Prevention and brain health

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

Hilary Evans

As Chief Executive since 2015, Hilary has led the transformation of the charity to one of the leading medical research charities in the UK. She has overseen a significant growth in income in recent years, with ARUK being one of the fastest growing UK charities. This growth has significantly enhanced the organisation’s ability to fund new innovative projects, particularly those that unite charity, academic and private sectors in the search for new dementia treatments.

Hilary is driven and fascinated by ideas that can make a difference and has led major public campaigns to change public perceptions of dementia and break down the stigma around these diseases.

Before joining Alzheimer’s Research UK Hilary worked at Age UK, improving the lives of people in later life both in the UK and internationally. She also brings experience of working in Government and with the pharmaceutical industry. Hilary is a Trustee of the Association of Medical Research Charities and holds an honorary doctorate in medicine from The University of Exeter.
Speakers

Kaarin Anstey
Kaarin Anstey is a professor of psychology and conducts public health research into dementia risk reduction ranging from analysis of cohort studies, development of risk assessment tools, and conducting risk reduction trials. Kaarin is the director of the University of New South Wales Ageing Futures Institute and is a conjoint senior principal research scientist at Neuroscience Research Australia. She chairs the International Research Network on Dementia Prevention and is a member of the governance committee of the Global Council on Brain Health, an initiative supported by AARP.

Miia Kivipelto
Miia Kivipelto, MD, PhD, is Professor in Clinical Geriatrics at Karolinska Institutet (KI), Center for Alzheimer Research and senior geriatrician and Director for Research & Development of Medical Unit Aging at Karolinska University Hospital, Stockholm, Sweden. Part of her Nordic Brain Network multidisciplinary research team (around 100 researchers and clinical staff) is located at University of Eastern Finland and Imperial College London, UK, where she has part time position as Professor. Her frontline research findings have been published in leading journals (330+ publications, H-index 75) and she has received numerous prestigious awards.

Dr. Kivipelto’s translational research focuses on the prevention, early diagnosis and treatment of cognitive impairment, dementia and Alzheimer’s disease (AD). Through epidemiological studies, Prof. Kivipelto has identified various lifestyle and vascular risk factors for dementia and interactions with genetic factors and clarified underlying mechanisms. She is the PI of the landmark FINGER trial and founder and scientific leader of World-Wide FINGERS network. Professor Kivipelto is often invited to leading global dementia conferences and task forces.

Sarah Lenz 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.
Thank you, Philip. And it’s wonderful to be with everyone today and to see some familiar faces in the flesh again, after all this time! This session is going to focus on prevention and brain health, and we have a fantastic panel who are all going to say a few words, in a minute. But this is also an interactive session, so as we’re all speaking, do have a think about some questions that you’d like to be asking the panel.

Just to set the scene with almost 153 million people expected to develop dementia globally by 2050, we need to act now to minimise the number of people experiencing the harm and heartbreak of dementia, and that is ultimately why we are all here doing what we’re doing. While we continue to put our efforts behind progress in the development of disease modifying treatments, we need to approach the challenge of dementia from all directions and ensure that we’re doing everything we can to prevent dementia developing in the first place.

Brain health is increasingly being used as a better way to frame dementia risk reduction, and while there are range of definitions, brain health at its broadest is about keeping the brain working properly throughout life. This concept enables a holistic approach, acknowledges the wider health of our brain beyond dementia and supports action at every stage of life. There’s a growing understanding and evidence of how a range of health and lifestyle factors can reduce our risk of developing dementia. The Lancet Commission in 2020 identified twelve risk factors that could potentially reduce the number of people globally developing dementia by 40%.

So how do we make the most of this evidence to ensure interventions and actions are implemented globally as soon as possible and with the most impact. We’ve got some fantastic speakers today who are going to offer their perspectives on the value of brain health interventions. How progress in research is finding new ways to reduce the risk of developing dementia. So, I’ll introduce each of our panel to say a little bit about them, they’ll probably be fairly well known to most of you in this room and they will then talk for a few minutes in terms of some of the work that they’ve been leading and then as I said, there will be a chance to ask any questions of our panel.

