

DEMENTIA IN EUROPE

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33AEC

Helsinki 2023 - Special Supplement

Listen to people with lived experience of dementia at our conference in Helsinki

33rd Alzheimer Europe Conference
New opportunities in dementia care: policy and research
Helsinki, Finland 16 - 18 October 2023 #33AEC



Chris Roberts & Pia Knudsen



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Kevin Quaid & Lieselotte Klotz



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Petri Lampinen & Anna Rosenberg



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Sonata Mačiulskytė & Trevor Salomon



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I am delighted to welcome you to a very special publication about the 33rd Alzheimer Europe Conference (33AEC) which took place from 16 to 18 October 2023, in Helsinki, Finland as well as online. If you were at the conference, we hope you enjoy looking back at some of the highlights from the event. If you were unable to join us in Helsinki (or online), we hope that this publication gives you a real flavour of our conference and encourages you to join us for a future event, perhaps even for our upcoming 2024 conference (34AEC) taking place in Geneva, Switzerland, from 8 to 10 October under the banner “New horizons – Innovating for dementia”.

In this publication we have a “Warmup” section, where you will find coverage of a number of important pre-conference meetings, organised by the European Working Group of People with Dementia (EWGPWD), the European Dementia Carers Working Group (EDCWG) and INTERDEM, as well as our own Annual Meeting with members from across the European region.

We then take a look at all of the conference plenary sessions (Opening Ceremony, Plenaries 1 to 5, Closing Ceremony) and I am especially excited to note that Plenary 1, which showcased the work of the EWGPWD in relation to Public Involvement in dementia research, was the first plenary session of its kind, organised, chaired and presented entirely by people living with dementia. Alzheimer Europe was extremely proud to be able to include this special and important plenary in its 2023 conference programme. The work of the EWGPWD and the collective voice of the group’s members are vital to our work and this long-standing collaboration continues to flourish.

Plenaries 2, 3 and 4 explored topics around “Brain health and prevention”, “Intersectionality in dementia” and “New opportunities”, respectively. Plenary 5 took the form of a roundtable, in which panellists discussed dementia as a European public health and policy priority.

On top of coverage of the ancillary meetings and plenary sessions in Helsinki, we are pleased to share some other aspects of the event, including: a special symposium presenting the work of ten early-stage researchers, who were selected by our jury to benefit from attendance bursaries provided by the Alzheimer Europe Foundation; a special award ceremony for the winners of our 2023 Anti-Stigma Award, held during the Networking Dinner; some thoughts from our conference co-hosts, the Alzheimer Society of Finland (Muistiliitto), about the conference and about some of the sessions they organised; some highlights from social media; and a few facts and figures surrounding the event.

I also invite you to view the photo gallery (pages 23 to 25) with, among others, shots of the many and varied poster presentations, and of the Networking Dinner held at Helsinki’s beautiful “Old Student House” on the evening of 17 October.

I hope you enjoy this very special conference publication!

Jean Georges,
Executive Director, Alzheimer Europe



WARMUP:

European Working Group of People with Dementia and European Dementia Carers Working Group hold pre-conference meetings in Helsinki

On Sunday 15 and Monday 16 October, the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) each held meetings in Helsinki, prior to the opening of the conference.



EWGPWD, Helsinki

EWGPWD

On 15 October, members of the group conducted a final practice session for their plenary session, titled "Turning Personal Experiences into Political Advocacy and Public Involvement in Dementia Research", which took place on 16 October. They also provided input on the recommendations for the 2023 Alzheimer Europe Yearbook presented by Owen Miller (Policy Officer, Alzheimer Europe). The Yearbook is focused on legal capacity and supported decision-making.

The following day, prior to the opening of the conference, Angela Bradshaw (Director for Policy and Research, Alzheimer Europe) joined the group to discuss the organisation's position paper on anti-amyloid treatments.

EWGPWD members worked on creating an easy-to-understand version of this document. Subsequently, Ana Diaz, (Public Involvement Lead, Alzheimer Europe) moderated a discussion regarding inclusive travel for people with dementia, and members worked on developing some recommendations targeted at people with dementia.



EDCWG, Helsinki

EDCWG

On the first day, the group offered feedback on the Alzheimer Europe Yearbook recommendations on legal capacity and supported decision-making. Clarissa Giebel, leader of the INTERDEM Taskforce "Inequalities in Dementia Care", then joined the meeting to present some of her research and gather input from group members. The EDCWG also made some final preparations for their workshop session titled "When Care Homes Stop Caring", held as part of the 33rd Alzheimer Europe Conference (33AEC).

On Monday 16 October, Soraya Moradi-Bachiller (Public Involvement Officer, Alzheimer Europe) shared some of the work conducted as part of the Pattern-Cog project, for which the EDCWG serves as advisory group members. The EDCWG expressed their perspectives on issues related to disclosing dementia risk and raising awareness about brain health. In the final part of the meeting, the group provided ideas on how to ensure that meetings and travel arrangements for people with dementia are inclusive.

Alzheimer Europe would like to thank both groups and their executive members, EWGPWD Chairperson Chris Roberts (United Kingdom – Wales) and Vice-Chairs Margaret McCallion (United Kingdom – Scotland) and Kevin Quaid (Ireland) and EDCWG Chairperson Sonata Mačiulskytė (Lithuania) and Vice-Chair Trevor Salomon (United Kingdom – England), for their impressive work organising these meetings and for their active contributions throughout the whole of 33AEC, including presenting, chairing and participating in other conference sessions, as well as disseminating information about the working groups.

INTERDEM network hosts Annual Meeting in Helsinki

INTERDEM is a network of researchers interested in psychosocial interventions. It is made up of 229 researchers and academics with different professional disciplines, spread across 21 countries (19 of which are in Europe). The INTERDEM network held its Annual Meeting at the conference centre in Helsinki on 15 and 16 October 2023, just prior to the 33rd Alzheimer Europe Conference (33AEC).

INTERDEM Chairperson Marjolein de Vugt kicked off the meeting by welcoming the researchers, followed by an introduction of new members and a keynote presentation titled “Working with artists to communicate research findings: examples from film, theatre, cartoons and opera”, delivered by Justine Schneider in a session chaired by Myrra Vernooij-Dassen.



The Annual Meeting also looked back at some highlights from the past year, as well as giving an update on projects and on the task force initiative. Alzheimer Europe is proud to be a key partner of INTERDEM.

