

Transcript of the Dementia Researcher Podcast

Prediction and Prevention and in Neurodegenerative Disease Conference

VO Welcome to the Dementia Researcher Podcast, brought to you by dementiaresearcher.nihr.ac.uk, a network for early career researchers.

Megan: Hello I'm Megan O'Hare and today I'm joined for this special podcast recording from the Prediction and Prevention in Neurodegenerative Disease conference at Queen Mary University by 3 fantastic panellists who have all been attending this conference, so please welcome, Phazha Bothongo, a PhD student from Queen Mary University London who can stay awake for 48 hours apparently, her field of study is social and ethnic determinants of dementia. Isabelle Foote, also a PhD student at the Wolfson Institute for Preventive Medicine at Queen Mary London, University London, Isabelle's field of interest is psychiatry and dementia and she has an irrational fear of slugs. And finally, Dr Harri Sivasathiaseelan a clinical research fellow at the Dementia Research Centre at UCL, who is in the final year of his PhD whose area of research is resultant changes in social and emotional responses in people with neurodegenerative disorders, who one year watched 565 films. Which is a lot of films.

The aim of this podcast is to share what we have seen and heard throughout the day today and to explore today's main conference theme which, as the title of the conference suggests; current issues around early detection and prevention of neurodegenerative diseases.

So, can we start with a quick round table from everyone, maybe Phazha:

Phazha: Sure, well I am currently focussing on the social, mainly on deprivation, aspects of dementia and ethnicity and my field revolves around finding risk factors that both change one's risk that are both increase one's risk but changes with one's ethnicity and as well as preventative factors which was a current theme in today's Symposium. I was particularly interested in Vanessa Raymont who today talked about the recent advancements in prevention of dementia, particularly when it comes to memory service clinics and our approach to dementia patients there so that was my key favourite part of today.

Megan: Ok, great. Harri?

Harri: Yep, I'm Harri, I'm a neurologist I did my clinical training here at the Royal London Hospital and then, and now now I'm currently in the final year PhD funded by the Wolfson Foundation. And my research has really been focusing on on the changes in people's Kind of social responses and emotional behaviour that occur in all dementias particularly in a group of dementias called Frontotemporal Dementias. it's a group of symptoms that affects people their carers, their loved ones massively but we don't really understand them that well. and actually really importantly we're not what that good that's picking up on them and actually formally testing them on things like memory and language so in my particular research what I look at is, I take non-verbal emotional sounds, so the sounds of people laughing or crying and look at the responses in

kind of both healthy control people but also people with different forms of dementia to see how it's maybe different, and what that can tell us about what's driving some of the changes in emotional and social behaviour. And kind of, I think overall today was really interesting. As a clinician working on dementia, especially from other medical colleagues,, I'm often told is pretty much all you do diagnose people, and then that's it, then there's no treatments, there's nothing really to make it better so I think the overall theme as a positive thing looking towards identifying risk and how that could be potentially important looking forward and changing people's prognosis and how things progress is particularly interesting.

Megan: You said about using non-verbal cues so laughing and then how people perceive that, could, how early do you look in the stage of disease and could that be a biomarker because they're always looking for biomarkers...

Harri: Yeah, so that's really the ultimate aim, so at the moment, I do it in people with established, different dementia syndromes, so Alzheimer's Disease as well as different forms of Frontotemporal dementia, the idea eventually will be to hone down, because actually my group people look at all sorts of different, sort of atypical features, or atypical stimuli that could be really relevant, so I look at emotional sounds, some of my colleagues look at music, and the idea is that between us we will eventually come up with tests that we will then extend out to a kind of early symptomatic, or even pre-symptomatic phase. In the frontotemporal dementias, because a lot of it is genetic, well a lot of certain forms are genetic, we have potential access to a group of people who we know are at risk of going on to develop the condition and therefore the tests we are trying to develop in the established diseases can eventually be tried in the pre-symptomatic or early symptomatic phase.

Megan: I guess that links to one of the Richard Milne's talks: Ethical challenges associated with prediction and prevention of Alzheimer's Disease so you will have a cohort of people who are potentially going to develop the disease and you have the ethical considerations of whether you tell them and then whether you test them and then if you test them you're telling them essentially that they have the...

