World Dementia Council
Leading the Global Action Against Dementia



Virtual Roundtable

Roundtable: Access to Treatments in Europe

Transcript

24 June 2026

Roundtable: Access to Treatments in Europe

Meeting transcript



Lenny Shallcross, *Executive Director, World Dementia Council*

I have my dog, who is tired and restless, so he may well kick off. But apart from that, it's all absolutely smooth and easy. I know all of you: Lenny Shallcross, Executive Director of the World Dementia Council. This is the first roundtable, I guess you would call it, that we are trying, which is a bit different from the virtual dialogues that we've done before. It's designed to be more conversational. I'm sure you all know Hilary Evans-Newton, who is CEO of Alzheimer's Research UK, and who is going to chair the roundtable. We'll begin with three speakers, whom Hilary will introduce, giving you a few reflections, or provocative thoughts, or say what you like.

It seems to me there are two interrelated questions, which you saw in the note that I circulated, and I'll take them in reverse order. We are at this unusual moment where we have treatments, but in large parts of the world they're not being paid for. So there is an immediate problem, which is how you get treatments to patients, and in the note I circulated I suggested some issues that may be the explanation for that.

But the immediate problem illuminates a broader question, which is how advocacy evolves in this era of treatments and diagnostics. So you've got the problem, which is that people aren't getting treatments, but there's a much broader strategic challenge that the Council is exploring through lots of activities, including this series of dialogues, which is: how do advocacy movements change?

As you all saw, by advocacy movements I don't just mean patient advocacy organisations, or umbrella organisations for patient advocacy organisations. If you look across Europe, or at the United States, or at Canada, there are lots of different types of organisations, and lots of different types of people who do advocacy. So in thinking about how you advance the conversation around treatments in Europe, and getting treatments to people, you have this broader question of how, ultimately, advocacy is going to change over the next few years. So that's my five pennies' worth at the start, and with that I will pass it to Hilary to start this roundtable.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Brilliant, thank you, Lenny. Lovely to see all of you, and lots of friendly faces. I think it's a really timely conversation for us to be having. A number of us have worked in this field for quite a number of years, and the advances that we've seen have been brilliant. In some respects they have probably come faster, and delivered more, than we might have expected when we were all sat around 10 years ago. But the challenge now is how we ensure that patients see the benefit from that science.

I think there's a wider conversation around the public, in terms of where they are in this, and a conversation around advocacy, in terms of where political leadership and our governments are. So I think it's a timely point for us to come together, and it's exactly what the World Dementia Council should be doing: sharing some of this thinking about what's happening in different settings around the world and in those different conversations. Who are the people getting it right? How are we pitching and framing these arguments?

What would be interesting, when we've heard the presentations coming up over the next 20 minutes or half an hour, is to then have a conversation and think about where we're getting it right and where we aren't. Being able to come together and agree some of that will be really interesting for us to do. So we've got a couple of great presentations or thoughts coming up.

We're going to do France, the UK and Sweden. So we're going first to Lorène, who I think has some slides from France Alzheimer… You don't have slides?



Lorène Gilly, *Head of Public Affairs, France Alzheimer*

No, I don't.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

You don't have slides. Brilliant, okay. David has slides; maybe it's just the UK doing slides. So, Lorène, would you like to introduce yourself? You've got the floor for the next five minutes or so.



Lorène Gilly, *Head of Public Affairs, France Alzheimer*

Yes, thank you. Five minutes is quite a challenge, but I'm going to try to explain the context and where we stand now in France. I'm Lorène Gilly, Head of Public Affairs for France Alzheimer.

To give you a little of the context: on 4 September 2025, the French National Authority for Health announced its decision to deny early access to Leqembi, and the experts of this High Authority did the same on 12 March this year, and on 26 May regarding donanemab. The French National Authority for Health concluded that these treatments do not provide sufficient clinical benefit and cannot be considered a therapeutic innovation.

Among other arguments, and we're talking about arguments here, the French Health Authority emphasised that the organisational requirements associated with these treatments would place an excessive burden on the current healthcare system. As if it weren't already necessary and urgent to make these organisational changes to our healthcare system, to face the growing number of people living with dementia and improve the daily lives of their families. And I'm going to ask here: how much longer will the needs of people living with dementia and their caregivers continue to be ignored, for unacceptable medico-economic considerations?

As you can imagine, this decision raises numerous questions, and has been met with incomprehension and despair among families. This innovation has generated genuine hope for many families facing a disease for which therapeutic options remain limited. And when I spoke about hope during one of the hearings with the High Authority, I was simply told that hope doesn't cure. What level of expertise does one need to make such comments in 2026?

This decision isolates our country. We are exposing French patients to an unbearable inequality in access to care. And this decision once again demonstrates the extent to which these diseases, and their impact on the daily lives of patients and caregivers, remain misunderstood. During hearings, family representatives such as France Alzheimer are given only five minutes (five minutes) to present their views, making it impossible to fully convey the realities faced by people living with dementia, their hopes and their distress, in the face of decisions that run counter to the ambitions of a country that seeks to become a leader in Alzheimer's disease research and innovation.

Indeed, the High Authority's position stands in stark contrast to the French government's objectives outlined in the new National Neurodegenerative Diseases Strategy 2025–2030. In this strategy, France expresses its ambition to strengthen research and innovation in order to regain a leading international role in this field. What a start!

