

Summit 2023

Dementia in a new era:
prevent, diagnose, treat



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


Post diagnosis in an era of treatments

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.

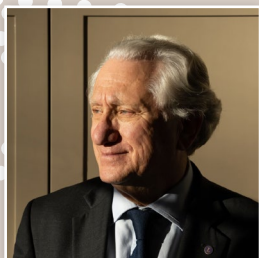
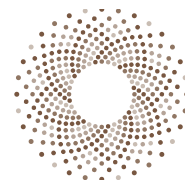
Speakers



Professor Alistair Burns CBE

Professor of Old Age Psychiatry NHS England Dept Health Lead

Alistair Burns is Professor of Old Age Psychiatry at The University of Manchester and an Honorary Consultant Old Age Psychiatrist in the Greater Manchester Mental Health NHS Foundation Trust. He is Director of the Manchester Institute for Collaborative Research on Ageing (MICRA) and the National Clinical Director for Dementia and Older People's Mental Health at NHS England and NHS Improvement. He graduated in medicine from Glasgow University in 1980, training in psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. He became the Foundation Chair of Old Age Psychiatry in The University of Manchester in 1992, where he has variously been Head of the Division of Psychiatry and a Vice Dean in the Faculty of Medical and Human Sciences, with responsibility for liaison within the NHS. He set up the Memory Clinic in Manchester and helped establish the old age liaison psychiatry service at Wythenshawe Hospital. He is a Past President of the International Psychogeriatric Association. He was Editor of the International Journal of Geriatric Psychiatry for twenty years, (retiring in 2017) and is on the Editorial Boards of the British Journal of Psychiatry and International Psychogeriatrics. His research and clinical interests are in mental health problems of older people, particularly dementia and Alzheimer's disease. He has published nearly 400 papers and 25 books in the field of mental health and dementia. He was made an honorary fellow of the Royal College of Psychiatrists in 2016, received the lifetime achievement award from their old age Faculty in 2015 and was awarded the CBE in 2016 for contributions to health and social care, in particular dementia.



Laurence Geller CBE

Chairman Geller Capital Partners

Since founding his first hotel in 1989, Laurence Geller CBE has built a global hospitality empire. Geller lost his parents to dementia and has since devoted his life to the prevention, treatment, and care of this condition. Geller has built a collection of world-leading dementia care facilities while funding innovation and research to bring residents the highest level of care and comfort. As Founder and Chairman of Loveday & Co, Geller has coordinated private, public, academic, and philanthropic partners to create a world-leading provider of specialist dementia care. Loveday & Co have been recognized as pioneers of dementia care, winning the 'Best for Nursing Care' award in 2019, 2021 and 2022, overall Gold trophy for 'Best Individual Care Home' in 2021. Loveday 'Loveday Chelsea Court Palace' has received an 'Outstanding Rating' by CQC. Geller is the Department for Digital, Culture, Media and Sport's Ministerial Adviser for Concussion in Sport (2021 –). As part of this responsibility Geller has worked to establish the UK as the global centre on concussion in sport and related neurodegeneration. He has coordinated his network among leading sport and medical experts in the UK, US, Canada, Switzerland. As Chancellor of the University of West London (UWL), Geller funds and oversees major life sciences projects through the Geller Institute for Ageing and Memory (GIAM), launched in June 2020 at UWL. GIAM has already secured £1.429 million of external funding, rising to £3.3 million when current bids are evaluated. Life sciences projects led by GIAM, include multisensory culture boxes to promote public health guidance and to support the wellbeing of people with dementia in care homes.



Ernst van Koesveld

Director General Longterm Care Government of Netherlands

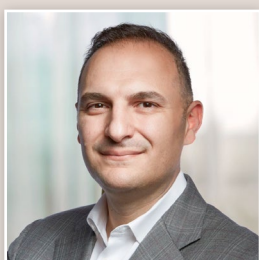
Ernst van Koesveld (51) is Director-General Long-term Care at the Ministry of Health, Welfare and Sport, the Netherlands. His fields of responsibility include care and support for children and young people, the elderly and persons with disabilities as well as institutional, financial and labor market issues in the health care system. Before, he was director Health Insurance. The Dutch health system typically combines private responsibilities with public guarantees and rules. The major challenge for all stakeholders is to promote and achieve people-centered, integrated care ("the right care at the right place"). Prior to working for the Ministry of Health, Welfare and Sport, Ernst van Koesveld held various position at the Ministry of Finance, dealing with international decision-making (IMF and the World Bank), budgetary policy issues and structural reforms (social security, labor market, housing, pensions, taxation and decentralization, 2001-2014). He also worked for the UN Development Program in Lithuania and Vietnam, the Ministry of Economic Affairs and the Erasmus University Rotterdam. His educational background is in economics.



