number of patients per month, classified according to region

\* Different between all groups ( $\alpha$ <.05)

\*\*Difference between North compared to South and East ( $\alpha < .05$ )

n.s.: Not significant; Sign: Significant difference

## Management, treatment, and diagnostics

All treatments available within their respective departments were reported (**Table 4**). Where medication was selected as an available option, the respondents were asked to indicate the specific drug in the 'other' free-text space. Here sound therapy is taken to include the use of hearing aids, and TRT includes any reportedly modified version of the treatment. Medications used in tinnitus treatment included betahistine, steroids, vasodilators, antidepressants, and anxiolytics. 'Other' treatment options reported as available were hyperbaric chamber therapy, laser therapy, transcranial direct current stimulation, Gingko biloba, Vitamin B12, hypnosis, sleep hygiene, osteopathy, cochlear implantation, and music therapy. Differences in treatment availability across regions were striking, particularly between the north and east. Indicative of the general trends, CBT was available from 34.3% of departments in northern Europe, compared to just 4.9% in the east. In contrast, medication was an option in 79.9% of the departments in the east, whereas only 27.3% used medications in the north. While medication

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was the most commonly available treatment option in the east, in both the north and south it was sound-based therapy (in 69.9% and 68.4% of departments respectively).

 Table 4. Treatments reported as available within respondents departments, reported by region.

	North (n)	%	South (n)	%	East (n)	%
Advice	2	0	0	0	0	0
Alternative therapies	16	7.5	33	14.7	19	10.3
CBT	74	34.3	35	15.6	9	4.9
Counselling	108	50	115	51.1	41	22.3
Coping training	0	0	0	0	0	0
Dental procedure	2	0.9	0	0	0	0
Medication	59	27.3	<b>1</b> 11	49.3	147	79.9
Mindfulness	5	2.3	0	0	0	0
Neurofeedback	16	7.4	13	5.8	9	4.9
Physiotherapy	52	24.1	27	12	59	32.1
Relaxation	108	50	71	31.6	34	18.5
rTMS	14	6.5	3	1.3	3	1.6
Sound therapy	151	69.9	154	68.4	49	26.6
TRT	1	0.5	69	30.7	29	15.8

Clinicians involved in tinnitus care ranged from just one discipline to a broad multidisciplinary team (**Table 5**). Multidisciplinary treatments (MDT) and having a psychologist in the team was more common in northern countries than in the east and south. In the east, most care appears to be delivered by medical professionals (otolaryngologists or neurologists). Other disciplines involved in tinnitus care, reported by 1-2% of respondents, included prosthetists, social workers, movement therapists, osteopaths, sophrologists, psychosomatic medicine specialists, acupuncturists, hearing therapists, ophthalmologist, dance movement therapists, general practitioners, cardiologists, maxillofacial surgeons, and radiologists. There were single reports of

an arts therapist, counsellor, speech therapist, mindfulness instructor, and hypnotherapist being involved in care.

	North	percent	South	percent	East	percent
ENT	118	54.6	43	19.1	87	47.3
Audiologist	132	61.1	39	17.3	57	31
Psychologist	136	63	32	14.2	24	13
Psychiatrist	33	15.3	39	17.3	39	21.2
Physiotherapist	19	8.8	3	1.3	3	1.6
Neurologist	20	9.3	19	8.4	81	44
Dentist	3	1.4	1	0.4	0	0

## Table 5. Disciplines involved in tinnitus care

 Conditions and or symptoms perceived as being of relevance when assessing and/or treating tinnitus are given in **Table 6**. Most respondents reported hearing loss and dizziness complaints as relevant, irrespective of the region.

Other conditions frequently reported by respondents as of relevance to tinnitus were suicidal tendency, otitis, eustachian tube dysfunction, acoustic neuroma, multiple sclerosis, and coagulation disorder. A minority (≤1%) additionally reported hyperacusis, autoimmune disease, neurovascular conflict, Pendred syndrome, stress, psychosis, nasal septal deformation, vascular disease, facial pain, sensory hypersensitivity, cardiac arrhythmia, arterial stenosis, sleep disorders, hypercholesterolemia, fibromyalgia, apnoea, and rhinosinusitis.

	North	percent	South	percent	East	percent
Hypertension	98	45.4	118	52.4	79	42.9
Diabetes	45	20.8	108	48	55	29.9
Thyroid dysfunction	0	0	1	0.4	0	0
TMJ disorders	92	42.6	125	55.6	28	15.2
Psychological/psychiatric disorders	155	71.8	163	72.4	73	39.7
Hearing loss	212	98.1	221	98.2	159	86.4
Hyperlipidaemia	16	7.4	61	27.1	31	16.8
Dizziness	191	88.4	200	88.9	161	87.5
Cervical disorders	100	46.3	98	43.6	94	51.1
Migraine	72	33.3	83	36.9	41	22.3
Allergy	21	9.7	35	15.6	11	6

# Table 6. Opinions on which conditions are taken into consideration in tinnitus diagnostics

There was a general consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice (**Table 7**). Most respondents reported that otoscopy and pure tone audiometry were used. There was some variability in the reported use of other diagnostic tools, e.g. percentage use of audiological assessments such as tympanometry or speech audiometry in the north was twice that in the east. 'Other' responses included clinical interview, Diagnostic and Statistical Manual of Mental Disorders, vestibular evoked myogenic potential, brainstem evoked response audiometry, tone decay, neck vessel ultrasonography, orthopantomography, blood analysis, vestibular testing (calorimetry), blood pressure, and auditory brainstem response, all of which were reported by  $\leq 3\%$  of respondents.

	North	percent	South	percent	East	percent
Otoscopy	169	78.2	211	93.8	135	73.4
Tympanometry	142	65.7	172	76.4	56	30.4
Nasal endoscopy	37	17.1	87	38.7	147	79.9
Pure tone audiometry	162	75	186	82.7	151	82.1
High frequency audiometry	64	29.6	48	21.3	27	14.7
Speech audiometry	119	55.1	93	41.3	44	23.9
Tinnitus pitch and	95	44	86	38.2	46	25
loudness						
LDL	2	0.9	1	0.4	0	0
LMM	1	0.5	0	0	0	0
IR	1	0.5	0	0	0	0
<b>Broadband noise EP</b>	0	0	0	0	0	0
Pure tone EP	0	0	0	0	0	0
(DP)OAE	68	31.5	54	24	35	19
AC-ASSR	9	4.2	18	8	4	2.2
EEG	14	6.5	3	1.3	16	8.7
СТ	17	7.9	34	15.1	44	23.9
MRI	76	35.2	119	52.9	100	54.3
Angio-MRI	28	13	37	16.4	19	10.3

 Table 7. Diagnostic tools used with tinnitus patients

Most respondents from northern and southern countries reported using some form of multi-item questionnaire, in comparison with only about one in five respondents from eastern European countries (**Figure 4**). In eastern countries, the use of these measures is much less common. The most frequently used questionnaire, irrespective of region was the Tinnitus Handicap Inventory (THI) [26]. Interestingly, the only anxiety/depression questionnaire used was the Hospital Anxiety and Depression Scale (HADS) [27] and this in Eastern countries. The Tinnitus Questionnaire (TQ) [28] was mentioned frequently in northern and southern regions. The more recently developed Tinnitus Functional Index (TFI) [29] was only mentioned in the North. Additionally, respondents from all regions specified to use visual analogue scales (though unspecified which) as well. Questionnaires reported as 'other' were unspecified.

# **INSERT FIGURE 4 ABOUT HERE**

Finally, regarding the satisfaction rate on the service provided by their health care unit, 81.7% respondents from the north, 38.5% from the South, and 35.0% from the east reported they were.

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In northern Europe professionals were largely satisfied, whereas in southern and eastern Europe opinions were more divided, and less than half of respondents claimed to be satisfied.

# Regression analyses

Regression analyses were conducted to establish whether there were statistically significant associations between average net income of the country of origin of respondents and the presence of specialised tinnitus-clinics, time for tinnitus-patients per consult, satisfaction of the respondent with their service, number of patients seen per month, the requirement of a referral by GP in their country, and whether or not clinical guidelines exist. Significant associations were found between net income per month and all variables in the model (**Table 8**). In summary, higher income was associated with more specialised clinics, longer appointment times, greater satisfaction with health-care options, fewer patients per month, more referral-necessity by GP, and more knowledge and use of clinical guidelines.

