IMI2 821513 – NEURONET

Efficiently Networking European Neurodegeneration Research

WP2 – Programme integration

D2.4 Report #3 on activity of SCB, WGs and TFs.

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Document History

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V0.1	16/05/2022	First draft
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Contents

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 (*terminated partner*)
8. **SARD**: Sanofi-Aventis Recherche & Développement
9. **PUK**: Parkinson's Disease Society of the United Kingdom LBG
10. **TPIZ**: Takeda Pharmaceuticals International AG

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

The NEURONET Coordination and Support Action has the main objective of setting up an efficient platform to boost synergy and collaboration across the IMI projects of the Neurodegenerative Disorders portfolio, assisting in identifying its gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide.

Deliverable D2.4 *Report #3 on activity of SCB, WGs and TFs* constitutes a report on the activities of the Scientific Coordination Board, the four Working Groups, and two Task Forces as they happened between the beginning of May 2021 and the end of August 2022 (i.e., the project end).

1 Introduction

NEURONET is the Innovative Medicines Initiative (IMI) Coordination and Support Action (CSA) that aims to support and better integrate projects in the IMI Neurodegenerative Disorders (ND) portfolio. The primary objective of the NEURONET CSA is to establish an efficient platform to drive synergy and collaboration across IMI ND projects, multiplying their impact, enhancing their visibility and facilitating dovetailing with related initiatives both in Europe and the rest of the world.

NEURONET is built around 5 Work Packages (WP) as shown in Figure 1.

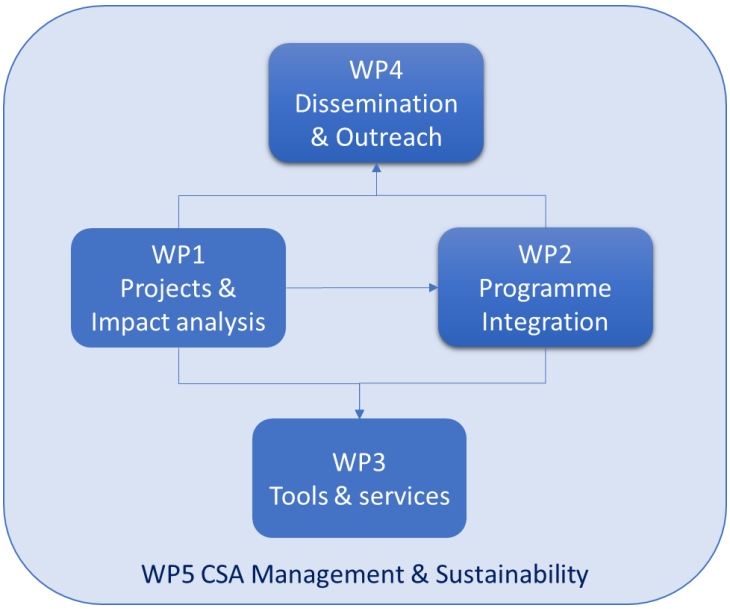

Figure 1. NEURONET WPs.

WP2 Programme Integration is responsible for creating and implementing the governance and organisational structures of NEURONET, including the definition of associated workflows and procedures.

The first task in this WP (*Task 2.1: Set up and maintenance of NEURONET structures, procedures and workflows for programme management*), entailed defining the terms and procedures for the creation of the Scientific Coordination Board (SCB) Working Groups (WGs) and Task Forces (TFs) that complement NEURONET's own governance structure, as reported in deliverable D2.1 *Report on establishment and procedures of SCB and foundational WGs*.

Figure 2 below provides a graphical view of the conceptual project design, with NEURONET providing the core connections between projects through the SCB, WGs and Task Forces (TFs), and acting as a link to external initiatives beyond IMI. All three bodies are conceived as open structures, therefore catering for new projects in the IMI pipeline and potentially including representatives from external initiatives or other stakeholders with whom NEURONET may want to collaborate.