Professor Anja Leist

Co-chair, World Young Leaders in Dementia. Anja Leist is Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on Socio-Economic Inequality at the University of Luxembourg

After her PhD studies in Psychology at the University of Trier, she had postdoctoral research stays at the universities of Luxembourg, Zurich, and Rotterdam. Her research focuses on cognitive ageing and dementia from a social and behavioural (risk reduction) perspective. Anja's research interests also involve social and life-course determinants of health, healthcare use, and use of technology at older ages. Anja is PI of several competitively funded research projects, among them a grant from the European Research Council on cognitive ageing and dementia with a focus on lifestyle behaviours and contextual inequalities related to education and gender. She is co-leading an interdisciplinary flagship project at her institution that investigates links between the social environment, microbiome, and dementia. Anja has received an 'innovative publication' award, is elected Fellow of the Gerontological Society of America, and co-founder of the World Young Leaders in Dementia a.s.b.l. (WYLD) network, now a registered non-profit organization facilitating careers of young professionals in dementia. She is member of several steering groups and scientific advisory boards. Anja is a Rotarian, married, and has two children.



Dr Andrew Trister

Deputy Director, Health Artificial Intelligence Bill & Melinda Gates Foundation

Andrew Trister leads digital health and artificial intelligence at the Bill & Melinda Gates Foundation. His team invests in innovations that weave together artificial intelligence, mobile applications, objective sensor-based measurements, clinical care models and interoperable data infrastructure to improve care delivery at all levels of the health system. Andrew is a physician scientist passionate about leveraging technology to improve health care for all. He joined the foundation from Apple, where he led clinical research and machine learning for health features on the Apple watch and iPhone. Prior to Apple, he was the senior physician at Sage Bionetworks, where he designed and shipped ResearchKit, an open-source tool for large-scale clinical trials and developed infrastructure to share and collaborate on medical imaging. Andrew completed clinical residency in radiation oncology at the University of Washington, with additional focus areas in medical- and bio-informatics, earned an M.D., Ph.D. in bioengineering, MSE and BSE in computer science, and a B.A. in biological basis of behavior (neuroscience) all from the University of Pennsylvania.



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

Let me invite the panellists again.

- **Professor Alistair Burns**, Professor of Old Age Psychiatry in Manchester and also the NHS England Dementia Lead. Welcome to the stage Alistair.
- **Laurence Geller**, Chancellor of the University of West London. He's trying to get himself freed out of the line. There he is, yes.
- And then we have **Ernst van Koesveld**, who is actually the Director of the General Long Term Care of the Government in the Netherlands. Welcome, Ernst.
- And **Andrew Trister**, Deputy Director of Health and Artificial Intelligence at the Bill and Melinda Gates Foundation.
- And, **Professor Anja Leist**, Associate Professor of Public Health and Aging. Welcome, welcome.

So you know the drill. It is just by giving a brief statement to the audience what you think about this particular topic. So diagnosis, post-diagnosis, in treatment and care, how does it look? So, Alistair, starting with you.



Alistair Burns, Professor of Old Age Psychiatry NHS England Dept Health Lead

Thank you very much for the invitation.

One of my jobs in the NHS is to make things accessible while reflecting the complexity that there is in dementia and Alzheimer's disease. And so, one of the things we did was we looked at what we call the wellbeing pathway, which is: preventing well, diagnosing well, treating well, supporting well, living well, and dying well. <https://www.england.nhs.uk/publication/dementia-wellbeing-pathway/>

I have three reflections in terms of the new treatments that would have an influence on four of these six pathways.



First, as we've heard others say today, there remains the perception in dementia that nothing can be done. And that brings therapeutic nihilism. Sube Banerjee, who's in the audience, 14 years ago in the National Dementia Strategy, made the point that that was part of the reason people not getting a diagnosis. As Fiona said today, fourteen years after the first dementia strategy, still only two-thirds of people get a diagnosis. So, the idea that nothing can be done has an important impact on behaviour. If there are new treatments and if they are effective, that has the potential to sweep away therapeutic nihilism.

The second is a timely diagnosis can also be an early diagnosis, as we've heard. The first new treatment will have a relatively small window when treatments need to start. I remember, as many people in the audience will do, when the cholinesterase drugs were introduced in the late 1990s, there was a narrow range on then the Mini Mental State Examination when they were available. So, the message we were giving people if there were above the range was "come back when you're worse!". And when they became worse, we said we'd stop them. The opportunity of the new treatments is that window extends further up the pathway, but widens as well.

Third, in terms of case finding and screening and I was interested to hear the discussion earlier. We introduced a policy in the NHS to have everyone above a certain age, who was admitted to the general hospital, "screened" We called it case finding and it was it was important because that enabled us to introduce it. So, I think these are my three reflections from me at the start of this conversation. 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 Alistair. Laurence.

