

Summit 2022

Looking to the future:
The dementia landscape



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

Global perspectives on public policy challenges

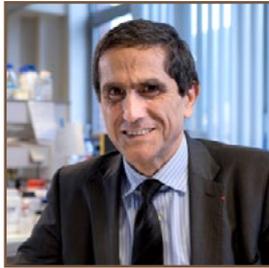
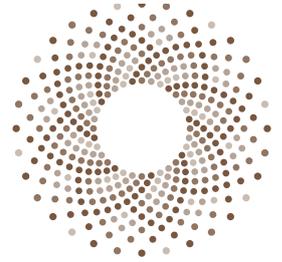
Transcript of a session from the
World Dementia Council summit
28 March 2022

Johnson & Johnson

**SCIENCE
FOR MINDS**

Lilly

Chair



Philippe Amouyel

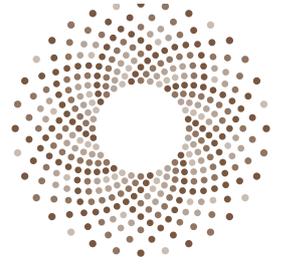
Philippe Amouyel, MD, PhD, chairs the EU Joint Programme on Neurodegenerative Diseases research (JPND), a 30-country led initiative, including Canada and Australia, aimed at tackling the challenge of neurodegenerative diseases, the largest global research collaboration in this field. JPND is a joint programming approach to research collaboration in Europe and beyond, bringing countries together to address challenges that are over the scope of any single nation. He is Professor of Epidemiology and Public Health at the University Hospital of Lille in France. He heads a large academic research unit working on public health and molecular epidemiology of aging diseases. His research is devoted to the study of determinants, mainly genetic, of Alzheimer's disease and to the prevention of cognitive decline. He participated in the discovery of more than 90% of the genetic susceptibility factors published in Alzheimer's disease. From 2002 to 2011, Philippe Amouyel headed Institut Pasteur de Lille. Since 2008, he has been the general director of Fondation Alzheimer, a private non-profit foundation dedicated to supporting innovative and cutting-edge research for Alzheimer's disease and related disorders that promotes the prevention of cognitive decline. Philippe Amouyel is member of the World Dementia Council for a global action against dementia.

Speakers



Sube Banerjee

Sube Banerjee is Executive Dean and Professor of Dementia in the Faculty of Health at the University of Plymouth. Trained at St Thomas' Hospital, The London School of Hygiene and Tropical Medicine, and the Institute of Psychiatry, King's College London, clinically he works as an old age psychiatrist in memory assessment services. He served as the Department of Health for England's senior professional advisor on dementia leading the development of its National Dementia Strategy. His research focusses on quality of life and quality of care in dementia and the evaluation of new treatments and services. He works with industry and governments on health services, policy and strategies to improve health for older adults with complex needs and those with dementia. He has been awarded national and international awards for policy and research in dementia.



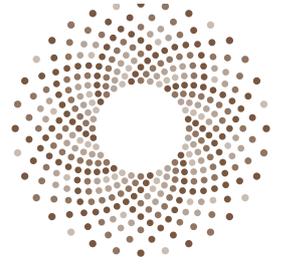
Joanne Pike

Joanne Pike, DrPH, is president of the Alzheimer's Association. In this role, she oversees the Association's global efforts to accelerate research; enhance care and support; advance public policy; strengthen diversity, equity and inclusion; increase concern and awareness; and grow revenue. Dr. Pike leads all field operations for the organization, including delivery of mission programs and fundraising for a nationwide network of chapters.

Dr. Pike most recently served as chief strategy officer of the Association, guiding the implementation of the strategic plan throughout all elements of the organization. Prior to that, she was the Association's chief programs officer and was responsible for overseeing care and support services offered to all those affected by the disease; outreach aimed at creating partnerships with health systems, physicians and other health care professionals; long-term care initiatives focused on person-centered care delivery models; and growth strategies to reach more individuals through quality improvement, education, and support programs and services.

During her 25 years in progressive leadership in social support and public health, Dr. Pike has developed and executed successful health-focused initiatives while implementing revenue strategies to support those outcomes. Throughout her career, she has successfully leveraged public and system policy to advance such public health outcomes with a particular emphasis on outreach to underrepresented and underserved communities.

Prior to joining the Association, Dr. Pike spent 13 years in leadership positions at the American Cancer Society and three years as executive director of the Preventive Health Partnership, a collaboration among the American Cancer Society, the American Diabetes Association and the American Heart Association aimed at preventing cancer, diabetes, heart disease and stroke. Dr. Pike holds a doctorate in public health leadership, focused on health policy and management, from the University of North Carolina at Chapel Hill.



Vijayalakshmi Ravindranath

Dr. Vijayalakshmi Ravindranath obtained her Ph.D from the University of Mysore in 1981. In 1986, after completing her post-doctoral training at the National Institutes of Health, USA, she joined the Department of Neurochemistry at National Institute of Mental Health and Neurosciences, (NIMHANS) Bangalore. In 1999, the Dept. of Biotechnology (DBT), Government of India sought her out to help establish the National Brain Research Centre (NBRC), an autonomous institution of DBT, Ministry of Science and Technology as a centre of excellence and to co-ordinate and network neuroscience research groups in the country. She continued as Founder Director, NBRC till May 2009, when she returned to Bangalore at the Indian Institute of Science (IISc) as Professor and Founder Chair of the newly created Centre for Neuroscience. She is currently Founder Director, Centre for Brain Research (CBR) at Indian Institute of Science.