And let's remember that in June 2018 France also decided to discontinue reimbursement for symptomatic Alzheimer's treatments. We haven't seen a single penny since then, even though

the savings made should have been directed towards strengthening non-pharmacological interventions.

For patients currently eligible for this type of treatment, and for their families, this decision also represents a tremendous loss of opportunity. It is unlikely that any additional treatment candidates will become available in France before 2029. This is a particularly serious situation for people living with dementia, where each passing day reduces the window during which they remain eligible for innovative therapies. It would also not be surprising to see research investment decline in response to the successive negative opinions issued by this High Authority, potentially reducing the number of clinical trials conducted in France and limiting French patients' access to cutting-edge research opportunities.

Despite its disappointment, France Alzheimer remains ready to engage with the High Authority, should it wish to deepen its understanding of Alzheimer's disease and its real-world consequences. It is essential that in this case, as in so many others, expertise be informed by lived experience, and that we move forward collectively in accordance with the fundamental principles of health democracy, because this is also what is at stake here.

On advocacy: our association, alongside other French foundations, experts and professionals from the Federation of Memory Centres, for instance, denounced these High Authority decisions as a serious loss of opportunity, and urges the public authorities to reconcile words with actions. We have been writing many letters to the government, and to the health advisers of our Prime Minister, of our President, and of our Minister of Health, because advocacy remains essential to ensure that France truly understands the issue at stake here, and truly leads in research, innovation and equitable access to therapeutic progress.

Months ago, that's why we joined a national community of different stakeholders, to advocate together, with testimonials from patients, to raise awareness and inspire action among decision-makers. And we are still doing this.

I also want to acknowledge that we had the support of Alzheimer's Disease International and Alzheimer Europe, and it has been key for us. Alzheimer Europe recently, on 8 June, published its new position paper on this matter, calling for equitable access to new Alzheimer's disease treatments across Europe. It will soon be available in French, and we will make sure that it is sent to the experts of the High Authority for Health as well. Thank you very much.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thank you, Lorène. We'll save questions till afterwards, and then we can come to all three panellists and open it up. So, David, we'll go straight to you for a UK perspective.

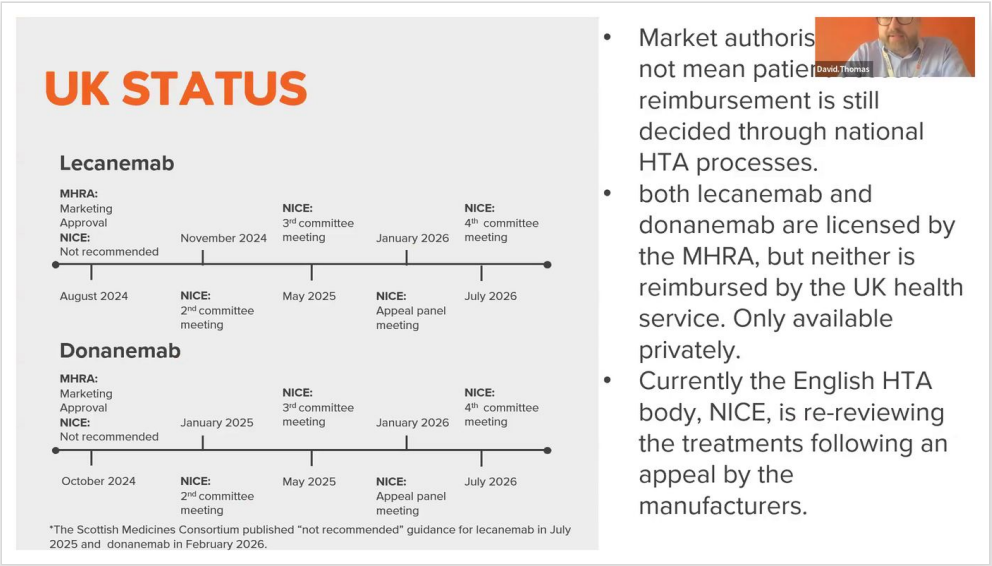


David Thomas, *Head of Policy, Alzheimer's Research UK*

Great, thank you, and nice to be here today. I'm just sharing my slides. Can people see my slides? Right, good.