Laurence Geller, Chancellor of the University of West London

Thank you. Let me start by saying... I'm deaf, I couldn't hear me. This is the second time I've come to this meeting, and I am in awe of the scientific intellect that is in this room. But I'm terrified because none of you are going to find what's going to help me as a 70-year-old plus.

And there's the story of my life. I lost my parents, spent a life in the hotel industry. And then decided to dedicate myself not to waiting for the miracle, not for the latest biomarker, not for the latest diagnostic syndrome test, but to making lives better longer and healthier for those that have dementia. So, i am very different starting place to many of you.

I started to develop care homes and wanted to do them in London. So that's not cheap to do! But I wanted to make lives better and I didn't want to copy what's been done before.

When someone comes to one of our homes they have an assessment from us or their doctors on their lifespan. But there is rarely a time, in the six years we have been doing this, that we don't smash through the lifespan assessment. We have people that are still with me six years later that were given six to nine months and their lives are better and more dignified.

So, I've dedicated my life, our research, our philanthropy, into finding out how do we make those lives better. I've developed technology, and I have wasted more money testing more technological gadgets, widgets, things, than Carter's had liver pills. I really wasted it, but I can tell you we're getting closer and closer to the holy grail. We have acoustic monitoring, we have circadian lighting, we have pads in the beds that do this and do that. We have CCTV's. We can change a lot of things. We add diet. We have one-on-one individualised therapies.

And we are constantly introducing new innovations, now we're working on technology, and I thank Philip for putting me onto it, where we have a, call it a light fitting, that tests a lot of stuff for us in someone's room. Every morning, every single morning, my team go in there download from the cloud and change the care plan.

We're doing this now, for the first time, in home care as well where I expect we'll see similar benefits. I want people to live longer with dignity and the point I want to make to you today is I don't want them to wait for you geniuses to make scientific breakthroughs we can do it now.



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 point.



Laurence Geller, Chancellor of the University of West London

That's why I'm here!



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

Anja, I forgot to mention that she is also the co-chair of the World Young Leaders in Dementia. Anja.



Anja Leist, Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on SocioEconomic Inequality at the University of Luxembourg

Thank you for that so it's difficult to follow that exciting and I think very moving contribution. And I'm still reflecting on the excellent points that have been made today and figuring out what to say new or perhaps emphasize and build on observations others have said.

One of the things that have been said today is how few people will actually receive the treatments, the medical treatments, when they are available and approved. Even with perfect accessibility and affordability, which we will not have, it's still a question of who will be eligible to receive the treatment based on the symptoms and who will need to stop the treatment for whatever reason. And the conclusion I draw from this is we shouldn't put all our eggs in one basket. We have to really at the same time as rolling out medical treatments think about non-medical treatments for the physicians, to offer new and better non-medical interventions as well.

Coming from a risk reduction and prevention perspective myself, I would say, and maybe this is naive to some of you, we shouldn't stop preventing because of a diagnosis of dementia, we could still think of all the modifiable risk factors and how to optimize them to improve cognitive performance on a daily level.

And I think this is where the data collection comes in again to our conversation, as it has already today. We don't have enough data on the kind of daily fluctuations of cognition someone experiences. And for this we need sensitive and not intrusive measurements of cognition and how it changes over



time. So, think of sleep. We know how to improve sleep quality. Why don't we systematically collect evidence from people living with dementia? Physical activity, does it help more in the morning? Does it help more in the afternoon? For whom? Which physical activity intervention work best? We don't know.

I think we need to think about these non-medical interventions in the future as well. And for this, more data collection is essential, and to be effective that means more non-intrusive data collection. Thank you.



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. Ernst, your turn.



Ernst van Koesveld, Director General Longterm Care Government of Netherlands

Thank you. Today too often people hear the message you have dementia and it's at an advanced stage. The discussion we had in the earlier panel shows there is a benefit of earlier and accurate diagnosis. I think on three levels that will be very helpful to make visible what is often hidden for people.

First, on a personal level, people really want to know about their situation and want to discuss that within their personal network and with a doctor and to discuss how to deal with it over the months and years ahead. How does it affect my situation? What can I do in terms of lifestyle? And are there any non-medical or non-drug options? So that's something that is happening at an individual level.

We need to have more information about early diagnosis at the group level to determine risk patterns, types of diseases, and also to find out what are the best possible treatments. Because groups are so different, people are so different.

And we need data on a national level to make visible what is often hidden. In the Netherlands we collect data on things such as the numbers of people that receive treatments. But that database needs to be enriched with more information about the actual path of developments of disease. Really to learn more how to reduce the risk of further development of symptoms of dementia.