The newly established Centre for Brain Research is a unique public-private partnership between IISc (a public funded institution) and Pratiksha Trust (a philanthropy) that funds CBR. Research at CBR is focused on aging brain and a large, prospective longitudinal study of 10,000 aging individuals has been initiated for the first time in India. In addition, she has received generous funding from Tata Trusts, which has paved the way for starting a longitudinal study in an urban cohort.

Dr. Vijayalakshmi Ravindranath is elected Fellow of all the 3 science academies in India, namely Indian National Science Academy, Indian Academy of Sciences, National Academy of Sciences, India. She is also a Fellow of the National Academy of Medical Sciences, India, Indian Academy of Neurosciences and Third World Academy of Sciences. She is a recipient of the prestigious S.S. Bhatnagar award (1996), Omprakash Bhasin Award (2001) and the J.C. Bose National Fellowship (2006), S.S. Bhatnagar Medal, INSA (2016) and the civilian honour, Padma Shri (2010). She is also a fellow of American Academy of Advancement of Science, USA (2019).



Gustavo Sevlever

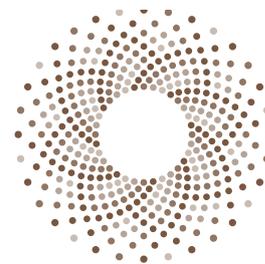
Dr Gustavo Sevlever M.D.; Ph.D. Fleni. Director, Teaching & Research- Fleni

Chairman, Neuropathology Depart. Director, Brain Bank.
Editor in Chief, Lancet Neurology, Spanish Edition.
Principal Investigator E-tumor (European Project).
Principal Investigator ADNI Argentina (Alzheimer Disease Neuroimaging Initiative), DIAN Argentina. Member of the advisor Committee in cell therapies and stem cells, Ministry of Science. National coordinator, Bi national program (Argentina-Brasil) for Cell therapies. Investigator DIAN, FINGERS, I LEAD.

Interests: dementia, brain bank, biomarkers, stem cell biology and disease disease modeling, brain tumors, prognostic markers, genomics and taxonomy, bioinformatics in brain diseases diagnosis.

136 scientific papers in peer review journals.

Discussion transcript



Professor Philippe Amouyel

Professor of Epidemiology and Public Health, University Hospital of Lille

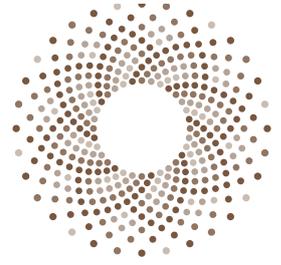
Good afternoon, ladies and gentlemen. I hope your lunch was fine. My name is Professor Philippe Amouyel, I am professor of Epidemiology and Public Health at the University Hospital of Lille heading a large academic research unit. I have also the honour to chair the largest collaboration in neurodegeneration disease research which is JPND – Joint Programming for Neurodegenerative Disease research. This is a research programme with thirty countries participating in the programme and address the scientific challenges that are beyond the scope of any single nation. I want to welcome you to this session the title of which is global perspectives on public policy challenges. We have four opening remarks from our outstanding panellists, five to seven minutes each, and then we will start the discussion.

Covid has been present at the forefront of the global public consciousness for the last two years, unfortunately in some countries the pandemic is still very present. What is important for us is that during this terrible period, patients with dementia have paid a very heavy price, at least in France. In addition, brain research has demonstrated the impact of Covid on the brain and vascular system. Several epidemiological studies demonstrate that between 5-10% of Covid infected individuals develop, months after their infection, cognitive symptoms. We do not know yet about the long-term impact of these cognitive symptoms yet of course.

Unfortunately, meanwhile the dementia pandemic didn't disappear. The projection of the number of people living with dementia in 2050 are still suggesting that more than 150 million cases will be diagnosed and that this remains valid. So, for the time being, we do not have the chance to have what we had in Covid, a vaccine, which makes it a problem of the organization of public health. We need to use the tools we have. We have some tentative treatments. As you know we have symptomatic treatments. We have one disease modifier that has only market approval in the US, the treatment tries to reduce the amyloid burden based on biotherapy. There is still discussion underway at the EMA.

And then we have prevention. Prevention is the area where we have had the quickest progress over the last few years. What is important for prevention is the presumption of causation from consistent epidemiological studies, long term prospective studies and from small scale intervention trials that try to demonstrate and convince more and more scientists, researchers and policy makers that prevention is a way to try and reduce the epidemic burden of dementia. This is fundamentally not so different from other chronic diseases like cardiovascular disease, diabetes or cancer where active disease modifiers do exist but the impact of these is so much greater when coupled with interventions mainly based on lifestyle changes. Like these chronic diseases, preventing Alzheimer's disease is primarily based on "procrastination" rather than primary prevention. Really the idea is to postpone the age of onset as far as possible, and until theoretically after death, something that would significantly reduce prevalence.

