Global dialogue on dementia and an ageing society: Transcript

The dementia landscape project

30 June 2021
Co-chairs

Professor Shekhar Saxena

Dr Shekhar Saxena is Professor of the Practice of Global Mental Health at Harvard T H Chan School of Public Health. He is a psychiatrist by training and has worked previously at World Health Organization for 20 years including as the Director of the Department of Mental Health and Substance Abuse, Geneva from 2010 to 2018. His expertise includes providing advice and technical assistance to policy makers on prevention and management of mental, developmental, neurological and substance use disorders and suicide prevention. He led the WHO team for adoption of the first ever Mental Health Action Plan by the World Health Assembly in 2013. He also led the adoption of WHO Action Plan on Public Health Response to Dementia and its implementation.

Sarah Lock

Sarah Lenz Lock is Senior Vice President for Policy in AARP’s Policy, Research and International Affairs (PRI) where she helps position AARP as a thought leader addressing the major issues facing older Americans. She leads AARP’s policy initiatives on brain health and care for people living with dementia, including serving as the Executive Director of the Global Council on Brain Health, an independent collaborative of scientists, doctors and policy experts convened by AARP to provide trusted information on brain health. She coordinates AARP’s role in the Leadership Council of Aging Organizations, and helps to ensure policy alignment within AARP.
Speakers

Professor Alexandre Kalache

Following his medical training in Brazil and then his MSc and PhD in the United Kingdom, dr. Kalache held research and teaching positions at both the Universities of Oxford and London for almost twenty years. From 1995-2008 he directed the World Health Organisation’s global Ageing and Life Course Programme from the Geneva headquarters. During his thirteen years at WHO he launched the Active Ageing Policy Framework and the global movement on Age-Friendly Cities among many other enduring initiatives. In 2012 Alexandre Kalache took up the Presidency of the newly-created International Longevity Centre-Brazil in his home city of Rio de Janeiro. ILC-Brazil is an autonomous think tank which is part of an international consortium of fourteen such centres. Concurrently, Dr Kalache serves as Global Ambassador of HelpAge International, Senior Advisor at the New York Academy of Medicine and sits on a multitude of boards ranging from the World Economic Forum to the Gulbenkian Foundation. He acts as worldwide adviser on ageing issues to national, state and municipal governments, civil society organisations and the private sector.
The dementia landscape project

Dr Adelina Comas-Herrera

Adelina Comas-Herrera is co-lead of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project. Funded by the Research Councils UK Global Challenges Research Fund, STRiDE is a multi-national project covering Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa. The project aims to build capacity to generate research that supports the development of policy responses to dementia, with related projects also under way in Hong Kong and New Zealand. She is the curator of LTcovid.org, an initiative linked to International Long-Term Care Policy Network that shares evidence and resources to mitigate the impact of COVID-19 amongst those who use and provide long-term care. Her main research interests are economic aspects of care, treatment and support of people with dementia, and long-term care financing, both in the UK and globally. She has extensive experience in developing simulation models of the future resources required to address long-term care needs and needs arising from dementia.

Lenny Shallcross

Lenny Shallcross is executive director at the World Dementia Council. Prior to that he was Head of Community Engagement leading programmes across the UK to establish Dementia Friendly Communities. This includes the Dementia Friends programme which is the biggest health social movement campaign delivered by 10,000 volunteers that have recruited 2 million individuals through a community, digital and corporate offer. Before working for Alzheimer’s Society he worked in the UK government as a political adviser at the Department for Culture, Media and Sport and the Department of Health, as well as working in Parliament and for the Labour Party.
Welcome everyone. I am Lenny Shallcross, Executive Director of the World Dementia Council. I realise many of you have participated in one of these global dialogues before or another Council meeting but for those of you who have not the World Dementia Council was established following the London dementia summit in 2013 hosted by the UK government as part of their G8 presidency.

The Council is chaired by Harry Johns, President and CEO of Alzheimer’s Association (US). There are 24 individuals who are members of the Council. Alongside them there are a number of government members.

As you know from the invitation and briefing note we sent, the Council will later this year publish a report looking at the progress the international community has made on the commitments that were made at the London summit. To help inform the report, we want to hear from experts around the world on different aspects of dementia policy. We will launch this report at an in person meeting here in London later in the year – if Covid allows!

This is the eighth dialogue we have held, previous conversations have been on biomarkers, clinical trials, technology, dementia in LMICs among others. 350 global leaders have participated in the dialogues. We have one more conversation next week on health system readiness.
The purpose of today’s dialogue is to explore the relationship between ageing and dementia policy. While a small proportion of people living with dementia are under 65, well over 9 in 10 people with dementia are over 65. Of that population cohort 70% are over 75. Dementia is not a natural part of ageing for many, dementia and ageing walk hand-in-hand.

It isn’t just that many people with dementia, around three quarters, have co-morbidities. Beyond healthcare someone with dementia has financial, social, care, support needs as a senior. The same argument can be made for brain health and primary and secondary prevention strategies; dementia may be the most feared disease of the over 50s, and a good lifestyle motivator, but from a public policy point of view healthy ageing is not disease specific.

That said, there are undoubtedly specific challenges faced by people with dementia that are related to the disease. Stigma and awareness being one obvious example that ADI highlighted as a global challenge in their report last year. But beyond that to what extent is the argument “you get it right for dementia you get it right for everyone” useful for public policy planning?

We look forward to hearing your perspectives on this and the relationship between ageing policy and advocacy and dementia. After this meeting we will produce a transcript of the meeting – which is why the meeting is recorded. For people who contribute live in this discussion we will check the transcript with you. We will also produce a collection of essays reflecting the flow of the discussion today and the issues raised.

I would encourage you to share your thinking either live in the meeting or in the chat conversation. As you will know from the agenda we will kick off with short opening perspectives and then there is a open discussion. To contribute to the conversation just raise your hand in zoom. I am sure you all know this by now but to do that click on the reactions button and select raise your hand.

And with that bit of housekeeping done I would like to introduce and thank the co-chairs of today’s workshop. Professor Shekhar Saxena, Professor of the Practice of Global Mental Health at Harvard (and formerly of WHO), and Sarah Lock, Senior Vice President for Policy at AARP. And I will now hand over to Sarah to start the meeting proper.
right before the meeting to go get some new clothes and a new necklace from Marks and Spencer! I’m wearing that necklace now in memory of the occasion! So it’s just really wonderful for us as friends and colleagues to gather here together virtually.

I wanted to state what we all know, something that we all have to rejoice about. And that is we are all ageing. And that is, frankly, one of humankind’s greatest achievements. And despite the terrible news of Covid globally, the age group of 65 plus is the fastest growing age group in the world.

In some places, in the United States, it’s the 85 plus, followed by the 100 plus that is the second and third fastest growing demographic. So that is a fabulous place to start this discussion. As many of you know, I of course am coming at this question that Lenny posed for us from an ageing perspective. I’m a relative newbie when it comes to dementia. And so in 2013, when the G8 summit was held with this idea of bringing people globally together to talk about dementia, it was really interesting to me because, of course, I thought of dementia as a subset of broader ageing issues.