**Table 8.** Associations between income and tinnitus care. Regressions summary: Dependent = income, Independents = Specialised clinics present, time per consult, Satisfaction of respondent with healthcare, Patients seen per month, Necessity of referral by GP, Existence of clinical guidelines, controlled for age and gender.

		Change Sta	tistics			
	R Square			L		Sig. F
Model	Change	F Change	df1	df2	Beta	Change
Age / gender	0.007	1.989	2	605	-0.033	0.138
Specialised clinic	0.266	220.407	1	604	-0.516	0.000
Time per consult	0.106	102.780	1	603	0.334	0.000
Satisfaction healthcare	0.048	50.505	1	602	-0.235	0.000
Patients per month	0.015	15.728	1	601	0.124	0.000
GP necesary	0.010	10.507	1	600	-0.106	0.001
Clinical guidelines	0.008	9.272	1	599	0.094	0.002

Coding: Specialised clinic: Yes=0, No=1; Time per consult: 1 = < 15 min, 2 = 15 - 30 min, 3 = 30 - 60 min, 4 = 60 - 12 min, 5 = > 120 min; Satisfaction healthcare: Yes=0, No=1; GP necesary: Yes=0, No=1; Clinical guidelines: Yes=0, No=1. Dependent: income

# Discussion

This survey sought to collate details and opinions on healthcare structure and clinical practices for tinnitus across Europe. The first interesting result from the survey was the difference between regions of Europe in terms of whether specialist tinnitus clinics are present. In the northern countries of Europe, most respondents confirmed the presence of specialised tinnitus clinics, in the South about half confirmed having specialist centres, and in the East most respondents reported not having specialised clinics. That there seems to be discord in knowledge or opinions in the rest of Europe is interesting. Where there are indeed specialised clinics, which professionals are aware of, they might more easily refer patients to these clinics without the need for a GP. On the other hand, when fewer clinics are present or known, tinnitus care more often falls to the GP, who might refer to a specialist, but not necessarily to a specialised centre. Opinions differ on whether a referral from a GP is necessary; the majority of respondents from Eastern Europe reported that it is indeed the case, whereas in northern and southern Europe less than half of respondents thought so. These findings indicate the importance of knowing the referral path. Addressing the lack of clinician's knowledge is key in the development of meaningful and actionable European guidelines. The lack of knowledge of existing specialised clinics also points to difficulties patients are likely to encounter in identifying the most appropriate healthcare. An uncertain healthcare journey and the lack of clear referral pathways is likely to exacerbate ongoing tinnitus distress, severity and chronicity.

In terms of national healthcare structure, the typical pathways differ by region. In the north they most commonly include specialised audiologists and otolaryngologists, who can presumably refer onto specialist centres where available. In southern Europe it was more common that people self-refer for tinnitus care. In Eastern Europe referral pathways were either less understood or less well-defined.

When asked which disciplines usually 'handle' tinnitus patients, the mix of disciplines reported was more evenly distributed across the counselling and medical professions in northern countries than other regions, i.e. tinnitus care was not more associated with one type of healthcare professional than another. In contrast, in southern and eastern countries it is reported that medical and technical professionals are most commonly involved. Interestingly this indicates a tendency

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towards a 'psychological' approach in the north compared to a more curative approach in tinnitus treatment in the other regions. Since there is ample evidence that psychological therapy is beneficial in any tinnitus treatment approach, and that there are regions in Europe where this is not provided, these findings highlight a *second barrier* in to the adoption and implementation of a Europe wide practice guideline.

In all regions, opinions varied on whether tinnitus is a peripheral or central auditory symptom or condition. This data will be useful in achieving a consensus definition of tinnitus within a European guideline. Interestingly, respondents from northern countries more often reported their average patients to be distressed, whereas most respondents from the south and east judged their patients to be neither distressed nor 'positive' but to be of a 'neutral' emotional status. This could indicate that in the north, the range of patients that are seen by experts is broader, i.e. patients with milder as well as more severe tinnitus are assessed by specialists. It is also possible that since northern countries dedicate more time per patient, physicians are more able to assess levels of distress. It might also reflect a greater awareness of the emotional distress of patients since in the north, a psychological assessment including clinical questionnaires is more often conducted. This is of interest because the level of distress of tinnitus patients is an important indicator of the need for onward referral for subsequent treatment options. A third barrier to the implementation of a European guideline may therefore be that in most regions of Europe, professionals responsible for tinnitus patients do not have a sufficient amount of time to adequately assess the level of distress of their patients.

The presence of a multidisciplinary treatment teams for tinnitus in northern regions was reported in most cases, including a psychologist working in most teams. By region however, it is noted that in the south many respondents report that there are no multidisciplinary treatment teams, and in the east, there was almost no psychologists involved in treatment. These findings represent a major fourth barrier in developing the development of meaningful and actionable European guidelines, if the guideline is to include evidence-based healthcare.

There is consensus across the regions on which conditions are important in tinnitus. Most respondents, irrespective of region, reported hearing loss, acoustic trauma, and vertigo as the

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most relevant conditions to consider in the assessment of tinnitus. This consensus represents a second facilitator in discussions on and implementation of European guidelines,

The treatment options reported by respondents also showed clear trends according to region. This finding can be classified as a *fifth barrier*, in that it might be difficult to get consensus on what works for whom when many treatment avenues are preferentially made available. When developing a guideline it is of importance to provide clear indications on which treatments are recommended, which are not recommended, and which have insufficient evidence to make a recommendation in either direction [30].

There was consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice. Although some small differences in procedures were reported, most experts use otoscopy and pure tone audiometry. There is some variability in the use of other diagnostic tools suggesting a potential third facilitator to discussions, on the inclusion of standardised diagnostic procedure in the guidelines.

A sixth barrier to standardised practice emerging from our data may be the limited use of clinical questionnaires in eastern and southern countries. Yet consensus exists that in research as well as the clinic questionnaires are key in assessment, both for screening and monitoring treatment progress [2, 31]. The most commonly used questionnaire however, irrespective of region, was the Tinnitus Handicap Inventory (THI). This finding is consistent with a previous study [32]. This might offer a fourth facilitator to discussions, on primary outcome measures to recommend within a guideline.

When asked how patients pay for treatment, respondents from southern and eastern Europe reported fewer patients pay privately for their tinnitus healthcare. Nonetheless, in all regions, tinnitus treatments were financed by national health insurance schemes. This may become restrictive if health insurance companies have a strong influence on what tinnitus treatment options are made available within a country. When patients pay for treatment privately, more treatment options might be on offer, even without adequate evidence of effectiveness. That there are differences in how patients pay for treatment is a seventh barrier to standard care across

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Europe, and a difficult one. In cases where the regulatory bodies in health care in a country are unwilling or unable to hold to the restrictions or recommendations stated in a guideline, the chances of implementation of this guideline drastically decrease.

Less than half of respondents from the south and east of Europe reported they were satisfied with current tinnitus healthcare in their country. This dissatisfaction may represent a fifth facilitator in that professionals are likely to be positive about progressive guidelines and towards changes in healthcare for tinnitus.

Finally, economic prosperity in a country often defines healthcare organization and healthcare satisfaction [33]. In the current study, it was hypothesized that the economic resources available to individuals in a country might dictate the view of professionals on levels of advancement in healthcare for tinnitus. This was indeed the case. Lower average net income in the country of origin of respondents was associated with reports of fewer specialized tinnitus healthcare; fewer specialised tinnitus-clinics, less time for tinnitus-patients per consult, and more often a lack (or use) of guidelines. Lower average income was also associated with lower satisfaction of the respondent with healthcare, and more necessity of referral by a GP. Interestingly, higher average net income in a country was associated with seeing more patients per month.

Some additional points are worthy of discussion. First, from the 24 countries who participated in the survey, some had many more respondents than others. This issue was presently solved by stratifying the countries according to region of Europe to yield similar respondent numbers per region. Nevertheless, responses from Lithuania and the Czech Republic might have a strong influence on the eastern region data, because of the large number of respondents from these countries. Second, most respondents were otologists. The large (over)representation of this discipline might indicate that other disciplines are less involved in tinnitus health care, and that current reports rely heavily on the clinical views and experiences of otologists and might not reflect views or opinions of professionals of other disciplines. Third, it is important to note that the current findings do not necessarily indicate or reflect a right or wrong in the organisation of tinnitus healthcare, the available assessment and treatment options for tinnitus in a country, or the advancement of specialised healthcare in a country. It is important that the current results are

seen in the light of establishing potential facilitators and barriers (see Box 1 below for summary) to the development and implementation of a guideline that can serve the whole of Europe, by being meaningful and actionable, and offer advice and options for professionals in the field, and the patients they care for.

