

WP4 – Dissemination & Outreach

D4.4 Public event proceedings and videos – Year 2

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Document history

Version	Date	Description
V0.1	18/01/2021	First draft
V0.2	16/02/2021	Review by WP4
V1.0	25/02/2021	Consortium review
V2.0	26/02/2021	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. 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 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.

Due to the COVID-19 pandemic, Alzheimer Europe organised a virtual conference instead of an in-person event in which Neuronet participated.

This document provides an overview of the annual event as well as associated outreach activities that have been conducted in the second year of the Neuronet initiative.

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 research and its findings.

In its role as an ambassador for the IMI ND portfolio, Neuronet organises an annual networking and communication event involving 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 second year of the Neuronet initiative. The event was organised virtually in October 2020, due to various COVID-19 restrictions throughout Europe that rendered an in-person event impossible to organise.

2 Themes

The Neuronet event took place at the virtual Alzheimer Europe Conference on 20-22 October 2020. The series of four themed parallel sessions was entitled “Working together to address common challenges for European neurodegeneration research”.

The main themes of the sessions revolved around four topics:

- Session 1: Efficient data sharing: a must for science to respond to societal needs
- Session 2: Ensuring ethics and patient privacy whilst boosting research
- Session 3: Regulatory & HTA assessment: a critical step in delivering innovation for patient benefit
- Session 4: Public-Private Partnerships in the post-COVID era

During sessions 1-3, representatives from IMI neurodegeneration projects delivered presentations focused on the session topics. Session 4 was organised as a roundtable discussion involving members of the Neuronet Scientific Coordination Board. Neuronet was also represented by its project coordinator Carlos Diaz who participated in a plenary on the topic “From research and innovation to clinical and care practice”. These recordings were also incorporated in the Neuronet website.

Furthermore, Neuronet invited Early Career Researchers (defined as graduate students or researchers within 10 years of completing their graduate studies) working on the IMI neurodegeneration portfolio to submit abstracts in order to showcase the breadth and depth of IMI-funded neurodegeneration research as well as the diversity of project collaborators involved.

3 Pre-event outreach

The event was announced through Neuronet communication channels and supported via partner channels. In addition to this, a social media campaign entitled “The value of public-private collaboration & findings highlights” was launched on 11 September during World Alzheimer Month and concluded with the conference. The timing of the campaign was set to draw attention to the Neuronet event and leverage the raised public attention on Alzheimer’s disease. Announcements and the campaign were shared with all communication representatives from the portfolio for further outreach and shared both via Neuronet and individual project social media channels. In addition, some projects (EPAD, AMYPAD, PD-MitoQUANT) announced the event through several internal reports for awareness of their respective consortium.

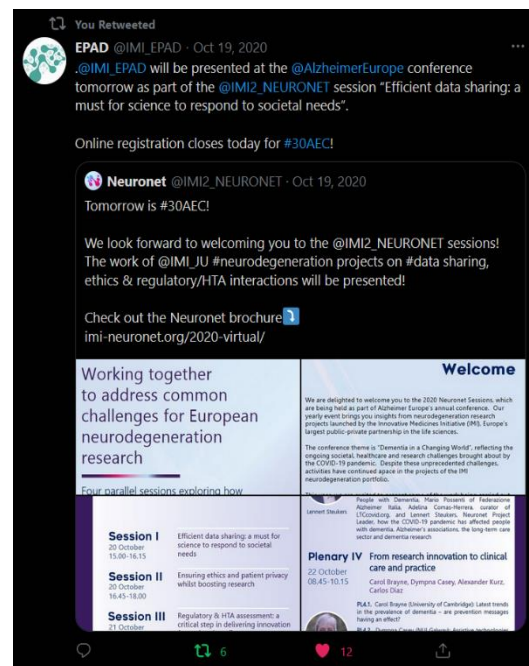
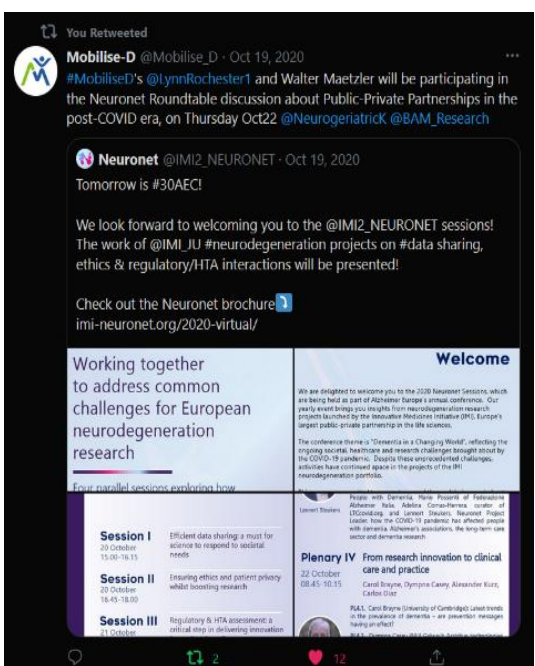
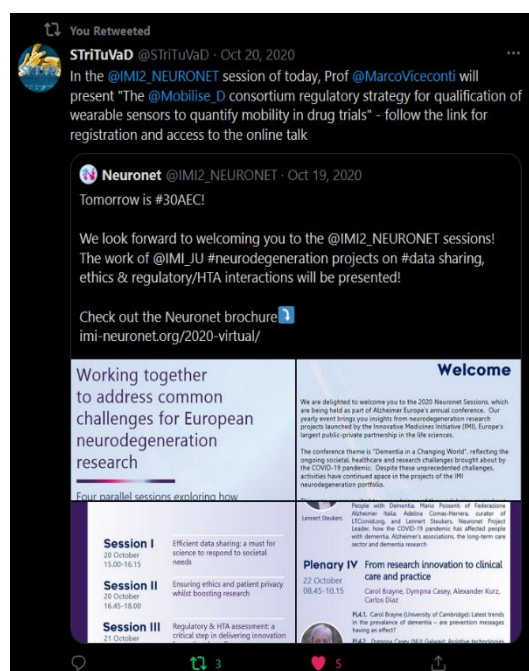
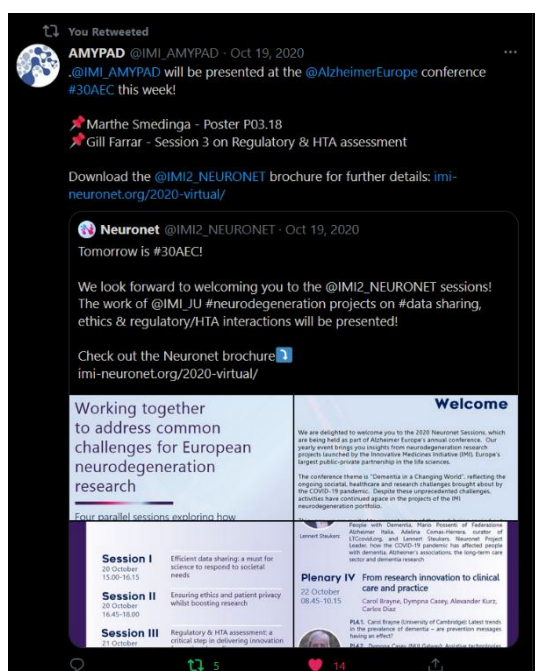
Partner/Project	Channel(s)	Title	Link(s)
Alzheimer Europe 13 August	Website & Newsletter	Neuronet to host an ECR session as part of its 2020 Public Event at #30AEC	https://www.alzheimer-europe.org/News/EU-projects/Thursday-13-August-2020-Neuronet-to-host-an-ECR-session-as-part-of-its-2020-Public-Event-at-30AEC (website) https://www.alzheimer-europe.org/content/download/206313/1531925/file/2020-07-08%20July-August.pdf (newsletter)
Neuronet, 30 June	Newsletter	Mark the dates!	https://mailchi.mp/46a51b0cb437/neuronet-newsletter-issue-4
Neuronet, 6 August	Website	Call for abstracts: Neuronet to host a session for ECRs at #30AEC	https://www.imi-neuronet.org/neuronet-sessions-2020-ecr/
Neuronet, 5 September	Newsletter	EU research collaboration in neurodegeneration research	https://mailchi.mp/d32a5368a010/neuronet-newsletter-issue-5
Alzheimer Europe 11 September	Website & Newsletter	Neuronet launches its social media campaign “The value of public-private collaboration & findings highlights”	https://www.alzheimer-europe.org/News/EU-projects/Friday-11-September-2020-Neuronet-launches-its-social-media-campaign-The-value-of-public-private-collaboration-findings-highlights (website) https://www.alzheimer-europe.org/content/download/211908/1570941/file/2020-09%20September%20.pdf (newsletter)
Neuronet 11 September	Website	Neuronet launches its social media campaign “The value of public-private collaboration & findings highlights”	https://www.imi-neuronet.org/neuronet-campaign-launches-on-social-media-the-value-of-public-private-collaboration/
PD-MitoQUANT 11 September	Website	Neuronet launches campaign: “The value of public-private collaboration & findings highlights”	https://www.pdmitoquant.eu/2020/09/neuronet-launches-campaign-the-value-of-public-private-collaboration-findings-highlights/
AMYPAD 2 October	Website	AMYPAD to be presented at #30AEC	https://amypad.eu/news/recent-news/amypad-to-be-presented-at-30aec/