Last point, but not least, care. To date that is what we do best, and we will need to continue with care whatever treatment is discovered or when prevention delivers. Care is what allows countries to support the burden of dementia. Take an example, I am a physician, an epidemiologist by training as I mentioned, so when the government asks me about the prevalence of Alzheimer disease and dementia in France, usually I will take population cohorts and epidemiological studies and estimate this number as about 1.3 million. They ask me, so how do you explain in our public national medical insurances we only have 600,000 registered? And my answer is always the same you should recognise that many people sit outside the insurance scheme because of the families of the parents, husbands, wives who commit to keep them at home as long as possible, if they didn't the current health care system would not be sufficient to support this economic burden.



Dementia is then a global challenge. Each country, each continent will have different answers according to their culture, their economy. It is very difficult to compare ageing in high income and low-and-middle income countries – where actually more than half the people living with dementia today are. So, the question of dementia and the public policy challenge raises several questions. Among these for example, what local public challenges are facing different regions of the world? What interventions should policy makers consider to improve care and quality of life? To answer the question and exchange views we have the chance to benefit from the insight of four outstanding speakers from various countries all over the world:

- **Dr Joanne Pike** from the United States who is the President of the Alzheimer's Association. She has also been the Executive Director of the Preventative Health Partnership a collaboration between the American Cancer Society, the American Diabetes Society and the American Heart Association. Her educational background includes a doctorate in public health leadership.
- **Dr Gustavo Sevlever** from Argentina who is chairman of the neurological department of the hospital of FLENNI in Buenos Aries and editor in chief of the journal of Lancet Neurology Spanish edition. He is also a member of the advisory commitment to the Ministry of Science in Argentina.
- **Professor Viji Ravindranath** from India. She is the director of the Centre for Brain Research at Indian Institute of Science, Bangalore. She was the Founder Director of National Brain Research Centre, an autonomous centre funded by Government of India. This is a centre of excellence she built up over the last twenty years. She co-ordinates and tries to network neuroscience researchers in her county.
- **Professor Sube Banerjee** who is Professor of Dementia at the University of Plymouth he works as an old age psychiatrist in a memory service and he served as an adviser to the UK Department of Health on the development of a national dementia strategy for England.

So now Dr Pike, the floor is yours for five minutes!



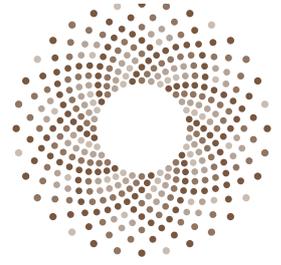
Dr Joanne Pike
President, Alzheimer's Association

Good afternoon. If there is anything we have learned so far, I am going to keep it tight, so you don't miss any of the other sessions or any of our other speakers! When I was thinking about public policy challenges I really doubled down on the challenges. Because I think some of the things we confront in the United States and in the West are very similar from a challenge perspective, if you take it at a very high level, to what you can see globally.

I wanted to focus in on things that I knew had application beyond just our region. But with the caveat that we need to consider from a public policy perspective what we can do in the United States with the knowledge that we have today and learn from each other as we begin to think about these things. The four things I am going to consider within that framework we have heard pieces of throughout the morning sessions. Philippe just now referenced a few of them.

I want to start with something the Dutch Health Minister Conny Helder talked about in the morning session, and that is stigma. Stigma is really the thing that stops individuals, and our communities, from being able to access or provide services. While we don't typically think of it as a public policy challenge, I would challenge you to begin to consider it within that framework. When we think about the bigger challenge behind it, diagnosis and how we deliver care, which were on the list of public policy challenges Phillipe just mentioned, you can't get there unless people walk through the door to receive the intervention.

From a diagnosis perspective, one of the biggest impediments we have is the lack of initiation. We have begun to look at that treatment landscape, as we are at a cusp in the Alzheimer's disease space right now of being able to offer treatment in the United States. We began by thinking about how we get people into diagnosis, and we focussed in on the health system



and the challenges within the health system that we see. The fact is we see significant drop off even before they hit the health system. While we can create interventions that drive diagnosis within the health system, we have to create an environment that values diagnosis before they even walk through the door.

The other key element to that is medical stigma, the physician on the other end. Let's say we create an environment for a patient to walk through the door. We have to create an environment for the medical provider to value giving a diagnosis as well. Then there are multiple factors beyond that, which begin to play into the American system of health care that are very complicated. We have a lack of specialists. We have a lack of advanced practitioners beyond just the medical doctors. We have significant cracks between diagnosis and the ability to deliver care.

That is on the diagnosis side. But stigma also plays a role in accessing quality care once you are diagnosed. The important piece to this is not just thinking about the patient who needs that care delivered but the caregiver that is with them. From the standpoint of being able to seek medical services and medical supports or community supports, someone has to be willing to walk through those doors and say, "I need assistance." They have to be able to trust that the system is going to be able to provide care. They have to be able to trust that they are not going to be marginalised – that their experience is normal. We have to think about how we build awareness of the system, of the value of diagnosis, and of the value of providing support beyond just within that system but also how we drive it from a policy perspective. How do we drive the investment in the awareness of the disease and the supports that can be provided from that,

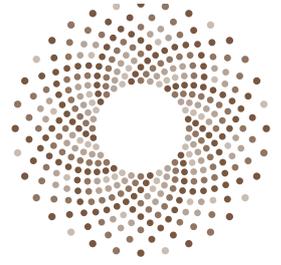
The other key bit I want to talk about is what does treatment and care look like when you are in the health system. One of the key things we have been looking at is what is the evidence for quality care once you do get into a health system and how do you integrate not just the medical side of that care but also the care supports. The care supports not just for the patient but also the caregiver. The Alzheimer's Association took a leadership role to look at the evidence behind what that system needs to look like. From that, there is legislation that we are working to pass right now called the Comprehensive Care for Alzheimer's Act. This looks at the whole framework of primary care, specialist care and caregiver support. It is based on models that were funded by the Center for Medicare and Medicaid Innovation at UCLA, UCSF and Indiana University. Taking those models that worked in a research framework, applying payment reforms – because remember payment is always an issue in the U.S. health care system – to deliver quality care.

