

WP4 – Dissemination & Outreach

D4.2 Public event proceedings and videos – Year 1

Lead contributor	Christophe Bintener (3 – Alzheimer Europe)
Other contributors	Angela Bradshaw (3 – Alzheimer Europe) Jean Georges (3 – Alzheimer Europe) Nina Coll (1 – Synapse) Laurent Pradier (8 – Sanofi)

Contents

Document history	3
Definitions and abbreviations	4
Abstract	5
1 Introduction	6
2 Themes	7
3 Pre-event press release	7
4 Conference brochure	8
5 Videos	8
6 Neuronet website	16
7 Public event proceedings	17
7.1 Press release	17
7.2 Online articles	17
7.3 Dementia in Europe Magazine (print media)	18
7.4 Electronic newsletter	18
8 Annexes	19
8.1 Annex I Alzheimer Europe Press Release	19
8.2 Annex II Dementia in Europe Magazine article	27

Document history

Version	Date	Description
V0.1	06/02/2020	First draft
V0.2	13/02/2020	Review by WP4
V1.0	17/02/2020	Consortium review
V2.0	28/02/2020	Final version – Submission to IMI

Definitions and abbreviations

Partners of the NEURONET Consortium are referred to herein according to the following codes:

1. **SYNAPSE**: Synapse Research Management Partners SL
2. **NICE**: National Institute for Health and Care Excellence
3. **AE**: Alzheimer Europe
4. **JANSSEN**: Janssen Pharmaceutica NV
5. **LILLY**: Eli Lilly and Company Limited
6. **ROCHE**: F. Hoffman – La Roche AG
7. **TAKEDA**: Takeda Development Centre Europe LTD
8. **SARD**: Sanofi-Aventis Recherche & Développement
9. **PUK**: Parkinson's Disease Society of the United Kingdom LBG

Grant Agreement: The agreement signed between the beneficiaries and the IMI JU for the undertaking of the NEURONET project.

Project: The sum of all activities carried out in the framework of the Grant Agreement.

Work plan: Schedule of tasks, deliverables, efforts, dates and responsibilities corresponding to the work to be carried out, as specified in Annex I to the Grant Agreement.

Consortium: The NEURONET Consortium, comprising the above-mentioned legal entities.

Consortium Agreement: Agreement concluded amongst NEURONET participants for the implementation of the Grant Agreement. Such an agreement shall not affect the parties' obligations to the Community and/or to one another arising from the Grant Agreement.

IMI: Innovative Medicines Initiative

ND: Neurodegenerative Disorders

WP: Work Package

Abstract

NEURONET aims to provide a platform for research projects that are focussed on medical conditions that cause neurodegeneration, defined as the progressive loss of brain cells. This includes diseases such as Alzheimer's disease and Parkinson's disease. In particular, NEURONET brings together research projects that are funded by the Innovative Medicines Initiative (IMI), Europe's largest funder of public-private partnerships in the life sciences.

Amongst others, NEURONET aims to support scientists to enhance the visibility of their research, providing a platform that will act as a multiplier of impact (towards the wider society but also selected stakeholders). NEURONET aims to identify research synergies and overlaps, creating links between IMI projects as well as with other international research initiatives and enabling stronger and more fruitful collaborations.

To help fulfil these aims, NEURONET supports the communication and dissemination activities of IMI projects working in the area of neurodegeneration, also highlighting the achievements and activities of the projects on a portfolio level. As part of these activities, NEURONET has established a network of communication experts drawn from the individual projects. NEURONET also organises an annual networking and outreach event in collaboration with the leaders of the individual projects, to shine a spotlight on the IMI neurodegeneration portfolio. The event proceedings are then disseminated to the general public through NEURONET's communication channels, which include a website, regular newsletters and social media feeds.

This document provides an overview of the annual event as well as related outreach activities that have been conducted.

1 Introduction

Dissemination of the activities and achievements of the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio (towards the wider society but also selected stakeholders) is of vital importance.

IMI-funded research projects are partly financed by taxpayers, who are justly entitled to be informed about how and why their money is being spent, the outcomes of research and how these in turn affect society, both as a whole and at the individual level. In this context, NEURONET aims to act as an “ambassador”, reaching out to the public and other stakeholders, raising awareness and highlighting the value of the research and its findings.

In its role as an ambassador for the IMI ND portfolio, NEURONET organises an annual networking and communication event involving all the IMI ND projects as well as relevant external experts and stakeholders. During this event, presentations on the individual projects are delivered to an audience of policy makers, academic researchers, representatives of industry, payers, regulators and HTA bodies.

In order to reach a wider audience, the annual networking and communication event is organised as a series of four parallel sessions as part of the Annual Alzheimer Europe Conference. Proceedings of the event have been published and disseminated as widely as possible.

The following document provides an overview of the public event proceedings and videos for the first year event.

2 Themes

The NEURONET event took place at the Alzheimer Europe Conference in The Hague on 24-25 October. The series of four themed parallel sessions was entitled “Collaboration in Alzheimer’s disease & beyond”. The title was adopted as legacy of the successful event hosted by IMI in 2017. Representatives of each of the IMI ND projects as well as an IMI representative (Scientific Officer, Elisabetta Vaudano) were invited to speak at the event. The main themes of the sessions revolved around four topics:

- Session 1: European research collaboration in Alzheimer’s disease and beyond
- Session 2: From risk to dementia – Understanding disease progression and its causes
- Session 3: Improving data access and the development of predictive models
- Session 4: Diagnosis, patient engagement and trials

3 Pre-event press release

The event was announced through free media services, social media and communication channels of the IMI ND projects supported by NEURONET. In addition, all communication representatives from the participating projects were invited to share an event announcement with their consortia.