4 Conference brochure



In order to further increase the visibility of the event and to introduce Neuronet's thematic Working Groups, as well as their work and topics of discussion, the consortium also developed a 14-page digital brochure that is available on the Neuronet website and was shared with representatives for further use. It was also featured in the virtual conference booth.

Graphics from the brochure were also used on social media channels to provide maximum exposure and were shared widely via the various participating projects as well as their collaborators:



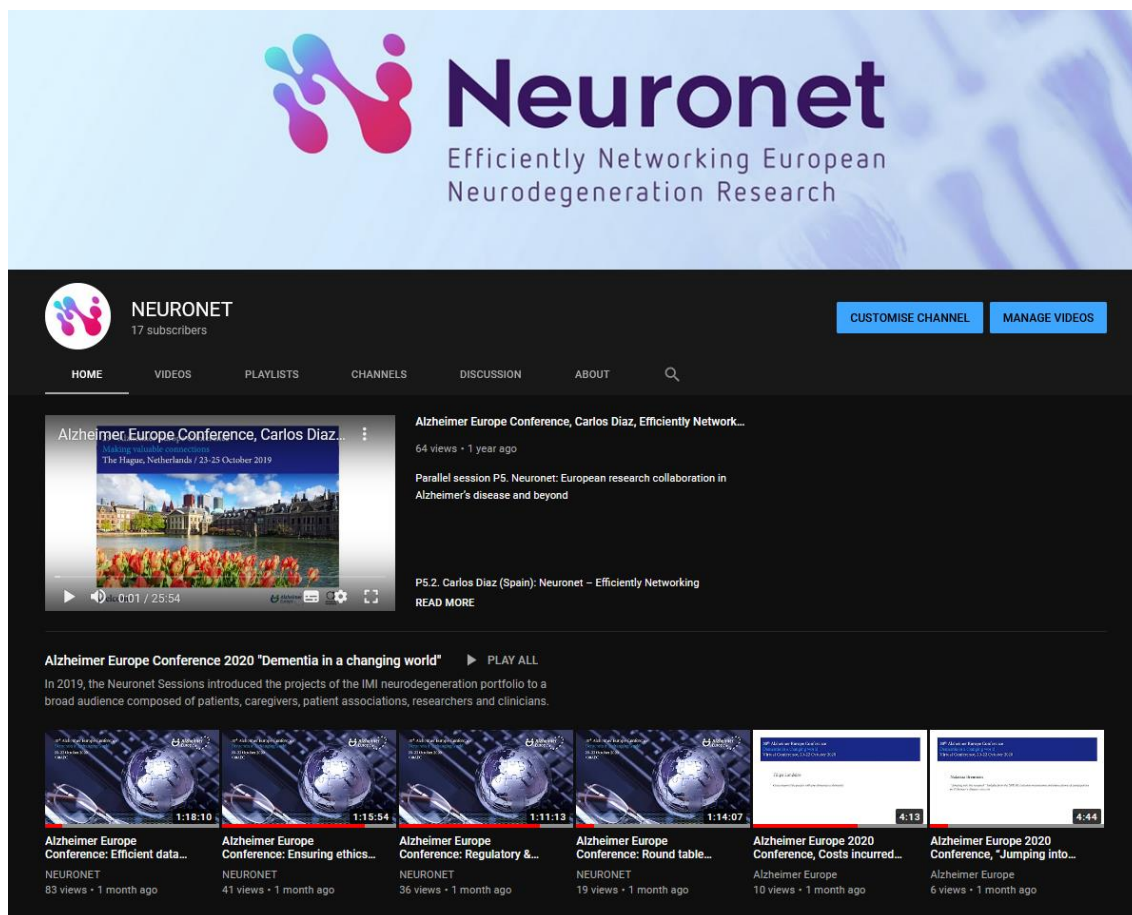
5 Conference Booth

Neuronet was also represented through a virtual booth that conference attendees could visit. This booth provided information on the research portfolio, included the conference brochure (with an overview of the different Neuronet sessions taking place), as well as links to the different platforms where Neuronet is represented. In order to enable interaction, participants could submit questions about the initiative via the virtual booth to two Neuronet representatives throughout the conference duration.

6 Videos

The presentations that were given during the event were recorded 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 shared via the Neuronet social media channels for wider visibility.

