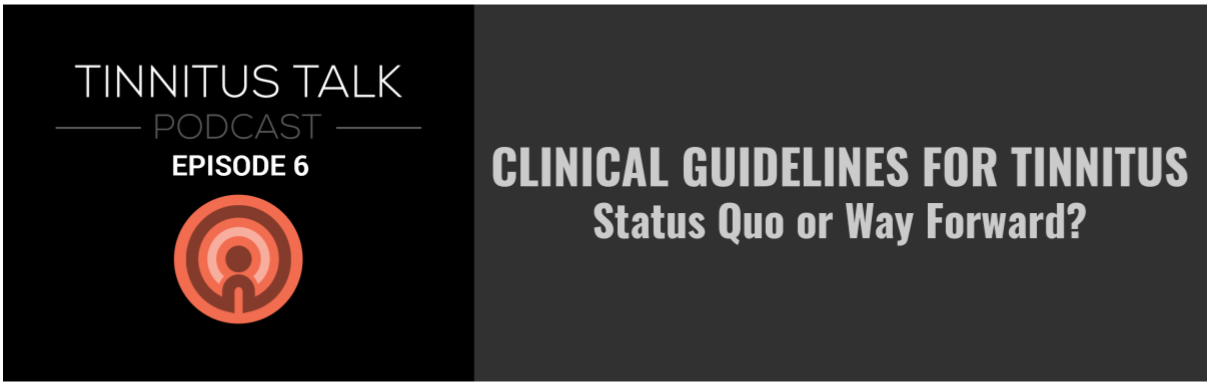

TINNITUS TALK
PODCAST
EPISODE 6

CLINICAL GUIDELINES FOR TINNITUS
Status Quo or Way Forward?

00:00 – Podcast intro

Sean: My name is Sean and I'm the host of Tinnitus Talk, a podcast on all things tinnitus.

Let me ask you this: Have you, as a tinnitus patient, had the experience of going to your doctor for help, and them telling you there's nothing they can do for you? It's a very common experience, unfortunately. Did you know though that there's such a thing as "clinical practice guidelines" for tinnitus? These are guidelines that doctors are supposed to be aware of (but often aren't), which set out a treatment pathway for tinnitus patients. Now, we all know that there's no cure, but that doesn't mean there's nothing doctors can or should do. That's what we're talking about today.

A few weeks ago, our Director Hazel was in Italy to attend a meeting of the European School for Interdisciplinary Tinnitus Research. It's a research consortium that we, Tinnitus Hub, are a formal partner of. We represent the patient voice to the researchers and try to find ways of getting patients more directly involved in the research.

While she was there, Hazel had a chance to sit down with two of the co-authors of the newly published European Clinical Practice Guidelines for tinnitus: Derek Hoare and Rilana Cima.

Hazel talked with them about why clinical practice guidelines are important for patients. They also went through some of the treatment recommendations from the guidelines and pointed at areas where more research is sorely needed.

The interview was conducted on site in rather imperfect conditions, with only one microphone. In case you do spot some minor flaws, keep in mind that we're making this podcast on a near zero budget, and thus don't have money for any fancy equipment.

Now, without further ado, let's listen to the interview!

01:54 – Kicking off the interview

Hazel Goedhart: Hi. I'm Hazel, I'm director of **Tinnitus Hub.** **Tinnitus Hub** is a patient organisation, volunteer based, non-profit, run for tinnitus patients by tinnitus patients. One of the main things we do is run the biggest online tinnitus support community called **Tinnitus Talk**. I'm here today in Milan with Derek Hoare and Rilana Cima.

Welcome. Would you both care to introduce yourselves?

Derek Hoare: Sure. So, I am Derek Hoare. I'm an Associate Professor in Hearing Sciences at the University of Nottingham. I am a Translational Researcher. I have a very large team who are primarily interested in tinnitus and hyperacusis and some work also in hearing loss, and I have a preference, or bias I suppose, towards psychological interventions, so I do a lot of work developing psychological interventions, developing self-management interventions. However, I'm also quite interested in bio-markers at the moment and how we measure the impact of tinnitus.

Rilana Cima: Hi, my name is Rilana Cima. I work as a Researcher at Maastricht University in the Netherlands. I also work as a Clinical Co-ordinator in Adelante which is a Clinical Centre also in the Netherlands very close to Maastricht. I have both a Research Team and a Clinical Team. My main research focus is on tinnitus. I also have a bias towards cognitive behavioural interventions for tinnitus complaints. My research interests focus on the psychological mechanisms underlying tinnitus; how we measure tinnitus and I also do some experimental research.