Dementia is really not only about people aged 65 plus and the disease, it is about how our families, our communities, how our governments engage with an older group of people, and the trajectory that every society is facing now due to this wonderful ageing population. If you think about my organization, AARP, our mission is to empower people to choose how they will live as they age. And dementia, of course, fits into that because it is one of the major ways that causes you to lose that option.

You don’t have the choice. If you are not cognitively intact, you don’t have those options to choose how you will live as you age. So it’s an incredible, incredibly important part of ageing, but it is only one part. And I would just say organizationally, I’ve had a challenge within my own group of ageing advocates to put dementia up on the agenda of priorities, frankly, because our bigger priorities are rising health and prescription drug costs, and protecting Social Security and Medicare. Those are the traditional areas that we’ve operated in. And looking at one disease well, we all know it’s not really one disease, it’s multiple diseases, right? But in the pantheon of health issues, this is only one. Seeing how we live in silos even within our own organization, we are treating dementia off one side of a broader agenda, and I’ve seen that reflected in many organizations that focus on ageing. For example, the WHO treats it separately as well. We are all trying to organize ourselves in certain ways, but it really is a very distinct and often isolated strand of a much bigger concept within ageing. And I think we (as dementia advocates) would be far better off, to recognize dementia as part of the broader policy agenda that Lenny was talking about, in the context of the economics, and the other ageing issues.

So, for example, when we look at caregiving, we know that our non-system in the United States of long term care, (total disaster that it has been finally recognized to be during COVID), depends on family caregivers. The economic impact of them not being able to work because they’re doing caregiving is astonishing. If we were able to help caregivers age 50 plus stay in the workforce, that could add $1.7 trillion in US GDP by 2030. Demonstrating that economic impact may well get the attention of policymakers. So welcome this dialogue. I’m very interested in what you all have to say, and I delighted to turn it over to Shekhar to get us started.
Thank you very much. Sarah, this is Shekhar Saxena, and I am delighted to join this dialogue. Thank you WDC for inviting me to join and also co-chair to the session. The topic is obviously very important, as has been pointed out by Lenny and Sarah, dementia and an ageing society within the Dementia Landscape Project. It’s extremely important that we share knowledge and we go forward based on the experience and evidence that all of us have. We have a very nice group today, about 50 people as I see it now. It’s exactly 50, actually. And we have a group of participants to represent a variety of expertise and experience. Obviously, we have researchers and academics. We have civil society participants. We have people who are living with the experience of dementia, they themselves or within their families and colleagues, if statistics is anything to go by, some of us will potentially live with dementia in future. So we are all in it in that kind of potential people living with dementia category. But we also have participants from industry, from government, especially policymakers as well as international organizations, participants from the WHO, one couldn’t think of a more diverse and more powerful group to discuss this topic.

So I’m delighted, really, that all of you have joined. I thank you for joining it and your time. In terms of gender, we are really very good. It’s exactly half men and half women as I saw in the participant list. In terms of region, we are not ideal. After all. We are convened by the World Dementia Council, which the critical word is world, and we could have been better. But believe me, enough attempts have been made and we are always striving towards having an ideal regional representation. I am very happy to see that we have a number of people joining who are living and working in low- and middle-income countries from all regions of the world. And we have many others who are living in a high-income country but working very much within the low- and middle-income countries. And I would especially request them to share their experiences so that we can truly be representative of the world that we strive to represent.

We have two people who are going to present their initial observations just to get the ball rolling. And I’m really delighted to welcome Alex Kalache who will be our first presenter. He is the President of the International Longevity Centre in Brazil, has had many other kind of experiences throughout his professional carrier. And I’m delighted to reveal the fact that he did work in WHO and he was a colleague there for several years. His longer bio can be found in the documentation that has been circulated.

So, Alex, I am happy to request you to present your views. You have about six minutes. So, Alex, over to you.
Thank you so much. Hello to everybody. Delighted to be here and grateful for being chosen to give an overview on such a complex subject, aware that I only have a few minutes.

To start with, I would like to bring some of the points raised by Lenny. Dementia is not a natural part of ageing, but for many they walk hand in hand, in addition to comorbidities - which three quarters of those living with dementia also present. Furthermore, Lenny has reminded us of additional needs such as financial hardship and, social care support. From a public policy point of view, healthy ageing needs to embrace these challenges as well as to deal with the stigma experienced by individuals living with dementia also suffered by their families and main carers. There is still a lack of awareness by the population as a whole – even among health professionals – that healthy ageing is more than absence of diseases. Thus, the importance of advocacy and appropriate, holistic policies on ageing.

Sarah you have reminded us the importance of considering longevity as the greatest achievement of the last hundred years. Yet, that is not, by and large, the way it is perceived. What predominates is the view that ageing is a burden to societies.

Taking into consideration the above points, I am going to focus on my country and will start with some basic demographics. Currently we have about 33 million people over the age of 60, but by the year 2050, the number of 60+ will grow to 68 million from 15% to 31% of the population. Just think of the magnitude of the challenge: less than 30 years, it truly a longevity revolution. And what is the baseline: currently, 15% of our older people leave alone, 36% with only one another person. 33% are illiterate and in addition 46% have less than eight years of formal education. This (low educational level) puts them at high risk of living with dementia side by side with unpreparedness, no coherent policy on ageing, let alone a policy on mental health and/or on dementia.

The reality is that developing countries like mine experience ageing in a very different context from that of developed countries which first got rich and then got old. We are getting old before we get rich, and not only in poverty but tremendous levels of inequality – which, in common with many other parts of the world, is on the increase. Combine this with lack of information for the population at large, but also for health professionals. This is feeding in one of the aspects that Lenny has mentioned: stigma and taboo, a prevailing ageism as we have seen clearly throughout the pandemic.

Thus, within the context of the Covid pandemic, just imagine what it is to live and care for someone with living with dementia. What a challenge! Imagine what it is to be locked with someone living with dementia for 16 months. Try to explain to that person, no, you cannot go out. Without the right policies, without respect, without sympathy, empathy from a government that insists on ignoring all those problems. By the end of June we had already experienced over 500,000 deaths, over half a million! And we know that this is an underestimation.
But we also know that many of the people who survive will experience 'long Covid', the comorbidities that Lenny talked about. It is disturbing. On top, abuse and neglect have increased by 500% over the period of the pandemic. Most of such abuse is occurring among someone living with dementia and/or their carers. Furthermore, we know that abuse and neglect is often perpetuated within the context of family care. Can we entirely blame them? Consider what should be the role of the government, their response? Total lack of empathy and solidarity. No respect to science. I would actually say, lack of decency. The response is "let them go, they have already lived, they are a burden".