6.1 Parallel sessions

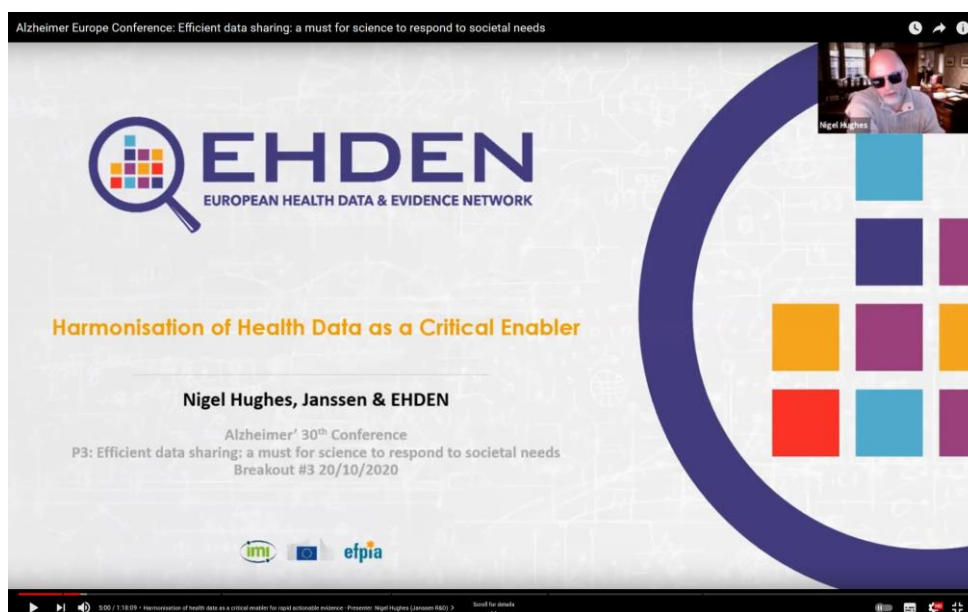


In addition, the videos have been added to the Alzheimer Europe Conference playlists which were also embedded into the alzheimer-europe.org website. Below is an overview of the presentations including links to YouTube.

Session 1: Efficient data sharing: a must for science to respond to societal need

The first session, chaired by Neuronet's Coordinator Carlos Díaz, was entitled "Efficient data sharing: a must for science to respond to societal needs". During this session, Nigel Hughes, Rodrigo Barnes and Colin Veal from the EHDEN and EPAD IMI projects discussed technical solutions that are being developed by IMI projects to overcome key obstacles to effective sharing of health data, including data harmonisation, federated networks, digital data discovery tools and research environments. Manuela Rinaldi (Neuronet consortium member) drew the session to a close by presenting the work of the Neuronet Working Group on data sharing.

P3.1 Nigel Hughes (EHDEN): Harmonisation of health data as a critical enabler for rapid actionable evidence



<https://www.youtube.com/watch?v=3m7G7cwQwmg&t=218s>

P3.2 Rodrigo Barnes (EPAD): Enabling analysis of pan-European datasets: the EPAD analytical database



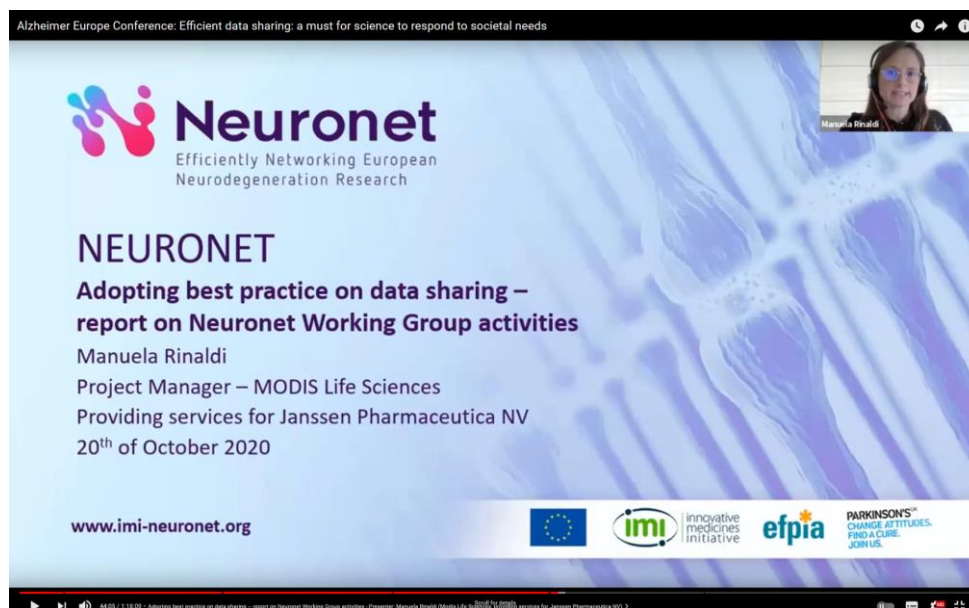
<https://www.youtube.com/watch?v=3m7G7cwQwmG&t=996s>

P3.3 Colin Veal (EPAD): Data Discovery to support Data Sharing to support Data Analysis



<https://www.youtube.com/watch?v=3m7G7cwQwmG&t=1835s>

P3.4 Manuela Rinaldi (Neuronet): Adopting best practice on data sharing –report on Neuronet Working Group activities

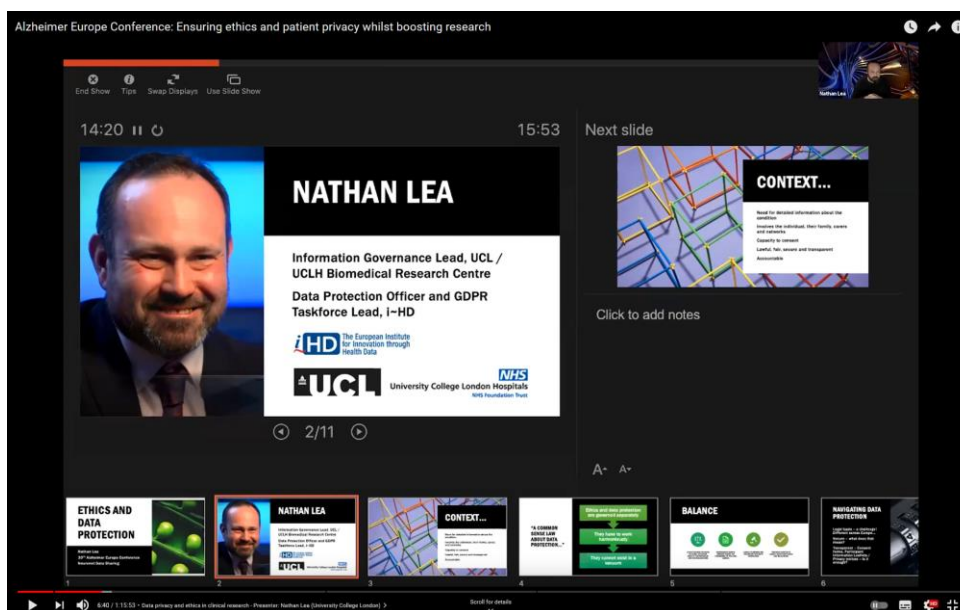


<https://www.youtube.com/watch?v=3m7G7cwQwmG&t=2605s>

Session 2: Ensuring ethics and patient privacy whilst boosting research

The second Neuronet session, entitled “Ensuring ethics and patient privacy whilst boosting research”, was chaired by Jean Georges and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. Angela Bradshaw (Neuronet consortium member) closed the session by presenting the work of the Neuronet Working Group on ethics and patient privacy.

