Getting Public Health to Address Dementia Risk:
A Center of Excellence Conversation

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More than 6 million older Americans are living with Alzheimer’s, with the number projected to reach nearly 13 million in 2050. It has been estimated that as many as 40% of dementia cases may be attributed to modifiable risk factors, meaning that a concerted public health effort to address brain health may help to reduce these numbers and lessen the burden on communities.

Two significant barriers, however, have worked to impede public health action to address dementia risk reduction. First, public health has traditionally not seen dementia as a public health issue. Second, even if they are convinced it is a public health issue, lack of funding often limits the issues state, local, and tribal public health agencies can address.

The Alzheimer’s Association® Public Health Center of Excellence on Dementia Risk Reduction, which is funded by the Centers for Disease Control and Prevention, is tasked with helping public health officials overcome these barriers — by convincing them to act on dementia risk reduction and by assisting them in efforts to address the risk factors for cognitive decline and dementia.

On July 14, 2023, at the Alzheimer’s Association International Conference® (AAIC®) in Amsterdam, the Center of Excellence hosted a conversation with international researchers and organizations to discuss successful ways to engage public health agencies on brain health. The purpose of the conversation was to learn, based on the research and experiences in other countries, what strategies and tactics have been successfully employed in convincing public health officials to act on brain health, what could be done to make it easier for public health to prioritize dementia risk reduction, and how public health officials can best be supported in this effort.

Following is a transcript of the conversation.
Participants

Kaarin Anstey

Kaarin Anstey is a Scientia Professor and Australian Research Council (ARC) Laureate Fellow in the School of Psychology at the University of New South Wales in Sydney, Australia. Anstey completed her undergraduate and honors training in Psychology at the University of Sydney and her PhD at the University of Queensland. After completing a National Health and Medical Research Council (NHMRC) Postdoctoral fellowship at Flinders University and the Prince of Wales Medical Research Institute, Anstey moved to the Australian National University in 2001 where she later established the Centre for Research in Ageing, Health and Wellbeing. Anstey moved to the University of New South Wales in 2018 where she is the Director of the Ageing Futures Institute. Anstey has been a Chief Investigator on the ARC Centre of Excellence in Population Ageing Research (2011-17) and is Co-Deputy Director of the current ARC Centre of Excellence in Population Ageing Research (2017-2024) where she also co-leads the Cognitive and Decision Making Stream. Anstey is Chair of the International Research Network on Dementia Prevention and a member of the Governance Committee of the Global Council on Brain Health, an initiative supported by the American Association of Retired Persons and AgeUK.

Matthew Baumgart

Matthew Baumgart is vice president of Health Policy for the Alzheimer’s Association in the United States. He heads the Public Health Center of Excellence on Dementia Risk Reduction, funded by the Centers for Disease Control and Prevention (CDC), and oversees the Association’s programmatic risk reduction efforts. In addition, Baumgart directs the Association’s global public policy efforts, working in collaboration with Alzheimer’s Disease International, the World Dementia Council and the World Health Organization. Baumgart joined the Association in 2009 and has served in roles overseeing policy development, public health policy initiatives, federal affairs and state government affairs. He represents the Association on several boards and committees, including the steering committees of the National Hypertension Control Roundtable and the Milken Institute Alliance to Improve Dementia Care, the executive committee of Dementia Friendly America, and the leadership core of the Public Health Center of Excellence on Dementia Caregiving.

Kristen Clifford

Kristen Clifford is chief program officer at the Alzheimer’s Association, overseeing the organization’s efforts in care, support and risk reduction. Clifford leads care and support services offered across the organization to those affected by the disease; health system outreach and quality improvement initiatives; long-term care initiatives focused on person-centered care delivery models; and growth strategies for reaching more individuals through quality improvement, education, and supportive programs and services. Clifford has nearly 20 years of experience in patient advocacy, health care relationship management, medical education and research. She served as national vice president, Healthcare Access for the National Multiple Sclerosis Society from 2016 to 2020. In this role, Clifford led initiatives for individuals living with MS, health care providers, and health system initiatives, including launching ECHO MS, developing health care programs to meet the needs of underserved patients, and developing a community health relations program to build successful and meaningful volunteer engagement.
Kay Deckers

Kay Deckers works as an Assistant Professor at the Faculty of Health, Medicine and Life Sciences, Alzheimer Centrum Limburg/School for Mental Health and Neuroscience, at Maastricht University in the Netherlands. Deckers was trained in neuropsychology and epidemiology. In his research, he investigates the effects of risk and protective factors for cognitive decline and dementia within several population-based cohort studies. He was one of the developers of the validated “Lifestyle for BRAIn health” (LIBRA) score, a modifiable dementia risk index, which quantifies an individual’s potential for dementia risk reduction. Additionally, he is concerned with preventive strategies for a brain-healthy society, such as the development and rollout of public health awareness campaigns and the development of the MijnBreincoach app brain-health tool. Deckers is member of the advisory board of the National Dementia Strategy 2021-2030 (Dutch Ministry of Health, Welfare and Sports) and is member/co-chair of the INTERDEM (INTERvention on DEMentia) Task Force on Primary Prevention. His two goals are (1) to raise more substantial awareness in the general public that people can do something about their own dementia risk and improve their brain health; and (2) to implement the topic of brain health/dementia risk reduction in primary care.

Amalia Fonk-Utomo

Amalia Fonk-Utomo is the Head of Accreditation for Alzheimer’s Disease International (ADI) and is based in the Netherlands. Amalia has a background in creative marketing. After working for the global agencies Lowe, DDB and Ogilvy, she started her own agency, Juara, which led her to do pro-bono work with Alzheimer’s Indonesia. She created the campaign “Jangan Maklum Dengan Pikun” (“Do Not Underestimate Memory Loss”). She also created a 10-warning-signs brochure, which has been translated into more than 25 languages. Since moving to Groningen, Netherlands, Amalia has been active as Chair for Alzheimer Indonesia Nederland Foundation and as an Honorary Board Member for Alzheimer’s Indonesia.