<https://interdem.org/>

Alzheimer Europe Annual Meeting adopts “Helsinki Manifesto”



Alzheimer Europe held its Annual General Meeting (AGM) on 16 October 2023, in Helsinki with representatives of its national member organisations. 33 out of 36 full members were in attendance or were represented. During the AGM, the “Helsinki Manifesto” was adopted. The Helsinki Manifesto sets out the current position of dementia in Europe as well as calling for action in four main areas: health, research, disability and social rights, and informal carers. The document, along with a public Call for Action and our 2024 European Parliament election campaign (Dementia Pledge 2024), were officially launched at our European Parliament lunch debate in Brussels, on 5 December 2023. The campaign is now in full swing and will run until June 2024. You can find out about our campaign, at: <https://bit.ly/AE2024EUCampaign>

The Alzheimer Europe AGM also celebrated the organisation’s achievements in 2022 and shared its plans for 2024 along with its 2022-2023 finances with meeting participants and observers.

The Chairperson of the European Working Group of People with Dementia, Chris Roberts (United Kingdom – Wales) and the Chairperson of the European Dementia Carers Working Group, Sonata Mačiulskytė (Lithuania) both addressed the attendees of the meeting and following their speeches, after which the meeting was closed with the unanimous adoption of Alzheimer Europe’s 2024 Work Plan and Budget.

DAY 1:

Opening Ceremony

The 33rd Alzheimer Europe Conference (33AEC) “New opportunities in dementia care, policy and research” was formally opened on 16 October 2023. The conference took place as a hybrid event, with delegates and presenters able to join either on site at the Messukeskus Helsinki Expo and Convention Centre or online, with the aim of ensuring the event was as accessible, inclusive and interactive as possible. A record number of over 1,100 participants (1,000 of these in person) from 48 countries attended the conference, which took place from 16 to 18 October 2023. The Opening Ceremony was co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events, as were all remaining plenary sessions (apart from Plenary 1).

Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, opened the conference. She extended a special welcome to the 56 people with dementia among the delegates, as well as to the 66 carers/supporters in attendance.

She stressed that in order to make a better world for people with dementia, all efforts must be focused in three main areas.

She highlighted the need to focus on finding and implementing better practices when providing care along the disease pathway, while investing in research into better pharmacological and non-pharmacological treatments. She finished by reminding the audience to continue fighting to ensure that dementia is recognised as a public health priority, both at European and national levels and that specific policies are put in place, accordingly. She also made reference to the newly-adopted Helsinki Manifesto, and felt sure that this would be another important milestone for the European Dementia Movement.

“The Alzheimer Europe conference is a place where we can take new steps forward”

Following these opening words, delegates were addressed by Jenni Kulmala, Chairperson of Muistiliitto and Associate Professor of Gerontology, Tampere University, Finland. “The Alzheimer Europe conference is a place where we can take new steps forward. We will



Jean Georges (left) and Kim Coppes (right) moderated the opening and closing ceremonies and plenaries 2 to 5

have dialogue between dementia researchers, healthcare professionals, policymakers and non-governmental organisations. Ultimately, multi-professional collaboration is the key to a more dementia-friendly world”, she said adding that “Finland is paving the way in dementia prevention research, and we also want to be a country where research meets practice”.



Speakers and moderators at Opening Ceremony (left to right): Chris Roberts, Petri Lampinen, Kaisa Juuso, Sirpa Pietikäinen MEP, Jean Georges, Jenni Kulmala, Marjolein de Vugt and Kim Coppes

Kaisa Juuso, Minister of Social Affairs and Health in Finland was next up to the lectern, addressing delegates on the topics of early detection of memory problems, research work and respect for people with memory disorders. The Minister also commented that the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) had shown that it is possible to prevent memory disorders by managing the risk factors associated with them when people follow a multidomain lifestyle programme. This can improve cognitive functions in older people, she insisted, and can also prevent memory decline, adding that the FINGER model will be implemented as a preventive measure throughout Finland. She stressed that the most important thing is to ensure we treat older people with respect for their right to self-determination,

and that we provide them with services that meet their needs, support their inclusion and make their lives as good as possible. She also noted that the conference would be a great opportunity to engage in extensive networking and that the event took an important step towards showing a stronger respect and appreciation for the views of people with memory disorders.

Marjolein de Vugt, Professor of psychosocial innovations in dementia at the Alzheimer Center Limburg, Maastricht UMC+ addressed delegates in her capacity as Chairperson of INTERDEM. “Focusing on everyday transformations to improve the lives of people living with dementia has the potential to reshape the landscape of dementia care, influence policy development, and cutting-edge research, emphasising the importance of psychosocial innovations”, she said. She also noted that, as the search for major breakthroughs continues, it is important to recognise the positive impact of psychosocial research and innovations in dementia.

“We who are diagnosed with dementia, want to make a difference with our loved ones in these matters. Because we can raise the issues, to the best of our ability. We can speak up for our rights. We have already been genuinely listened to and our opinions have also been valued. This has felt very good!”

Sirpa Pietikäinen MEP (Finland), Chairperson of the European Alzheimer’s Alliance stressed that dementia care needs to be person-centred, integrative and transformative. She also emphasised the need to take technology and its opportunities into account. “These are the new avenues for better care for memory-disabled persons in Europe”, she concluded.

Petri Lampinen was the final speaker at the Opening Ceremony and spoke on behalf of the European Working Group of People with Dementia (EWGPWD). Petri is from Finland and has been a member of the EWGPWD since 2017. Chris Roberts, Chairperson of the EWGPWD translated Petri’s words into English. “In the coming years times will be challenging”, Petri said, “because of the increasing numbers of people with dementia”. Conducting active research and investing in citizens’ brain health is vital, as is making decision-makers aware of the importance of these issues in society. “We who are diagnosed with dementia, want to make a difference with our loved ones in these matters. Because we can raise the issues, to the best of our ability.”



Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, opened the conference

We can speak up for our rights. We have already been genuinely listened to and our opinions have also been valued. This has felt very good!”

He expressed his gratitude to Alzheimer Europe, its member associations and to dementia organisations over the world, for supporting people living with dementia. “Year after year”, he said, “we feel more part of society”. In closing he reminded delegates that together, we can change perceptions of living with dementia and reduce the stigma they cause. “My advice is not to give up. It is worth going through the emotions, even the difficult ones.”