P7.1. Nathan Lea (EMIF): Data privacy and ethics in clinical research



https://www.youtube.com/watch?v=o5KnpGBy_Yk&t=174s

P7.2 Pilar Cañabate (MOPEAD): Preservation of autonomy throughout dementia



https://www.youtube.com/watch?v=o5KnpGBy_Yk&t=1482s

P7.3 Sébastien Libert (RADAR-AD): Remote monitoring and digital devices: ethical and patient privacy implications in RADAR-AD



https://www.youtube.com/watch?v=o5KnpgBy_Yk&t=2494s

P7.4 Angela Bradshaw (Neuronet): A dopting best practice on patient privacy –report on NeuronetWorking Group activities



https://www.youtube.com/watch?v=o5KnpgBy_Yk&t=3380s

Session 3: Regulatory & HTA assessment: a critical step in delivering innovation for patient benefit

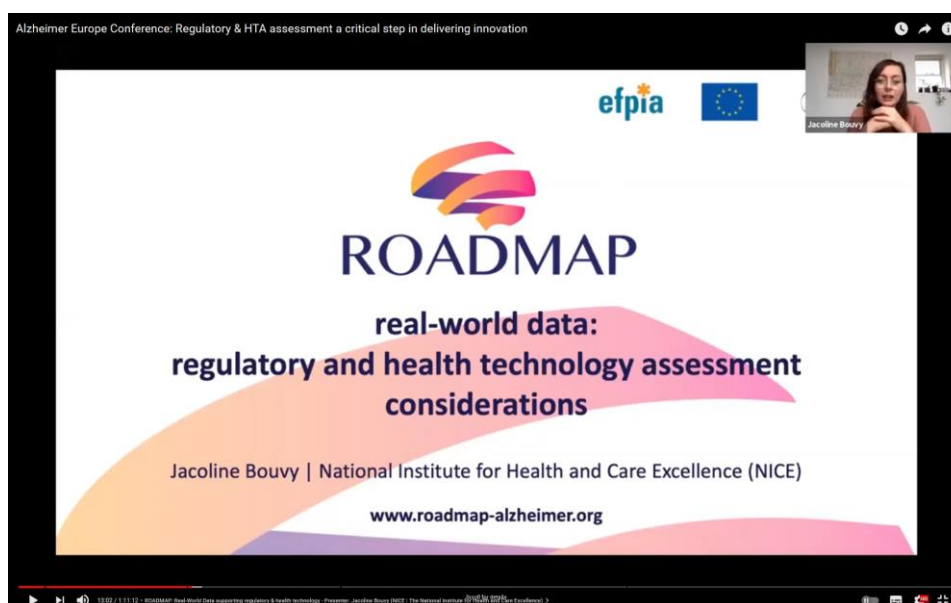
The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Diana O'Rourke of NICE. Diana O'Rourke (Neuronet consortium member) opened the session by providing an overview of Neuronet Regulatory/HTA Working Group. Presentations from Gill Farrar, Jacqueline Bouvy and Marco Viceconti illustrated how the AMYPAD, ROADMAP and Mobilise-D IMI projects are actively engaging with European regulators, to identify pathways for approval of neuroimaging and digital biomarkers.

P15.1. Diana O'Rourke (Neuronet): Neuronet Regulatory Working Group: focus on the Decision Tool



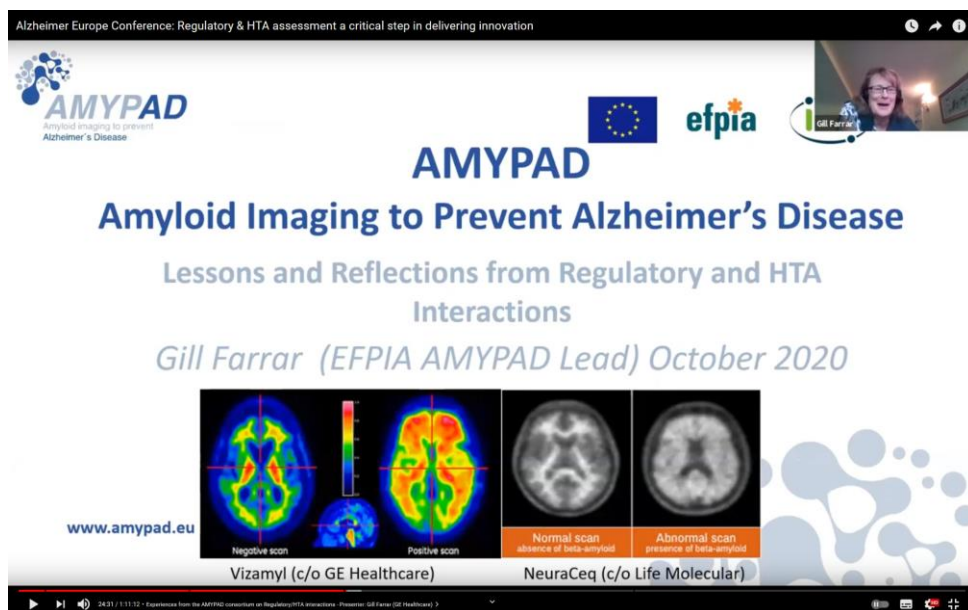
<https://www.youtube.com/watch?v=4hZqcXy3jc8&t=120s>

P15.2. Jacqueline Bouvy (ROADMAP): ROADMAP real-world data supporting regulatory and health technology



<https://www.youtube.com/watch?v=4hZqcXy3jc8&t=765s>

P15.3. Gill Farrar (AMYPAD): Experiences from the AMYPAD consortium on regulatory/HTA interactions



Alzheimer Europe Conference: Regulatory & HTA assessment a critical step in delivering innovation

AMYPAD
Amyloid imaging to prevent Alzheimer's Disease

EUROPEAN UNION

efpia

Gill Farrar

AMYPAD

Amyloid Imaging to Prevent Alzheimer's Disease

Lessons and Reflections from Regulatory and HTA Interactions

Gill Farrar (EFPIA AMYPAD Lead) October 2020

www.amypad.eu

Negative scan
Vizamyl (c/o GE Healthcare)

Positive scan
NeuraCeq (c/o Life Molecular)

Normal scan
absence of beta-amyloid

Abnormal scan
presence of beta-amyloid

<https://www.youtube.com/watch?v=4hZqcXy3jc8&t=1463s>

P15.4. Marco Viceconti (Mobilise-D): The Mobilise-D strategy for the qualification of wearable sensors to quantify mobility in drug trials



Alzheimer Europe Conference: Regulatory & HTA assessment a critical step in delivering innovation

Mobilise-D

The Mobilise-D consortium regulatory strategy for qualification of wearable sensors to quantify mobility in drug trials

Marco Viceconti, Sabina Hernandez Penna, Wilhelmus Dartee, Claudia Mazzà, Brian Caulfield, Clemens Becker, Walter Maetzler, Judith Garcia-Aymerich, Giorgio Davico, Lynn Rochester, and the MOBILISE-D Consortium