And as a government, we can help here a lot, as we do also in the Netherlands. We have a public-private partnership on personal treatment, prevention and diagnosis. And that is really a broad group of organisations, from society, from science, from medicine, and also from the private sector. Because, as we've learned today, many solutions also lie just before the traditional medical system of physicians and hospitals. Doctors in the sector are inevitably very much focused on medical interventions, but there are lifestyle issues and there are technologies that other disciplines can bring that may be very helpful. The consumer market can also help to develop innovative applications and approaches. Also, we need input from the social sciences point of view, because, as was said in an earlier session, people really have to cope with early detection.

And what we try to do in the Netherlands. To take that holistic view. As part of our national dementia strategy, we never ask one discipline, or one university, or one research centre, to do research. As a prerequisite, we always say you have to work together with a number of organisations. The Netherlands is a small country, but still even here it's possible, perhaps easy, to work in silos, and what we want to do is to move away from those silos into cooperation across different disciplines and across universities.



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. Thank you. Andrew.



Andrew Trister, Deputy Director, Health Artificial Intelligence Bill & Melinda Gates Foundation

Thank you. I am probably the least qualified person to be in this room, but I appreciate the invite to be here. I'm a radiation oncologist. I see patients with a disease that may allow us to understand a little bit about dementia, but I actually cause dementia, perhaps because I treat whole brain radiation. So, this is maybe something that I don't want to admit outside of this room, but that's the way that things go! My work at the Gates Foundation informs what I'd like to share here, and that is given the fact that these meetings are meant to inform what will be a series of discussions towards government meeting at the end of the year. And toward that end, let me give two observations.

The first is borrowed from Clay Christensen, a Harvard Business School professor. One of his very last books, before he passed away a few years ago, was *The Prosperity Paradox*. It was written with companies in mind but we can apply the thinking to countries. The book is about innovation, which is really at the very core of what we've been talking about throughout this day. How is innovation going to lead to the democratisation of technologies?

I come from a technology background. We often talk about the zero to one. That's an entrepreneur taking an idea and being able to build a product. Those of you in industry know this very well. This is R&D in pharma. Zero to one requires a lot of science, a lot of application, and a lot of risk. And we can mitigate that risk with funding, or we can accept it, but we say we're going to get from zero to one.

But the thing that VCs, in particular in technologies, digital has come up a few times over the course of the day, really want to know how is it how you go from one to many. It's the scaling question. What is the market and what is your go-to-market strategy? Who is it that you're actually going to address? And I think that it's very important that we keep this in mind, that we're going to innovate on one hand and that we're going to understand who is it that we're actually helping. And that's at the core of a lot of what you've heard.

Now, Clay Christensen's book introduces a third phase, which is kind of eye-opening for me and at the core of a lot of the work that I do now. And that is, how do you go from many to all? That democratisation phase, and each of these require different stakeholders. Now the lessons are drawn from case studies, as Harvard tends to do! These are a diverse bunch of case studies from automobiles to Kodak. But one of the lessons relates to the fact that you may be able to build a product and you may have a really good go-to-market strategy but you're likely to harm people.

And the fact is that regulators are usually are behind the curve when it comes to these innovations. These innovations are being pushed into market and there is a market. As we've heard a couple of times now in these panels, people want information, they want the biomarkers, they definitely want the therapies, this market is like other markets demand exists. And, in many cases, what we find is that the introduction of these new technologies, innovations, tends to start to harm a little bit before the regulators actually come in and clamp down.

Now, there's been a lot of discussion is regulation appropriately for the innovation we need. What has been discussed here a few times is we have to work with urgency, we have to move quickly. But I would argue we as a group need to think about, and certainly when engaging with policy makers like Ernst here, we need to think about how is it that we may actually lower those barriers to market entry and lower the regulatory risks. So, we can deliver innovation that addresses the demand, since there is demand in all our countries. People want these things for themselves, for their loved ones. We need to support regulators to use this as a regulatory science question.

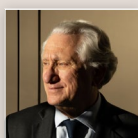
And then finally, in the many to all phase, this democratisation, that is work that has to happen with government. It's only government really that drives this. It's about public sector investment and drive. With the exception of the smartphone perhaps, a lot of technology innovation has really been driven by governments.

I'd just like to offer that as a framing when I think about the problems that we're all facing and the ways that we might be able to offer to G7 leadership and the meeting the government of Netherlands are hosting how they might together drive progress.



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, thank you. So, we all agree, I think, at the panel that even the introduction of disease-modifying therapies will not erase the need for care. It will always be there. So how are we going to fund this? How are we going to accommodate this? Laurence, you have established, I've been there actually, here in London a beautiful care home. You could almost say, I wish I would end up there. Well, hopefully not, hopefully I will not have dementia. But Laurence how are you going to scale that up, to deliver the quality of care on the scale that we all need without bankrupting nation states!



Laurence Geller, Chancellor of the University of West London

If I can try and address government for a little bit. Forgive me starting with sport, I used to be an international rugby player as a younger person. Because of that and because of my dementia work I suddenly get tapped to try and lead the UK government's efforts on concussion in sport. We're doing work there. One of the things we've undertaken is a major prevalence study on all of this. How much is it costing the nation?