You end up feeling diminished, with low self-esteem, low self-confidence. What we are experiencing is not a pandemic, it is a convergence of many different crises, sanitary of course, but also ethical, inequalities increasing, unemployment, hunger. A syndemic. We live in a country that exports food. It’s either the first of the second food producer in the world and yet 56% of the population is currently living with food insecurity and 20 million people are permanently hungry – nothing to eat, unless it is donated.

In addition to all this, we now see the effects of a resolution of the World Health Assembly (WHO governing body) proposing that old age becomes part of the international classification of disease, ICD. You might, officially, die of old age. We are orchestrating an international campaign and I am in contact with Shekhar and our old colleagues at WHO to try to find a solution, because if that happens, we will see the world with an epidemic of people dying from old age. This would turn into a blurred epidemiological scenario - 10 years from now we could look retrospectively and find “epidemic of old age”, no longer able to discern what is actually killing older people. Cancer? Cardiovascular problems? Diabetes? No: old age!

So, these are some of the challenges that we are faced with. Again, I thank you so much for giving me the opportunity to share some of my views in six minutes. What a challenge!

Thank you very much, Alex. We have done an excellent job of using the time that we had, but this is just for the beginning. You are as well a participant, feel free to come back later and share some other experiences. I also would like to thank you for giving an example, a good or a bad example, whichever way you look at it. But there is a lot to learn from that example. So we really appreciate your intervention and your challenges that you are posing to the society as well as to us, the participants of this dialogue.

I would like to now invite Dr Adelina Comas-Herrera to present her views. She’s the co-lead for the Strengthening Responses to Dementia in Developing Countries (STRiDE). Adelina over to you.
Thank you very much. It is an honour to be representing the STRiDE project today, and I’m very happy to see many members of our advisory group and STRiDE colleagues in the meeting as well. I hope I do justice to this project. As Shekhar said, STRiDE is the acronym for Strengthening Responses to Dementia in Developing Countries, this is a four year program to build capacity in research to support the development and strengthening of dementia care systems, so that people with dementia can live well and their carers don’t face excessive burdens.

The project is happening in Brazil, as Alexandre knows well, India, Indonesia, Jamaica, Kenya, Mexico, South Africa. It’s a partnership between researchers and advocacy organizations. We also work very closely with policymakers. The project formally ends in March 2022, but we’re now gathering ideas to extend this collaboration, we’re very keen to hear from any of you who’d be interested in being part of a future STRiDE network. We would like this to include a wider number of countries, with the aim of continuing to share and expand the research methods and resources for research to support the development of dementia policies and strengthen care systems, both in low- and middle-income countries, but also in high-income countries. As has been said before, when it comes to dementia care, very few countries can really call themselves "fully developed".

The way we started the STRiDE project, in each country, was holding a workshop with a wide range of dementia stakeholders, ranging from government officials in health, social development and social protection, to neurologists, people living with dementia (where we could), carers and local care and advocacy organizations. The stakeholders co-developed, using Theory of Change, a strategic map to improve dementia care, treatment and support in their countries. In all seven countries, one of the key issues that were identified as a challenge was the lack of understanding and awareness about dementia and stigma. I think that this speaks to the theme of today’s dialogue on ageing and dementia and some of the things that previous speakers have already said.

I’d like to reflect a bit on dementia knowledge and stigma and I would like to share with you two quotes from two recent STRiDE papers. One of the quotes is from Kenya and I’d like to mention that Christime Musyimi, who is the first author of the paper is here, so maybe she can talk a bit more about this later. This is the quote I’d like to highlight: “I have always thought that dementia is due to old age. At a certain age, elderly people are turning into old babies and forgetting all they were doing, just like small babies.”

The other quote is from STRiDE research in Brazil. This is a quote from somebody talking about their experience of going to the doctor: “the doctor said it was normal, that it was really due to age, that with time the mind gets wasted”. We have also had similar quotes from the other STRiDE countries. These views about dementia, as being a “normal part of ageing”, are not only held among the public, but also among health professionals, as also shown in the World Alzheimer’s Report of 2019, a great resource on research in attitudes about dementia and stigma.
In the context of today’s meeting, I think we need to reflect on the fact that these quotes are not only showing us lack of understanding about what is dementia, but they are also showing us that how prevalent it is to have very low expectations about ageing and very low expectations about our older selves. These very low expectations seem to have resulted on decline that is actually linked to a health condition being assumed to be a normal part of becoming older and, as a result, on many people missing on the opportunity to access care, treatment and support as a result.

And I do believe that these low expectations about ageing are also contributing, in ways that perhaps we don’t fully understand, towards making it too easy to lose sight of the value of older people. As Alex was saying, the Covid-19 pandemic has shown very tragically that the decisions made in many countries revealed an alarming disregard for the value of the lives of people who are old, who have dementia, and especially those who are living in care homes. Initiatives like LTCovid and Corona Older, that have documented this all over the world. Behind the huge losses of life of people living in care homes, and of people with dementia, there is fact that in so many countries care systems are underdeveloped, understaffed and under resourced. The pandemic didn’t find us in a good place in relation to our care systems and has amplified all the problems we already knew were there. We need to learn from this and we have the opportunity to learn and do better.

We need to find a good balance between mobilizing the potential for healthy ageing, for reducing the risk of dementia, for finding treatments that change the course of the disease, with investing in care approaches that work. And this also requires investing in stronger health and care systems. Perhaps having this in place will enable us to be less fearful and to have higher expectations for our older selves. I think that, particularly in dementia advocacy, we may have put too much emphasis on presenting care as a cost. Perhaps focusing on communicating its enormous value will help make sure we don’t under invest in care, getting us away from a vicious circle in which fears about old age may be undermining the development of the very policies that can help make ageing something less frightening. The fact that we are having this discussion today gives hope that we can join efforts towards breaking this cycle. Thank you very much.

**Professor Shekhar Saxena**
Professor of the Practice of Global Mental Health at Harvard T H Chan School of Public Health

Thank you so much again for so succinctly summarizing some of the issues that we need to discuss. So thank you again for your participation and your intervention. I would also like to remind the participants that there is an active chat going on and there are already a few comments which might be requiring further discussion. But for that, I want to hand over to Sarah for take us forward with the discussion. So, Sarah, over to you.
Sarah Lock
Senior Vice President for Policy, AARP

Thank you so much Shekhar and I can’t think of a better way to launch this discussion providing current context of the intersection of Covid and dementia. Thank you so much for that. And I’m going to pitch it over to Alana because some of the themes that were coming up in the chat of defining normal ageing and definitions of what is old age. I tell you, we have these debates all the time. Some say it when you hit 65, but for AARP membership it’s 50 plus. At what point is it that we really are talking about ageing? Is it from childhood and development all the way through the lifespan? So, Alana, why don’t you share a little bit with the rest of us verbally what you were mentioning in the chat?