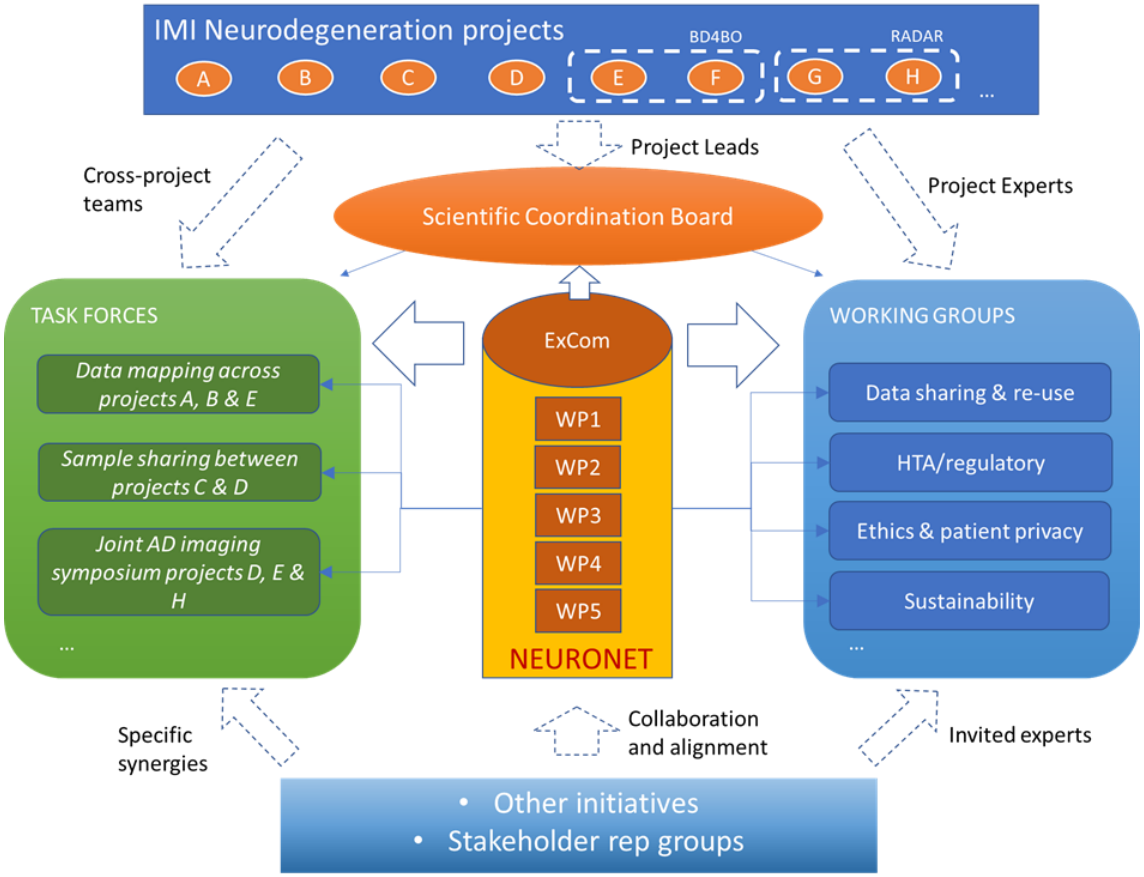

Figure 2. NEURONET operational framework.

2 The Scientific Coordination Board

2.1 Scope and membership

The Scientific Coordination Board (SCB) is a pivotal body in NEURONET's governance structure, because it plays a crucial role in the definition of the strategic agenda for the CSA. The SCB objective is to provide expert advice, recommendations and guidance in terms of scientific and strategic evaluation of synergies, priority areas and opportunities for collaboration within NEURONET, while also pointing at gaps in the portfolio or specific areas that require concerted action.

Each IMI ND project nominates one representative for the NEURONET SCB. Normally it should be either the academic lead or the EFPIA lead, but the project may choose to nominate another person that the project leadership decides to delegate to.

As shown in the table below, there are currently 18 project leads sitting in the SCB, gathering a total of 20 IMI ND projects (Dag Aarsland and Hugh Marston are representing two projects: RADAR-AD and PD-MIND; and PRISM and PRISM2, respectively), which represents the virtual totality of the IMI ND portfolio.

Name	Project	Background	Organization
Margot Bakker	ADAPTED	EFPIA	Abbvie
Martin Hofmann-Apitius	AETIONOMY	Academia	Fraunhofer Gesellschaft
Gill Farrar	AMYPAD	EFPIA	GE Healthcare
Pieter Jelle Visser	EMIF	Academia	Maastricht University and VU University Medical Center
Craig Richie	EPAD	Academia	The University of Edinburgh
Raj Long	EPND	Other	Gates Ventures
Malcolm Macleod	EQIPD	Academia	The University of Edinburgh
Walter Maetzler	IDEA-FAST	Academia	University Medical Center Schleswig-Holstein
Dominique Lesuisse	IM2PACT	EFPIA	Sanofi
George Tofaris	IMPRIND	Academia	University of Oxford
Lynn Rochester	MOBILISE-D	Academia	Newcastle University
Mercè Boada	MOPEAD	Academia	Fundació ACE
Dag Aarsland	PD-MIND & RADAR-AD	Academia	King's College London
Jochen Prehn	PD-MITOQUANT	Academia	Royal College of Surgeons in Ireland
Andreas Ebneth	PHAGO	EFPIA	Janssen
Hugh Marston	PRISM & PRISM2	EFPIA	Eli Lilly
Matthew Hotopf	RADAR-CNS	Academia	King's College London
John Gallacher	ROADMAP	Academia	University of Oxford

2.2 SCB Meetings

In the second year of the project, the SCB has met online on two occasions, representing their 7th and 8th meetings for the whole project:

7th meeting	21/10/2021
8th meeting	30/03/2022

In the following sections we will provide a summary of discussions and decisions made at these SCB meetings.

