

# Summit 2023

Dementia in a new era:  
prevent, diagnose, treat



**World Dementia  
Council** Leading the Global Action  
Against Dementia

## Equity

Transcript of a session from the  
World Dementia Council summit  
20 March 2023



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The World Dementia Council has 24 members working across six continents. Council members are global leaders who work in research, academia, industry and civil society. They attend meetings, vote on key issues and participate in the organisation's work. The council also includes members who are living with dementia.

The Council also has multiple associate members consisting of international organizations as well as national governments. They help to ensure that the council's agenda aligns with other global dementia initiatives, providing the council with important strategic advice, guidance and intelligence. As they do not have full membership status, associate members don't vote on issues such as the election of a new chair or new members, or on matters of governance.

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## Chair



### **Philip Scheltens**

**Professor of Cognitive Neurology and Director Alzheimer Center, University of Amsterdam Medical Centers**

Prof. dr. Philip Scheltens studied at the VU University Amsterdam, Netherlands, gaining his MD in 1984, and PhD in 1993. He became Professor of Cognitive Neurology and founder of the Alzheimer Center at Amsterdam University Medical Centers in 2000, which he directed until 2022. Currently he devotes most of time heading the Dementia Fund at EQT Life Sciences, that he started in 2020. He has been the (inter)national PI for over 35 studies, including phase 1-3 multicenter clinical trials. He supervised >75 PhD theses since 2000. He founded the Dutch national plan against dementia and served as chair of the board. He is co-editor-in-chief of Alzheimer's Research & Therapy and co-leads various EU projects. He authored over 1100 peer reviewed papers and > 75 book chapters and co-edited several major textbooks. He is member of the Royal Dutch Academy of Arts and Sciences (KNAW) since 2011. In 2016 he was awarded the European Grand Prix for Alzheimer's Research. In 2020 he was Knighted in the Order of the Netherlands Lion by the King of the Netherlands. In 2021 he was elected honorary member of the European Academy of Neurology and was appointed chair of the World Dementia Council.

## Speakers



### **Professor Ricardo Allegri**

**Director of the Ageing and Memory Centre, Fleni Neurological Institute**

Dr. Ricardo F. Allegri is Head of the Department of Cognitive Neurology, Neuropsychiatry and Neuropsychology and Director of the Memory and Ageing Center at the Neurological Research Institute Fleni, Buenos Aires, Argentina. He is Professor of Neurology in the School of Medicine at the University of Buenos Aires, and Superior Researcher from CONICET (National Agency of Research from Argentina). He has chaired the Buenos Aires Health Research Council from 2008-2014 and from 2020 until today. Dr Allegri has working extensively in Latin America on cognitive neurosciences and dementia and nowadays he is PI in Argentina from DIAN (Dominantly Inherited Alzheimer Network), and LatAm-FINGER (Latin American FINGER Project). Professor Allegri is Fellow of the American Academy of Neurology, chair of the Scientific Council at the Argentine Association against Alzheimer's disease (ALMA), Member at the medical advisory of Alzheimer Disease International and Council Member and Trustee of the World Dementia Council.

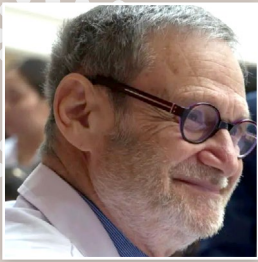
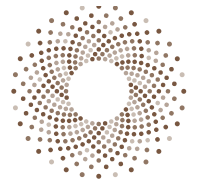


### **Paola Barbarino**

**CEO, Alzheimer's Disease International (ADI)**

Paola is CEO of ADI. Prior to this, she was CEO of LIFE and occupied senior positions with Cass Business School, Tate, British Library and IIED. Previously she was a Non-Executive Director of the Non-Communicable Disease Alliance (NCDA), a Trustee of Shelter, the housing/homelessness charity, and of MLA London. She holds a degree cum laude in Classics from Federico II Napoli University, an MA in Field and Analytical Techniques in Archaeology and an MA in Library and Information Science both from University College London. Paola leads on all aspects of ADI's work. Together with the Board, Paola ensures our strategy is implemented and resourced. Paola is ADI's main spokesperson and represents the organisation internationally.

