

## MINUTES WG1 MEETING YEAR 1 – ATHENS JULY 2014

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### Short summary meeting WG1 Clinical July 4th, 2014 Athens

On July 4<sup>th</sup> 2014 in Athens, Greece (hosted by the University of Athens) the first WG1 ‘Clinical’ was attended by 20 participants. The countries represented were: Greece, The Netherlands, Portugal, Italy, Spain, Sweden, Poland, The Czech Republic, Romania, and Malta. The meeting proved very productive in that it led to consensus-based decisions about the work-group aims, yearly estimated progress of our work group, rich brainstorm sessions, a plan of action for the coming years, and a first step in the development of a questionnaire. Data gathered from a variety of clinicians across Europe by means of this questionnaire will lead to a description of the ‘Clinical’ status quo in Europe in tinnitus healthcare & assessment in the first year. Combining these results a stepped-care tinnitus health-care and assessment proposal will be drafted. This proposal will be assessed by using the ‘Delphi’ method, after which we aim to provide a description of ‘Consensus-based, harmonized, and adaptive guidelines for demographic and clinical assessment of tinnitus-patients’ by the end of the TINNET project.

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## DISCUSSIONS

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### **Main problem:**

Current tinnitus-care in Europe is unknown

- Standard of care?
- Types of treatment options?
- Assessments?
- What sub-groups of patients? Which criteria?
- Which measurements/methods of assessment? (WG 5 Deb Hall cooperation needed)
- Which setting/resources?
- Disciplines?
- Referral pathways?
- Triage?

At present not clear who is doing what, when, how and why. A Snap shot of current situation in tinnitus health care across Europe is needed

### **Discussions in the group:**

WG1 Goal:

Description of practical and usable guidelines for tinnitus assessment and patient characterization within the upcoming 4 years the following issues have to be clarified:

- What is current state of practice?: (might be basis for larger study and grant proposal)
- If we look at WG1 goals: first a current state of practice description might be best starting point to come to harmonized guidelines
- There should be a distinction between an ideal level of standard of care and a minimal acceptable standard of care
- If we look at the goal of WG1, consensus is reached to re-describe it as follows:
- 'Consensus-based, harmonized, **and adaptive** guidelines for demographic and clinical assessment of tinnitus-patients'
- The TRI flowchart could be the basis for wg1 tasks which might help the discussion of subtypes and classification of tinnitus patients
- If we are to have a meaningful snapshot/ or an overview of the standard of care across Europe the following has to be provided
- Standard care for Tinnitus patients.
- Inventory of possible specialist with experience in the development and study of Guidelines (invite one or two of them for the WG1 Workshop)
- Example: Guidelines for cochlear implants, Guidelines for nasal poliposys

### Plan of action

- Questionnaire will be built and sent regarding current status of care
- It was discussed which platform to use:
  - Thanos Bibas offered to look at possibilities using Google-survey, since he has experience with this
  - Rilana Cima offers to use Maastricht University platform 'Emium'
  - Consensus was reached to initially start with a Google-survey
- Survey with questionnaire will be web based (google).
- Both official national organizations and clinics will be approached by each representative of WG1. Questions will be adaptive, in case the user has cumulative data

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- Financial aspects will be included as well
- A first draft of the questionnaire will be circulated at the end of October 2014, WG1 members will provide feedback, feedback will be incorporated and by early to mid November 2014 a finalized questionnaire (via google-survey) will be disseminated to the WG1 members
- The 19<sup>th</sup> of January a MC-meeting will be held in Brussels as part of the COST action, Plan: The WG1 members will meet a day before the MC meeting to discuss results of the survey and to prepare presentation for the MC-meeting

### **Brainstorm**

What items should be included in Google-survey?

Timeline: Draft in the end of August/2014.

Finalized: mid September/2014 and sent out.

2 questionnaires: one for health professionals and another for Tinnitus patients.

Results from brainstorm: Potential Questions to Professionals/Health care centers:

1. Referral patterns (pathways), how much GP's are necessary before referral to ENT?
2. Need: number of patients per year?
3. Average time per patient?
4. Reimbursement?
5. Auditory assessment. Which ones and by performed by whom? High frequency measurements?
6. Type of usual diagnostic tools used? Which questions (questionnaires) to assess severity (See also Deborah Halls survey)
7. Is there a protocol for Tinnitus management in the represented countries? If yes, what is the frequency of use (subscaling to some of the tools)
8. Is there a multidisciplinary approach to study the Tinnitus patient.
9. Are there specialized clinics for Tinnitus assessment?
10. Treatments options?
11. Role of media? Level of public awareness.
12. What is lacking in your country?
13. Do you take high frequency audiometry, if not, would you want to, and why?
14. Which medical conditions are ruled out or taken in consideration?
15. What disciplines handle the tinnitus patients in your country? Which is first one/where would a tinnitus patient go first?
16. Is there a multidisciplinary approach? if yes which professionals are included? Are there local centers or do you need to travel elsewhere?
17. Average number of referrals
18. How much the GP is required prior referral to ENT? Referral pathway in your country?
19. What is the perception of your patient in tinnitus management at the moment of first consultation? Neutral, negative, catastrophic, positive?

