

#### **IMI2 821513 – NEURONET**

Efficiently Networking European Neurodegeneration Research

### WP1 – Projects and Impact Analysis

# D1.5 Integrated Programme Analysis v2

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#### **Document History**

Version	Date	Description
V0.1	23/12/2021	Outline
V1.0	24/01/2022	First draft
V1.1	10/02/2022	Feedback from partners
V1.2	11/02/2022	Final version











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### 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**

NEURONET is a Coordination and Support Action (CSA) aiming to support and better integrate projects in the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio. WP1 *Projects & Impact Analysis* is a descriptive and methodological work package (WP) that collects information (e.g., scope, deliverables, funding etc.) about IMI ND projects to enable an integrated view of the IMI ND project portfolio in terms of relative specialisation, timelines, expertise, and outputs. As part of WP1 activities, NEURONET conducted an analysis of IMI ND projects at the programme level in order to obtain the first integrated view of the portfolio (Deliverable 1.2). This deliverable reports an update to the first approach, representing five new projects that have been added to the IMI ND portfolio. This deliverable also provides a refined understanding of the portfolio's project outputs and potential synergies.











### 1 Introduction

NEURONET is a Coordination and Support Action (CSA) aiming to support and better integrate projects in the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio.

WP1 Projects & Impact Analysis is a descriptive and methodological work package (WP) that collects information (e.g., scope, objectives, deliverables, partners, funding, results, obstacles, etc.) about projects in the IMI ND portfolio, analysing their workplans and outputs, and establishing measures for impact appraisal.

In this report, we describe the analysis conducted at the programme level by WP1 in order to update the previous integrated view of the IMI ND portfolio, submitted as D1.2 in 2020. The content in this deliverable reflects the addition of five projects to the portfolio, therefore considering data for 20 projects in total. Due to the significant volume of information gathered, NEURONET decided to report the same metrics for these new projects as those reported in the last deliverable (e.g., funding, countries, and participants), but to also dedicate particular focus to the number of assets developed across the whole portfolio and the development of potential synergies. The list of all projects in the portfolio, and therefore reported on here, is provided in Annex I.

### 2 Methods

### 2.1 Project information gathering

The information collected from projects (as described in D1.1) was designed to provide NEURONET with a solid understanding of the IMI ND projects, including their scope and relative specialisation, funding, expertise, outputs, assets, and achievements, as well as any potential unmet needs or difficulties they may have encountered in key project areas (e.g., ethics, data sharing, etc).

As in Deliverable 1.2., the strategy used to search and obtain such information relied heavily on NEURONET partners' links to the IMI ND projects (see Annex 1) while also being aware of upcoming projects within the IMI framework. It is of note that, due to the experience of maintaining the IMI ND portfolio, the link and communication between NEURONET and new project leads was greatly facilitated. A subgroup of NEURONET partners formed a "data collection team" that collected the necessary data to allow for an integrated analysis of the portfolio, including the identification of potential synergies, dependencies or best practices that could be shared between projects.

As depicted in Figure 1, there were two phases in the data collection process necessary for this update:

- Phase 1: NEURONET consulted public sources of information, such as the IMI website, the CORDIS portal
  (i.e., the primary source of results from the projects funded by the EU's framework programmes for
  research and innovation) and the project websites.
- **Phase 2:** NEURONET extracted information from the projects' Descriptions of Action (DoA), project newsletters, deliverables, and other project reports. Using this information and the data collected in Phase 1, a dossier for each project was created (see Annex II for the dossier template).

These phases were completed for all the new projects that were identified as constituting the IMI ND portfolio.











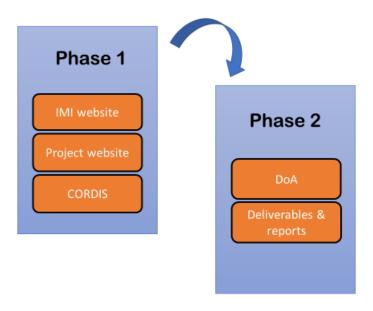


Figure 1. Data collection approach for D1.5.