WATCH NOW:
Opening Ceremony



Marjolein de Vugt addressed delegates in her capacity as Chairperson of INTERDEM



Petri Lampinen (right) spoke on behalf of the EWGPWD, welcoming delegates to his home country of Finland while Chris Roberts (left) translated his words into English

DAY 1:

Welcome words from European Commissioners for Equality, and for Health and Food Safety

Alzheimer Europe was delighted to have the support of EU Commissioners Helena Dalli and Stella Kyriakides, who each recorded a welcome video, addressing conference delegates during the Opening Ceremony.



Helena Dalli (left, on screen)

WATCH NOW: Commissioner Dalli's video

In her address, EU Commissioner for Equality, Helena Dalli highlighted the European Commission's Strategy for the rights of persons with disabilities, which aims to ensure full participation of persons with disabilities in society, and to prevent any discrimination based on the grounds of disability.

"To ensure that persons with disabilities can fully enjoy their rights, the Strategy sets out seven flagship initiatives, one of which is the recently-proposed European Disability Card, which aims to facilitate the right of free movement for persons with disabilities in the EU", she said. She also pointed out that when persons with disabilities travel to other Member States for short-term stays, card holders would benefit from the same

preferential conditions when accessing services, as are granted to residents of the Member States due to their disability.

Finally, Commissioner Dalli reminded delegates that in June 2023, the Commission adopted a Communication on a Comprehensive Approach to Mental Health. "This is a starting point for a more holistic and ambitious approach, that goes beyond the health sector and identifies numerous funding opportunities. Its 20 flagship initiatives and key actions, backed by over EUR 1.2 billion in funding, cover areas in health policy and beyond", she said.

EU Commissioner for Health and Food Safety, Stella Kyriakides began by thanking Alzheimer Europe and its members, for their dedication in tackling dementia and in supporting people living with dementia, their families and carers.

"I assure you, that you are not alone in your efforts and we stand ready to support you in practical and concrete ways", she said. "This is the solidarity that characterises the strong European Health Union that we are building and the priority to build better health for all citizens, regardless of their health challenges."

Echoing Helena Dalli, she also highlighted the Commission's Communication on a Comprehensive Approach to Mental Health,



Stella Kyriakides (on screen)

WATCH NOW: Commissioner Kyriakides' video

an initiative which aims to put mental health on par with physical health and to ensure a new, cross-sectoral approach to mental health issues. The funding for this initiative covers the areas of prevention, early detection, strengthened research on brain health and breaking down stigma, prejudice and discrimination. Commissioner Kyriakides also mentioned the "Healthier Together" initiative launched in June 2022, which has one specific strand focused on neurological disorders and emphasises the need to make societies and communities more dementia friendly.

Commissioner Kyriakides noted, too, the EU Best Practice Portal and some of the best practices on health promotion, all of which are publicly available on the portal. Financial support is being provided by the EU4Health programme, she noted.

In closing, she said that governments and public health authorities alone cannot tackle the mental health burden on society and that the views of people with dementia and their families must be included in policies and research on treatment and care. A joint effort is vital, she reminded delegates, in order to deliver new opportunities in dementia care, policy and research.

Plenary 1 EWGPWD takes centre stage

The Opening Ceremony was followed by the first plenary session of the conference, “Transforming personal experiences into political advocacy and Public Involvement in dementia research” which showcased the work conducted by the European Working Group of People with Dementia (EWGPWD). Speakers drew on their personal experiences, both at national and European level. This was the first plenary session of its kind, organised, chaired and presented entirely by people living with dementia. It was chaired by Chris Roberts (United Kingdom – Wales) and the four speakers were Kevin Quaid (Ireland), Pia Knudsen (Denmark), Věra Ryšavá (Czech Republic) and Nigel Hullah (Wales, United Kingdom).

Chris Roberts presented the group and some of its main achievements over the years. “I’m very honoured to be the current Chairperson of the EWGPWD and am so proud to welcome you to the first Alzheimer Europe Conference plenary session entirely organised and presented by our group”, he said. “The EWGPWD was launched by Alzheimer Europe and its member associations in 2012 and the group celebrated its 10-year anniversary last year. They do a lot of Public Involvement (PI)

work with researchers across many different projects, sharing their vital insights, as experts by experience. Members are nominated to the group by their national Alzheimer associations. There are currently 15 members, four of whom are keynote speakers at this first plenary of the Alzheimer Europe Conference in Helsinki”, he said and introduced the first speaker, Kevin Quaid.

Kevin focused on his experience of PI in Ireland and the impact of such involvement on dementia research and on his personal life. “I am not an expert in too many things, but I am an expert in what it’s like to have Lewy Body Dementia”, he said, insisting that when it comes to PI, people with lived experience must be front and centre. Being an advocate for the past seven years, Kevin has seen a major change in the way research is done and in how people with dementia are viewed when it comes to research. Not so long ago, involving someone with dementia was nothing more than a ‘tick-box’ exercise, but he was pleased to say that researchers have



Chris Roberts

now realised how much people with dementia have to offer. In conclusion he implored researchers: “Invite us into the research space, listen to our insights and we will help you keep your focus on the real-world impact your work can have on someone. It’s not to put pressure on you, we are just invested in your work and your research in a different way to you. We have insights that can help. We can help you consider things you maybe hadn’t thought of before. And if we don’t understand something, we’ll let you know.”

Pia Knudsen introduced herself and after sharing that she has two children, loved her job as a teacher for many years and is a keen and talented artist she also said, “by the way, I am here today because I was diagnosed with Alzheimer’s disease back in 2020”. As one of the newest members of the EWGPWD, she is delighted to have already been involved in several projects. and believes it is incredibly important to involve people with dementia in everything that has an impact on them. “It gives me SO much energy and purpose to use my voice and raise awareness”, she enthused. “I am just a human being struggling with a difficult life situation. Otherwise, I am fully functioning. Almost.” After losing her beloved job as a teacher when she was diagnosed, she said she now has a new job as a spokesperson for people with dementia. Based on her experience, she noted three important points about involving people



Pia Knudsen

DAY 1:

with dementia. The first was to listen to people with dementia as they are the ones experiencing dementia from within. Second was to create the framework and foundation that gives people with dementia the possibility to get involved. She encouraged the delegates to take action, adding, “Make the words matter and implement the opinions and experiences shared, so they impact on real lives.” In closing, she said: “I know that there is a long way to go and we are not even close to making voices of people with dementia matter all over the world. But if we all start to whisper, eventually it will become a loud roar.”