Bor	riors
I	Lack of knowledge about or non-existence of specialised tinnitus clinics or teams makes it difficu
•	for tinnitus patients to find their way to the most appropriate professionals in a country.
2	Lack of time or other resources for adequate counselling
3	Lack of time or other resources for professionals responsible for tinnitus patients to be able to adequately assess the distress-level of tinnitus patients
4	Lack of multidisciplinary teams, and/or availability of psychologists in southern and eastern European countries
5	High variation in available treatment options; more medical-pharmacological treatment in souther and eastern countries. psychological-rehabilitative approaches more available in northern countries. When many treatment avenues are considered viable it may be difficult to reach consensus on wh works for whom
6	The use of self-report instruments is much less common in southern and eastern countries
7	There are differences in how patients pay for treatment. If regulatory bodies in healthcare in a
	country are unwilling or unable to hold to the restrictions or recommendations stated in a guideling
	the likelihood of implementation of this guideline is lower.
Fac	ilitators
1	Common ground in expert-opinion that tinnitus is a central auditory symptom. This offers options
	for discussions on the definition of tinnitus in a European guideline
2	Consensus across regions on what conditions are relevant or associated with tinnitus. Harmonies such as these are to be highlighted where possible to facilitate implementation of a standard guideline
3	Though some small differences in procedures were reported, most experts use otoscopy and pure tone audiometry. Findings will facilitate discussions on diagnostics to include in the guidelines
4	The most commonly used questionnaire irrespective of region is the Tinnitus Handicap Inventory. This may facilitate discussions on assessment methods to recommend within a guideline.
5	The percentage of respondents satisfied with current tinnitus healthcare in their country in southe and eastern Europe was low; less than half of respondents reported they were satisfied. Healthcar professionals are likely to be positive towards progressive guidelines and towards changes in hea care for tinnitus.
rihu	torshin statement
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RC wrote the first draft of the manuscript and performed the statistical analyses. DK and TB developed and designed the online questionnaire and performed preliminary analyses. DH provided extensive feedback on the initial draft and cowrote further versions of the manuscript. All remaining authors (BM, HH, CC, AN, AL, TB) provided feedback and offered critical analyses of the main text and results on all drafts of the manuscript.

1	
2 3	Acknowledgements & Funding Statements
5	The current study was carried out within the Framework of a EU COST projec named TINNET.
6 7	TINNET is a European research network funded from April 11, 2014 to April 10, 2018 by the
8 9	COST program under the Action number BM1306. the survey was carried out within the network
10	of experts, who provided the information. No patient data was used. All participants were
11 12	informed and did provide their consent.
13 14	RFFC is funded through The Netherlands Organisation for Scientific Research (NWO);
15	Innovational Research Incentives Scheme Veni
17	DJH is funded through the National Institute for Health Research (NIHR) Biomedical Research
18 19	Centre programme. The opinions expressed are those of the authors and not necessarily those of
20 21	the NIHR, the NHS, or the Department of Health and Social Care.
22	
23 24	Competing Interests
25 26	All authors have declared that there are no competing interests
27 28	
28	Data are available upon reasonable request
30 31	Deidentified participant data will be made available through corresponding author
32 33	
34	
35 36	Figure captions & Legends
37 38	FIGURE 1. Responses from each participating country
39	FIGURE 2. Discipline of respondents
40 41	<ul> <li>FIGURE 3: Most common referrals according to region</li> <li>FIGURE 4. Main questionnaire used per region</li> </ul>
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90x72mm (300 x 300 DPI)





90x72mm (300 x 300 DPI)

#### Self-referral most common



#### Referral by ENT most common



## Referral by Audiology most common



Figure 3. Most common referrals according to region

90x172mm (300 x 300 DPI)



Su	upplemental information 1: The survey
DE	MOGRAPHICS
1.	Age
2.	Gender
3.	In which country do you reside?
ł.	What is your profession? (Multiple choice). Options: GP, ENT, psychologist, psychiatrist, neurologist, audiologist, other, namely
5.	Where do you work? (Multiple choice). Options: Public hospital, private hospital, university, university
	hospital, private office/practice, other, namely
NA	TIONAL HEALTH-CARE STRUCTURE
5.	Are there specialized tinnitus healthcare-units in your country? (yes/no)
	What referral pathways for tinnitus patients are typically used in your country? (Multiple choice).
	Options: GP, ENT, Internet, directly, hospital, psychologist, dentist, community services, other, namely
3.	Is a consultation with GP necessary to go to a tinnitus unit/clinic/ENT/Audiological centre? (yes/no)
STA	ATUS OF THE PATIENT
9.	Do you consider tinnitus to be? (Multiple choice). Options: Symptom, disease, audiological problem,
	psychological problem, none of the above, other, namely
10.	What is on average the emotional status of your patient at the moment of first consultation? (5-point
	Likert). Options: Very positive, somewhat positive, neutral, distressed, very distressed
11.	Do you see predominantly? (Multiple choice). Options: Chronic tinnitus (more than 3 months), acute

tinnitus (less than 3 months), both 12. How much time can you allocate to an individual tinnitus patient in one consultation? (Multiple choice). Options: 1-10 min, 10-30 min, 30-60 min, More than 60 min

13. How many tinnitus patients do you see in one week? (Multiple choice). Options: Less than 1, 1-5, 6-10, More than 10

# MANAGEMENT OF THE PATIENT

14. Is there a protocol for tinnitus management in your country? (yes/no)

- b. If yes, how often do you use it? (5-point Likert). Options: Always, almost always, sometimes, almost never, never
- 15. What disciplines most often handle tinnitus patients in your country? (Multiple choice). Options: ENT, audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely...

16. Is there a multidisciplinary approach to treat the tinnitus patient? (yes/no) b. If yes which professionals are included? (Multiple choice). Options: ENT, audiologist, psychologist, psychiatrist, physiotherapist, neurologist, dentist, other, namely... 17. Which medical/psychiatric conditions are taken into consideration when examining tinnitus patients? (Multiple choice). Options: Hypertension, diabetes, thyroid dysfunction, TMJ disorders, psychological/psychiatric disorders, hearing loss, hyperlipidaemia, dizziness, cervical disorders, migraine, allergy, other TREATMENT AND DIAGNOSTICS 18. What kind of clinical department in your country treats tinnitus patients? (Multiple choice). Options: ENT, audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely... 19. What are the treatments options for tinnitus patients in your center? (Multiple choice). Options: TRT, CBT, mindfulness, relaxation, coping training, counselling, medication, advise/counselling, alternative therapies, sound therapy, rTMS, neurofeedback, physiotherapy, dental procedure, other 20. What diagnostic tools do you use on a tinnitus patient? (Multiple choice). Options: Questionnaires, micro-otoscopy, tympanometry, nasal endoscopy, pure tone audiometry, high frequency audiometry (12, 16, 20 kHz), speech audiometry (hearing loss), tinnitus pitch and loudness – LDL – LMM – IR, broad band noise EP, pure tone EP, (DP)OAE, air-conduction auditory steady-state responses (AC-ASSR), EEG, CT, MRI, angio-MRI. 21. Which questionnaires do you use to assess tinnitus severity? (Multiple choice). Options: TQ, TRQ, TFI, THI, TFI, TSCH, HADS, BDI, STAI, VAS scales, Grade from 1 to 10, other, namely 22. How do your patients pay for treatment? (Multiple choice). Options: Public health, health insurance,

23. Are you satisfied with the current service provided by your healthcare-unit? (yes/no)

privately, other, namely...