Harri: That's really true, and that's one of the big differences so with the, particularly the genetic cohorts, which would be the ones that are pre-symptomatic, it's a really difficult, ethical kind of quandary of, specifically if you have a mutation that you know is going to cause the condition or has a high penetrance, or high chance of actually causing the condition so there is a lot that comes with that so when people take part in the research they don't always necessarily know their genetic status so some of them choose to take part in the research without actually knowing if they're positive or negative and that's because often the people we are studying, we want control subjects as well. So, there is a difficulty there because the way you as a researcher behave around the person, the way in which data is handled, the way in which the person is going to respond to other tests and I think that was really brought up today, especially right now when we don't have disease modifying treatments about how you deal with that information knowing that there isn't necessarily something we can do about it right now but hopefully there will be in the future.

Megan: Yeah, there was that really interesting two columns he had, like a pro and a cons list, but the Promise and the, what was the other word he used, Problems. You know the promises are you have a right to know, then you have access to care and then you can make decisions. The problems are, there is no cure so why would you find out, you know, with cancer you could totally understand you'd want to know, you'd want to get into the system on that pathway, but if there is

no treatment why are you getting the information. Anyway, it was quite interesting, was it Alastair Noyce asked the audience to put up their hands to say whether they would find out and not very many people put up their hands [*laughing*], did they? I don't know whether any of you have had...

Isy: I've done the 23&Me testing..

Megan: Have you? This is Isabelle Foote.

Isy: [*laughing*] Yep, hi! And it gives you the chance to say whether you would want to know the risks for things like dementia and Parkinson's Disease, and I personally did and I've got friends who also did and they found out their ApoE4 status for example, and actually have started doing more exercise and things like that for example so I think maybe also because I'm younger, it seems like something that's a lot further off so I don't know whether maybe if I was older and closer to the point, that might affect my judgement of whether I'd want to know or not.

Megan: Yeah, they did mention about the closer you get to the timepoint where it might actually be a reality, you know, your anxiety goes up, so you're far removed from it in your 20s.

Isy: Yeah exactly, and I think you kind of feel like there's a lot of things, there's a lot of things spoken about about healthy lifestyle and things like that and if you know that you've got a lot of, or probably got a lot of decades [*laughing*] to kind of try and do something then it's better than maybe finding out when you think 'oh maybe it's too late' for me to make that difference so...

Phazha: But what I've found particularly interesting today and wasn't quite mentioned was that a lot of these genetic risk factors have a, studies are based on predominantly Caucasian subsets and recent studies particularly concerning where I'm interested in, that ApoE4 carriers, I think done in America for African-Americans, aren't as predictive of your risk of getting dementia and studies have pointed towards that in fact it's an ancestral gene and that within West Africa, I think there was a study in Nigeria, that those who had an ApoE4 allele it in fact didn't increase their risk, and I think that when it comes to prevention and particularly when we're talking about genetics that in having a holistic approach that one may have one of these risk factors and get all this anxiety and worry but is it truly applicable to you considering your cultural and racial background and I think that was, that was one of the interesting things today that no one really highlighted was that how true and diverse and inclusive are these risk factors and are we focussing on them so much that we're not realising that ok within different cultural groups they actually differ, because ApoE4 is the main one you hear about with Alzheimer's Disease but very little is talked about risk considering racial and cultural backgrounds.

Megan: I actually wanted to ask and I realised this is relevant to you because of your field of study for your PhD, not just the genetic risk, sort of a, they were saying today about how you find out and you might be scared and have anxiety but whether that's a cultural thing, in that in the Western world we have more of a fear of death and it's not part of the culture to accept death and I wondered whether there would be a difference between religion, race, you know, how you perceive that risk. You know, maybe you don't see it as a risk because it is just part of the aging process for you and your culture.

Phazha: A lot of cultural groups, there are differences in stigma, and I think the stigma is the main thing backing it up as some cultural backgrounds it's taboo to talk about dementia, they might say, I know within the Caribbean, they might say it is a bad spirit and there's just general lack of

awareness and more interestingly even ethnic minorities within western countries, there's very little understanding between what's normal aging and dementia so I think that people just don't know and I think that when you just don't know what's going on there is already fear there and there sometimes the fall back might be oh this is something spiritual going on or rather there is an element of shame and I think that first step will be to break down the stigma, the shame being ostracised from your community for having these neurodegeneratives and that will open the space and then more people will want to know if they had a risk because there is no shame connected to the risk and then that opens the discussion of your fear of death but I think firstly shame and being ostracised from your society should be tackled first.