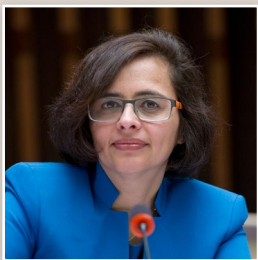




### Howard Bergman

Professor of Family Medicine, Geriatric Medicine and Oncology,  
McGill University

Howard Bergman, MD, FCFP, FRCPC, FCAHS, is professor of Family Medicine, Medicine and Oncology and Assistant Dean, International Affairs, Faculty of Medicine, McGill University. He was Chair of the Department of Family Medicine (2012-2019), the inaugural Dr. Joseph Kaufmann Professor of Geriatric Medicine (2001-2015). He is a Fellow of the Canadian Academy of Health Sciences (CAHS) and of the College of Family Physicians of Canada and of the Royal College of Physicians and Surgeons of Canada. He is internationally renowned for research which has influenced policy change in primary care and aging, with over 190 peer-reviewed publications. Dr Bergman has extensive experience in health policy and implementation. In 2000, as a member of the Quebec Government Commission, he authored the recommendation creating the medical home in Quebec. In 2009, he authored the Quebec Alzheimer Plan and works with the government on its implementation. In 2019, he chaired the CAHS Expert Panel for the development of a Canadian Dementia Strategy, at the request of Public Health Agency of Canada. He co-leads the Canadian Team for healthcare services/system improvement in dementia care (ROSA research team). Dr. Bergman is one of 24 members of the World Dementia Council.



### Tarun Dua

Unit Head, Brain Health, World Health Organization (WHO)

I am the Unit Head of Brain Health Unit in the Department of Mental Health and Substance Use at World's Health Organization Headquarters. The aim of the unit is to promote optimal brain development, cognitive health and wellbeing for all, and prevention and management of neurological disorders across the life-course. The unit is responsible for coordinating the implementation of the intersectoral action plan on epilepsy and other neurological disorders as well as the specific global action plan on public health response to dementia.





## Discussion transcript



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

To quote Monty Python: and, now for something completely different. We are going to have a session on equity and this is as important as the previous ones. There are different forms of equity, equity in research, equity in looking at high income versus low-income countries, clinical practice, et cetera, et cetera. You'll get your coffee after this equity session. We'll all be equal getting the same coffee. I'll invite the panel up here.

- **Professor Ricardo Allegri**, Director of Aging and Memory Center of Fleni
- **Paola Barbarino**, CEO of Alzheimer's Disease International
- **Howard Bergman**, Professor of Family Medicine and Medicine at McGill University
- **Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

So give them a big applause to start with. It's fine, it's fine, whatever you want. I mean, it's all equity. It's all. This already is an interesting phenomena. Group dynamics, ladies and gentlemen. So, we know that the world is not equal. Dementia diagnosis is not equal in every country, within countries, within even countries that may be huge differences. So, it's a topic we need to address. And that's why we have this distinguished panel here to talk about equity, inequity, in the various sort of reasons I already addressed, in research, clinical practice, drugs not being paid for or being paid for. There are many, many things that we can discuss. So let me just ask the panellists first to give a short perspective, an opening perspective on what they think is important when we talk about equity. Paola, can I start with you?



**Paola Barbarino**, CEO of Alzheimer's Disease International

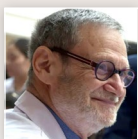
Good morning, everybody. Equity, oh Gosh, where does one start? The situation at the moment is so iniquitous!

So, some broad figures. We've calculated that about 75% of people in the world who have dementia, haven't received a diagnosis. That is actually the global average. It is 90% in lower and middle-income countries.

In part the reason for this comes from our survey on stigma in the World Alzheimer Report: attitudes to dementia in 2019, 62% of global health care professionals still think that dementia is not a disease. They think it's just normal aging.

Thinking of the previous panel, these inequities are going to follow the pricing of drugs, I don't know if any of you saw Anders Wimo's lovely and provocative paper that was published last week? That paper, for example, pointed out that the entire budget for pharmaceuticals in Sweden would be wiped out if the list price of lecanemab were to be applied.