Lisa McGuire

Lisa McGuire is Lead for the Center for Disease Control and Prevention’s Alzheimer’s Disease Program, with more than 100 articles and book chapters on aspects of cognition, caregiving, and aging. McGuire is a member of the National Alzheimer’s Project Act Federal Advisory Council; National Advisory Committee on Seniors and Disasters; Editorial Board of The Gerontologist; co-lead for Healthy People 2020/2030 Older Adults and Dementia Including Alzheimer’s; and holds Fellow Status in the American Psychological Association and the Gerontological Society of America. As a former caregiver for her mother with mixed dementia, McGuire is professionally and personally passionate about caregiving and issues related to dementia.
Katrin Seeher

Originally trained as a psychologist, Katrin Seeher has been working with people with neurological disorders, such as dementia, and their families for almost 20 years. In her current role at the World Health Organization’s (WHO) Brain Health unit, Seeher is responsible for the implementation of the Global Action Plan on the Public Health Response to Dementia, 2017-2025 and has been coordinating the development of WHO’s position paper on optimizing brain health across the life course.

Margaret “Candace” Spradley

Margaret “Candace” Spradley is a public health advisor/project officer for the Alzheimer’s Disease Team in the Healthy Aging Branch (ADHAP) of the Centers for Disease Control and Prevention. She brings to this role more than 20 years of experience with non-profits, including directing continuing education programming, managing projects/programs, and working with diverse stakeholders in the medical and scientific communities of rheumatology, microbiology, pathology and magnetic resonance in medicine. Spradley previously worked with the CDC Foundation on the project, “Maintaining the Physical and Mental Well-Being of Older Adults and Their Caregivers During Public Health Emergencies,” in which CDC and ADHAP provided technical assistance utilizing funds from the CDC Foundation’s COVID-19 Response Fund.
Matthew Baumgart: Good afternoon. We really appreciate you taking a couple of hours to be a part of this conversation today.

Opening Presentation

Matthew Baumgart: To tee us off, I asked Kaarin to give us a short presentation. She has done a lot of thinking on this and a lot of research on this over the years -- and has some practical experience out of Australia. So, I asked her to set the stage for us by putting some ideas and thoughts on the table about how we can get public health agencies to work on dementia risk factors.

Kaarin Anstey: Thank you for asking me to speak. I wasn’t quite sure how to pitch this. So, these are just some thoughts really to get the conversation going.

I want to step back and say, what is a population health approach? In the Alzheimer’s area, most people are not working in population health. If you look at this conference [AAIC] or conferences in Australia where I’m from, we have a limited amount of real population health research. So, I want to step back and say, population health addresses all influences on health, not just the clinical influences that you would see in the health system. We are looking at whole groups of people — populations — not just the people that are attending the clinics. But, most of our risk reduction work is really based on very highly selected groups of people in the clinics.

The population health approach also aims to improve health status and reduce health inequalities. I think that is another really big feature in this approach. Having expensive, intensive, personalized medicine approaches for risk reduction are fantastic for the few people who can receive them. But they will actually increase health inequality. A population health approach ideally will improve everybody’s health status and reduce those inequalities.

The socioecological model, which actually came from the CDC [Centers for Disease Control and Prevention], was originally developed for HIV and illicit drug use research. But I think it is an interesting way to help us think about this issue and to frame what we are looking at.

The socioecological model is a public health model premised on the idea that to achieve sustainable change, prevention efforts must focus on the different levels of influence surrounding an individual. More information is available on the CDC website.
With dementia and dementia risk reduction, most of us are focused, at least in academia, on things like behavior change and interventions and risk assessment, which is really focused at the individual level. We also focused on chronic disease management. But we also need to look at the social settings in which this is taking place: primary health care, workplaces and community groups. Another thing that we need to look at is the environmental setting of the country or region. And then finally, we need to look at the sectors of influence: government, which is who we are trying to influence in this conversation; advocacy groups like Alzheimer’s Disease International [ADI]; and the public health system.

I think in the socioecological model, we should be including some of the big corporations. Groups like Amazon and Meta. Our health is actually being influenced now by some of these very big companies. We are trying to think about the whole social context in which people live and how health is being influenced and how dementia risk is being influenced. We need to look at the whole big picture.

In terms of going to government, based on my own experience, I think people are still very much focused on the individual risk reduction approach with brain health. And that’s because I think that is what people understand. They understand messaging about physical activity and diet. The default is to think about individual health in the health system. You really need to get the argument straight for policymakers. Be very clear and convincing around why we need to take a population health approach and why it is economically beneficial. At the end of the day, the economics has to come in.

The argument that I put together, which others have also put together, is that the risk factors for dementia come from the multiple domains that affect human health. They don’t just come from the behavioral area. They come from air pollution, education, and cardio-metabolic disease.

Cognitive impairment and dementia are highly prevalent. One in five adults over the age of 70 has cognitive impairment, according to the Health and Retirement Study data. About 6% to 8% of older adults — those over the age of 65 — have dementia. Altogether, that is about 1 in 4 people — 25% — over age 70, which means that we are talking about something highly prevalent, unlike some other diseases which are not highly prevalent where a population health approach isn’t what’s needed. This is the sort of disease where we absolutely need to be looking at a much bigger picture. And then on top of that, the modifiable risk factors account for a large proportion of risk for dementia.

Clearly, the population health strategies have the largest potential to reduce future incident cases. Just the logic of that needs to be communicated, and then the economic argument needs to be made on top of that.

I am not an economist, but there are three parts that I think are important to the economic argument for policymakers.

One is the cost effectiveness of the multi-domain intervention. We have already shown that highly intensive interventions like the FINGER trial and trials that we
have conducted are cost effective. By theoretically reducing cognitive decline and reducing the risk of dementia, we would save money because dementia is such an expensive disease. It costs the health system so much that it is cost effective to do risk reduction even for that small group of people who are privileged enough to participate in those highly intensive interventions.

But there is also cost effectiveness research that could be brought into this argument with policymakers around the individual risk factors. There has been a lot of work looking at the cost effectiveness to governments of reducing smoking. There is cost effectiveness work around healthy diet and physical activity. If you are trying to build the argument for government, we could draw on all of that other literature, which was done in a recent review led by Sebastian Walsh.