The third thing I would really think about, especially in this time where we have treatment in front of us, is the real-world data we have. And how do we create a public policy intervention to support the application of real-world data and the gathering of that data. Within our health systems we have a landscape of electronic health data, but it is not consistently gathered and it is not gathered quickly enough to make decisions daily, weekly, monthly. Sometimes we might get annual data. But we have to begin to think about how we incentivize the use of real-world data, and real-world live experience, faster. How we can use our own legislative levers to drive that through, whether that is Medicare, quality indicators, or another source.

And then finally the last thing I would touch on is our own investment in brain health and risk reduction. The United States has a robust public health infrastructure from the NIH and CDC at the national level to our state, county, community, and city public health infrastructure. Many other countries are built the same way. How can we use that existing public health infrastructure to drive public knowledge on the information we already have on the cardiovascular risk factors that could have an impact on brain health? Or, similarly, on physical activity? How do we use those investments, how do we make investments, to push ourselves forward?

Those are, to conclude, what I believe are the types of interventions we could provide for individuals to get them in the door, to get them the supports they need once in the door, and to provide quality of life on brain health as well.

Thank you.



Dr Gustavo Sevlever
Chairman, Neuropathology Department, FLENI

Latin American initiative for lifestyle Intervention to Prevent Cognitive Decline and reduce risk study

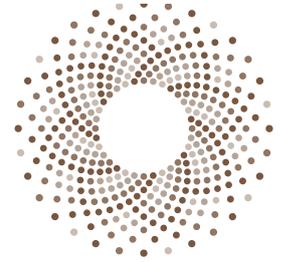


Thank you very much and thank you to the organizers for the invitation. I will share with you some of the health service problems and some of the solutions in Argentina and Latin America.

One of the first things I want to stress is across Latin America the public health system is extremely heterogenous at the national level, the regional level, even the union level – the unions fund some of the health system. This is a very heterogenous ecosystem and there is as a result a lack of coherent public policy. We have in some places a government led so called Alzheimer’s plan for care and prevention. But it is even worse than nothing because in many cases it is an empty statement. These plans mean we believe we have some kind of programme, but in reality it doesn’t exist.

One of the main problems in addressing this, is that across the region there are different health priorities, transmissible infectious diseases, Covid pandemic and so on, which means dementia is not a priority. This is true in Argentina and across Latin America. But one distinct thing across Latin America is cities are ageing. In Buenos Aeries the proportion of the population over 65 is 25-26%, it is more similar to a western country than a Latin American one. This means dementia is going to be a national health problem and a regional problem in particular. But the top-down approach is, to date, almost non-existent.

So, what I want to share with you today is the bottom-up programme. We have been doing this Latin American initiative for lifestyle interventions to Prevent Cognitive Decline and reduce risk study (LatAm Fingers). The application of the Finger system by Dr Kivipleto and the Finish Group to Latin America.



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Latin America takes centre stage in dementia prevention

The Lancet Neurology




1. Argentina
2. Bolivia
3. Brazil
4. Chile
5. Colombia
6. Costa Rica
7. Dominican Republic
8. Ecuador
9. Mexico
10. Peru
11. Puerto Rico
12. Uruguay

• 1200 participants with risk factors for dementia from 12 different countries



This has been an extremely important experience for all of us. We had as you can see on the slide a piece in Lancet Neurology about the start up meeting. And as you can also see on the slide we have twelve countries across Latin America that are involved, gathering patients for a prevention programme. As far as we know this is the first time not just in dementia or neurology but in medicine where we can gather twelve countries in Latin America doing the same protocol with harmonization system, at the same time. All of this is funded by the Alzheimer’s Association which has made this programme possible. The programme is coordinated out of Argentina, and some of the participants are here, which includes digital communication, education material for physicians and patients and so on.

LatAm Fingers Results



Randomized subjects

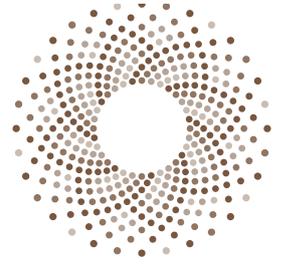
Country	Count
Argentina	10
Bolivia	50
Chile	35
Colombia	5
Costa Rica	40
Ecuador	30
Mexico	35
Peru	30
Uruguay	85

Screened subjects

Country	Count
Argentina	30
Bolivia	40
Chile	85
Colombia	100
Costa Rica	40
Ecuador	40
Mexico	45
Peru	45
Uruguay	100
NA	5

- A total of 645 participants concluded screening
- A total of 255 participants were randomized and started the intervention

On this slide you can see the numbers we have at this moment. A total of 645 participants concluded their screening and 255 participants were randomised and started their intervention in their different country. As you can see on the slide, we have some slight differences in terms of numbers between countries and this is understandable, you have different systems, different approaches and even different medical approaches.



