# Podcast transcript: Harnessing the power of the UK collaborative research culture

With Jameel Muzzaffar, Rishi Mandavia, Matthew Smith

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#### **SPEAKERS**

Jameel Muzzaffar, Rishi Mandavia, Matthew Smith

#### Intro 00:01

Welcome to our clinicians in conversation podcast series, part of the NIHR the National Institute for Health Research podcast programme. In this episode you will hear from the National trainee leads for ENT, Jameel Muzzaffar, Rishi Mandavia and Matthew Smith, who is also the co-founder of the INTEGRATE UK Trainee Network. They will be taking a look at how the research environment in the NIHR and the INTEGRATE network has enabled and developed researchers in ENT clinical trials.

#### Jameel Muzzaffar 00:37

So to start with, could I just ask each of you to introduce yourself to our listeners?

#### Rishi Mandavia 00:42

Hi, everyone. My name is Rishi Mandavia. I'm an ENT trainee in London. And I've sort of been on the NIHR academic clinician training pathway since graduating from medical school, I was an academic foundation Dr. And then I did the ACF, the Academic Clinical Fellowship and then I carried out a PhD funded by the NIHR as well. I've got a strong interest in research across all this time and I'm currently working as the NIHR CRN trainee lead for ENT in my region. And I'm leading the National SeaSHeL study, which is the largest European core study on sudden hearing loss.

# Matthew Smith 01:25

I am Matthew Smith, and I'm about to take up a post in Cambridge as a senior clinical lecturer, as an Honorary Consultant ENT surgeon, I have been involved with the NIHR for several years working as the East of England trainee lead in the network and completed a PhD during my training, but outside of the NIHR for that. Then more recently been awarded some funding as co Chief Investigator for a randomised controlled trial under the HTA scheme, which we'll be completing over the next few years.

# Jameel Muzzaffar 02:03

And I'm Jameel Muzzaffar and TWJ Foundation, Fellow and Otology in Auditory Implantation in Cambridge, and I'm a National Trainee Lead for ENT. So Rishi and Matt, I know both of you through the National NIHR ENT Clinical Research Network where we've all been regional leads. Matt, I know you've also been the chair of INTEGRATE, could you tell us a little bit more about what INTEGRATE is?

#### 02:26

Sure. So, INTEGRATE is the UK ENT Trainee Research Network and this is something that I co founded in 2015, with a small group of trainees who were interested in trying to bring together the collaborative effort of trainees across the country to deliver very large scale trials that wouldn't otherwise be possible. And this came on the back of work done in Birmingham by the surgeons there and slightly after the neurosurgeons as well, who had all delivered quite large trials by that point. Some working with the NIHR, the NIHR standard funded interventional trials and it's now become a relatively commonplace thing amongst surgical specialties and to a degree amongst medical specialties to have these trainee networks. And INTEGRATE you know, over it's time over the last six years or so, has delivered seven national trials, recruited patients totaling around about 6000 now and working with around 75-80 hospitals regularly and over 100 at least once. And so it's become quite a big, big group of individuals that have interest in research and we now have several different pieces of work going on in parallel for different sub-specialties of ENT and many of the individuals who headed up the groups and have been part of it have gone on to work with the NIHR and other groups and lead studies themselves.

#### Jameel Muzzaffar 04:05

How does the experience the trainees are getting through Integrate lead into the NIHR network and projects?

#### Matthew Smith 04:11

See, what INTEGRATE does is give trainees experience of quite large studies where they are a lead at a single centre, it's equivalent to a PI really for a larger study. And they gain experience of getting approvals in motivating and organising people within their centre, collecting data and dealing with some of the data management issues relating to that. And all these things are skills that are very translatable to research later on in their career. And they're also things that the NIHR has helped with and although most of our work hasn't been funded therefore hasn't been adopted on to the NIHR portfolio. We have worked with the NIHR with the research design service, and trainees have good experience of using that and then gone on to use it again themselves. And we have hopefully instilled some enthusiasm and interest and skills in people. And certainly individuals I know now who have gone on to work with the NIHR and become part of bigger studies.

# Jameel Muzzaffar 05:21

Rishi, could you tell us a little bit about sudden onset sensorineural hearing loss? And why we might need more studies in this area?

#### Rishi Mandavia 05:29

Yeah, absolutely. So sudden onset sensual hearing loss is basically a rapid loss of hearing due to some abnormal functioning either in the inner ear, the auditory nerve, or areas of the brain that are responsible for hearing. It's quite rare with around 30 cases per I think 100,000 each year. And you know, there's been a lot of reporting from various national bodies and guardian organisations like NICE, for example, that have highlighted that there's a posted evidence assessing the comparative effectiveness of the various treatment options for idiopathic sudden onset of hearing loss. I mean the treatment options mainly being steroids via different routes. And it's also been apparent that we're not quite clear what the patient pathway is for patients with sudden onset hearing loss. This is not just in the UK, but outside of the UK as well and there's a big core to answer these questions. So we actually understand, you know, how is it that that patients are being treated? So there's a big call to carry out research studies to address some of these questions. And I know that Matt, for example, is leading one of the one of the biggest studies now, looking at the comparative effectiveness of the most common types of medications used to treat the condition.

#### Jameel Muzzaffar 06:53

So how does the SeaSHeL Study fit into that landscape?