The announcement was also posted through the following networks and websites:

Network	Network description	URL
ScienceX Network	ScienceX is a network of high-quality websites that provides the most complete and comprehensive daily coverage of science, technology, and medical news.	https://phys.org/wire-news/331020005/250-million-eur-research-programme-on-neurodegeneration-featured.html
PRLOG (Press Release Distribution)	PRLOG is a free press release and press room hosting that provides free distribution to search engines.	https://www.prlog.org/12791004-250-million-eur-research-programme-on-neurodegeneration-featured-at-alzheimer-europe-conference.html
EU Health Policy Network	The EU Health Policy Platform is an interactive tool to boost discussions about public health concerns, share knowledge and best practices. Posted news are also distributed towards a mailing list of members. In addition, the event was also added to the EU Health Policy Network Calendar.	https://webgate.ec.europa.eu/hpf/item/item/21757
EU Monitor website	Automatic repost from EU Health Policy Network post	https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vl2e7kdk74zt?ctx=vg9hoiwjgczm&tab=1
Marie Curie Alumni website	Automatic repost from EU Health Policy Network post	https://www.mariecuriealumni.eu/events-rss/250-million-eur-research-programme-neurodegeneration-featured-alzheimer-europe-conference

4 Conference brochure



In order to further increase the visibility of the event and to introduce the individual projects, raising awareness of these public-private partnerships, NEURONET also developed a 12-page conference brochure in collaboration with communication representatives from the IMI ND projects.

The digital version of the [brochure](#) is available on the NEURONET [website](#) and was shared with representatives for further use. It was also included in all conference bags that were distributed to the 950 conference delegates.

5 Videos

The presentations that were given during the event were professionally filmed and the videos have been uploaded to the NEURONET YouTube channel (see screenshot below). The videos are also available on the NEURONET website, and have been disseminated via the NEURONET social media channels for wider visibility.



In addition, they have been added to the Alzheimer Europe Conference playlist and embedded into the alzheimer-europe.org website. Below is an overview of the presentations including links to YouTube.

Session 1: European research collaboration in Alzheimer's disease and beyond

The first session aimed to set the scene for NEURONET, giving an overview of the IMI ND portfolio (Elisabetta Vaudano, IMI), summarising the aims of the NEURONET Coordination and Support Action (Carlos Díaz, SYNAPSE Research Managers) and showing the value of establishing meaningful connections with the patient community (Ana Diaz, Alzheimer Europe).

P5.1 Elisabetta Vaudano - The Innovative Medicines Initiative and its neurodegeneration portfolio



<https://youtu.be/5iaS3rB4Fmo>

P5.2 Carlos Díaz - Neuronet – Efficiently Networking European Neurodegeneration Research



<https://youtu.be/rU6JzdMoz4>

P5.3 Ana Diaz - Patient and Public Involvement in the IMI research portfolio



<https://youtu.be/CVIYYL92DAU>

Session 2: From risk to dementia – Understanding disease progression and its causes

The second session aimed to showcase some of the fundamental, mechanistic work that is being carried out by projects in the IMI ND portfolio. To start with, Maria Eugenia Saez from the ADAPTED project showed how they are using cell models and clinical data to understand the role of the common AD risk factor, APOE. Angela Hodges of the PHAGO project then presented their work on brain inflammation in AD, which is deciphering how two key proteins regulate the behaviour of brain immune cells. Finally, Martin Hofmann-Apitius of the AETIONOMY project described how their data mining approaches led to the identification of new disease mechanisms that may drive the development of AD and PD.

P13.1. María Eugenia Sáez - ADAPTED – Alzheimer's disease apolipoprotein pathology for treatment elucidation and development



<https://youtu.be/hAoe8m1kn8g>

P13.2. Angela Hodges - PHAGO – Targeting TREM2 and CD33 of phagocytes for treatment of Alzheimer's disease



<https://youtu.be/Kfbp3Bydy2U>

P13.3. Martin Hofmann-Apitius - AETIONOMY – Disease Mechanisms for Patient Subgroup Identification and Disease Progression Modeling



https://youtu.be/VFJz_K7B8KU

Session 3: Improving data access and the development of predictive models

The third session was primarily focused on data-driven projects that aim to facilitate the identification and use of preclinical and clinical datasets. Malcolm Macleod of the EQIPD project described how their work on preclinical models of AD is aiming to increase the potential for translation of basic science insights into treatments for disease, by enhancing the quality and rigour of these experiments. Pieter Jelle Visser showcased the EMIF project, which developed a common information framework for patient-level data, facilitating access to these valuable datasets and creating new opportunities for research. John Gallacher described the ROADMAP project approach to enhance the use of “real-world data” on patient outcomes for clinical research, developing new tools and resources that facilitate the use of these valuable data resources. Finally, Dominique Lesuisse of the IM2PACT project presented their research on the blood-brain barrier, which is aiming to provide in-depth insights to enable therapeutic treatments for ND to effectively reach the brain.

P21.1. Malcolm Macleod - EQIPD – Data quality in preclinical research



<https://youtu.be/B1VrOR-RuNo>

P21.2. Pieter Jelle Visser - EMIF – European Medical Information Framework



<https://youtu.be/YPH4CmBfmTk>

P21.3. John Gallacher - ROADMAP – Real world outcomes across the AD spectrum

<https://youtu.be/HpQP2Nn7lss>

P21.4. Dominique Lesuisse - IM2PACT – Discovery of blood-brain barrier targets and transport pathways to treat neuro/metabolic diseases

<https://youtu.be/Hn0gqmRsZlo>

Session 4: Diagnosis, patient engagement and trials

The final NEURONET session revolved around projects that directly involve patients and people living with ND. First, José Luis Molinuevo described how the AMYPAD project is studying the clinical value of performing PET scans to detect amyloid proteins in the brains of people in the early stages of AD. Then, Craig Ritchie of AMYPAD's sister project, EPAD, showcased how they are creating a EU-wide longitudinal cohort of people at risk of developing AD, some of whom will be invited to participate in proof-of-concept drug trials. Mercè Boada from the MOPEAD project showed how they tested four different approaches to engage patients for clinical research on AD, identifying ways to improve the early detection and diagnosis of AD. Finally, Dag Aarsland of the RADAR-AD project discussed their approach to use digital technologies such as wearable devices to more accurately detect and assess the progression of disability associated with AD.