### 2.2 Integrated programme analysis

After completing the process described in Section 2.1, NEURONET held a substantial volume of information about the IMI ND portfolio. To synthesise and analyse these data, and upon the recommendation of its Scientific Coordination Board (SCB), NEURONET reports, in this deliverable:

- 1. IMI ND portfolio metrics, as per D1.2 (Section 3.1).
- 2. The identification of key results and outputs developed by the IMI ND portfolio projects (Section 3.2).
- 3. The status of synergies, new ideas, and collaborations across the portfolio (Section 3.3).

In the case of key results and outputs, NEURONET focused on what are referred to as project assets. The potentially ambiguous differentiation between project outputs, results and assets has necessitated a definition for the latter. For the present programme analysis, and for future categorisation and illustration, NEURONET has defined an asset as any project output that satisfies all of these five characteristics.

- **Existence.** An asset must exist. It cannot be a planned or future outcome, or something that no longer exists (e.g., a cohort that existed but is not actively being followed up after project completion)
- **Specificity**. Assets need to be concrete, not a category of results or an abstract description. E.g., "Body of publications" would not be considered an asset.
- Tangibility. Data sets, tools, guidelines, a white paper, software, etc. can be considered assets if they
  can be accessed, incorporated, consulted, or leveraged in some way. "Expertise in XYZ" in general is
  not tangible, therefore not considered an asset. Also, if a research outcome is not accessible at all, it
  may not be considered an asset either, as it would not meet the usefulness criteria described below.
  - There is a grey area where NEURONET could be flexible. For instance, a "site network" would meet the tangibility criteria if they use common practices, team dynamics, common protocols, etc.
- Re-usability. Assets should be amenable for re-use by others. If something is so ad hoc that it can only
  be useful for the originating project, it may not be considered an asset.











• **Provenance**. Assets need to be defined by basic parameters such as description, ownership, authorship, location (link for example), access/use conditions, etc. in sufficient detail. If this information is unknown, the asset may not be incorporated into the asset map, as assessment of some of the other criteria would not be possible.

IMI ND portfolio assets were and continue to be identified as part of an ongoing data collection activity, with internal review cross-referencing asset descriptions against the above definition.

The current status of project assets, and how they are represented in the Asset Map, are both reported in Section 3.2.

### 3 Results

In this section we will provide summary statistics and metrics about the IMI ND portfolio according to the data gathered by NEURONET.

Five new studies are included in this update in addition to the previous projects: EPND, IDEA-FAST, Mobilise-D, PD-MIND and PRISM2. This brings the total number of represented IMI ND projects to 20.

Looking at total funding invested in the IMI ND portfolio (Figure 2), we see that 48% of funds (€ 196,430,703) come from IMI JU, 47% from EFPIA in kind contribution (€ 192,806,922) and 5% (€ 23,148,539) from other sources (e.g., in cash contributions from EFPIA or other associated partners, etc.). In total, € 412,3 million are Mobilised thanks to IMI for neurodegeneration research, with a mean funding of € 20,619,304 (median € 16,803,006) per project.

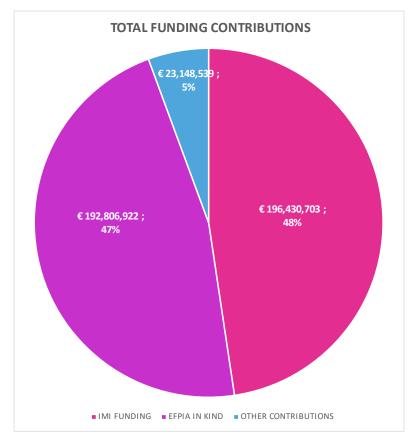


Figure 2. Overall funding contributions for the IMI ND portfolio.











We were interested in obtaining estimates for the size of the workforce involved in IMI ND projects. To do this, we decided to use the total number of contacts included in the overall consortium mail distribution list (including researchers, project managers, admin staff, legal staff etc.) as a proxy. We obtained the total number of contacts included for 19 of the projects, which was 2,912, representing a mean number of 153 contacts per study.