- To start with, we’ve got Professor Kaarin Anstey, who is the professor and director of University of New South Wales for Aging Futures Institute and is a senior principal research scientist at Neuroscience Research Australia. Professor Anstey lead research into dementia risk reduction, including analysis of cohort studies, development of risk assessment tools, and conducting risk reduction trials. She also chairs the International Research Network on Dementia Prevention and is a member of the Governance Committee of the Global Council on Brain Health.

- We also have Professor Miia Kivipelto, who leads research focusing on the prevention and early diagnosis of treatment of cognitive impairment, dementia and Alzheimer’s disease. She’s principal investigator for landmark Finger Trial and founder and scientific leader of the Worldwide Fingers Network. This brings together research teams from over 40 different countries and promotes a novel approach to clinical trials, identifying geographical appropriate strategies for prevention and risk reduction.

- And lastly, we have Sarah Lenz Lock. Sarah leads AARP’s policy initiatives on brain health and the care for people living with dementia. She is executive director of the Global Council on Brain Health an independent collaborator of scientists, doctors and policy experts convened by AARP to provide trusted information on brain health. The Global Council on Brain Health has published a range of reports on key topics supporting brain health and most recently, on behaviour change to promote good brain health.

So, we have a fantastic panel here. An all-female panel, which is brilliant to see! And so, we’re going to just spend a few minutes just hearing about some of the work that you each of them have been doing. Thank you.
Well, it’s fantastic to be here after a couple of years being in Australia, locked down with Covid and not being able to come to any international meetings. It’s wonderful that my first meeting is on dementia. In my talk today, I will set some of the landscape for dementia prevention and for thinking about the big picture.

In the last five years there has been a huge amount of research published from observational studies and trials, so the field has really taken a major leap forward. There’s been some very significant papers. We’ve had the Lancet Commission report, the US Academy report, we’ve had the WHO guidelines, there’s been some very big data synthesis projects. We’ve also seen much increased collaboration globally amongst researchers, with Miia being a significant leader in that area. We’ve got the International Research Network on Dementia Prevention and the Worldwide Finger Movement. And we’ve got much greater engagement of governments and researchers working together with the inclusion of dementia risk reduction in national dementia plans.
So, we’ve really come a long way, but it hasn’t been fast. It’s taken us a long while to get to where we are. I think that Lenny’s comment in the session before that knowledge is progressing all the time is really important. And this slide illustrates an example of our knowledge on physical activity. So the reason we know physical activity is a risk factor for dementia is because back last century, about 60 years ago, when people started the longitudinal aging studies, they included measures of physical activity. And then, after decades of following all these people, they realised that the people who were more physically active, didn’t develop dementia at the same rate. So that knowledge then led to clinical trials. And then we were able to conduct data synthesis on the publications from the observational studies and trials. This led to the WHO guidelines having enough evidence to make a strong recommendation that physical activity is an effective for reducing the risk of cognitive decline and dementia. So, research is slow, but the evidence is accumulating all the time.

**What are the risk and protective factors?**

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<thead>
<tr>
<th>Risk/Protective factors</th>
<th>2020</th>
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<td>Physical activity</td>
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<td>Education</td>
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<td>Cognitive engagement</td>
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<td>Social engagement</td>
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<td>Hypertension treatment</td>
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<td>Diabetes management</td>
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<td>Cholesterol management</td>
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<td>Healthy weight</td>
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<td>Stop smoking</td>
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<td>Manage stress and depression</td>
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<td>Avoid antichol medicines</td>
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<td>Avoid head injury</td>
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<td>Reduce air pollution</td>
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<td>Y</td>
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- Combines findings from reviews of observational evidence and interventions
- Table does not indicate age at which risk factor is important
- Table References:
  1. Livingstone et al, Lancet Commission, 2020
  2. World Health Organization Guidelines for Risk Reduction of Cognitive Decline and Dementia, 2019;

*Adapted from: Krivanek et al, Promoting Successful Cognitive Ageing, Journal of Alzheimer’s Disease, 2021*

*See also: Yu et al, JNPP, 2019; Anstey et al, JAD 2019*
So, what are the risk and protective factors for dementia? Now you will have seen various lists like these. I've got lists shown here from four authoritative sources: the Lancet Commission; WHO guidelines; the National Academy of Sciences report; and the Institute of Medicine.