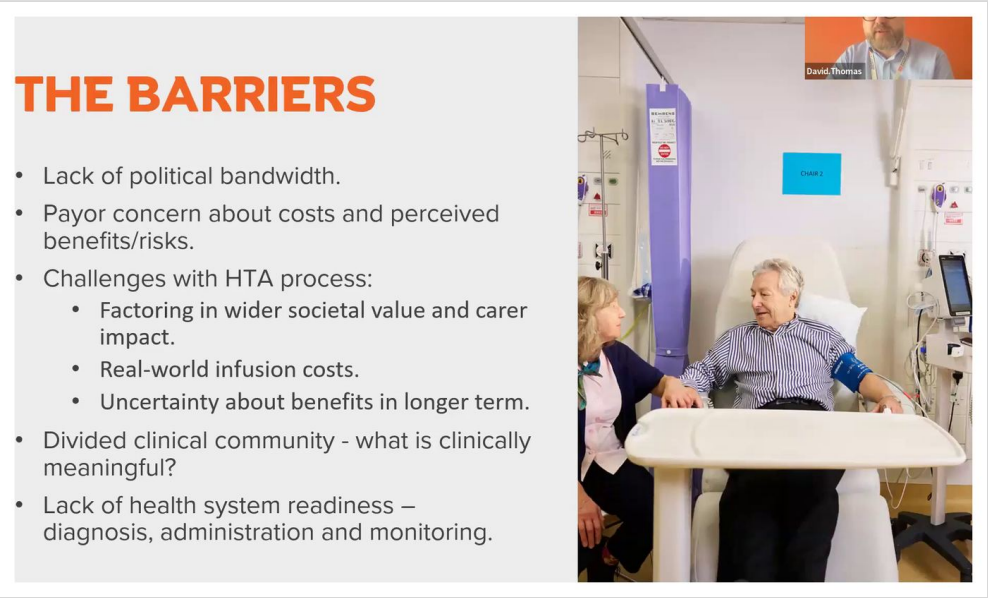
I'm going to talk a little about where we are in the UK (I can see quite a lot of UK folk on this call, which is great, so they'll know some of this context), what some of the barriers are, and what we, as Alzheimer's Research UK, as an advocacy organisation, have been doing to try to address the situation.



I won't talk through the piece on the left in detail, but it is designed to show the long and winding road that we're still on with the two treatments. Both are licensed in the UK; they were approved by the MHRA back in 2024. But, as it says in the text there, in the system here, just because you've got a licence doesn't mean that you get access in our health service. We have health technology appraisal bodies that make the decision about whether treatments are cost-effective, and therefore whether they can be funded.

There are two of these key agencies in the UK. One, which I think we're all very aware of, is NICE. As you can see, NICE has been through a number of committee sessions to look at the cost-effectiveness of lecanemab and donanemab. It ultimately turned them down, saying that the benefits did not outweigh the costs to the health system and to patients. But both companies that manufacture these drugs have appealed, and that's where we are currently: there will be a meeting in a few weeks' time when NICE will be re-looking at these two treatments. So that is still unfolding. It's important to recognise as well that we also have the

Scottish Medicines Consortium, a separate HTA body, which has also looked at both of these drugs and has not approved either of them for access.



So, to reflect on some of the barriers that we've seen in the UK that I think are driving the situation where we have licensed treatments but no access to them. Part of this is a lack of political bandwidth. As Lorène was talking about, there are lots of plans, a life sciences strategy within our government, commitments that they've made on dementia, and more work being done on that at the moment at a national level. But getting ministers to engage with this issue has been a challenge, and lots of advocacy groups, not just us but other charities in the UK, including Alzheimer's Society, have been doing a lot of work to ensure that we get the bandwidth that we need. And I think other countries have this as well: there is quite a bit of turmoil in UK politics at the moment, which I think has hampered our ability to really engage ministers in the detail of this and the risk. I'll talk a bit more later about how we're addressing that.

We have also seen payer concern about costs and the perceived benefits and risks, and again I'm sure this is common everywhere. There's a lot of worry about whether these drugs are safe enough. But there's also a lot of worry, I think, about the demand that they will put on the system, both to administer the drugs, and because the health system is very worried about lots more people coming forward who weren't previously in the system: people in the very early stages of Alzheimer's disease, or people who are worried that they've got cognitive problems but haven't actually reached the stage of dementia. That could potentially swamp what is already a system buckling under lots of demand pressure.

We have a particular issue, which we have raised as Alzheimer's Research UK, around the HTA process: that it doesn't factor in wider societal value. I think we all know that when it comes to dementia, the impact is not just on the individual and the health service; it's also on carers and on society more widely, and our system doesn't reflect that. There's been a long discussion about the real-world costs of infusion. This is something that's being looked at as part of the appeal, to try to reflect those costs accurately. And there's also the question that our HTA bodies want certainty about how these drugs will perform in the longer term. Obviously we haven't seen how these drugs will perform in the very long term, because we've only got a limited amount of data on that. So how you address that uncertainty has been a challenge.

I also wanted to mention, and I suspect this is the same in other places, that we have a divided clinical community. When we think about these drugs and the benefits that they bring, there are strong views on either side about the clinical meaningfulness of that, so that's something we've been very aware of the need to navigate. And the other thing to say is that we haven't

got a health system that is well set up to administer these drugs, and from a diagnosis point of view, we're not routinely using biomarker diagnosis in healthcare settings at the moment. That provides a particular barrier.



I just wanted to finish with some of the approaches that we are taking to try to address this. Part of what we've been doing is actively inputting to the HTA process, bringing lived experience to the process; again, I think Lorène spoke about this well. I'm speaking at the NICE committee in a couple of weeks' time from a patient advocacy point of view, and we've also put forward people with lived experience. But we've also been looking to challenge that process, and to work with other stakeholders on whether the methodology is right when we think about something like wider societal value.

As well as making the argument about the benefit to individuals and the huge need that dementia is placing on our society, we've also been looking to make the political argument about the link between access to these treatments and growth. If you want to encourage clinical trials and investment from life science companies, then having no access to these treatments, as I think Lorène was saying, feels out of kilter with what our government is trying to achieve.