Alana Officer
Senior Health Adviser, World Health Organization (WHO)

Thanks. It’s great to be here in an illustrious group of people which is a real privilege. We were speaking much more specifically to this issue of the International Classification of Disease, which I think is a very important issue, but maybe one not specific in terms of or the most specific in terms of this conversation, because I think this conversation is really important around, we’ve heard a lot about it, the importance of health as being central to our experience of older age and the opportunity sort of brings. Healthy ageing is not about being disease free, it’s not about not having dementia, but it’s about how we can continue to be and do what we have reason to value, while still having one or more chronic diseases. That’s what healthy ageing is about. And in terms of getting out and about, going to contribute and participate. So not a very narrow perspective.

And I think in this discussion around dementia specific ageing, is this incredible opportunity that we have around the decade of healthy ageing. So the UN designated 2021 to 2030 as the decade of healthy ageing. And so initiatives taken as part of the decade are intended to do four things. And I’ve already heard them all today. Change how we think about ageing, ensuring that communities foster the abilities of older people, delivering integrated care and primary care, and making sure that those who need long term care actually get it.

Now, if you think about those four things in relation to dementia, all of them are relevant to the lives of people with dementia, their families, their caregivers, and the communities in which they live. You know, we heard already the need to address stigma and discrimination in terms of people with dementia, that has to be integrated within the work we do around ageism. We need to make communities not just age friendly, but also dementia friendly. And there is a real opportunity where we’ve learned so much about dementia friendly initiatives. We can integrate and bring these worlds together to be able to really advance communities that they’re more inclusive of all people as they age. And obviously, providing integrated care and long-term care is absolutely essential if we’re going to enable people with and without dementia as they age to get the support and services that they need.
So I think the decade is a really incredible opportunity to advance these issues. And already we’re starting, as I mentioned the WHO we do things differently, and I think there is a specific need to focus on dementia, in ageing we need to do that better, but we need to make sure we don’t leave people with dementia and their families and their caregivers behind. So having guardians keeping an eye on that and providing specific support to me is a really positive opportunity. But we need to integrate and leverage opportunities as we can and work together to be inclusive in our strategies. And I think WHO is really doing that, and you’ll see, maybe I’ll post some more resources and show you some of the links that we’re making in terms of the work that we’re doing both on dementia and our ageing, which is a huge opportunity. Thank you.

Sarah Lock
Senior Vice President for Policy, AARP

Alex, let’s talk about dying of old age. You mentioned in the chat, let’s pick that up.

Professor Alex Kalache
President, International Longevity Centre-Brazil

As you know, ICD is regularly reviewed. We are coming to the 11th edition, which should be implemented from the first of January 2022. However, physicians around the world can already use this 11th version, which was approved by the World Health Assembly (WHA) in 2019. I want to stress this was not a WHO decision, but a recommendation made by committees to WHA. Once approved and endorsed by it, the WHO secretariat must comply. The whole process takes years, from the expert committees through WHA and, eventually, for WHO to put into practice.

To a large extent the insertion of ‘old age’ was a response to years of criticism and opposition to the word ‘senility’ which was included in previous ICD versions. So it came up because the word that was there before (senility) attracted a lot of criticism. Senility was not a good work, so it was replaced by old age. In my opinion, and that of many, the ‘cure was worse than the disease’. While WHO not saying that old age is a disease, and that is clear, the perception goes the other way round. And perceptions are important, particularly when taking into consideration that most health professionals lack proper understanding about the ageing process. The temptation of ‘ticking the old age box’ may become too big to be avoided. Like it was the case in the following example:

When the Duke of Edinburgh died a few months ago, the royal physician put a cause of death ‘old age’. Not cardiovascular disease despite the fact that early this year he was admitted to hospital for a few weeks to treat a CVD condition. Well, if that was the ‘temptation’ of the is the royal physician, one can only imagine what could happen around the world, given the ignorance of so many physicians about ageing. The epidemiological implications are immense. I do know that the ICD-11 did not intend it to be that way – but the risk is there.
What would be the consequences? Ten years from now, we could be faced with an epidemic of people dying from old age. We need therefore to address this. And I appreciate that colleagues from WHO are more than willing to do so. As Alana Officer has already put in the chat, a solution will be found. I suggest that one way would be for WHO to call upon a group of experts to discuss this openly because we still have six months for the 11th edition of the International Classification to be enforced. Alternatively, the same group of experts who have already advised WHO on ICD could be requested to provide alternatives.

We still have plenty of time to find solutions. Academic and civil society organizations have been inundated with criticism and the media is giving visibility to the issue. There is willingness to fix the problem and it is in nobody’s interest to throw mud on WHO. On the contrary, it’s enough to think of my government which wants to bash WHO. But civil society organizations, do not want to see WHO in trouble. We want to find a solution and it will be found. We have the opportunity provided by the organizers of this webinar to come up with ideas. Thank you.

Sarah Lock
Senior Vice President for Policy, AARP

I am reminded, if you want to speak, make sure you raise your hand. Lots of people are entering great comments in the chat. I’ll go through them, but make sure you raise your hand and I’ll be looking for that to see that you want to jump in. Actually, I just saw Vladimir raise his hand because he’s right in the centre of the screen. So go for it. Vladimir, you’re on mute.

Professor Vladimir Hachinski
Professor, Western University, Canada

Thank you very much for inviting me. I want to talk about a phenomenon that has been neglected, and that is that although the number of the dementia cases are increasing, the number per thousand, the incidence is decreasing in some countries. For example, in the province of Ontario of Canada, the government introduced a program to treat and reduce the incidence and the consequences of stroke. It was documented that subsequently the outcomes were better, fewer people died, more went home. Knowing that the risk factors are the same for stroke and dementia and that stroke doubles the chances of developing dementia, we decided to take a look, and we found that over a 12-year period, the incidence of stroke in Ontario has decreased by 32% and the incidence of dementia by 7%.

If you multiply that by a population of 14 million in Ontario, that’s thousands of individuals who were spared a tragedy and also saved social and economic costs. We have just been funded to look comprehensively as to why this is, what are we doing right, or what is it that’s happening that’s allowing for this decrease by thousands? Typically,
people look at populations, or they look at individual risk, or they look at socioeconomic factors, they look at access, but never together. I’m happy to say that we’re looking at everything together probably for the first time ever.

We are looking at the environment, social demographics, individual based factors and also brain health. The idea is that it’s only by being comprehensive, looking at everything at once and only then targeting what’s most important in a particular area. For example, Canada is a big, small country. 85% of the population lives next to the American border. What happens in the North is very different. I live in London, Ontario, and hypertension is not a major problem. It is in the North. On the other hand, diabetes is a rising threat in my city.

So it has to be targeted. And thirdly, in addition to being comprehensive and targeted, it has to be cost effective. Governments don’t realize that there is a price for inaction, and we need to find out to show them in dollars what it is costing each time they do not prevent a stroke or do not prevent dementia. By the same token, we have to offer the best solution for a particular jurisdiction, and that cannot be countrywide. It has to be targeted. It has to be implemented in actionable units, typically in most countries, it’s a municipality or health region.