Věra Ryšavá talked about her experience contributing to the work of the Czech Alzheimer Society to raise awareness and tackle the stigma of dementia in her country, as well as their efforts to ensure that issues of relevance to the lives of people with dementia are taken on board by policymakers. She opened by sharing her personal experience following her diagnosis: “After my diagnosis, I didn’t live, I just survived, crying at night, thinking about the information about Alzheimer’s disease that I had known from the press and TV up to that point. Unfortunately, it was mostly information about the last stages of the disease. It wasn’t until I discovered the



Věra Ryšavá

Czech Alzheimer Society and then Alzheimer Europe that I began to bounce back. Now I’m kind of internally reconciled with my illness and thanks to a timely diagnosis, I have the opportunity to organise my future.” Through the EWGPWD, she now feels able to understand her diagnosis better, to get answers to her questions but also to contribute. She thanked the audience, saying that she greatly respects and appreciates people who are trying to change the current situation in care and who provide help for people with dementia so they can live their lives with dignity.

Nigel Hullah reflected on the relevance of PI for local and national initiatives and how such involvement can give people with dementia a purpose, a sense of belonging and hope. PI, he said, “is significant when making decisions that affect a community. It is vital that everyone has their voice heard. An active and well-supported PI approach allows people to engage in meaningful and genuine co-production and allows everyone involved to share responsibility and power in a reciprocal and supportive manner”.



Nigel Hullah

“The outcomes”, he stressed, “can be hugely empowering for all concerned, helping create a more inclusive and supportive society”.

“I always feel better after participating in a PI event because I’ve been focusing on my sense of worth. It’s a complex process, but it’s worth it. When I feel good about myself, I’m much more confident and capable of achieving my goals. To be listened to, really listened to, is a transformative experience in a world where the deficit agenda of dementia looms large. It’s essential for people affected by dementia to remember that their dementia does not define them and that they are still valuable members of their community.” Addressing the audience and especially the researchers in the room, he said, “please ask us not what you can do for us but how we can work together, by engaging with us as equals”.

The plenary session ended with a standing ovation for the speakers.



Kevin Quaid



Welcome Reception at City Hall



To close day one of the conference, a Welcome Reception was held at Helsinki City Hall, hosted by the Mayor of Helsinki whose representative, Helsinki City Councillor Jenni Pajunen gave a speech to all the delegates. She shared some interesting facts about Helsinki and about City Hall, including that the building was designed by German architect Carl Ludvig Engel in 1833. It was originally a hotel, but the building has been the City Hall since the 1930s. The Helsinki coat-of-arms can be seen on the tympanum.

With the exception of the facade, the building was completely rebuilt in 1967-1970, designed by the Finnish architect Aarno Ruusuvuori.

Jenni Pajunen said she was honoured to be able to welcome the participants of the 33rd Alzheimer Europe Conference to Helsinki City Hall and commented, "We need fresh ideas on care, policy and research to take care of our ageing population. We also need a lot of Finnish 'sisu'. 'Sisu' is a uniquely Finnish concept, that can be roughly translated into English as tenacity, strength of will, determination, or perseverance in the face of adversity.



Jenni Pajunen



DAY 2:

Plenary 2 “Brain health and prevention”



Plenary 2 speakers (left to right): Giovanni Frisoni, Miia Kivipelto, Katja Kanninen, Nikolaos Scarmeas, with moderator Jean Georges (furthest right)

Professor Miia Kivipelto from the University of Eastern Finland and Karolinska Institutet began the session with her presentation on “Building the evidence base for multi-modal interventions through European and International collaborations”. She said that risk reduction of cognitive impairment and dementia is possible and indeed is already happening. Brain health, she stressed, should be a priority for society. She then urged everyone to ensure that we “fill the implementation gap” and start fully implementing the available evidence. She reminded the audience:

“It is never too early, never too late. We can and we should offer preventive interventions supporting brain health to people without cognitive symptoms, but also those already experiencing symptoms, to help maintaining brain functions.”

With an increasing body of evidence from clinical trials to show that multidomain interventions targeting several risk factors are effective and feasible, the EU-FINGERS and World-Wide FINGERS networks are now working on further developing and adapting these interventions to different target populations and settings.

In closing, she stated that:

“We need to connect and combine prevention, early detection, and interventions, both non-pharmacological and pharmacological. We are moving towards precision prevention and combination therapies.” She also stressed the importance of global strategies, public engagement and broad collaborations with all key stakeholders including academia, industry, advocacy groups, regulatory bodies and citizens.

Nikolaos Scarmeas, Professor of Neurology from the National and Kapodistrian University of Athens was next to take the floor with his presentation “The role of nutrition in the prevention of dementia”. He highlighted the associations between healthy dietary patterns and risk reduction for dementia, noting that these have been reported but have not yet been fully confirmed in randomised trials.

Many different aspects of nutrition, including chronobiological aspects (i.e. at which times during the day, or in relation to sleep, or how often we eat certain foods and nutrients, etc.) are still unexplored, he said, also noting that new studies have started utilising precision nutrition approaches in relation to cognitive function. “Chrononutrition and precision nutrition are new avenues of exploration in relation to cognition”, he enthused.

The third speaker in this plenary session was Professor Katja Kanninen from the A.I. Virtanen Institute for Molecular Sciences at the University of Eastern Finland, who spoke about environmental factors and air pollution as risk factors for dementia. She highlighted that there are 12 modifiable risk factors that account for around 40% of worldwide dementias, noting that air pollution had recently been added to the list of modifiable risk factors for dementia.

Epidemiological studies, she said, demonstrate that “life in highly-polluted areas is linked to increased incidence of cognitive impairment and risk of neurodegenerative disease”.

The fourth and final speaker in this plenary session on Brain health and prevention was Giovanni Frisoni, Director of the Centre de la mémoire at Geneva University Hospital and Professor in Clinical Neurosciences, University of Geneva. His presentation, titled “Dementia prevention in memory clinics: recommendations from the European task force for brain health services” opened with the assertion that dementia prevention is currently done either when it is too early (primary prevention in the general population) or too late (tertiary prevention in those who already have dementia).