If we look at the duration of IMI ND projects (Figure 3), it can range from 24 months in the case of ROADMAP to 72 months in the case of RADAR-CNS. The average project duration is 51.25 months.



Figure 3. IMI ND project durations in months.

Regarding the disease areas targeted (Figure 4), there are 12 projects investigating Alzheimer's disease (ADAPTED, AETIONOMY, AMYPAD, EMIF, EPAD, IMPRIND, MOPEAD, PHAGO, PRISM, PRISM2, RADAR-AD, ROADMAP), 6 projects investigating Parkinson's disease (IMPRIND, PD-MITOQUANT, AETIONOMY, PD-MIND, IDEA-FAST, Mobilise-D), 2 investigating Multiple Sclerosis (RADAR-CNS, Mobilise-D) and 1 investigating Huntington's disease (IDEA-FAST). In addition, there are 5 projects that are not focused on particular neurodegenerative diseases or have more general objectives (AETIONOMY, EPND, EQIPD, IM2PACT, IMPRIND). In comparison to the previous deliverable, the addition of these five projects has resulted in a more diverse portfolio. Specifically, the majority of studies in the portfolio as reported in the previous deliverable constituted a focus on Alzheimer's disease (58% of targeted diseases); the current portfolio shows a reduction of that proportion (46% of targeted diseases). This coincides with a proportional increase in projects targeting









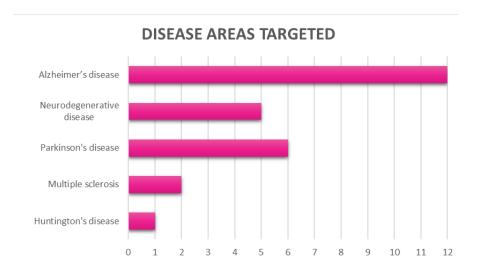


Figure 4. Disease types addressed by IMI ND projects. Note that some projects focus on more than one condition.

When looking at the different types of institutions involved in IMI ND projects (Figure 5), there are 158 academic institutions, 54 SMEs, 40 EFPIA partners, 7 patients or carers organizations, 1 HTA body, 1 regulatory agency and 9 organizations that fall under other types (including non-SMEs, non-EFPIA organisations, CROs, public bodies, etc.), for a total of 270 different institutions actively participating in the IMI ND portfolio.

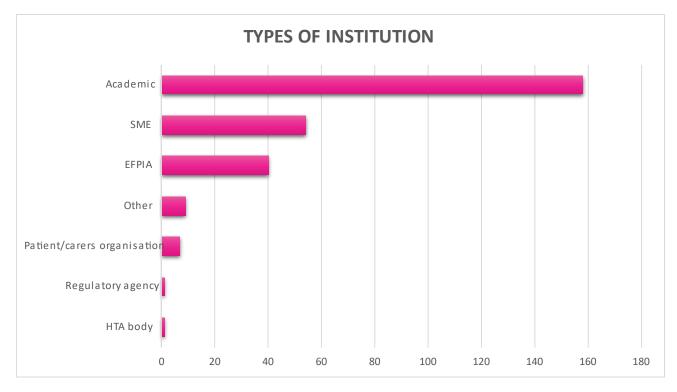


Figure 5. Number of participants in IMI ND projects, as represented by their institutions.









In relation to the countries of the institutions participating in IMI ND projects, 52 are based in the United Kingdom, 46 from Germany, 25 from the Netherlands, 24 from France, 21 from Spain, 17 from Italy, 12 from Belgium and 12 from Switzerland; followed by smaller numbers of partners coming from other European and non-European countries (Figures 6 and 7).