So despite the rising numbers, the incidence of dementia is declining in some countries, there’s something we’re doing right. And I think that we should find out not only in Canada, but in parts of the United States, where decreases have been reported, in Sweden and in other countries, the sooner we find out what we are doing right, the sooner we will begin to delay, mitigate or altogether prevent some dementias.

I see that there are four electronic hands being raised, so I would like to take your permission Sarah, and invite Brian Kennedy to make the first comment, please.

Thank you. So if you don’t know me, I’m more of an ageing researcher than an Alzheimer’s researcher, and I’m director of that Centre for Healthy Longevity at the Yong Loo Lin School of Medicine at National University Singapore. I’ve met some of you before. I wanted to make this comment about ageing, because I think we get bogged down into arguing about whether it’s a disease or not a disease, whether it’s a risk factor for disease or not. And I think that misses the point. What is undeniably associated with ageing is dysfunctional decline. I saw David Beckham at the Euro 2020, he looks great, but he wasn’t playing on the field. He’s in his 40s and you experience cognitive decline throughout your life. It’s associated with almost every disease. It’s associated with severity of infectious diseases, we found out in a very sad way over the last couple of years. And fundamentally, the problem is we’re not doing anything about it.
So we know that preventative strategies can extend health span, they need to be life course strategies, not things you do after you get sick. And we need to refocus medicine not so much on sick care, but on health care. And one of the ways to do that is the target ageing. The challenge with that is that there is no fundamental way to do that if it’s not listed as a disease indication or something that you can get reimbursed, because pharmaceutical companies a very little interest in things that are not reimbursable. That’s starting to change. There is a big longevity industry growing, but there’s still no way if you have a magic drug that’s flowed ageing and compress morbidity, which some of them do in animal models, to get that into humans, because there’s no way to get that reimbursed.

So I think that part of this effort to redefine ageing is to find a fundamental strategy to target the ageing process before people get sick as a means of extending health span. And that, I think, is driving a lot of these changes and definitions. And I think it’s a good thing, because, I am biased, obviously, but I believe that it’s going to be much easier to maintain people in their healthy state than it is to try to treat them after they’re sick. And we’re spending too much effort doing that right now. So that’s why I think a lot of this debate going on. But to me, I don’t care what you call ageing or disease or risk factor. Fundamentally, it’s the biggest driver of functional decline and the onset of diseases, and we have strategies to do something about it, and we have no way to validate them easily in humans right now, and that’s a problem.

Sarah Lock
Senior Vice President for Policy, AARP

Maintaining people's heath longer is critically important. So I’m going to go next to Mike Hodin and then Chris Lynch after that.

Dr Michael Hodin
CEO, Global Coalition on Aging

Thank you. It’s nice to see everyone, a lot of old and hopefully new friends, and it looks like everyone’s feeling pretty good so that’s great. A couple of quick points. One is on the discussion a few minutes ago on what I’ll refer to as the philosophical questions of ageing. For those of you who attended our Global Coalition on Ageing Silver Economy Forum in Helsinki in July 2019, you all would have received this little book that Cicero wrote in 44 BC, How to Grow Old. And the reason I raise it is that we’ve always had old people. We’ve also had a lot of people for millennia writing, thinking and talking about old age or ageing. The big difference today, that we all know on this call but is worth really emphasizing, is the 2 billion of us that will be on the planet over 60 and what age we use to define that is important because it makes a difference in the popular discussion. That number, 2 billion, is sort of an interesting point, rather than getting caught up at 65 or 50 or anyway.
And secondly more old than young, which we all know. So the big difference is, what do we do about public policy? Because we’re talking about billions of people getting old or tens of millions of people having Alzheimer’s. That’s the thing that makes a difference, not that there are a relatively limited number. That brings me to my main point, which at least it’s my interpretation, perhaps wrongly, of a comment that Jane Barrett made in the chat about looking for the enablers for the decade of healthy ageing.

I would suggest, linking to the point that Brian just made so well, that one of the core enablers is a public policy environment for innovation. Innovation in medicines, innovation in new technologies like digital health, innovation in caregiving, innovations in how we reframe retirement policies (certainly in the private sector, I’m thinking of America here mainly) but these things are not going to happen if we don’t have public policy support. One thing that Alzheimer’s is teaching us, that we also are learning from of Covid-19, is that the twentieth century models for valuing technology or innovation, whether it’s medicines or digital health, and the regulatory systems in which those get approved for us, from our societies, are outdated.

Twentieth century models just will not work in the context of an ageing society. Our FDA here in the US is an interesting example where we just had a little debate. It’s a debate which is based on do we want to look at the twentieth century model for approving a medicine or a twenty first century model, which gives a different sets of values and opportunities through the ageing lens. I think there’s a lot we must do here, but we have to really start with breaking the old models.

Well, it’s interesting. We’re having a raging debate now about whether caregiving is fundamental infrastructure in the United States, and it’s one of the oldest models of dealing with aging, right? Family care. So I really appreciate that point about looking at models differently. Chris, I’m going to call on you next, but then, Stefania, if you would get ready, you’ll be up.

Super. Thanks so much. Really delighted to be part of this. Mike your timing was perfect because I’m going to reference some of the work we did together as well. But, Brian, I wanted to pick up on something you said and tie it into what Alana said recently as well. So it’s really about semantics. And initially I thought that this juxtaposition that occurs between the phrase healthy ageing and then a condition or disease group like dementia is actually quite awkward. And I’ve struggled with that myself quite a lot. However, I really began to realize now that strategically is actually quite an opportunity, and when it works, it works well.
In policy advocacy terms, when Japan had the presidency of G20, we used healthy ageing as the vehicle for getting dementia as a priority onto the program on the agenda, and that manifested itself with the Health Ministers’ meeting with some very, very specific dementia centric outcomes that came out of that. Now I was really kind of saddened this year, I suppose with the G20 process, there was no real continuity. After Japan, it started to falter under Saudi’s presidency, the healthy ageing prioritization started to fade, and then, of course, Covid happened, and everything changed anyway.

But even this year, in the build-up to the G20, the C20 planning sessions, trying to get healthy ageing and dementia onto the radar, it’s been really hard. But if you consider that the older person’s age group has been the most affected by Covid, it’s really quite ironic that it’s very difficult to get that prioritization message there. But kind of coming back to a little bit of work that we did with Mike and his team recently, which sticks profoundly in my head, and he ties very much into something Alana was talking about, was that a lot of this ageing population demographic increase is taking place in urban environments. And we did this 30 Cities report last year with Mike’s team at Global Coalition and nearly two thirds of all people in that demographic group are going to live in cities in the next 20 or 30 years. And I think there’s something very important about how do we use some strategic frameworks like Decade of Ageing and dementia friendly and age friendly cities to try and actually bring some resolutions to that? But really I wanted to bring it back to that semantic question, is the use of healthy ageing, and then a neurodegenerative disease like dementia - can we bring those two terminologies together to better work in a policy and an advocacy framework?

Great, great question, Stefania.

Thank you very much. And let me also say I’m so delighted to be part of the conversation. That has been fascinating. I think Chris beat me to the punch. But maybe if you’ll allow me just two minutes to make the same point from a care perspective. I also want to make a call for more integrative approaches to advocacy and research on dementia and trying to align this better with the larger global discourse on care. And my own work focuses on long term care.

And I appreciate, of course, the specific challenges that dementia poses. But at the same time, there’s a lot of potential to align dementia priorities with the long-term care agenda more generally. And the pandemic maybe is unexpected promoter of the long-term care agenda in the countries where I’ve worked recently, primarily Western Balkans, Eastern Europe, but also some Western European countries. The pandemic has really pushed dementia down policy priority list, we have two projects that have
been pretty much ground to a halt that focus on dementia and keeping [indistinct] in their implementation. But there is renewed, constant, renewed interest in development of long-term care systems because the pandemic has affected so severely long-term care facilities, but also has raised the issue of caring the community and informal care sustainability. Maybe there’s still untapped potential here. For example, the Social Protection Committee of the European Union has recently published a report on long term care that focuses on long term care priorities generally, but mentions dementia repeatedly, uses examples that are dementia specific and is very well aligned to my understanding with priorities on dementia care. So, again, just a call to think a bit more integratively about how we approach democracy and research and really aligning the focus efforts on dementia with long term care and ageing more generally in the global policy agenda. Thank you very much.

Sarah Lock
Senior Vice President for Policy, AARP

Thank you, Stefania. I’m going to go to Myrra next, followed by Surya. And then I’m going to flag Jane, you had a comment about social ability. I’m going to go to you after Surya.

Professor Myrra Vernooij-Dassen
Professor Emeritus, Radboud University Medical Centre

I’m professor emeritus at Radboud University in the Netherlands, and I’m chair of INTERDEM, a Pan-European multidisciplinary network of dementia researchers. I want to raise the point of ageism and its dangers for healthy ageing. Ageism discriminates people because of their age and reduces the possibility of older people to actively participate in society. In a recent WHO report ageism has been associated with poor health, especially with poor social health and poor cognition. Ageism in the media negatively impacts health and cognitive performance. Ageist stereotypes in the media can have a negative impact on older people’s self-esteem, health status, physical well-being and cognitive performance. There also is the link between ageism and dementia. In our ongoing study, funded by JPND, we find accumulating evidence for the influence of social health on cognition and on the onset of dementia.

By ageism, the societal value of harmoniously living together between generations is undermined. It’s completely ridiculous to have a battle between generations. The forced societal withdrawal of people because of their age and its negative consequences on well-being and cognitive functioning even brings along additional burden for younger generations having more older people who cannot take care for themselves.

Covid-19 fuelled ageism in the media. While discrimination based on race or homosexuality raises great aversion, ageism is nearly fashionable. The consequences of research on ageism and cognitive functioning should be taken very seriously and considered in policy. This is really a point on which we can do something and make a difference. Thank you
Sarah Lock
Senior Vice President for Policy, AARP

That is certainly true. Surya.

Surya Kolluri
Managing Director, Policy & Market Planning Retirement, Bank of America

Sarah, thank you. What a fantastic conversation, it is quite energizing. As a representative from the financial sector please let me add a point that wealth-spend might play a role hand in hand along with health considerations.

A perspective from research my firm has done. At least in the US, let’s say you have a healthy 65 year old couple. The chances are one of the two spouses living to age 92 is 50%. The chances of one of the living to age 95 is 25%, and the chances that they would live to age 100 is 10%, which means that as financial advisors help clients to build up their savings for their longer lives, they should be thinking about not actuarial numbers of 84 to 85, but these longer lives, which means financial assets need to last longer.

We can then add the complication of dementia to this conversation. This can be challenging as a conversation between advisor and client. And so I will propose a proactive strategy and a responsive strategy. The proactive strategy is, helping the client think through how their financial aspects can be managed in such a way that they can accommodate these longer lives we are talking about. The responsive strategy is to determine how to help if the client with dementia makes a financial mistake. Which if you look at the literature can be a real problem. What if the client is defrauded and is subject to abuse and fraud?

We need to take into account what these proactive and responsive strategies to help people live these longer lives, both with health spend and wealth spend. Finally, to coin a term we can combine wealth planning and health planning into "wHealth planning...!"

Sarah Lock
Senior Vice President for Policy, AARP

Thank you, Surya. I’m going to jump back to Jane Barrett, because when you’re talking about functional ability, it reminded me of a framing the disability community uses and used. When they began to focus on abilities, as opposed to disabilities, policies started to change and there was a different way into a lot of these conversations. I would love for you to expand a little bit on that. And then I’m going to go to Walt Dawson and Jane Rylett.
Thanks very, very much, Sarah. And thanks for the opportunity. So I’ve got to go back to the definition of WHO’s healthy ageing, and that’s the process of developing and maintaining the function that enables wellbeing an older age. You know, I have a does a lot of work in vision, we do hearing, oral health, but we don’t talk about the diagnostic conditions. We talk about the functional ability of that person and the impact that that has on health systems. And I think sometimes we get stuck, rightly so, on a diagnostic category and burden, which is appropriate in some context, as is the social and economic consequences.

But a person with the diagnosis of dementia or diabetic eye disease, you know, what they’re most concerned about is their function. How do they function? What is it going to take in the environment that enables that person to continue to function as best as they can? And so I think that’s an important pivot point in this conversation about strategy, which is not often talked about.

And so I can I look at dementia through the four action areas, but also the enablers of the decade. Most of us know the action areas, but not many know the enablers. One of being voice and engagement, one being leadership and building capacity, one being research. So I think it’s the intersection of the decade, the global report on ageism, the World Report on Dementia and the enablers. So I think there are a number of different pieces, but at the heart of this is a person’s function and I’m sorry for being so simple in this very important and complex discussion, but that’s what a person wants to know. How long can I keep functioning?

Thanks Jane, great points. Walt.

Hello, everyone. Thanks so much. I am incredibly happy to be here and to be a part of this important conversation and really appreciate the comments made so far, particularly on the intersections that exist here, as well as about the public policy opportunities that exist to address the challenges and risks posed by dementia, as well as how to kind of disentangle that from the policy and social issues related to ageing and advanced age. I believe, just to go back, to perhaps your comments, Sarah, that thinking about, or viewing, many parts of the health and social care systems as perhaps infrastructure, or viewing, many parts of the health and social care systems as perhaps infrastructure, I think you gave an example of caregivers,
that is really an important way or an example of thinking about policy in kind of new and perhaps innovative ways.

And as many have already mentioned during the dialogue today, I think another opportunity here is really the chance for far greater collaboration and coordination across countries and regions of the world. Be it through policy, be it in public and private partnerships or in research. And really, if anything is clear, the Covid-19 crisis has really made that much more true today than ever and I just really hope that we’re able to continue to think about these issues and approach them in innovative ways. There really are some real opportunities for cross-national approaches to policy. Thank you.

Sarah Lock
Senior Vice President for Policy, AARP

Thank you, Walt. Jane Rylett.

Professor Jane Rylett
Scientific Director of the Canadian Institutes of Health Research (CIHR)
Institute of Aging

Thank you so much, Sarah. I’m just so pleased to be able to be here today, this is an interesting and invigorating conversation. I think a lot of great ideas can come out of it. My point leverages off a number of the comments made by other speakers and actually goes back to the beginning of of the conversation and that is around semantics. Semantics about when does someone become an older adult? Is it at age 50? Is it at age 65? What is that age? My point is that it can be harmful to apply these kinds of definitions and maybe we need to think differently about what constitutes older age or older adults and definitions of what the needs for those individuals are. So obviously, there can be a large difference between biological age of an individual and chronological age of an individual. If we forget about that biological component as opposed to the chronological aspect, I think we’re doing a disservice to individuals.

Then comes to the program deliveries. What can people access? This includes Jane Barrett’s point around functional abilities. Someone who may be younger and experiencing more advanced or rapid ageing, with their functional abilities declining, may not be able to take advantage and participate in some of the opportunities that may be available to older adults within that society. My point is related to thinking about the ageing process and older adult definition differently, how functional abilities play into this and change our semantic approach to some aspects of this, and then start looking from a lifespan, life course, lifecycle approach.

This comes back to the comments made by my colleague here in London, Ontario, Vladimir Hachinski around the fact that incidence of dementia seem to be decreasing in some parts of North America and some European countries. In fact, this may relate to our ability to be able to mitigate some of those risks. Identifying and defining that and
working with that to find new ways of looking at public policy and approaches to this, I think it can make a huge difference so we need to think more broadly and think a little differently about aspects of this.

Sarah Lock  
Senior Vice President for Policy, AARP

Yeah. Jane, we’ve seen many articles and academic work around the relationship of education and dementia, but education is really often aimed at the youngest of us. Thinking about that and how it affects dementia down the road, maybe that is something that we can discuss a little further along. I’m going to go next to Christine (I’m going to butcher your last name, Christine!) But you’ll be next, followed by Howard and Silvia.

Dr Christine Musyimi  
Community Researcher (Stride), Africa Mental Health Research and Training Foundation

Thank you, Sarah. I’m Christine. Thank you for you mentioning the last name correctly [Musyimi], that’s the correct pronunciation. I’m happy to be part of this excellent conversation and I just wanted to say something in regards to healthy ageing but I will first talk briefly about the work we are doing. Just to put a disclaimer - it may be impossible to separate healthy ageing from stigma reduction because individuals and groups understand dementia from different perspectives, for example from cultural perspectives or traditional perspectives. This results into stigmatizing attitudes among old people. One of the statements from the Kenyan work we conducted through STRiDE is very stigmatizing as people with dementia are considered to have little brains or considered to behave like small babies.

So those are really stigmatizing statements. In one of the local communities in Kenya the local term is “Thing’ai” (pronounced as thing-i) which originated from the term thinking high. The term used refers to “to what goes up must come down”, which is a really very stigmatizing statement because the community is imagining if something is rising, it will eventually come down. According to the local community interpretation, people who show dementia-like symptoms, have retired and were not visiting their rural homes while in formal employment are considered to have developed dementia because of pride.

So that’s how most people view dementia in Kenya. In regards to safeguarding the human rights of people, reducing stigma at the individual level, family level and at the community level is an great way to promote quality of life of people with dementia and their family carers. And this is definitely a contribution towards dementia-friendly societies. Within the STRiDE project, we are developing an anti-stigma toolkit to create awareness on dementia among members of the general public, and promote engagement within community settings through interventions. As a starting point to developing the stigma toolkit, Kenya and Brazil are developing culturally relevant anti-stigma
interventions which include content developed through involving various stakeholders such as persons living with dementia and their carers. Generating or developing interventions that create awareness on dementia and those that improve quality care and dementia friendly societies, would be a contribution to the 2025 goals.

It will also help dispel myths and recognize the human rights of persons with dementia. In all the seven STRiDE countries that are involved - that Adelina mentioned, we are engaging persons with dementia as well as their carers to discuss their experiences and the process of gaining a fulfilling life. So this will contribute to the next set of goals. Thank you very much.

Sarah Lock
Senior Vice President for Policy, AARP

Great. So we are closing in on only about nine minutes left for our group discussion. I'm going to go to Howard Bergman next, Silvia, and then Facundo.

Professor Howard Bergman
Professor of Family Medicine, Medicine (Geriatrics), and Oncology, McGill University

Thank you for this great discussion and for being able to be part of this discussion. Let me come to this discussion from my experience as a clinician, as a policymaker and as an older person. I sometimes am a little concerned about the concept of healthy ageing in the sense that we have to be careful it doesn't become a way of stigmatizing people who are not ageing healthily, if I may use that term. And the other concern I have is about fragmentation, that we fragment our concept of ageing according whether your healthy or not or whether you have one chronic disease or another chronic disease.

I think people have emphasize the importance of understanding older persons in their complexity. I think we learned one thing: older people are very heterogeneous from a health point of view, from a functional point of view, from a social point of view, from a cultural point of view. I think we need to understand and embrace that heterogeneity in order to understand that we need a complex combination of health and social services, the complex combination of policy as well, to take into account the heterogeneity. So I would argue for a more integrated concept of ageing. You know, Browning said the best is yet to come. Many older people like me would say not so sure about that. So, you know, I think we have to understand this integrated and realistic point of view of ageing and how society can approach it.

Sarah Lock
Senior Vice President for Policy, AARP

Silvia, thank you.
Thank you all. I want to bring the aspect of human rights into the mix that nobody yet mentioned, as it does relate to a lot of what has been said about the integration, about heterogeneity and about disabilities. Dementia is at the intersection between ageism and ableism. We should take seriously the Convention on the Rights of Persons with Disabilities as it applies a lot to persons living with dementia. It’s not just about keeping or maintaining our functional ability, it is about what society enables us to do with the abilities that we do have. So instead of looking about we cannot do, we should always look at what we can do.

There is a lot of legislation, and that’s why I bring the law into the mix here. It’s not just policy is law, the laws that discriminate against persons with dementia. The moment you get a diagnosis, even though you are still able and you will be able to do a lot, you are not allowed to do what you can do. And I think that is why I advocate for the rights of older persons and I advocate for looking at dementia also through a human rights lens. And because there is no more time, I will leave it there. Thank you.

I appreciate that Sylvia. Facundo Manes from Argentina.

Thank you, Sarah. And thank you for the invitation. It’s a great honour to be here. Before the pandemic, dementia was having a huge social and economic effect in Latin American countries. The situation now is ever more difficult, as South America is the world’s hardest-hit region by the COVID-19 pandemic. Latin America faces the same challenges in dealing with dementia as rich countries do, but with a much lower level of training and little awareness.