But this approach, the bottom-up approach in these twelve countries in Latin America is extremely important for initiating something. We have to do translation medicine, not in the common sense of the word, the translation from basic medicine to bedside. Rather, the translation of the small-scale clinical trial to the national health system. We have begun to have some conversations at the city level in Buenos Aires and this is doable on a big scale.

This is what I want to share with you today because I think it is a great experience for all of us in Latin America. The sharing of a common experience, the sharing of a protocol the sharing of a harmonization system. It is the first time we have been working together as a region on a defined public health challenge. Thank you.



Professor Viji Ravindranath
Director, Centre for Brain Research, Indian Institute of Science

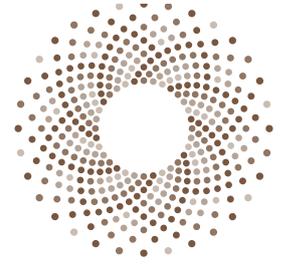
Thank you very much I want to thank Lenny for inviting me. My first trip outside India in two years. It is great to be here and to see you all. As I was listening to Joanne talking, I realise I represent the far end of the other spectrum coming as I do from India, but what I am going to share with you today probably applies to other LMIC countries.

So, we know that the majority of new cases of dementia will emerge from LMICs and predominately will be from India and China. India is a young country demographically but then we are a populous country, therefore the number of people over 60 will be large number and growing in India.

To date, the public health agenda in LMICs, including India, has focussed on two major categories, infectious diseases and maternal and child health, including vaccinations and so on. I think it is only in the last decade or so that the burden of non-communicable diseases was realised through the generation of evidence, this in turn was presented to the government, so that certain policies could be designed to reduce the burden of NCDs. And it is a major challenge. India is called the diabetes capital of the world. The rapid change in the lifestyle has resulted in the enormous increase in vascular risk factors.



The last two years have been a disaster for the world, and particularly for a country like India, because in addition to dealing with the pandemic, it has set the agenda for NCDs far back. I was remarking to someone today that we have may been set back by almost ten years because we are now preparing for another wave of covid, and another round and another.



So, given the scenario how does one address the challenges of policy? We know there is going to be tremendous burden. You were talking, Joanne about not having adequate care facilities. We have literally none. I think 99.99% of dementia patients are cared for at home. So, in these circumstances how do we bring about a policy change and make governments address this public health problem? The dementia crisis is going to be a major one and we don't really have reliable prevalence rates. Policy is developed based on knowledge generated as evidence, and we need to present that evidence to our governments. But then generating evidence requires resource in terms of money, infrastructure, and most importantly research personnel that are capable of carrying out the necessary research.

Unfortunately, it has been really hard to find funds for such research, importantly longitudinal studies in aging cohorts to identify risk factors for dementia in the particular geographical context. I waited 20 years for funding. And it was only when philanthropists came forward that we were able to start a longitudinal cohort in rural and urban India. There is large diversity in India and importantly two-thirds of India's population live in villages, with low socio-economic status and low levels of literacy. Then you have the middle-class Indians who are well educated, living in cities and here the challenge is the rapid rise of cardiovascular risk factors. Therefore, not only does the evidence have to be generated but it has to be generated understanding the diversity of our country. And this applies to most other countries too. So interestingly, private philanthropy has come forward to fund. And I think this is increasing. Hopefully this will help us generate rigorous evidence we could present to government. And that is the hope I have.

But as we go forward, what else could we do? I think it is so important for countries like India to learn from the experiences of the western world. We cannot translate them directly into our country. We cannot even extrapolate it. Evidence will have to be generated by us in our country. But we could always learn, and that interaction is very important. And, actually, it has helped me so much to broaden my outlook, working with the Alzheimer's Association (USA), Maria and Heather have been holding my hand for several years now.

The second thing is the need for LMIC countries to work with each other. It is not possible for every country among the LMIC group to generate data and have the resources to do it. So, it will be very important for us to share our experience and most importantly to share data. Sharing data is absolutely necessary, and it will help us to drive policy. To show what are the differences and to show what are the similarities and how we can impress on our governments to shape the policy.

So that is what I wanted to share with you today. Thank you very much.

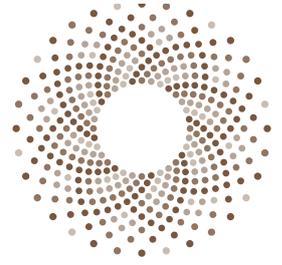


Professor Sube Banerjee
Professor of Dementia, University of Plymouth

Thank you very much. Thank you to the organizers for having me. It is lovely to be among people. I now remember what they look like! Obviously, there are all those jokes about not having your names in front of you and not being in little boxes, but it is just delightful to be meeting together and to be doing so to talk about dementia. When I was asked to speak I thought, well I have five to seven minutes, I won't use any slides, so here you go. I think there are just two really important things we need to think about in terms of health policy.

The first thing is to consider where we have come in terms of public policy on dementia. I think if we look at the last twelve, fifteen years, we have come a great long way. There have been substantial and important changes in terms of people's attitudes to and understanding of dementia. And some growth in improved services for people with dementia. And while that is true in high income countries, it is also true in terms of development of understanding in low-and-middle income countries.

