Neuronet

IMI2 821513 – NEURONET

Efficiently Networking European Neurodegeneration Research

WP2 – Programme Integration

D2.2 Report #1 on activity of SCB, WGs and TFs.

Lead contributor	Nina Coll (1– SYNAPSE)
Lead contributor email	ncoll@synapse-managers.com
Other contributors	Carlos Díaz (1– SYNAPSE)
	Sandra Pla (1– SYNAPSE)
	Lennert Steukers (4 – Janssen)
	Manuela Rinaldi (4 – Janssen)
	Diana O'Rourke (2 – NICE)
	Angela Bradshaw (3 – Alzheimer Europe)
	Jacoline Bouvy (2 – NICE)

Contents

Document history

Version	Date	Description
V1	30/01/2020	Outline
V1.1	20/02/2020	First draft
V1.2	23/03/2020	Comments
V1.3	26/03/2020	Final version

Definitions

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

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.

CSA: Coordination and Support Action.

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

IMI: Innovative Medicines Initiative.

ND: Neurodegenerative Disorders.

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

SCB: Scientific Coordination Board.

SGG: Strategic Governing Group.

TF: Task Force.

WG: Working Group.

WP: Work Package.

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.

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 gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide. Deliverable *D2.2 Report #1 on activity of SCB, WGs and TFs* constitutes a report on the activities of the Scientific Coordination Board and the four Working Groups in the first year of the project (no Task Forces have been established yet).

1. Introduction

NEURONET is the Innovative Medicines Initiative (IMI) Coordination and Support Action (CSA) aiming 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 globally.

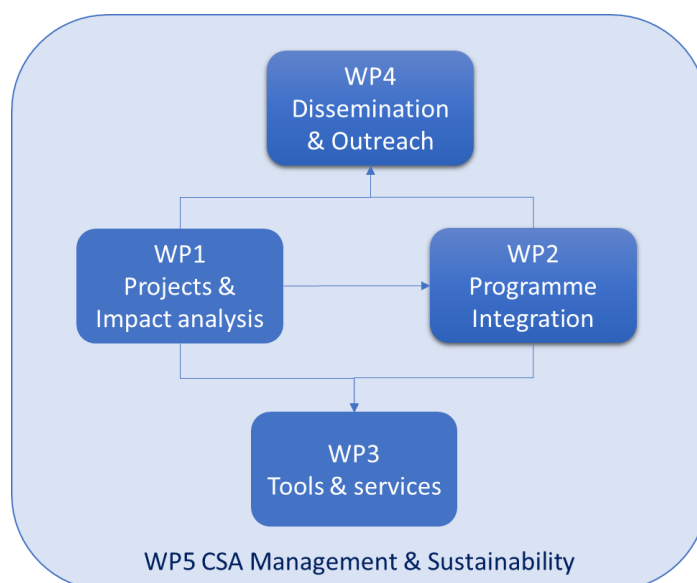NEURONET is built around 5 Work Packages (WP) as shown in Figure 1.