2.2.1 7th SCB Meeting (October 2021)

Ten SCB members attended the 7th SCB meeting. The agenda for the meeting is included in the Annexes.

There was an update on NEURONET latest activities from the project leaders, including the news of the granted 6-month project extension requested to IMI, followed by an introduction of the two new projects onboard: PRISM2, represented by Hugh Marston and EPND, represented at the SCB by Raj Long.

Then, an overview of the NEURONET Asset map was given, where the NEURONET team specified a definition of "asset" based on 5 criteria to harmonise the assets presented across projects. Subsequently, attendees discussed the current layout and structure of the Asset Map, and suggested changes for improvement (e.g., re-naming some of the categories or having empty categories to show where the gaps are).

NEURONET underlined the importance of the collaboration and synergies, and reported on three collaborative efforts among IMI projects and partners identified: PHAGO – EPAD, IDEA-FAST – MobiliseD, and NEURO-cohort. The SCB underlined the importance of up-front and realistic discussions on the cost associated to such collaborations, in particular when these involve sharing biological samples, and the need to establish property rights and ownership of samples/data/results from the start.

NEURONET leaders also spoke about NEURONET sustainability, highlighting feedback from projects on the value added by NEURONET for the IMI NDD portfolio as a supporter and facilitator of new relationships, mutual knowledge and collaboration across the portfolio. However, without a clear path forwards, NEURONET still needed to work to identify further avenues for sustainability, such as exploring options with other stakeholders beyond IMI channels.

Regarding the future plans of NEURONET, several activities were highlighted:

1. Impact assessment
   An impact survey for EFPIA partners participating in IMI NDD project about the value added from participation in IMI NDD projects. Results were still being collected and analysed.
2. Landscape Workshop
   NEURONET to organise three workshops for researchers, Regulators/HTA and patients/participants and carers as part of a WP1 exercise to map the landscape of important research initiatives in NDD and identify the priorities and gaps of different stakeholders.
3. Digital Endpoint Workshop
   NEURONET co-organising (led by NICE) a workshop on digital endpoints at ISPOR conference, with involvement from Mobilise-D and IDEA-FAST.
4. Neurodegeneration Summit
   The aim would be to bring together key opinion leaders in the NDD field for discussing priorities, global efforts and research agenda for the next decade. NEURONET to organise a small pilot meeting involving 10-15 participants to test the idea.
5. Possibility of a NEURONET Academy
   The objective of the Academy would be to support and connect the early career researchers and younger investigators. However, the SCB agreed that without additional funding for a further time period for NEURONET this idea should not be further pursued.

Elisabetta Vaudano presented an overview of the priorities in the new IHI framework and summarized some of the final IMI activities.

To conclude, Lewis Killin presented an overview of the NEURO-Cohort task force, summarising its aims, philosophy, current participants, logistics, financial model and progress. Carlos Díaz clarified that NEURO-Cohort is working against strong forces of inertia and “business as usual”, so the initiative should be seen as a pilot designed to assess feasibility. It will be reviewed in 6 months to see if the concept works.

2.2.2 8th SCB Meeting (March 2022)

Nine SCB members attended the last SCB online meeting. The agenda for the meeting is included in the Annexes.

After a short introduction from Carlos Díaz, Lewis Killin presented the updates of the Neuronet asset map, including assets for three initiatives: NEURO Cohort, DPUK and a collaborative initiative between IDEA-FAST and Mobilise-D.

Fatima Salih provided an update on the Regulatory and HTA engagement Decision Tool, which was developed in part thanks to Neuronet Regulatory Working Group activities. The tool was developed to support engagement with regulators, HTA and payers and is accessible through the KB. It is aimed at identifying suitable processes and procedures for interacting with regulators, HTA bodies, and payers along the medicines development, approval, and reimbursement pathway. It provides a clickable overview of the processes and procedures for regulatory interactions at different stages of the development pipeline.

Next Angela Bradshaw provided an update on work underway to support a new special issue of Frontiers in Neurology, entitled "Impact of public-private collaborative research on AD: the case of the IMI". Angela also provided a brief update on a manuscript that is being developed by WP1 of Neuronet, drawing on a deliverable that performed an integrated programme analysis of the project portfolio. This manuscript details the characteristics, structure and collaborative networks of projects, looking at how different organisations partner across projects (EFPIA partners often act as central nodes in the collaborative networks). The article also details the findings of several interviews and surveys with project leads, which identify areas of challenge for collaborative projects and potential solutions that could address these issues.