A European Task Force, he noted, has summarised available evidence for the much-needed area of secondary prevention, for example in persons without dementia but at a higher risk of dementia. Procedures have been drafted for dementia risk assessment, communication and risk education, as well as cognitive enhancement, he said, while emphasising that these would need to be delivered in ad hoc services called “Brain Health Services” for the prevention of dementia.



Plenary 3

“Intersectionality in dementia”

A presentation on “Achieving Cultural Inclusivity in Dementia Care” was delivered by Karan Jutla, Head of Health Research Centre & Dementia Lead for the University of Wolverhampton. Dr Jutla discussed ways for improving cultural inclusion to reduce inequalities in dementia and to ensure that widespread accessibility to care becomes a reality. As evidenced in her latest report, co-production is integral to achieving equitable access to support services for people with dementia and their family members and carers. She also highlighted the importance of co-production and invited the audience to consider how culturally-inclusive care can be achieved via a person-centred approach: “In order to achieve cultural inclusivity in dementia care, we must recognise the importance of intersectionality and practice person centred dementia care”, she said.

Dr Alain Dekker from Alliade Care Group and University of Groningen/UMCG (Netherlands) discussed “Dementia in people

with intellectual disabilities: introduction to both Down syndrome and severely disabled populations”. He began by stating that a diagnosis of dementia in people with intellectual disabilities is important for understanding changes and making informed choices about support, treatment and organisation of care. People with Down syndrome, he noted, are at extremely high genetic risk to develop dementia due to Alzheimer’s disease. In people with severe/profound intellectual disabilities, whom he said are until now a largely neglected group when it concerns dementia, the observability of dementia symptoms is different and diagnosing dementia therefore requires closer observation of small changes, in specific daily contexts. He said this depends on acquired skills at baseline and requires a newly-developed diagnostic aid.

Linn Sandberg, Associate Professor Gender Studies, Södertörn University (Sweden) presented “Are they here, are they queer? LGBTQ People with Dementia and the limits

of person-centred care”. She reminded delegates of the importance of challenging heteronormativity in dementia care. Dementia care staff in her current research often stated that they ‘treated everyone the same’ and that sexual and gender identities were very rarely discussed. But, she said that this results in a continuous invisibility and lack of recognition of lesbian, gay, bisexual, trans and queer (LGBTQ) people living with dementia. “Having to repeatedly ‘come out’, to navigate heteronormative care, and to advocate for one’s rights puts undue stress on LGBTQ people living with dementia and on their partners”, she said, stressing that dementia illnesses, as well as the organisation of dementia care, poses particular challenges for LGBTQ people to communicate their life histories, maintain relationships and connections to communities that have been significant to them.

Päivi Topo, Ombudsman for Older People in Finland, discussed “How to better support people living with dementia from socio-economically disadvantaged groups”. She highlighted several virtual health promotion activities, including web-based activities that require no digital skills, since digital skills are rarer among older adults in lower socioeconomic groups than other older adults. She said, “people with dementia living alone with no social network are at high risk of not receiving the support, services and care they need across all socioeconomic groups”. It was most important, from her perspective, that older adults find the activities on offer to be both interesting and beneficial. Group activities are particularly helpful in this respect as they help create social contacts, she noted. Two national programmes promoting health and exercise for older adults exist in Finland, with emphasis being put on better access to care of older adults in socially disadvantaged groups, but improvements are needed in several areas.



Plenary 3 moderators and speakers (left to right): Jean Georges, Karan Jutla, Päivi Topo, Alain Dekker, Linn Sandberg and Kim Coppes

WATCH NOW:
Plenary 3

DAY 2:

Plenary 2 and 3 photo gallery



Dementia Researchers of the future

From 12.00-13.00, a special symposium was held, to present the work of the ten early stage researchers who were selected by our jury in July 2023 to benefit from the bursaries provided by the Alzheimer Europe Foundation and invited to attend and present at 33AEC.

The selection of the ten bursaries was based on the best average scores each received from the jury members. The session, called “Dementia Researchers of the future”, was chaired by Iva Holmerová (Czech Republic) and Fania Dassen (Netherlands).

The researchers, and their presentations, were:

- Thanos Chatzikostopoulos (Greece): The effects of pomegranate seed oil on mild cognitive impairment
- Carlos Gómez Martínez (Spain): COVID-19 and cognitive impairment in older adults: Longitudinal analysis from the PREDIMED-PLUS Cohort

- Ieva Petkutė (Lithuania): Photovoice practice and carer of people living with dementia involvement for transformative change in Lithuania
- Thais Lorenzo (Spain): Engaging participants in lifestyle interventions to prevent cognitive decline: The role of psychoeducation in the Pensa study
- Aysan Mahmoudi Asl (Spain): Acceptability of the Social Robot Mini and Attitudes of People with Dementia and Mild Cognitive Impairment
- Miren Altuna Azkargorta (Spain): Down Syndrome - Basque Alzheimer Initiative (DS-BAI): Integrative health care plan based on personalized medicine and clinical-biological research cohort
- Rafaela Trolou (Greece): Music-making for older people with and without dementia in residential care facilities: Preliminary findings from a community music intervention



*Iva Holmerová, Treasurer,
Alzheimer Europe Foundation*

- Naia Ros (Spain): Including the socio-emotional approach in a finger-like multi-domain intervention to prevent cognitive decline. CITA Go-On Study
- Electra Chatzidimitriou (Greece): Premorbid personality traits and their relationship with functional impairment in early-stage behavioural variant frontotemporal dementia
- Marina Makri (Greece): Attitudes, motivations, and barriers to pre-symptomatic Alzheimer's disease screening: a comparison between informal caregivers in five European countries.



This session was organised by the Alzheimer Europe Foundation and the INTERDEM Academy, with thanks to Roche for supporting the meeting space.

DAY 2:

Black and Minority Ethnic Dementia Service wins Alzheimer Europe's Anti-Stigma Award at a special ceremony in Helsinki

At a special award ceremony during the Networking Dinner of 33AEC, Touchstone's BME (Black and Minority Ethnic) Dementia Service was announced as the winner of Alzheimer Europe's 2023 Anti-Stigma Award. Touchstone provides health and wellbeing services to thousands of people across Yorkshire, in the United Kingdom.