Megan: So Isabelle, we never got round to your introduction [*laughing*].

Isabelle: So I'm also a PhD student here at the Wolfson Institute of Preventative Medicine but I'm focussed more on the link between depression and dementia so there's a lot of literature out there but it's quite a messy area of literature as to what the basis of the link between depression and dementia is. There have been some meta analyses performed that show that if you have depression early in life it does increase your risk of getting dementia later in life but then also because you have the preclinical phase of up to 30 years you have the problem of reverse causation and you don't know whether depression is actually part of the prodrome and it's actually a symptom of dementia and it happens early on and not everyone with depression goes on to get dementia so my work is trying to look at kind of shared genetic and environmental pathways especially looking at inflammation and HPA axis dysfunction to try and...

Megan: Sorry, what's that?

Isy: That's, it's basically the stress function in your brain, so it's the hypothalamic-pituitary-adrenal axis. So it basically, you get elevated cortisol when you're, when you are anxious and people who have depression but also people who have dementia has been studies that have shown that they have a chronic elevated level of cortisol and also so that can then also that can be influenced by having increased chronic inflammation so it might be that you have these two processes going on and if you have it early in life say if you are depressed and you have kind of, it's affecting your hippocampus. So then basically you end up losing some cognitive reserve that might make you more likely to go on and get dementia later on because there is already some pathology there. So it's kind of this idea of maybe there's a shared biological pathway that might be affecting similar parts of the brain so trying to unpick that and see whether they are mediating factors in the link depression and dementia, if that makes sense?

Megan: Yep, so what, we sort of touched a little bit on some of the talks but where there any that really stood out for you or really resonated with your own research?

Isy: Well actually I think one of the things that was interesting that really I found interesting that isn't directly related that isn't directly related is Dennis Chan and Vanessa Raymont both mentioned needing better outcome measures for earlier on and I think we use the MMSE and Mocha and things like that very much cognitive measures a lot in memory clinics at the point of diagnosis and try and use them earlier on but in fact the memory impairment actually happens after probably the psychiatric impairment so it was interesting this idea of trying to come up with new measures that you might use earlier on in life that might be more effective in predicting cognitive decline and risk.

Megan: So Dennis Chan he did a talk on Virtual reality tests of entorhinal cortex functions in prodromal Alzheimer's Disease and he showed how the VR works and that they put virtual reality on mice [*laughing*]

Harri: Which was very cool, I just liked the idea that they essentially had a mouse walking on a tiny trackball, moving it which was really clever. Just coming back to that, that's something that's really interesting, we sometimes talk about this idea about something called stress tests so we kind of took this from, we learnt this from cardiac health where you may have tests on your heart function like an ECG that might prove normal but we usually don't say that's enough, and instead we'll put someone on a treadmill to really stress the heart a bit and see that when it's really working toward its maximum can we pick up some changes that indicate early problems here. And then people will get treated, so even if people haven't had any symptoms really, but there is a risk of cardiac problem, they have a stress test, it shows there is a problem so they have treatment, I think a similar approach is being alluded to in cognitive problems in dementia. We've got our standard cognitive battery which is fine when you've got established disease or in some cases even early stage disease but perhaps we need to move towards a side of these stress tests that pick up earlier changes that can only really be found when you're testing you know at the limit of what the normal brain can do, it would be way too difficult perhaps in established dementia and therefore in the past people often thought well we need to be able to do tests so we can see how people progress over time and therefore they need to be doable for people quite far into the condition something like the MMSE is an example of something we can use to track people you know from diagnosis to maybe how they get on, but those same tests are not so good in those early stages...

Megan: Well it's not a diagnosis test, it's more for as your condition progress...

Harri: Yeah

Megan: But I think it was Dennis Chan did say that they, that now, there used to be the is it the MOCA test, where you have to remember certain things, I actually don't know, but anyway, you have to remember a certain list of numbers, letters, words and now they phone you a week later and see if you can remember and that is an evolution of the test - it used to be can you remember after 5 minutes and now they realise and extra step on that is phoning a week later which is so simple but it probably tells you a lot more and could pick up, you know, earlier in the disease process. So anyone else anything?

