Podcast 5. Antje Heinrlch. “Outcomes measurement choosing the right tool for the question”

Hello and welcome once again to a ManCAD / British Academy of Audiology podcast. You might well know that ManCAD stands for Manchester Centre for Audiology and Deafness and that we are located at the University of Manchester in the UK.

I am Gabrielle (Gaby) Saunders. I’m a Senior Research Fellow at ManCAD and I moderate these podcasts.

We always try to address the topics pertinent to the practise of audiology but also want to make sure that they are relevant to researches and anyone interested in hearing and hearing loss. Some of them are specific COVID related issues and others are more general considerations in audiology.

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Today our speaker Is Antje Heinrich. She's a Senior Lecturer in Audiology and Hearing Sciences at ManCAD and she's going to be answering some questions that I always ask her on the topic of outcomes measurement, choosing the right tool for the question.

Before I begin, I’m going to hand you over to Antje who's just going to tell us a bit about herself.

Antje: Thank you Gaby. To introduce myself I would say that I consider myself a speech scientist who is interested in all aspects of speech perception across the lifespan. Most of my work is based around behavioural testing so where we present stimuli to a listener and then record their reaction. However, more recently I’ve also been very interested or become very interested in self-report measures; initially as they relate to speech perception but now also much more widely and I’m particularly also interested in looking at their validation.

My background is in Psychology. I did my first degree at the Technical University in Dresden, Germany and then my Master's and Doctoral degrees at the University of Toronto, Canada.

I came to the UK in 2005 and have been pretty much on pure research work for much of the time that I’ve been UK. First in Cambridge and then in Nottingham. At the beginning of 2018 I started at ManCAD and through the supervision of rather a lot of students who come from particularly from a lot of clinical backgrounds I’ve been much more aware and have much more exposure to clinical questions and the challenges that come with them.

Gaby: Interesting thank you. What made you choose outcomes measurement as a discussion for this podcast?

Antje: It has become quite clear to me over the last few years that outcome measures are an incredibly important aspect of clinical intervention, any clinical intervention process.   As many of you probably know, particularly the clinicians among you, is that there's a bewildering range of outcome measures that one could choose from and it's not always clear which one you should choose and which one is the best. In this podcast I’m hoping to discuss some of the questions that I think we should be thinking about and we should be asking ourselves before we settle on a particular outcome measure.

Gaby: Good. We'll start at the beginning.   So what's the ultimate purpose of an outcome measure and why is it important that we should be measuring It?

Antje: Ultimately as a clinician, you want to know whether your intervention was successful for a patient. Related to that, you not only want to know whether the intervention was successful but also whether the patient, in this case the listener, is a successful listener now. Like is doing something better now than they did before the intervention and for this particular listener. You want to be able to distinguish a successful listener (whatever that is) and we will be talking about what that is from an unsuccessful listener.

Gaby: That makes a lot of sense and it sounds simple. I'm sure it's not, so you talk about success. How would you define success?

Antje: It turns out it's actually not a simple question at all. There are many different dimensions/ ways in which you could be talking about success. The question is: What do you want your patient to get better at? In terms of listening, do you want them to have improved performance or better listening and aided performance for instance compared to unaided performance. That would be some sort of benefit in speech perception. Do you want to have a satisfied patient? What does satisfied actually mean? Satisfied as satisfied with their hearing aids, satisfied as with their communicational needs, satisfied as a better quality of life. There are lots of different aspects you could be thinking about here. You could be asking yourself would your intervention be a success if your patient used the hearing aid for instance or whether they report some sort of reduction in handicap. There are many different ways in which you could answer that question.

Gaby: And is there one that's more important than another?

Antje: Another very good question also very difficult to answer. Two things that I would say. One is all of these different dimensions that I've talked about are actually not very closely related to each other. It's not like you can just choose one measurement and it will automatically assess all the other dimensions as well. You actually do need to choose what you want and the second thing I would say is at the end of the day you need to decide what you want to measure, and what defines success for you.

Gaby: In other words they're just various different dimensions of outcome. Presumably, you couldn't measure all of them for everybody because that's an awful lot of measures. So what should we be measuring? Is there a baseline of a minimum set that we should measure or what should we do?

Antje: Honestly, there is not an agreed minimum set of outcome measures. I do have colleagues who I know work on such a minimum set. The problem also is that it's not always entirely clear who's asking the question and whose viewpoint we are taking.