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n		Region	n	Percent	Income*	
1	ALBANIA	3	2	0,3	370	
2	AUSTRIA	1	1	0,2	2009	
3	BELGIUM	1	54	8,6	2091	
4	CROATIA	3	2	0,3	754	
5	CYPRUS	2	2	0,3	1658	
	CZECH					
6	REPUBLIC	3	68	10,9	772	
7	DENMARK	1	14	2,2	3095	
8	FINLAND	1	1	0,2	2509	
9	FRANCE	1	39	6,2	2157	
10	GERMANY	1	28	4,5	2265	
11	GREECE	2	29	4,6	947	
12	ISRAEL	2	12	1,9	1924	
13	ITALY	2	50	8	1725	
14	LITHUANIA	3	82	13,1	616	
15	MALTA	2	9	1,4	1021	
16	NETHERLANDS	1	41	6,6	2263	
17	POLAND	3	19	3	677	
18	PORTUGAL	2	64	10,2	984	
19	SERBIA	3	8	1,3	377	
20	SLOVENIA	3	3	0,5	692	
21	SPAIN	2	59	9,4	1718	
22	SWEDEN	1	23	3,7	2465	
23	SWITZERLAND	1	3	0,5	4760	
24	UK	1	12	1,9	2120	
24	Total		625	100		

\*Average net monthly income

Region	total	mean	n	
1	25734	2573,40	10	_
2	9977	1425,29	7	
3	4258	608,29	7	

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# **BMJ Open**

# Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029346.R2
Article Type:	Original research
Date Submitted by the Author:	03-Oct-2019
Complete List of Authors:	Cima, Rilana FF ; Universiteit Maastricht Faculteit der Psychologie en Neurowetenschappen, Clinical Psychological Science; Adelante , Centre of knowledge and expertise Kikidis, Dimitris; National and Kapodistrian University of Athens Mazurek, Birgit; University Medicine Berlin Haider, Haúla; Hospital Cuf Infante Santo, ENT department Cederroth, Chistopher; Karolinska Institutet Norena, Arnaud; Universite de Provence Lapira, Alec; University of Malta, Otolaryngology Bibas, Athanasios; National and Kapodistrian University of Athens Hoare, Derek; University of Nottingham, NIHR Nottingham Hearing Biomedical Research Unit
<b>Primary Subject Heading</b> :	Health services research
Secondary Subject Heading:	Health policy, Ear, nose and throat/otolaryngology
Keywords:	Tinnitus, Health services evaluation, standard of care, Pan-European, Guidelines, Barriers
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SCHOLARONE<sup>™</sup> Manuscripts

# Title page

Title:

Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe

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## Abstract:

Tinnitus remains a scientific and clinical problem whereby, in spite of increasing knowledge on effective treatment and management for tinnitus, very little impact on clinical practice has been observed. There is evidence that prolonged, obscure, and indirect referral-trajectories persist in usual tinnitus care.

**Objective:** It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and implementation activities are systematically tailored to the specific determinants of practice. The aim of this study was to administer a health-service evaluation survey to scope current practice- and knowledge of standards in tinnitus care across Europe. The purpose of this survey was to specifically inform the development-process of a European clinical guideline that would be implementable in all European countries.

Design: A health-services evaluation survey was carried out

Setting: The survey was carried out online accross Europe

**Participants:** Clinical experts, researchers and policy makers involved in national tinnitus healthcare and decision making

**Outcome measures:** A survey was developed by the study steering group, piloted on clinicians from the TINNET network, and underwent two iterations before being finalized. The survey was then administered to clinicians and policy makers from 24 European countries.

**Results:** Data collected from 625 respondents revealed significant differences in national healthcare structures, use of tinnitus-definitions, opinions on characteristics of tinnitus-patients, assessment procedures, and particularly in available treatment options. Differences between northern and eastern European countries were most notable.

**Conclusions:** Most European countries do not have national clinical guidelines for the management of tinnitus. Reflective of this, clinical practices in tinnitus healthcare vary dramatically across countries. This equates to inequities of care for people with tinnitus across Europe and an opportunity to introduce standards in the form of a European clinical guideline. This survey has highlighted important barriers and facilitators to implementation of such a guideline.

**Keywords:** Tinnitus, health-service evaluation, Standard of care, Pan-European, Guidelines, Barriers, Facilitators

# Strengths & Limitations of this study

# **Strenghts:**

- This is the first and only pan-European health-service evaluation to scope current practice and clinical standards in tinnitus healthcare
- Results provide health service information and expert opinions on national healthcare structures, reflecting a truly pan-European point of view.
- Result define important barriers and facilitators to propel development and implementation of meaningful and actionable guidelines

# Limitations:

- Two of the 24 countries who participated, had many more respondents than others, possibly influencing data excessively
- Most respondents were otologists, which might indicate lesser involvement of other disciplines in tinnitus health care at present and underrepresentation of viewpoints in results



#### Introduction

Tinnitus, the perception of a phantom sound, is a widespread auditory symptom [1]. It can occur with several audiological and/or otological disorders, such as sensorineural hearing loss. In rare cases, tinnitus can be traced to an underlying pathology, though uniform aetiology remains undetermined [2]. Epidemiological findings are difficult to pool across studies due to differences in methodologies [3]. Nonetheless, assuming a conservative tinnitus prevalence of 10% (severe tinnitus of 1%), tinnitus affects more than 42 million European Union (EU) adults and is a severe problem by more than four million adults. According to data from two large cohorts from Wisconsin (USA), tinnitus prevalence is increasing over time (on average by 1.4% each 5-year birth cohort) [4]. Assuming this increase is linear and of similar magnitude, prevalence estimates will double by 2050.

Tinnitus is residing within and confined to the individual's subjective perceptual experience, not measurable or quantifiable by objective physical recordings, and furthermore very rarely traceable to disease, injury, or pathology in the brain or elsewhere. Even though knowledge on the pathophysiology of tinnitus has made some progress [5, 6] there is still little evidence for effective curative tinnitus treatments or licensed pharmacological therapy [7]. The Cochrane Library currently includes nine systematic reviews on different tinnitus treatments [8], all of which are reported to have little, if any, quality evidence [9]. Patients report difficulties in concentration, being anxious and distressed, difficulty sleeping, being interrupted in their daily tasks, and feeling helpless and despondent most of the time. A wide range of evidence corroborates the theory that cognitive misinterpretations, negative emotional reactivity, and dysfunctional attentional processes are of main importance to the severe tinnitus condition [10-20].

From a scientific and clinical perspective, the increased knowledge on treatment and management for tinnitus has had minimal impact on clinical practice [2]. There is evidence that prolonged, obscure and indirect referral-trajectories persist in usual tinnitus care [21]. Tinnitus is indeed a highly complex condition with a multifactorial origin. Heterogeneous patient-profiles lead to a lack of consensus on standard assessment and treatment approaches, which in turn again lead to increasing complaints, prolonged suffering, and endless referral trajectories, resulting in enormous psychological, societal, and economic burden [22].

In 2014, the EU approved funding for a four-years COST Action (TINNET) to create a pan-European tinnitus research network. TINNET's working group 1 (WG1) consists of clinical and

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academic experts in tinnitus from across Europe whose joint objective is to develop meaningful and actionable clinical guidelines for the assessment and treatment of tinnitus patients, and to provide a consensus-based clinical definition and characterization of tinnitus<sup>1</sup>. Ultimately, a European multidisciplinary clinical guideline would be a first step towards a common minimum standard of care for tinnitus patients across Europe [23]. To ensure from a development perspective that a European guideline would become implementable, it became essential to scope current existence and knowledge of standards in tinnitus care across the continent. Without knowledge on the current 'state of the art' and standards in tinnitus healthcare, a consensus-based, meaningful, and actionable guideline could not be ensured. It is widely acknowledged that efforts to change professional practice are more successful if barriers are identified and guidelines for implementation activities are systematically tailored to the specific determinants of practice [24]. As such, a pan-European survey of clinicians and policy makers was carried out to gain service information and expert opinions on national healthcare structures, tinnitus-definition, general characteristics of tinnitus patients, and assessment and treatment options.

## Methods

The method for scoping current knowledge, opinion, and practices in tinnitus care across Europe, a web-based survey was developed by consensus of members within TINNET WG1. Participation was on a voluntary basis and all data were submitted anonymously.

#### Survey development

The survey was developed during three consecutive WG1 meetings. It was agreed that the survey would be developed in the English language, since it was expected that most responders would be able to understand English, irrespective of the country of origin. The development involved two phases. First, based on their shared knowledge of tinnitus, nine members of the WG1 steering group generated a list of domains of interest, formulated a set of questions for each domain, and generated a set of response options for each question. This list of questions was subsequently piloted in a larger group of WG1 members (n=81) via e-mail, and during a WG1 management meeting. Consensus-rounds were used to either include or exclude items. The remaining survey items were then re-disseminated to all WG1 members who had been involved in the development and piloting

<sup>&</sup>lt;sup>1</sup> http://tinnet.tinnitusresearch.net/index.php/2015-10-29-10-22-16/wg-1-clinical

stages with a request to provide comments on any necessary alterations, changes to wording or response options, and for any general remarks. A final survey was agreed upon and produced for online dissemination using Google-forms. The final survey contained items grouped as (1) Demographics, (2) National healthcare structure, (3) Tinnitus-definitions and characteristics of the tinnitus-patient, and (4) Management, treatment and diagnostics.