Potential questions to the patient: target tinnitus support groups from the country

1. What is lacking in your country?
2. Level of support?
3. What did your doctor prescribe? (list options for closed questions)
4. Where did you go first?
5. How much the media influences your seeking care?
6. How frequently do you need to see a specialist?
7. Do you feel there tinnitus is treatable? There are treatment options?

### **Other points on the agenda:**

- WG5 Workshop in Amsterdam, November 13: Small meeting of WG1 MC members as to follow up on plans of action

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- Aiming towards future guidelines : Guidelines will be adaptive, taking into account variance in resources and treatments available in every country
  - Preliminarily contact ICD11 – to adopt the new classification
- WG1 meeting before/after MC meeting 19<sup>th</sup> of Jan 2015 in Brussels such as to discuss result from survey
- Organize workshop WG1 during or close to MC meeting in Brussels in Januari 2015 or at a later date in second year before or after WG1 meeting year 2
  - To this end, committees who have already constructed similar guidelines will be contacted in order to share the know how
  - Inventory of possible specialist with experience in the development and study of Guidelines (invite one or two of them for the WG1 Workshop)
  - WHO/IV+CF: Alexandre Birsford
  - Contact Wytke Fokkens
  - Specialists of Delphi method to be invited
  - High frequency audiometry speaker and standardized assessments (christopher)
- Dissemination
  - Discussion paper? Results of survey
  - Consensus paper after Delhi rounds
  - Raise Awareness role of mass media was discussed and it was agreed to focus on interviews and press releases
  - Tinnitus week of awareness: Marathon?
- Plans for year 2 and 3
  - See workshop plans above
  - Data gathered across Europe by means of the survey will lead to a description of the 'Clinical' status quo in Europe in tinnitus healthcare & assessment in the first year.
  - Combining these results a stepped-care tinnitus health-care and assessment proposal will be drafted.
  - An ideal vs minimal guidelines about a standard will be developed
  - This proposal will be assessed by using the 'Delphi' method
  - A consensus paper/manuscript will be drafted
- Plan for year 4
  - After the DELPHI rounds we aim to provide a description of 'Consensus-based, harmonized, and adaptive guidelines for demographic and clinical assessment of tinnitus-patients' by the end of the TINNET project
- Christopher Cederoth's offers the possibility of including a company interested in high frequency measurement techniques. Discussion has been about whether this would be necessary from a clinical point of view.
- Olav /wagenaar: talks about prevention of psychiatric problems in GP office E-health
- Haúla Haider presented a research plan for a trial on Tinnitus and presbycusis.
- António Lopes Escames invited all to contribute with families for genetic studies on tinnitus.
  - Human genome study, clinical phenotype, families with several members with tinnitus, hearing disorder
  - Searching patients / At least 2 cases in an individual family
  - Short summary of criteria and required information/questions answered is needed

### Initiatives from the group

- Horizon2020
  - 80 billion euro
  - keen to identify groups already working together in particular COST-groups: during coming years: research project ideas
  - solving problem population
  - industrial problems
  - idea: lack of awareness in GP's / gen public

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- Dimitris is looking at calls which might be appropriate for a research group of our work package
- Call: Health section. Dimitris circulates the results
- ITN Initial training network: Marie Curie
- STSM
  - At least 1 in the first year from our group
- A plan for WG1 look book is offered: Each participant's centre/what do you? Ask Winny about possibilities

### PLANNING OF YEAR 1 AND 2

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Task Description	Year 1	Year 2
<b>Questionnaire Survey: snap shot (1)</b>	<b>x</b>	
Drafting/sending around	x	
Linkedin discussion forum/feedback by email	x	
Final version of survey	x	
Performing the survey (physicians and patients)	x	
Analysis of the data (at the level of the country, and EU)	x	
Presentation of the data so far	x	
<b>Description of minimal vs ideal assessment based on consensus decision (2-5)</b>		<b>x</b>
Definition of the problem		x
Definition of stakeholders (e.g. patient repr.)		x
Stepped-care tinnitus health-care and assessment proposal will be drafted.		x
Delphi method		x
Analysing results and presentation		x
Consensus Paper Draft		x