Lewis Killin then provided an update on the NEURO Cohort, an initiative stemming from the EPAD LCS study. He outlined that almost 40 sites have signed Expressions of Interest, representing an estimated 25,000 research participants, with seven sites engaged as pilot sites. Lewis has been liaising with sites on a 1-to-1 basis to collect information about the cohorts and studies they are running.

Lewis finished by providing an update on interactions with the Davos Alzheimer's Collaborative (DAC). DAC are in the progress of developing a global cohort of participants to address the lack of diversity in research populations, initially focusing on LMICs for blood sample/GWAS, digital phenotyping and metabolomic/metagenomic analysis. NEURO Cohort sites could represent the European subset of the DAC global cohort initiative (conversation ongoing).

After that, Nina Coll went through the list of planned upcoming meetings of NEURONET, including the Summit (29 April), the joint meeting of Regulatory WG and digital endpoints experts (tbc), the Dementia Data Model Initiative (tbc), the Sustainability WG final meeting (6 May) and the final meeting of the NEURONET consortium (1 July).

The next session evolved around the focus and priorities in the final months of the project. Lennert Steukers, Project Lead, explained that Neuronet developments in the sustainability front are a bit disappointing in the light of apparent lack of interest from IMI and EFPIA, but it is still work in progress. Lennert shared that IHI did not show great interest in funding the Neuronet sustainability phase. Instead, they have encouraged that any Neuronet proposal should go through the typical procedure (i.e. submitting a proposal to a call, developing a new project). Conversations within EFPIAs have not been successful so far either, mainly because of the uncertainties around the new IHI framework, not because they do not see value in NEURONET.

Carlos Díaz, Project Coordinator, reported that in the BD4BO sustainability meeting they proposed organizing cross-project sustainability meetings, just like NEURONET WG on sustainability has been doing in the last 3 years. The fact that some of the novel services and ideas provided by Neuronet are now also being discussed and tackled by other initiatives indicates that there is a need for the services provided by NEURONET.

To conclude the final meeting of the NEURONET SCB Carlos Díaz thanked members for their continued support and contribution, and for making NEURONET a success.

3 The Working Groups

3.1 WG1: Data sharing and re-use

3.1.1 Membership

The WG on Data sharing is led by partner Janssen. The current members of the WG are:

Name	Organization	IMI project
Andrew Owens	King's College London	RADAR-AD
Andrew Peter McCarthy	Eli Lilly	n/a
Angela Bradshaw	Alzheimer Europe	NEURONET
Anthony Brookes	University of Leicester	EMIF / EPAD
Carlos Díaz	SYNAPSE	NEURONET
Chris Bintener	Alzheimer Europe	NEURONET
Clint Hansen	Kiel University	Mobilise-D
Cindy Birck	Alzheimer Europe	NEURONET
Francoise Le Vacon	Biofortis Mérieux NutriSciences	n/a
Jean Georges	Alzheimer Europe	NEURONET
Judi Syson	University of Edinburgh	EPAD
Lennert Steukers	Janssen	NEURONET
Kirsten Emmert	University Medical Center Schleswig-Holstein	IDEA-FAST
Lewis Killin	SYNAPSE	NEURONET
Loes Rutten-Jacobs (*from May 2021*)	Roche	NEURONET
Manuela Rinaldi (*until Oct 2021*)	Janssen	NEURONET
Martin Hofmann-Apitius	Fraunhofer	AETIONOMY
Niamh Connolly	Royal College of Surgeons in Ireland	PD-MITOQUANT
Nigel Hughes	Janssen	EMIF-AD
Nikolay Manyakov	Janssen	RADAR-CNS/RADAR-AD
Pieter Jelle Visser	VUmc & Maastricht University	EMIF-AD
Rodrigo Barnes	Aridhia	EPAD
Sandra Pla	SYNAPSE	NEURONET
Serge Van der Geyten	Janssen	EPAD
Walter Maetzler	University Medical Center Schleswig-Holstein	IDEA-FAST

3.1.2 Meetings

The WG met three times this reporting period; three teleconferences.

June 22nd 2021

This meeting was composed of a general NEURONET update, and conducting a thorough review of the latest draft of the next deliverable. Based on the feedback received & discussed, the second draft of the deliverable was shared afterwards with the working group members. A key suggestion in terms of lessons learned was to have practical examples from IMI projects to be included in the deliverable. Once finalized, the WG experts need to consider whether preparing a publication based on the deliverable could be a value add.