Does successful mean successful for the clinician. If we're talking from a clinician point of view then there are a few minimal outcome measures that for instance look at things like if you've had intervention surgery. For instance to get a cochlear implant fitted. Was that successful as a technically successful. You can measure that and that's an important measure outcome measure for a clinician. However, it's less likely to be important for a patient. Do we have measures that assess the patient point of view. Do we think that's equally as important as the clinician? Should we assess that? So it really is, to an extent, it's a consensus project where lots of different people who are involved with that intervention like clinicians, patients, maybe also relatives of patients need to come together to design what is success and what is the minimum outcome set that we need to measure to assess whether success has been achieved. Until that exists I think from a clinician point of view we just need to define that for ourselves and be very clear in our head what success is for us and how we measure it and be able to justify that and I think that's the next best thing we can do.

Gaby: So can you elaborate more of what you mean by you know defining success from a clinician. You said until we know what that is, where are you going with that thinking?

Antje: Clinician essentially means that, this is essentially how outcome measures have been developed for the past however long they have been developed and I'm sure they have a very long history. Is that clinicians have basically been set in their practice and saying okay I'm seeing a lot of different patients and I know I have a very good sense of what I think is important as a measure of success in order to make patients succeed in their real lives or maybe also in order to meet some other targets. They came up with questions that they think represent patient dimensions. So how true that is, how complete that is and how good that reflects the patient experience is not very clear. More recently, there have been efforts to sort bring in the patient voice much more strongly and at a much earlier level of development of these outcome measures. I'm aware of at least two projects that I think are absolutely brilliant where patients were very much involved from the very first stage of development of these outcome measures and they were asked for their views:

> What is important for them?
> What can they live with?
> How important are certain aspects?

That has then been carried forward all the way into the formulation of questionnaire questions and I think ultimately that is the way to go.

Gaby: So do you know these new questionnaires well enough to give some examples of where they really diverge from what the clinician-centred questionnaires were like. What it matters, things that patients bring up, that clinicians haven't really considered in the past.

Antje: The one that I know in most detail is Sarah Hughes listening effort questionnaire for cochlear implant users. I haven't seen the finished questionnaire yet. What I know that she did which I really like, she really did canvas a large number, both in terms of running focus groups and having qualitative explorations, a lot of listening situations and listening environments and listening just life situations of adult patients with profound hearing loss essentially who were then fitted with a cochlear implant. In order to really understand what their frustrations are and what their problems are. That was then turned in a multi-stage process into questions that again were put back to the patients for them to say; does this question, as it is now in this questionnaire, reflect what you wanted to have reflected in this question and what your original concern was. I think that was so much better than having you know three audiologists or hearing scientists get together in a pub and write down questions on the back of an envelope and say I think this is what patients should need to consider.

Gaby: I guess this approach is becoming more and more relevant. In all of medicine people are realizing that you go to the patient, the person who's got the condition, and ask them what they're looking for and that that does make an awful lot of sense.

Antje: I think just to come from a scientist point of view I think it requires a very particular set of skills and the problem is that skills are so specialized normally and I think it's not that common to find people who know how to develop questionnaires and can also use qualitative research methods well. I think that's a really you know specialized sort of overlap in skills that we really do need. The best projects are all interdisciplinary, there's no question about it, but I think that makes questionnaire development really interdisciplinary as you need qualitative skills at the beginning but then and I'm sure we're going to come up onto this later for the validation to make sure that the questionnaire actually measures what it's meant to measure. It's a completely different skill set and to find the same research group or the same scientists who can do all of it I think is quite special and that is one of the reasons I think why it's not that common.

Gaby: So do these sort of patient questionnaires developed with patient input. Do they kind of break down into the benefits satisfaction use, reduction in handicap dimensions or do they go down a whole different route.

Antje: Actually I have no idea. So that actually touches on a completely different question and which again comes back to what it is that we should be measuring.

There are two different sort of fundamental approaches:

One is to just put a lot of data into it and see how all these different outcome measures that have been developed over the 30 last years and if you give them to the same participant do they all tend to answer all of the outcome measures in the same way or not? So can you boil it down to like three and those are the three that you use. When you do that what comes out is how actually they all contribute unique things to it. You either bombard a patient with different outcome measures and get a very comprehensive overview or you basically focus on the ones that you want; that's one option,

The other option is to take more of a conceptual view and I think that's what you are asking. We know from frameworks that these are the important aspects of success so we should have a questionnaire that very systematically measures each aspect of that concept essentially. The concept that is the most current one that tends to be used is the ICF that people might have heard of which asks about impairment, activity limitation and participation restriction.

I don't think I've seen the finished article of Sarah's questionnaire so I don't know how explicitly she relates back to these things. That is the level of conceptual framework you should be thinking about when coming up with an outcome measures.