P29.1. José Luis Molinuevo - AMYPAD – Amyloid imaging to prevent Alzheimer's disease



<https://youtu.be/262ZulAwglU>

P29.2. Craig Ritchie - EPAD – European prevention of Alzheimer's dementia consortium



<https://youtu.be/OGDt62DOgAg>

P29.3. Mercè Boada - MOPEAD – Models of Patient Engagement in Alzheimer’s Disease

<https://youtu.be/9m2DuaKeX9w>

P29.4. Dag Aarsland - RADAR-AD – Remote Assessment of functional decline in Alzheimer’s Disease

<https://youtu.be/O1cU7ybhssw>

6 Neuronet website

All public information on the event was brought together on a dedicated subpage of the imi-neuronet.org website. The website subsection is set up with anchors so that users can click on the title of a selected session which will direct them towards the right part of the page. The videos and the presentation slides are all accessible on the imi-neuronet.org and alzheimer-europe.org websites.



HOME ABOUT ▾ EVENTS ▾ NEWS ▾ PROJECTS ▾ DOWNLOADS ▾

2019: The Hague

Session 1 Session 2 Session 3 Session 4

European research collaboration in Alzheimer's disease and beyond

A series of four parallel sessions introducing you to the state of the art in European neurodegeneration research

Alzheimer Europe Conference
The Hague, Netherlands

Neuronet organises an annual networking and communication event. This involves Innovative Medicine Initiative projects that work in the area of neurodegeneration research. The 2019 event took place at the Alzheimer Europe Conference in The Hague on 24-25 October.

Click here to download the conference brochure. The slide presentations and recordings can be downloaded below.

Session 1: European research collaboration in Alzheimer's disease and beyond

Session 2: From risk to dementia – Understanding disease progression and its causes

Session 3: Improving data access and the development of predictive models

Session 4: Diagnosis, patient engagement and trials

Session 4

Diagnosis, patient engagement and trials

The fourth Neuronet session was chaired by José Luis Molinuevo, Neuronet Scientific Coordination Board member. AMYPAD and EPAD, two sister projects of the IMI neurodegeneration portfolio, highlighted their achievements in using amyloid-PET scans to diagnose AD (AMYPAD), and in creating clinical trial registries and cohorts of people at risk of developing Alzheimer's dementia (EPAD). The leader of the MOPEAD project then presented the four patient engagement models that they are currently testing, aiming to improve early patient engagement in clinical trials. The final Neuronet session was brought to a close with a presentation on the RADAR-AD project, which is exploring how digital technologies can be used non-invasively to measure the progression of disability associated with AD.

José Luis Molinuevo



BarcelonaBeta Brain Research Center, Spain

P29.1. José Luis Molinuevo - AMYPAD – Amyloid imaging to prevent Alzheimer's disease.pdf

Craig Ritchie



University of Edinburgh, United Kingdom

P29.2. Craig Ritchie - EPAD – European prevention of Alzheimer's dementia consortium.pdf

Mercè Boada



Fundació ACE, Spain

P29.3. Mercè Boada - MOPEAD – Models of Patient Engagement in Alzheimer's Disease.pdf

Dag Aarsland



King's College London, United Kingdom

P29.4. Dag Aarsland - RADAR-AD – Remote Assessment of functional decline in Alzheimer's Disease.pdf



7 Public event proceedings

7.1 Press release

Following the event, Alzheimer Europe launched a press release (see Annex I) that included an outline of the four parallel sessions. The press release was sent to the 8,500 subscribers on the organisation's mailing list. It can be accessed here:

<http://alzheimereurope.newsweaver.com/ConferenceAnnouncement/1sy5ob68ev9>

7.2 Online articles

Following the initial press release, an article about the event was posted on the imi-neuronet.org website: <https://www.imi-neuronet.org/neuronet-convenes-annual-event/>

This article was also shared with the communication representatives to be cloned and amended for further outreach. The table below shows the news posts by individual projects and by IMI ND project partners.

Project or Partner	Link
ADAPTED	https://www.imi-adapted.eu/single-post/2019/12/03/Watch-ADAPTED-at-NEURONET-Annual-Conference-The-Hague
AMYPAD	https://amypad.eu/news/recent-news/amypad-presents-at-the-29th-alzheimer-europe-conference/
EPAD	http://ep-ad.org/2019/10/25/neuronet-convenes-annual-event-on-european-research-collaboration-in-alzheimers-disease-and-beyond/
MOPEAD	https://www.mopead.eu/single-post/2019/10/21/IMIs-neurodegeneration-projects-gather-at-29th-Alzheimer-Europe-Conference-in-The-Hague
ROADMAP	https://roadmap-alzheimer.org/news/roadmap-presents-at-neuronets-annual-event-on-european-research-collaboration-in-alzheimers-disease-and-beyond/
RADAR-AD	https://www.radar-ad.org/newsroom/radar-ad%E2%80%99s-project-leader-dag-aarsland-talks-29th-alzheimer-europe-conference-hague-%E2%80%9Cmaking
Alzheimer Europe	https://www.alzheimer-europe.org/News/EU-projects/Friday-25-October-2019-Neuronet-convenes-annual-event-on-European-research-collaboration-in-Alzheimer-s-disease-and-beyond (also via newsletter)
Alzheimer Europe	https://webgate.ec.europa.eu/hpf/item/item/23475
Fundació ACE	https://www.fundacioace.com/en/press-room/castell-de-peralada-festival-and-fundacio-ace-present-the-music-for-memory-project-at-alzheimer-europe-2019.html

7.3 Dementia in Europe Magazine (print media)

An article on the event has been written up in collaboration with the communication representatives for the Dementia in Europe Magazine (see Annex II).

Alzheimer Europe publishes the Dementia in Europe magazine in print three times per year with a distribution that varies between 3,000 and 3,500 copies. It is delivered to all the Members of the European Parliament (MEPs) and many high-level decision makers in the European Commission. It also reaches lawmakers and politicians in the countries of Alzheimer Europe's member associations, who receive and further distribute numerous copies of each issue. In addition, the magazine is read by research professionals from public and private bodies, such as the JPND and the 2nd EU Joint Action on Dementia. Finally, the magazine is distributed to academic and scientific partners who work together with Alzheimer Europe in various projects.