So where do you start with equity? It's something that we have been working on for years. Healthcare system preparedness is bad all over the world. There's no country really where this is properly addressed. South Korea is probably the best, but even there, there is not complete coverage of the territory.



**Howard Bergman**, Professor of Family Medicine and Medicine at McGill University

Thank you. As I begin my remarks, I can just think of my colleague, a researcher in aging, who phoned me up this fall to tell me that she had a diagnosis of Alzheimer's disease in 2020 and would have medically assisted dying in the beginning of this year, which she did.



When we think of equity, I think we need to think of access. And we know there's a widespread variation. Even in high-income countries, people talk about the postcode lottery, for access to diagnosis and availability of high tech in rural communities, low income neighbourhoods, etc. Then there is global equity with fiscal capacity in low- and middle-income countries. All this in the context of higher burden of disease in low socioeconomic populations and in the low- and middle-income countries.

And this is in the context of the vast demand, the potentially vast demand for new treatments. There was an interesting Kaiser commentary on the discussions that took place after introduction of high-cost treatments for hepatitis C, where the case of hepatitis C drugs cured the disease and were approved for a much smaller patient population. I think we have the double challenge of this reflecting on the discussion of clinical meaningfulness that has just taken place.

But the second and perhaps more difficult challenge is assuring equitable access to diagnosis and management and treatment to the populations that perhaps need it the most. So, for me, the key questions for discussion is how will our healthcare system assure a feasible, cost-effective, population-based capacity to clinically manage the process for the potentially vast demand for diagnosis and treatment including biomarker, treatment administration and monitoring. In the context of what we've been discussing of the uncertainty of real-world patient-centred impact, how do we assure equity and access for rural populations, ethnic communities, lower socioeconomic populations, indigenous populations, and global equity to low-and-middle-income countries. You can just think of the situation with COVID and all the challenges that were experienced there.

How will our healthcare systems manage financial and fiscal burden? Gillian mentioned the burden to the healthcare system and to our budgets in general that new treatments could cause. The financial burden include of course potential out-of-pocket costs for patients, care givers.

And how will our healthcare systems balance the benefits of expensive medications introduced as disease-modifying medication, which are absolutely necessary, against the effective use of financial resources for lifestyle medications, for which also we know that there is more and more evidence showing the benefit.

So in this context of drug development, in this context of this new era, which is extremely exciting, I think we need to give as much weight to the study of implementation into our healthcare systems as we are into drug development, and perhaps do it at the same time. Thank you.





**Dr. Tarun Dua, the Lead of Brain Health at the World Health Organisation**

So, inequities and health, I think as we think about it, they go hand in hand. If you think about many other programs, for example, maternal child health programs or HIV or TB programs, inequities are still persisting. So, it's not that something that we have been able to identify a solution.

And the most important thing is, building on what others have just said, how do we understand these equities better? So, one of the dimensions of inequities is about the health status. For example, we know the burden being higher in women. We know that women are providing caregivers. So how are we looking at these inequities from different lenses? And the point that I wanted to make here is that very often we do not look into the different dimensions of inequities. So we are looking at the in-country inequities that are existing. And having good data around those inequities is extremely important. So that's point number one, is that what are we doing to monitor those inequities?

And then comes in that what are we doing to address those inequities? How are we taking positive actions. How, for example are we using the concept of universal health coverage, or the primary health care, the systems-based approaches, to address inequities across different countries.

We have seen with COVID-19 that there was a lot of disruption of services. There has been actually increasing inequities that we are seeing across the world, and especially for chronic diseases. And I think this is important to reflect on when we are thinking about any new treatments and any new diagnostics. We heard a lot about in the first session about use of technology, artificial intelligence, smartphones, smart homes. But what about the digital divide that's existing? So if we are thinking about these, are we going to a path where the inequities are going to increase? And I think that's where, that we need to have a whole society, a whole sector response, you know, to address those inequities.

And third thing is, which in a sense would be nice to hear from people with lived experience and their families, because they are the ones who are at the centre of any care, any services. So how can we involve them in our policymaking, in our service strengthening, so that we are able to keep addressing those inequities in mind.