Now you can say that as time goes on the list gets longer but the tests don’t agree altogether. This is in part because papers tend to focus either on risk reduction, (what’s been effective for reducing risk, which is what the WHO guidelines and the National Academy of Sciences focused on), or they focused on what are the risk factors. We know a lot more about what the risk factors are than we know about how to reduce them, and obviously it’s the latter that’s important to us today.

Across these lists there is strong agreement on physical activity, education, cognitive engagement and treating hypertension. We also have agreement on smoking, limiting unhealthy or hazardous alcohol drinking and a number of the other factors you can see on this slide. But there are some differences. The Lancet Commission didn’t mention a healthy diet (in its table of key risk factors), whereas the WHO guidelines did find sufficient evidence to recommend a healthy diet to reduce risk of cognitive decline in dementia. So, it isn’t completely straightforward. We do know a lot, and the evidence is accumulating all the time, and there’s a lot that sits behind, as it were, each of these documents.

Isn’t this all just healthy lifestyle? That’s simple?

- No – it is complicated because:
  - We know more about what the risk factors are, than how to reduce them
  - There are overlaps with chronic disease, but these occur at different ages, risk factors differ between and within countries, and there are risk factors that are not shared
  - There are new risk factors emerging all the time, everything we know now is based on the past, and on people in their 80s who had different lives than us
  - People are not interested in preventing dementia when they are young – they have other pressing needs and wants
  - Many of the risk reduction strategies require adequate resources

I am often asked - why can’t we just copy what’s been done for heart health and just apply it to brain health, isn’t it all the same? What’s new? Why do we have to keep doing research on this topic? And I always say no, it’s actually quite complicated. We know a lot more about the risk factors than we know about how to reduce them. Yes, there are overlaps with other chronic diseases, but often they’re occurring at different ages and their outcomes are at different times in their life cycle. There are also risk factors for dementia than not shared with other chronic diseases, and vice versa. And also the level of efficacy or the level that a risk factor needs to be modified, might be different. So, for physical activity we know that you need quite a high level to have a neurological benefit, whereas for other conditions like falls prevention balance exercises may be more important. The same intervention may not work across all outcomes at the same level of intensity.

There are also a lot of new risk factors emerging and basically everything we know about dementia risk factors is based on cohorts of people who are very old or have already passed away. What we really need to understand is the risk in emerging cohorts. The people who have been exposed to Covid, diabetes, obesity, whose brains have been shaped by the internet, who have had a different diet because of the availability of processed foods. So really, we need to keep looking at emerging risk factors all the time.
Another factor that we need to consider is that the average person in the street doesn’t really prioritise dementia prevention and dementia risk reduction. We’ve done national surveys and we have looked at this. Whilst people don’t want to get dementia, and they are fearful of dementia, they have absolutely no intention of changing their behaviour. They also have a lot more urgent priorities to deal with in their daily lives. And many of the risk reduction strategies actually require quality resources either personal, psychological, family or social resources, and some people just don’t have those resources or access to them.

What does it mean to take a population approach to dementia prevention?

- Engage a broad range of stakeholders – governments, industry, workplaces, town planners to address factors that affect brain health through public policies and organisations
- Aim to make environments healthy and choices that will promote brain health the easy choices (e.g. physical activity, healthy food, increasing education, reduce air pollution).
- Work with other non-communicable diseases
- Another way of viewing this is that cognitive health is an asset or a form of capital, and we need to invest in it through the life course to reap the dividends of having a cognitively healthy older population

Many people would endorse a population-based health approach to dementia prevention, but people mean different things by that. Generally, it would mean that we need to engage with a broad range of stakeholders. We need to have governments, we need industry, we need workplaces, and we need town planners, to together address the broad range of factors that affect brain health through the life course from birth. We need to be really thinking about early childhood education and growing better brains across the community. We need to make environments healthy, so people don’t have to make the individual choice themselves, but their environment actually facilitates their behaviour in a way that is brain healthy or neuroprotective.

We have to work with other non-communicable diseases where the science indicates that is needed, and where it makes sense. Also, we need to think about this in terms of healthy aging. So, we don’t only need to work with other chronic diseases, but we also need to work with programmes to promote healthy aging over the life course.

And just to finish off from me, another way of viewing this is that cognitive health is an asset. It’s a form of social capital and we need to invest in it through the life course to reap the dividends of having a cognitively healthy older population.
Thank you so much it is my great, great pleasure to be here today and see you all in real life. As Kaarin said, we have been really missing this opportunity to have this social interaction and discussions. And I’m very happy to talk about prevention and risk reduction and I will especially focus on how we are moving from observation to action and towards personalised dementia prevention and global strategies.

I think there has been a lot of progress in the prevention field, but it takes time, like Kaarin said. We need to have this time perspective. As we have just heard there is this great prevention potential, around 40% of all dementias may be linked to modifiable lifestyle related, vascular and environmental risk factors. We have been working with the WHO risk reduction guidelines. For me it’s really a nice document setting out the strong evidence base for implementation activities, and it also describes what are the gaps in knowledge.
And given the multi-factorial aetiology of dementia and late onset Alzheimer’s disease, we probably need to have multidomain interventions targeting several risk factors and mechanisms simultaneously to really get the optimal preventive effect. At the same time, one size doesn’t fit all. We still need to refine and target the intervention so that we can maximise the individual’s prevention potential.

The Finger Trial provided the first evidence from a randomised controlled trial that lifestyle-based intervention can give cognitive benefits. And what I think is interesting alongside the effects for cognitive and functional decline new results are showing 20% lower risk for cardiovascular events, 60% reduced risk of multi-morbidity and better health related quality of life. There are also health economic benefits and clear cost savings if this model could be run on longer time and larger scale.

And one question is really, what dose is needed? How intensive this intervention needs to be to give these effects?
We have recently been analysing the Finger data and we can see this nice dose response relationship. What this showed was that for those persons who had active participation of at least 50% of the intervention we could see the clear benefit. What this means is there needs to be a more long-term commitment to see these effects for the brain health. I agree, as Karrin said, it’s not only a question of individual choice, but how can we enable the community to support this, to make healthy choices the easy ones.

And there are many multidomain interventions going on globally to test and adapt and optimise the Finger Model in different settings. I think this is very important to really make the interventions sustainable and feasible. We launched the World-Wide Fingers in 2017 to support these activities. Prospective harmonization is a key part so that it’s easier to compare the results, and we also want to share of course data but also experiences. We can always learn from the previous trials and take all the lessons learned to improve the models.
I think it’s really great that today we have 45 countries from all continents as part of this network. Since we started World-Wide Fingers we have for example the US Pointer study, we have MIND-AD, a MIND-China trial, Australia is having 2 trials. There is the LatAm-Fingers with twelve countries involved. There are many studies in Europe and also many low-and-middle income countries are starting studies which is important.

Covid has, of course, been a huge challenge as you can imagine for this kind of trials. What we did was we launched a Covid survey to try to understand the indirect effect of the pandemic on lifestyle and risk factors for dementia, medical care, and mental wellbeing.

Now, you may not see all the numbers here, but there are more than 20,000 participants already on this WW-FINGERS covid survey across many countries. And for me, it has been quite striking to see that there have been many negative effects of the pandemic and what you see is quite similar numbers on this in many countries. As you can see 50% are reporting less physical activity. There are more unhealthy snacks, more sleeping problems and more loneliness, and people also feeling that memory is not working so well. So clearly prevention activities are needed more than ever in this current landscape.

New technology & Digital solutions:
Personalized, Effective and Feasible, Scalable Interventions and Implementation

E-Health & M-Health tools
Machine learning and AI
Clinical decision support
The pandemic has been accelerating the use of digital tools, the concept E-Fingers. We need to use new technologies and digital solutions to support the interventions and measurements. Some of these examples I’m showing here using E-health and M-health tools were started before the pandemic. During the pandemic some trials were converted from real life to virtual. And now there are new studies using only virtual tools in the intervention or hybrid models.