Gaby: Is there any current wisdom on how you should go about choosing what to measure. What's the current thinking to go back to the ICF.

Antje: Well the thing is that many of the currently available questionnaires it's not entirely clear how closely they really relate to the ICF framework. Particularly I think the impairment is fairly well designed and there's a lot of consensus on how to measure impairment. How to measure activity limitation and participation restriction is a lot less clear. That even starts with that there's a lot less consensus in what that means. Which sort of activities go into which category sort of thing and as long as that is not clear it's really difficult to categorize questionnaires.

Probably what I would is to improve the aid of benefits or the aided speech perception benefit. That seems obvious as an important dimension and that can be measured as an objective measure for instance. So as a speech noise outcome to always be speech noise outcome test, behaviour test for instance, I would probably also add a self-report measure for benefit that is patient reported. Just to make sure that you do have two very different aspects of the success that you're measuring. This is by no means exhaustive in any sort of way but I think it does tap into two different dimensions that if you want to have a good outcome measures they should probably score well on these two dimensions.

Gaby: What happens if you get a direct conflict? Someone says there are not getting benefit and you can measure a big benefit or you get the converse, you cannot measure a benefit and patient says its great it's doing everything I need it to do.

Antje: That's exactly my point. That the measures don't relate very well and that if you're measuring once that doesn't by any means mean you're assessing the other thing as well. I think you bring up a very good example of when that happens. I think in that case you just have to remember that these are two separate dimensions and not every patient has to score highly on both of them and you can say on this dimension they are doing well, on the other one they don't. Does that for instance warrant some additional intervention to bring the other dimension up as well. I don't know. I think that is part of the thought process of trying to decide a) what sort of outcome measure you want to do and b) if you get a certain outcome, a certain result on an outcome measure does that trigger anything. Does that have any consequence whatsoever or are you just happy to know and to either say okay that makes my intervention successful or not. Those are things that just need to be very clear in your head before you start choosing an outcome measure.

Gaby: I think that's a very good point. That you don't just measure it but you probably should be doing something with the information you get and if you're not doing anything with it one could say why bother measuring it.

So that is a good point but I think it's a difficult one. Do you listen? Do you take the assumption the patient knows and if they're saying they're not feeling any benefit even if you can measure it, well you know I trust your perception and likewise you burst the bubble if they say really this is helping me and you can't measure it.   I mean you could assume it's because the measure you're using for it isn't working or it's complex.

Antje: It is entirely possible if you can't measure it, there are many reasons why you may not get a measure as a benefit. It might be that it just measures the wrong thing. It might be that it's such a noisy and insensitive measure that you're not picking up anything and there are lots of different ways and it's not entirely clear why you get the result that you do and to be entirely honest I don't think it's necessarily the job of the clinician to decide that either.

I think as a clinician, you can expect to have sensitive measures and that is what research is for. To develop you with the tools that you need in order to do your trade as a clinician. In terms of self-report, I don't know is self-report inherently more important or more sensitive to something than objective measures. I don't know. I would probably always have it in there because I think it's important to have the patient’s voice. I don't know whether I would make my only outcome measure.

Gaby: I think they're going to be lots of strong opinions about that out there. I think that's a really hard one.

So you've just sort of alluded to this. There are lots of different tools out there and if you do want to make some kind of assessment of quality and sort of stand back and say well there are all these different measures and they all claim to measure satisfaction. How should you go about thinking about I'll pick that one over that one. What are some of the things to consider?

Antje: Very good question and another difficult one to answer. What I would say is there's a concept called validation where you're basically trying to answer questions around how accurate is your measure. If I give a patient the same measure twice and nothing changed in the middle in between giving, I should in theory get exactly the same score and how likely I am to get the same score tells you something about the accuracy of the measure. So if the score just fluctuates randomly then you know, when you do have an interaction when you have an intervention in the middle you have absolutely no idea. Do you get a change in score because there's some fluctuation going on anyway or is that because really something changed.

So if you can choose a measure that gives you the same result every time you run it ,if nothing changed in between, that would be a real plus.   The problem is that it's much easier to get that sort of test retest reliability, which is the technical term for that sort of accuracy, for behavioural measures and they tend to be a lot more stable than self-report measures. So that's one thing to keep in mind. The other thing to keep in mind is to sort of look at your outcome measure and think like how comprehensively does it assess what it is that I want to assess. Behaviour measures such as speech and noise tests are normally not very comprehensive because they only test one particular listening situation whereas in the questionnaire you can ask about many. You also want to ask: okay if this questionnaire which says it's assessing satisfaction. Does that give you a similar result to other questionnaires that also say that they assess satisfaction?