**Professor Ricardo Allegri, Director of Aging and Memory Center of Fleni**

Thanks for the invitation to be here and for the possibility to share our experience in Argentina, Latin America. I agree that inequity is a problem for people in low and middle-income country and also, as has been said, in high-income countries. I think it is more of a challenge in low and middle-income country, but there are many problems also in high-income countries.



In Latin American countries, which are typical of middle-low-income countries, the hallmark is diversity and disparity. Diversity because we have many cultures, different ethnicities, different population, and different economical level. This is a hallmark in Latin America. Actually, It is an advantage. Diversity is not a disadvantage.

The problem is the disparity, the economic disparity, the lack of possibility to access to the health system. In the same country, we have the combination with people below the poverty line without access to the health system, and in the same country, 50 km away from this place, we have all the possibility to diagnosis or treat patient, even the biomarker. We have to work with this difference.

One month ago, we had a meeting in Nairobi, a meeting related to the update on diagnosis, treatment, care, and prevention in low and middle income countries. And two weeks ago we launched a statement with the actions that we need to take to address this inequity. One of the things is to rethink the global action on dementia. We need to include the low- and middle-income countries, we need to include the under-represented population in high-income country. Secondly, we need to shift the economic balance. We need to shift the economic support for research. We have to support research in these countries and among these populations and sub-populations. And I think if I can make one suggestion to governments is that prevention is the most important thing to focus on.

And in relation to that and the point about increasing research capacity, our experience is that networking collaboration, international collaboration are very, very important. For example, in our institute, we grew a lot with the collaboration we started with ADNI, with the collaboration we were able to include the biomarker in our institute. And we continued with DIAN and LatAm Finger. With this collaboration we have the possibility to improve the research in our region. LatAm Finger is with 12 countries, 12 countries working together on prevention and I believe that this is a very good option. So these kind of international research collaborations are an important way that we can help reduce inequity in research Thank you.



**Philip Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you very much for sharing your thoughts on this. I thought, clinical meaningfulness was a difficult topic, but this is even worse, I would say. And you perfectly laid out the various aspects to the topic and how there are different angles you can look at it. And your last remark was, of course, extremely important. By the way, prevention will be dealt with in the end by a specific panel as well. But I have already one comment here, and two.



*Participant* | **Peter Varnum**, Secretariat Davos Alzheimer's Collaborative

Thank you. Curious, maybe a question for the organisers and also panellists, why equity is its own session as opposed to being sort of woven in throughout the entirety of the programme.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

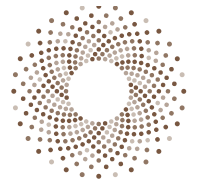
Good question, well, because we thought it was an important topic that we couldn't just assume that it was already sort of covered in all the different sessions, but your point is correct, I mean it should of course be.



**Paola Barbarino**, CEO of Alzheimer's Disease International

Can I make a point on that. I hope one day we'll be able to have it not as a separate session, but right now it's a massive, massive issue which needs to be highlighted. We could talk for hours about inequity! So, I think it's a good idea to have a separate session, but the ultimate aim should be not to have it.





**Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

Maybe the next conference is on inequities.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Oh yeah, I'm sure this first actually he was here. There are seats by the way, Martin you can sit over here if you want.



*Participant* | **Hans Moebius**, Chief Medical Officer of Athira Pharma

So it's soon going to be 120 years since Alois Alzheimer himself described plaques and tangles in the disease, and today's diagnostic systems are still focused on that. Can we have this equality discussion without reconsidering how we make the diagnosis, or in other words, I'd like to come back to what was said before, do we have to wait for Tik Tok to use all the sensors in an iPhone to give us the lead in areas where no PET scanning, lumbar puncture and so on are possible.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Wow. Somebody on the panel?