#### MAP OF REPRESENTATIVE COUNTRIES OF INSTITUTIONS

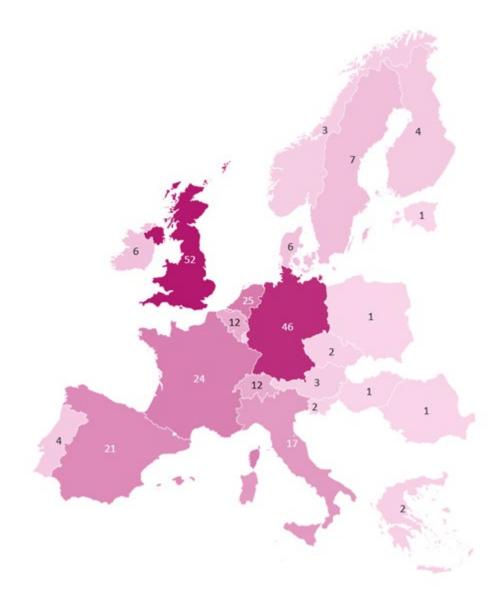


Figure 6. Number of IMI ND project participants as represented by their location in Europe.









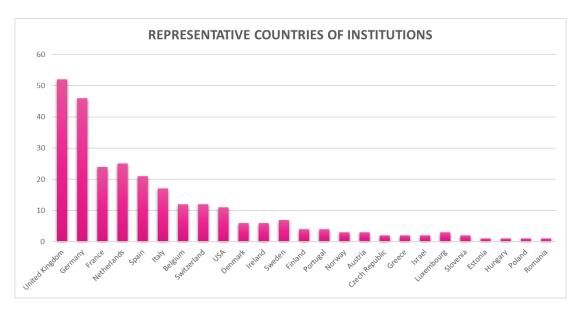


Figure 7. Number of IMI ND project participants as represented by their global location.

Finally, we looked at the countries of the institutions leading the projects, considering both the academic leader (i.e., the project coordinator) and the EFPIA leader (i.e., the project leader). As shown in Figure 8, there are 15 from the United Kingdom, 8 from Belgium, 5 from Germany, 4 from the Netherlands, 2 from Spain, and Switzerland, and 1 from Sweden, Denmark, France, Ireland, Israel, and the United States of America.









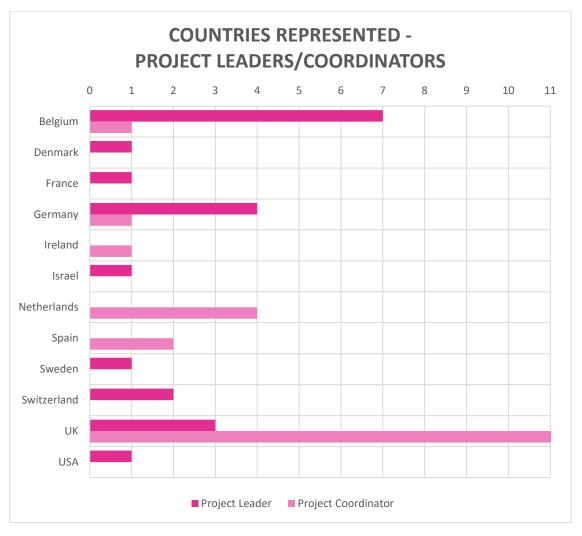


Figure 8: Number of IMI ND project leaders and coordinators as represented by their global location.

### 3.2 Asset Map

As described in Section 2.2, NEURONET has collected and reviewed the assets produced by IMI ND projects.

After the review process described above, NEURONET has represented the current state of IMI ND project assets with its Asset Map (Figure 9). Here, icons of project logos are distributed across the map, reflecting their nature (datasets, disease models, cohorts, etc.) and position along the drug development pipeline (non-clinical, clinical, etc.).

The Asset Map is a critical aspect of the integrated portfolio analysis, and for this reason was published as part of the NEURONET Knowledge Base (KB) as of February 2021 (<a href="https://kb.imi-neuronet.org/">https://kb.imi-neuronet.org/</a>). The KB is also dedicated to the representation of the integrated IMI ND portfolio, reporting on the aggregated project metrics from Section 3.1, such as funding, number of partners, organisations, countries, and publications.