Figure 1. NEURONET WPs

WP2 Programme integration is the work package 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) and the Working Groups (WGs) 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 core connections between projects through the SCB, WGs and TFs, and acting as link with 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 establish a collaboration with.
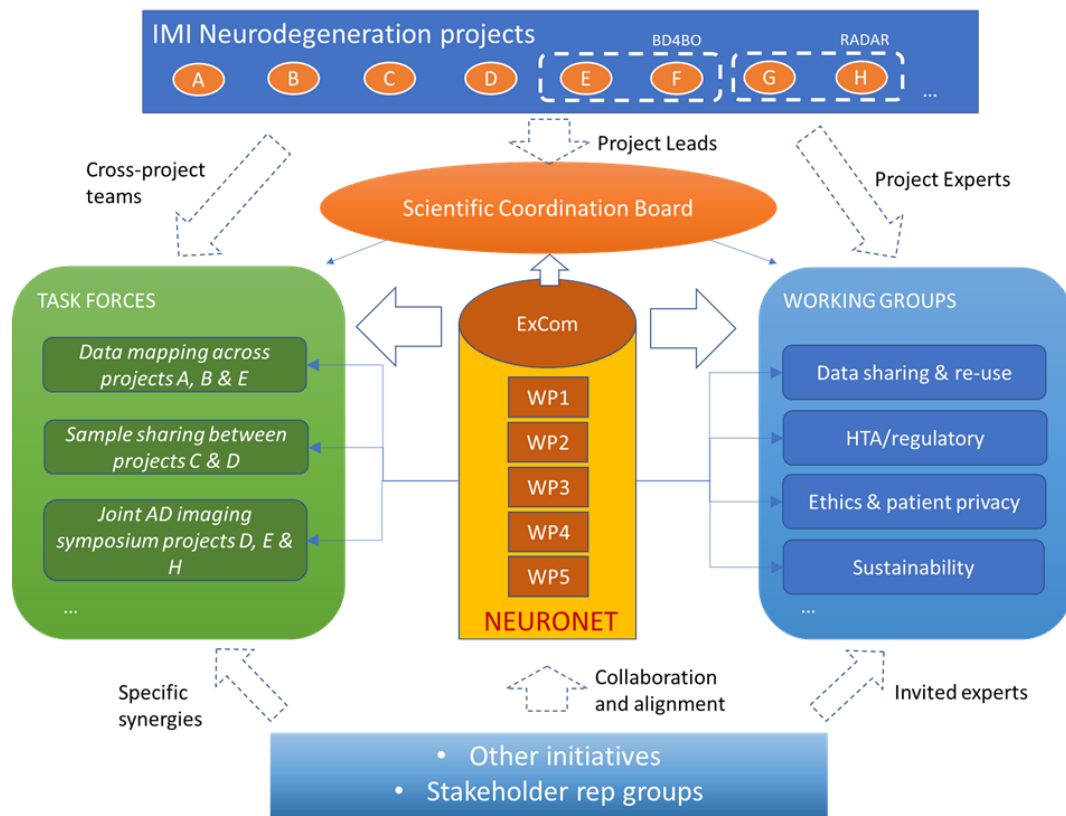
Figure 2. NEURONET operational framework

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 on.

As shown in the table below, there are currently 15 project leads sitting at the SCB, representing a total of 16 IMI ND projects (Dag Aarsland is the project lead for two projects: RADAR-AD and PD-MIND), 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
J. Luis Molinuevo	AMYPAD	Academia	BBRC
Pieter Jelle Visser	EMIF	Academia	VU University Medical Center
Craig Richie	EPAD	Academia	The University of Edinburgh
Malcolm Macleod	EQIPD	Academia	The University of Edinburgh
Dominique Lesuisse	IM2PACT	EFPIA	Sanofi
George Tofaris	IMPRIND	Academia	University of Oxford
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	EFPIA	Eli Lilly
Matthew Hotopf	RADAR-CNS	Academia	King's College London
John Gallacher	ROADMAP	Academia	University of Oxford

In addition, two new IMI projects, MOBILISE-D and IDEA-FAST, have recently been approached by NEURONET, and will confirm their participation in the CSA over the next few weeks.

2.2 SCB meetings

In the first year of the project, the SCB has met face-to-face on three occasions:

1st meeting	02/07/2019	Madrid, Spain
2nd meeting	23/10/2019	The Hague, Netherlands
3rd meeting	28/01/2020	Madrid, Spain

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

1st SCB meeting (July 2019)

The first face-to-face meeting of the SCB gathered nine project leaders in Madrid. The meeting agenda can be found in the Annexes. NEURONET leaders presented the NEURONET concept and vision to the SCB, making clear the philosophy was to establish an operational, pragmatic and agile instrument that could serve projects and not vice versa.

Subsequently, NEURONET leaders explained the rationale followed by the consortium for the definition of the scope of the CSA: All IMI projects targeting neurodegeneration or neurodegenerative disease would be in scope, while other related IMI projects (e.g. those

dedicated to pain or stem cells) would not be included in NEURONET, at least in the initial phase. Links and potential synergies with sister initiative European Brain Research Area (EBRA), an H2020 project coordinated by the European Brain Council, were also discussed.

When asked about common issues and needs across the portfolio, the SCB flagged up the following topics:

Legal obstacles preventing collaboration

SCB members highlighted that there is considerable paperwork and legal obstacles that are preventing data/sample sharing amongst projects. This is a burden that does not facilitate collaboration between consortia. There are usually important delays in the signature of Collaboration Agreements, and it would be good to create the figure of the legal advisor to support projects in this process. NEURONET could help standardize or simplify the signature process of Collaboration Agreements for new IMI ND projects, e.g. proposing new guidelines on how to collaborate with other IMI projects (e.g. informed consent allowing to provide CSF or blood samples to a sister IMI project). Additionally, just as new IMI projects now must submit a Data Management Plan, in future calls IMI could also request projects to plan for their interactions and collaborations with other IMI projects. This could encourage and facilitate collaborations between IMI projects.