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Lilly and Roche launched a call for applications in April 2023, with the aim of giving recognition to an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. This year's call focused on initiatives and campaigns addressing the stigma experienced by people with dementia and their carers from minority ethnic groups, the LGBTQ+ community, people with intellectual disability and/or Down syndrome and from socio-economically disadvantaged groups. Applications were open to individuals and organisations established in a member country of Alzheimer Europe for initiatives and projects which were developed and/or implemented in the past three years (2020-2023).

The first place award, together with a cash prize of EUR 5,000 was presented by Iva Holmerová, the Treasurer of the Alzheimer Europe Foundation.

The second place award, with a cash prize of EUR 3,000, was presented by Helen Rochford-Brennan from the Alzheimer Europe Foundation. It was awarded to Brighton and Hove LGBT Switchboard's initiative "Rainbow Neighbours". Switchboard is a charity for LGBTQ people looking for a sense of community, support or information.

The third place, with a cash prize of EUR 1,500, was scooped up by Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for its campaign "Assess your assumptions". The award was given by Heike von Lützu-Hohlbein, Chairperson of the Alzheimer Europe Foundation.

During the Networking Dinner on the evening of 17 October, held at The Old Student House in Helsinki and moderated by Kim Coppes from Live Online Events, the three finalists were invited to present their initiatives before the winner and runners-up were announced.

Assess Your Assumptions



Gili Yaron

Third place was awarded to Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for "Assess your assumptions". The campaign was presented by Gili Yaron. Studies by the Hogeschool Windesheim research group "Living Well with Dementia" found that health and social care professionals hold stereotypical beliefs about people with dementia especially those from minority

ethnic communities. Addressing these beliefs is vital to ensure this group receives good care and support. Based on input from professionals and informal carers, the Hogeschool developed a pocket-sized card deck featuring 16 common misconceptions about culturally sensitive dementia care, to be used as conversation starters or 'serious games' (e.g. stereotype bingo) in practice and education.

Accepting the third place prize, Gili Yaron said:

"We're so proud to win this award, which helps us further our goal of enabling people with dementia to live well—regardless of their background. We know that professionals are eager to provide culturally sensitive dementia care and support. By raising awareness about inclusivity, our card deck helps them do so!"

Rainbow Neighbours



John Hammond

"Rainbow Neighbours", the initiative winning second prize was presented by John Hammond from Brighton and Hove LGBT Switchboard, which takes a creative approach

to addressing the stigma, loneliness and isolation that can be experienced by LGBTQ+ people living with dementia, particularly those who are living in residential care settings. Rainbow Neighbours provides transport for LGBTQ+ people living with dementia at residential care settings to join Switchboard's fun and engaging peer support activities and broader wellbeing events. The project also gives those living at residential care settings access to ongoing multi-generational support from other LGBTQ+ people - a "Rainbow Neighbour".

Accepting the Award for second place, John Hammond said:

"Brighton and Hove LGBT Switchboard's dementia support service tackles the stigmas and stereotypes that LGBTQ+ people living with or affected by dementia experience. We are delighted to have this work recognised by Alzheimer Europe and we share the organisation's passion for changing perceptions of dementia and prioritising inclusive dementia care for all."

"We feel seen, we feel heard"



Ripaljeet Kaur

The winning initiative was presented by Ripaljeet Kaur from Touchstone for its project BME Dementia Service. BME Dementia Service provides specialist support to people living with memory problems or a diagnosis of dementia and their carers/family members from

Black and Minority Ethnic communities focusing predominantly on South Asian community living in and around Leeds.

Accepting the 1st place Anti-Stigma Award, Ripaljeet Kaur said:

"I am deeply humbled to be selected for the Anti-Stigma Award 2023. I share this award with a dedicated team and the courageous individuals who have shared their dementia journey stories.

Let this award be a symbol of hope, encouraging others from diverse communities to speak up and seek help so they too may be able to live well with dementia without the multi layers of stigma attached.

Thank you to everyone who has contributed to and networked with our service. Let's continue this journey towards a more inclusive and empathetic world.

Our work continues, but today, we celebrate progress. Thank you for this incredible recognition.

We feel seen, we feel heard."

More information about the Anti-Stigma Award can be found at: <https://www.alzheimer-europe.org/our-work/anti-stigma-award>



Anti-Stigma Award winners (left to right and from third place to first place): Gili Yaron (Assess your assumptions), John Bond (Rainbow Neighbours), Ripaljeet Kaur (BME Dementia Service)



Heike von Lützu-Hohlbein (centre), Chairperson of the Alzheimer Europe Foundation, presented the third place award to Gili Yaron (right) and colleagues



Helen Rochford-Brennan, member of the Board of the Alzheimer Europe Foundation (left), presented the second place award to John Bond

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma award: Alzheimer Europe Foundation, Lilly and Roche.

DAY 3:

Plenary 4 “New opportunities”

Nicolas Villain, Associate Professor of Neurology at Sorbonne University, Paris, France and the Institute of Memory and Alzheimer's Disease, Department of Neurology, Pitié-Salpêtrière Hospital, Assistance Publique – Hôpitaux de Paris, opened with a presentation looking at “How to evaluate the efficacy and safety of anti-amyloid treatments as a researcher, a clinician or patient”. Anti-amyloid therapies have shown efficacy in the early stages of Alzheimer's disease. However, serious side effects are a potential concern that cannot be overlooked, he stressed, noting that the complexity of their implementation in the healthcare system can affect their accessibility as a treatment option. Dr Villain stated that, when assessing drug efficacy, “it is essential to consider the perspectives of various stakeholders”. This is because while minimal benefits may be meaningful for some individuals, a quantitative evaluation of drug efficacy that takes into account the complete disease course is necessary “to provide a global perspective and balance the risks”. He also stressed the importance, in the future, of clinical trials aiming to better capture the potential efficacy and risks according to the overall disease course. Additionally, he emphasised that such trials should take into account the complexity

of implementing the treatment within the healthcare system, to help ensure it can be an accessible treatment option. Summing up, he said: “Anti-amyloid therapies hold promise for Alzheimer's treatment, but they are not a cure-all. A fair and quantitative evaluation of their risks and benefits, not just statistical significance, is crucial to assess their value.”