So is there some sort of similarity between outcome measures that are saying they're measuring the same thing and by the same sort of the complementary question then is questionnaires or outcome measures that are meant to assess something very different do they give you a different result. So you kind of need to know for your outcome measure:

How accurate it is.
How comprehensive and sensitive it is to exactly the particular dimension you want to assess.
How different it is to other dimensions that it is not meant to assess.

So just how specific it is. This sort of assessment, which I think is very important for all outcome measures, hasn't really been very comprehensively done for a lot of outcome measures. I think if you go through your outcome measures you will find out very quickly that there are some that are fairly well validated and there are many that are not. Maybe if you have a lot of outcome measures to choose from anyway you might as well choose the ones that are better validated because then at least you can trust the numbers.

Gaby: And to do that you have to go to the literature.

Antje: You would have to go to the literature. Unfortunately, that is not particularly easily available information.

Gaby: I guess something that comes to mind and maybe I missed whether you said it. You talk about, so you've got to get if no intervention happens you want the same results both times but presumably you also want it to be sensitive enough to small changes so that you can measure a difference.

Antje: Yes that's right.

Gaby: Which is another difficulty with choosing outcome measures.

Antje: Yes exactly and I think that is part of being sensitive. So only if really, really, really nothing changed you get exactly the same result and very little variation and you know around that result. As soon as something changes, on a dimension that you're interested in changing, (not on a dimension that's completely unrelated to what you're measuring) then you want to get a change in the score. Actually it's quite nice from that, if you run sort of a test re test study where you measure how accurate re-measurement of the same thing is.

You can actually work out what sort of change you would need in order to have faith in whatever change you're seeing is a real change in the underlying dimension. So you can work that out. I think that is really helpful. If you have a questionnaire that goes from zero to 50 and my patient scores 20 and then I do an intervention and after the intervention they score 25. Because I know that this is a very accurate questionnaire and they state the measures are very sensitive and stable outcome so if I repeatedly measure without the intervention it would always get 20, then 25 is a massive change and you can believe in it that's something of the underlying dimension change. Whereas if you have something that's not very accurate where the score can vary anything between 15 and 25 then you're much less you know exactly that the 25 actually means anything. I think that is actually quite important in our outcome measure to know what the test retest reliability is to be able to work that out.

Gaby: That does sound very important and I guess from a clinical point of view people really need to understand that difference that critical difference before they can really interpret it.

Gaby: So you've shared a lot. It's all pretty darn complicated. What's your key message that you'd like people to take away?

Antje: That there are lots of different outcome measures, as I'm sure all of you know. I would advocate that you think carefully about what it is that you want to measure and try to answer some of the questions that we have discussed in this podcast and basically select a measure based on the answers to these questions rather than selecting a measure simply based on popularity or accessibility of what has been used before. I think that's the best way to move this area forward in a good way.

Gaby: Interesting and do you think it's okay if everybody goes away and selects their own measure or should there be some kind of uniformity of the measure that people use?

Antje: I think we've sort touched on this before. I think there's a tension in this answer because I think ultimately your measure needs to measure whatever you think the important outcome dimension is of your intervention. However, in order to make interventions comparable you have to have a minimum outcome set as well. But that minimum outcome set needs to be agreed with all interested parties and we don't have that yet. I think that is something we should strive for and then we should have one or two measures that we all include, regardless of whether we think this is the right answer to our particular question. Just in order to make our study comparable to all the other studies. That's a bit of community service that we do. Then again you know for clinicians and if the data never go to research or whatever I think they should go for whatever best measures what they want the dimension that they want to see change on that's what they should measure.

Gaby: Great thank you. I think that's very useful. Do you want to add anything else just before we end and any other things that we didn't cover.

Antje: I think that was a very brief but hopefully very comprehensive overview over the different dimensions that you need to think about when choosing outcome measures and as I said I'm perfectly aware that I didn't give a whole lot of answers but I think that is just where the field is at the moment.

I think you know just to say to clinicians you know as long as you know why you're choosing something and you have a justification in your head you're doing the right thing don't be afraid to ask these questions and to find answers for yourself.

Gaby: Thank you Antje. I think maybe what would be good if we add some references of key articles that maybe people could look up in the transcript that might be helpful.

All it remains for me to do is say thank you Antje for your time and sharing your thoughts obsession.

Thank you. If the audience have any follow up questions, feedback or share ideas for future topics please contact me. You can send me an email. Gabrlelle.Saunders@manchester.ac.uk

I hope you enjoyed this discussion and are going to come back to the next podcast. Until then farewell and stay well.

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