The third area that I think needs to come into the economic argument for the public health approach to dementia risk reduction is healthy aging. We are in the decade of healthy aging. If we sift through the UN's [United Nations] documents and the WHO [World Health Organization] documents on aging and the decade of healthy aging, we can show through the longevity dividend that there can actually be an economic benefit from population aging.

At the moment, as we are seeing an increase in longevity globally, we are also seeing an increase in disability and chronic disease. So, we are not getting an economic benefit from the increased longevity. But, if we promote healthy aging — and reducing risk of dementia is a huge part of that because of the shared risk factors with chronic disease — we can actually start to turn that around. We can get a benefit of the increased longevity because people are able to work longer, pay taxes longer, and contribute more, such as taking on unpaid care roles.

These are the three parts to the economic argument that I think we can take to government. If an economist does it, I think it is stronger than us. So, in terms of the strategy, the question is who do we need to enlist in this effort?

In another paper published by Sebastian Walsh, we discussed the advantages of a population approach where it's not requiring people to individually decide to reduce their risk of dementia. It is creating an environment where that is the default option.
It is really, really difficult. You can see at the moment with the cost of living crisis in Australia where people are starting to cut back on healthy food, which is going to increase dementia risk. Or during the pandemic when people stopped physical activity and started treating themselves with food because they were stuck at home. It is really complicated. But the ideal population health approach would change the whole environment to make better health choices and healthy lifestyles the default option.

There has been some other work looking at the different things that we would need to do to achieve a population health approach. We need to look at education, public messaging, workforce education and so forth. An example: if you want to address obesity and physical activity, the individual approach, which is what we focus on most, is identification of at-risk individuals via routine health checkups and referring people to programs, which is good. But a population approach would be looking at investing in walking and cycling infrastructure, investing in more green space, and designing buildings to make staircases more prominent. There are a lot of examples about the different ways of approaching the same risk factor from an individual approach and a population approach.

There is not one right or wrong way. I think what is happening is, if you look at this whole space of dementia risk reduction, it is like a natural evolution. We had to do the individual risk reduction research to find out what works. It was essential. You cannot have population strategies without the individual. The individual is what’s informing the population strategy. Some people think it should all be population health and no individual; some people think it should all be individual, no population health. The two have to work together, and they inform each other all the time.

**Opening Comments**

Matthew Baumgart: Thank you.

I have a lot of questions. But before I ask any, I want to give everybody a chance to react to Kaarin’s presentation and add any thoughts you have. You can either react to something that Kaarin said, add to it, or disagree with it. Then, once everyone has a few minutes to say a few words, we can dig into a conversation. Kay, why don’t we start with you, if you have anything that you want to add to the table.

Kay Deckers: Thank you, Kaarin, for this interesting view. I totally agree with you. We have to combine individual and population level approaches.

In our approach, we use a public health campaign focused on dementia risk reduction implemented through municipal health services. They are responsible for health policy in the Netherlands on a region level, and they pick the topics they want to focus on and invest in. We always try to get dementia risk reduction on their agenda. We have a positive framing. We focus on all the positive things that people do right and where there is some room for improvement.
In 2025, we will also start a booster campaign, focusing on those with low socioeconomic status and people with a migration background. As Kaarin said, we often increase the gap between the high and the low socioeconomic status with these kinds of campaigns. The campaign is being co-created with these high-risk groups to have their ideas that are in line with our own ideas.

We also developed an app, the MyBrainCoach app, to give people an idea of the room for individual improvement in their brain health. We have found that people really appreciate knowing that they can do something about their brain health. We are really cautious with the measures that we give; we talk about “brain health”; and we focus on the positive.

My own view is that we have to go through primary care — general practitioners [GPs]. I would guess that about 80 percent of the dementia risk factors overlap with cardiovascular disease. In the Netherlands, we have an existing cardiovascular risk management program implemented by GPs. And I think that we can just add brain health to this as a topic. I would put my money on implementing dementia risk reduction in primary care.

Matthew Baumgart: Thank you, Kay. Katrin.

Katrin Seeher: I fully agree with what has been said.

Prevention and promotion are key. They are integral parts of the two global mandates that WHO has in the area. One, the global dementia action plan and, second, the new intersectoral action plan on epilepsy and other neurological disorders. At WHO, they both have strategic objectives on promotion and prevention. We also released our position paper on optimizing brain health, which takes a life course approach. We are making it very clear you cannot leave risk reduction to the last third or end of life. It is a problem or issue across the life course.

What the concept of brain health also gave us is the opportunity of branching out. As Kaarin said, this is not just an issue for the health sector or a public health issue. We need to talk and engage multiple other sectors, multiple parts of government, and bring them on board. If we really want to do this at the population level, you cannot just focus on treating individuals or trying to convince individuals to change their behavior. They need the infrastructure, they need to live in environments that make it easier to be physically active, and so on. We need this multisection approach. Our brain health position paper includes determinants that we need to change or that we can influence, that are our levers, and where governments can become active.

We see how this works in the area of NCDs [non-communicable diseases]. We always look a bit envious at the NCD work because they have stronger data and stronger evidence. For dementia, we are very certain about the association between risk factors and dementia. But when it comes to interventions, evidence is more scarce. And when it comes to population-level interventions, it gets even trickier. So, when we look at our WHO guidelines for dementia risk reduction, they focus more or less on clinical guidelines and interventions for individuals. I
In its report, Tackling NCDs, the WHO has identified policy interventions to prevent and control non-communicable diseases. The most cost-effective and feasible to implement are labeled “best buys.”

We want to get there for dementia. Right now, we are just lagging behind in terms of evidence and research. But we are catching up.

Matthew Baumgart: Amalia.

Amalia Fonk-Utomo: I totally agree.

At ADI, we work with our member associations — and we have more than 100 members — to do risk reduction campaigns and education campaigns. We also have a campaign called “What’s Your Plan?” to promote the development of dementia plans, which should include risk reduction.