Data management & Sustainability

The SCB declared that there is a strong need to build a big public repository in Europe gathering all IMI ND assets (e.g. cell lines, antibodies etc.) and datasets, with dedicated eCRF's (like DPUK). Developing a ND database to store all assets and datasets generated by IMI ND projects could become a future IMI project.

Sustainability of results is a real problem for most projects. Data repositories are needed beyond the project end, and therefore it is important that the dedicated platform would be sustainable in the long-term (considering funding, etc).

Dissemination, communication, visibility

There is also a need to increase awareness and visibility about IMI ND projects and their research findings, and NEURONET could play an important role in this area for maximizing the portfolio impact. In particular, the importance of understanding and using social media for that purpose was highlighted by the SCB.

Patient privacy & Ethics

The SCB mentioned important delays related to institutional review board (IRB) and ethics approval are becoming more and more common, and suggested NEURONET could provide general guidance and recommendations, e.g. for informed consent procedures, disclosure of biomarker results, genetic testing, etc. NEURONET has a dedicated WG on Patient privacy & ethics to deal with these issues, where experts will share learnings and best practice.

IMI rules and regulations

The SCB expressed that, occasionally, it may be better to grant additional funding to a project/or assets of value in need than funding a brand-new project, and this is something IMI should consider when devising its future funding scheme or mechanisms. Besides, SCB members expressed that having some flexibility on the budget distribution would be appreciated. Finally,

Grant Agreement changes should be easier to implement because usually the process of DoA amendment is not very flexible.

In order to assess the impact of the portfolio and show the value of IMI ND research, NEURONET WP1 proposed some impact key performance Indicators (KPIs) that were regarded by the SCB as a very theoretical exercise. The SCB proposed instead that NEURONET could identify all assets produced by projects, and document use of those assets. It was agreed NEURONET would schedule individual interviews with SCB members to learn about the strengths and needs of the respective projects and further discuss about their main assets or results. Further to this, the SCB declared that bringing together all IMI ND projects information in an online portal would be a good way of demonstrating what projects have generated so far and making it more visible. However, it became clear there might be limitations about what projects are able or willing to share with other IMI consortia.

Potential synergies and collaborations identified included the exportation of the training component of the EPAD Academy to create the NEURONET Academy, the dissemination of MOPEAD models for engaging people in the earliest stages of AD in trials (e.g. RADAR-AD, EPAD) and the Research Participant Panel developed in EPAD could also be leveraged as examples of participant involvement in IMI ND projects.

Finally, the SCB members agreed that the SCB should be chaired by NEURONET project leaders to keep it free from potential bias.

2nd SCB meeting (October 2019)

Nine SCB members attended the 2nd SCB face-to-face meeting, which was held in The Hague a day before the 29th Alzheimer Europe Conference and Neuronet Annual Event. The agenda for the meeting is included in the Annexes. Some comments were raised regarding the composition of the SCB, in the sense that EFPIA members were underrepresented and NEURONET should therefore try to encourage the participation of more EFPIA members.

SCB members pointed out that the IMI Neurodegeneration SGG might not have all the information about the different IMI ND projects (objectives, timelines, outputs, etc.) so NEURONET could have an active role in compiling and making available this information, thus increasing awareness about the portfolio of projects and the assets developed.

During the meeting, a big part of the conversation evolved around sustainability of results, which is clearly a challenge for most projects. The SCB criticized the fact that there are no options to ask for continuation of IMI funding even when a project has successfully achieved its objectives or set up an infrastructure or platform that is worth sustaining. The SCB said IMI should recognise the most important results and assets developed by past and current projects, and devise ways to sustain them. With this purpose in mind, it was suggested NEURONET could map the assets, showing the links between them, so that instead of sustaining single IMI projects you sustain a shareable, interlinked network of assets. In the view of the SCB, this approach could potentially be more attractive for attracting future funders (e.g. EFPIA, philanthropy, etc).