Ulrika Granér, Silvia Nurse, MSc Specialist Nursing – Elderly Care and Cognitive Impairment Care at Stiftelsen Silviahemmet then shared her presentation “Vision zero: A Swedish model for dementia care without restraint”. Despite current legislation and declaration of human rights, restraint in dementia care is still common, she said, which both violates self-determination and causes reduced quality of life for people living with dementia: “Reflection on the use of restraint in dementia care and working with person-centred methods are basic prerequisites for safeguarding the human rights of people living with dementia”, she commented. Her presentation demonstrated that working with a person-centred approach to prevent the use of restraint is possible, as long as the care team in question has the knowledge, structured tools and clear leadership that is absolutely vital for

success. She particularly emphasised the importance of strong leadership in this area.

The third speaker up to the podium was neurologist Eino Solje, Adjunct Professor and research director at the University of Eastern Finland and at the Brain Research Unit and Kuopio University Hospital Neuro Center. He made the point that accurate diagnosis of both dementia with lewy bodies (DLB) and frontotemporal dementia (FTD) is essential, to ensure the correct disease management is attributed to the right patient, stressing the important differences that exist in the management of common neurodegenerative diseases. “The role of the correct diagnosis will become even more pronounced in the future, when disease modifying, biology-specific medications become available”, he finished.

Professor Martin Orrell, Director of the Institute of Mental Health at the University of Nottingham United Kingdom, was the fourth and final speaker in Plenary 4. His talk revolved around ways to improve the lives of people with dementia through the use of technology. Technology can help people living with dementia to maintain their independence and autonomy, he noted, but said that it was not always clear what technology was needed or what works well. This is due to a poor understanding of how people with dementia use technology in everyday life, he said, and new applications are designed without an in-depth appreciation of people's needs, preferences, and difficulties. In closing, he highlighted that international consensus on good practice guidelines could enable researchers and developers to design better technology to help improve lives for people with dementia: “Designing better technology based on the needs and preferences of people with dementia can help them feel more confident managing at home, and maintain their independence for longer”.



Plenary 4 speakers and moderators (left to right): Jean Georges, Martin Orrell, Eino Solje, Kim Coppes, Ulrika Granér, Nicolas Villain

WATCH NOW:
Plenary 4

Plenary 5

“Dementia as a European public health and policy priority”

To open the session, Dr Natasha Azzopardi Muscat, Director of the Division of Country Health Policies and Systems at the WHO Regional Office for Europe, addressed delegates on behalf of Hans Kluge, WHO Regional Director for Europe, in a video message.

Roundtable panellists were: Andy Heffernan, Chief Executive of The Alzheimer Society of Ireland; Taru Koivisto, Deputy Director General for the Department for Communities and Functional Capacity, Ministry of Social Affairs and Health, Finland; Sonata Mačiulskytė, Chairperson of the European Dementia Carers Working Group (EDCWG) and Board member of Dementia Lithuania; Anne Remes, Vice-Rector and Professor of Neurology at the University of Helsinki, Finland; Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD) and Elina Suzuki, Health Policy Analyst,

Organisation for Economic Co-operation and Development (OECD).

Andy Heffernan noted that Ireland is approaching 10 years since the inception of its National Dementia Strategy, with philanthropy being very much the catalyst initially. The strategy included 35 actions, and a review on its 10th anniversary in 2024 is timely, he said. He also highlighted that significant Government funding and support in recent years have been championed by the Department of Health, The Health Service Executive and a very interested and committed Minister. The launch of the Model of Care for Dementia in Ireland in June of this year has the potential to be a ‘game changer’, as it sets out a range of targets and advice on assessment, diagnosis (and communication of diagnosis), treatment, care and support. Finally, he noted that the Assisted Decision Making capacity Act commenced in April 2023, having being legislated for as far as back as 2015. It moves away from a ‘best interest’ approach towards that of graduated support.

Taru Koivisto emphasised that “good brain health should be promoted in all stages of life - prevention of memory disorders can be improved. We need an active and visible debate on the memory disorders, with the voice of older people at the centre. A whole-of-society approach is necessary, as the population’s ageing will affect all sectors of society”.

Sonata Mačiulskytė stated that people often tend to shift the responsibility for delayed or misdiagnosis of dementia on to the professionals and to blame shortcomings of diagnostic practices, while less consideration is given to the lack of brain health awareness among the general public, which continues to allow stigma to thrive. “The level of dementia awareness varies between countries with

and without national dementia plans, but it is still insufficient everywhere”, she said. Regarding the situation in timely dementia diagnosis, she pointed out the inequalities in health services access across and within countries, saying “we are used to focus on the development of diagnostic infrastructure, leaving the gatekeeper – primary health – behind our field of vision. We should maintain an equal focus on the preparation of GPs and their teams to play a leading role in timely diagnosis”. She also stressed that European governments shift the burden of ageing and long-term care onto the community and onto families, but don’t think about the long-term economic consequences for the labour market and the impact on the national GDP. Real support, she said, tends to come from the NGO sector, but it is not sufficiently developed and supported by the state in all countries.

Anne Remes felt that memory disorders should be included in national health-related strategies, either as separate programmes (memory programmes) or integrated into broader public health promotion efforts. However, she said, “mere strategic discourse is not sufficient; practical measures and adequate financial resources are needed”. More investment is also needed in research and “actions are required to make the field of memory disorders and dementia attractive to researchers, clinicians, and healthcare personnel”, she commented.

Chris Roberts commented that, from his perspective, “everything is changing but nothing is changing regarding dementia; We need to do more!”. With one in three people affected by dementia, he pointed out that nobody is safe and that we need to work together to solve this. On the topic of making dementia a public health priority, he stated “dementia ‘IS’ a European public health and policy priority!” and reminded those present that “we have a right to quality care and services, don’t leave us behind!”



Roundtable panellists and moderators (left to right): Jean Georges, Andy Heffernan, Taru Koivisto, Sonata Mačiulskytė, Anne Remes, Chris Roberts, Elina Suzuki and Kim Coppes



DAY 3:

Plenary 4 and 5 photo gallery



Closing ceremony “Hyvästi Helsinki, Hallo Genf!”

The closing ceremony of the conference included a presentation by the winner of the Anti-Stigma Award, Ripaljeet Kaur, representing Touchstone’s BME Dementia Service. Closing comments were then made by Anne Remes, in her capacity as President of the Union Council of The Alzheimer Society of Finland (Muistiliitto) and Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, who then invited Stefanie Becker, Executive Director of Alzheimer Switzerland up to the stage and share her excitement that the 34th Alzheimer Europe Conference (34AEC) will be held in Geneva, from 8-10 October 2024. See you there!