Harri: So similar to the, on a similar theme to Dennis Chan's work was maybe Rimona Weil's stuff and she was looking at Parkinson's Disease and trying to predict who, in people who already have Parkinson's Disease which ones might go on to develop Parkinson's Dementia is a slightly different prodromal thing because they've already got the condition but you want to know if they're gonna be that group within Parkinson's Disease who go on to get dementia and so then again looking at this idea of stress tests, so I think she was looking at this quite novel idea of if you take a picture of a cat or a dog and stretch it or warp it a certain amount you can work out someone's threshold of where they can no longer differentiate it between a cat and a dog and what she showed, really cleverly I think, is that people who go on to develop dementia have difficulty doing this test before they've actually developed dementia. So if you take people with Parkinson's who have the same cognitive baseline those that perform worse at this test, there is the suggestion that they may go on to have a higher risk of developing Parkinson's dementia so I think again, similar to Dennis Chan's idea of taking new tests that are almost completely removed from the standard cognitive

battery that we use but that are testing different cognitive domains that might be affected earlier on which I thought was quite interesting.

Phazha: And I think that, what's particularly interesting about these tests is that they minimise barriers that may happen through education language and culture and I think that one of the main problems in tracking and the prodromal phases of dementia or even making a diagnosis with some of the tests is that memory services may be a bit more reluctant if English isn't your first language or that you have a lower educational background, they don't understand are you performing poorly on these tests because of other factors and in some cases where there is the presence of a disease individuals may only get diagnosed much later on because there is this bias whereas like with Dennis Chan the virtual reality, I found it so cool because there is very little complication in the instructions, it is walk here, go to this point and I think that the great thing about this test and the visual acuity test is that you know everyone knows what a cat and a dog is you know and that certain questions that he was talking about in the standard battery test you know prime ministers and things like that, some people may not really be aware of that and they may only be aware of prime ministers of their original countries but the great thing about this is it can be used across all cultures and I think there is an important need to call for these types of tests particularly at the early detection that can be used in any country in any setting and it harmonises it so we're clearer on dementia.

Isy: I think also because it was interesting because he mentioned about how essentially the task he was doing with the virtual reality was quite similar to the four mountains task but was actually more effective and then he was saying it was actually because there's fewer confounding factors like you say of kind of education, IQ, things like that, which is so important in cognitive decline because you know education comes up as one of the biggest early life risk factors so minimises that confounding factor might help.

Megan: Well because you don't start with a baseline do you when you do these tests so...

Isy: Exactly

Megan: So in a way some of them are testing education level and your IQ without you realising. We should say for the people that weren't there, the virtual reality test works by, you put the thing on, the mask, whatever you want to call it [*laughing*], he said you could buy them in Argos [*laughing*]...

Harri: Yeah, for like £600...

Megan: And you're told to find a cone within a landscape and you actually physically walk within a room while looking at virtual reality to the first cone, then you walk to the second cone, then you walk to the third cone then you're asked to return to the first cone so you are then using all the spatial cues, the visual cues that you've seen to try and navigate back to the first cone, so yes, like you say, it removes education, or knowledge from it, you know, it's spatial navigation which we all do all the time to get around our worlds and that's what they also did on the mice!

Isy: I think what was also really interesting was that you wouldn't have to do just virtual reality that the other thing that he spoke about was the fact that they've been developing an app that uses GPS in your smartphone and that you could technically, you can work out whether there's changes in someone's spatial navigation over time is maybe, and also how fast they walk and

things like that which that kind of was eluded to quite a lot throughout the day where you could have technology-assisted and wearable devices and I think that's a very big area that will be important in the whole predictive and preventing area of all kinds of neurodegenerative disease.

Megan: It was interesting though, was it Richard Milne at the end obviously brought in all the ethical considerations and challenges and he talked about that but also saying those companies maybe heavily invested in that then they're providing you the answer so they see value in watching you walk around so they can then sell you something, you know, the risk business.

Isy: I think it's very a difficult, I think you've got to put in some sort of controls into how these sorts of things are used because in some countries, I think, some countries are more strict than others in putting in these regulations but it can be difficult now with the advent of the internet it's so easy to access information that might not actually be that valid right now, because for instance you've got the websites where you can look up your polygenic risk scores but actually they have been validated in a lot of disease groups so and if people don't understand that it causes them more stress and all kinds of other factors and it was interesting what, I think it was Alastair, that the Royal College of General Practitioners had actually kind of urged GPs not to take notice of the people who come in who have had these direct-to-consumer tests.