#### *Participants*

The recruitment targeted clinical experts, researchers and policy makers involved in national tinnitus healthcare and decision making. A total of 625 participants were recruited using the COST-TINNET network. Firstly, members of the management committee of TINNET were contacted via e-mail with a link to the survey (Supplemental information 1 provides the questions used in the survey) and were requested to forward the invitation to clinical experts, researchers, and tinnitus-organizations in their respective countries (n=24; Table 1). Secondly, another round of targeted dissemination was performed in July 2015, as at that time it was noted that there was a lower response rate from some countries. The low response rate from Italy and Spain was identified as being a language barrier and therefore the survey was translated by native-speaking TINNET members and re-distributed in their national language. The reason for low responses from other countries was not identified. The survey was open from January to October 2015.

## Patient and Public Involvement

The aim of the current study falls within the framework and main aims of the COST TINNET project<sup>1</sup>. The project, and in particular working-package 1, focussed on the objective "Clinical and audiological assessment of tinnitus patients according to common standards". The current study was an essential step in the roadmap towards the aim of the project [25]. In the development and execution of the TINNET project, patient-organisations throughout Europe were consulted and were actively involved in several stages. In the current survey, no individual patients were recruited, nor were they involved, since this study involved the evaluation of health-services by clinicians, policy makers, and individual professional expert opinions on national healthcare structures. Results of the current study were disseminated to all existing European patient organisations using a Delphi consensus methodology in the development of harmonized and adaptive clinical European guidelines for tinnitus entitled "Multidisciplinary European Guideline

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for Tinnitus: Diagnostics, Assessment and Treatment"[23]. These have been presented to the scientific community as well as national patient organisation symposia.

## Analyses

Results were first described and depicted descriptively. Because the number of responses from each country differed, data were stratified according to whether the country was in northern (higher income), southern (moderate income), or eastern (lower income) Europe (**Table 1**). (Supplemental information 2 gives the average monthly net income per country and per region). The rationale for this classification was that economic prosperity might lead to differences in health-care for tinnitus patients, since lesser resources indicate lower availability of specialized health-care. One-way ANOVA and regression analyses were performed to assess differences and associations between variables in, northern, southern, and eastern countries. All analyses were performed in IBM-SPSS version 23.

#### Results

#### *Demographics*

Survey responses (n=625) were received from participants across 24 countries (**Figure 1**) with a large number of participants from Lithuania, Czech Republic, Portugal, and Spain. The mean age of respondents was 43.9 years (SD=12.4), 49.7% were male and 50.3% were female. Respondents were from many disciplines (**Figure 2**) and worked in public healthcare (n=291), private healthcare (n=199), university (n=89) or other setting (n=48). Some respondents reported more than one workplace (n=213).

# INSERT FIGURE 1 ABOUT HERE INSERT FIGURE 2 ABOUT HERE

Table 1. Classification and percentage of respondents according to region; 1=North, 2	=South,
3=East	

Country	Region	n per countrv	n per region	Pecentage of total
Region 1		v	216	34.6%
AUSTRIA	1	1		
BELGIUM	1	54		
DENMARK	1	14		
FINLAND	1	1		
FRANCE	1	39		
GERMANY	1	28		
NETHERLANDS	1	41		
SWEDEN	1	23		
SWITZERLAND	1	3		
UK	1	12		
Region 2			225	36.0%
CYPRUS	2	2		
GREECE	2	29		
ITALY	2	50		
ISRAEL	2	12		
MALTA	2	9		
PORTUGAL	2	64		
SPAIN	2	59		
<b>Region 3</b>			184	29.4%
ALBANIA	3	2	4	
CROATIA	3	2		
CZECH REPUBLIC	3	68		
LITHUANIA	3	82		
POLAND	3	19		
SERBIA	3	8		
SLOVENIA	3	3		
Total		625	625	100

# National healthcare structure

Across all three regions of Europe, tinnitus healthcare is in most cases financed by national health insurances. This was particularly evident for eastern countries where 90.8% of respondents

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reported that their service is publicly funded. Privately funded treatment is most common in southern Europe (48%) (Supplemental Information 3).

The most common referral pathways as well as the description of services and patient's status are given in **Figure 3** and **Table 2** respectively. In taking a regional perspective, difference across Europe became clear. Specialised tinnitus clinics (or teams) are perceived to be most present in the Northern regions (more than 50% of respondents confirmed), where referral by ENT and/or Audiology seems common. Whereas in Southern Europe many people appear to self-refer to specialists, in Eastern Europe referral opinions vary or are less understood by respondents. More northern European respondents reported having and using clinical guidelines (Supplemental information 4) than respondents from southern or eastern Europe.

# **INSERT FIGURE 3 ABOUT HERE**

## Tinnitus, definitions, and characteristics of the tinnitus-patient

In all regions, more experts report that, in their opinion, tinnitus is either a central auditory symptom (**Table 2**). Still, more than 10% from all regions considered tinnitus a disease, whether auditory or psychological. Differences were found between higher and lower income regions with respect to the perceived emotional status of their 'typical' patients (**Table 2**) and the time spent with individual patients during the first consultation (**Table 3**). The majority of respondents from northern Europe (41.7%) reported spending between 30-60 minutes with tinnitus patients on the first appointment, in contrast to 43.9% in the south and 56% in the east spending between 15-30 minutes. Patients in northern Europe were evaluated as being more often "somewhat distressed" in comparison to a more "neutral" status in the south and east (see also Supplemental information 5).

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# Table 2. View of 'Tinnitus' and emotional status of patients, classified according to region

	N	orth	South		East		Sign.
What Is Tinnitus?	N	%	Ν	%	Ν	%	
A central auditory disease	8	3,7	9	4,0	17	9,2	
A central auditory symptom	88	40,7	64	28,4	37	20,1	
A peripheral auditory disease	11	5,1	17	7,6	12	6,5	
A peripheral auditory symptom	100	46,3	126	56,0	110	59,8	
A psychological disease	4	1,9	1	0,4	5	2,7	
Combination/ Multiple causes/ Other	5	2,3	6	2,7	3	1,6	
Cannot answer/does not know			2	0,9			
Chronic or acute?							n.s.
Chronic (>3months)	123	56,9	144	64,6	104	56,5	
Acute (<3months)	19	8,8	18	8,1	27	14,7	
Both	74	34,3	61	27,4	53	28,8	
Emotional status most patients?							**
Very positive	1	0,5	0	0	5	2,7	
Somewhat positive	22	10,2	22	9,9	25	13,6	
Neutral	56	25,9	102	45,7	96	52,2	
Somewhat distressed	113	52,3	87	39,0	43	23,4	
Very distressed	24	11,1	12	5,4	15	8,2	
* Different between all groups ( $\alpha$ <.05)					),		

\*\*Difference between North compared to South and East ( $\alpha$ <.05)

n.s.: Not significant; Sign: Significant difference

	North		South		East		Sign.
Duration of the 1st consultation	N	Percent	N	Percent	N	Percent	*
less than 15 minutes	23	10,6	37	16,6	55	29,9	
15 to 30 minutes	51	23,6	98	43,9	103	56,0	
30 to 60 minutes	90	41,7	58	26,0	21	11,4	
60 to 120 minutes	44	20,4	25	11,2	5	2,7	
more than 120 minutes	8	3,7	5	2,2	0	0	
Number of patients per month	Ν	Percent	Ν	Percent	Ν	Percent	*
≤10	73	33,8	117	52,2	101	54,9	
11-30	96	44,4	87	38,8	61	33,2	
31-50	33	15,3	12	5,4	9	4,9	
> 50	14	6,5	8	3,6	13	7,1	

Table 3. Appointment duration and number of patients per month, classified according to region

\* Different between all groups ( $\alpha$ <.05)

\*\*Difference between North compared to South and East ( $\alpha < .05$ )

n.s.: Not significant; Sign: Significant difference

## Management, treatment, and diagnostics

All treatments available within their respective departments were reported (**Table 4**). Where medication was selected as an available option, the respondent were asked to indicate the specific drug in the 'other' free-text space. Here sound therapy is taken to include the use of hearing aids, and TRT includes any reportedly modified version of the treatment.