IMI innovative medicines initiative

EUROPEAN UNION

efpia

<https://www.youtube.com/watch?v=4hZqcXy3jc8&t=2772s>

Session 4: Public-Private Partnerships in the post-COVID era

Neuronet project leader Lennert Steukers closed off the 2020 Neuronet Sessions, moderating a discussion on how COVID-19 has affected large public-private partnership projects. In this roundtable session, IMI project leaders who are experts on mobility disorders, digital biomarkers, stratified medicine and dementia prevention discussed the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

Andrew Owens



King's College London

**Martin Hofmann-
Apitius**



Fraunhofer Institute
for Algorithms
and Scientific
Computing

Walter Maetzler



University Hospital
Tuebingen

Jochen Prehn



Royal College of
Surgeons in Ireland

Lynn Rochester



Newcastle University

Pieter Jelle Visser



Maastricht University,
Amsterdam UMC

<https://youtu.be/xolwenJqlAQ>

6.2 Early-Career Researchers (on-demand presentations)

Quick Oral Presentation 4.01 Natassia Brenman (EPAD): “Jumping into research”: insights from the SPEAR study into motivations and expectations of participation in Alzheimer’s disease research



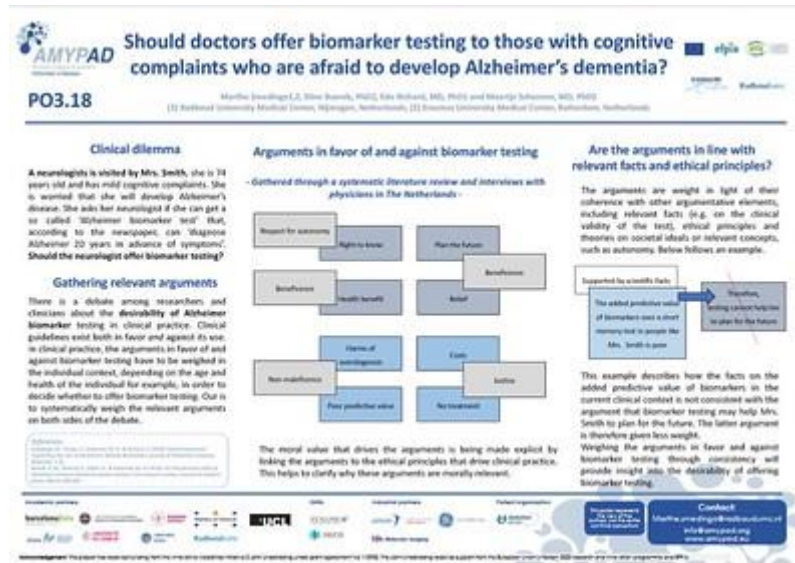
<https://www.youtube.com/watch?v=FOTILpWpNOc>

Quick Oral Presentation 5.05 Filipa Landeiro (ROADMAP): Costs incurred by people with pre-dementia or dementia



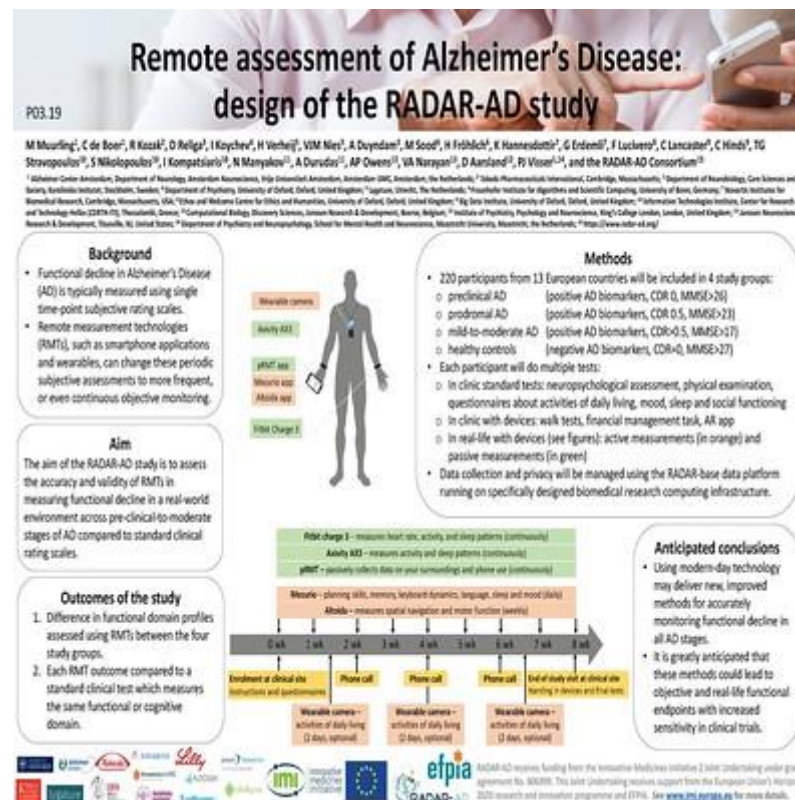
https://www.youtube.com/watch?v=C_Rk3gd2pgA

Poster Presentation 03.18 Marthe Smedinga (AMYPAD): Should doctors offer biomarker testing to those with cognitive complaints who are afraid to develop Alzheimer's dementia



<https://www.flickr.com/photos/190526237@N04/50458926392/in/album-72157717839703002/>

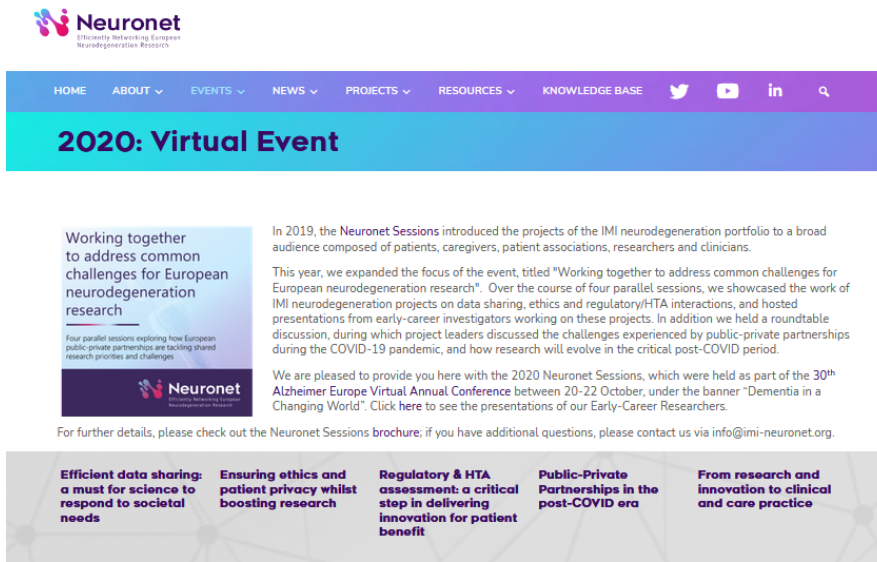
Poster Presentation 03.19 Marijn Muurling (RADAR-AD): Remote assessment of Alzheimer's disease: the RADAR-AD study







<https://www.flickr.com/photos/190526237@N04/50458926392/in/album-72157717839703002/>

7 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.