7.4 Electronic newsletter

The event was announced in the first NEURONET Newsletter issue (sent to 106 recipients on 19 September 2019): <http://bit.ly/Neuronet-newsletter-1>

Furthermore it was featured in the second issue of the NEURONET newsletter (sent to 125 recipients on 6 January): <http://bit.ly/Neuronet-newsletter-2>

8 Annexes

8.1 Annex I Alzheimer Europe Press Release

Making valuable connections



Final day of Alzheimer Europe Conference “Making valuable connections” focuses on dementia-inclusive societies and dementia prevention

The Hague, 25 October 2019 – The 29th Alzheimer Europe Conference (#29AEC) “Making valuable connections”, came to a close this evening, 25 October 2019, in The Hague. The focus of the final day was on dementia-inclusive societies and on dementia prevention.

Making our societies more dementia-inclusive

The third plenary session “Making our societies more dementia-inclusive” was chaired by Jim Pearson (Scotland, UK) and opened with a presentation by Bernd Heise, a member of the European Working Group of People with Dementia (EWGPWD), who shared his expectations from dementia-inclusive communities, with the audience. A dementia-friendly community, he said, may be built from several single initiatives, if they can work together towards a common goal. “Such communities are founded on the consensus of all responsible persons and on greater persistence”, he stressed. He also emphasised that a truly “dementia-friendly” community requires the full inclusion of people with dementia (hence the term “dementia-inclusive”) and must promote their existing skills and interests.



Mohammed Akhlak Rauf, Founder & Director of Meri Yaadain CiC, used his presentation to discuss “Embedding intercultural care to support dementia care amongst minority ethnic communities”. He began by drawing attention to the impact that migration and migratory history have had on the level of trust accorded to statutory agencies. This lack of trust understandably reduces the uptake of health and social care services among migrants and people from minority ethnic communities, including those living with dementia. “Questions should be asked as to why minority ethnic groups are absent from services”, he urged. He also highlighted the importance of considering the needs of people with dementia and their family carers and of incorporating these into research, planning, design and delivery, from the off, rather than such supports being an “add-on” or an extra specialism, as is so often the case. In conclusion, Mohammed Akhlak Rauf stated that “understanding intercultural care needs requires an awareness of faith, language and wider cultural norms and how they influence conceptualisation as well as coping with dementia.”

Julie Meerveld, Manager of Regional Support and Advocacy at Alzheimer Nederland, presented “The Dutch National Programme for a dementia-inclusive society – a collaboration involving national and local authorities, associations and companies”. Alzheimer Nederland began its national campaign to make Dutch society more inclusive for people with dementia, in 2016, with the goal of educating the public about dementia and how to communicate better with people living with dementia. The campaign has been a success, she was pleased to say. After three years of campaigning, 80% of the public in the Netherlands is aware of the campaign, 280,000 people have signed up to support the campaign and 58% of those have completed training courses. 350 companies are also involved, training their employees and informing their customers. “It works. Dutch society has become a more dementia-friendly society, because the public and dementia friends feel more confident and able and family carers feel more supported and more able to ask for outside help”, she said. Alzheimer Nederland has been monitoring progress via panel consultation and research involving members of the public and informal carers. “Our three vital ingredients are: a large-scale scope of the campaign to create a responsive basis, close collaboration with companies and the twelve different online training courses and one offline training” she concluded.

Elina Suzuki, an Advisor to the Director of Employment, Labour and Social Affairs at the Organisation for Economic Co-operation and Development (OECD), was the final speaker at this plenary session. She presented on the state of dementia care and dementia-friendly initiatives across OECD countries. She reported that the quality of care for people living with dementia remains poor, even in many countries with strong health and social care systems. She also spoke about the rising interest in

developing dementia-friendly initiatives in OECD countries, noting that at least 90% of OECD members reported having at least some dementia friendly initiatives in their countries.

How can research lead to better prevention?



The last plenary session posed the question “How can research lead to better prevention?” and was chaired by Marco Blom (Netherlands). It began with a presentation on “Multidomain lifestyle interventions to prevent cognitive impairment and dementia: From FINGER to World-Wide FINGERS”, given by Tiia Ngandu, Research Manager and leader of the Dementia Prevention group at the Finnish Institute for Health and Welfare in Helsinki. She emphasised the importance of finding effective preventive interventions for dementia and Alzheimer’s disease (AD), given the growing number of cases, worldwide. The multifactorial etiology of dementia and late-onset AD mean that multi-domain interventions targeting several lifestyle-related and vascular risk factors are most likely to be effective, she said. “FINGER” is a pioneering trial providing the first evidence that a multi-domain lifestyle intervention may prevent cognitive impairment. The FINGER intervention, she commented, also has a beneficial effect on daily functioning, health-related quality-of-life and reduces the development of new chronic diseases. The implementation of the FINGER model in a public health context is ongoing and the FINGER model is being adapted and tested in new trials around the world, within the framework of “World-Wide FINGERS” network. In closing, Tiia Ngandu urged all stakeholders to work together to promote better brain health and dementia prevention.

Next, Meike Vernooij, Professor of Population Imaging at the Erasmus University Medical Center, discussed “The role of imaging in epidemiological studies: findings of the Rotterdam Scan Study”. She began by stating that the use of non-invasive imaging in population studies can help unravel preclinical brain changes in asymptomatic people, and as such can improve our understanding of the etiology of Alzheimer’s disease, as well as improving risk stratification and prediction of the disease. Besides informing researchers about (preclinical) disease, this so-called “population imaging” can also help us to better understand the (normal) brain ageing process, she said. This has value in clinical practice in the context of assessing whether an individual has brain tissue loss that is normal for their age. New advanced image processing methods that apply artificial intelligence techniques “may lead to detection of new biomarkers that may further improve risk prediction”, she told the audience. It is imperative, however, to keep in mind that the quality of data used will impact results, and therefore to be aware of how results have been generated.