October 14th 2021

This meeting was composed of a general NEURONET update, final endorsement of the next deliverable content, and discussing the EPND data sharing strategy. It was decided to continue to liaise with EPND on making sure approaches are aligned with lessons learned/recommendations coming forth from the ND portfolio.

March 1st 2022

The meeting started with a general NEURONET update but mainly focused on setting priorities for 2022, defining focus areas until project end and mapping out plans beyond project life. The WG discussed the idea of striving for a 'Dementia Data Federation' initiative, an open-source community approach to work towards a common view (set aside cultural issues) for making data more accessible, findable as to foster better collaborations and less competition. A key challenge will be how to overcome silos in the data landscape. The proposal would be that this Dementia Data Federation Initiative will be a spin-off of the Data sharing WG and its accomplishments and will continue to function beyond the Neuronet grant life.

The working group is currently writing a publication for submission in Frontiers of Neurology on challenges, lessons learned and best practices to enable efficient sharing and access to data while taking into consideration all relevant data sharing barriers specifically in the context of IMI & PPPs in the Neurodegeneration field.

3.2 WG2: HTA/Regulatory interaction

An HTA and Regulatory interaction WG was established to generate insights into the regulatory and HTA challenges and opportunities that are unique to neurodegenerative diseases.

3.2.1 Membership

Name	Organization	IMI project
Angela Bradshaw	Alzheimer Europe	NEURONET
Carlos Díaz	SYNAPSE	NEURONET
Christophe Bintener	Alzheimer Europe	NEURONET
Cristina Saugar	SYNAPSE	NEURONET
Dalia Dawoud	NICE	NEURONET
Emilse Roncancio	GE	NEURONET
Gul Erdemli	Novartis	RADAR-AD
Jean Georges	Alzheimer Europe	NEURONET
Lewis Killin	SYNAPSE	NEURONET
Mikkel Misfeldt	ROCHE	NEURONET

Name	Organization	IMI project
Nina Coll	SYNAPSE	NEURONET
Raj Long	Gates Ventures	EPND
Robin Thompson	Biogen	ROADMAP
Sandra Pla	SYNAPSE	NEURONET
Suzanne Foy	Janssen	EPAD
Vera Nies	Lygature	RADAR-AD

3.2.2 Meetings

The WG met once virtually in the past year on 25th May 2022.

The meeting began with a summary of the WG activities to date including the key challenges and learnings. This also covered the Decision Tool for HTA and Regulatory Engagement, and how the WG feedback had been incorporated which was:

- Signposting to more detailed published ND or other relevant guidance
- Providing case studies from Neuronet projects that have been through regulatory or HTA processes or procedures
- Signposting to relevant agencies and organisations, tools and projects
- Updating the signposting information generally including changes to organisations and processes and removing any that are not available

The final report for the Decision Tool for HTA and Regulatory Engagement was submitted on 1st March 2022.

The meeting concluded with a updates on HTA and regulatory interactions that had taken place since the previous WG meeting, and a roundtable discussion on the key challenges and learnings that had been presented. The group agreed with the key challenges and offered suggestions on how to present them in the write up. They also added additional ones such as the changing landscape making it hard to know which organisation to engage at which point for different products.

3.3 WG3: Ethics and patient privacy

3.3.1 Membership

The WG on Patient Privacy and Ethics is led by partner Alzheimer Europe. WG members are listed in the table below:

Name	Organization	IMI project
Angela Bradshaw	Alzheimer Europe	NEURONET
Carlos Díaz	SYNAPSE	NEURONET
Christophe Bintener	Alzheimer Europe	NEURONET
Cristina Saugar	SYNAPSE	NEURONET
Diana O'Rourke	NICE	NEURONET
Dianne Gove	Alzheimer Europe	NEURONET
Edo Richard	Radboud UMC	AMYPAD/EPAD
Federica Lucivero	University of Oxford	RADAR-AD
Jean Georges	Alzheimer Europe	NEURONET

Mercè Boada	Fundació ACE	MOPEAD
Nathan Lea	UCL	EMIF
Nikolaus Forgo	University of Vienna	AETIONOMY
Pilar Cañabate	Fundació ACE	MOPEAD
Rebecca Pinto	King's College London	PD-MIND
Richard Milne	University of Cambridge	EPAD

3.3.2 Meetings

The working group met three times this period, via teleconference on all occasions. On 24 March 2021, the meeting was focused on an upcoming deliverable for the Working Group, which aimed to analyse clauses relevant to patient privacy in informed consent forms and data management plans created by projects. The goal of this work was to identify commonalities and areas of good practice, and discussions highlighted the contributions made by Working Group members to deliverables addressing consent and data management. The EPAD staged consent model was highlighted as an example of good practice for adaptive or platform trials, ensuring that participants are provided with relevant information at each stage and asked for informed consent at key points, whilst also obtaining information about the totality of all stages. Attendees included experts working on the AMYPAD, EPAD, EMIF and PD-MIND projects.