We've also tried to take some inspiration from other disease areas. We looked at how the UK responded to rolling out COVID vaccines, with a much more ambitious approach of looking at deployment and development of drugs together rather than as very separate processes, and working much more in partnership, particularly with industry. That's something that we've been working on with government, and Hilary has a particular role within our government that has been driving that agenda forward.

We identified diagnosis as a key barrier, and so we launched a very big campaign with our supporters. We had a petition signed by 67,000 people about the need to improve early and accurate diagnosis, because obviously that's such an enabler of access to these treatments. And again, we're not alone in that; there's been a lot of advocacy from a number of groups about the lack of accurate diagnosis in the UK for people with dementia.

And finally, as an organisation we have been investing much more in our clinical relationships. Where we're trying to get to is to really identify clinical champions who can make the case for innovation, and to look at how we can drive changes in practice.

So those are some of the things that we've been doing from a UK perspective. It's still very much a work in progress, and we'll see what happens over the weeks and days to come, but I

hope that has inspired some thoughts about what we can all do collectively to ensure that people with dementia can benefit from these new innovations.



Professor Linus Jönsson, *Professor of Health Economics, Karolinska Institutet*

Okay, so I think it's my turn. Thank you, and it's nice to be with you. I'm Linus Jönsson, Professor of Health Economics at Karolinska Institutet in Stockholm. I was asked to give a few reflections, maybe starting with the question of whether I was surprised by what we have seen over the last months and years when it comes to the introduction of these new drugs in Europe. And I guess the answer is no, I was not surprised that we're seeing these challenges with market access.

I think you can't really separate these decisions from the pricing of these drugs. That's of course completely central. This goes back all the way to the initial launch price of aducanumab. There was the establishment of this impression that there is a wide gap between the price expectations for these products and the value that they are perceived to deliver, and I think that has been plaguing this type of product since then. The launch price of aducanumab was something like 56,000 per year. That has of course come down over the years, but still, if you compare the list prices of these drugs with the results from the independent economic evaluations that I've looked at (what is the threshold price, the maximum acceptable price that we would expect European countries to be willing to pay for these drugs?), there's been a wide gap. We're talking about somewhere in the vicinity of 5,000 to 10,000 euros per year. So there's been this big gap, and that's of course behind all of this.

I think it has not only affected countries like the UK and Sweden, where economic evaluation is used directly. I would expect that this has also affected countries like France and Germany, where the initial assessment is based more on the clinical effect (I'll come back to that a bit later; perhaps there are two different systems in Europe). But that's behind all of it. It's not that the countries are saying no to these drugs in general; they're saying no to the drugs at a particular price. Of course, the issue of the clinical effect, and the divided clinical community that David was talking about, is also not helping in this case.

I would say, though, that there's been quite a lot of discussion about the uncertainty in the economic evaluations of these drugs, and comparatively speaking, the uncertainty is actually not that high. We've had economic evaluations going back 20 years in this area. There's quite well-established methodology for how to assess this type of product that slows the progression of Alzheimer's disease, and there have been quite consistent results in terms of how much a drug with these properties will be worth to healthcare systems. It does depend to some extent on how much you factor in effects on caregivers and things like that, and countries vary a bit in how they do it. But in terms of methodology, we have fairly good data and fairly well-established methods. So it's not really that there's uncertainty on the economic evaluation side either.

So that's where we are. What can we do about it? This sounds a bit bleak, but actually I'm quite optimistic. In particular, for countries that apply economic evaluation, I think that we will in the end see these drugs being reimbursed, and there are several reasons for that. There are reasons to believe that the cost-effectiveness calculus can improve over time, with optimised dosage and new forms of administration that will greatly improve the cost-benefit calculus.

I also think we haven't really exhausted all the options for building real-world evidence into these estimates. What I am a little surprised by is the lack of imagination, both from the company side and from the authorities. We have really good opportunities in Europe to construct schemes that would allow some type of risk-sharing agreement. For example, if a company really believes that its drug will show strong clinical efficacy beyond the time frame shown in a clinical trial, then you have to put your money where your mouth is, and commit to a scheme that actually follows that up in practice. That's very possible to do, and I'm surprised we haven't seen much of it. There is also quite encouraging data coming out of the long-term follow-up registries, both in Japan and in the US, and I expect this type of data can be used in resubmissions over time.

Again, a lot of the issues we're seeing are due to this mismatch between the price expectations of the industry and the actual value these drugs demonstrate, and I expect that will also correct over time. So maybe these are slightly provocative statements, but I believe this is where we are. But again, I'm also a little optimistic.

Just to end: what about countries that primarily make their decisions based on clinical data, as we have in Germany, for example? There, of course, price expectations shouldn't actually factor in; the negative assessment by the G-BA was based on a reanalysis of the clinical trial data. There I think there's a huge potential for advocacy to really show that within the clinical community and among patients we see real value in these treatments. And again, with more real-world experience coming in, showing that these drugs can actually be implemented safely in clinical practice, I think that can also help in those circumstances. I'll end there. Thanks for your attention.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thanks, Linus, and thanks to everyone who's presented. This is a chance now for a bit of discussion for the next 20 minutes or so, and for any questions that people want to ask any of the presenters, before I open it up and maybe ask a few myself. You can drop them in the chat, or put a hand up if there's anything specific. I can see quite a lot, including a long statement from Frank, which I'll get to in a minute.