**Paola Barbarino**, CEO of Alzheimer's Disease International

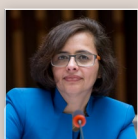
That is a very good point. We looked at this very carefully in 2021, when we published the World Alzheimer Report on diagnostics. The reason for this was that we were seeing that lecanemab required a confirmatory diagnosis with a PET amyloid scan. We thought well, in the vast majority of countries in the world, they not only don't have PET capacity, but they don't even have the neurologist that can read them or the technician that can administer them. We also asked the team that wrote the report from McGill University

Because what I was thinking was, if I want to know if I'm obese I go to the BMI calculator on the NHS website, I live in England, and it tells me if I am or not. And then I have a piece of chocolate, which is a terrible thing to do for someone who does my job. But I thought, can we do something like that for



a cognitive impairment diagnosis? Could we have something similar for dementia? The short version of the story is that in the end, after a lot of meetings, we didn't feel we could have something that we could really recommend. There couldn't be a definite answer.

That is because there are well over 100 ways to get to dementia, as we've been discussing recently. So, it's so difficult. Plus, once you've got the diagnosis, the great disaster, as we found out in this year's World Alzheimer Report, which was on post-diagnostic support, is then what? The vast majority of governments do not provide clear health or long-term care pathways, and people have no idea that there is so much that can be done, for example those adaptations that the previous panel was talking about, but they're not even given that. So that is very iniquitous in itself.



**Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

So yeah, just to, in terms of, I think what you raise is a very important point. And let me bring some ground realities here. Talking about most of the low and middle income countries, do we know how many neurologists are there, leave aside the PET scan, you are talking about one neurologist for a three million population.

I mean, think about that's the reality. There is no way that if we would all invest all the resources in building the capacity that we are going to have these diagnostics or the specialized workforce in 75% of the world.

Somebody in the previous section talked about the issue of psychosis. Do we know what is the service coverage for psychosis in low-and middle- income countries? Only one third of people receive the treatment. For epilepsy, only 25 to 30% people in low income countries, they receive the treatment. So, this is the reality when we are talking about cost effective. Treatment for epilepsy is as low as \$5 US per person per year. And still 75% of people in low-income countries do not receive the treatment.

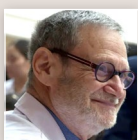
I think if we are not going to use the primary healthcare system, a clinical diagnosis approach, strengthening the capacity of the health system to deliver it through the primary healthcare workforce, we are not going to reach even the 50% diagnostic rate that the target we have in the global action plan.

There's an old saying, perfect is the enemy of good. So, let's not go the perfection route, but think about the majority of the people where such care and services are needed.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Howard, brief comments from you, because we have many people who want to ask questions.



**Howard Bergman**, Professor of Family Medicine and Medicine at McGill University

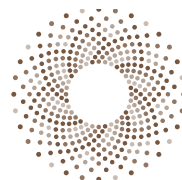
So somebody mentioned the fact that perhaps having equity is a cross-cutting theme and not having it as a stand along session. And perhaps having equity as a cross-cutting theme in drug development as well. In other words, do we think about the cost-effective access to the diagnostic and treatment that we're developing?

To Tarun's point about access to diagnosis, I have a neurologist colleague in a rural, outlying area in my province Quebec, which is a high-income country as far as I know, and he says we'll never be able to use these medications because we don't have the number of neurologists, we don't have the number of MRIs and we don't have PET. It was said to me it seems to me to have access to these medications, you have to be very rich and live very close to a university hospital.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Well, fair comment.



*Participant* | **Jane Rylett**, Scientific Director Institute of Aging (CIHR)

One thing that we haven't heard from the panel so far relates to ageism. It seems to me that ageism is a root of much of the inequity that we see, certainly in terms of allocation of limited resources and desire from some societies to be able to continue treating older adults, particularly when you look at later decades of life.

Things like palliative care is a very rare resource for people at end of life with dementia. So can you comment on how we can actually approach ageism and use that as a way to solve some of the problems with inequity.

**Paola Barbarino**, CEO of Alzheimer's Disease International

It's a very complex issue. Ageism is everywhere. We find it even at the highest levels. I mean, most recently, we've had a big debate with the WHO on why, in non-communicable diseases, mortality is not looked at in people beyond 69, they are not considered as having a premature death, and therefore, dementia isn't counted as a leading cause of death. I oversimplify, I know. But this was basically the point.

We also work with ageing organizations obviously, but it's also difficult for dementia, because actually, we are now finding increasingly that people are being diagnosed in their 40s and in their 50s. Even in the scientific community, I could see a split with aducanumab between geriatricians that said, ah, but this is not applying to our typical patient, and neurologists that say, ah, but this really helps the people that come and see us in their 40s and 50s. Again, I oversimplify, but the approach is dualistic. For us, it's a constant issue to have to walk the tightrope in one way or another.