03.50 – Introduction to clinical practice guidelines

Hazel: Right, thank you guys. So, I invited you here today to talk about the new European Clinical Practice Guidelines for Tinnitus. So, Derek, can I start with you and ask you to explain what are actually Clinical Practice Guidelines?

Derek: Well, as they say, they are guidelines, so they are a set of statements that have been put together very systematically to enable careful, informed, shared decision-making between clinicians and patients. So they bring together the best available research evidence and, where there are gaps in that evidence, it draws together expert opinion and, by expert, I mean clinician opinion, patient opinion, consensus, and really considers all of those elements.

Hazel: Rilana, why is it important that we have Clinical Practice Guidelines?

Rilana: Well, as you might know, within tinnitus healthcare many things are possible but there is also, often, not only with patients but also with healthcare providers, a sort of lack of knowledge of 'what can I do, what is the evidence, the state of evidence at this time? What is best for this patient in particular? What do I need to focus on?'.

It's not only the case - for example, I work in the Netherlands - in the Netherlands, as we have noticed across Europe, we see it happening that tinnitus healthcare is often very fragmented, so tinnitus patients end up almost anywhere actually and with no clear direction of where to go when they seek help or care, so that is why it is very important to have some sort of guide to set off the need statements.

05:52 – Current standards of care across Europe and beyond

Hazel: So were there other problems that you identified with the current standards of care across Europe and were there also noticeable differences?

Rilana: Yes, as expected actually. We found that the healthcare across Europe is very differentiated and it is hardly comparable and that the reason for that is possibly that we have differences in resources we can use for healthcare or the organisation of healthcare and as I said previously, tinnitus is a complex problem as we say. It's where a group of patients, if you look at them, they are very heterogeneous, meaning that many disciplines are involved in the healthcare trajectory for tinnitus patients, so it's scattered everywhere and nowhere so that is what we have seen.

Derek: Absolutely. We just don't have a common standard currently and we see that in every single country. I can certainly speak to it from a UK perspective in that patient experiences are very different. We have the National Health Service. It should be equal and open to everybody but actually for people who have tinnitus their experience can be dramatically different and there are lots of factors, so it depends on their geography, which department they attend and even which clinician they see within a department. So, without some guidelines or without some standards a lot of care is really informed by the experience of the individual and what elements of training they have chosen to undertake, what tools they've used within their assessment and, again, what resources they have to hand, so what their department can actually offer. And I don't think many patients will not be aware of the variability that there is.

It's very good that patients speak now but these guidelines will hopefully introduce a standard that people can aspire to and work to.

Hazel: I can actually attest to that as a tinnitus patient. I had to pretty much figure that out. I am also based in the Netherlands and I had to figure out that there were actually available services that my GP didn't know about so, yes, you really have to figure it out for yourself. Can you say anything – I know you didn't specifically look at that for these guidelines – but in terms of differences between Europe and the rest of the world, maybe particularly North America?

Rilana: We were able to work on this guideline for four years because of funding from the European Commission, I believe, and the main goal was to try and develop a standard set of guidelines for Europe. What we did when we were in the final draft of the guideline was to involve experts from overseas. So there were some experts from the Americas, as well as Australia, for example, but we were not able to investigate the situation properly in those areas so unfortunately I can't say anything in comparison. We did a review of existing guidelines and one which was included in this review was the American guideline. As we looked at it, we believe that the situation in America to Europe is possibly quite comparable.

Derek: Absolutely, I think so. In terms of availability of available treatments it's pretty much on par. The American guidelines were actually one of the stronger of the guidelines that we reviewed, and they emerged as being actually very high quality. They took a very rigorous approach to reviewing evidence for particular elements of care and all of those elements of care in fact are elements of care that are also used or available within Europe

Hazel: I'm sure that's good to know for our American listeners.

10:09 – Patient/stakeholder involvement in the guidelines

Hazel: You mentioned already a little bit about the different stakeholders involved in drawing up the guidelines. How were patients consulted or involved in the process?

Rilana: So, the guidelines are based, first of all, on a review of existing guidelines, one of which the American guidelines. We took from the results from the combined guidelines to base part of this guideline on as well to see whether it's comparable, or on a par.