Neuronet
Efficiently Networking European Neurodegeneration Research

HOME ABOUT ▾ EVENTS ▾ NEWS ▾ PROJECTS ▾ RESOURCES ▾ KNOWLEDGE BASE    

2020: Virtual Event

Working together to address common challenges for European neurodegeneration research
Four parallel sessions exploring how European public-private partnerships are tackling shared research priorities and challenges.

In 2019, the Neuronet Sessions introduced the projects of the IMI neurodegeneration portfolio to a broad audience composed of patients, caregivers, patient associations, researchers and clinicians.

This year, we expanded the focus of the event, titled "Working together to address common challenges for European neurodegeneration research". Over the course of four parallel sessions, we showcased the work of IMI neurodegeneration projects on data sharing, ethics and regulatory/HTA interactions, and hosted presentations from early-career investigators working on these projects. In addition we held a roundtable discussion, during which project leaders discussed the challenges experienced by public-private partnerships during the COVID-19 pandemic, and how research will evolve in the critical post-COVID period.

We are pleased to provide you here with the 2020 Neuronet Sessions, which were held as part of the 30th Alzheimer Europe Virtual Annual Conference between 20-22 October, under the banner "Dementia in a Changing World". Click here to see the presentations of our Early-Career Researchers.

For further details, please check out the Neuronet Sessions brochure; if you have additional questions, please contact us via info@imi-neuronet.org.

Efficient data sharing: a must for science to respond to societal needs
Ensuring ethics and patient privacy whilst boosting research
Regulatory & HTA assessment: a critical step in delivering innovation for patient benefit
Public-Private Partnerships in the post-COVID era
From research and innovation to clinical and care practice

Session 1

Efficient data sharing: a must for science to respond to societal need

The first session, chaired by Neuronet's Coordinator Carlos Díaz, was entitled "Efficient data sharing: a must for science to respond to societal needs". During this session, Nigel Hughes, Rodrigo Barnes and Colin Veal from the EHDEN and EPAD IMI projects discussed technical solutions that are being developed by IMI projects to overcome key obstacles to effective sharing of health data, including data harmonisation, federated networks, digital data discovery tools and research environments.

Nigel Hughes (EMIF & EHDEN)



Janssen Research & Development

Rodrigo Barnes (EPAD)



Aridhia

Colin Veal (EPAD)



University of Leicester

Manuela Rinaldi (Neuronet)



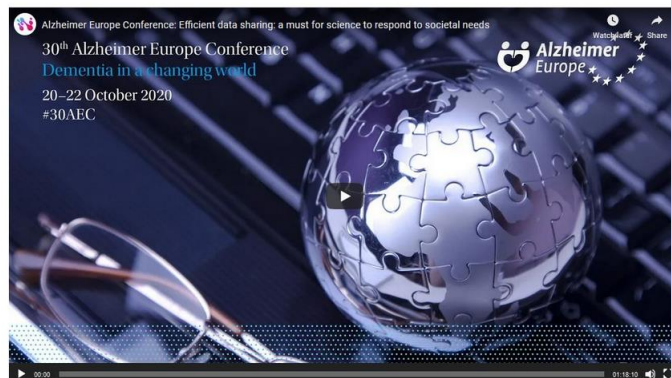
MODIS Life Sciences

Harmonisation of health data as a critical enabler for rapid actionable evidence

Enabling analysis of pan-European datasets: the EPAD analytical database

Data Discovery to support Data Sharing to support Data Analysis

Adopting best practice on data sharing – report on Neuronet Working Group activities



8 Public event proceedings

8.1 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 8,000 subscribers on the organisation's mailing list. It can be accessed here:

<https://alzheimereurope.newsweaver.com/ConferenceAnnouncement/1rg5tgxih6v>

8.2 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/showcasing-imi-projects-neuronet-at-30aec/>

This article was also shared on different platforms and with partners for further outreach. The table below shows the news posts, some of which have also been shared with the individual consortia via their newsletters.

Project or Partner	Link
AMYPAD	http://ep-ad.org/2020/11/04/amypad-presents-at-the-30th-alzheimer-europe-conference/
ROADMAP	https://roadmap-alzheimer.org/news/roadmap-presents-at-neuronets-annual-event-on-working-together-to-address-common-challenges-for-european-neurodegeneration-research/
RADAR-AD	https://www.radar-ad.org/newsroom/radar-ad-represented-30th-alzheimer-europe-virtual-conference-dementia-changing-world-20th
PD-MitoQUANT	https://www.pdmitoquant.eu/2020/10/3475/
Alzheimer Europe	https://www.alzheimer-europe.org/News/EU-projects/Thursday-22-October-2020-Working-together-to-address-common-challenges-for-European-neurodegeneration-research-Neuronet-hosts-four-sessions-at-30AEC (also via newsletter)
SYNAPSE	https://synapse-managers.com/neuronet-30th-alzheimer-europe-conference/
ScienceX	https://sciencex.com/wire-news/364883389/showcasing-innovative-medicines-initiative-projects-neuronet-at-3.html
Neuronet	https://www.imi-neuronet.org/386-million-eur-research-programme-on-neurodegeneration-featured-at-alzheimer-europe-conference/ (Announcement that recordings are public)
PrLog	https://www.prlog.org/12854379-386-million-eur-research-programme-on-neurodegeneration-featured-at-alzheimer-europe-conference.html

8.3 Dementia in Europe Magazine

An article on the event has been featured in the online Dementia in Europe Magazine – to be published (see Annex II).

Alzheimer Europe publishes an online Dementia in Europe magazine three times per year to a mailing list of 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 forward 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.

9 Annexes

9.1 Annex I Alzheimer Europe Press Releases

Dementia in a changing world



Final day of Alzheimer Europe's first ever virtual conference focuses on moving from research and innovation to clinical and care practice, and on dementia as a European priority

Luxembourg, 23 October 2020 – The 30th Alzheimer Europe Conference (#30AEC) “Dementia in a changing world”, came to a close yesterday evening, 22 October 2020. The focus of the final day of this virtual event was on moving from research and innovation to clinical and care practice, and on dementia as a European priority.

From research and innovation to clinical and care practice



The fourth plenary session took place at 8.45am CET. Carol Brayne, Professor of Public Health Medicine and Co-Chair of the Cambridge Public Health Interdisciplinary Research Centre in the University of Cambridge, opened with a talk on the latest trends in the prevalence of dementia and discussed whether prevention messages are having an

effect.

Dementia is changing across generations and within populations, she said. The evidence on prevention clearly points to the fact that primary prevention for dementia risk profiles for whole populations, combined with effective management of existing risk conditions in individuals, is the most effective strategy. On the other hand, she stressed that “there is no evidence that screening and early detection will be effective at present”.

Up next, Alexander Kurz, senior scientist at the Department of Psychiatry, Klinikum rechts der Isar, Technical University of Munich and Director of the university’s memory clinic, shared some of the findings of “INDEED, an interprofessional intervention in dementia education for South-Eastern European countries”. Dementia is a complex disorder that can only be tackled by several health and social care professionals working together, he said. He also stressed that inter-professional shared education is key for collaboration and networking, and can take advantage of modern digital learning formats. The INDEED project provides an online e-learning programme, addressing multiple professions simultaneously and conveys a person-centred, holistic concept of dementia care, he summarised.

