

Welcome

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

Alzheimer Europe Virtual Conference
20-22 October, 2020
#30AEC



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We are delighted to welcome you to the 2020 Neuronet Sessions, which are being held as part of Alzheimer Europe's annual conference. Our yearly event brings you insights from neurodegeneration research projects launched by the Innovative Medicines Initiative (IMI), Europe's largest public-private partnership in the life sciences.

The conference theme is "Dementia in a Changing World", reflecting the ongoing societal, healthcare and research challenges brought about by the COVID-19 pandemic. Despite these unprecedented challenges, activities have continued apace in the projects of the IMI neurodegeneration portfolio.

This year, we are excited to present some of the work being carried out by IMI projects on three important topics: data sharing, ethics and patient privacy, and regulatory & HTA assessment. COVID-19 also has a place on our agenda: IMI project leaders will discuss the future of neurodegeneration research post-COVID-19 in a roundtable session at the end of the conference. The research leaders of tomorrow are the early-career researchers (ECRs) of today, and as such we invite you to learn about the work of ECRs on IMI projects through quick oral and poster presentations in the main conference.

Finally, in the opening Plenary sessions on 20 and 22 October we look forward to sharing the work Neuronet has been doing to support the IMI neurodegeneration portfolio.



CARLOS DIAZ
Neuronet Project Coordinator
*CEO, Synapse Research
Management Partners*

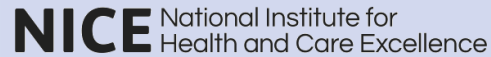


LENNERT STEUKERS
Neuronet Project Leader
*Associate Director, Experimental Medicine,
Janssen Pharmaceutica NV*

NEURONET PARTNERS

Small & Medium Enterprise

Regulatory Agency



Patient Organisation

IMI Associated Partner



EFPIA Partners



Schedule

Session I

20 October
15.00-16.15

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

Session II

20 October
16.45-18.00

Ensuring ethics and patient privacy whilst boosting research

Session III

21 October
14.15-15.30

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

Session IV

22 October
14.15-15.30

Neuronet Roundtable: public-private partnerships in the post-COVID era

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No. 821513. The IMI Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.



Tuesday, 20 October
15.00-16.15



P3 Moderator Carlos Díaz (Spain)

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



P3.1. Nigel Hughes (Belgium)

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



P3.2. Rodrigo Barnes (Scotland)

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



P3.3. Colin Veal (England)

Data Discovery to support Data Sharing to support Data Analysis



P3.4. Manuela Rinaldi (Belgium)

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

EFFICIENT DATA SHARING: A MUST FOR SCIENCE TO RESPOND TO SOCIETAL NEEDS

HUGHES Nigel¹, BARNES Rodrigo², VEAL Colin³, RINALDI Manuela⁴ and DIAZ Carlos⁵



¹Janssen R&D, Beerse, Belgium, ²Aridhia, Edinburgh, Scotland, ³University of Leicester, Leicester, England, ⁴MODIS Life Sciences, providing services for Janssen Pharmaceutica NV, ⁵Synapse Research Management Partners, Madrid, Spain

The archives of hospitals, academic institutions and clinical trial centres contain a wealth of scientific and health data. However, while the benefits of sharing of data for clinical research and healthcare improvement purposes are undisputed, there remain technical, ethical, legal, financial and motivational challenges that impede data sharing.

In this session, we will explore some of these challenges and discuss the 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.

Tuesday, 20 October
16.45-18.00



P7 Moderator Jean Georges (Luxembourg)

Ensuring ethics and patient privacy whilst boosting research



P7.1. Nathan Lea (England)

Data privacy and ethics in clinical research



P7.2. Pilar Canabaté (Spain)

MOPEAD: preservation of autonomy through dementia



P7.3. Sébastien Libert (England)

Remote monitoring and digital devices: ethical and patient privacy implications in RADAR-AD

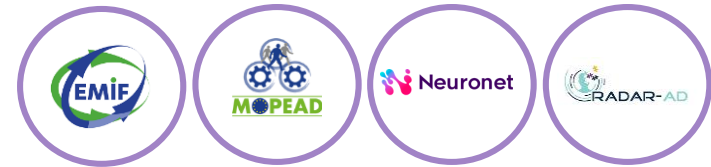


P7.4. Angela Bradshaw (Luxembourg)

Adopting best practice on patient privacy – report on Neuronet Working Group activities

ENSURING ETHICS AND PATIENT PRIVACY WHILST BOOSTING RESEARCH

LEA Nathan¹, CANABATE Pilar², LIBERT Sebastien¹, BRADSHAW Angela³ and GEORGES Jean³



¹University College London, London, England, ²Fundacio ACE, Barcelona, Spain, ³Alzheimer Europe, Luxembourg

To ensure that patient privacy is adequately respected, data protection and ethics form an integral part of EU-funded health research; indeed, they are viewed as pivotal for achieving concrete benefits for patients and citizens. However, neurodegenerative disease research raises specific ethical and legal challenges, including how to ensure fairness and equity in research participation, disclosure of risk and informed consent, capacity and cognition. In this session, experts from EMIF, MOPEAD and RADAR-AD will discuss how these projects have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research.