**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Myrra is after you. You are first, and then Myrra.

*Participant* | **Filipa Landeiro**, Senior Researcher in Health Economics University of Oxford

I would argue that it's not just a low and middle income country issue, but it's also a rich country issue. Because at the moment, I cannot see how we can demonstrate cost-effectiveness for the new drugs. And I'm not just talking about the drug itself, but I think we should also consider the whole dementia pathway, including the diagnosis of it, with PET scans being highly costed and MRI machines being needed for the follow-up of patients. So even if we throw in societal costs, such as productivity losses and such as informal care and even if on the outcome side we look at impact on carers' quality of life with the current threshold of 20 to 30 thousand pounds per quality gained, it's not going to be possible to demonstrate cost effectiveness in the UK for these drugs.





**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Comments?



**Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

I think an important point, the panel, all of us did say at this point that inequities are everywhere. And these are unfair. These are unacceptable. And the one Ricardo talked about how we need to address the social determinants of health to address some of those inequities.

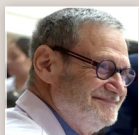
But then the important thing is, how do governments in countries invest in reducing those inequities and getting the diagnosis and the treatments. And that takes us to the point of prioritisation by the government. This is a preaching to converted. We are here because we all think that dementia is a high priority. But I think if you walk and talk in other corridors you realise the resistance that you face building up these programmes that are required for dementia. And I think this is where the global advocacy movement has to go beyond the usual suspects, beyond the usual corridors, and getting the kind of investment that is required for dementia.

Many people say it, but I think this is really true about health systems. If you think of dementia as the lowest common denominator. Get it right there for people living with dementia and their families and you will find there are many more chronic diseases easier to address. And I think there are those models that we need to take forward and this requires governments to prioritise this. There is no way that you know this can be this can happen outside the government sector.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. Howard do you have a comment?



**Howard Bergman**, Professor of Family Medicine and Medicine at McGill University

Yes, just briefly I would say that a challenge to researchers and industry is to look for simple biomarkers. Blood-based biomarkers. Simple markers for following the disease and I think that would go a long way to help equity.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. We have Myrra waving her hand for a long time already.



*Participant* | **Myrra Vernooij-Dassen**, Professor emeritus Radboud University Medical Centre

Well, we are talking about inequity, when a country is richer there are better solutions even if we are not satisfied about the solutions we found so far. If you look at lower income countries, they have to deal with the same problems and they have to as far as possible make a good quality of life for people with dementia with the limited resources they have. And maybe that is not worse than in our countries. Maybe they actually find better solutions and we can learn from them as well. So, for instance in Indonesia, they don't label dementia as "dementia" but they describe the problems that flow from that and the local community is aware of these problems and helps primary care to deal with it and find ways to keep people into the community. So they find their own solutions and maybe we can learn a lot from them to improve the quality of life.



**Philip Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. Howard, you had a comment as well? Can we give the mic to Howard and then I'll go over there and over there.



*Participant* | **Howard Fillit**, Co-Founder and Chief Science Officer Alzheimer's Drug Discovery Foundation (ADDF)

I just want to say in a developed country, the United States, about 70% of prescriptions for Donepezil are written by primary care doctors. And clinical practice guidelines in the States generally say that specialty care is only required in cases that are unusual, such as suspected FTD or things like that. So, I think that there's no doubt that cost-effective and quality care for people with Alzheimer's and related dementias can be done in primary care and might be more even cost-effective.

The other thing I wanted to say is that this first generation of disease-modifying drugs, which are biologicals, are quite expensive. I don't think that health economics will be able to prove that these drugs are cost-effectiveness. And it's going to be a big barrier to widespread adoption with all of the safety things that we have to do requiring neuroimaging and so on.

And so, I think part of the solution to equity is developing small molecules that can be widely distributed. I think those are for the first time really on the horizon. So small molecule anti-amyloid drugs, for example, but even on these many other targets that we're looking at now, blood-based biomarkers will also enable more cost-effective care. And so, I think that's the future, where science can meet health equity.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

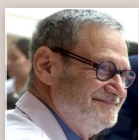
Thank you very much, Howard, for the mystical note that I completely agree with.