We also have World Alzheimer's Month in September. This year's campaign is “Never too early, never too late.” We focus on 12 risk factors. We developed an infographic with simple messaging. And our members can translate and adapt it to their local culture and language.

Our accreditation process includes risk reduction within the community. It's not just academic accreditations. We are challenging and reminding them to work together with the society and the government, with all other sectors. Education on healthy living within the society and community as early as possible is so important.

Matthew Baumgart: Thank you, Lisa.

Lisa McGuire: I really don't have much to add other than I wholeheartedly agree that, to truly make the impact that we are all desiring to see, it is going to take that multi-pronged, multi-sector approach — not any one group or organization can do it alone. It is going to take a lot of coordinating and collaborating to get a policy system and environment approach.

Matthew Baumgart: Candace.
Candace Spradley: I agree with Lisa’s comment. As they say, it takes a village. And I definitely think it is going to take that coordinated effort to start to see, or be able to look at, measuring impact.

Lisa McGuire: I think having meetings and dialogues like this where we can listen and learn what other groups, countries, and organizations have done is extremely beneficial because this problem is so complex. It really is talking about every aspect of human physiological functioning and behavioral change. It is almost like we have to get behavioral change experts and to keep pulling different groups of people together to really piece together this big plan.

**Types of Public Health Interventions**

Matthew Baumgart: Thank you. I came to this meeting with a lot of questions. Kaarin, your presentation raised some more. But before getting to some of those, I just want to ask a couple of clarifying questions.

Kaarin, when you talk population health, the examples you gave were all, as Lisa just said, policy and systems change, as we call it in the United States. The opposite you called individual health. Kay referred to it as what primary care doctors do. That’s clinical. To me, there is something in between those two. To me, there are population level, community-based interventions that would address individuals and individual risk factors. Kind of a hybrid. I think of the CDC’s Community Guide, where public health can go and find, short of policy and systems change, public health interventions that can be implemented in the community to get individuals to eat better or to exercise more or to control their hypertension.

I just want to make sure I understand whether you are classifying what I’m calling population level or community-based interventions that are individually focused separately from “clinical.”

Kaarin Anstey: I think this is a continuum. But there is a distinction between interventions where the individual has to take responsibility for changing their behavior, which could be done at a primary care level or at a government level, versus interventions which are changing the actual environment and the person doesn’t have to make a decision. It’s just enabling. We need both.

**Role of Primary Care**

Matthew Baumgart: The other clarifying question is for you, Kay, since you mentioned primary care. What is the public health role in getting primary care engaged? Understanding that the clinical evidence is not the same level of strength as perhaps the epidemiological evidence is, what is the role of primary care physicians and what is the role of public health in working with primary care?

Kay Deckers: In the Netherlands, the GP has a pronouncing role in advising people about health. If people hear advice from the government, they think, okay, that’s nice to
hear, but I lay that aside. But, in the interviews we conducted, if a GP says something to the person, the response is always, “Okay, the GP has a big influence on my decision regarding my health.”

While I agree that the evidence for prevention of dementia is still scarce, I think just from a positive framing, we definitely can say based on the evidence that we can reduce dementia risk. I think that is also an opening for GPs to start a conversation. What we see in our studies is that when people heard that they have a risk factor for dementia, they are really inclined to do something. They may already know that their diet is perhaps not that healthy. But if they know that doing something about it may also foster their brain health or reduce their dementia risk, that is a new input.

We also see this when we work with municipal health services. They have sent a message 20 times already to people that they need to exercise more or eat healthier. But if the municipal services have the extra insight that it might also help with brain health, with dementia risk, that is a new input, and the municipal services want to use it in their messaging. That is a new extra input for behavior change. But it’s difficult.

Matthew Baumgart: I want to make sure everyone feels like they can jump in at any time. Feel free to jump in even if the original question isn’t directed to you.

Kaarin Anstey: Well, just a couple of responses to Kay. I think you need to look at the country’s health system. Does the Netherlands have universal health care? Does the government provide the health care in the Netherlands so that everybody would have a GP that is covered by the government?

Kay Deckers: No. It is not provided by the government, but the GP is the referral person to health care in the Netherlands. Without insurance, you have to pay for your visit to the GP.

Kaarin Anstey: It’s this access that is key. What you described would work for the people who are accessing primary care and have a relationship with a GP. But in different health systems, what you described may miss a proportion of the population. That’s one issue.

Another thing that comes to mind: I 100% agree that you need a GP, but if your GP is telling you to exercise and eat healthy but you cannot afford healthy food, or there is no access to fresh food, or it is very hard to exercise, then you can be made to feel guilty. And then you end up making dementia a lifestyle disease and stigmatizing people by saying it’s their lifestyle.

So again, I think it’s getting the balance and getting all of the different pieces of the puzzle to work together. We can end up with some things going the wrong way by putting it all on the individual if we don’t have the other supports in place.

Kay Deckers: Yes, I totally agree.
Lisa McGuire: We keep talking about primary care and GPs, but I think we need to broaden that thought process. For example, many women don’t see a GP or a primary care provider, but they may be meticulous about seeing an OB/GYN who is providing pretty much primary care for that person. We need to think of some of those other specialties that somebody might go see as their primary care person.

Also, a lot more people, at least in the U.S., instead of seeing a GP are starting to see what people call the “doc in the box,” or visit urgent care, or go to chain stores that have clinics in them. We also need to think about the people who are providing care there. They may tell you that you have strep throat, but maybe they can also integrate a little bit of healthy lifestyle behavior or dementia risk reduction messaging in those visits as well.

And I don’t want us to forget about some of the more allied health professions — even your dental hygienist or the person doing your mammogram. There are so many different trusted health providers who have an opportunity other than a primary care doctor.

Kristen Clifford: As you mentioned, Kaarin, our systems are all so different. We can learn from each other around what is working. But the U.S. health care system is so fragmented that there are some unique challenges. Even if you do see a primary care provider and you do have insurance, they have five to seven minutes to cover many things. So, I think some of it is normalizing brain health messaging with the public so that they are empowered to initiate these conversations and understand what we mean when we talk about brain health.