And if I think my life, my experiences here, is that the cost question is an important policy driver. If we know we can keep dementia patients out of the hospital beds, if we can ensure they live with at home for longer, if we can have a consistent national standards when they are in the hospital, a consistent discharge protocol and so on, if we can do all of that then we can save money. And I am convinced we can because it is what I'm doing across all four homes and on a micro scale, it seems possible. Keep people well and you save money. What does it cost for a hospital bed in a year? It costs approximately a hundred thousand pounds, say, for an NHS bed a year, is that about right? So, if I could save a thousand bed years, you can show the government the monetary side of it. You can show the monetary side of it, you get more money for research, you get more money to train carers, next subject quickly.

You can roll this thing out nationally if you parallel the investment not only in intellectual research, the way many of you are doing it, but also in the technological research. If you can monitor people in their homes and be able to make rapid adjustments. I am absolutely convinced that the lessons from care homes such as mine can and must be rolled out into the home. Because we are making lives better and saving money.

The final piece of it is education. We have mostly untrained carers as an industry. We call them carers, but there's no common theme, there's no common certification, no grades of carers, no monetary inducement attached.



We need to do these things in parallel with what you are doing. While you're doing trial to test and to prevent and please god to cure. Is that hope naïve? Well, no because I'm doing it!



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

There is nothing wrong with being a bit naïve! Questions from the audience or comments from the panel on what Laurence has just said? It's not about biomarkers, but it's about care! John, of course.



Participant | **Professor John Harrison**, Chief Scientific Officer at the Scottish Brain Sciences

So, I listened with interest to the care home model Laurence has just spoken about and Professor Burns comments on the NHS. I think this is mostly directed at you two, but I suspect others may have a view from their perspective.

I listened to a podcast by Alan Milburn, the former UK Health Secretary, where he did a really good analysis of the NHS and said we're uniquely well positioned, we have socialised medicine, we have extraordinary data that we could interrogate it and come up with the innovative approaches and capitalise on all that information that we have. That is undoubtedly true. And as a collective in this room, as experts and stakeholders of one part or another of the system, we seem to have a very clear view on what needs to be achieved. Yet domestically, we don't seem to be able to move the dial.

So, the same question to you, if I may, as I asked Fiona on the last panel, is the solution political? And what do we need to do to get people to take that seriously, to make a difference?



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

Alistair, your turn.



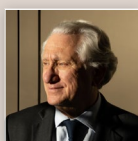
Alistair Burns, Professor of Old Age Psychiatry NHS England Dept Health Lead

I was going to say as well, and further to the point that Laurence made, it can often be cheaper to do the right thing and more expensive to do the wrong thing. And so, the right thing isn't necessarily always more expensive, as you've shown.



I think it's a number of things. We've seen in the last 10 years or so where there has been political interest it can have a great effect. I think, as someone said earlier on, the power that's in this room to actually look outside is very important. Fiona said that we know it's been a time of relative political instability, so asking people who the Prime Minister now feels like a test of short-term memory! I think it's fair to say as well, and everyone would agree, there have been other things going on in the last two or three years. So inevitably, the Government and the NHS has been distracted.

Fiona's mentioned the diagnosis rate target/ambition. Things are beginning to improve, but it's a very good point. I wish I had a simple answer, but I think it's the power in this room that's important. Remember, "Don't hit the target and miss the point!"



Laurence Geller, Chancellor of the University of West London

So, Fiona mentioned the major conditions strategy. I'm a passionate believer in it. A month or so back, the government announced it was going to develop a major conditions strategy. Thank god for politics, there's an election coming up, so they'll accelerate it to get it done. And dementia is a major condition, because dementia goes through everything it clearly goes through every morbidity.

That major condition strategy, I personally believe this through my own work with the government, demonstrates that dementia is a priority for the government and frankly the past two prime ministers have also believed this is a priority. We have a unique advantage as does the Netherlands as we heard where you can come to a nationally agreed strategy on health policy. The United States where I spent 40 years it's state-wide at best. So, this is this is a motivated government. And that's why I'm focusing time and money to show the government how much this is worth to them. To demonstrate it's not just a social, it's a fiscal issue. You know, it's not, oh, it's not about money. It is about money.



Ernst van Koesveld, Director General Longterm Care Government of Netherlands

Yes, maybe to add to that. I think the way we've discussed today tests and biomarkers is on the one hand you have a technological, scientific push. And this is combined with a demand pull as it were. Because people want to know what their status is, if there is a reason to believe that they may have a form of dementia or at least impairment of functioning of their brain.