Secondly, we did a pan-European survey where we asked several stakeholders about the situation as it is in their particular country, in their particular institute or setting. These two information resources were the foundations on which we based the first draft of the European guidelines. So, when we did all of that work in the first few years, we compiled evidence and data and then we did a large literature research to see what new evidence we could incorporate and that gave us a first draft. This first draft was sent out between ourselves first to see if we did include everything that the experts believed should actually be in there. A second consensus round was third party stakeholders which included all Patient Associations known to us and they were enabled to comment in a quite detailed way on the whole guideline, and they did. It was quite extensive and really nice to experience the commitment of going through.. I mean, we wrote 80 pages of documents and we got detailed comments on many issues in the guideline so, yes, they were quite involved.

Hazel: And did the patient input lead to any significant revisions?

Rilana: Yes, they did. All of the consensus rounds. One of the main principles is there is a small Steering Group of which both of us were a part and others who are also the authors of the current guideline and we started the venture with the principle that it should be consensus based. So everyone we involved should have a say and a vote. So, one of the consequences was that every comment was to be considered by the Steering Group and answered and replied to. So we took a lot of time to go through all of the hundreds of comments to try and change either the text or, if not possible or if for some reason we believed this might be something different, then we replied to the comment asking for either understanding or more information from the commenter. One of the things we also did was to ask each commenter whether or not they were experts or patients or policy people or insurance people.

We asked them to make a rating if they had a comment, to say, 'ok, this is an **essential** change. You **have** to change this otherwise we will not agree with this guideline'.

Then it was **possible** change. And then they could say **'this is just a comment, please answer my question or comment on this comment'** so all the **essential** ones, the ones scored with a '1' were the ones that that one we were obliged to change.

Derek: Completely. I think for me, what I recall quite strongly is the final chapter of the guidelines. So we wrote an entire chapter dedicated to very straightforward, very clear information that should be conveyed [to the patient], kind of separate from the randomised control trial discussions that were going on in other chapters for example and there actually patients really informed the content. There were lots of elements in there that they did not understand or they contested or they thought were missing, so there was certainly lots of input and lots of modifications to the guideline based on that.

Hazel: Very good to hear.

Derek: 660 comments altogether.

Hazel: I don't envy you.

Rilana: It was days and days of going through comments.

15:30 – Coping mechanisms versus treatments that reduce tinnitus

Hazel: I think some patients, maybe, when they see the guidelines might be slightly disappointed with a perceived focus more on the coping mechanisms and the psychological interventions rather than the treatments which would make the tinnitus go away. Why this focus?

Derek: So, there is a focus, I think, in terms of the volume of the guideline that is dedicated to that, however that was represented off the evidence base. You know, one marker of a good guideline is that it is comprehensive and that it completely covers the population of interest. So, hence the need for the European survey. We looked at everything and we identified everything that was used as part of tinnitus assessment or used as part of tinnitus therapy or treatment and everything that's in use we made sure to cover in the guideline so for a lot of the more treatment, if you want to call it, 'spectrum of approaches', we just had very, very limited evidence. So, they are in there and we were able to make some level of recommendation but however where we have a volume of evidence it is related to psychological intervention.

Hazel: So, it's more about the quality of the evidence and what is available right now in terms of treatment that informed this focus. It's not that you're saying psychological intervention is the only way to go, for instance?

Rilana: No.

Hazel: Right, just to clarify that.

17:17 – Potential benefits for severe sufferers

Hazel: Thinking of the group of patients that really fall into the extreme end of the spectrum; the most severe sufferers who are probably the hardest patients to treat. Do you think they will benefit from these guidelines?

Rilana: I believe they will. I think any patient or even family of patients, healthcare providers, even the ones who are not involved daily with tinnitus patients, that they can benefit from guidelines. It just offers a framework and a sort of pathway for people to get information. That is the goal of the guidelines.

To give people a sort of 'state of the art' or as a situation sort of 'these are the treatments; these are the ways we measure; these also are the ways at this time we try and solve issues, and this is the evidence'.

So, anyone could benefit from that, I believe. In treatment, however, that is a different question. Obviously, the guideline does not say what is effective and for whom. That is a different question and that involves obviously a very personalised approach for the specific patient or healthcare seeker at either end of the spectrum. There are also many people with mild tinnitus complaints who also feel they don't know where to go. They just want some information and answers so to service them is also of high importance and obviously, the people at the very severe end of the spectrum as well, as soon as possible, I believe. It's important for all of these people to take a very personalised approach.