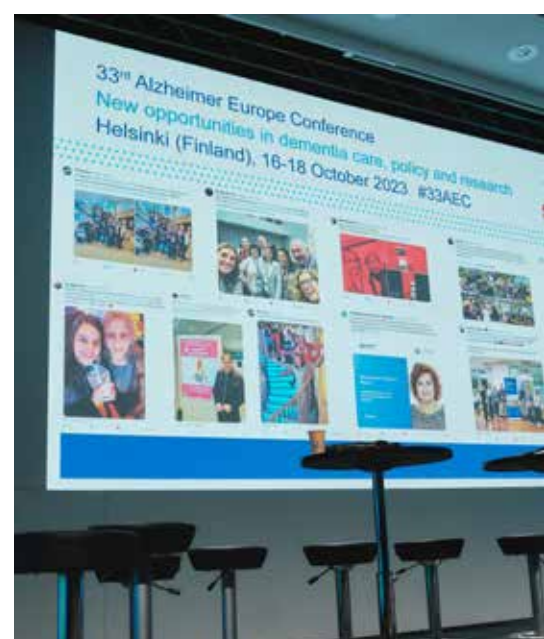
Anne Remes



Rosário Zincke dos Reis



Stefanie Becker



WATCH NOW:
Closing ceremony

CO-HOSTS:

Thoughts from our co-hosts

The Alzheimer Society of Finland (Muistiliitto) on "Co-hosting the 33rd Alzheimer Europe Conference – the Finnish experience"



The Alzheimer Society of Finland, Muistiliitto, welcomed the conference to Helsinki after 26 years. Bringing insights from the Finnish dementia scene, we were glad to have the opportunity to work with the dedicated Alzheimer Europe team to build a topical programme. With a multitude of plenaries, parallel sessions, quick oral presentations

and posters we wanted to reflect the richness of approaches to dementia in current research, care and best practices. With prevention potential of 40 percent, promoting brain health during the whole life course needs to be a worldwide priority in tackling the growing number of diagnoses in the future.

Finland has been paving the way in dementia prevention research; thus, latest developments in FINGER trials around the world took centre stage in the programme, Katariina Suomu, Executive Director, points out. An emerging theme, inclusion, aroused interest among many delegates. Both research findings and personal accounts stressed the importance of equal access and opportunities to all people living with dementia and their carers. Overall, the voice of people living with dementia was perhaps stronger than ever. The work of EWGPWD members and other individuals sharing their stories is key to making sure that people living with dementia remain the common thread of our work.

Finally, it was a great delight to see a new generation of researchers joining the conference. We need passionate professionals also in the future. A special programme of Finnish sessions offered (Finnish) delegates an opportunity to learn in depth about developments in Finland as well as to network with their local colleagues. Among other things, it provided a sneak peek of latest statistics of prevalence and incidence of dementia in our country. A session with the Finnish Institute of Health and Welfare shed light on their long-standing memory service path project that aims to provide older population and at-risk groups with preventive measures and to strengthen equality of services and works in close cooperation with a number of actors to implement lifestyle interventions. A live event is very much about networking, building bridges between countries and individuals, theory and practice. The buzz created by over 1,000 delegates sent a strong message about our common will to work towards a dementia-friendly world, and the ambitious steps taken in this direction.



Jenni Kulmala

PHOTO GALLERY:

The voice of lived experience at 33AEC

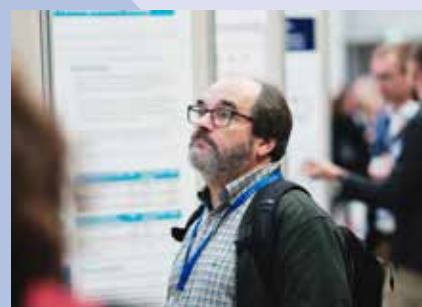


CHECK OUT:

Our full selection of photos
from 33AEC

PHOTO GALLERY:

Posters



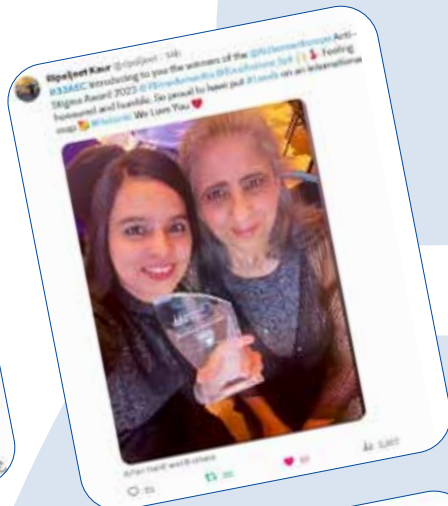
CHECK OUT:
Our full selection of photos from 33AEC

Networking dinner





SOCIAL MEDIA HIGHLIGHTS:



FACTS AND FIGURES:

Total delegates in 2023: **1130**

Delegates per country

Finland	251
United Kingdom	184
Netherlands	153
Germany	62
Italy	52
Norway	39
Ireland	38
Iceland	36
Sweden	32
Switzerland	25
Luxembourg	25
USA	22
France	20
Denmark	19
Belgium	14
Spain	14

Estonia	14
Austria	13
Greece	11
Canada	10
Czech Republic	9
Australia	9
Portugal	8
Taiwan	8
Lithuania	8
Malta	6
Slovenia	5
Hungary	5
Cyprus	4
Poland	3
Slovakia	3
Bulgaria	3

Romania	2
Japan	2
Armenia	2
China	2
Ukraine	2
Argentina	2
Croatia	2
Malaysia	2
Uganda	2
Turkey	1
New Zealand	1
Israel	1
Brazil	1
Jordan	1
Pakistan	1
Uzbekistan	1

Delegates per category

Academics/Researchers	404
Alzheimer organisation staff & volunteers	217
Health or social care professionals	214

Students	96
Industry representatives	68
People with dementia	52
Carers	41

Civil servants	21
Press	10
Policy Makers	7

93.79%

would recommend
Alzheimer Europe Conferences
to others

87.11%

rated the opening ceremony, plenaries
and closing ceremony of the conference
to be good/very good

34th Alzheimer Europe Conference

New horizons –

Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences