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Medications used in tinnitus treatment included betahistine, steroids, vasodilators, antidepressants, and anxiolytics. 'Other' treatment options reported as available were hyperbaric chamber therapy, laser therapy, transcranial direct current stimulation, Gingko biloba, Vitamin B12, hypnosis, sleep hygiene, osteopathy, cochlear implantation, and music therapy. Differences in treatment availability across regions were striking, particularly between the north and east. Indicative of the general trends, CBT was available from 34.3% of departments in northern Europe, compared to just 4.9% in the east. In contrast, medication was an option in 79.9% of the departments in the east, whereas only 27.3% used medications in the north. While medication was the most commonly

available treatment option in the east, in both the north and south it was sound-based therapy (in 69.9% and 68.4% of departments respectively).

 Table 4. Treatments reported as available within respondents departments, reported by region.

	North (n)	%	% South (n)		East (n)	%
Advice	2	0	0	0	0	0
Alternative therapies	16	7.5	33	14.7	19	10.3
СВТ	74	34.3	35	15.6	9	4.9
Counselling	108	50	115	51.1	41	22.3
Coping training	0	0	0	0	0	0
Dental procedure	2	0.9	0	0	0	0
Medication	59	27.3	111	49.3	147	79.9
Mindfulness	5	2.3	0	0	0	0
Neurofeedback	16	7.4	13	5.8	9	4.9
Physiotherapy	52	24.1	27	12	59	32.1
Relaxation	108	50	71	31.6	34	18.5
rTMS	14	6.5	3	1.3	3	1.6
Sound therapy	151	69.9	154	68.4	49	26.6
TRT	1	0.5	69	30.7	29	15.8

Clinicians involved in tinnitus care ranged from just one discipline to a broad multidisciplinary team (**Table 5**). Multidisciplinary treatments (MDT) and having a psychologist in the team was more common in northern countries than in the east and south. In the east, most care appears to be delivered by medical professionals (otolaryngologists or neurologists). Other disciplines involved in tinnitus care, reported by 1-2% of respondents, included prosthetists, social workers, movement therapists, osteopaths, sophrologists, psychosomatic medicine specialists, acupuncturists, hearing therapists, ophthalmologist, dance movement therapists, general practitioners, cardiologists,

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maxillofacial surgeons, and radiologists. There were single reports of an arts therapist, counsellor, speech therapist, mindfulness instructor, and hypnotherapist being involved in care.

	North	percent	South	percent	East	percent
ENT	118	54.6	43	19.1	87	47.3
Audiologist	132	61.1	39	17.3	57	31
Psychologist	136	63	32	14.2	24	13
Psychiatrist	33	15.3	39	17.3	39	21.2
Physiotherapist	19	8.8	3	1.3	3	1.6
Neurologist	20	9.3	19	8.4	81	44
Dentist	3	1.4		0.4	0	0

# Table 5. Disciplines involved in tinnitus care

Conditions and or symptoms perceived as being of relevance when assessing and/or treating tinnitus are given in **Table 6**. Most respondents reported hearing loss and dizziness complaints as relevant, irrespective of the region.

Other conditions frequently reported by respondents as of relevance to tinnitus were suicidal tendency, otitis, eustachian tube dysfunction, acoustic neuroma, multiple sclerosis, and coagulation disorder. A minority ( $\leq$ 1%) additionally reported hyperacusis, autoimmune disease, neurovascular conflict, Pendred syndrome, stress, psychosis, nasal septal deformation, vascular disease, facial pain, sensory hypersensitivity, cardiac arrhythmia, arterial stenosis, sleep disorders, hypercholesterolemia, fibromyalgia, apnoea, and rhinosinusitis.

	North	percent	South	percent	East	percent
Hypertension	98	45.4	118	52.4	79	42.9
Diabetes	45	20.8	108	48	55	29.9
Thyroid dysfunction	0	0	1	0.4	0	0
TMJ disorders	92	42.6	125	55.6	28	15.2
Psychological/psychiatric disorders	155	71.8	163	72.4	73	39.7
Hearing loss	212	98.1	221	98.2	159	86.4
Hyperlipidaemia	16	7.4	61	27.1	31	16.8
Dizziness	191	88.4	200	88.9	161	87.5
Cervical disorders	100	46.3	98	43.6	94	51.1
Migraine	72	33.3	83	36.9	41	22.3
Allergy	21	9.7	35	15.6	11	6

Table 6. Opinions on which conditions are taken into consideration in tinnitus diagnostics

There was a general consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice (**Table 7**). Most respondents reported that otoscopy and pure tone audiometry were used. There was some variability in the reported use of other diagnostic tools, e.g. percentage use of audiological assessments such as tympanometry or speech audiometry in the north was twice that in the east. 'Other' responses included clinical interview, Diagnostic and Statistical Manual of Mental Disorders, vestibular evoked myogenic potential, brainstem evoked response audiometry, tone decay, neck vessel ultrasonography, orthopantomography, blood analysis, vestibular testing (calorimetry), blood pressure, and auditory brainstem response, all of which were reported by  $\leq 3\%$  of respondents.

	North	percent	South	percent	East	percent
Otoscopy	169	78.2	211	93.8	135	73.4
Tympanometry	142	65.7	172	76.4	56	30.4
Nasal endoscopy	37	17.1	87	38.7	147	79.9
Pure tone audiometry	162	75	186	82.7	151	82.1
High frequency audiometry	64	29.6	48	21.3	27	14.7
Speech audiometry	119	55.1	93	41.3	44	23.9
Tinnitus pitch and	95	44	86	38.2	46	25
loudness						
LDL	2	0.9	1	0.4	0	0
LMM	1	0.5	0	0	0	0
IR	1	0.5	0	0	0	0
<b>Broadband noise EP</b>	0	0	0	0	0	0
Pure tone EP	0	0	0	0	0	0
(DP)OAE	68	31.5	54	24	35	19
AC-ASSR	9	4.2	18	8	4	2.2
EEG	14	6.5	3	1.3	16	8.7
СТ	17	7.9	34	15.1	44	23.9
MRI	76	35.2	119	52.9	100	54.3
Angio-MRI	28	13	37	16.4	19	10.3

Table 7. Diagnostic tools used with tinnitus patients

Most respondents from northern and southern countries reported using some form of multi-item questionnaire, in comparison with only about one in five respondents from eastern European countries (**Figure 4**). In eastern countries, the use of these measures is much less common. The most frequently used questionnaire, irrespective of region was the Tinnitus Handicap Inventory (THI) [26]. Interestingly, the only anxiety/depression questionnaire used was the Hospital Anxiety and Depression Scale (HADS) [27] and this in Eastern countries. The Tinnitus Questionnaire (TQ) [28] was mentioned frequently in northern and southern regions. The more recently developed Tinnitus Functional Index (TFI) [29] was only mentioned in the North. Additionally, respondents from all regions specified to use visual analogue scales (though unspecified which) as well. Questionnaires reported as 'other' were unspecified.

#### **INSERT FIGURE 4 ABOUT HERE**

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Finally, regarding the satisfaction rate on the service provided by their health care unit, 81.7% respondents from the north, 38.5% from the South, and 35.0% from the east reported they were. In northern Europe, professionals were largely satisfied, whereas in southern and Eastern Europe, opinions were more divided, and less than half of respondents claimed to be satisfied.

## Regression analyses

Regression analyses were conducted to establish whether there were statistically significant associations between average net income of the country of origin of respondents and the presence of specialised tinnitus-clinics, time for tinnitus-patients per consult, satisfaction of the respondent with their service, number of patients seen per month, the requirement of a referral by GP in their country, and whether or not clinical guidelines exist. Significant associations were found between net income per month and all variables in the model (**Table 8**). In summary, higher income was associated with more specialised clinics, longer appointment times, greater satisfaction with health-care options, fewer patients per month, more referral-necessity by GP, and more knowledge and use of clinical guidelines.

**Table 8.** Associations between income and tinnitus care. Regressions summary: Dependent = income, Independents = Specialised clinics present, time per consult, Satisfaction of respondent with healthcare, Patients seen per month, Necessity of referral by GP, Existence of clinical guidelines, controlled for age and gender.