But vis-à-vis the mix of technological push and public demand you have the caregiver population and the healthcare professionals. How to deal with it? That's not an easy task. And that's not an easy task because there is a shortage of people working in healthcare. The pressure on the labour market from the healthcare sector is huge and increasing. It is actually not affordable. So yes, it is a matter of costs. So, it helps very much to let the dog see the rabbit, see what the advantages of early diagnosis are down the road, what are the cost savings. Can we really say we can not only do a better and early diagnosis but prevent other diagnoses or costs? That would help a lot.

But there is another dimension to it, and that's how do we get the people to deliver the kind of care we need for this group? And how do we equip them with the right skills? Because what I see in practice is that many people in the healthcare sector find it very difficult to manage post diagnosis. How is it best to deal with it? What is the best response? What is my perspective as a professional? What can I give back to people? How to help them help themselves, their social environment, how to help this patient. What can I do as a GP, a general practitioner, or as a social worker? And that's why we have to do much more work to equip them with the right skills, how to deal with the situation, given the scarcity we have.



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. A question from the audience.



Participant | **Lucia Crivelli**, Neuropsychology Coordinator FLENI

I hear this conversation about treatment inequalities, about care homes, and everything that happens after diagnosis or during diagnosis, but I wanted to see a perspective about prevention. We all know that dementia is more prevalent in low and middle-income countries and the challenges this presents. I've seen it first hand in our trial, in our efforts to recruit people with low levels of education.

So, during the whole day I've been impressed by every presentation on technical tools, screening measures, access to biomarkers, but I think before all of this we have to comment on what can we do to recruit the most effective people and how can we help them from the beginning, from a preventive perspective.



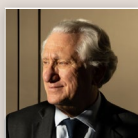
Professor Philip Scheltens, chair of World Dementia Council, Professor Emeritus at Amsterdam University Medical Centers and head of the EQT Life Sciences Dementia Fund

Yeah, I'm not sure. We do have a session on prevention after the break, but let's see whether the panel quickly can sort of...

Anja Anja Leist Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on SocioEconomic Inequality at the University of Luxembourg

I'm afraid to go and take away from the panels that will take place later. But you're absolutely right. I think a population health strategy to act on the risk factors and to reduce the prevalence of people in need for care is vital. And having worked with people with a lower level of education, to some extent, myself, I know it's a real challenge because the awareness is really not there. So, we really need to educate at population level what we can do to prevent.

Also, after diagnosis, I think there's still a lot of potential to modify lifestyle. And we don't know much about it, because there are not the right trials in the field that really look at these modifiable risk factors. So, I fully agree, and I fully agree that we should target populations with lower education, lower socioeconomic status, because they are at greatest risk and there's much more risk to be reduced in these individuals.



Laurence Geller, Chancellor of the University of West London

Look, if I can, the challenge that my side of the world has and that your parents and uncles and aunts and grandparents have, it's nursing, it's carers, it's lack of professionalism. We funded at the University of West London the first master's degree in dementia care to start that off. But it's training. If you don't make care an industry with the right dignity, the right pay, the right qualifications, for the next decade we're going to be whining about a hundred thousand people lacking carers. And the reason will be because it's a lousy job. We have to make it a better job and give people pride in it. Not so that they run around and have to give 20 minutes every day to 20 people. As I said right at the beginning, you can't ignore that this has to become a professional industry to do what you guys need to do. I'm not going to talk about prevention, I can barely spell it, but you've got to make this an industry and I'm dedicated personally to doing the little I can towards it.



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 a question there and then Myrra.



Participant | **Emiliano Albanese**, Professor of Mental Health Università della Svizzera Italiana

I think the elephant in the room is the informal caregiver. So, we disclose a timely, or late, whatever diagnosis to a family. So being a little bit provocative here.

We have Tarun Dua sitting in the room. We have area five of a policy that we have, a global policy for dementia, entirely devoted to caregivers. I'm not testing you, but I wonder how many of you know



about iSupport, which is the official tool to support caregivers? And I'm asking you this not because we shouldn't trust health and social workers to do the work on behalf of others, but because the optimal pyramid of services or mental health services tell us that self-care and community care are at the very core. And these are technically outside health services and systems. So, I think if we keep talking about a clinician-patient relationship, but ignoring about disclosing to a community, made up of family members and all those are surrounding them in the neighbourhood and wherever you can think of, we're not going to make any improvement.

We have to recognise that awareness comes with a lot of stigma and fear. It is not going to in general improve how many people will seek help for themselves. There will need to be different messages to different target populations. So, I think that the key message, and I'll take advantage of this, is that a network worldwide of different interest groups adapting to the local culture and context iSupport are working really hard for this. And we will present this, hopefully, if it is accepted at the Alzheimer's Association International Conference in Amsterdam on behalf of the World Health Organization. So I think this is critically important for what happens after diagnosis. I wonder, a few comments from you about that.



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

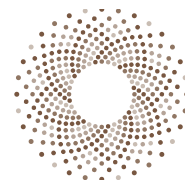
Who wants to comment quickly?