To your point, Lisa, I was going to mention a very similar point. At least in the U.S. system, a lot of people have one or two places where they might get their information, and it often will not be a GP. It might be their OB/GYN, as Lisa mentioned. Or, as more treatments for Alzheimer’s become available, we might see what we’ve seen in some other diseases such as Multiple Sclerosis. Whoever their specialist is, whoever their prescriber for their chronic illness is, will then be their go-to for all health care, even though they’re really not meant to be that.

We need to be thinking about all of those different touch points and where we can start to influence and normalize. Thinking about how we talk about brain health with those different touch points in communities provides opportunity.

Candace Spradley: Also, Native Americans. There is a large clinic setting for those living on reservations, and there are a lot of intricacies in terms of that setting.
Katrin Seeher: I think, similarly, we should take advantage of whenever we can benefit from infrastructure such as regular appointments so that prevention messages are ingrained in people's thinking. In the sense of health promotion, we should include dementia messages in those visits also. That might help in the sense that it doesn't put the blame on the person. "You're doing something bad and that's why you might be getting dementia." Instead, if you are going for, say, your heart checkup anyway and dementia messaging is just folded into that appointment — "We're trying to get your blood pressure down now, and it will also help with preserving or protecting your brain" — there isn't the blame. I think that will also save resources. Use whatever avenue you can. Primary care is a good mechanism. And then whatever regular visits you have, set up dementia messaging within those.

Amalia Fonk-Utomo: In the low- and middle-income countries, where I came from — I come from Indonesia — we have universal health care insurance. But stigma on health conditions is really big. People have a universal health care system but are still afraid to go to a primary care doctor for help. They often don't want to go to the doctor and don't have a regular checkup.

The society — the cultural approach — is key to really changing the behavior sometimes. They hear more from society than they do from doctors sometimes. If the area, the country, does not really have good structures in the health care system — or if people avoid the health care system because of stigma — the social approach really works better in changing behavior for risk reduction. Educating people about the risk factors of dementia sometimes is easier when the doctor is not the one giving the information, but it comes from the head of the village.

**Convincing Individuals**

Matthew Baumgart: Kay, you said something else that I wanted to probe a bit on. You talked about how, when individuals hear that this might affect their risk for dementia, that it sparked interest, possibly action. And I am struggling with this. If you can't get someone to exercise, control their blood pressure, or change their diet when you tell them they could have a heart attack five minutes from now, how are you going to change behavior with the message that you might get dementia 40 years from now?

Kay Deckers: I think it is in line with awareness. What we see is that a lot of people do not know that these risk factors for cardiovascular disease are also risk factors for dementia. We surveyed people across, I think, seven European countries. We found that especially the cardiovascular risk factors — hypertension, cholesterol, diabetes, smoking — are not recognized as risk factors for dementia. I think a maximum 30 percent of the people know that. We also surveyed GPs and people working in primary care. We were astonished that 1 in 4 GPs or health care professionals did not know that these are risk factors for dementia. That is why we also focus on increasing awareness on this topic.

Matthew Baumgart: That raises the issue of whether we need to take a step back and spend a lot of time focusing on education as opposed to leaping to solutions. But do you think knowing about dementia risk helps in changing behavior on risk factors — that it is going to change behavior knowing that it may affect me 40 years from now?

Kay Deckers: That is something that we also came across in our project. We call it in Dutch “Far from my bed show.” You only see the effects of what you’re doing now in 40 or 50 years, and perhaps you don’t see any effects at all because you die of something else. It is a really difficult topic.

When we give lectures in our project, we sometimes skip the term dementia risk and use a more sexy term like “brain health.” That also helps involve younger people in making changes for their brain because they know that the brain is a very important organ — and they may not understand “dementia risk.”

That is the route we walk at the moment. But, it is a really difficult topic to engage people on.

Katrin Seeher: The long-term consequence is a tricky thing when it comes to behavior change because it’s something that is very distant — it is very hard to feel the immediate consequences. That makes educating difficult.

What helps in behavior change, or in motivational psychology, is something called the ultimate why. You try to really get to the bottom of why people are doing, or wanting to do, something. From this perspective, if my GP tells me not to do something because it is bad for me, it’s not likely going to help with changing the behavior. But if a person is really, on an emotional level, fearful, afraid, worried about developing dementia — and a lot of people do say they worry about developing dementia — it might constitute that ultimate why, and therefore be a much stronger motivator than something that they are less fearful of or “My wife is nagging me to stop smoking” or something that might not have an emotional trigger. I think working with the fear people have of developing dementia might be a silver lining in a sense.

It’s not only the fear of developing dementia that might be a great motivator. No doubt, people are more afraid of dementia because there isn’t a treatment or cure. But a positive ultimate why such as “I want to be independent and healthy as I get older” might be equally motivating and a positive reason that people want to keep their brains healthy.

Matthew Baumgart: I asked a clinician this question a couple of years ago, and she actually said that she would love to get to a comfort level on the clinical evidence on the risk factors for and prevention of dementia because she said, “My threat of a heart attack doesn’t work anymore.” So many people survive heart attacks now that she said her patients don’t fear that any more. But, she said, they all sit there in her exam room and fear what will happen when they get old and the possibility they will get dementia.
**Convincing Policymakers**

Matthew Baumgart: Similar to the individual long term, you talked, Kaarin, about the economic argument. This is an argument that's also way down the road. But politicians — and public health officials, whether they're at the state or local level, answer up to what is eventually a politician — stand for reelection every two, four, six years. How do we get public health officials comfortable with the idea that it is worth their time and some of their scarce resources to do something that, ultimately, they will not be able to show up the chain of command to the politicians that it brings in a benefit until those politicians will potentially be long gone?

Kaarin Anstey: Very difficult. Maybe we need to look at other areas. Why would you invest in public education? We know that having a better educated community is going to have economic benefits — but far down the road. I guess maybe we need to try to find some analogies, and then learn the strategies that worked with those.

Katrin Seeher: Climate change.

Matthew Baumgart: But we can't do anything on climate change, at least in the United States, for this exact reason. There isn't a short-term benefit. There isn't the short-term gain that the politician can claim credit for. It's all short-term pain, which is why they don't want to do it.

Kaarin Anstey: You still have those multilateral international global commitments to climate change. And we can work on educating the population that these are global goods, global targets — things that we are collectively working toward — and that we are all more or less entitled to having our governments invest in work toward achieving, not ignoring. There are big enough risks that if we leave them unaddressed, we won't be able to manage. That can create a sense of urgency. And using that as an argument might help.

Similarly, too, when seatbelt laws came into effect, at the beginning, people weren’t so thrilled, and still, in some countries, there are people trying to avoid putting them on, or finding interesting ways of using seatbelts. But with time, they are being implemented.

**Educating Young People**

Lisa McGuire: When the big movement in the U.S. started to get people to wear seatbelts, it was the kids who were educated on it, and they pretty much shamed their parents for not doing it. Somehow, we need to figure out what the lever is — and it could be multiple levers. But sometimes it is really educating the kids, because they come home and shame their parents because we are not recycling the way we should be, or we are not wearing seatbelts, or fill in the blank. Kids can be pretty judge-y and very influential.

Kristen Clifford: I totally agree with this.
All of our kids came home and talked about heart health from the time they were about five years old in school. It’s ingrained in them. My 13-year-old this morning, as soon as she woke up, saw the news and sent me a message that said, “Mom, it’s so great you never let me have soda because of the aspartame news that came out today.” Heart health is so ingrained, and we talk about it like it is such a normal thing that everyone should know. Wouldn’t it be great if they talked about brain health in the same way versus trying to start that messaging with folks who are middle-aged and starting to deal with other chronic conditions?

Amalia Fonk-Utomo: It’s similar with mental health. To my daughter, talking about mental health is normal, not like us in the past where we would deny having mental health issues. It’s also like the paper straw. I don’t like it. But the younger generation now is used to it — it was normalized among younger people.

Matthew Baumgart: I was at a lunch a few years before COVID, and one of the people at my table owned a restaurant. I don’t remember how it came up, but he said, “I have to have the paper straws or I would have no business among anyone under the age of 35.”

Prioritizing the Risk Factors

Matthew Baumgart: One of Kaarin’s slides listed six different modifiable risk factors. The Lancet Commission had 12, and the Alzheimer’s Association focuses on 10. That is a lot of issues to tackle.

When we try to convince public health to do something on dementia risk, how do we help them choose what to pick? Do you have any ideas on how we help public health prioritize?

The worst-case scenario is a public health official looks at the list and says, “Oh, there’s too much. I can’t do that much.” And, so, they don’t do anything. At the same time, I would hate to say, “Everybody just focus on hypertension. Every place in the country, focus on hypertension and hypertension only.” That narrows it, and makes it easier. But that might not be the best focus everywhere.

BRAIN HEALTH CURRICULUM FOR SCHOOLS

Educating young people about brain health promotes a life course approach to dementia risk reduction. It also instills at a young age the importance of brain health, which can make individuals more receptive and understanding to dementia risk reduction messages later in life.

There are several examples of brain health education programs for students.

- Brain Health Scotland developed a curriculum — My Amazing Brain — to help children aged 8 to 12 explore, through hands-on activities, how to keep their brains healthy.
- The Wisconsin Department of Public Instruction created Advocacy for Self and Others: Brain Health, a curriculum focused on having middle and high school students lead brain health advocacy campaigns.
- Brain Healthy is a curriculum in Connecticut and New York City public schools exploring brain health through the lens of promoting careers in data science. It primarily serves students from underrepresented racial and ethnic groups.

**Kay Deckers:**  For hypertension, the evidence is the strongest. But I love one of the pieces of risk factor advice that we give. Stay curious in life. People think that is a really interesting risk factor — being mentally and socially active. I really like the positive framing of “stay curious in life.”

**Kaarin Anstey:**  I personally think improving education is the key one for multiple reasons — it has so many benefits for individuals and society. We know keeping kids in school longer improves brain health. I would focus on that because education then feeds into everything else. Also, educating kids about dementia.

Some of the other risk factors are being addressed through non-communicable disease plans, and you can tag those and put dementia messaging into those efforts. It is almost a low-hanging fruit.

And then with legislation, I think it is important to legislate around healthy foods. In Australia, we’ve had big success on issues like seat belts, wearing sunscreen and hats to prevent skin cancer, and smoking. All of them have had a carrot and a stick, legislation, and a school education program. It was multi-pronged.

Again, though, I feel like improving education is so important, especially early childhood education. Education improves health literacy, and health literacy means when the messaging comes later in life, people are more receptive to it and more able to make changes in their behavior.

**Matthew Baumgart:**  Through a model that was developed by the Centers for Disease Control known as PLACES, we can get data in the United States down to the ZIP code and census tract levels on the prevalence of six different risk factors: hypertension, obesity, diabetes, smoking, physical activity and sleep. That means we can show public health officials that in their state or in their county, this is the prevalence of hypertension; this is the percentage of people who are not meeting physical activity guidelines; this is the percentage of people who are obese; this is the percentage of people who have diabetes; and so forth.

I suppose that’s one way to help public health answer the question, “What should I focus on?” Show them what their prevalence numbers are on these risk factors. Is that worthwhile? Are there other ways to help public health figure out what to focus on?

PLACES does not have education — we could get that data — but I think I’m going to have a problem in the United States convincing a lot of public health officials to focus on improving education.

**Kaarin Anstey:**  But there is also education about dementia.

**Matthew Baumgart:**  That might be it. That would be a different story in terms of education. Education policy overall would be a problem. But I think you could do something on dementia education.
Katrin Seeher: Looking at prevalence, or how big is the problem for each of these risk factors in your community or in your country, is certainly going to help. But I would say this is just one factor to look at when prioritizing.

We don't have a magic formula at WHO — use x percent of the prevalence, multiply it by this — we don't have that. The way we would engage with our member states is to sit down, look at these risk factors, conduct a situational analysis of what other activities are currently happening in the country, identify what are the low-hanging fruit that Kaarin mentioned, and where can we start addressing dementia risk. Don't start with the hardest one, because you will likely fail, and then everyone gets frustrated and may stop the whole effort. Don't come with a list because that is also going to be too hard. Be strategic in selecting the ones that you can do and do well.

I just came back earlier this week from a country in northern Africa. They are rolling out a huge policy campaign on tobacco cessation. For them, I would say now is the time to make sure that in all of the messaging, it should not just focus on lung cancer and cardiovascular health, but should also include dementia. And I would say for dementia risk reduction, focus on tobacco because, right now, the entire government is focused on banning tobacco from public events. That is your opportunity. Other countries might have different ones.

Kristen Clifford: Something you just said was interesting in terms of don't go for all of it because that's overwhelming. Some of the potential challenges ahead are with a multivariate approach where we are seeing positive findings with interventions that address multiple risk factors. It's great to have research coming out that could potentially show positive findings, but at the same time, how do we then approach that challenge of not just having to deal with one risk factor, but having public health pursue a multivariate approach?

Lisa McGuire: With this research, we need to keep in the back of our minds some of the things that we don't know yet. One of the things that I think about is the financial impact. With each of the risk factors, is there one of them, or is there a combination of them, that if we could get people to act on them, it would have a bigger economic impact than others?

**Messaging**

Kay Deckers: In our work — which we based on the epidemiological evidence and on trials of modifiable risk and protective factors — we developed three public health messages for our campaign. That is: stay curious; eat healthy; and exercise regularly. In combination, that tackles obesity, depression, physical activity, and social and cognitive activity — all of the things we want to tackle. We tried to summarize it in three easy-to-understand public health messages.

Even then, you still miss some important factors such as cardiovascular health. But these were the three things that we focus on in our campaign, and also the things that people like to work on. They know that they have to address their
hypertension. But if you explain that you can do it through healthy eating and regular exercises, that opens up a new opportunity for them, I think.

Lisa McGuire: I love it. Hopefully Matthew wrote that down.


Kay Deckers: Those are the three slogans we use in our public health campaign on dementia risk reduction.

Lisa McGuire: If you think about those and the way that they’re phrased, they are going to have so much impact on some of those cardiovascular risk factors. Some of those are the key. But the question now is, are those the right ones for us to target? My gut says yes, but we need to have some science behind it, too.

Matthew Baumgart: To Kristen’s point, you have the FINGER study and in a few years, you will have the USPOINTER results — both of which are multivariate interventions. One theory behind the trial is that the risk factors are interrelated. It is hard to parse out which risk factor is causing dementia and which risk factor intervention might help. So, we throw everything and the kitchen sink at it, and something is bound to work.

But one of the fears I have with these multivariate studies is that they may lock in this notion that it’s all or nothing. That is how some people will interpret it, as opposed to the way Kay framed this: stay curious, eat healthy, exercise regularly. I think, Kay, you would be happy if people did one of those things. You are putting the three out there, but you are not saying you have to do all three.

And I have this fear that we are going to get the USPOINTER results, a multivariate study, and people will say you’ve got to do all of these things because we don’t know which one of these things will actually work for you, so you have to do it all. That to me is a scary outcome from the perspective of persuading public health to pursue interventions.

Kristen Clifford: And to Lisa’s point, some of those levers will have a bigger impact than others. But how are people going to interpret the study results, and how does public health work with clinicians to get the message out about how we prioritize them. Because some people will just feel too overwhelmed.

Lisa McGuire: This goes back to Dr. Tisamarie Sherry’s remarks at the Dementia Risk Reduction Summit in May, that as a health care provider, she was looking at all that she was telling her patients to do. And then she started thinking, “I don’t want to do that. That’s unrealistic.”

We have to take into account humans who have choices and free will, whether we want to acknowledge it or not.
Katrin Seeher: Our WHO physical activity colleagues have actually done a brilliant job in translating the physical activity guidelines into public health messages. The last time I spoke with them, they said, "You need to really reduce it and simplify it and simplify it further" — even at the risk of getting a bit away from the strict conclusions of the evidence. The evidence says 150 minutes per week of vigorous exercise and blah, blah, blah. That sells very poorly. So, we say, every step counts; just take any opportunity you have to be physically active instead of taking the car or the elevator; every step counts. It is much easier to achieve that than getting to 150 minutes every week, which scares everyone away. That's where we ultimately need to go in order to reduce risk, but the messages need to . . .

Kristen Clifford: . . . feel more attainable.

Katrin Seeher: Yes. Show up every day and do baby steps.

Amalia Fonk-Utomo: That is what my yoga teacher tells me as well. If you show up on the mat, that's enough. A first step.

**Nomenclature**

Matthew Baumgart: I want to talk about nomenclature. We avoid the "P" word — prevention — like the plague. Instead, we talk about "risk reduction." We have all said that multiple times today. I personally think that is a combination of words that the general public doesn't get. When you say "risk reduction," what does that mean? At the ADI conference in June of last year, a clinician on one of the panels — I am not going to be able to quote him exactly — basically said, "Risk reduction" is what scientists say. Real people say 'prevention.' That's a word that means something to them.

Recently, people have started saying "brain health." There was some public opinion work done in the UK by Alzheimer's Research UK that found "brain health" resonated with people, that people understood that.

I just wanted to put on the table that this is something I struggle with all the time. What words are meaningful to real people?

Amalia Fonk-Utomo: If you use "prevention," it's like you are promising something.

Matthew Baumgart: That's the fear of using that word.

Amalia Fonk-Utomo: Yes.

Matthew Baumgart: We are afraid to use the P word because the clinical evidence isn't there, right?

Amalia Fonk-Utomo: You still can't vet it. Yes.

Matthew Baumgart: But a public health person argued to me, the epidemiological evidence is there. From a public health standpoint, it is prevention. We never had clinical evidence on smoking. There was no randomized controlled trial on smoking. There was no
randomized controlled trial on condomsto prevent HIV/AIDS. There has been no randomized controlled trial about wearing helmets when you ride a bike. So, people have argued that while it is not prevention in the clinical sense, it is prevention in the public health sense. But we are all afraid to use that word.