At the time of writing this deliverable, there are currently 100 project assets represented on the Asset Map. Figure 9 represents the current map, where Annex III details the process of development between the first and current version of the Asset Map. Of note, two projects outside of the IMI ND portfolio (EBiSC2 and DPUK) have assets represented on this map on the recommendation of the SCB.









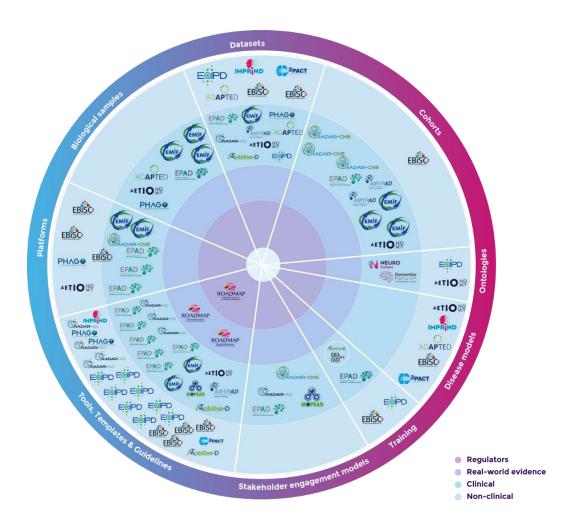


Figure 9. Asset Map as of January 2022

The current distribution of assets reveals important characteristics of the IMI ND portfolio's overall output.

- Since the inception of the Asset Map, there have been very few outputs relevant for regulatory
  purposes and real-world evidence studies. There is only representation from the ROADMAP project in
  this space, but, given that this was a two-year exploratory project, there was little scope for producing
  more assets. Admittedly, the state of progress in Alzheimer's trials and a cautious mood across
  industry may have hindered the creation of new projects with direct relevance in this area.
- There has similarly been a lack of outputs in terms of taxonomies/vocabularies, although most projects will, at some point, have had to engage with assets of this type. This may indicate that the field is assumed to be adequately covered in terms of taxonomies and therefore 'off-the-shelf' solutions are generally used. On the other hand, this clashes somewhat with known difficulties associated with the interoperability of data sets. It may be that the term "taxonomies" is more restrictive that "ontologies," as in the latter, there is more scope to include assets such as common data models. This change in term was advised by the SCB and constituted part of the recent Asset Map update.
- Areas relative to platforms, data sets, samples and cohorts seem to be covered by several projects.

The Asset Map is constantly undergoing review and updated *ad-hoc*. It is expected that a continuously updated map will allow to better illustrate the results and impact of the IMI ND portfolio, but also reveal clear gaps that could inspire new projects to address unmet areas of research. It may also help to devise flagship projects that









specialise in solving common challenges to allow repetition of efforts and overlapping objectives, leading to more efficient use of resources.

### 3.3 Update on identified synergies and new ideas

In the previous deliverable, we reported a list of potential synergies and new ideas that could leverage the ND portfolio's collective efforts and assets. These collaborations were drafted after identifying links and commonalities between projects and adopting a holistic view of the portfolio.

In this section, we report on how some of these synergies, collaborations and new ideas have been realised and developed.

#### 3.3.1 IDEA-FAST and Mobilise-D: Digital Health Catalyst

IDEA-FAST and Mobilise-D (in addition to RADAR-AD and RADAR-CNS) were identified in our previous deliverable as projects that focus on digital and mobile technologies. Given their shared experience and expertise, they were therefore well positioned to share assets, such as a common database, digital management platform, or protocols for data integration, analysis, storage and sharing. In the spirit of sharing expertise, IDEA-FAST and Mobilise-D have collaborated to produce the Digital Health Catalyst (<a href="https://digitalhealthcatalyst.org/">https://digitalhealthcatalyst.org/</a>), which is designed to offer early career researchers support and "exposure to a rich scientific environment, training, publishing assistance, networking, and more." Here, we see this collaboration as a representation of the shared and common expertise of two IMI projects being leveraged for the benefit of new researchers.