Sebastian Köhler, Associated Professor at the School for Mental Health and Neuroscience at Maastricht University and Senior Researcher at the Alzheimer Centrum Limburg at Maastricht UMC+ used his session to stress the importance of immediate action, where dementia prevention is concerned. “Our own research shows that most people think dementia is inevitable. We need to inform the public better about what can be done to reduce the risk and create awareness”, he urged. There is consistent evidence that several lifestyle factors improve brain health later in life, he said, and that, while there is currently no sure way of predicting who will or will not develop dementia and that a healthy lifestyle is not a guarantee, it does lower the risk. In conclusion, he said that without a game-changing drug, which has not yet materialised, promoting a brain-healthy lifestyle is “the best and only the only option we have.”

Empowerment and wellbeing among people with dementia

The keynote presentation was delivered by Debby Gerritsen, Professor of Wellbeing among Frail Elderly People and People with Chronic Illnesses in Long-term Care, at the Department of Primary and Community care of the Radboud University Medical Center in Nijmegen. Her presentation, “Empowerment and wellbeing among people with dementia”, emphasised that the healthcare sector and healthcare professionals need to focus more on people’s strengths and their need to feel useful, rather than on what they are no longer capable of. She also highlighted the importance of specifying what empowerment means and includes for people with dementia, and how it can be shaped in the relationship between the individual and the people in their environment.



Vaarwel, Den Haag. Salut, Bucharest!

The three-day conference was formally closed by Alzheimer Europe Chairperson Iva Holmerová and Alzheimer Nederland Executive Director Gerjoke Wilmink, who thanked speakers and poster presenters for sharing their research, projects and experiences. Iva Holmerová thanked Alzheimer Nederland for co-hosting the 29th Alzheimer Europe Conference and said a special thank you to the various sponsors of the conference:

The European Union Health Programme (2014-2020), Roche, Eisai, Biogen, Janssen, Amgen, Otsuka, the Alzheimer Europe Foundation, The Hague Convention Bureau, The City of The Hague, Skyteam, Lufthansa.

She then invited all delegates to mark the dates of the next Alzheimer Europe Conference (#30AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 20 to 22 October 2020.

Data sharing in dementia research



This Special Symposium, which was sponsored by a grant from Gates Ventures, was chaired by Angela Bradshaw of Alzheimer Europe. Focused on the topic of data sharing, the Symposium aimed to provide a broad overview of the state-of-the-art on health data sharing, from clinical research to data protection and, finally, the views of patients.

First to speak in the Symposium was Pieter Jelle Visser, Associate Professor at the Alzheimer Center of Amsterdam University Medical Center. Highlighting the lack of effective drug therapies for Alzheimer’s disease, he underlined the importance of accessing large clinical datasets to speed up research. He discussed a number of recent initiatives aimed at facilitating data sharing, including Dementias Platform UK (DPUK), the Netherlands Consortium of Dementia Cohorts and the European Medical Information Framework - Alzheimer’s disease (EMIF-AD) project.

He concluded his presentation by giving some examples of how data sharing has advanced our understanding of Alzheimer's disease.

Moving on from these concrete exemplars of data sharing in clinical research, Manuela Mayrhofer of the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) focused on the legal frameworks that underpin responsible data sharing in health research. She started by outlining one of the central ambitions of the General Data Protection Regulation (GDPR): to strike a balance between the protection of individuals' personal data, whilst also enabling the free movement of this personal data. Next, she spoke about the scope of the GDPR; who and what it affects, and how it imposes data protection obligations and responsibilities on researchers and organisations. To finish her presentation, she discussed some recent data scandals, outlining how the EU are handling these situations to ensure our data is held, processed and shared securely.

Nicola Bedlington of the European Patients' Forum (EPF) drew this Special Symposium to a close by speaking about the views of patients and the general public on data sharing. Nicola started off by presenting the work that the EPF has undertaken with their member organisations, enabling them to understand the general views of patients on the sharing of their health data. She then introduced the audience to the 'Data Saves Lives' initiative, a multi-stakeholder platform hosted by the EPF that aims to provide up-to-date information about health data in an accessible format. Nicola drew the Special Symposium to a close by providing a snapshot of the EPF's various digital health projects, all of which aim to ensure a strong patients' voice in driving change for the benefit of patients.

Showcasing IMI projects - Neuronet at #29AEC

Neuronet, a coordination and support action funded by the Innovative Medicines Initiative (IMI), brings together 15 IMI consortium projects working on neurodegenerative disease, encompassing over EUR 290 million in research funding. The Neuronet programme held four parallel sessions as part of the Alzheimer Europe conference, showcasing projects that are working to improve our understanding, diagnosis and treatment of neurodegenerative disease.



The first parallel session was chaired by Lennert Steukers from Janssen, and was entitled "European research collaboration in Alzheimer's disease and beyond". The three speakers in this session introduced the work of the IMI on neurodegenerative disease (Elisabetta Vaudano, IMI), presented an overview of the Neuronet project (Carlos Diaz, Synapse Research Partners) and highlighted the importance of meaningful patient and public involvement in IMI research projects (Ana Diaz, Alzheimer Europe).



The second parallel session was chaired by Craig Ritchie, Director of the Centre for Dementia Prevention at Edinburgh University, and was entitled "From risk to dementia: Understanding disease progression and its causes". In this session, leaders of the ADAPTED, PHAGO and AETIONOMY projects presented their work on characterising some of the key molecular drivers of Alzheimer's disease, such as the ApoE genetic risk factor and the innate immune receptors CD33 and TREM2.

The third parallel session was chaired by Jacqueline Bouvy of NICE and was entitled “Improving data access and the development of predictive models”. Four IMI projects were presented in this session: EQIPD, EMIF, ROADMAP and IM2PACT. The EQIPD project is developing a framework for improving research quality, aiming to improve the drug development pipeline, while the EMIF and ROADMAP projects showcased the new platforms and tools they have developed to help researchers visualise and access clinical research data and real-world evidence. This session finished with a presentation on the IM2PACT project, which is working to understand the blood-brain-barrier in health and disease.