Andrew Trister, Deputy Director, Health Artificial Intelligence Bill & Melinda Gates Foundation

So, I endorse this completely. The global majority are seeking care in their homes, many in rural settings. It's been brought up on this panel and on others about workforce limitations, the estimates now are we'll have, we're short a million in the workforce to provide care globally. These are staggering numbers.

We will not be able to keep up with the demand necessary to provide care without augmenting the existing workforce. The augmentation that you have heard about already, not surprisingly, is going to be digital. It makes most sense, provides tools that allow a caregiver or a person themselves to access care and decision-making with agency and autonomy that is contextual, that relates to exactly their language to what is available to them. I think that this is a critical path, one WHO absolutely endorses, and one that we have been exploring in other domains outside of providing care for dementia.



But it is to recognise the fact that, again, from government standpoint, that there has to be a tool necessary that could be endorsed and appropriately used, because this isn't a marketplace like the App Store. It's not, I'm going to go and download TikTok because that's going to solve my grandmother's dementia. I don't foresee that as a model that is really going to work in this space. It has to be in conjunction with, even if it is informal caregiving, still in conjunction with public health services and some private provision as well.



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

Alistair, do you want to comment?



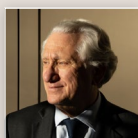
Alistair Burns, Professor of Old Age Psychiatry NHS England Dept Health Lead

It's just to emphasise the role of carers, as Myrra will almost certainly say in a minute, and as everyone has said, is absolutely crucial. We have heard fantastic examples from Laurence and others about how this can work. I guess one of the issues is with the advents of new treatment, is that going to change that that much? I'm not sure if it will. Care is still going to be needed. It's still going to be the most important thing.. And so, I think bringing the two together is crucial.



Anja Leist, Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on SocioEconomic Inequality at the University of Luxembourg

Can I comment on what you said? Because you mentioned workforce and digital and technologies in the same sentence. And we are training nurses in Luxembourg in the master programme in gerontology. And we have found a reluctance to accept or adopt new technologies because of the fear of jobs being replaced and also because of the difficulties handling the new technology. So, I wonder to what extent technology solutions can be really implemented in the care homes. And of course, adjusting the light is not really something where a nurse should be afraid of her job, right? This is just facilitating the lives of the people living there. But something like robots, I don't know, cleaning up waste or something, this is really then replacing part of a job.



Laurence Geller, Chancellor of the University of West London

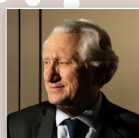
I've yet to meet an empathetic robot. And empathy is quite important. However, look, care homes in the United Kingdom have an average annual turnover of work force of 35%. 35% of that home's workforce is going to turn over annually, be replaced somewhat by agency coming in for an hour. Knowing who you are caring for is impossible in those circumstances. We did the research on that early on in the University of West London. We found out issue was workload. One carer has to look for anywhere between six and nine people in a care home. Well, that's kind of miserable. The stress and pressure is high. So we looked at that model and said okay we've now got to find a model where one carer can do less. Now I'm at the high end of the market, I can afford one carer for two, but my nirvana is one carer for every four patients, four residents. That takes training, it takes technology. Our nurses and our carers love the technology where if somebody is moving wrongly in their bed or not moving as the norm is, it comes up on their app. They can be in the room. And this prevents problems arising. We know if somebody is moving badly, maybe they need to go to the bathroom and that's where they'll fall over, we can get there first.

That's comes back to the workforce again. And I think it is where academia and industry have to work in a public-private partnership on it. And we're doing that. It's starting. But my gosh, it's a journey. But it isn't just finding the scientific result. And I made fun of the robot. But a robot can't hold your hand and stroke it, and that can make people calm down.



Anja Leist, Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on SocioEconomic Inequality at the University of Luxembourg

But have you seen the research on the doll Alice, for example? There are ethical questions, but it's amazing how people respond to such a robot.



Laurence Geller, Chancellor of the University of West London

I was going to marry her.



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

Yeah, yeah. Okay, okay. Let's stop on that. So, I have a question from Myrra and a question from Rhoda. So, Myrra first and then Rhoda, and then we have to wrap up boys and girls.



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

Thank you. Well, there has been a lot of research on caregiving. It's not only about a person with dementia but also about the caregiver. But across the research there is consistency in findings that care should be personalised and that we should pay attention to the needs of persons with dementia and the carer. And there comes the complexity. There might be a different interest between the person with dementia and the carer, who can be very overburdened. So, it's essential to understand individual need. And in defining these needs, the person with dementia is often overlooked. The care to be given, it's not discussed with the person with dementia, but with the caregiver. And in our latest research we found that one of the major tools to strengthen dignity is to discuss with a person with dementia care and to make them a partner in decision making. So, these are, as it were, the broad principles.