- 3.3.2 Integration of registers and prospective data collection across Europe
  This idea, as prepared in the previous deliverable by Pieter Jelle Visser (EMIF-AD Academic leader), was focused on achieving two objectives:
  - 1. Set-up a federated database in order to obtain information on prevalence and course of AD using data routinely collected in memory clinics across Europe.
  - 2. To facilitate access to data from research cohorts.

Broadly, these two objectives have been realised as two separate projects: NEURO Cohort and the IMI European Platform for Neurodegenerative Diseases (EPND), respectively. Although there is overlap and planned collaboration between NEURO Cohort and EPND, since they are both housed within the NEURONET framework, they approach each of these objectives with different perspectives and remit. Nonetheless, while it is of note that the former represents a collaborative network, and the latter an IMI-funded project, both are different types of solution that represent the potential efforts that can leveraged within the ND portfolio.

Details of the NEURO Cohort have been reported in other deliverables (e.g., Deliverable 2.3: Report #2 on activity of SCB, WGs and TFs) as it has been created as a NEURONET Task Force in January 2021.

In summary, and in relation to this particular synergy, NEURO Cohort has established a federated network across 40-research active sites in Europe, representing 13 countries and at least 25,000 individuals. NEURO Cohort proposes a minimum harmonised dataset of ten variables, including diagnosis, neuropsychological assessment, and biomarker information. These data are collected routinely at site, either through memory clinic procedures or research protocol activity. Furthermore, sites may indicate whether they record and store data of interest that is not first captured by this minimum dataset (e.g., tau PET images). This minimum dataset, in principle, can be used to represent the longitudinal characterisation of cohorts from these sites and respective countries, and as such provide insight into the prevalence and course of dementias. Similarly, by returning aggregated, anonymized site data via the Medical Informatics Platform, NEURO Cohort aims to make site-level data more accessible to other researchers.











Overall, these data are intended for use in feasibility analyses that can facilitate recruitment for sponsors and projects. In this way, NEURONET aims to position itself as an honest broker between the community of sites and investigators, leveraging the collective asset of the former to aid the work of the latter.

With a light governance structure and minimal baseline funding, NEURO Cohort represents a coalition of willing partners, identified initially within the EPAD LCS consortium, and then across the wider IMI ND study groups and beyond. Therefore, it confirms the potential for collaboration within the portfolio to seed new initiatives.

EPND is an IMI2-funded project that began in November 2021. Overall, this project focuses on biomarkers for neurodegenerative diseases, and, relatedly, the need to remove barriers that delay or prevent researchers' access to relevant biorepositories for identification and/or validation of biomarkers. EPND aims to do this by developing a secure platform as the EU node of the AD Workbench of the Alzheimer's Disease Data Initiative (ADDI), allowing researchers to share, access and analyse data and biosamples. Specifically, EPND will develop sample access and data discovery tools for a network of over 60 cohorts with Alzheimer's disease, Parkinson's disease, and related disorders.

Beyond establishing the network, the project aims to develop principles to enable access to clinical samples and data at a European scale and establish fair and transparent governance and processes.

In summary, EPND will therefore make data and biosamples more accessible to other researchers, and this in turn will accelerate neurodegenerative disease research.

#### 3.3.3 High level neurodegenerative disease summit

This concept, as prepared in the previous deliverable by Craig Ritchie (EPAD Academic lead), represented "a high-level forum for programme leads to ultimately develop a global research strategy for neurodegenerative disease research developed by the programme leads in isolation of the pressure from funders, commercial drivers and other stakeholders with vested interests in a specific approach."

At present, the summit remains an important future activity in NEURONET. The necessity was underlined as part of the work conducted to complete Deliverable 1.6: Map of relevant initiatives and gap analysis V2. Specifically, as part of a mapping and gap analysis workshop held online on 2<sup>nd</sup> November 2021, the IMI ND project leads in attendance agreed that a review of current ND initiatives would be most useful to the extent that it was critical, rather than a plain indication of initiatives' influence or impact. Overall, the attendees discussed the necessity for change in how research initiatives are structured and supported. Aspects of this discussion made the need for a forum such as a summit very clear. A shortlist of attendees has been created by NEURONET and the summit is expected to take place Q2 2022.