The scope of the four WGs (shown in blue in Figure 2) was discussed. SCB members were requested to suggest priority topics for discussion at the WG meetings as well as additional WG candidate members. Furthermore, in order to learn why some cross-project collaborations work well but others don't, SCB members were asked to share their experience and lessons learnt from either past or current collaborations. The SCB agreed that *quid pro quo* is not always immediate or direct, as sometimes the return comes much later in time. However, sharing data

across projects should be almost an obligation when data has been obtained with public funding. In any case, the SCB upholds that IMI projects are usually very rigid and, generally, there is an over-regulation of collaborations, especially in the newer projects. Setting up collaborations entails paperwork, bureaucracy and legal advice, and that is complex path that can be difficult to navigate for some. At present there isn't a specific "IMI collaboration framework" to follow, therefore, it would be good to set out some simple rules for collaboration between organizations and/or projects.

Lastly, four ideas of potential joint interest for the portfolio were proposed to the SCB members for discussion:

1. Virtual incubator for sustainability
2. High level neurodegeneration summit
3. Harmonisation of ND datasets across Europe
4. Integration of registers and prospective data collection across Europe

Four topic champions (M. Hofmann-Apitius, C. Ritchie, P.J. Visser and C. Díaz) were designated to take on the task of further developing these topics into a two-pager.

3ʳᵈ SCB meeting (January 2020)

The 3rd face-to-face meeting of the SCB was attended in person by six members and another five joined remotely via teleconference for some of the sessions. The meeting agenda can be found in the Annexes. In this meeting, the main achievements of NEURONET were highlighted: A total of 16 projects are represented at the SCB, and the 4 WGs are established. Moreover, updates on the development of the Knowledge Base and Forum were presented, and SCB members were invited to provide their feedback on the proposed structure.

The first version of the asset map, which offers a visual overview of the most relevant project-developed outputs, was also shown, obtaining positive feedback from the SCB. Members of the SGG present at the meeting said the asset map could easily reflect the current gaps within the IM ND Portfolio, and help IMI in directing investment to those areas. However, more granularity on parameters such as data quality, availability of data etc. would be appreciated.

The communication activities carried out by NEURONET were also very well received by the SCB. In particular, the 2019 Twitter campaign was very successful and NEURONET tweets obtained a high number of *impressions*, greatly increasing the visibility of the respective projects.

In relation to the ongoing collaborations mapping analysis being conducted by NEURONET, preliminary findings were discussed, highlighting the over-regulation and rigid IMI structure, which, according to the SCB, does not encourage projects to collaborate. Collaboration between projects are included 'by design' (they are frequently mentioned in the call texts) but these 'forced marriages' may not always work, as no support is provided for the materialization of the actual collaboration (e.g. legal, financial). In that sense, the SCB thinks it would be advantageous to have a discretionary budget for collaborations, or, alternatively, NEURONET could act as an "honest broker" distributing financial resources to projects to enable collaborations – unfortunately, there is no budget for this in NEURONET. The SCB members exposed that personal relationships are another key component of collaborations between projects, because previous mutual knowledge and trust play an often overlooked yet very important role.

Regarding the four ideas for potential new call topics discussed at the previous meeting (see above), and which had been developed into 2-pagers by the respective topic champions,

members of the SGG informed it was already too late and there was not enough time to submit them for consideration as potential new topics in the upcoming IMI call 21. However, SCB members argued that the four topics discussed all represent areas of interest for the neurodegeneration research community and should therefore be pushed forward, exploring potential ways to develop and fund the ideas regardless of IMI timelines/funding. Furthermore, NEURONET presented an idea for a "Neurodegeneration European information portal" (so-called NEUPORTAL), which could be an ambitious platform that tries to integrate IMI ND data across cohorts, samples and datasets. The SCB regarded the proposal as very ambitious and extremely complicated to implement, and therefore recommended starting small by focusing on the biorepository component of the platform and, if successful, trying to escalate in the future.

Finally, in relation to Horizon Europe and the 'new IMI' programme, SCB members made the remark that the groups/companies involved in the new scheme do not seem to be aligned with the priorities set out by the programme itself – namely, integrated care solutions, citizen engagement, social care etc. For example, it was surprising not to find any insurance companies (payers) on the list. The SCB suggested NEURONET could provide recommendations to IMI about the structure of the new funding scheme.