Again, it's something I struggle with and something I have to live with because I can't really use the P word.

Lisa McGuire: I think it is an excellent point. I think those of us who started using “risk reduction” are scientists, and to scientists, prevention means you do X, and Y will happen. From the federal U.S. perspective, when we started working in this space, it was our scientific colleagues who were very vocal and very strong against using the P word because they said the science is not there.

I am not sure how much evidence it will take to get the science there, or whether there is a chance to revisit the issue. But coming from an agency where our name is “Centers for Disease Control and Prevention,” we are obviously very comfortable with the P word. But I am not sure if the rest of my colleagues are comfortable with it in the dementia context.

Kristen Clifford: We are in the same boat, Lisa. But I think the point is, how do we make it real talk? To Kay’s messaging, I love “stay curious.” It’s not scientific; it’s not clinical. But it resonates, and it feels like something that real people would say.

Lisa McGuire: Yes.

Matthew Baumgart: Right. But, you are “staying curious” why? Not to “prevent” dementia. To “reduce your risk” for dementia. And so, we are back to where we started. Let me ask point blank: is “brain health” something that we are comfortable with? I think our scientists are comfortable saying “brain health.”

Lisa McGuire: Yes.

Matthew Baumgart: And does “brain health” resonate with people in a way that I don’t think “risk reduction” does?
Katrin Seeher: We put a lot of thought into brain health when we created the unit at WHO. We had multiple options. The final two were “brain health” and “neurology.” We opted for brain health because we felt that within public health, this is much better. Although I must say, critically reflecting now, it translates horribly into other languages, which is something that we did not consider. It sounds totally awkward in non-English.

Matthew Baumgart: That makes me wonder whether the whole prevention versus risk reduction discussion is an English-only thing. Kay, English is not the native language of the Netherlands. Does the prevention versus risk reduction conundrum translate into other languages?

Kay Deckers: Yes, it is the same issue here. I am very cautious about using “prevention.” I always talk about “risk reduction” or “potentially lowering your chances.”

Matthew Baumgart: But then, Lisa and Kristen, when you were working to update the Public Health Road Map, I was hearing that some people may have concerns about “brain health.” We are discussing using it in the context of healthy aging. Others were wondering, is mental health “brain health”? Are other neurological conditions, “brain health”? Intellectual and developmental disabilities — is that “brain health”? By using that phrase, do we run the risk of muddying the waters the other way?

Katrin Seeher: I would caution against equating brain health with dementia risk reduction or minimizing dementia risk because, at least at WHO, we would say brain health is a lot more. That is why we say it is across the life course. Brain health is everything that we do to our brains — the physical brain structure and maintaining brain function. Dementia plays a huge role because it impairs brain function. But brain health is much broader. Is that necessarily a bad thing? I don’t think so. Similar to when we said if we address non-communicable diseases, we’re also helping the brain. By promoting brain health, we are also reducing dementia risk. I think there is a lot of potential in putting it under this bigger umbrella. Just knowing what we can do to optimize or promote brain health will have multiple impacts or lead to potentially many benefits, not just dementia risk reduction.

Kaarin Anstey: I think it depends on the audience, and you might need to do some research about your audience for this strategy. I don’t mind the term “prevention,” and the economic arguments don’t really work without using “prevention.” The whole cost-effectiveness model is based on preventing cases. In a population, delaying dementia actually will prevent incident cases, epidemiologically. So, a lot of our arguments — our strongest arguments — are based on preventing dementia. You have to be careful not to throw the baby out with the bath water by not using that term, especially if you want to convince policymakers. You need to have prevention as part of it. Otherwise, it gets too watered down.

I understand the flip side of giving the wrong message to the public — that it is their fault; that if they get dementia, they didn’t prevent it by their lifestyle. That is not the message you want to send. We do need to be careful with messaging.
But I also think you can go too far and then the economic argument becomes much harder to make.

**Longevity Dividend**

Matthew Baumgart: Kaarin, in your opening presentation, you talked about the longevity issue. One of the things we often hear is that keeping people alive longer actually ends up costing us more money. It is a very cynical argument, but it is not an unheard-of argument. I just want to make sure that understood you correctly. You are saying that with aging, all things being equal, simply keeping people alive longer is more expensive. But if we can make them healthier as they age, more longevity won't be a cost?

Kaarin Anstey: That is where we get the longevity dividend.

Scott A. Achieving a three-dimensional longevity dividend. Nat Aging 2021;1(6):500-505. What we want is compression of morbidity, so that we get a longevity dividend. This is another economic argument. With healthy aging, you can lift the retirement age and people can remain productive in the workforce for longer. You need your brain to be able to do that.

Katrin Seeher: That is also a strong argument, in the context of dementia, to try to enable rather than disable, and to try to maintain function for as long as possible. Some are not only diagnosing earlier but we are actually trying to maintain independence for as long as possible, which is often not the case. If you look at how reimbursement for medical care and treatment works, the more impaired you are, then the higher the reimbursement is. There should be an incentive to enable rather than disable, for exactly that same economic reason.

Amalia Fonk-Utomo: Risk reduction is not only about people who do not yet have disease. People already diagnosed also need risk reduction — also need to change lifestyles — to help maintain their function and independence.

**Concluding Remarks**

Matthew Baumgart: We are, unfortunately, out of time. This has been such a great conversation, and I hope we will have more in the future. Thank you all for participating. I will let Kristen close us out.

Kristen Clifford: I want to thank everyone so much. It is really exciting to be able to prioritize having these conversations. We know that there is a long way to go in all of our countries in terms of public health understanding of dementia and the science behind risk reduction, but it feels like an exciting time with progress, movement and momentum. We would love to continue these conversations in some form. It sounds like we all have learnings that we can continue to share — whether that’s around public health campaigns, ways to change behavior, or new science. We would like to keep in touch and find a way to bring this group and some others together again to continue these conversations and learnings. Thank you so much.