Wednesday, 21 October

14.15-15.30



P15 Moderator Diana O'Rourke (England)

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



P15.1. Diana O'Rourke (England)

Neuronet Regulatory Working Group: focus on the Decision Tool



P15.2. Jacoline Bouvy (England)

ROADMAP: real-world data supporting regulatory and health technology



P15.3. Gill Farrar (England)

Experiences from the AMYPAD consortium on regulatory/HTA interactions

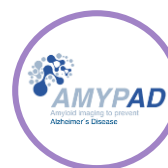


P15.4. Marco Viceconti (Italy)

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

REGULATORY & HTA ASSESSMENT: A CRITICAL STEP IN DELIVERING INNOVATION FOR PATIENT BENEFIT

O'ROURKE Diana¹, BOUVY Jacoline¹, FARRAR Gill² and VICECONTI Marco³



¹National Institute for Health and Care Excellence, London, England, ²GE Healthcare, Amersham, England, ³Università di Bologna, Bologna, Italy

To maximise the impact of outputs from IMI projects and ensure that they are usable within a regulatory and HTA context, there is a need for timely and effective engagement. This is particularly important within the field of neurodegenerative disease research, where there remains a lack of effective treatments. In this session, experts from the AMYPAD, ROADMAP and Mobilise-D projects will outline their experiences of engagement with the EMA, discussing specific issues around the use of real-world evidence, novel neuroimaging biomarkers and digital technologies for assessment of mobility. The Neuronet regulatory Decision Tool will be presented, identifying the key procedures for engaging with authorities during the drug development process.

Thursday, 22 October
14.15-15.30



P23 Moderator Lennert Steukers (Belgium)

Neuronet Roundtable: public-private partnerships in the post-COVID era

Roundtable Participants



Martin Hofmann-Apitius
Fraunhofer SCAI
Germany



Walter Maetzler
Kiel University
Germany



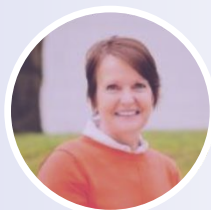
Andrew Owens
King's College London
England



Jochen Prehn
RCSI
Ireland



Craig Ritchie
University of Edinburgh
Scotland



Lynn Rochester
University of Newcastle
England



Pieter Jelle Visser
Maastricht University
Netherlands

NEURONET ROUNDTABLE
PUBLIC-PRIVATE
PARTNERSHIPS IN THE
POST-COVID ERA



The Neuronet Coordination and Support action brings together 18 neurodegeneration projects funded by the IMI. In this live roundtable session, Neuronet project leader Lennert Steukers will moderate a discussion on how COVID-19 has affected large public-private partnership projects, involving IMI project leaders who are experts on mobility disorders, big data, digital biomarkers, stratified medicine and dementia prevention. Specific topics to be addressed include the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

Plenary I Roundtable discussion: Dementia in a changing world

20 October
13.15-14.30

Adelina Comas-Herrera, Mario Possenti, Helen Rochford-Brennan, Lennert Steukers

The COVID-19 pandemic has caused disruption to all aspects of life across the world, as measures aimed at slowing the spread of the virus have interrupted our usual routines, interactions and ways of working. In this symposium, we will discuss how the pandemic has changed the dementia landscape. We will find out from Helen Rochford-Brennan of the European Working Group of People with Dementia, Mario Possenti of Federazione Alzheimer Italia, Adelina Comas-Herrera, curator of LTCovid.org, and Lennert Steukers, Neuronet Project Leader, how the COVID-19 pandemic has affected people with dementia, Alzheimer's associations, the long-term care sector and dementia research



Lennert Steukers

Plenary IV From research innovation to clinical care and practice

22 October
08.45-10.15

Carol Brayne, Dympna Casey, Alexander Kurz, Carlos Diaz

PL4.1. Carol Brayne (University of Cambridge): Latest trends in the prevalence of dementia – are prevention messages having an effect?

PL4.2. Dympna Casey (NUI Galway): Assistive technologies – the role of social robotics in dementia

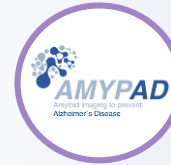
PL4.3. Alexander Kurz (Technical University Munich): An interprofessional intervention in dementia education

PL4.4. Carlos Diaz (SYNAPSE): The neurodegeneration portfolio of the Innovative Medicines Initiative: from project results to sustainable assets



Carlos Diaz

Early-Career Researchers On-demand presentations



QOP4.01 Natassia Brenman (University of Cambridge)

"Jumping into research": insights from the SPEAR study into motivations and expectations of participation in Alzheimer's disease research



QOP5.05 Filipa Landeiro (University of Oxford)

Costs incurred by people with pre-dementia or dementia



PO3.18 Marthe Smedinga (Radboud UMC)

Should doctors offer biomarker testing to those with cognitive complaints who are afraid to develop Alzheimer's dementia?



PO3.19 Marijn Muurling (Amsterdam UMC)

Remote assessment of Alzheimer's disease: the RADAR-AD study