There are many interventions already. We have so many! You can't imagine an intervention which is not already in place somewhere. Many of them have been tested in randomized controlled trials and some has to be proven effective. So, there comes the other problem. There is a mismatch between the needs of the individual and the care that is given. There are many interventions which are not used and are not in place but would bring benefit.

So, the knowledge is in place, the interventions are in place, what is really important is that we change our practice to deliver the potential benefit.



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 for that, Myrra. And I think Rhoda we have to skip your question, sorry because we are out of time. I'm going to ask the panel to respond to Myrra's point and for the last remarks, from all the five panellists, just one last remark that you want the audience to be discussing during coffee.



Andrew Trister, Deputy Director, Health Artificial Intelligence Bill & Melinda Gates Foundation

Oh, perfect, yeah, so we're between you and coffee! The thing that I think we've been circling around is what does it take to do this digital transformation in this phase, right? How do we get to the AI piece that we've been talking about?

I'd just like to offer an insight from some of the work that we've been doing. That this transformation actually requires five different components. AI is one of them. We need to be able to make different kinds of measurements to feed that AI. So that's sensor-based, say on a smartphone, as we've talked about before. Then there has to be some ability to introduce these tools and the measurements into a



workforce as we've talked about. There are barriers, as Anja touched on. We have to see people have access to this. And I think that generally speaking, we have seen that there have been models that have improved community-based access to a lot of these measurements. But that has been the other elephant in the room, democratization. We've touched on this when we've talked about things like biomarkers, PET to blood is an example. I think digital is exactly the same. Building it in a way that's democratized is going to be critical.

And then finally, I think that it's quite important to recognize that the pathway that leads to the differentiator, I think is one that has this interoperable framework. And it's something Rhoda and I were just chatting about. So that if we build interoperability just for AD, that's great, right? A lot of you are working in this phase of data sharing and we've talked about that. This is a big area of interest for me. But if it's separated from the rest of the health system, it is really going to be problematic. We have to recognise that the kinds of data that we would want to be able to inform something like dementia also could be interesting for things like cardiovascular disease, cancer, maybe even infectious diseases and vice versa. So having interoperability, but having it as a platform across the entire health system as primary care, is a critical path right now.



Ernst van Koesveld, Director General Longterm Care Government of Netherlands

I fully agree with that. I was thinking of the famous poem by T.S. Eliot about information. We need information, we need a lot of information. We need early detection and diagnosis, so we have even more information. That is extremely important. At the same time, we have to add knowledge to that information about causality, about context. And even knowledge is not enough. We need also a bit of wisdom, how to apply all that information and to apply all that knowledge. And I think that comes to daily practice, how to use the wisdom of everything we know as a healthcare professional, work together with informal care, with family, with the people themselves. So, the wisdom of that is that we should have a people-centered approach. What flows from a medical question may be a medical answer, but it also can be a social answer or a psychological answer. The solution may be outside healthcare systems, which also helps us to make sure that those that are really in need of healthcare can benefit from it.



Anja Leist, Associate Professor in Public Health and Ageing and Vice-Head of the Institute for Research on SocioEconomic Inequality at the University of Luxembourg

The first comment or question is: with which disciplines should we be speaking to now? So, shouldn't computer scientists be sitting here? Shouldn't engineers be in the room as well? The second point I want to make is, again, on cognition. We've spoken so much about the desire to have more measures



systematically implemented that are sensitive to change. So, is there a way, again, coming back to us in this group, to maybe write up a consensus paper to systematically provide guidance on what should future technology trials involve, for example?



Laurence Geller, Chancellor of the University of West London

Very, very, very simply, as I see it, and I urge everybody to not go back into their little boxes and say it's all about me, about my field of study. It is human, we need carers, we're dealing with the patient, we're dealing with the families, we're dealing with the well-being of the carers, so it's the human side of it. The technology is critical, we cannot reach everybody without major advances in technology and here I've learned something I chair one of the government committees on innovation technology for sport. I was looking at everything that was being sent to us and then we put the whole group together and we said what are the priorities and then we saw that should we sent a challenge out to everywhere we could come up with a technological solution to this problem rather than have a widget that may be nice. So that's the third one. And then it's a race against time because early prevention, early diagnosis, how many types of dementia, God only knows there must be. It's a race against time and we have to make sure we put enough emphasis on the care plans, modern care plans driven by AI and the human touch to make lives better while you're doing your work.



Alistair Burns, Professor of Old Age Psychiatry NHS England Dept Health Lead

Finally, I think one of the things was digital technology and certainly we've been talking and the importance of person-centred care and the importance of having an individual approach as we've heard is really key. As my colleague Martin Rossor has said, remember not all cognitive impairment is dementia. And also, not all dementia is Alzheimer's disease.



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. Okay. So, we get energised during the coffee break see you back in half an hour.

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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