3. The Working Groups

NEURONET has successfully established the four thematic Working Groups (WGs) as per the DoA description. These groups are cross-project spaces for experts to discuss on common issues, priorities and opportunities for synergy and collaboration, providing NEURONET with expert advice on the four identified areas of interest:

WG1. Data sharing and re-use
WG2. HTA/regulatory interaction
WG3. Ethics and patient privacy
WG4. Sustainability

Details about the process for defining the areas of interest covered by the WGs were given in the first WP2 deliverable, D2.1 Report on establishment and procedures of SCB and foundational WGs.

The expected WG results are, among others:

• More consistent and informed decision-making.
• Improved awareness and re-use of project results and outputs.
• Enhanced networking across projects and more exposure of expert knowledge.
• Creation and homogeneous application of standards.

Ultimately, the aim of NEURONET is to leverage and compile the knowledge that is presently scattered across the different projects in these key areas.

3.1 WG1. Data sharing and re-use

The WG Data sharing and re-use will focus on developing specific guidance to aid projects on data sharing policies and tools, incentives, value propositions, infrastructural solutions, etc. With

the support of the Data sharing and re-use working group, Task 3.2 will develop guidelines aimed at facilitating the sharing of and access to data, biological tools and other materials amongst IMI projects, as well as with other interested researchers at a European and global level.

Membership

The WG Data sharing and re-use, led by partner Janssen, consists of subject matter experts in data sharing and NEURONET members. The current membership is:

Name	Organization	IMI project
Rodrigo Barnes	Aridhia	EPAD
Niamh Connolly	Royal College of Surgeons in Ireland	PD-MITOQUANT
Martin Hofmann-Apitius	Fraunhofer	AETIONOMY
Nigel Hughes	Janssen	EMIF-AD
Sidonie Lavergne	Biofortis Mérieux NutriSciences	n/a
Nikolay Manyakov	Janssen	RADAR-CNS/ RADAR-AD
Andrew Owens	King's College London	RADAR-AD
Andrew Peter McCarthy	Eli Lilly	n/a
Philippe Rocca-Serra	University of Oxford	IMPRiND
Agustín Ruiz	Fundació ACE	ADAPTED
Pieter Jelle Visser	VUmc & Maastricht University	EMIF-AD
Serge Van der Geyten	Janssen	EPAD
Judi Syson	University of Edinburgh	EPAD
Angela Bradshaw	Alzheimer Europe	NEURONET
Carlos Díaz	SYNAPSE	NEURONET
Emma Dodd	Roche	NEURONET
Jean Georges	Alzheimer Europe	NEURONET
Jill Gallagher	Parkinson's UK	NEURONET
Manuela Rinaldi	Janssen	NEURONET
Lennert Steukers	Janssen	NEURONET

Meetings

The first teleconference meeting of the WG was scheduled on 29 November 2019.

The meeting provided an introduction to the NEURONET project and an opportunity to discuss the scope setting of the WG:

1.   Data Sharing
    a. Legal/Financial

      b.   Organizational (e.g. honest broker model)
      c.   Technical (e.g. Databases, Infrastructure)
      d.   Political (e.g. FAIR principle)
      e.   Psychological/Social (e.g. Trust)
      f.   Ethical
      g.   Metadata

2. Data Standardization/Harmonization (e.g. common data model)
3. Discuss specific usage scenario's
4. Sample Sharing

The scope setting will be further discussed and worked out during the F2F meeting of the WG, which will take place on 26 February in Diegem, Belgium.

It is anticipated that at least regular quarterly meetings will be held for this working group, preferably via teleconference. Members of the WGs will be expected to prepare for and actively participate in these meetings, engaging in discussions, bringing relevant topics to the table and providing their expert opinion as needed. Whenever possible, face-to-face meetings will be organized next to major events and conferences in Europe.

Finally, the WG will provide input on two related WP3 deliverables:

D3.2 First version on guidance tools on data/sample sharing (postponed until M15).

D3.7 Final version on guidance tools on data/sample sharing and use (due M30).

3.2   WG2. HTA/Regulatory interaction

A HTA and Regulatory interaction WG has been established to generate insights into the regulatory and HTA challenges and opportunities that are unique to neurodegenerative diseases. Specifically, the WG will:

- Contribute, as applicable, to the development of tools to support effective engagement with regulators, HTA agencies and payers in the EU.