In the third presentation, Dympna Casey, Professor and Head of School in the School of Nursing & Midwifery NUI Galway looked at assistive technologies and explored what the role of social robotics could be in dementia.

Carlos Díaz, CEO of Synapse Research Management Partners and Coordinator of the IMI NEURONET project, was the final speaker in plenary four. He argued for a systems leadership approach in science in order to overcome fragmentation, and how NEURONET was an example of such an approach applied to the neurodegeneration portfolio of the Innovative Medicines Initiative (IMI).

Globally, society is facing several highly complex, urgent challenges, and to be able to respond, he said, scientific research may need a paradigm change in how it is organised. A systems leadership approach is being explored in the IMI neurodegeneration portfolio and it is hoped this will help to propel scientific efforts towards the much-needed actionable results.

Following this session, delegates were again given the option to join one of four possible parallel sessions, covering national dementia strategies; acute hospital care; the ethical, legal and social implications of using AI in dementia research (session organised by the VirtualBrainCloud project); and the blood-based diagnosis of Alzheimer’s disease (session organised by BBdiag).

Following this were two symposia, hosted by Biogen and the European Academy of Neurology (EAN) respectively, and four further parallel sessions, on risk factors and prevention; involving people with dementia; a Neuronet session on public-private-partnerships in the post-COVID era; and finally an INTERDEM session looking at the “Impact of COVID on dementia services and staff: inspiration for novel research”.

Maintaining dementia as a European priority

The fifth and final plenary session was held at 4pm CET on Thursday 22 October, and took the form of a second roundtable discussion (the first roundtable took place in plenary one, on Tuesday) as part of this year's interactive virtual conference format. The discussion revolved around "Maintaining dementia as a European priority" and the panellists were Maria Carrillo, Chief Science Officer, Alzheimer's Association (US) global research program; Dan Chisholm, Programme Manager for Mental Health at the WHO Regional Office for Europe, Nils Dahl, Senior Policy Advisor at Germany's Federal Ministry of Health; Charles Scerri, Chairperson of the Malta Dementia Society, Vice-Chairperson of Alzheimer Europe and National Focal Point on Dementia in Malta; and Nicoline Tamsma, Policy Officer at the European Commission's DG for Health and Food Safety, Unit Health Promotion, Disease Prevention, Financial Instruments.



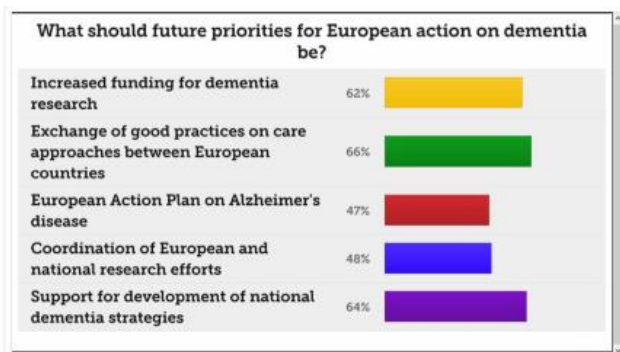
Panellist Maria Carrillo shared the perspective of the Alzheimer's Association (US) during the conversation, stating that "even now - especially now - Alzheimer's and all other dementias must be maintained as a global priority. Even during the pandemic, at any given moment, discovery is happening and must not be delayed. As the world's largest non-profit funder of Alzheimer's and dementia research, the Association's commitment to advancing the critical work of the scientific community is unwavering. We are committed to funding researchers directly, as we also relentlessly pursue additional resources on all fronts, including through our federal advocacy efforts."

She went on to stress the significant impact that the COVID-19 global pandemic is having on Alzheimer's and dementia research. That being said, she qualified that some trials - as they are able - are exploring innovative approaches to keep the momentum of their study, and that it is rewarding to see the research community keep this important work going, all the while bearing in mind that "the Alzheimer's Association's first priority is the health and safety of study participants and study staff, especially vulnerable elders and people with dementia and their families." With the COVID-19 pandemic creating multiple challenges for people living with dementia; and with nursing homes, assisted living communities and the families and caregivers of people with dementia all being at the frontline of this crisis; Maria Carrillo also said that the Alzheimer's Association is working with national, state and local agencies to ensure people living with dementia have access to high quality, person-centred care.

During the discussion, Dan Chisholm emphasised that dementia represents a public health challenge of international concern, especially in the context of rapidly ageing populations and drew attention to the fact that COVID-19 has served to expose the shortcomings of most countries' preparedness and response capabilities, not only with respect to viral disease outbreaks but also to healthy ageing, dementia and long-term care.

"The WHO continues to work through the crisis with its Member States and partners to develop and make available tools and other measures to support implementation of its global action plan on the public health response to dementia, including a dementia-friendly and inclusion toolkit as well as risk-reduction guidelines for cognitive decline and dementia", he said, and he pointed out that the WHO has also rapidly stepped up its work to provide guidance to countries on COVID-19, including clinical management, psychosocial support needs and maintenance of essential care and services.

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Results from one of the many polls in which delegates participated during the conference plenaries

Nils Dahl assured delegates that, during the past decade, Germany's Federal Government has initiated numerous programmes and measures to support people with dementia and their relatives, culminating in the development of the country's national dementia strategy and its adoption by the Federal Cabinet in July 2020. Amid the pandemic, the implementation of the dementia strategy remains a priority for the government, he stressed. He also emphasised that all actors involved in the process of the strategy's implementation would take into account that persons with dementia might not only be at high risk of falling seriously ill if infected with

COVID-19, but that they can be adversely affected by COVID-19-related restrictions as well.

Speaking about the current pandemic and its impact on people with dementia and carers, Charles Scerri stated that "times like these have taught us the importance of coming together, as European nations, in supporting individuals living with dementia" and that this could be achieved through innovative resources directed towards maintaining their wellbeing. We have also learned that individuals living with dementia, and those who care for them can become particularly vulnerable during such a crisis, he continued, insisting that "Europe must do more by investing in more research, putting dementia as a top priority in its health and social programmes."

Nicoline Tamsma drew attention to some of the Commission's efforts to see dementia recognised as a priority, such as supporting initiatives via the EU Health Programme, including two Joint Actions, the second of which helped advance work on diagnosis and post-diagnostic support, crisis and care coordination, residential care, and dementia-friendly communities. Since 2014, via Horizon-2020, EU funds targeted to brain research totalled EUR 3.17 billion, which included EUR 683 million for research into neurodegenerative diseases, the majority of which, she noted, had been dedicated to Alzheimer's disease and dementia. The Commission also continues to support the work of Alzheimer Europe.

With regards to how the pandemic has affected progress in the area of dementia research, the Commission is working with Member-States and international partners to tackle COVID and its consequences, she said. Together with WHO Europe and the European Observatory on Health Systems and Policies, the Commission monitors how national health systems respond to the pandemic, including a focus on measures taken to protect care homes.