I think we can see here that we are all battling the same kinds of challenges: either political will or health systems. And I think Linus's point about the lack of imagination is absolutely key, because there are things that we could have done, there are things that government can do, and there are things that health systems either haven't been willing to do, or for which maybe the case hasn't been made in the right way.

So maybe I just want to start there, and put it out to everyone here. What do we think we've got right in terms of making the case? Are there things that we've missed? And as a community, have we told the story in the right way about where we are with these disease-modifying treatments? There's been quite a bit of focus on these two DMTs right now, but this is actually about a future and a world where we are testing, diagnosing and treating people at risk of dementia. This is a world that we haven't been in before, and it's a world that we've all been fighting for over many years in our various guises, whether as scientists, clinicians, advocacy groups or the leaders on this call.

So I do think we now have quite a pivotal moment to get this right. That's why it's good to have this kind of dialogue, sharing where some of these arguments are working, what data we need to share, and what evidence we may be missing that would help our case. And are we really clear and united in how we're making this case? Because ultimately our health systems, particularly across Europe, aren't where they need to be, and perhaps they're not seeing a path by which they can understand where that innovation and some of that thinking can come in.

So I'll open that out to start with. I can see a couple of hands up, so I'll bring in Michelle. Michelle Dyson, whom some of you may have met but others may not yet have, is the relatively new Chief Executive of Alzheimer's Society here in the UK.



Michelle Dyson, *Chief Executive, Alzheimer's Society*

Thank you very much, Hilary. Yes, I haven't met most of you, but I look forward to doing so. Really great presentations, very thoughtful. I wanted to come in on the question Hilary's just raised, because I've come from government. I was very senior in our Department of Health, and in fact one of the things I had responsibility for was dementia policy. So I wanted to give you a perspective almost from the other side. I guess I'm a poacher turned gamekeeper, or the other way round.

I can see a world where we get these drugs, or something like them, through NICE and through all our systems in the UK, but they still don't get picked up by our National Health

Service, because there isn't enough money and there isn't the will, because there are so many other pressures on the system. I imagine others have this issue as well. In those circumstances, the question I ask myself is how we would actually persuade government to shift. And I know the answer to that question from having sat on the other side, which is that ultimately this will only cut through when it becomes a political issue.

We can make all the sensible, evidence-based arguments, and we absolutely should make them: we should show why this is cost-effective and why it really matters to people. But until you turn this into a political issue, an issue that the public really cares about at scale, an issue that politicians feel is going to hit them electorally, at the ballot box, because it's coming up on the doorstep, then in my view, in this country at any rate, you're always going to be on the back foot, because there are so many other issues demanding politicians' attention.

Lenny said this some time ago, and I think, Lenny, you wrote a blog about it: there's so much anger in the world, why is there no anger about dementia? I think until you get that public anger, and until politicians are really feeling it, this won't cut through. So in answer to your point, Hilary, that's the thing I think we have to do. We have to try to light as many fires as we can, because ultimately what we're trying to do is get this to cut through politically, and that's when things will move. Thank you.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thanks, Michelle. On that point, I'm just going to bring George in, and then, Sasha, I know you've got your hand up, so I'll come to you. But George, it would be really interesting to have your views as someone who's led many an advocacy campaign.



George Vradenburg, *Chairman, Davos Alzheimer's Collaborative*

Well, we had the same issues here in the United States. Our payer agency, Medicare, initially refused to cover these drugs except in a coverage with evidence development trial that they would conduct. And we went to war through our Congress. I recognise our politics works differently from yours. We had close to 50% of the members of our Congress either write, hold hearings or otherwise call Medicare and say that's intolerable. Our polling had indicated that close to 50% of Americans of voting age had had this in their family, or now had it in the family. That kind of polling indicated to politicians that this was an issue affecting not just the 7 million in the United States that we have traditionally cited as affected by dementia, but more like half of Americans, or half of American families. So it was very much a political argument. Michelle is absolutely right; that's how we made the argument.

What we're doing now is trying to lower the cost of detecting this disease and of administering the drugs, and getting real-world evidence of the effectiveness of these drugs, which is, I think, significantly greater than what the clinical trials would suggest. And the safety issues are even lower than the clinical trials would suggest, because we have some MRI safety mechanisms here. We now have 50 countries around the world that have approved these drugs and are paying for them. Well, "paying for" is not quite right: in Japan and China this is a private-pay marketplace, but it's a significant marketplace. So these drugs are out there, and I think real-world evidence is going to be critical going forward to persuade Europe to follow the rest of the world.

We can now lower the cost of detecting the pathology through blood tests. Eisai now estimates that 25% of the confirmations of pathology for the purposes of access to their drugs are done by blood tests. We have been asked, as one of our organisations, to come to Europe to talk about blood tests, how they're being used and how effective they are in different contexts. And this summer we will get an FDA approval of the auto-injector means of administration, as opposed to infusion. So what's happening is that there are lower-cost, easier ways to get access to the product. There are blood tests and digital cognitive assessments, which can test for clinical symptomatology as well as the underlying pathology.