The Working Group meeting held on 11 June was attended by representatives of EPAD, AMYPAD, RADAR-AD, MOPEAD, EMIF and AETIONOMY projects, among others. Discussions were focused on the ways in which ethical, legal and social issues are identified and addressed in public-private partnership projects, and how to enhance collaborations between industry and academic partners.

One of the Working Group members provided an update on a proposal for embedding reflective ELSI practices in collaborative research projects, identifying a 3-stage model for reflective ELSI practice in projects, that could bring together all clinical projects of the IMI ND portfolio. This model would be a way to rapidly gain a deeper understanding of the issues that a project is likely to face, and identify constructive ways to address them – also creating a framework for knowledge transfer and interactions across projects. Colleagues in the working group suggested the inclusion of public involvement activities within this framework, to provide the perspectives of people with lived experience of disease for ELSI reflection work. In addition, attendees with clinical responsibilities in cohort studies identified COVID-19, and the modifications to research conduct the pandemic entailed, as learnings that could be shared via such a framework.

The final Working Group meeting was held on 24 March 2022. The meeting started with an update on recent Neuronet activities, including the development of the Neurocohort task force, updates to the Neuronet Knowledge Base, and information on the stakeholder workshops that were held as part of efforts to identify gaps and priorities for neurodegenerative disease research. The Working Group also discussed an upcoming special issue in Frontiers in Neurology, which aims to highlight the work of IMI projects working on Alzheimer's disease. In particular, the group addressed the possibility of developing a collaborative article on the patient privacy and ethics work in the IMI portfolio.

3.4 WG4: Sustainability

The Sustainability WG looks at exploitation activities and sustainability models (spanning business design, modelling, financial estimates, IP issues, organisational models, legal solutions, etc.) that can help projects with long-term sustainability. The idea is to compile sustainability and business models used in (or applicable to) IMI projects, focusing on common issues related to sustainability, namely IP, legal, financial, technical issues. WG members provide their expert feedback and perform a critical analysis of the models identified.

3.4.1 Membership

The WG on Sustainability is led by partner Synapse. The current members of the WG are:

Name	Organization	IMI project
Anneleen Stinckens	Janssen	NEURONET
Carlos Díaz	SYNAPSE	NEURONET
Caroline Schuster	ARTTIC	PHAGO
Frank Tennigkeit	UCB	EPAD
Gill Farrar	GE	AMYPAD
Jean Georges	Alzheimer Europe	NEURONET
John Gallacher	University of Oxford	ROADMAP
Lennert Steukers	Janssen	NEURONET
Lewis Killin	SYNAPSE	NEURONET
Martin Hofmann-Apitius	Fraunhofer	AETIONOMY
Nathalie Piton	Sanofi	NEURONET
Nina Coll	SYNAPSE	NEURONET
Paul Peeters	Janssen	NEURONET
Pieter Jelle Visser	VUmc & Maastricht University	EMIF-AD
Thomas Steckler	Janssen	EQIPD

3.4.2 Meetings

The WG met six times this since the start of NEURONET. The first four of these meetings were focussed on the sustainability plans and strategies of specific projects in the IMI ND portfolio, while the fifth focussed on a sustainability tool and framework, intended for use across IMI projects.

The sixth and final meeting of the WG took place on the 6th of May 2022 by teleconference. The best practices and recommendations for sustainability included in the first deliverable of the WG were reviewed and fine-tuned with contributions from the attendees. Next, Carlos Díaz outlined the strategy and steps taken by NEURONET for its own sustainability, and Lisa Leenhouts-Martin from The Forward Group spoke about the EFPIA & IMI *Field Manual on Scaling Innovations emerging from Public-Private Partnerships,* a resource designed to help investigators overcome common challenges that come from making IMI project assets sustainable. Specifically, it is intended to provide a pragmatic framework that can help project teams develop sustainable assets by, for example, considering their targeted market and research landscape. In the general discussion, both scientists and members of industry shared their views on how to improve sustainability planning and exploiantion of project results/assets, with some commonalities in their respective ideas. Some of the ideas discussed were rather general, such as for example the need for transparency, improved communication and alignment of goals across stakeholders, while other were much more concrete, such as setting up a multidisciplinary team of experts (knowledge hub) that can support projects when devising and implementing their sustainability strategy (aka a “Virtual Incubator” for IMI/IHI projects).

4 Task forces

4.1 NEURO Cohort

The NEURO Cohort TF continued to meet through this period with the membership below.