- Identify projects' needs and knowledge gaps in relation to specific procedures and processes for engagement with HTA and regulatory bodies where external expertise may be sought.

- Provide a forum for projects to share lessons learned from previous HTA and regulatory engagement

- Support the projects in the development of their regulatory, HTA and payer strategy, as applicable.

Membership
The HTA and Regulatory interaction WG, led by partner NICE, brings together a selection of representatives of the individual IMI neurodegenerative projects with members of the NEURONET consortium. External experts may also be invited to attend meetings as and when required.

The WG members are listed in the table below. There is flexibility in the membership with the opportunity for new project members to join the WG or to attend specific meetings depending on the needs of their project.

Name	Organization	IMI project
Andre Broekmans	Lygature	RADAR-CNS
Suzanne Foy	Janssen	EPAD
Robin Thompson	Biogen	ROADMAP
Diana O'Rourke	NICE	NEURONET
Jacoline Bouvy	NICE	NEURONET
Emma Dodd	ROCHE	NEURONET
Nina Coll	SYNAPSE	NEURONET
Angela Bradshaw	Alzheimer Europe	NEURONET
Jean Georges	Alzheimer Europe	NEURONET
Jill Gallagher	Parkinson's UK	NEURONET

Meetings

The first meeting of the WG was held as a teleconference on 14 January 2020. The meeting provided an introduction to the NEURONET project and an opportunity to discuss members' experiences of HTA and regulatory interactions, including any challenges they had experienced.

The key points discussed at the meeting were:

- The potential need for guidance on how to effectively engage with HTA and regulatory bodies on the design of clinical studies.
- The value of regulatory interactions (specifically, scientific advice) in IMI projects although there is need for allocated funding and resource to support this.
- The WG could undertake a mapping exercise of projects' experiences of engaging with HTA and regulatory bodies. In addition, the WG could identify relevant reports, such as Qualification of Novel Methodology outputs relating to neurodegenerative disease. Sharing this learning and information could help to reduce duplication across projects. The knowledge base could provide the platform for easy access to relevant information for projects.
- Specific WG meetings could be dedicated to key topics, for example, questions relating to HTA/EMA parallel scientific advice. External expertise could be brought in for these sessions and projects not currently represented on the WG could be invited to attend.

The WG will continue to meet every 2-3 months depending on the needs of the projects. Meetings will take place via teleconference to minimise the resource requirements for projects, but face-to-face meetings will also be an option.

Decision Tool for HTA and Regulatory engagement

A key output of Task 3.3 is a 'Decision Tool for HTA and Regulatory engagement' which was submitted to IMI as deliverable D3.3. The aim of the Decision Tool is to identify the key opportunities to engage with EU regulatory and HTA agencies at key timepoints during the development of an 'asset' (e.g. drug, device, new methodology or analysis). The tool shows the relevant informal and formal processes and procedures for engagement with these agencies that are available based on the stage of research and 'asset' being developed. The Decision Tool will be made available to the IMI ND projects through the IMI ND Knowledge Base. By utilising the Knowledge Base, it will make the Decision Tool an interactive, web-based visualisation of all procedures as they might be relevant at different points along the medicine development, approval and reimbursement pathway.

The first version of the Decision Tool will be shared at the second meeting of the WG for discussion and feedback. The WG interactions are expected to provide further insight into the specific needs of individual projects. It is expected that as these interactions progress, the tool will be updated to be more tailored to the projects' needs for regulatory, HTA and payer interactions. An updated version will be submitted in month 30 as deliverable D3.8 Final version of regulatory/HTA/payer interaction guidance.

3.3   WG3. Patient privacy and ethics

Compliance with the ethical and data protection requirements that underly patient privacy is seen as pivotal to achieve real excellence in health research. However, patient privacy concerns have also been perceived as a barrier to primary health research and, in particular, research that involves secondary use of patient data. An initial survey performed by NEURONET identified "guidance/best practice on data privacy and related regulations" and "guidance/best practice on ethics approvals and Informed Consent Forms" as priority areas in which IMI ND projects would like more support. The WG on Patient Privacy and Ethics was formed in 2019 to meet this need.