So I think the prediction from Sweden, that eventually this is going to get covered in Europe, is right. But the next set of drugs may be approved by our FDA for pre-symptomatic populations, maybe next year. So you're going to confront the issue of a current version of this drug, maybe as an auto-injector, maybe with detection by blood tests and digital cognitive assessments, in an asymptomatic population. And the anticipated potential costs to your health systems are going to balloon. You're confronting a current set of issues, but the concern about the cost is going to go up when we get an intervention before people have symptoms.

So this is a political issue, very much a political issue. If 50% of Americans of voting age have this disease in their family, that means 50% of the members of our Congress have it in their family, so this should be hitting people personally. Now, your politics work differently from ours. We can work with the Congress; your parliaments may just not have that kind of oomph. But policy and politics are going to change the dimensions of this.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

For sure. A couple of us have been up with Frank in Scotland over the last couple of days for his Brain Health Scotland Summit, which has been fascinating and quite thought-provoking. It's really made us think about how we can show the UK, or Europe, or the rest of the world, what can happen. Some of the things that are happening in Scotland are fascinating in terms of what this could look like, and what the science can actually deliver.

How can we tell that story, so that we can show our patient populations, on that point about getting people angry, that this is what it should look like, and this is what you don't have access to? I think there is still that sort of mindset where people are angry about the condition, angry at the lack of support, angry that there isn't a diagnosis or that they're having to wait to see a clinician, but still don't quite know what it should look like. I think we have to both be angry about what people are not getting and be really clear about what they're missing out on. And hearing from George, it's clear that Europe is at risk of being left behind, and I think that helps us in our political story.



George Vradenburg, *Chairman, Davos Alzheimer's Collaborative*

I noticed that Sasha has her hand up.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Yes, Sasha, it would be really interesting to hear from you.



Sasha Bozeat, *External Engagement Lead, Roche*

No problem. I actually put my hand up because I wanted to ask a question about clinical meaningfulness, but I think it's very related to this conversation anyway, so I was pleased to see that David mentioned it. It's something that, obviously, we're giving a lot of thought to at Roche. I think it's a topic that's evolved a lot over the last couple of years. A lot of work has been done to try to humanise the endpoints (what does the CDR actually mean?) and of course now we're moving to time saved. But I still hear this topic of clinical meaningfulness raised.

Firstly, how much is it really a factor in the decision whether to reimburse these drugs or not? But more importantly, what is it about clinical meaningfulness that we really need to tackle? Because I think it's a very broad term that could probably be interpreted in different ways. And

I suspect that a big part of it is actually some ageism going on here, because I feel we're doing a lot to make these endpoints more meaningful, to talk about time saved. In other indications, like cancer and MS, it wouldn't even be questioned, but we're still being asked what the value of six months is to people at this stage in their life. So I think there's a big piece around ageism and stigma that also needs to be tackled. But I'm interested to hear the perspectives of those who have spoken on clinical meaningfulness. What is it that we need to be doing to address this?



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thanks, Sasha. I'll let a couple of people respond to that in a minute, but Lenny, I'll bring you in first.



Lenny Shallcross, *Executive Director, World Dementia Council*

Actually, the point I was going to make was unrelated to that.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Okay. So does any of the speakers, or anyone else, want to come back on clinical meaningfulness?



David Thomas, *Head of Policy, Alzheimer's Research UK*

I can have a quick stab at it, because I very much agree with what you're saying, Sasha. I think it reflects the journey that clinical specialities are on at the moment, going from very limited treatment options to something that could actually affect the course of the disease. What it's really getting at is: what's the benefit for the patient? That's the key thing for me. It's less about clinical meaningfulness and more about what means something to the patient, and that's really where we should have that conversation. It'll be different for different people, because people are individuals, and this is where we need that freedom of conversation between the clinician and the individual about what really matters to them, and about side effects, just as we have in all other areas.

So there may be some things that we can do, as you mentioned, in how we design this into trials and how we work on different measures. But fundamentally it's about reframing dementia, so that we see it more as we see other disease areas. That's the conversation we need to be having. I think what sometimes sits behind it is also a sense that we're waiting for a perfect drug, a drug that leads to dramatic changes over years and years, rather than recognising that this is an incremental business, and each new discovery will build on the drugs that we have access to at the moment. So my overall message is: let's reframe this around what's meaningful to the patient, rather than anything else.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

I think the other point is what we're helping governments to do in preparing their health systems. We're not expecting huge numbers of people coming forward and getting access. Particularly in the UK, we're starting with incremental, small numbers: let's have some innovation, let's test what works and show what we can do. We're starting to see some conversations happening in that space that we haven't seen in the last year or two, which is good. But I think health systems generally are either fearful of or overwhelmed by what this could look like, and that's also about us helping them shape what this looks like. Taking some of that risk or fear away will probably help in some of those conversations. Lenny, shall I bring you in at this point?