And we are also using new technology and techniques to analyse the big data we are collecting, for example machine learning and AI. So, the concepts of E-fingers and AI-fingers are now developing very fast.

We are working with data harmonization, and I think this is very important that we really can accelerate discovery if we can share the data in an easier way within these trials. With harmonization we are not only focusing on clinical outcomes, but also biomarkers. I think this has great potential, if we could do more joint analysis, to enable us to really understand more about the many pathways to make even more effective interventions and new kind of discoveries here.
And finally, we are developing the next generation of clinical trials. In the future I think we can combine lifestyle and some disease modifying drugs. We have already first models in place like MIND-AD with lifestyle and medical food. In the Netherlands, there will be a larger trial with this combination among at risk persons. And we’re starting soon the MET-Finger trail with metformin, diabetes medication, using a re-purposed drug approach. And in the future, we could add to this cocktail more specific Alzheimer’s drugs.

So, we still need to refine the knowledge, but we also need to move on with the implementation, using the knowledge available and this needs collaboration where all key stakeholders globally are needed and that’s very important.

I’m very grateful for all your support, and I see really the prevention as the key element in managing the global dementia epidemic. Thank you so much.

Sarah Lenz Lock
Senior Vice President for Policy, AARP

Thank you. I would like to thank the World Dementia Council and the sponsors of this event, how incredible is it that we are actually able to get here together in person. It really is fantastic. I especially want to thank Lenny Shallcross and Josh Newlove for doing amazing work to organise this and get us all here despite the uncertainty of whether it could actually happen or not. I also want to thank my frequent collaborators who are here. It’s phenomenal to have Miia and Kaarin together on the stage. Thank you, Hilary, for that lovely introduction.

We have been working on identifying the evidence on what people can do to reduce risks to their brain health as they age over the last six or seven years. The Global Council on Brain Health is a collaborative. Many of you at the meeting today have been participating in our effort, and thankfully have shared your knowledge as leaders, as experts with us. Here in the UK, we have worked with the Alzheimer Society, ARUK, Age UK and others. We have seen the benefit of collaboration, the power of us getting together and sharing the information and knowledge. And I think the World Dementia Council is another perfect example of power of collaboration. And this is a critical juncture so that we can do exactly what we’re doing and I’m looking forward to questions and dialogue that we’re going to have in a few minutes.

Some of you may not be aware of AARP. Our name used to be the American Association of Retired People, but our name is actually now just the four letters! It’s like the artist Prince who changed his name to just a symbol. Our name is only the symbol of the four letters AARP now. We are a non-profit, nonpartisan organisation of 39 million people over the age of 50 and our mission is to empower people to choose how they live as they age.

And you know, of course, dementia is the cruellest thief of that choice.

The Global Council – or GCBH - is an independent organisation, which AARP supports to facilitate collaboration to foster better brain health for people as they age. You can see that we have members from Australia, from Sweden, the United States, the UK but we also have members around the world because we know that knowledge about what works to promote brain health doesn’t exist in any one place. Earlier, Lenny was talking about the accumulation of knowledge. What is fascinating to us at the Council is that this knowledge does exist, it does exist, and these studies about what works to promote brain health have been going on and we’ve been building on this knowledge for decades. But the progress that we have made in the last decade has truly been phenomenal because for the first time, Brain Health is a “thing” now. That is a tremendous difference from where we were when the G8 met and the World Dementia Council was first founded in 2015. Brain health was not even discussed as a thing back then.
So, the accumulation of knowledge is important, but the next step is perhaps even more important: the sharing and communication of that knowledge to drive change. We have to change attitudes and we have to change behaviours if we are going to be able to improve brain health of older adults. The Global Council has collected the knowledge of what people should do in order to maintain their brain health or to reduce risk for cognitive decline as shown here. But now we’re getting to the really hard part, and that is the how. It’s all very well and good to tell people they need to exercise, but as you all know, behaviour change is hard. As you know, the change of just getting back into the office after COVID and two years of being away, how difficult it was to change your actions to do something different, even doing something that you had done every day for the previous several decades of your life. Change is very difficult and so we can’t expect people to change if the responsibility to do so sits on the shoulders of those individuals alone.