### 4 Conclusion and next steps

As with the previous deliverable, the picture revealed by the integrated analysis of the IMI ND portfolio is one of a complex landscape in IMI ND research. Given the amount of information and data associated with these projects, NEURONET has returned to the overall metrics associated with the portfolio, but also represented an overview of its projects' outputs through the Asset Map and Knowledge Base.

Overall, the metrics, representing an update, reflect shifts in the portfolio makeup; most noticeably the increased focus on conditions outside of Alzheimer's disease, including Parkinson's and Huntingdon's disease.

While it can be argued that the latter activity regarding outputs has identified gaps in our knowledge, it is clear that the overall view of the IMI ND portfolio, if not also the ND landscape in general, invites a critical and qualitative review of the combined research efforts, and how they have impacted the field. To that end, the integrated analysis presented here could stand as a point of reference that may inspire new directions or











approaches for investigation. Nonetheless, it is important to emphasise that the synergies and projects that were created to address previous gaps in our knowledge (e.g., NEURO Cohort and EPND) were produced as a consequence of strengthened and facilitated connections between project leads, teams, and partners. In this sense, the IMI ND community has shown its ability to collaborate at different levels and act as a collective driver for change and innovation.











### 5 Annexes

### 5.1 Annex I. IMI ND projects participating in NEURONET

The 20 IMI projects of the ND portfolio participating in NEURONET at the time of writing this deliverable are given below. Projects added in this particular update are given in **bold.** 

- 1) ADAPTED
- 2) AETIONOMY
- 3) AMYPAD
- 4) EMIF (focusing on EMIF-AD)
- 5) EPAD
- 6) EPND
- 7) EQIPD
- 8) IDEA-FAST
- 9) IM2PACT
- 10) IMPRIND
- 11) Mobilise-D
- 12) MOPEAD
- 13) PD-MIND
- 14) PD-MITOQUANT
- 15) PHAGO
- 16) PRISM
- 17) PRISM2
- 18) RADAR-AD
- 19) RADAR-CNS
- 20) ROADMAP











# 5.2 Annex II. Project dossier template

Project inf	ormation		
Project title:			
Project websi	te:		
Project Leade	r/Co-ordinator:		
Project summ	ary (IMI):		
Project dates:			
Project budge	t (EUR):		
IMI funding:			
EFPIA funding			
Other contribu	utions:		
Total budget:			
Project partne	ers:		
X academic pa partner	rtners, Y EFPIA partners, Z SMEs, X patient organiza	ation, Y regulatory ager	ncy, Z associated
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na	me	Type of Institution	Country
Institution na		Type of Institution	Country
Project object		Type of Institution	Country



etc







etc

WP2



#### A FULL LIST OF WP OBJECTIVES AND DELIVERABLES IS PROVIDED IN THE ANNEXES

### Project scope - Research and data collection

Does the project involve clinical studies?	Yes/No/Don't know (if yes, provide details)
Type of study	
Disease being studied	
Disease stage targeted	
Member states in which	
participants are being recruited	
Prospective data collection in	
<u>humans</u>	

#### Project outputs/results

Is the project developing/has the project developed any of the following outputs/results?

Yes/No

If yes, please provide a brief description.

	Yes	No	Description
Large datasets			
Biomarkers			
Methodologies / Techniques / Assays			
Classifications / Taxonomies			
Tools			
Infrastructures			
Other new disease knowledge			
White papers, Guidelines, templates			
etc.			
Diagnostic / prognostic tools			
Organisational models			
Clinical cohorts			
Other			

Is the project participating in the Horizon 2020 Open Research Data pilot\*?

Yes; No; Don't know

If yes, what data is being included, and what platforms/repositories are you using to host this data?

\*EPAD, RADAR-AD, IM2PACT and PD-Mitoquant are from Call 11 onwards, which means they automatically participate.











#### Project expertise

Has the project developed (or does it have plans to develop) expertise in any of the following areas?