		Change Sta				
	R Square					Sig. F
Model	Change	F Change	df1	df2	Beta	Change
Age / gender	0.007	1.989	2	605	-0.033	0.138
Specialised clinic	0.266	220.407	1	604	-0.516	0.000
Time per consult	0.106	102.780	1	603	0.334	0.000
Satisfaction healthcare	0.048	50.505	1	602	-0.235	0.000
Patients per month	0.015	15.728	1	601	0.124	0.000
GP necesary	0.010	10.507	1	600	-0.106	0.001
Clinical guidelines	0.008	9.272	1	599	0.094	0.002

Coding: Specialised clinic: Yes=0, No=1; Time per consult: 1=< 15 min, 2=15-30min, 3=30-60min,4=60-12min, 5=>120min; Satisfaction healthcare: Yes=0, No=1; GP necesary: Yes=0, No=1; Clinical guidelines: Yes=0, No=1. Dependent: income

## Discussion

This survey sought to collate details and opinions on healthcare structure and clinical practices for tinnitus across Europe. The first interesting result from the survey was the difference between regions of Europe in terms of whether specialist tinnitus clinics are present. In the northern countries of Europe, most respondents confirmed the presence of specialised tinnitus clinics, in the South about half confirmed having specialist centres, and in the East most respondents reported not having specialised clinics. That there seems to be discord in knowledge or opinions in the rest of Europe is interesting. Where there are indeed specialised clinics, which professionals are aware of, they might more easily refer patients to these clinics without the need for a GP. On the other hand, when fewer clinics are present or known, tinnitus care more often falls to the GP, who might refer to a specialist, but not necessarily to a specialised centre. Opinions differ on whether a referral from a GP is necessary; the majority of respondents from Eastern Europe reported that it is indeed the case, whereas in northern and southern Europe less than half of respondents thought so. These findings indicate the importance of knowing the referral path. Addressing the lack of clinician's knowledge is key in the development of meaningful and actionable European guidelines. The lack of knowledge of existing specialised clinics also points to difficulties patients are likely to encounter in identifying the most appropriate healthcare. An uncertain healthcare journey and the lack of clear referral pathways is likely to exacerbate ongoing tinnitus distress, severity and chronicity.

In terms of national healthcare structure, the typical pathways differ by region. In the north they most commonly include specialised audiologists and otolaryngologists, who can presumably refer onto specialist centres where available. In southern Europe it was more common that people self-refer for tinnitus care. In Eastern Europe referral pathways were either less understood or less well-defined.

When asked which disciplines usually 'handle' tinnitus patients, the mix of disciplines reported was more evenly distributed across the counselling and medical professions in northern countries

than other regions, i.e. tinnitus care was not more associated with one type of healthcare professional than another. In contrast, in southern and eastern countries it is reported that medical and technical professionals are most commonly involved. Interestingly this indicates a tendency towards a 'psychological' approach in the north compared to a more curative approach in tinnitus treatment in the other regions. Since there is ample evidence that psychological therapy is beneficial in any tinnitus treatment approach, and that there are regions in Europe where this is not provided, these findings highlight a *second barrier* in to the adoption and implementation of a Europe wide practice guideline.

In all regions, most experts report that in their opinion tinnitus is a central auditory symptom, which might indicate agreement between the regions, and offers *a first facilitator*. This data will be useful in achieving a consensus definition of tinnitus within a European guideline. Interestingly, respondents from northern countries more often reported their average patients to be distressed, whereas most respondents from the south and east judged their patients to be neither distressed nor 'positive', but to be of a 'neutral' emotional status. This could indicate that in the north, the range of patients that are seen by experts is broader, i.e. patients with milder as well as more severe tinnitus are assessed by specialists. It is also possible that since northern countries dedicate more time per patient, physicians are more able to assess levels of distress. It might also reflect a greater awareness of the emotional distress of patients since in the north, a psychological assessment including clinical questionnaires is more often conducted. This is of interest because the level of distress of tinnitus patients is an important indicator of the need for onward referral for subsequent treatment options. A third barrier to the implementation of a European guideline may therefore be that in most regions of Europe, professionals responsible for tinnitus patients do not have a sufficient amount of time to adequately assess the level of distress of their patients.

The presence of a multidisciplinary treatment teams for tinnitus in northern regions was reported in most cases, including a psychologist working in most teams. By region however, it is noted that in the south many respondents report that there are no multidisciplinary treatment teams, and in the east there was almost no psychologists involved in treatment. These findings represent a major fourth barrier in developing the development of meaningful and actionable European guidelines, if the guideline is to include evidence-based healthcare.

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There is consensus across the regions on which conditions are important in tinnitus. Most respondents, irrespective of region, reported hearing loss, acoustic trauma, and vertigo as the most relevant conditions to consider in the assessment of tinnitus. This consensus represents a second facilitator in discussions on and implementation of European guidelines,

The treatment options reported by respondents also showed clear trends according to region. This finding can be classified as a *fifth barrier*, in that it might be difficult to get consensus on what works for whom when many treatment avenues are preferentially made available. When developing a guideline it is of importance to provide clear indications on which treatments are recommended, which are not recommended, and which have insufficient evidence to make a recommendation in either direction [30].

There was consensus on the diagnostic tools to be used to assess tinnitus patients in clinical practice. Although some small differences in procedures were reported, most experts use otoscopy and pure tone audiometry. There is some variability in the use of other diagnostic tools suggesting a potential third facilitator to discussions, on the inclusion of standardised diagnostic procedure in the guidelines.

A sixth barrier to standardised practice emerging from our data may be the limited use of clinical questionnaires in eastern and southern countries. Yet consensus exists that in research as well as the clinic questionnaires are key in assessment, both for screening and monitoring treatment progress [2, 31]. The most commonly used questionnaire however, irrespective of region, was the Tinnitus Handicap Inventory (THI). This finding is consistent with a previous study [32]. This might offer a fourth facilitator to discussions, on primary outcome measures to recommend within a guideline.

When asked how patients pay for treatment, respondents from southern and eastern Europe reported fewer patients pay privately for their tinnitus healthcare. Nonetheless, in all regions, tinnitus treatments were financed by national health insurance schemes. This may become restrictive if health insurance companies have a strong influence on what tinnitus treatment options

are made available within a country. When patients pay for treatment privately, more treatment options might be on offer, even without adequate evidence of effectiveness. That there are differences in how patients pay for treatment is a seventh barrier to standard care across Europe, and a difficult one. In cases where the regulatory bodies in health care in a country are unwilling or unable to hold to the restrictions or recommendations stated in a guideline, the chances of implementation of this guideline drastically decrease.

Less than half of respondents from the south and east of Europe reported they were satisfied with current tinnitus healthcare in their country. This dissatisfaction may represent a fifth facilitator in that professionals are likely to be positive about progressive guidelines and towards changes in healthcare for tinnitus.

Finally, economic prosperity in a country often defines healthcare organization and healthcare satisfaction [33]. In the current study, it was hypothesized that the economic resources available to individuals in a country might dictate the view of professionals on levels of advancement in healthcare for tinnitus. This was indeed the case. Lower average net income in the country of origin of respondents was associated with reports of fewer specialized tinnitus healthcare; fewer specialised tinnitus-clinics, less time for tinnitus-patients per consult, and more often a lack (or use) of guidelines. Lower average income was also associated with lower satisfaction of the respondent with healthcare, and more necessity of referral by a GP. Interestingly, higher average net income in a country was associated with seeing more patients per month.

Some additional points are worthy of discussion. First, from the 24 countries who participated in the survey, some had many more respondents than others. This issue was presently solved by stratifying the countries according to region of Europe to yield similar respondent numbers per region. Nevertheless, responses from Lithuania and the Czech Republic might have a strong influence on the eastern region data, because of the large number of respondents from these countries. Second, most respondents were otologists. The large (over)representation of this discipline might indicate that other disciplines are less involved in tinnitus health care, and that current reports rely heavily on the clinical views and experiences of otologists and might not reflect views or opinions of professionals of other disciplines. Third, it is important to note that the current

 findings do not necessarily indicate or reflect a right or wrong in the organisation of tinnitus healthcare, the available assessment and treatment options for tinnitus in a country, or the advancement of specialised healthcare in a country. It is important that the current results are seen in the light of establishing potential facilitators and barriers (see Box 1 below for summary) to the development and implementation of a guideline that can serve the whole of Europe, by being meaningful and actionable, and offer advice and options for professionals in the field, and the patients they care for.