So Philip, you ask - how do we do it now and what can we do to make it faster? We have to get more people in the room having this conversation with us. We have to work with policymakers. We have to work with employers. We have to work with health care providers, and we have to get them into the brain health conversation along with ourselves in this room and show them, give them the knowledge, the motivation and the confidence that we can change the culture to drive better brain health for people as they age. We have to show them that we can provide the supports that people need to actually help them implement and sustain healthy lifestyles. And I am not talking about reducing risks to brain health only for those who are still cognitively, functionally, all intact. Instead, we have to think about this as a spectrum of driving behaviour change for better brain health for people of all ages and health conditions. The need of brain health behaviour change is also for people already living with mild cognitive impairment through the disease states all the way to the end of their lives.

I have talked a little bit about where progress has been made. The fact that we are at an international dementia meeting talking about prevention, the very first panel of the day of the WDC, with four ladies as the speaker line-up, is an example of that progress!

So, what’s new? I think we have to go this idea of implementing thresholds of marginal gains, how do you build on the individual brain health pillars step by step to get to the point where people implement enough brain healthy behaviours over time that you actually can make a difference in reducing risk. I think that’s going to be a critical area next. But the other area, and I think that we’re seeing signs of change in this already, is focusing on building brain health equity. It’s the members of our society who are most vulnerable, who are at greatest risk for dementia. We know in the United States that African Americans are twice as likely to have dementia as those who are white, and Hispanics a third more likely, and women – particularly women of colour who are most vulnerable of all. So, finding ways for communities
and for policymakers, at all levels of society, to support those communities who are most vulnerable is absolutely the next critical step that we have to take.

In summary, to maximize change, all sectors must contribute to make brain healthy behaviours easier to sustain. All sectors must understand that they are actually going to benefit from these changes that we need to put in place. We need to, and can, sustain brain healthy behaviour as the new Global Council on Brain Health report sets out. Employers are going to benefit because as the demographics change and our workforce ages, it’s going to be critically important that the brains of the workforce is there to support our economic wellbeing. And of course, governments and families are going to succeed when they are not outlaying huge sums of money for care for illnesses and disabilities that could have been prevented or delayed. And governments are going to receive the benefits of the taxes we’re all going to pay as our brains stay intact. Because better brain health enables us to continue to earn, contribute to our communities, and we can continue to enjoy life.

So, Lenny I’m awfully glad this meeting didn’t happen in December, not only because the weather is better now, but because it enabled the Global Council to jump into this next step where we just published our report and infographic last week on how to drive brain health behaviour change. And the question here is not only how we institute brain health behaviour change amongst individuals, but how we sustain that change. Because one day of exercise is not enough, or one piece of good food is not enough to reduce risks and improve quality of life for people living with dementia.

So, I thank you for listening and look forward to the conversation.

Hilary Evans  
Chief Executive, Alzheimer’s Research UK

Right, really comprehensive talks there! I think you’ll agree with covered a huge amount of ground in the last 10 minutes or so. I’m sure that all will have provoked some questions from our audience. Does anyone have a question they like to open with a couple of? Paola from ADI look like she has a question. There are some mikes in the middle, or you’re welcome to shout.
We will shout. It is so lovely to be with everyone together! It’s really important. All of you have pointed out how difficult it is to solely rely on individual choices. I have learnt so much in the last two years of the pandemic. I kept thinking if you repeated the message enough each of us would take responsibility to do something. But now with Covid we know that is not true. You can tell someone until you are blue in the face to do something that is good for their health, and they just don’t listen!

I have really a reflection and a question. There are things in the twelve factors like pollution. What are you going to do about pollution? This is also linked to climate change. It is so complex. And there are simpler steps like healthy lifestyles which we know now people are not all going to do. So, in your experience is there any immediate action we should be taking in the next, three years or five years to take this forward? Thank you.