The fourth Neuronet session was chaired by José Luis Molinuevo, Neuronet Scientific Coordination Board member, and was entitled “Diagnosis, patient engagement and trials”. AMYPAD and EPAD, two sister projects of the IMI neurodegeneration portfolio, highlighted their achievements in using amyloid-PET scans to diagnose AD (AMYPAD), and in creating clinical trial registries and cohorts of people at risk of developing Alzheimer’s dementia (EPAD). The leader of the MOPEAD project then presented the four patient engagement models that they are currently testing, aiming to improve early patient engagement in clinical trials. The final Neuronet session was brought to a close with a presentation on the RADAR-AD project, which is exploring how digital technologies can be used non-invasively to measure the progression of disability associated with AD.

Conference co-host Alzheimer Nederland holds three special symposia

Alzheimer Nederland, co-host of the 29th Alzheimer Europe Conference, held three special symposia, during the event, the first of which, “Alzheimer Café on hospital care and dementia”, was held on 24 October from 12.15-13.45. In a special edition of an Alzheimer Café, the famous writer Nicci Gerrard was interviewed about her latest book, “What Dementia Teaches Us about Love”. The book gained a lot of awareness in the media and among the general public.



After her own father dying from dementia, she set out to explore the illness. Her book is an attempt to understand and is filled with stories, both moving and optimistic, from people living with dementia to those planning for the end of life, from the scientists unlocking the mysteries of the brain to the therapists using art and music to enrich the lives of affected people; from the campaigners battling for greater compassion in care to the families trying to make sense of dementia. The book explores memory, language, identity, ageing and the notion of what it truly means to care.

After the interview delegates were invited to participate in a lively discussion and to ask questions.



The second Alzheimer Nederland symposium focused on the Netherlands' national dementia strategy, the "Deltaplan Dementie". It was held on 24 October from 17.45-19.00 and speakers at the session were Philip Scheltens (Deltaplan Dementie), Marianne De Visser (ZonMW Program Committee), Dinant Bekkenkamp (Alzheimer Nederland) and Karlijn Kwint (Vilans). All four speakers are closely involved in the implementation of the Deltaplan.

The Deltaplan was launched in 2012, to address and manage the growing problem of dementia in the Netherlands. This second national strategy was launched by the Ministry of Health, Welfare and Sports and comes to an end next year. It relies on three main pillars, focussing on, respectively: Scientific research (basic research, prevention, finding a cure for dementia, research with a focus on treatment, support and quality-of-life); improving care; and creating a dementia-friendly society. The plan has a dedicated budget of around EUR 90 million, financed by the government and by private organisations.

The Deltaplan Dementie is also a cooperative network with member organisations in the fields of science, education, healthcare, healthcare insurance and business, as well as patient organisations.

The third and final symposium organised by Alzheimer Nederland, "Innovations in dementia care in the Netherlands", was held on 25 October from 12.15-13.45. Speakers at the session were Bere Miesen (The Hague), Bernadette Willemse (Reigershove), Simone De Bruin (RIVM – Netherlands National Institute for Public Health and the Environment) and Willem Draaisma (Participe).



One of the Dutch innovations examined during this session was the concept of the "Alzheimer Cafe", presented by Bere Miesen, the "founding father" of these Cafes. New developments in small-scale housing and care farms as an alternative to regular daycare and nursing home facilities were also presented. Small-scale housing is now used in many nursing facilities. Care farms are a more recent addition, with some promising initiatives ongoing, both in the Netherlands and internationally.

Since innovation can also mean expanding on ideas from other countries, the final speaker examined how the Danish concept of "Odensehuizen" was picked up and developed into a new facility in the Netherlands.

Poster awards

The Alzheimer Europe Foundation has awarded a prize to the top two poster presentations for today, as voted by conference participants. The winner will be awarded EUR 750 and the runner-up gets EUR 250.

The two winners for today were Marjolein Scholten for PO17.3. Marjolein Scholten (Netherlands): Green Care Farms, a new old housing concept? (runner-up) and Monika Wilhelmi for PO9.5. Monika

Wilhelmi (Germany): Hands-on Dementia. The interactive way to understand dementia. A method to feel the symptoms of dementia (first place).

Congratulations to both of them!

Alzheimer Europe would like to thank to all delegates who joined us at #29AEC, and wish everyone a safe trip home. See you next year for #30AEC!

For further information, contact:

Jean Georges, Executive Director of Alzheimer Europe, 14, rue Dicks, L-1417 Luxembourg, Tel.: +352-29 79 70, Fax: +352-29 79 72, jean.georges@alzheimer-europe.org

Notes to editors:

Alzheimer Europe is the umbrella organisation of national Alzheimer associations and currently has 42 member organisations in 37 European countries. (www.alzheimer-europe.org).

The NEURONET initiative (Efficiently Networking European Neurodegeneration Research) is a three-year coordination and support action aiming to set up an efficient platform to boost synergy and collaboration across the Innovative Medicines Initiative (IMI) projects in the Neurodegenerative Disorders (ND) portfolio. Neuronet has received funding from the IMI 2 Joint Undertaking under grant agreement No 821513. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and Parkinson's UK. (www.imi-neuronet.org)

Alzheimer Nederland (founded in 1984) has approximately 100 employees at its head office in Amersfoort and 3,500 volunteers across the country, providing information about dementia, offering support and promoting better care for people with dementia. Alzheimer Nederland works closely with regional and national healthcare institutions and raises money for, among other things, scientific research into dementia. (www.alzheimer-nederland.nl)

The 29th Alzheimer Europe Conference in The Hague, received funding under an operating grant from the European Union's Health Programme (2014-2020). Alzheimer Europe and Alzheimer Nederland gratefully acknowledge the support of all conference sponsors.



Published by Alzheimer Europe © 2019 All rights reserved.