Name	Organization	IMI project
Angela Bradshaw	AE	NEURONET
Carlos Diaz	SYNAPSE	NEURONET
Isadora Lopes Alves	VUMC	AMYPAD
Lennert Steukers	Janssen	NEURONET
Lewis Killin	SYNAPSE	NEURONET
Nina Coll	SYNAPSE	NEURONET
Sandra Pla	SYNAPSE	NEURONET

Following on from the pre-KO in 5th March 2021 (see deliverable 2.3.), the TF continued to work on three fronts. The first was to continue collaboration with the Medical Informatics Partnership (MIP) to complete the technical pilot with 7 of the now 40 interested sites. The second was to complete a series of one-to-one meetings with all 40 sites to discuss NEURO Cohort, its aims and practicalities in detail to better understand what the initaitve would mean for each site. The third front was to continue collaboration with potential funders and other initiatives. Chief among these were the conversations held with the Davos Alzheimer's Collaborative (DAC). The summary progress across these three fronts was communicated in a site-wide meeting, co-presented with DAC and EPND representatives, on Monday 13th June, 2022.

4.1.1 Technical pilot

The technical pilot of NEURO Cohort was created to establish the proof-of-concept of the project. Specifically, a site that successfully completes the pilot would be able to identify its source data, convert it to the NEURO Cohort common data model and upload it as aggregated data to the MIP.

In this reporting period, all stages of the technical pilot have been achieved. In full, these stages are:

1. Drafting and signing letters of understanding and service level agreements with sites
2. The collaboration and creation of a common data model
3. Installing local MIP nodes at site or providing access to the cloud via EBRAINS
4. Producing data quality tools for data merging and conversion to common data model
5. Test of tools on local datasets
6. Creation and upload of synthetic test dataset

The technical pilot was also designed to obviate the need for data use or sharing agreements, in that no live or patient data would be processed as part of the activity. Furthermore, the completion of the pilot would represent an established and tested workflow, which would facilitate subsequent approvals.

4.1.2 One-to-one meetings

Between August and December 2021, the NEURO Cohort TF met with 36 of the 40 NEURO Cohort sites to relay the core tenets of the initiative, leading to a review of the practical and financial implications for the site. These one-to-one meetings were done to create a dedicated time to discuss any questions that the sites may have had, in addition to confirming the intention

behind NEURO Cohort. In summary sites often raised questions regarding: the scientific value of the project, including how it is differentiated from other initiatives; the logistics of the project, including ethics, assessments and data sharing; financial and contracting obligations; and the form of communication between sites and the TF.

4.1.3 Collaboration with funders and initiatives

In this reporting period, the NEURO Cohort TF met with the Davos Alzheimer's Collaborative (DAC), the Global Alzheimer's Platform (GAP) Foundation, the Latin America and Caribbean Consortium on Dementia (LAC-CD) and the European Platform for Neurodegenerative Diseases (EPND) project.

NEURO Cohort TF met with DAC 12 times this reporting period. Here, the TF initially met to understand the scope of DAC's Global Alzheimer's Cohort, and sites within NEURO Cohort that would be interested in the initiative, in principle. Further meetings were dedicated to identifying candidate sites, aligning on the protocol/order of work and the associated budget. Overall, these meetings served to finalise a protocol and contract that could be put to NEURO Cohort sites who wanted to participate in the Global Alzheimer's Cohort. These meetings are still ongoing as the protocol and costing models are refined. NEURO Cohort TF met with the LAC-CD to discuss whether they in turn would be interested in participating in the Global Alzheimer's Cohort, as advocated by the TF.

NEURO Cohort and GAP met as a consequence of conversations with DAC. GAP is a collaborator of DAC, and has established as a "*network of over 90 clinical trial sites across North America, who benefit from sharing knowledge and experience in order to effectively and efficiently work toward research progress in neurodegenerative conditions*." GAP currently has ambitions to expand its model to European sites. In discussions with GAP, NEURO Cohort TF explained that NEURO Cohort is agnostic to the types of research it would like to facilitate – to this end, it would not necessarily compete in efforts to deliver clinical trials to sites.

Similarly, discussions with EPND were facilitated due to the project's membership of NEURONET. Furthermore, EPND is associated with DAC through its shared partnership with the Gates Foundation. EPND is "*is to establish a collaborative platform that would link up existing European research infrastructures… where sample and data discovery tools will be connected to a network of over 60 cohorts with Alzheimer's disease, Parkinson's disease, and related disorders. Between them, these cohorts will facilitate access to samples and data from over 120 000 research participants."* Given the potential shared constituency between EPND and NEURO Cohort cohorts, both initiatives have met to help align on strategy and communication. Although the aims of the projects are different (i.e., NEURO Cohort is tasked with producing a network to facilitate study recruitment, where EPND is concerned with sample and data access), meetings are ongoing to find a common ground for collaboration.