Addressing the mental health impact, she pointed to a specific network space on the EU Health Policy Platform, set up by the Commission to support stakeholders and to facilitate practice and knowledge exchange, also with regard to vulnerable groups such as people with pre-existing conditions. Alzheimer Europe is among more than 65 participants.

Answering the question, "how can we ensure that dementia remains a priority at national, European and global level and what should priority actions be?", Nicoline Tamsma highlighted the Commission's mandate in the field of public health centres on providing support to Member States and shared that DG SANTE had set up a mechanism to identify and implement good practices and implementable research results. Through the Steering Group on Health Promotion, Disease Prevention and Management of NCDs, Member States select priorities and practices of most relevance to them and the Commission then supports their implementation through EU financial instruments, such as the Health Programme.

All plenary sessions at the conference were co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events.

Goodbye, virtual world. Hello, Bucharest!

The three-day virtual conference was formally closed by Alzheimer Europe Chairperson Iva Holmerová who thanked speakers and poster presenters for sharing their research, projects and experiences. She also said a special thank you to the various sponsors of the conference:

The European Union Health Programme (2014-2020), Roche, Biogen, the European Federation of Pharmaceutical Industries and Associations (EFPIA) and BBDiag.



All delegates were invited to mark the dates of the next Alzheimer Europe Conference (#31AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 29 November to 1 December 2021.

Showcasing EU projects – Neuronet and VirtualBrainCloud at #30AEC

Working together to address common challenges for European neurodegeneration research

Four parallel sessions exploring how European public-private partnerships are tackling shared research priorities and challenges

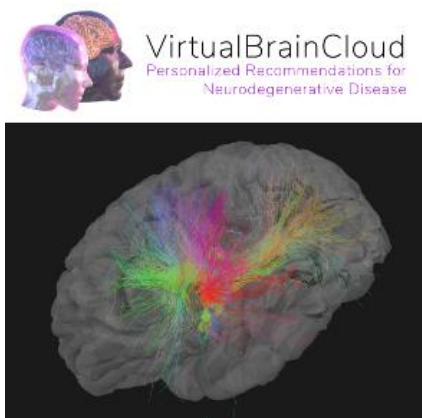


Neuronet has been designed to boost synergy and collaboration across the projects of the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio. With a total funding budget of EUR 386 million, and addressing the whole R&D spectrum from preclinical science to real-world data, the IMI ND portfolio brings together 18 consortium projects and over 230 partnering organisations. Since its launch in 2019, Neuronet's support activities have focused on key areas identified by projects as challenging, including data sharing and accessibility, working with Regulators, and ensuring patient privacy. The Neuronet parallel sessions held as part of the conference were designed to showcase the work of IMI ND projects in this key areas, stimulating discussion on major issues and how to address them.

The first session, chaired by Carlos Díaz (SYNAPSE Research Management Partners), was entitled “Efficient data sharing: a must for science to respond to societal needs”. During this session, Nigel Hughes, Rodrigo Barnes and Colin Veal from the EHDEN and EPAD IMI projects discussed technical solutions that are being developed by IMI projects to overcome key obstacles to effective sharing of health data, including data harmonisation, federated networks, digital data discovery tools and research environments. The second Neuronet session, entitled “Ensuring ethics and patient privacy whilst boosting research”, was chaired by our very own Jean Georges and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Diana O'Rourke of NICE. Presentations from Gill Farrar, Jacqueline Bouvy and Marco Viceconti illustrated how the AMYPAD, ROADMAP and Mobilise-D IMI projects are actively engaging with European regulators, to identify pathways for approval of neuroimaging and digital biomarkers. Neuronet project leader Lennert Steukers closed off the 2020 Neuronet Sessions, moderating a

discussion on how COVID-19 has affected large public-private partnership projects. In this roundtable session, IMI project leaders who are experts on mobility disorders, digital biomarkers, stratified medicine and dementia prevention discussed the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

Elsewhere at #30AEC, the Horizon 2020-funded VirtualBrainCloud (TVB_Cloud) project held two sessions on the use of artificial intelligence (AI) in dementia research. In the first session, chaired by Katarina Stevanovic of TP21, project leader Petra Ritter (Charité Medical University Berlin) presented the TVB_Cloud approach to develop a cloud-based platform for personalized diagnosis and treatment of dementia. Martin Hofmann-Apitius of Fraunhofer SCAI outlined their knowledge graph approach to increase our mechanistic understanding of neurodegenerative disease, and to identify potentially druggable pathways. Viktor Jirsa (Aix-Marseille University) rounded off the session, illustrating how algorithms developed to analyse complex systems could help us understand brain networks in health and in disease.



The second TVB_Cloud session addressed the ethical, legal and social issues raised by the use of AI in dementia research. Bernd Stahl, Ethics Director of the Human Brain Project, outlined how some of the ethical issues raised by the use of AI in healthcare research could be mitigated at policy, organizational and project levels, to ensure that the benefits of AI do not outweigh the risks. Data protection is a major concern for big data research using AI, and Michael Cepic (University of Vienna) guided the audience through the General Data Protection Regulation, showing how it protects patient privacy whilst enabling health and care research. Rounding off the session, Richard Milne of the Wellcome Sanger Centre addressed the benefits and harms of risk disclosure when risk is detected using algorithm-based approaches, describing a potential route to mitigate harms whilst maximising benefit.

Alzheimer Europe would like to thank to all delegates who joined us at #30AEC, and we hope to see you next year for #31AEC!

For further information, contact:

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Notes to editors:

Alzheimer Europe is the umbrella organisation of national Alzheimer associations and currently has 39 member organisations in 35 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)

VirtualBrainCloud is a four year project (2018-2022) developing and validating a decision support system that provides access to high quality multi-disciplinary data for clinical practice. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments for neurodegenerative diseases. The interdisciplinary VirtualBrainCloud consortium will also develop robust solutions for legal and ethical matters by interacting with the HumanBrainProject, Alzheimer Europe and ELIXIR, an organisation that manages and safeguards EU research data. The project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 826421. (<https://virtualbraincloud-2020.eu>)



The 30th AE Conference received funding under an operating grant from the European Union's Health Programme (2014-2020). Alzheimer Europe gratefully acknowledges the support of all conference sponsors.

9.2 Annex II Dementia in Europe Magazine article

SPOTLIGHT ON 30AEC

Showcasing European research initiatives at #30AEC

Neuronet – A coordination and support action bringing together 15 IMI consortium projects working on neurodegenerative disease and the Horizon 2020-funded VirtualBrainCloud (TVB_Cloud) project were strongly represented at the 30th Alzheimer Europe Conference (#30AEC).

Working together to address common challenges for European neurodegeneration research

Four parallel sessions exploring how European public-private partnerships are tackling shared research priorities and challenges



Neuronet

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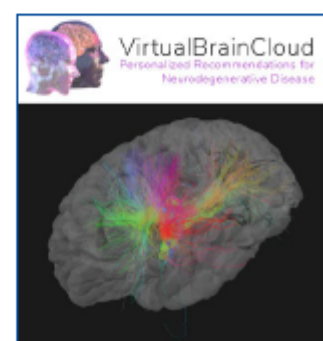
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SPOTLIGHT ON 30AEC

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