8.2 Annex II Dementia in Europe Magazine article

SPOTLIGHT ON 29AEC

European research collaboration in Alzheimer's disease and beyond presented at #29AEC

Neuronet, a coordination and support action bringing together 15 IMI consortium projects working on neurodegenerative disease, held four parallel sessions as part of the Alzheimer Europe Conference.

When it comes to neurodegenerative conditions (such as Alzheimer's disease) there is little to no way to avoid being affected by them, either directly or indirectly. Dementia alone is already estimated to directly affect over nine million people in Europe, subsequently impacting carers and whole families. Unfortunately, development of treatments takes years and so far there are no cures available.

On 24 and 25 October 2019, a group of 14 experts in neurodegeneration research set out to present on efforts in tackling the challenges around the high-unmet medical need of people affected by such conditions. The expert presentations were held throughout four parallel sessions organised by Neuronet at Alzheimer Europe's Annual Conference under the banner "Making valuable connections".

Neuronet is a coordination and support action funded by the Innovative Medicines

Initiative (IMI), bringing together 15 European IMI consortium projects working on neurodegenerative diseases, encompassing over EUR 290 million in research funding.

Opening session – Breaking down silos and establishing valuable connections with the patient community

The opening session set the scene, providing a bird's-eye view on European research collaboration in Alzheimer's disease (AD) and beyond.

The Innovative Medicines Initiative and its neurodegeneration portfolio

The first presenter was Elisabetta Vaudano, Principal Scientific Officer at IMI, an EU public-private partnership funding health research and innovation. She introduced its neurodegeneration research portfolio and explained how it aims to accelerate innovation in dementia research by enabling

collaborative research between industry, academia and patient organisations as well as SMEs. IMI has invested significantly in a broad portfolio of projects on neurodegeneration with a specific focus on AD. They are now starting to harvest the first results from these initiatives.

Neuronet – Efficiently Networking European Neurodegeneration Research

The second presentation was given by project coordinator Carlos Diaz from Synapse Research Management Partners SL (SYN-APSE), introducing Neuronet itself. He explained that Neuronet aims to set up an efficient platform to boost synergy and collaboration across the IMI projects of the neurodegenerative diseases portfolio. This will assist in identifying gaps, multiplying the portfolio's impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide. In order to be able to do so, Neuronet set up a Scientific Coordination Board formed by the leaders of the 15 IMI neurodegeneration projects. This Board provides expert guidance and recommendations in terms of scientific and strategic evaluation of synergies and priority areas for the whole programme.

Patient and Public Involvement in the IMI research portfolio

The third speaker highlighted IMI's awareness that involving the patient community in its research projects is indispensable. Ana Diaz, Project Officer at Alzheimer Europe presented on patient and public involvement (PPI) in the IMI research portfolio. As co-coordinator of the European Working Group of People with Dementia, she gave concrete examples of how people with dementia can actively and meaningfully contribute towards the research process as part of a true partnership between them, researchers, policy makers and other members of society.

From risk to dementia – Understanding disease progression and its causes

The second session dove into the world of hands on work in research projects, showcasing connections and sparking ideas for further collaboration.



Carlos Diaz, Elisabetta Vaudano, Ana Diaz



SPOTLIGHT ON 29AEC



Maria Eugenia Saéz Goñi, Angela Hodges, Martin Hoffmann-Apitius

ADAPTED – Alzheimer's disease apolipoprotein pathology for treatment elucidation and development

Maria Eugenia Saéz Goñi from the bioinformatics research centre in Andalusia presented the first project, entitled "ADAPTED". The ADAPTED project investigates the function of the APOE gene, which is an area of AD research that has previously received little attention. Carrying the genetic variant known as APOE ε4 is the most prevalent genetic risk factor for developing AD, but little is known about precisely why this is. ADAPTED uses the combined expertise of researchers across different fields to systematically investigate APOE biology, and aims to provide the research community with a new generation of human cell-based tools to investigate the causes and progression of the disease.

PHAGO – Targeting TREM2 and CD33 of phagocytes for treatment of Alzheimer's disease

Angela Hodges from Kings College London spoke about the PHAGO project. One of the project aims is to gain profound knowledge about the role of the innate immune receptors TREM2 and CD33 in AD. The other aim is to develop novel and innovative tools which might help to pave the way for new therapeutic strategies. PHAGO has already started to generate TREM2 and CD33 reporter systems and assays to support screening and drug development pipelines. The project also established a knowledge platform with data from partners, enriched with literature data from public resources.

AETIONOMY – Disease Mechanisms for Patient Subgroup Identification and Disease Progression Modeling

Martin Hoffmann-Apitius from the Fraunhofer Institute for Algorithms and Scientific Computing introduced the activities and learnings from the completed AETIONOMY project. Data and knowledge about disease mechanisms are frequently scattered, biased, heterogeneous and sometimes simply wrong. AETIONOMY therefore aimed to pave the way towards a new approach to the classification of neurodegenerative diseases, particularly Alzheimer's and Parkinson's diseases, thereby improving drug development and increasing patients' chances of receiving a treatment that works for them. In this pursuit, the project developed two key tools:

- The AETIONOMY Knowledge Base, a unification point of the knowledge and data management on neurodegeneration with a main focus on Alzheimer's and Parkinson's diseases.
- A mechanistic interpretation of multiscale, multimodal clinical data, representing essential pathophysiology mechanisms of neurodegenerative diseases (NeuroMMSig). It is the largest inventory of computable disease mechanisms underlying neurodegeneration worldwide.

Improving data access and the development of predictive models

The following session brought together project leaders from the United Kingdom, the Netherlands and Belgium.

EQIPD – Data quality in preclinical research
Malcolm Macleod from the University of Edinburgh introduced the EQIPD project, which aims to tackle the challenge of a slowing in the development of new medicines throughout the past decade. The project aims to tackle the root of this problem and reverse this trend. It is conducting systematic reviews of data from published and unpublished experiments to evaluate the performance of key preclinical experimental approaches. The team is also conducting a series of *in vivo* experiments (Open Field, Sleep Wake EEG and Irwin test) across multiple academic and industry labs to explore reasons for different findings across labs. In



Malcolm Macleod, Dominique Lesuisse, Jacqueline Bouvy, Pieter Jelle Visser, John Gallacher

SPOTLIGHT ON 29AEC

addition to this, they are developing the content and governance of a research quality system suitable for implementation across different types of labs.