For example, we have published a few years ago that even among neurologists, a substantial number of physicians that diagnose dementia will do so without providing a specific diagnosis of the dementia type. Inadequate knowledge of the difference between normal cognitive ageing and dementia is sufficient awareness of the importance of timely detection, stigma towards mental health, and particularly about dementia make it difficult for many people to obtain medical help. Another important challenge in some region of Latin America is to diagnose dementia in people with low education. The escalating burden of dementia on healthcare resource requires a long-term national strategies, and I agree with Brian that intervention must focus not just on dementia
but also on the health system overall. Translation of these strategies into operational plan, however, poses great challenges, particularly for countries like us with the scarce resources. Thank you.

Sarah Lock
Senior Vice President for Policy, AARP

Thank you Facundo. Kavitha I think you're going to be the last comment. If you have other comments, make sure you take advantage of the chat and add it, but Kavitha if you would go off mute and speak with us.

Dr Kavitha Kolappa
Consultant, World Health Organization (WHO)

Thank you, Sarah. Lucky me. It’s been such a pleasure to listen to all of you very brilliant people and seeing you connect the dots, I quite agree with Adelina that Covid did not find us in a good place in terms of dementia care pathways and our countries and really all of us are unprepared for the demographic changes that we will face. I want to talk about two things. I’ll be as brief as possible understanding our time limitations. Just want to take a moment here to point out that we’re roughly halfway through the implementation of the Global Action Plan on the Public Health Response to Dementia, I might be remiss here to not highlight Shekhar’s forward thinking leadership as this action plan really came to fruition under his charge.

And as you may all know, that countries have committed to reporting on seven key action areas within this action plan through the global dementia observatory. So stay tuned. We’ll be releasing a report on their halfway implementation status in September. I just want to home in on one action area and that’s a risk reduction, because I found that this has come up continually in our discussions today and particularly relevant for ageing societies. I want to all come back to Sarah’s point here. Kind of how do we raise attention for dementia amongst this pantheon of illnesses that ageing societies may face? And I think that risk reduction is really the key here, that really we need to promote a whole society approach to tackle shared risk factors, air pollution for example, social determinants of health, including social inequities, disadvantage and social isolation tackling these will really allow us to make great gains for all illnesses, not only dementia, but will also reduce the incidence and prevalence of dementia. And the decade of healthy ageing was really the prime opportunity to do that to kind of follow the task at hand of building the necessary bridges and making linkages across silos.

And lastly, we really need equity monitoring. I believe this is mentioned by Alexander and others that in order to really understand which subpopulations are most at risk, even in countries where it may appear that prevalence of dementia and other chronic illnesses are decreasing, we really need to make sure that a rising tide lifts all boats and that requires really well defined, disaggregated data equity. Thank you all so much. It’s a pleasure to be a part of this meeting.
Thank you for your comments, Kavitha, very important. I think we may have time for one more before Shekhar takes this home with his closing reflections. I think Carrie you raised your hand. I see that you’re talking about stigma. AARP just did research on stigma, which I’ll be happy to share links in the comments afterwards. I think it’s a really interesting way to address it. And then Kavitha, you are talking about equity and stigma, and the issues where they intersect are actually quite fascinating. And we may want to find an opportunity to talk about that more.

Thanks for the opportunity to be here today. I did try to post something in the chat, and it was really reflecting on something that Christine had talked about. I guess I’m quite humbled to think about where I’m coming from and even though we all face stigma it’s not like in some of the other countries around the world, it’s not really even a comparison. So how can we learn from each other and share with each other? And I think really having that multi-pronged approach, so trying to educate the general public, trying to educate healthcare providers, but also the youth. That’s where we’re going to really start to see some benefit over time and finding ways to integrate education around ageing and around dementia in schools and finding opportunities for youth to work together and talk with older adults, talk with people with dementia so they can see and learn the value and the contributions that the people with dementia can make. Thank you very much.

That’s a great comment to take it back to Shekhar and ask him to share his closing thoughts.

Thank you so much, Sarah. Such a rich discussion, it might be actually quite impossible and also futile to try to wrap it up in a structured way in a couple of minutes. But I’ll give it a good try. From my perspective, I think the overriding impression that I got from the discussion was that there is a lot of need for synergy and coordination between these two efforts on the ageing side and the dementia side, and there is a lot of willingness to
do that actually from people we heard from. I think that is one of the most important messages that I received from this discussion. But there are some other buckets that I would like to point out which are important ideas which come together.

One of them is the concept of health versus disease, the terminology, the ICD and related to that, the stigma and ageing bucket. And I think there's a lot to be said about that further. There is a lot to discuss there, but these are issues that we have in both the fields. The ageing field is where the dementia field are struggling to some extent, dementia much more than ageing field, but it is a continuum. I think we need to really have a much greater clarity on what we say, how we say it, and that how it applies to the policy. So that is one important set of comments that I very much appreciated. The second set of comments is around the functional abilities and also on the prevention side: how can we prevent unhealthy ageing as well as dementia? And what are the enablers which actually work well for us to go for as much healthier and as much functional ageing as we can? And even with people who are living with dementia, these are equally applicable. That's my second bucket, as I would say. The third important message that I received was about the human rights and law. I think these are again very important for both the field, that we honour human rights which almost all countries have signed on, including from the conventions and the rights of disability, as well as other conventions of the United Nations. We really need to honour that, national policies and laws need to be adapted, modified, revised to take care of them, and implemented, which is even more difficult, but that needs to be done.

I would also lastly mention the aspect of economic planning and management, which was raised by Surya. I think this is important for both fields. How can we have economically secure ageing as well as economically secure disease status like dementia? That is something that we just touched upon but does require a lot of further discussion. And lastly, a point that I was very much struck with is the heterogeneity of situations for individual in both of these situations, that our needs are different, our capacities are different, and our support systems are different. How can we have uniform policies and laws but is still in some way, make sure that individually we all benefit from them. And that's a serious discussion that we need to have. How can uniform, regular policies still benefit people with different needs and different capacities who are in different stages of their life and disability? I got a lot out of the session. I hope you also did. With that, back to Lenny.

Thank you, Shekhar, and thank you, Sarah. Thank you, everyone is participating. As I said, at the top, we will be producing a transcript of this call which we will circulate to you all over the next few days. I normally do this from Hackney, and those of you can’t quite see, I’m actually in a very rural part and depopulated part of Wales right now, and I’ll leave you with this thought, which is in Hackney, in central London for those who don’t know that, 80% of the population is under 65. Here, a quarter of a population is over 65. My local hospital is five minutes down the road, my parents’ local hospital is over that mountain range that you see behind me. One of the things about ageing and
dementia, which I think we don’t often talk about is not just the public policy around ageing, but also where people age, and a lot of the challenges that come with space on top of everything else. So with that closing thought, as I’m back for a family reunion and my brother can finally visit from Israel, I will sharply at half past the hour say thank you very much and wish you a good morning, evening and night. Thank you all.
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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