Thank you ok who wants to kick off with that. Sarah, do you want to start with?

I think it’s incredibly important that we get in a room but when there we stop talking about twelve factors, eight factors, six factors, five factors, three factors and so on. I think that we have to get in a room and we have to agree on common messages and a common goal and knock them down one at a time. I think the plethora of different messages is very harmful and very confusing. If we rally around a set of messages and clearly agree that we’re going to hit on some specific messages, that will make an enormous difference.
But we have to tap into the motivations of the actors that we need. So, for example, if we're looking at individuals, we have to give them the tools and the skills that create the environments. But we have to understand what it is that will motivate their change, but we have to also understand what is going to motivate governments to change and what is going to motivate employers, health care providers in the individual components.

And then work on it with a sustained communications campaign. I think we have an enormous opportunity. The World Health Organisation, I know Tarun we're going to hear from a little bit, but they're moving in this direction and are shortly about to release a paper on behaviour change. And this is a great opportunity for momentum going forward.

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**Professor Miia Kivipelto**  
Professor in Clinical Geriatrics, Karolinska Institutet

Yeah, I fully agree. On the first increasing the knowledge and awareness is important at all levels: individual, society, policy, everywhere. To increase knowledge about what can be done. That there is this prevention potential. And it’s not just through talking about preventing dementia. Brain health may, as you say Hilary, also motivate people to do more.

I think that it’s never too early to start to prevent. Maybe we should focus on younger persons, even at school where you create your habits. Learning thinking that this is something that is good for your brain health is good for the future. So that is one thing.

We also saw from Finger, as I described in my talk, that it takes time. It requires quite a lot to make the long-lasting changes and the individual can’t do them always alone. In the trial, when we had a control, where we only gave advice, nothing happened for that cohort. People know the theory, but you really need to have more hands-on support. How to do that, how to have the resources, what is the idea or optimal way and how the environment can support making healthy choices easy ones. I think are important questions.

Finally, I’m thinking what we have learned from the pandemic, like new technology, which I briefly mentioned. Could it help us? Could it somehow support interventions giving more motivation, at least for some target populations if maybe not for all? I don’t think it can totally replace, because we need to have the social interaction, but it could be some kind of hybrid model where you can use new technology to support people but also to reach persons who wouldn’t otherwise engage. So, there might be an interesting area to study that.
I would just to add to what everyone’s already said, I guess my perspective is that we do need a cohesive strategy. This needs a broad stakeholder group. The academics provide the science, but we need the lobbyists, the policymakers, and so on to develop strategy.

I think we can pick off some of areas and deal with them separately. For example, on air pollution there has been a change. In China with the Clean Air Act they demonstrated reduction of air pollution was associated with improved cognition, and that’s through public policy change. So, I think there are some the issues which we could have specific strategies and campaigns and lobby governments on. And do so in partnership with other areas of chronic disease, so obviously you know lung function, asthma etc are all going to benefit from changes to air pollution.

And then we’ve got the bucket of health-related behaviour change type modifications. So, I think I think we just we really need a high-level strategy and to achieve that we need everyone working together, people like ADI, AARP all of you, and getting into the media as well.

Well one of the things that that comes to mind is this idea that there’s appropriate strategies for each individual. But I think changing the narrative about dementia and talking about brain health is really a critical component of it. The idea that nothing can be done is a very destructive message. I think in the long haul it’s very important to influence governments to talk about how dire the situation is, because we need the funding, no doubt. But finding the right balance between talking about the urgency and then providing hope that’s something can be done. Because both for individuals before they get to the point of dementia and then for those who are living with dementia, I think that message of hope is incredibly important.

And if I may just quickly add, you made a very good point, I also think hearing that voice of the patients and persons who have the disease, like we did today, is so important. What are the expectations? What is needed? And we should always have this in mind. We have in our MIND-AD trial, interviews with the patients, really understanding how they would like to have the interventions, what is important. And it’s not only cognition. It’s the quality of life and the functional level.