Megan/Harri: Yes...

Isy: Which, I think that's a difficult one because yes there's a lot of false positives and false negatives but the doctors are going to be the first point of call that those people then go to so it's difficult if those people then don't give support.

Harri: I think it's, I think it is really difficult for them to say to just dismiss and not engage with it because I think if you're somebody's family doctor, you know, it's not like they're going to go and see lots of doctors possibly, you are their regular GP, I don't know how the GPs can literally say I'm not going to engage with this, I'm not going to look at this. We in our clinic, I do a cognitive clinic, and in our clinic we are seeing now an increasing of people who are getting referred in who are cognitively healthy but have a 23&Me or alternative company report that has mentioned for example, the ApoE4 status or their polygenic risk and I think that perhaps dealing with the potential increase in numbers and which services are going to deal with it is a really difficult one, on the one hand I'd say to a GP well if you're unsure of how to interpret this then perhaps referring to a specialist area is the way to go but then I don't know how, or who knows what knock on effect that could have to the services because if you've got wait 8 months until you see the specialist that's a bit sub-optimal. But I think it does need to be discussed with people and we have to accept as Alastair was saying, people are going to, this technology is available as much as we try and caution people are going to want to have these tests done and therefore as a medical profession and involved with people with these conditions we need to kind of start thinking about how they're going to address that, you know...

Megan: Instead of just stepping back and saying hands off...

Harri: Because I don't think we can, because the person is going to want to see another health professional at some point that can give them some context.

Megan: And surely it's better that they do see a health professional than like we just said search on the internet for someone else interpretation who is not clinically trained.

Harri: So it kind of ties to another thing that was coming up a lot today which was this idea of kind of more personalised medicine which I think kind of cuts across a lot of what we have been talking about, ethnic differences, differences in your socio-economic status, differences in your educational background, the idea that when we are looking at risk, when we're looking at information about pre-symptomatic testing it's really important to think of the individual and where, putting that information in context rather than trying to just get this information quite blanketly without really necessarily thinking about the impact it could have. One thing that comes up with the tests and the idea of coming up with cross-cultural tests is also when we think about trials, there is a real worry that we are going to be excluding a large proportion of society from trials because they are going to rely, so I know for example a lot of Alzheimer's trials rely on a certain MMSE score, that MMSE score will, whether you're referred into a trial or not will come from the person in clinic doing the MMSE score, how far they decide to go with a translator is a little bit at the discretion of the clinic to some extent.

Megan: Well also like Phazha you said about certain cultures don't come forward early enough or aren't in the system early enough, well this is something that comes up a lot, we've talked about people, so their score is going to be not correct for the clinical trial, too far along or not far enough along, you know...

Harri: There is also the differing approaches not only to the diagnosis but also in terms of what can be done, you never want to generalise, but there are certain trends you sometimes see in clinics where people may come along and get a diagnosis but because there isn't a curative treatment at the moment, they might disengage from healthcare because the kind of attitude to healthcare is well I come to the clinic for a treatment if there isn't a treatment then I don't need to come to clinic anymore which is really difficult because that doesn't take into consideration what we're talking about here which is the idea of you may be able to modify how rapidly it progresses or engage with the support that would be there even with an established diagnosis so it is about, yeah, getting...

Isy: I think that's one of the areas where this kind of concept of the brain health clinics might be useful because it seems like the idea behind it is focussed on kind of lifestyle factors and general factors and kind of maintaining brain health rather than really focussing really on the disease and saying you're here for the disease it's about prevention and prediction and things and I feel like maybe that is a good way to go in terms of a systems level because it seems like society is going that direction anyway of their own accord by using all these apps out there and maybe that's the way that the medical systems and the healthcare systems can actually provide the support that's necessary for how we are looking at these diseases now because it's only really a recent phenomenon that people have started looking at dementia as a disease and not just an aging process so I think that is one of maybe, that came up a couple of times today as well and I think there's been other events I've been to recently where they've brought that up so maybe if they trial that in some areas and that works it could be a good way forward.

Megan: Was it Carol Brayne brought up that actually it is very difficult to change people's behaviours so you can have a clinic, you can't get people to come, if they come they might not change their behaviours...