Lenny Shallcross, *Executive Director, World Dementia Council*

Yes, it was related to something you said earlier, and to George. One of the interesting things about this space is that there are lots of stories from the US and other countries about how the treatment is working, and lots of clinical experience from people who are actually delivering treatments and are very optimistic about it. And there is a tactical question about how you capture those stories and tell them in jurisdictions where people aren't experiencing that. There are lots of people who are very internationally engaged, but there are clinicians in the UK who just have no idea. I saw Ricky post something along similar lines in the chat: there are lots of patients in the US who can answer the question about clinical meaningfulness, because they're going and getting the treatment. So there is a tactical question about how you share what is happening elsewhere in the world, bring that into jurisdictions where it's not happening, and use it.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

I think that certainly is key. From our experience, only a few days ago we had an event in the UK Parliament with about 90 members of Parliament. We had a wonderful speaker, Larry, who was on the lecanemab trial and is, I think, eight or nine years into his diagnosis. He spoke at the event, and then talked to people around the room about his experience of being on the drug, what life is like for him, the independence that he still has, and the change that it's made. That was incredibly useful. When people around the room were nervous ("We're not really sure about this drug; I wouldn't want my grandmother having it"), we could say, "Can I introduce you to Larry? He will talk to you about his experience of being on one of these drugs, what the trial was like, what his life is like now and the difference it's made." His wife was there with him, but he is living very independently, getting up and speaking. You can quite clearly see that he has some cognitive challenges, but eight or nine years into a diagnosis, this would look very, very different if he didn't have access to this treatment.

So I do think that one of the things we have struggled with as a field is that we haven't had our survivors, people standing up and championing what this can look like. There's that case, as well as "let's get angry and frustrated and mount a big campaign against government". Being able to do both, while also giving the health system confidence, in tandem, is a real strength that we are starting to have, because we do have that patient population. Linus, I'll bring you in, and then George.



Professor Linus Jönsson, *Professor of Health Economics, Karolinska Institutet*

Thanks. Just in support of Lenny's comment, I think it's really critical, because it goes to this aspect of uncertainty: can we actually deploy these treatments? What will happen? Will this really create a lot of issues for us in the healthcare system? That's one of the uncertainties around these drugs that we actually can do something about. We should look at all the opportunities for smaller-scale trial deployments, coverage with evidence development programmes and these types of things in European environments, and also use the places where the drugs are actually being used, like Germany, making sure that we really pick up those examples and spread the data and results around, because that can help to alleviate the uncertainty around deployment. That's one of the few things we can actually do something about.

Just one comment also on clinical meaningfulness. One of the most disingenuous arguments that I've heard (not here today, but mainly from HTA bodies and so on) is that in this disease patients will never be able to tell the difference whether they get these treatments or not. I think that's just the silliest thing, because that's obviously the case with almost all medical interventions that we have. There are very few things where you can actually tell for yourself what the clinical benefit was; it's basically only certain symptomatic treatments. With most of the preventive therapies that have been extremely successful in cardiology, oncology and so on, you have absolutely no way of saying what the clinical effect is at the patient level. I think we have to find a counter-narrative that allows us to shoot down that type of argument, because I hear it over and over again as a reason why we shouldn't reimburse these drugs, and I think it's really disingenuous.

But finally, it is really hard to get around the issue of cost-effectiveness, because that is also a very powerful counter-argument from the payer side. They say that all the evidence shows that we can get more health for our patients with dementia by putting the money elsewhere in the system. That's how we maximise the gain for the patients, and improve their lives more: not by giving them these drugs, but by giving them other things, because the cost-effectiveness is not there. You have to address that. As long as you don't, it's very difficult, I think, to get wide access to these treatments in environments that care about cost-effectiveness. Thank you.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thanks, Linus. George?



George Vradenburg, *Chairman, Davos Alzheimer's Collaborative*

This is a very tactical point, but we submitted patient examples, stories and surveys from Americans to the EMA when they were looking at these drugs. The population is not that dissimilar. I think that was helpful, but not decisive. We haven't done it with HTA authorities.

But we have been looking at how to model changes in CDR sum of boxes into a time-saved argument, and talking pretty consistently with the EMA about how to do that. They are open to looking at clinical meaningfulness from a more patient-centric perspective, but want some scientific consensus on that model. So what we're doing here, with researchers and health economists, is to build this model and try to get a broad consensus and some published papers on it.

And we're concerned that these preclinical drugs are going to show a smaller change in CDR sum of boxes, because it's going to be earlier in the course of the disease. They're going to look at CDR sum of boxes in a symptomatic population and there's X change; they're going to look at the CDR sum of boxes change in a preclinical population, and it'll be half X. Our FDA understands that, and is saying that it doesn't expect a CDR sum of boxes change in the pre-

symptomatic population comparable to what we're getting in the symptomatic population. But if you're having a problem explaining clinical meaningfulness with the modest change in CDR sum of boxes in symptomatic populations, you're never going to get a preclinical therapy through.

So this is now looking forward a couple of years, but it's going to be essential for us to develop this time-saved argument: to demonstrate that that's what patients care about, and that they're not expecting a cure. They're not expecting their clinical symptoms not to decline. They appreciate that it's a delay in the course of the disease, and they're willing to value time saved: not the six months in the clinical trial, but we're obviously getting some studies that say it's a year, a year and a half, the earlier you go. And it's going to be longer in a pre-symptomatic intervention. So I do think that getting a scientific consensus on the modelling of CDR sum of boxes at different stages of the pathology is going to be important for ever getting clearance for a pre-symptomatic drug. That's just looking forward, and what we're trying to do on that score.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thanks, George. That relates nicely to a point that John Hardy has just left in the chat. John, can I just bring you in? It's a really key point to make here on statins.