And I really like the idea from Sarah of hope related to action. There is always a need for more studies, but we need to have hope and we need to have action related to the call.
I think just to add them to that Alzheimer’s Research UK we launched just over twelve months ago our first brain health campaign, Think Brain Health. And that reached an entirely different audience to who we would normally be talking to as a charity. We were reaching younger people, people in midlife, it was very aspirational, it was very positive. The imagery was very different. And it was all about empowering people about what they could do. And engaging them in a very different way and using very different language from maybe what we’ve used before as a dementia organisation or as a sector. What we saw was a much better response rate to that campaign than we’ve ever seen before.

So, what we know is that that people want to learn, and I think we’re engaging with some of these challenges that are out there and lots of other organisations and issues are behind, such as climate change or air quality. Talking about this from a dementia lens is a different perspective. But we’re not then talking about dementia risk reduction, which isn’t particular engaging. We’re talking about the things that you can do to look after your brain and the fact that the brain is something that we can look after and the things that we can do to improve our brain health. And what we have found is that people want to engage, they want to know what they can do, because they’re terrified of dementia and so, I think that there is a different kind of motivation, there.

We’ll move to another question. Does anyone else want to ask the panel?

Thanks very much. I just wanted to follow up on what Sarah said about brain health equity. I think that the people who might benefit the most are those that are very much at risk of getting left behind. We don’t have much data on ethnic minorities who are most at risk. So, I am just curious about the panel’s views on how we can catch up policy wise with regard to those people who are at risk of being left behind at a time when we can really do a lot about our brain health?
Yes I think that’s really front of mind in terms of our Think Brain Health campaign and actually this year our big focus is in terms of how we get those messages too hard to reach communities. So, I’m sure the panel will have something to say. I think Sarah let’s start with you and we can move along again.

Sarah Lenz Lock
Senior Vice President for Policy, AARP

I think part of it is being in a community, at the local level, as a trusted partner for the community. I’ll just say from AARP’s perspective that the idea that if you show up and you’re gone quickly, that you’re just coming in for what you want, you’re just asking them to participate in research, is a recipe for failure. Being there supporting the causes, the issues, that the communities themselves tell you they’re interested in, makes all the difference in the world. And I think that there’s a lot of trust that we have to rebuild before we can get there.

So, I think that’s most fundamental, but from a policy perspective if we can begin to lead and show that the efforts are being made to be inclusive in research that will help. To be supportive and providing supports in the community and finding the communities that are most vulnerable and addressing their concerns first.

Professor Miia Kivipelto
Professor in Clinical Geriatrics, Karolinska Instutet

Yeah, I fully agree. From the research point of view, it’s so important to include diverse population in the studies. In the US-Pointer study, where we have had the support from Alzheimer’s Association, we have had the goal to really increase the diversity of patient groups who are normally not part of trials. And the lesson so far has been that you need to have this more community-based involvement to take the persons that that’s very, very important.

We have LatAm-Fingers in Latin America with twelve countries. I’m sure we will learn a lot, what’s the best way to in case like this. With ADI we want to work in more low- and middle-income countries. Again, maybe the same model, but you need to have the local understanding and support to get there. So, from the research point of view, I hope we can improve our models in the future.

Professor Kaarin Anstey
Professor of Psychology and Director Ageing Futures Institute

I think just to add to that, we can require it in our funding policies. I agree we have to work with communities, we also have to make resources available to do that. And often that’s only achieved by actually making a requirement that a certain percentage of funding is allocated to those communities. In Australia we have a problem with our indigenous communities, with shorter life expectancy and higher rates of dementia, so we have special funding allocated to research into dementia in indigenous communities, and it takes a lot longer to develop the relationships with those communities, but there’s been some fantastic progress made through during that. We’ve also had to develop new tools, new assessment tools, we can’t make assumptions that the way we do things, the way we assess cognition and so on, is valid in other cultures and communities.
Right, I think we probably need to wrap up this session here. I’ve promised to try and keep to time. We’ve got some other fantastic speakers that we want to make sure we’ve got time to hear from. Thank you to this wonderful panel, I think it’s such an exciting area to be working on and there’s huge developments and potential which we will be talking about in the coming months and years. So, thank you panel.
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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