Isy: And I think that was interesting, because Seb Koehler when he did his talk about the My Brain Coach app, what was really good about that is the fact that it really focuses on kind of

achievements and challenges and it is very personalised so he was saying I think there were three different scores where you had something you were doing really well at and didn't need to worry about, something else that you could work on then something to do with chronic co-morbidities and that kind of focus so that is something where it could complement and kind of try to continue the usage and the interest of people over time after they've seen a doctor in a brain health clinic for example and keep them engaged because I think he said they'd been engaged for quite a while and it carried on using the app so maybe that, it is quite an easy thing, you don't have to go into a clinic, you can just have the information and if something pops up as being something's changed and it is a red flag then maybe they could get called back and sort of followed up.

Megan: So, yeah, what Carol said, she said if you know your genetic or phenotypic risk it doesn't necessarily, it doesn't change your behaviour, but we don't know from that whether they were given an app, whether they were given monitoring along the way or they were just told and then a year later asked have you changed your behaviour passively.

Phazha: And I think like one of the audience members questioned her, were these people who already knew they were at high risk so the information that you were adding, was it novel or they already knew it, was that why? And I think that you know the recent interest in people wanting to know their genetic risks and stuff, you know we should not overlook that people are trying to be empowered to know that they have some sense of control or some contribution. And I think that when advising about you know general brain health and giving people a chance to measure engagement, you can say exercise more and eat more of your veggies but how much is that going to help me, and I think that if an individual goes and gets a diagnosis for let's say dementia or Parkinson's, having a means in which they know oh I can still improve, or if they find they have a genetic risk, I have something that, you know, I'm still in control in some way or form but for now people to just redirect it in a way by way these lifestyle risk factors, most of which like vascular ones start in midlife, you do have a sense of control and you do have a way in which, but in ways that keep them engaged, like how much should I run, how much should I exercise, and how will that individually affect me personally.

Isy: Yeah, and at what stage as well because what I think one of the interesting things that came up again a few times today, was the idea that you have biomarkers, you might have biomarkers or risk factors of life that are important and that that's really important in preventing because you might, you know, they talk about midlife obesity being more of a risk factor than having, than being obese later in life for example so I think that would be a really important thing as well where you could have a timeline or something of things that were, it might increase, that's what you might focus on because that person is at that age so it's not kind of bombarding a person with every single thing they've got to do, all their life but maybe have maybe in your midlife you've got to focus on one thing more and then later in life that might adapt and that might be a bit more manageable than having this constant bombardment of you've got to have every single thing healthy because for a lot of people that can be quite challenging and also especially in people, I think one of the things that could potentially be one of the areas that depression could get linked with dementia is if you're depressed, you're far less likely to live a healthy lifestyle and you become much more socially isolated and you might not care so much about what you eat and exercise and things like that so all these things really kind of intermingle and that's where it's good to have a personalised regime I think.

Megan: And also I think it was Alastair at the end said about you know, cardiovascular risks have gone down and cardiovascular disease have gone down and that was possibly in part because of

public health messages and if you can link dementia to that as it has already been shown to be successful then you know, you're not just seeing them at the clinic where maybe it is too late, this is a public message that gets out there earlier and as you say it is a life course thing, talking holistically about your whole life.

Isy: With the cardiovascular, that shows that people can change their behaviours because people have started to eat more healthily and although not everyone might at all points there are definitely trends if you look at population level there is behaviour changes and also things like reduction in smoking that was just, that was through a lot of health promotion, health education and I think if you start to bring in these things at a level where a lot of people will see them, then maybe you will get some behaviour change anyway and then you might target it more at a personalised level and find out who might be needing that extra support and who might do it automatically on their own.

Megan: Ok great, has anyone got any final comments about the day, just that it was a great day and that the drinks are starting soon [*laughing*].

Phazha: I think it was a fantastic day, I love that there was a range between these neurodegenerative conditions and one thing I do wish was that there was more members of the public there and I think it's important to note that, because some people asked me when I told them about the symposium that a lot of these talks are free you know, it is not like you are in a room full of people who will judge you if you ask a question and everyone really explained thoroughly you know so I think that sometimes with these sorts of talks is just for academics and people who understand but I think if more members of the public got engaged, got in contact or just emailed some of the people that they see like, we're kind, we want to talk about this because it's important, but I think those people missed out.

Megan: Ok, great, thank you very much and please subscribe to our podcast. Bye!

VO This was a podcast brought to you by Dementia Researcher: everything you need in one place. Register today at dementiaresearcher.nihr.ac.uk.