But what has become clear in last two years, the two years of Covid, is that those improvements and changes, the policy priority for dementia, which is what we have worked so hard for in the last 10 years to achieve, is fragile. We had worked toward an understanding that dementia is a priority, that it is one of the great challenges of the 21st century. But that



is very fragile. If you look at the experiences of people with dementia over the pandemic, uniformly, whatever country you go to, people with dementia have borne a disproportionate amount of the harm. And people caring for people with dementia have also borne a disproportionate amount of the harm of Covid.

In the UK, we have done over the decade preceding covid, some fantastic stuff in increasing diagnosis rates, in decreasing the use of anti-psychotics for behavioural disorders. But if you look now, recently the dementia diagnosis rate has plummeted because those services were not prioritized. And the number of people with dementia has decreased markedly because of the selective mortality of people with dementia during this pandemic. People with dementia have died much more commonly than those without dementia and that is in care homes and in their own homes. If you look at the proportion of people prescribed anti-psychotics, we got it down to two-thirds of the level it was in 2009. But it has gone back up again. Because people are deploying simple harmful solutions for distress in people with dementia.

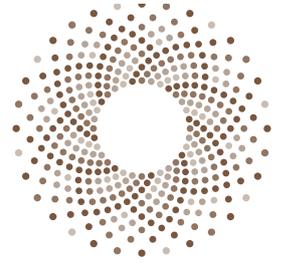


So, there is a fragility to the gains that we have made, and we need to be wary of that. The NHS in the UK, where I have worked all my professional life, is now in many ways reduced to a cancer and covid system rather than a national comprehensive health system. We will spend the next five years playing catch up with the surgical treatments that have not been done over the pandemic. Dementia is not on the radar in any way as a priority and it was before. It has not been deeply imbedded in the public policy culture in the UK and that is how this has been enabled to happen.

This is not a council of despair. We have gone back ten years in two years, as was said by a previous speaker. We have lost ten years. but we can recapture that. But we can't rely on the system to adjust itself to do that automatically. We can't rely on the case we made five, ten years ago, to have salience now. We can't rely on being heard. We can't rely on being listened to. And most importantly, we can't rely on those past promises for action. We need to act, advocate, and militate again to put people with dementia back on the agenda.

Second, if we are looking at the positive, there has been an improvement in the amount of research and science there is out there across the piste. I think this is brilliant. I absolutely, fundamentally believe in the importance of basic biological research and in the importance of research into biological treatments that will, slow, reverse and prevent dementia.

But I think, and we were making this mistake even before the pandemic, that the public policy agenda has turned the complexity of dementia into a single problem. It is lunacy to think there is one simple silver bullet to make it all go away. Yet the direction of international policy and much of national policy has come focussed in on this idea that if we invest enough



in enough bright young biomedical scientists and invest in enough biomedical science, and build enough beautiful buildings, then we will solve dementia in the same way we solved cancer. And there is a truth in that but there is also an absolute fallacy here.

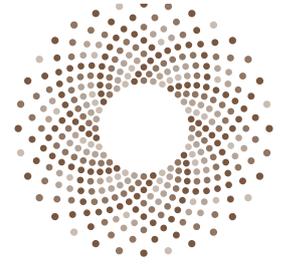
Because the issue with dementia is how to live well with dementia. Yes, we want it not to be there, yes, we want to be able to prevent dementia and to have a cure. But we also need to allow people who have dementia now to live good lives. For their dementia to be appropriately supported. For their carers to be appropriately supported. The category fallacy we have here is that there is no treatment available for people with dementia. Because those that make the case strongly for the biological treatment, do so by either ignoring or decrying the social, psychological, or familial interventions that enable people to live well with dementia.



There are already a gigantic number of randomised control trials and other studies that show if you communicate well with people with dementia they do better. That show if you provide care and support that is tailored to those individual needs that they do better. And studies show people who do better use less services not more services. And yet none of the policies that are out there deliver what we can already do for people with dementia. So, I think there is a diversion that comes from this idea that there is a magic bullet. It takes our eyes off the ball, the real ball, that is there are vast numbers of people living with dementia and families caring for them all over the world and they are generally not receiving much in the way of treatment and care. And if they were receiving more in terms of treatment and care they would do better, we would do better, societies would do better.

There is already so much we can do, and we are not doing it. So, we need to improve social care. We need to be clear and professionalise what good quality post diagnostic care is. Just as we need to be clear and professionalise what a decent diagnostic procedure looks like that gives people the information, they need early in their illness to enable them to live well with their illness. But there are these dichotomies that come up. So, you say we need better diagnosis, and someone says well we will wait for the magical biomarker. We are spending £50 million on biomarkers or whatever it is and, so the argument goes, that is bound to sort it out. But that is nonsense. It is not bound to sort it out. Those countries that can afford the biomarkers will be a tiny proportion of the countries that need them. And we already have ways of diagnosing people with dementia. It takes a bit of time. It takes a bit of energy and effort. But that is exactly how we diagnose cancer. We throw time, energy, effort and professionalism at it. And that is what we should do for dementia rather than waiting for a magical cure or biomarker to solve our problem.

People talk about the need for better treatments. But if we wait for magic silver bullet that will simply make it go away, we will be waiting a very long time for that infusion or that tablet. I passionately want us to do that work. We will find tens, hundreds of different



interventions for the tens or hundreds of different dementias that are out there. And I look forward to seeing that happen. But we must be able to provide care as well. There is a snobbery that exists in terms of the hierarchy of the value of provision and research that basically counts out social care. That says that is someone else's business. Health care is good, and we will spend money on health care and R&D. But social care? Not so much.

To bring it all together, the problem we have is one we have all referenced in this session, that dementia is a complex and big problem dementia and is broader and more difficult to treat and manage than cancer has been. That we are talking about people living for long periods of time with a long-term illness rather than trying to prevent mortality. We are talking about quality of life. We are talking about the brain as the most complex organ and older, frailer individuals that have multiple morbidities.

What do we do to improve things? We take a step back; we say we are not willing to accept that simple formulation of dementia that is essentially jam tomorrow. That we will provide you with a bit of money for cure and biomarker research now and it will all be sorted out in ten years. Well, we want bread today in terms of improving the quality of care. There is so much we could be doing which we are not doing, in high income and in low-and-middle income countries to improve the lives of people with dementia today. We have the evidence we need, now we need the policy priority and action to deliver that. Thank you.



Question from audience

Thank you for four very interesting discussions and commentaries. I am a neurologist and a neuroscientist by background and my main job is research. But I am also co-founder of an organization to help support internally displaced people. There are more than 50 million people internally displaced globally. And why I am raising this is that these people are completely unrecognised. They are displaced internally. They don't migrate. They can be experiencing multi-generation displacement. We know very little about their needs and health care priorities. Specifically, around non-communicable diseases, vascular risk factors, cognitive risk factors and dementia. There is some evidence around acute response, post-traumatic stress disorders and so on. But these people are internally displaced, often because of conflict and as a result can be unsupported by their governments. How can we understand as a global community their needs to develop basic method of support? I don't know whether that can be answered but just wanted to raise the concept and the need of what are too often invisible people on this planet.



Professor Philippe Amouyel

Professor of Epidemiology and Public Health, University Hospital of Lille

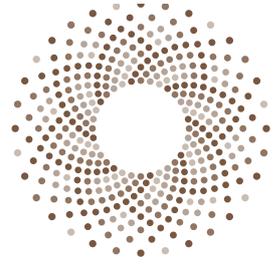
Thank you very much. It is very difficult to address. As you know the development of the response in terms of cardiovascular and cancer is totally different to the cognitive side. But you are right we will have to address that in the next years because of the growing displacement of people, internally and externally, all over the world. Any other questions please?



Professor Dame Louise Robinson

Professor of Primary Ageing, University of Newcastle

I will just shout! I would like to know how it is we are where we are. There is this glimmer of light on the horizon in terms of disease modifying treatment but today there is so much we can do, as Sube said, but we are not doing it. It is like we are our own worst enemy in dementia with this division between focussing on the now and focussing on the future.



Professor Sube Banerjee
Professor of Dementia, University of Plymouth

So, I absolutely agree and what we need to be doing is speaking with one voice. For everyone to be saying we need jam tomorrow, but we need bread today. We can make the bread. We know how to enable people to live well at the moment. We know what a good service would look like. It is just that almost everywhere you go there is gigantic variation from area to area. It is just luck what people get and that is what we need to eradicate.

The contrast with cancer is really interesting. There is expectation that wherever you go in the world you will get the same diagnostic process, the same treatment, the same care. With some variation. None of that is true for dementia. And that is partly because it is a bit more complicated. But if we were to demand that there is a kind of parity of esteem for people with dementia compared to cancer. And if we were able to expect from our governments investment to deliver dementia care as well as cancer care. Where that would take us is we would have a system that is far more equitable but we would also have a system where there is substantial improvements in health throughout.

I would just make one more point, which is most cancer researchers that work in basic biology would be gigantically supportive of the work of palliative care. And we need to speak with one language with basic science supporting care and delivery research and delivery science supporting basic science.



Dr Gustavo Sevlever
Chairman, Neuropathology Department, FLENI

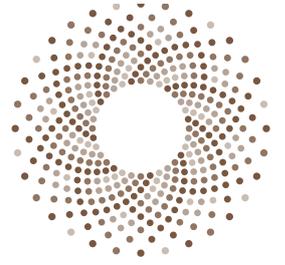
I spoke about the heterogeneity of the health system in Latin America. I want to state an enormous amount of information came from the consortiums. For us, Argentina, Latin America to be members of the ADNI consortium, the very first consortium in terms of diagnosis, has been important for us in terms of standardization of diagnosis. So even in low-and-middle income countries this has been a step forward in terms of harmonization of diagnosis in the whole region. I want to stress that because being part of international consortium and this translation and this sharing information is a big step forward for all of us



Dr Joanne Pike
President, Alzheimer's Association

The one thing I would add is where I started out in my presentation, which is that glimmer of hope on the horizon. What we see in the potential of treatments in the pipeline makes no difference if we can't change our environment and our cultural approaches towards those with dementia, if we can't create a value in diagnosis and knowledge, and if we can't get someone the care they need.

The other piece is that we know that is not a cure. The glimmer, what is on the horizon, is not a cure. It is a disease modifier. But we also know the power of that treatment in changing stigma. The value of that goes beyond the medical support to changing stigma and changing the community to be a more supporting environment. So, I agree today we are nowhere near where we need to be. But tomorrow is not far off. We have got to get to changing stigma and value in diagnosis and care delivery.