The primary aim of this WG is to compile and share learnings on patient privacy, to ensure best practice, reduce duplication of effort and create resources that will be of value to existing and future IMI ND projects. Goals for 2019-2021 include the following:

- Mapping and understanding the ethical and legal frameworks of IMI ND projects supported by NEURONET, focusing on:
  - Patient & data privacy
    - Data governance systems
    - Data protection: challenges and best practice
  - Informed consent
    - Patient information sheets and informed consent forms
    - Clauses for data sharing and reuse
    - Ethics: challenges and best practice

In addition, the WG on Patient Privacy and Ethics will act as a forum for discussion of key ethical and legal topics currently being addressed in the individual IMI ND projects. Where necessary, the WG can also provide support to IMI ND projects on new ethical and legal challenges that may arise. Finally, the WG will provide input on two related WP3 deliverables:

D3.4 First version of guidance on standards and practices for protecting data privacy (submitted)
D3.9 Final version of guidance on standards and practices for protecting data privacy (due M30)

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
Edo Richard	Radboud UMC	AMYPAD/EPAD
Rebecca Pinto	King's College London	PD-MIND
Richard Milne	University of Cambridge	EPAD
Federica Lucivero	University of Oxford	RADAR-AD
Nikolaus Forgo	University of Vienna	AETIONOMY
Mercè Boada	Fundació ACE	MOPEAD
Pilar Cañabate	Fundació ACE	MOPEAD
Nathan Lea	UCL	EMIF
Dianne Gove	Alzheimer Europe	NEURONET
Angela Bradshaw	Alzheimer Europe	NEURONET
Jean Georges	Alzheimer Europe	NEURONET
Jill Gallagher	Parkinson's UK	NEURONET

Meetings

The WG held its first meeting on 8 January 2020. During this meeting, NEURONET was introduced to the Working Group members, and the scope, approach and next steps for the Working Group were discussed. Going forwards, quarterly teleconferences will be held. This will be complemented by a yearly face-to-face meeting, the first of which will be held in July 2020.

3.4   WG4. Sustainability

Sustainability WG will look 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 will provide their expert feedback and perform a critical analysis of the models identified.

Membership

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

Name	Organization	IMI project
Thomas Steckler	Janssen	EQIPD
Rebecca Pinto	King's College London	PD-MIND
Kirsty Draper	University of Edinburgh	EPAD
Philippe Rocolle	Sanofi	IM2PACT
Philippe Rocca-Serra	University of Oxford	IMPRIND
Stephane Pollentier	Boehringer Ingelheim	EPAD
Frank Tennigkeit	UCB	EPAD
Jean Georges	Alzheimer Europe	NEURONET
Natalie Piton	Sanofi	NEURONET
Paul Peeters	Janssen	NEURONET
Saira Ramasastry	SYNAPSE	NEURONET
Carlos Díaz	SYNAPSE	NEURONET

Meetings

The first meeting of the WG took place on 12 March 2020. The WG goals and priorities were discussed, and members shared ideas for topics of interest to be discussed at subsequent meetings. In the next WG meeting, expected to be scheduled for mid-April 2020, WG members will briefly present the sustainability work done in their respective projects. The outcome of WG discussions will inform two related WP3 deliverables providing practical advice and tools for decision making:

D3.5 First version of guidance on sustainability (postponed until M15).

D3.10 Final version of guidance on sustainability (due M30).

4. Task forces

As mentioned in previous sections, NEURONET aims to become a platform for cross-project collaboration and exploitation of potential synergies. To carry out this work, NEURONET will rely on the SCB at the strategic level and the WGs at the technical level but, ultimately, the implementation of such synergies will usually involve the creation of Task Forces (TFs).

Task Forces are small multidisciplinary cross-project teams set up upon recommendation of the SCB. TFs are expected to intensively and effectively work together for a limited period of time towards achieving a specific output or objective, therefore, TFs objectives, timelines, resources and expected results must always be clearly defined from the outset.

To date, no TFs have been set up but as soon as NEURONET identifies new opportunities for synergy and collaboration between projects it will certainly promote the creation of TFs to turn those into reality.

5. Conclusion

Two of the key organisational structures described in NEURONET'S operational framework (Scientific Coordination Board, Working Groups) have been successfully set up, complementing the project's own governance structure built around 5 Work Packages and an Executive Committee.