#### Rishi Mandavia 06:56

Yeah, so the SeaSHeL study is a national multi-center cohort study of patients with sudden onset central hearing loss in the NHS. It's taking place across 75 trusts in the UK. And it's basically looking to help address a lot of the questions that I was talking about before, namely, what is the patient pathway for the condition? You know, where do patients present? What treatments are they provided with? How do they fare? What are the outcomes? So is looking to answer all these questions, but in quite a novel way. You know using that integrated approach, harnessing the power of collaborative trainee research. So SeaSHeL is working with INTEGRATE it's working with the NIHR champions, SFO UK and the NIHR CRN. It means we've had access to a vast array of expertise trainees and other junior doctors across the country. And because of that with very little funding we managed to recruit over 650 patients in 75 trusts with as I said a very small amount of funding, harnessing the power of that collaborative research model.

# Jameel Muzzaffar 08:09

As a trainee, what have you learned from your involvement with Seashell?

#### Rishi Mandavia 08:12

I think I have learnt is that you know, carrying out this research is hard. That is the first thing I am sure Matt will agree with me. You realise just how important research governance is, ethics is and how to navigate that process. You know, how you need help. This is why you as the NIHR CRN have been really helpful in helping us navigate all of this, for example. And it's also shown you how powerful trainee collaboratives are and how enthusiastic trainees are across the country. And these are people who are giving up their time for free to upload information on patients to further our understanding. So it just showed me what commitment people have to research, to patient care across the country. And it's often is used as a soundbite, but I think it's true, that patients and our colleagues are given their free

time to further our understanding for the benefits of patient care. So that's one of the key things I've learned as well.

#### Jameel Muzzaffar 09:11

How has the network of Local Clinical Research Networks been supportive of SeaSHeL?

#### Rishi Mandavia 09:16

Yeah so SeaSHeL was, I think the first ENT training study that was adopted on the NIHR portfolio. And at the beginning, I didn't really fully understand how the NIHR CRN could help and over time it has been extremely helpful. We've had help from NIHR funded research nurses, that have helped in certain sites recruit patients, particularly sites where we need ethics, where we need consent from patients. So the research nurses have been very helpful from that perspective. And they've also been very helpful with using the research department, research and governance departments and driving through this study in terms of the approval processes, and it's also been very important to have them on board with regards to publicising the study and recruiting site leads, and helping to act as a conduit between ENT trainees and audiologist as well. That's that's my experience so far in terms of assistance.

# Jameel Muzzaffar 10:20

Matt, you've been a driving force behind the upcoming Starfish study? Could you tell us a little bit about the study how it's going to be delivered, and what role trainees might have in that?

#### Matthew Smith 10:29

Sure. Starfish is a response to a call from the NIHR from the Health Technology Assessment group, which wanted to explore the efficacy of different routes of restorative administration for sudden sensorineural hearing loss. And Rishi's explained a bit of the context to that because it's relatively rare, but it's a very important condition, with life changing effects on people. And yet, we don't really know how best to manage them. And so we put together a funding bid my co Chief Investigators, James Tyson in Cambridge, and we've got a team of various other experts working with Birmingham Clinical Trials Unit to deliver this. And this is a going to have to be guite a big trial, because of the rareness of sudden sensorineural hearing loss, it means you've got to work over quite a large number of sites. And also, because of the numbers, we need to explore this, because of the nuances of the way that we have to measure this with differences in sound intensity change in hearing threshold. And because we actually wanted three arms for this, because we wanted to look at three different interventions compared to each other. So what we've done is go back to the kind of INTEGRATE model and the NIHR network model. And we're going to have 75 sites, recruiting patients to the study. And what's going to be key here is that because it's the trainees that see these patients often it's the people who are on call 24 hours a day, who get these calls from GPs who see these people coming in at weekends and times when perhaps a more conventional trial structure wouldn't necessarily pick up all the patients. Because of that, we're going to have a lot of emphasis on trainee participation and in particular the NIHR associate PI scheme. And any trainee who takes part in this will take on the role of an associate Principal Investigator (PI) at their centre and they will then learn all the things that a consultant PI would learn. Hopefully they will gain some experience and some enthusiasm to take them

forward to research in the future. And importantly, with the NIHR scheme they also get that recognition and the formal recognition on their CVs, and additional training and support from the NIHR.

# Jameel Muzzaffar 13:01

How is the NIHR supporting Starfish?

#### Matthew Smith 13:04

So I mean the most important thing is that they are our funder. You know this is a major grant that we've been awarded. And with that funding comes a lot of other support from the NIHR. So we have people within the Health Technology Assessment group who are advising us on setting up contracts who are helping us through that process, and who are going to be basically keeping a check on us, but in a kind of friendly way where we can talk to them if we're having problems, they can help us. And then of course you know we're opened up on the portfolio to the support that the network can give and Rishi's alluded to that. And we're also going to rely a lot on this multidisciplinary network of consultants, ENT trainees and audiologists, everyone working together to hopefully deliver this trial, on time and on budget.

# Jameel Muzzaffar 13:53

Yeah, thank you both making the time to talk to us and to help people listening to this podcast understand a little bit more about the landscape around bi sensory neural hearing loss, and the way the trainees have been integral in driving this forward in the ENT.

#### Outro 14:09

To find out more about how the NIHR supports trainees and ENT research, please visit the NIHR website. This was an episode of the NIHR clinicians and conversation podcast series. Thank you for listening.