Derek: Exactly. And I would add one of the most important parts of the guidelines and one of the emphases that we place is in establishing what the impact of tinnitus is for the individual. So, again, there is a complete lack of uniformity in how tinnitus is assessed, hence we don't really have a good comparison or a good definition of what is more extreme; so we have very clear guidance on using standard report measures to establish just how bothersome tinnitus is and triaging and directing people to the right care. That's not happening. I know certainly in the UK – again, not wanting to focus too much on the UK necessarily – I'm sure it happens everywhere. We have family doctors or Primary Care physicians who do not refer people onwards. So people present with bothersome tinnitus and present again and present again and maybe present three or four times before they eventually get a referral. So what we're very clear about here is that if someone has a bothersome tinnitus they need referral. They need proper assessment by ENT and Audiology. They need further assessment if their tinnitus is severe. They need referral to specialist tinnitus services, and even within specialist tinnitus services there is a need for further assessment just to establish just how severe the tinnitus is and what approach should be taken.

Hazel: Yes, I can again attest to that. I had to almost beg for a referral after going in the second or third time to my GP. I think that it's very common, unfortunately.

Rilana: For me too. I can attest this is recognisable from all the patients that I speak with that it's this story, actually: **'Why didn't I know about this about two years ago. This would have saved me so much suffering'**, and we wanted to do something about this.

21:31 – Break: support our podcast!

Sean: Next up, we'll continue with a discussion on the treatment review part of the guidelines, where you'll find out what the current scientific evidence tells us about different treatments.

But we did want to take a quick moment to ask you, if you're enjoying this episode so far, to please consider donating.

If you're willing to support us financially, even with just a few dollars, we'll be able to reach even higher quality standards, and we can for instance travel to interview the most interesting guests.

You can find all the information about how to make donations on our own podcast page at tinnitustalk.com/podcast.

22:06 – Treatment review, what does 'no recommendation' mean?

Hazel: So, let's move on to the treatment review part of the guideline which I think is probably the core of it. So this is where you guys looked at all the currently available treatments and then gave a recommendation based on the currently available level of evidence as to how safe and how effective is this treatment. And I think many will be surprised to learn that actually the majority of the treatments you looked at received a **'no recommendation'** verdict. I am actually just going to list them for the listeners and viewers, so:

- **Cochlear Implants** got a **‘no recommendation’** (only recommended for hearing loss but not for tinnitus per se)
- **Transcranial Electric Stimulation**
- **Vagus nerve stimulation**
- **Acoustic Neuromodulation**
- **Invasive neurostimulation**
- **Tinnitus Retraining Therapy**
- **Sound Therapy, and**
- **Acupuncture**

So, these all got a ‘no recommendation’ verdict. And, Derek, what does that mean, ‘no recommendation’?

Derek: So, in making these judgements we were primarily focussed on randomised controlled trials and systematic review level evidence, so that top of the pyramid evidence, which are really the gold standard for evaluating any therapeutic interventions, so what we were looking for was evidence of benefit on relevant outcomes and what we found for most, or all, of these treatments was limited, or no, randomised controls or systematic review. What we’re concluding with a ‘no’ recommendation is that we have insufficient evidence to make a judgement in either direction. So, it’s not a judgement against. It’s not a judgement for. What we’re saying is we simply don’t have the evidence we need for an informed recommendation.

Hazel: That’s very good to clarify. So, just to be extra clear on this, you are not saying that these treatments don’t work. For all we know, they could, but it just hasn’t been studied thoroughly enough.

Derek: Absolutely.

24.28 – Recommendation against drug treatment for tinnitus

Hazel: I’ve just picked out a few other things from the treatment review. I did notice that you gave a recommendation against, or it was a weak recommendation against, drug treatment. Why is that?