BO	X 1: Summary of Barriers and Facilitators
Bar	riers
1	Lack of knowledge about or non-existence of specialised tinnitus clinics or teams makes it difficult
	for tinnitus patients to find their way to the most appropriate professionals in a country.
2	Lack of time or other resources for adequate counselling
3	Lack of time or other resources for professionals responsible for tinnitus patients to be able to
	adequately assess the distress-level of tinnitus patients
4	Lack of multidisciplinary teams, and/or availability of psychologists in southern and eastern
5	European countries High variation in available tractment antions: more medical pharmacological tractment in couthern
5	and eastern countries psychological-rehabilitative approaches more available in northern countries
	When many treatment avenues are considered viable it may be difficult to reach consensus on what
	works for whom
6	The use of self-report instruments is much less common in southern and eastern countries
7	There are differences in how patients pay for treatment. If regulatory bodies in healthcare in a country
	are unwilling or unable to hold to the restrictions or recommendations stated in a guideline, the
	likelihood of implementation of this guideline is lower.
Fac	ilitators
1	Common ground in expert-opinion that tinnitus is a central auditory symptom. This offers options
	for discussions on the definition of tinnitus in a European guideline
2	Consensus across regions on what conditions are relevant or associated with tinnitus. Harmonies
	such as these are to be highlighted where possible to facilitate implementation of a standard guideline
3	I hough some small differences in procedures were reported, most experts use otoscopy and pure
1	tone audiometry. Findings will facilitate discussions on diagnostics to include in the guidelines
4	This may facilitate discussions on assessment methods to recommend within a guideline
5	The percentage of respondents satisfied with current tinnitus healthcare in their country in southern
	and eastern Europe was low: less than half of respondents reported they were satisfied. Healthcare
	professionals are likely to be positive towards progressive guidelines and towards changes in health
	care for tinnitus.

## **Contributorship statement**

RC wrote the first draft of the manuscript and performed the statistical analyses. DK and TB developed and designed the online questionnaire and performed preliminary analyses. DH provided extensive feedback on the initial draft and cowrote further versions of the manuscript.

All remaining authors (BM, HH, CC, AN, AL, TB) provided feedback and offered critical analyses of the main text and results on all drafts of the manuscript.

# Acknowledgements

We are thankful to all participating professionals, who have dedicated their limited time to address our queries. We are also grateful to all project-members, work package-leaders and management of TINNET (COST Action, number BM1306, a European tinnitus research network funded from April 11, 2014 to April 10, 2018), who disseminated our requests for participation in their respective countries and networks. Special thanks are due to Thomas Fuller who attended some of the discussions in the final stages and offered valuable insight and assistance during consensus voting.

## **Funding Statements**

The current investigation was funded by the European Commission by under the COST program; Project TINNET with Action number BM1306, a European tinnitus research network funded from April 11, 2014 to April 10, 2018.

RFFC is funded through The Netherlands Organisation for Scientific Research (NWO); Innovational Research Incentives Scheme Veni

DJH is funded through the National Institute for Health Research (NIHR) Biomedical Research Centre programme. The opinions expressed are those of the authors and not necessarily those of the NIHR, the NHS, or the Department of Health and Social Care.

# **Competing Interests**

All authors have declared that there are no competing interests.

## Data are available upon reasonable request

Deidentified participant data will be made available through corresponding author

## **Figure captions & Legends**

- FIGURE 1. Responses from each participating country
- FIGURE 2. Discipline of respondents
- FIGURE 3: Most common referrals according to region

1 2 3 4 5 6	FIGURE 4. Main questionnaire used per region
7 8 9 10 11 12 13 14 15 16 17 18 19 20	
20 21 22 23 24 25 26 27 28 29 30 31 32 33	
33         34         35         36         37         38         39         40         41         42         43         44         45	
46 47 48 49 50 51 52 53 54 55 56 57 58 59	Page 23
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#### Self-referral most common



#### Referral by ENT most common



## Referral by Audiology most common



Figure 3. Most common referrals according to region

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Su	upplemental information 1: The survey
DE	MOGRAPHICS
1.	Age
2.	Gender
3.	In which country do you reside?
ł.	What is your profession? (Multiple choice). Options: GP, ENT, psychologist, psychiatrist, neurologist, audiologist, other, namely
5.	Where do you work? (Multiple choice). Options: Public hospital, private hospital, university, university
	hospital, private office/practice, other, namely
NA	TIONAL HEALTH-CARE STRUCTURE
5.	Are there specialized tinnitus healthcare-units in your country? (yes/no)
	What referral pathways for tinnitus patients are typically used in your country? (Multiple choice).
	Options: GP, ENT, Internet, directly, hospital, psychologist, dentist, community services, other, namely
3.	Is a consultation with GP necessary to go to a tinnitus unit/clinic/ENT/Audiological centre? (yes/no)
STA	ATUS OF THE PATIENT
9.	Do you consider tinnitus to be? (Multiple choice). Options: Symptom, disease, audiological problem,
	psychological problem, none of the above, other, namely
10.	What is on average the emotional status of your patient at the moment of first consultation? (5-point
	Likert). Options: Very positive, somewhat positive, neutral, distressed, very distressed
11.	Do you see predominantly? (Multiple choice). Options: Chronic tinnitus (more than 3 months), acute

tinnitus (less than 3 months), both 12. How much time can you allocate to an individual tinnitus patient in one consultation? (Multiple choice). Options: 1-10 min, 10-30 min, 30-60 min, More than 60 min

13. How many tinnitus patients do you see in one week? (Multiple choice). Options: Less than 1, 1-5, 6-10, More than 10

# MANAGEMENT OF THE PATIENT

14. Is there a protocol for tinnitus management in your country? (yes/no)

- b. If yes, how often do you use it? (5-point Likert). Options: Always, almost always, sometimes, almost never, never
- 15. What disciplines most often handle tinnitus patients in your country? (Multiple choice). Options: ENT, audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely...

16. Is there a multidisciplinary approach to treat the tinnitus patient? (yes/no) b. If yes which professionals are included? (Multiple choice). Options: ENT, audiologist, psychologist, psychiatrist, physiotherapist, neurologist, dentist, other, namely... 17. Which medical/psychiatric conditions are taken into consideration when examining tinnitus patients? (Multiple choice). Options: Hypertension, diabetes, thyroid dysfunction, TMJ disorders, psychological/psychiatric disorders, hearing loss, hyperlipidaemia, dizziness, cervical disorders, migraine, allergy, other TREATMENT AND DIAGNOSTICS 18. What kind of clinical department in your country treats tinnitus patients? (Multiple choice). Options: ENT, audiology, psychology, psychiatry, physiotherapy, neurology, dentistry, other, namely... 19. What are the treatments options for tinnitus patients in your center? (Multiple choice). Options: TRT, CBT, mindfulness, relaxation, coping training, counselling, medication, advise/counselling, alternative therapies, sound therapy, rTMS, neurofeedback, physiotherapy, dental procedure, other 20. What diagnostic tools do you use on a tinnitus patient? (Multiple choice). Options: Questionnaires, micro-otoscopy, tympanometry, nasal endoscopy, pure tone audiometry, high frequency audiometry (12, 16, 20 kHz), speech audiometry (hearing loss), tinnitus pitch and loudness – LDL – LMM – IR, broad band noise EP, pure tone EP, (DP)OAE, air-conduction auditory steady-state responses (AC-ASSR), EEG, CT, MRI, angio-MRI. 21. Which questionnaires do you use to assess tinnitus severity? (Multiple choice). Options: TQ, TRQ, TFI, THI, TFI, TSCH, HADS, BDI, STAI, VAS scales, Grade from 1 to 10, other, namely 22. How do your patients pay for treatment? (Multiple choice). Options: Public health, health insurance,

23. Are you satisfied with the current service provided by your healthcare-unit? (yes/no)

privately, other, namely...

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n		Region	n	Percent	Income*	
1	ALBANIA	3	2	0,3	370	
2	AUSTRIA	1	1	0,2	2009	
3	BELGIUM	1	54	8,6	2091	
4	CROATIA	3	2	0,3	754	
5	CYPRUS	2	2	0,3	1658	
	CZECH					
6	REPUBLIC	3	68	10,9	772	
7	DENMARK	1	14	2,2	3095	
8	FINLAND	1	1	0,2	2509	
9	FRANCE	1	39	6,2	2157	
10	GERMANY	1	28	4,5	2265	
11	GREECE	2	29	4,6	947	
12	ISRAEL	2	12	1,9	1924	
13	ITALY	2	50	8	1725	
14	LITHUANIA	3	82	13,1	616	
15	MALTA	2	9	1,4	1021	
16	NETHERLANDS	1	41	6,6	2263	
17	POLAND	3	19	3	677	
18	PORTUGAL	2	64	10,2	984	
19	SERBIA	3	8	1,3	377	
20	SLOVENIA	3	3	0,5	692	
21	SPAIN	2	59	9,4	1718	
22	SWEDEN	1	23	3,7	2465	
23	SWITZERLAND	1	3	0,5	4760	
24	UK	1	12	1,9	2120	
24	Total		625	100		

\*Average net monthly income

Region	total	mean	n	
1	25734	2573,40	10	_
2	9977	1425,29	7	
3	4258	608,29	7	

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