**Paola Barbarino**, CEO of Alzheimer's Disease International

A very good point Howard. This year we put in a request for donepezil to be on the WHO essential medicines list. This is because in America it may be accessible, but in so many countries around the world, including some high-income countries, it isn't reimbursed. The war in Ukraine really escalated the issue, because we couldn't actually force anyone to send it to Ukraine, because it wasn't considered an essential medication.

Just to point out, sometimes we need to get out of our mindset of high income countries, where the journey begins when you go to the doctor. To add to what Tarun said earlier, to think that even a medication that costs \$5 per person is still not reimbursed, it is clear we still have a long way to go. This is where we as a community must help, because in an inequitable world, there is always going to be a society where some have and some have not. In this case, even at this low pricing, some have not, which is chilling.



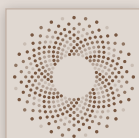
**Howard Bergman**, Professor of Family Medicine and Medicine at McGill University

I co-founded and co-led a memory clinic, one of the McGill University memory clinics for many years, with my colleague Howard Chertkow. The best memory clinic in the world, except it took 8 to 12 months to get in. So maybe the best in the world, but not very useful. And why? Because about 90% of the people we were seeing were typical cases that could have been seen in primary care. And in fact, in Canada, dementia detection, diagnosis and treatment is anchored in primary care with specialty care for the complex case. And that's feasible, it's possible. But it takes effort, and it takes training, etc. But it's possible. And that's an important element of accessibility and equity.



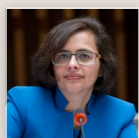
**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Exactly. So we're entering the last five minutes. So, yours is a comment?



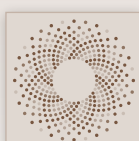
*Participant* | **Louise Robinson**, Professor of Primary Care and Ageing Newcastle University

So as a primary care physician, I'm really intrigued as to why we still pursue this drug-focused specialist dementia model after what we've been hearing today. And of course, that focus goes back to how research is funded. I can only speak from the UK perspective, but the vast majority of research goes on biomedical models and the amount that goes into health and care and prevention is minuscule. And I'm not quite sure why dementia is so different. For many years, as a family physician, a person who has depression, I can offer them non-drug therapies, which are routinely available and are evidence-based and are available to all, as well as drug therapy or a combination. I don't see non-drug therapies for people with dementia easily available. And it's perpetuated by this drug-focused model and the idea that dementia is a specialist illness, if you like.



**Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

So very briefly on this, the primary care approach, I think it's good that we are hearing in this room about the primary care approach that is needed. I would encourage funding agencies to think more about implementation research rather than just the basic science and translational research because that's going to get the treatments more out to the people living in, you know, remote parts to help reduce those inequities.



*Participant* | **Caleb Webber**, Director of Informatics and Data Science for the UK Dementia Research Institute Dementia Research Institute (DRI)

There's sort of two comments, technical ones really, and I don't mean to divert from the fundamental structural inequalities that underlies things, but the use of perhaps common platforms, such as smartphones, to be able to spread those diagnostic or those predictive measures across. And I give one example that we have a paper coming out of, a study coming out of the UK DRI, that shows that wrist





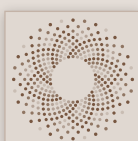
based worn accelerometers worn for one week in the UK biobank population can predict Parkinson's up to seven years later. So that's there to be explored as we bring in the data scientists.

And then secondly, we're using stem cell models. They're becoming quite common and there's a lot of hope attached there. It's taken us a very long time, even for a few institutes to agree on a common control. What we really need there is an ethnic diversity panel of stem cell models that are available for common use. When we did the human genome, it was originally constructed from 24 individuals, and then we had a great sort of exploration of human diversity. We now need that in these stem cell models, which we're increasingly turning to.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. I have another comment over here.



*Participant*

Well, I think this discussion has become very interesting. The panel has addressed inequities in treatment, in healthcare, in access to biomarkers, and in prevention. But there's a thing that all these topics have in common, and it's the inequity that you can find in recruitment. Recruitment for clinical trials, recruitment for prevention trials. So, I wanted to see if they have a comment on how to improve equity in recruitment.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Good that you bring that up, Paola?