Derek: So, again, it’s important to be clear about what we’re talking about when we talk about drugs. Or drugs specifically for tinnitus. So, there is no drug that has ever shown a significant benefit specifically for tinnitus and change on tinnitus severity. There are obviously lots of trials using anti-depressants or anti-anxiety drugs or sedatives of some form. However, these have their own place. So the recommendation here is clearly about not specifically prescribing them for tinnitus and it’s a weak recommendation against because clearly drugs have potential for side effects. So, anti-depressants, where there are lots of issues with sedation, with dependency, these are all known side effects so do not prescribe them just for tinnitus. Clearly, they are indicated if somebody has a clinical depression or a clinical anxiety, then you are following a different treatment pathway. You are not following a tinnitus pathway, so this is clearly specifically about tinnitus and prescribing for tinnitus.

Hazel: Right, so if someone were severely anxious or depressed, maybe because of their tinnitus, then some of those drugs could be used to treat that anxiety and depression, but it shouldn’t be used just to treat the tinnitus.

Rilana: No, they should be used following the guideline for depression or anxiety. That is a different guideline, different problems, other group of experts.

26:30 – No evidence for Tinnitus Retraining Therapy

Hazel: The guidelines also state there is no strong evidence for Tinnitus Retraining Therapy, however this does seem to be in some countries, I think particularly in the US, something of a gold standard, very generally applied, treatment. So why do you think this is and is this something that should change?

Rilana: Yes, well we see that is indeed the case not only in North America but also in Europe. It is, up to this date, maybe even the most common way of treating tinnitus patients. Well, the reason for that might be that it is heavily protocolised so it's a standard way and it gives regulations so healthcare providers have a book or set of rules they can follow. People get a device which they can take home. I can believe all of this is very helpful with a group of patients who usually end up bouncing from one place to the other. I think it's practicality mostly that makes this the standard approach.

A different story is obviously whether it works, so there have been many studies using TRT as either the main intervention of study or as a comparison. TRT is also highly modular so it's not just one thing that combines into TRT so it's difficult to see what specifically in studies was used as being TRT. But if we look at studies performed by the people who developed the TRT then we see that, indeed, at this time, even after so many years and so many studies, we were unable to say whether it worked or not.

Hazel: And that's it.

Rilana: And that's what we saw, and so at least that should not inform the standard of care. I think, but that's my opinion, that standard of care might be better informed by evidence.

29:07 – Upcoming and emerging treatments, e.g. bimodal neuromodulation

Hazel: So, I think people out there who have been following the research news closely will notice the absence of upcoming or emerging treatments. I think a big one now is bimodal neuromodulation and, yes, they will wonder why these things are not covered. Why is that?

Derek: So, emerging treatments. We only included in the guideline treatments that are actually used in practice, so that was many, and we chose to not report emerging studies where there was no evidence currently in the literature, randomised control level evidence. So we had a certain level of conciseness, I guess, but emerging treatments will not feature in the current guidelines because this is about what clinicians and patients can talk about today in their clinic and what they can do today in their clinic and what is available. But these guidelines are going to change. We will be revising them in three- or four-years' time and so anything that is emerging further and actually being used in practice will be featured in the guidelines in future.

Hazel: Right, so anything that comes on the market in the next few years, and if there are studies published on its safety and effectiveness, you can include it then?

Derek: We must.

Hazel: You must include it then, good!

30:43 – Where do the guidelines point tinnitus researchers?

Hazel: So, I am also thinking in terms of what direction do the guidelines point tinnitus researchers. I mean, one thing that's clear is that most currently available treatments have not been studied thoroughly enough. What do you think this tells researchers in terms of the focus areas for future studies?

Rilana: Well, I think Chapter 4 says a lot. It quite strongly states that for most of the treatments available there's unfortunately not enough evidence to make a decision, so that is in a way a little bit disturbing for people involved with these intervention pathways. The ones you listed just now. It's a call to please provide better quality evidence maybe, or give us a solution to what to say in the next version of the guideline. What I think the guideline as a whole makes clear is that lots of effort in tinnitus research is being allocated, funding as well, but that we're not there yet. Far from it. But we have a lot if you look at everything we had to include in the guideline. But we have also had to conclude that for most of it we are not yet there to make a definite decision. We don't have enough evidence yet.

Derek: Just from a researcher perspective, guidelines are also critically important. So we are constantly asked about demonstrating the impact of our work and the impact of our research, so what benefit is this having for patients? Without a guideline it's quite difficult to demonstrate that. However, with a guideline, you can show that we have produced some high-level evidence here and it has informed these clinical guidelines and these guidelines will inform clinical practice. So, this is the kind of pathway to impact. So a guideline now has really laid down the challenge for researchers to do research at a standard, at a quality, that makes it usable and actually useful. So, if people are pursuing tracts of research, they need to do so at a level that is going to be informative.

I think that a lot of the literature and a lot of the things that you have mentioned have been subject to lots of small-scale studies, not controlled studies. They all have their place, however, to reach conclusions we need good quality, high level evidence, and lots of it.

Hazel: So that's large scale, randomised control trials for example?

Rilana: Yes.

Hazel: Well, let's hope that happens then.

33:54 – Cognitive Behavioural Therapy (CBT) and funding

Hazel: I think that actually the only treatment in the guidelines for which there was a large volume of high-quality evidence, and that pointed in favour of the treatment, is Cognitive Behavioural Therapy. I know that some patients worry that more funding for CBT, since it has already been extensively studied and proven to be effective, would draw resources away from cure focussed research. Is that a legitimate concern do you think?

Rilana: Well, since I am very much involved in trying to develop effective CBT interventions for tinnitus, I can say it's not the case that there is a lot of funding. There is a lot of funding going towards the cure, more the causative factors of tinnitus which is obviously very important. I believe there is minimal funding for the actual intervention based on CBT. You speak of the large quantity of funding which has been spent, but actually we speak here of only a few studies of high quality and very limited funding so it's a miracle the evidence is there. I cannot attach to the large parts of funding going forwards. I think it should be evenly spread actually in all areas of research, so what caused it, the causative factors and mechanisms in the ear and brain; how can we cure it maybe, or lessen it in that respect, also on brain level or perceptual level, but in the meantime, there are many people suffering. How can I cure them without waiting for answers about the causative factors and areas of the brain, but how can I help them now? And I think all of these three things should be heavily funded at the same time.

Hazel: What's your view on that Derek?

Derek: It's something I'm very conscious of and raises an issue very regularly. As a translational researcher I am sitting in the middle between basic and clinical and the expectation is that I am doing something that will have benefit for patients in the short-term. Developing a new drug or developing new surgical procedures, that takes many, many years and it needs to start from a very basic science. We have, and I think many countries have, very separate funding for basic science, for translational science, for applied, more clinical, science and that money doesn't shift between, so we have completely separate funders for these work streams. The hope is that the basic science feeds into the translational science and the translational science feeds into the clinical science but, in terms of funding, for most it is quite separate, so it doesn't impinge.

Hazel: I think that’s a very useful clarification; since they are different funding channels you’re saying that it’s not the case that if a certain amount of funding goes to for instance **CBT** studies that it is somehow taken away from or stands in the way of finding a cure.

Derek: No, absolutely. That is a really important point. We are both involved, as are you, in a European Doctoral Training Programme. That’s another stream of funding specifically about training and training the next generation of researchers, and so I think a useful example of funding allocation is that here we have 14, and soon to be 15, PhD students, so a lot of funding, a lot of European funding, but I think only one of the 15 is actually working on a **CBT**-related project. So we have 14 out of the 15 working on other clinical application or other basic science studies.

Hazel: Yes, this is the ESIT Programme (European School for Interdisciplinary Tinnitus Research).

38:36 – Educating doctors (and patients)

Hazel: I would like to end by talking to you a little bit about patient/doctor communication. What would you like doctors to take away from the guidelines in terms of how they communicate to tinnitus patients?

Rilana: Well, first of all is that there is something for them, since the most mentioned message people get from their GP or ENT is still, unbelievably, ‘well, you just have to get used to it, there is nothing I can do.’

This message should stop. Hopefully, after reading the guideline any physician or doctor is informed and can, at least, point towards this information source, which is included, as well, for patients in the guideline, if they cannot provide the service themselves. So, it should be a guide for informing patients about the situation as to what treatments are available and what the evidence is. Derek can add about the specific Chapter actually.

Derek: Yes, Chapter 5 of the guideline is entirely about communicating information to the patient, so it’s written with clinicians and patients in mind so, hopefully, it is a chapter that patients can use and access and bring it to their GP. I think there is a responsibility on both sides; for patients to keep themselves informed and also for our GPs, our family doctors, to be versed in tinnitus and to not be afraid to talk about the impact that it is having on somebody and to establish whether or not there is that need for referral. GPs are generalists. They can’t know everything, they don’t know everything. Your GP might have a special interest in Ear Nose and Throat and then they are more likely to know something about tinnitus but they just need to really establish whether it’s something that has an impact or not and if it does have an impact and that’s not something they can deal with, then they need to acknowledge that and they need to appropriately refer.

Hazel: How can we ensure that doctors actually pick up these guidelines and then start using them?

Rilana: That’s a good point. Maybe sending it to them or emailing them the link or obviously as Derek said, these people have to deal with many different problems and they have to deal with many different guidelines, I believe so it’s the responsibility as well from the person but it is also for the patients to inform their GP or their healthcare provider to say, ‘listen, I hear there is this guideline’.

We do our best obviously in our networks to try and disseminate, like we are sitting here today, that this guideline is here and for all to look at.

Derek: So, it’s been published in full and is openly available. So, it’s fully open access by everybody. We have obviously been disseminating it. We have been disseminating it right through the entire process and will continue to do so. I think, importantly, we have involved lots of societies from right across Europe and they have essentially endorsed the guideline as part of the process that we’ve gone through and so it should be on the alert for every single clinician across Europe.

42:30 – Where do patients go for more information?

Hazel: You said patients also should inform themselves. So if they read the guidelines and then wonder ‘oh, where do I actually find these treatments that you mention, how do I get access to this?’ What should they do?

Derek: That is a difficult one and what I would probably say first is that actually the guidelines are there to hopefully shape and form the service, and so a lot of these things that we are recommending and a lot of the pathways that we are recommending are not going to be in place everywhere. However, it will involve a little bit of searching potentially in the first instance. So, speaking to others, speaking to people on Tinnitus Talk about things that they’ve read and things they are interested in pursuing and also contacting national organisations. We have provided a list in the guideline and contact details of national patient organisations for various countries across Europe and they quite often hold really good information about what is available to you, and from whom and where.

Rilana: So, if you see something in the guideline, maybe a treatment mentioned or anything mentioned, then in the final chapter we will have hopefully added as many as possible patient sites and information resources where people can ask about these issues in their own country. So that is the issue. It is a European guideline, so there will be many patients from different countries. Everything is organised a little bit differently in each country, so to manage that a little bit we have inserted a list of all the resources we could find.

Hazel: Right, so let’s have hope that these guidelines will really take tinnitus care to the next level across Europe and hopefully beyond.

Rilana: Yes, and the evidence as well.

Hazel: And the research as well. Inform the research and take that to the next level. That would be wonderful.

Hazel: So, Derek and Rilana, I want to thank you so much for this informative discussion. I think that patients really appreciate hearing directly from you guys on what you’ve been working on, and thank you so much.

Derek and Rilana: Thank you, very interesting. It’s been a pleasure.

45:03 – Outro and practical info on our podcast

Sean: Okay folks, thank you so much for listening! We hope you enjoyed the interview and learned something from it too. My take on this is kind of conflicted. On the one hand, it’s disappointing to learn about the lack of rigorous evidence for most treatments, and certainly for any treatments that actually reduce the tinnitus itself. But at least we now have an overview of currently available options and the state of the evidence, and it’s clear that we should not let our doctors send us off without even so much as a proper evaluation.

You can find the link to the new European Clinical Practice Guidelines on our own podcast page at tinnitustalk.com/podcast. We also included a link to the US guidelines, for those of you based there.

Okay, we’ll end with a bit of housekeeping:

This podcast is distributed through many channels like iTunes, Spotify, Google and SoundCloud. But if you want to read more background information, or leave comments, please visit our own podcast page at tinnitustalk.com/podcast. Here, you can also get access to written transcripts of our episodes, through the “CC” button on the player. And we’ve created time stamps for each episode, allowing you to jump straight to different sections of the episode, depending on which topics you’re interested in listening to.

Also, on the Tinnitus Talk support forum, that’s tinnitustalk.com, you will find a sub-forum entirely dedicated to this podcast, where you can discuss episodes with other members, propose ideas for new episodes, and submit questions for upcoming podcast guests. This makes it a much more interactive experience, so we’d love to see you there! Of course, the Tinnitus Talk forum is also a great place to visit if you’re struggling with your tinnitus and need some friendly support from people who understand what it’s like.

Finally, we’d like to ask that you subscribe to this podcast through whatever your preferred platform is, and don’t forget to rate us and leave a review! You can also show your support by sharing episodes through social media.

Have a good day, and we hope to see you around on Tinnitus Talk!