EMIF – European Medical Information Framework

Pieter Jelle Visser from Amsterdam UMC highlighted the learnings from the completed European Medical Information Framework (EMIF) project. EMIF aimed to develop a common information framework of patient-level data that links up and facilitates access to diverse medical and research data sources, opening up new avenues of research for scientists. The project focussed initially on questions relating to obesity and AD to provide a focus and guidance for the development of the framework. During its project lifetime, EMIF developed the EMIF Data Catalogue and made it publicly available to the research community. The EMIF Data Catalogue is a text-book example of EMIF's mission to improve identification, access and assessment, and (re)use of health data within the European Union.

ROADMAP – Real world outcomes across the AD spectrum for better care: Multi-modal data access platform

John Gallacher from the University of Oxford introduced the ROADMAP project, completed in 2018. Currently, strictly controlled clinical trials are used to assess the safety and benefits of potential AD treatments for patients. However, clinical trials do not provide information on the health benefits for patients in their daily lives, the “real world”. The ROADMAP project aimed to deliver a series of methods and tools to allow the scalable, transferable integration of real world data on patient outcomes. The tools were developed and tested through pilot exercises. The project conducted patient engagement activities and addressed ethical, legal and social implications of adopting a real world evidence approach to AD. One of its key outputs is an Interactive Data Cube that offers an overview of available European real-world data on AD.

IM2PACT – Discovery of blood-brain barrier targets and transport pathways to treat neuro/metabolic diseases

The final speaker at this session, Dominique Lesuisse from Sanofi spoke about the

IM2PACT project. The blood-brain barrier (BBB), as the name suggests, tightly controls access to our brains, allowing nutrients and essential substances through, but blocking pathogens, for example. Getting medicines through this protective shield is a major challenge for drug developers, particularly those developing biopharmaceuticals, which are based on large molecules like proteins and antibodies. The goal of IM2PACT is to advance our understanding of the BBB to facilitate the development of more effective treatments for a range of neurological and metabolic disorders.

Diagnosis, patient engagement and trials

The concluding Neuronet session at the Alzheimer Europe Conference revolved around research projects that directly involve patients.

AMYPAD – Amyloid imaging to prevent Alzheimer's disease

As first speaker in this session, José Luis Molinuevo from the BarcelonaBeta Brain Research Center introduced the AMYPAD project. He explained that a common sign of AD is deposits of a protein called beta amyloid in the brain. The AMYPAD project studies the clinical value of using an imaging technique called positron emission tomography (PET) to scan people's brains

for these deposits, for the purposes of diagnosis and patient monitoring. The project is carrying out amyloid PET imaging on a large number of people who are suspected to be in the early stages of AD. AMYPAD works closely with the EPAD project.

EPAD – European prevention of Alzheimer's dementia consortium

Craig Ritchie from the University of Edinburgh introduced the EPAD project. This project is pioneering a novel, more flexible approach to clinical trials of drugs designed to prevent Alzheimer's dementia. The goal of the initiative is the prevention of dementia in people with evidence of AD (such as biomarker abnormalities) who still may have little or no clinical symptoms. EPAD aims to establish a European-wide cohort of at-risk subjects, of which many will be invited to participate in a trial to test new treatments for the prevention of Alzheimer's dementia. The project's cohort study has already screened 2,000 research participants and has 29 Trial Delivery Centres open as at the start of 2020. A proof of concept trial is planned and the project has already opened applications for external researchers to access baseline data from its first 500 participants.

MOPEAD – Models of Patient Engagement for Alzheimer's Disease

Mercè Boada from Fundació ACE presented the MOPEAD project. This project has established multiple regional project sites



John Gallacher



SPOTLIGHT ON 29AEC



José Luis Molinuevo, Craig Ritchie, Mercè Boda, Dag Aarsland

(Germany, Netherlands, Slovenia, Spain and Sweden) to test models for the early identification of mild Alzheimer's dementia as well as prodromal AD. They include online screening, open house initiatives at memory clinics, and the involvement of general practitioners as well as diabetologists' offices. The advantages and obstacles of each of the models encountered in the five countries are now being compared to identify ways to improve early detection and diagnosis of AD. The project also plans to provide access to its research data to the scientific community.

RADAR-AD – Remote Assessment of functional decline in Alzheimer's Disease

Dag Aarsland from King's College London concluded the last session with a presentation of the RADAR-AD project. This project aims to improve AD assessment and care. The project will do so by looking at how digital technologies – such as smart phones, wearables and home-based sensors – can be used to measure the progression of disability associated with AD. It is currently unclear how to maximise their potential in this area and the project hopes to find this out.



More information about the research projects and the Innovative Medicines Initiative can be found at: www.imi-neuronet.org

✉ info@imi-neuronet.org
 🌐 www.imi-neuronet.org/
 @IMI2_Neuronet
<http://www.linkedin.com/company/imi2-neuronet>
 ▶ bit.ly/YoutubeNeuronet

“Neurodegenerative diseases are an area of major unmet medical need and have been a priority for IMI since the very beginning. By bringing together IMI's excellent projects in this important area, Neuronet will help the projects to collectively make progress and give new hope to the millions of people in Europe and beyond who are affected by these diseases.”

Pierre Meulien, Executive Director, Innovative Medicines Initiative

**Acknowledgement**

Neuronet has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 821513. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and Parkinson's UK. Any information in this article solely reflects the author's view and neither IMI nor the European Union, EFPIA, or any Associated Partners are responsible for any use that may be made of the information contained herein.



PARKINSON'S™ CHANGE ATTITUDES. FIND A CURE. JOIN US.

Dementia in Europe 57



innovative
medicines
initiative



PARKINSON'S™
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.