**Paola Barbarino**, CEO of Alzheimer's Disease International

We have been doing a lot of work on this, because as Ricardo was saying in his opening address, this one of the biggest problems facing those living with dementia. One of those problems is that the pharmaceutical industry doesn't necessarily want to conduct clinical trials in countries which are more challenging for them. Some countries are ready for clinical trials, but just they don't broadcast the fact sufficiently. Others simply have too much difficulty.



I remember having a good conversation with Lynn Hughes about that very early on in my tenure at ADI. So, we need to encourage that, even more so now, as a consequence of the focus on diversity. I look at Harry and the Alzheimer's Association which has done so much work around that, around diversity of populations within the U.S. Of course, for us, the issue is that you shouldn't need to look at it that way. We should already be going to those populations directly

We have also done a very complex series of webinars that also look at the experience of the people living with dementia who have participated in clinical trials, because that's the other issue. In a lot of countries, people who participate in clinical trials may be abandoned after the clinical trial closes. There are also issues of misinformation, or non-information, to carers and people living with dementia.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

We have the last question from Steve here, and then we'll wrap up.



*Participant* | **Steve Salloway Martin M. Zucker**, Professor of Psychiatry and Human Behavior, Professor of Neurology Kent Hospital Rhode Island

Yeah, I want to urge all of us, I guess, it's not just the panel, because we're all in this together. I know there's a lot of complexity to inequities, so my comment will not address all of them. But one key component I think we can do, I think we need to kick ass a little bit, way more than we're doing. And one suggestion is with blood biomarkers, as Howard raised this issue. If we had blood biomarkers, which are looking increasingly robust, we are going to improve in developed countries and eventually in undeveloped countries a molecular confirmation of the diagnosis of Alzheimer's disease. That's going to move the field forward quite a bit. But I think what we have to do is make sure that the cost is not too high. Because I've been in discussion with some of the companies developing these tests. They're not cheap. They're cheaper than PET scans. But we need pressure, again, to make this affordable so we can help address the inequities.



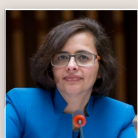
**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you very much, Steve. One last comment from each of you. Just one last final sentence to leave the audience at the coffee with.



**Professor Ricardo Allegri**, Director of Aging and Memory Center of Fleni

Yes, I believe that the inequity is a big problem. We have to work in low and middle-income countries despite the difficulties, and one of the problem is the disorganization of the health system.



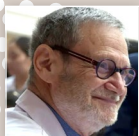
**Dr. Tarun Dua**, the Lead of Brain Health at the World Health Organisation

So while we know inequities are everywhere, I think that my ask to everybody is that whether you are a care practitioner or a researcher or in any other role, think in terms of practical ways of addressing those inequities in your daily work plan. Set some milestones, some targets to achieve because unless and until we do that as a community, the inequities are going to increase with the new treatments that are coming and that's what I'm worried about.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. Improve the world and start with yourself. Howard?



**Howard Bergman**, Professor of Family Medicine and Medicine at McGill University

I would make a plea. We talked a lot about real-world evidence. I would make a plea that when we talk about real-world evidence, that we talk about implementation research at the same time. As we link drug development, we link real-world evidence, and at the same time, implementation research on how this is going to land in our health care system. If we want to convince our ministers of health, who I'm sure are shaking in their pants now, thinking of the cost they're going to meet for this, we need to do very serious implementation research, as rigorous as all the biological research that we're doing.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you. The final words for Paola.



**Paola Barbarino**, CEO of Alzheimer's Disease International

I am with Louise Robinson on this one, we talk a lot about things that are just around the corner. I mean, biomarkers, for example. Since I started at ADI six years ago, they were always almost there, but they were not quite there yet. In the meantime, there is so much we can do about care and there is so much that can be done to make people's lives better. We obviously need to work on new drugs because that's our hope for the future.



**Professor Philip Scheltens**, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Thank you very much and that's a nice bridge to the next session. The panel is released and you are also released to get your coffee and we'll reconvene in 30 minutes.



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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