Professor John Hardy, *Professor, University College London*

Yes, sure. With statins, the pathologists and then the geneticists showed that cholesterol was not a good thing in your arteries, and persuaded the FDA and others that reducing cholesterol was a good target. Statins did reduce cholesterol, and therefore cholesterol was approved as a target for drugs, and Mevacor was approved, I think, eight years before any statin was shown to be useful against heart disease. That's the next stage we have to campaign for. We have to be saying, for the next round of drugs, let's use biomarkers as a valid outcome. Of course we're going to get pushback on that too, but I think that's the way we have to go, and it would speed up drug development.

I'll just say one last thing, Hilary. Here in the UK we've got stuck, among experts, with people saying yes to these drugs and people saying no to these drugs. That's really unfortunate, because I think the right answer is yes, but which patients? That's where we should have been, rather than in a yes–no argument. Here, the psychiatrists in general, who see a very high proportion of dementia patients, are not happy with biomarker data, imaging data and infusions in their clinical practice, so they have generally been against it, whereas the neurologists, who are happy with those things, have been for it. So we've got into an unfortunate set of arguments which are only peripherally to do with the drugs themselves. We have to avoid those side issues as well. Sorry to go on there, Hilary.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

No, it's good to have you here, John, and it's absolutely the key point. That's why it's really important that we all come together and share what's happening in different countries. There are things that we can all learn from each other, but we also need to be united and really clear in some of our messaging, and share some of the data. On the points that have been made in conversation here, and in some of the messages I can see in the chat, having robust economic data is obviously going to be really important. In order to get the wins that we need from our health systems, and to deliver for patients and future populations, we have to win these battles, and we're going to have to do it on a number of different fronts.



Professor John Hardy, *Professor, University College London*

Sorry, one more thing. I'm on the editorial board of Brain Communications, which is one of the Brain journals, and I suggested, and they were trying to get, an editorial on the health economics of these drugs, because those of us who work on these drugs actually have no idea how the health economics works. I actually think almost a lecture on health economics would be a great thing to have as an article for the rest of us.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

I can see a few people nodding there, so that might be something, Lenny, that we could pick up from a World Dementia Council perspective. Giovanni, really quickly, I'll bring you in, and then we'll wrap up so that we're on time.



Professor Giovanni Frisoni, *Clinical Neurologist and Professor of Clinical Neuroscience, University of Geneva*

Yes. I wanted to touch on an issue which can be extremely sensitive, and which is being overlooked by specialists, experts, pharma and advocates, for very good reasons: age. What do I mean by that? Alzheimer's disease in a 50-year-old person and in a 90-year-old person poses different challenges. We say that it's the same disease. Biologically that's almost correct, but in terms of personal and societal impact they are two different worlds. It's like living at the North Pole or living in Ghana: they're all human beings, but they have radically different values and expectations.

The progression in 50-year-old patients is 4.5 to 5 MMSE points per year. At 85 it's 1 MMSE point per year, and we pool them together. And we complain that we cannot get across the message to politicians and to society that these drugs are helpful. Of course, because society's idea of Alzheimer's is not the 50-year-old, it's not Still Alice. It's the 85-year-old. They see twenty 85-year-olds for every 50- or 55-year-old. If we had a clinical trial showing efficacy in 50- to 65-year-olds, do you think we would be here discussing reimbursement? Do you really think so? I think they would have been reimbursed without a quibble.



Hilary Evans-Newton, *Chief Executive, Alzheimer's Research UK*

Thank you, and I think that's a very good point for us to end on, in terms of how we reframe some of this conversation. It's obviously an ongoing challenge for us when we talk about brain health, and what that means and looks like for our health systems, as opposed to diagnosing and treating people with dementia now. I think that will evolve greatly in the next five to ten years, but it's an education point, and, based on where we are in our understanding of the science, we can tell that story now in a really powerful way.

I'm going to wrap up now, because I'm aware we're a minute over time, so apologies. Thank you, everyone, for joining us. It's been a really useful initial conversation. What would be excellent for World Dementia Council colleagues to think about is how we can continue this conversation. We've already heard one idea: a conversation about the health economics and what that looks like, bringing some of our scientists and clinicians closer to those conversations. But also bringing to the table a number of the advocacy leads from the organisations here today, and others that I know are following this and that Lenny will be working closely with, sharing some of this information and having some common language, will be really, really helpful. So it would be great to hear from people, and maybe we can follow up, Lenny. I'll let Lenny have the last word, but again, thank you to our speakers today, and for joining me.



Lenny Shallcross, *Executive Director, World Dementia Council*

We've overrun, so I will just say thank you very much as well. We will be back in touch. One of the interesting points is not just health economics. Hilary and I were both at Frank's meeting in St Andrews, and one of the things I thought was really interesting was that the closing session had people speaking about brain health and the brain health services they were setting up, and they were all thinking in the context of treatment. How you capture those people working in the system, who are in a sense advocates, because they're changing the system through what they are setting up, and how you also capture those stories and bring them in, is, I think, going to be one of the things that really matters. Anyway, on that note, enjoy the rest of your sweltering days, wherever you are in the world. Thank you very much, everyone.

World Dementia Council
Leading the Global Action Against Dementia

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

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