A total of 18 IMI neurodegeneration projects have been approached by NEURONET so far, and 16 of them have a designated representative at the SCB. NEURONET has generally been very welcomed by IMI ND projects, and the interest and engagement of the project leaders has allowed the CSA to successfully bring them together around a table on three occasions in the past eight months. On all three, SCB members actively discussed in a dynamic way and appreciated the opportunity for exchange of views with peers, which is a unique benefit of NEURONET.

The next face-to-face SCB meeting is planned for July 2020 in Amsterdam, next to AAIC, although this is subject to the evolution of the COVID19 pandemic and associated travel restrictions in the next few months. Output from future SCB and WG meetings and discussions will be compiled and submitted to IMI as project deliverables:

D2.3 Report #2 on activity of SCB, WGs and TFs (due in M24).

D2.4 Report #3 on activity of SCB, WGs and TFs (due in M36).

6. Annexes

6.1   1st SCB meeting agenda

Scientific Coordination Board (SCB) Meeting

Meliá Barajas Hotel - Madrid

Tuesday, 2nd July 2019

No	Topic	Speakers/ Topic leads	Time - CET
	Welcome Coffee - Time for gathering		*11:30*
1	**NEURONET concept and vision – including Q&A from SCB members**	**NEURONET Project Leads (Carlos/Darrel)**	12:00
2	**IMI ND Portfolio - presentations (10' per project)** • **Project overview** • **Key outputs, assets and results** • **Gaps, difficulties and needs** • **Q&A**	**SCB members**	12:30
	Lunch 30'		*14:00*
3	**Open discussion:** • **Synergies & collaboration** • **KPIs for impact analysis – current exercise being made by NEURONET** • **Working Groups – potential members from projects** • **Knowledge Base – gathering feedback from SCB on the first prototype**	All	14:30
4	**Portfolio gaps & new ideas for future projects**	**SCB members**	16:30
5	**Wrap up & next steps**	**NEURONET Project Leads (Carlos/Darrel)**	17:20
	End of the meeting		*17:30*

6.2   2nd SCB meeting agenda

NEURONET 2nd Scientific Coordination Board meeting

World Forum, Meeting Room Europe 1 (ground floor)
Churchillplein 10, 2517 JW The Hague, Netherlands

23rd October 2019

No	Topic	Speakers/ Topic leads	Time - CET
	Light lunch		*12:00*
1	NEURONET update and feedback from SCB members - Brief presentation of new projects included in NEURONET - Project governance framework - Knowledge Base/forum - Working groups: • WG1. Data sharing and re-use • WG2. HTA/regulatory interaction • WG3. Patient privacy and ethics • WG4. Sustainability	NEURONET Project Leads	12:45
2	Collaborations between IMI projects: • Past collaborations: Difficulties & lessons learnt • Opportunities for new collaborations & tangible NEURONET results	SCB members	13:45
	Coffee break		*15:00*
3	Brainstorming about new IMI call topics: • Current gaps in the IMI portfolio • Potential new call topics	SCB members	15:30
4	Wrap up: overall conclusions and next steps	NEURONET Project Leads	17:50
	End of the meeting		*18:00*

6.3 3ʳᵈ SCB meeting agenda

NEURONET 3ʳᵈ Scientific Coordination Board meeting

Hotel Meliá Barajas
Madrid, Spain

No	Topic	Speakers	Time - CET
	Coffee		*10:30-11:00*
1	**Brief introduction for new SCB members** **NEURONET: What has been achieved in year 1?** 1. Governance bodies: SCB, WGs 2. Knowledge Base & Forum 3. Asset Map 4. Communication activities	NEURONET Project Leads	11:00- 11:45
2	**IMI ND portfolio: discussion** • Lessons learnt from projects collaborations • Opportunities for new collaborations & tangible NEURONET results • Improving and leveraging the Asset Map	All	11:45- 13:15
	Lunch break		*13:15- 14:00*
3	**Gaps and opportunities within NEURONET** • New topics (two-pagers) • Needs on portfolio level • Horizon Europe and the 'new IMI' • Other initiatives and possibilities for future research	Hugh Marston, Lennert Steukers, Laurent Pradier, Carlos Díaz	14:00- 16:00
	Coffee		*16:00- 16:15*
4	**Immediate plans & concrete actions for NEURONET**	All	16:15- 16:45
5	**Wrap up: overall conclusions and next steps**	NEURONET Project Leads	16:45- 17:00
	End of the meeting		*17:00*