Question from audience

In a world where societies are socially and economically recovering from Covid how can we make dementia a public policy priority again? Particularly in those countries where it wasn't a priority in the first place. And that is before we start to account for other priorities globally like climate change and other troubling events in Ukraine for example.



Professor Viji Ravindranath

Director, Centre for Brain Research, Indian Institute of Science

I think that is one of the biggest challenges particularly in the economically less developed countries. It is a small way, but Covid is going to have a long-term impact and I think we should have a strong agenda to look at the impact of Covid on brain function and cognition. And from there we move into dementia. Provide the evidence around those things that we know about Covid, we have vascular issues, brain fog and a lot of people reporting cognitive impact. Lot of people in the community keep asking us so what is going to be the impact of having a Covid agenda. I think we should drive that agenda and try and understand it and bring the focus back on dementia. I see that as one road we can take. And hopefully there is not a new variant that derails that.

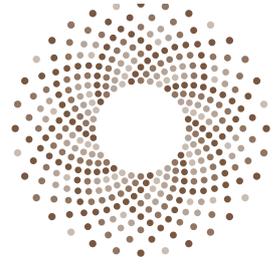


Dr Gustavo Sevlever

Chairman, Neuropathology Department, FLENI

I think we have a paradox here. In 2020 Covid was not the main issue, it was the only issue. All the policies, governments, health systems were focused on Covid. But later when we realised the impact of Covid, of isolation, quarantine, lockdown and everything, on older people and the cognitive impact we have a new problem. This is our experience, the Covid pandemic and the impact of it on older people means people are now thinking about the impact of Covid and the lockdown on cognition. So our group has recently published a meta-analysis about this impact.





Professor Sube Banerjee
Professor of Dementia, University of Plymouth

There was a very clear and strong economic case for improving dementia care before Covid. If you look at the major drivers of costs in developed countries: hospital costs loom very large as does long term care. If you look at long term care 90% of those have dementia. Preventing those admissions and enabling people to live well in care settings is generally cost effective. In hospital settings somewhere between 25-55% of people have dementia. The people who the system can deal with easily at any time, with or without Covid pandemic, are those people who have single illnesses. People with dementia have more multi-morbidities than anyone else and it is the dementia that stops them moving on. If we develop better systems to care for people with dementia and support them in the community, we will prevent admissions and there is an economic benefit that comes from that and facilitates discharge then there is economic benefit that comes from that. Yes, we need to recover from Covid, yes, we have to deal with patient backlog for elective surgery and so on, but we also need to redesign our services so that they deal with complexity better.



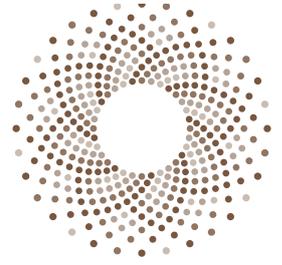
Nora Super
Executive Director, Milken Institute

I did want to challenge one of the things that Sube said about the standard of care for cancer. I think one lesson we sadly came to realize in Covid was the colour of your skin can change the way you are treated in health systems across the globe. In the US, we are working to model a standard of dementia care in the state of California where they have put significant resources into Alzheimer's disease and have a tremendously diverse population. Could the panel talk about the equity issue because I do think there needs to be a focus on the people who are most at risk of dementia (such as Latinos and Blacks)? How do we get policy makers attention on that?



Professor Sube Banerjee
Professor of Dementia, University of Plymouth

I couldn't agree more with the observation that there are profound inequalities and inequities that are driven by things like race and ethnicity within systems as well as between systems. Generally, people from minority ethnic groups receive poorer health care than majority ethnic populations. I am sure that is true across countries. It is a focus of public health across the world. If you look at those inequalities and inequities in dementia, they are absolutely there, but worse. If you look at the cancer analogy that I was making. The diagnosis rates are fairly high across the place, still worse for black and other minority ethnic groups, but fairly high. The difference is 10-15%. But when it comes to dementia you have a diagnostic rate 50-100% difference. There is an agenda for inequality and inequity across the world of dementia just as there is the world of health. I do think as we look to improve health, we need to do so by crafting solutions and messages that work with those minority populations and as we craft health messaging, we need to make sure we include dementia messaging. Dementia needs to be included in those things.



Professor Viji Ravindranath
Director, Centre for Brain Research, Indian Institute of Science

I just want to add inequity is not just based on colour. You see it among those who can afford care and those who cannot. I see it in the villages in India. It is very important to think about that aspect as well. How do you ensure a minimum level of care for everyone in a country equitably?



Dr Joanne Pike
President, Alzheimer's Association

I would add similarly inequities that we see in the United States, especially as we think about diagnostic, treatment, access and long-term care services there is a big gap. There is a big gap in not just racial socio-economic status but also geographic. Rural / urban issues magnify someone's ability to access a specialist or primary care that has knowledge about dementia at all much less things that go beyond basic primary prevention. So, we have multiple areas of inequity from a public policy priority that only get exacerbated as we extend our pipeline without addressing them. We learned in cancer that treatment divides access. Health access is completely divided in the United States due to payment system. And we are about to enter an era of healthcare treatment inequity now in the dementia field if we do not act now. And we should probably have acted 5-10 years ago to have made sure we are not in this space right now.



Professor Philippe Amouyel
Professor of Epidemiology and Public Health, University Hospital of Lille

Thank you very much we will now have a coffee break and resume in plenary.



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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