Yes/No

If Yes, please provide a brief description, including whether any reports or guidelines on the topics have been produced (deliverables or other).

	Yes	No	Description
Data sharing and re-use			
Patient privacy, data protection and			
GDPR			
Interactions with regulatory bodies			
and HTAs			
Exploitation and sustainability of			
project results			
Communication and dissemination			
Patient engagement strategies			
Digital solutions and use of technology			

#### Collaboration

Has the project used the outputs/results generated by:

Another IMI project? Yes; No; Don't know. If yes, please provide details.

A non-IMI project/initiative? Yes; No; Don't know. If yes, please provide details.

Have any of the project outputs/results been shared for use by another (IMI or non-IMI) project?

Yes; No; Don't know

If yes, please provide details.

Beyond NEURONET, is the project involved in a collaboration or network with another IMI project (e.g. memorandum of understanding or collaboration agreement signed)?

Yes; No; Don't know

If yes, please provide details.











Have any <u>new</u> collaborations or networks been established between project partners as a result of their involvement in this project?

Yes; No; Don't know

If yes, please provide details.

#### Professional development

Has the project provided any professional development activities for researchers working on the project (e.g. training or mobility programmes)?

Yes; No; Don't know

If yes, please provide details.

#### Patient and public engagement

Are patient/healthcare professional/carer organisations involved in the project?

Yes; No; Don't know

If YES, are they involved as:

Project partners: (yes/no/don't know)

Advisory board members: (yes/no/don't know)

Working group members: (yes/no/don't know)

Please provide details on the scope of their involvement (e.g. responsible for ethics deliverables, advising on consent forms, involved in communication & dissemination etc).

Are there any specific patient or public outreach/engagement activities that have been carried out within the project?

Yes; No; Don't know

If yes, please provide details.

#### Needs and difficulties

Based on initial discussions with the projects, the following four topics were identified as being key areas of difficulty: Data sharing and accessibility; Working with regulators; Patient Confidentiality; and Sustainability. For these areas, please describe any issues your project has experienced and any











approaches you have taken to overcome these. Please indicate if they are unmet needs (i.e. issues have yet to be resolved).

The table is aimed to help guide your conversations with the projects (i.e. no need to have an entry for each of these areas).

	Issue, and (if relevant) approach used to resolve the issue
Data Sharing	
Interacting with data sources	
Data sharing agreements	
Data/metadata standards	
Harmonisation of data/metadata from different sources	
Data FAIRification	
Data sharing infrastructure or tools (e.g., catalogues, repositories)	
Biological sample sharing (blood, CSF etc.)	
Financial cost of data sharing	
Patient data, privacy, and ethics	
Informed consent	
Institutional Review Board or Ethics Committee approval	
Issues related to GDPR & data privacy	
Participant recruitment issues (high screening failure rate, etc.)	
Communication of research results to lay audiences	











Sustainability	
Funding models post-IMI period	
IP rights and exploitation	
Procedures for patents, licenses, and trademarks	
Regulatory/HTA interactions	
Scientific Advice Procedure	
Engagement with regulators and HTA agencies	
Other areas	
Recruitment and retention of skilled staff	
Career development support for ECRs employed	
Administrative/bureaucratic tasks (e.g., reporting, deliverable submission, etc.)	
Decision making and conflict resolution within the Consortium	
Legal issues	
Budget management	

The aim of NEURONET is to boost synergy and collaboration across the neurodegenerative disease portfolio of the IMI. Beyond the issues or unmet needs identified in the previous questions, how could NEURONET best support your project in achieving this goal?











## 5.3 Annex III: Asset Map development

The Asset Map was first created in January 2020. Since then, it has been revised and updated to reflect new assets and more efficient forms of categorisation.

Мар	Date	Notes and significant changes
DATED PHAGE  AND PHAGE	January 2020	Initial asset map, representing the categories:  Disease models Cohorts Taxonomy Other Knowledge Stakeholder Engagement Models Tools Platforms Biological samples Datasets