4.2 EPAD - PHAGO

The EPAD-PHAGO TF was first established in August 2020, and finished activity in January 2022.

The members of the TF were:

Name	Organization	IMI project
Andreas Ebneth	Janssen	PHAGO
Angela Hodges	King's College London	PHAGO
Carlos Diaz	SYNAPSE	NEURONET
Craig Ritchie	University of Edinburgh	EPAD

Henrik Zetterberg	University of Gothenburg	PHAGO
Jean Manson	University of Edinburgh	EPAD
Lewis Killin	SYNAPSE	NEURONET
Natalia Matveyev	University of Edinburgh	EPAD
Nina Coll	SYNAPSE	NEURONET

This TF represented the first formal collaborative effort between two IMI ND projects for NEURONET. Specifically, both EPAD and PHAGO stood to benefit from the analysis of CSF samples collected by the former, as CSF samples collected from the EPAD cohort were to be identified, sent over to, and analysed by the PHAGO team using the Roche Diagnostics NeuroToolkit. Successfully completing this work would have satisfied a clause in the EPAD LCS protocol to conduct TREM2 analysis and would enrich PHAGO's overall sample data.

Within the TF, NEURONET had acted as a key facilitator in producing management and action plans, convening a further meeting since the last reported deliverable.

The initial intention of the TF was first focus on a pilot of sample analysis (specifically, the analysis of samples containing TREM2 and CD33 variants), and to leverage the results of this pilot as the basis of a larger proposal that could fund analysis of the full EPAD sample.

NEURONET convened a TC in May 2021 to confirm the logistical issues associated with the agreed pilot work, including sample matching, material transfer, and timelines.

However, after having confirmed the criteria for sample selection, the costs associated with the identification of the samples from the EPAD team were ultimately prohibitive for the PHAGO team. Relatedly, the number of TREM2 R47H samples provided by the EPAD team were too few for PHAGO's targets.

Overall, the decision to not proceed with this collaboration was confirmed by the PHAGO team on the 10th of January 2022, and the TF was effectively disbanded.

5 NEURONET Summit pilot

The aim of the Summit was to convene a high-level forum of selected project and opinion leaders to discuss priorities in neurodegeneration (ND) research over the next decade. We envisioned this pilot meeting as a small 2-hour virtual meeting providing a comfortable free-thinking space for people to act as individual experts, i.e., not constrained by the pressures or priorities of funders, funding frameworks, commercial drivers or institutions with specific interests.

NEURONET convened the Summit Pilot on 29th April 2022, with fourteen attendees, representing nine experts and five NEURONET facilitators. Here, attendees were encouraged to innovate and 'speak their mind' as individuals, including revolutionary or unusual ideas, in the context of a non-judgmental environment. The nine attendees discussed the gamut of issues in the field from their perspective, covering: the experiences of the EPAD project; the role of the pharmaceutical industry; methodology, and the development of new or innovative research protocols; and the role of clinical practice.

Given the free-thinking and safe environment, the proceedings of the Summit were used to summarise the discussion rather than be used for external publication. However, the proceedings, representing a summary of the main themes and open questions, has served as a point of reference that could be used for a future Summit or potential position publication.

6 Annexes

6.1 7th SCB meeting agenda

NEURONET 7th Scientific Coordination Board meeting

21st October 2021

No	Topic	Speakers	Time - CET
1	**Brief introduction and general updates from NEURONET** • General updates • New projects (EPND & PRISM2) • Asset Map and Knowledge Base • Collaborations • Evaluation and sustainability of NEURONET	NEURONET Project Leads	11:00
2	**Future activities** • Impact assessment • Landscape Workshop • Digital Endpoint Workshop • Neurodegeneration Summit • Possibility of a NEURONET Academy	NEURONET Project Leads	11:45
Break			12:30
3	**Neurodegenerative priorities in IHI Framework**	Elisabetta Vaudano	12:45
4	**Neurodegeneration European Parent Cohort (NEURO-Cohort)**	NEURO Cohort TF	13:30
5	**Wrap-up and review**	All members	14:00
End of the meeting			14:15

6.2 8th SCB meeting agenda

NEURONET 8th Scientific Coordination Board meeting

30th March 2022

No	Topic	Speakers	Time
1	**Introduction and updates from NEURONET** • Asset Map and HTA Decision Tool update • NeuroCohort update • White papers and Publications in the pipeline • Upcoming meetings	NEURONET team members	15:00
2	**Last six months of NEURONET** • Focus and priorities of NEURONET • Sustainability of NEURONET • How could NEURONET help IMI ND projects	All	15:30
3	**Wrap-up and conclusions**	NEURONET leads	16:20
End of the meeting			