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Efficiently Networking European Neurodegeneration Research

WP1– Projects & Impact Analysis

D1.8 White paper on project impact analysis

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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. **TAKEDA AG**: 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

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Abstract

Neuronet is a Coordination and Support Action (CSA) operating in the neurodegenerative disease space that aims to identify research gaps, communicate research findings and create links between Innovative Medicines Initiative (IMI) projects that form the IMI neurodegenerative disorders (ND) portfolio.

Work Package 1 (WP1) of Neuronet carried out an impact analysis to assess the scientific and socio-economic impact of the IMI ND portfolio across the European Union (EU). The impact analysis was conducted in two stages: an initial stage developed the scope of the project, impact indicators and defined measures, and a second stage further explored various measures of impact by surveying staff on the perceived impact of the IMI projects they are involved in. The 'First report on impact of IMI neurodegeneration portfolio' (deliverable 1.4[1]) was completed in February 2021 and the final report (deliverable 1.7) detailing the survey and data collection is expected to be completed by the end of the project. These two deliverables report the two stages of the impact analysis respectively.

This paper outlines the key learnings from undertaking the impact analysis exercise. They span all stages of the impact analysis ranging from ensuring collective decision making on key items at exercise outset, design of data collection tools and considerations for a working group composition that ensures a diversity of roles and perspectives. The insights and lessons learned from this impact analysis can guide those undertaking similar endeavours to plan for efficient processes and avoid potential pitfalls.

[1] https://www.imi-neuronet.org/wp-content/uploads/2020/11/D1.4-First-report-on-impact-of-IMI-neurodegeneration-portfolio.pdf

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How to use leverage these learnings in your own work

We have structured the learnings into a 2-page overview that can be used as a reference guide or a checklist for planning similar activities. Click on any step for more detail and it directs you to the relevant section in this paper. Use the navigation in the footer to get back to top or to the overview again.

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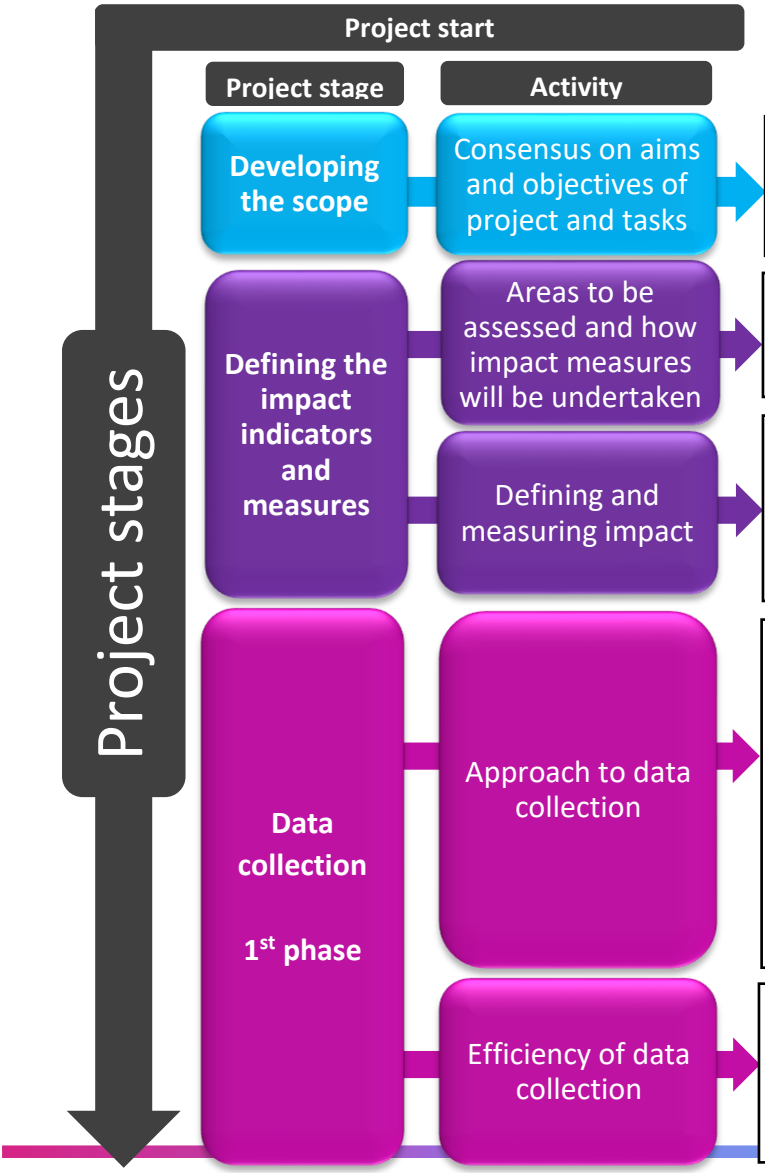
Overview of Key Learnings

This overview can be used as a reference guide or checklist to help plan impact assessments or activities with similar scope and aim. Each impact assessment stage and activity are explained in the following sections of this paper. Click on each project stage or activity button to jump to the relevant section for details and use the navigation in the footer to come back to this overview.



- With consortium partners, agree the project's overall aims and objectives, including those for the individual tasks, before trying to identify measures to assess impact.
- Align with consortium partners on the most feasible approach to carry out an impact assessment based on time and resource available.

- Outline the areas of impact that will be assessed and how these will be measured at the beginning of new projects
- Include milestones to assess change during a project to negate collecting information retrospectively. It can be forgotten or lost and people and resources change thus the process of evaluation can take significant time.

- Involve key stakeholders from the outset in determining the scope of the impact assessment and in defining the indicators and measures of impact.
- When identifying indicators for impact, ensure that the measurement of each indicator is feasible and relevant to what is being measured, and that data is accessible.
- Have regular touch points with key stakeholders and note any general changes eg staff, policy, processes etc.

- Have a dedicated team who is responsible for data collection and gathers all publicly available data to avoid duplication at the project level.
- Use a standardised data collection form to ensure that team members are clear about what data to collect and in what format.
- Design the data collection form to support data analysis (e.g., collating figures relating to funding etc.).
- Consider the burden of translating information between different MS programs eg from an excel form to word. This issue was encountered in Neuronet and was time consuming.
- Identify different sources of information and methods for collecting data, particularly if data is missing from primary sources.
- Perform interviews to engage more active participants such as Principal Investigators (conference setting worked well)

- Be clear from the outset on what you want to evaluate and what data is needed to measure that change. In this exercise data was collected but not used. This ensures data is not collected unnecessarily and that further data is not required later in the process. It also helps to hone questions in any interviews conducted.
- Showcase the output regularly to key stakeholders to valorise their contribution and show usefulness of the data collection.

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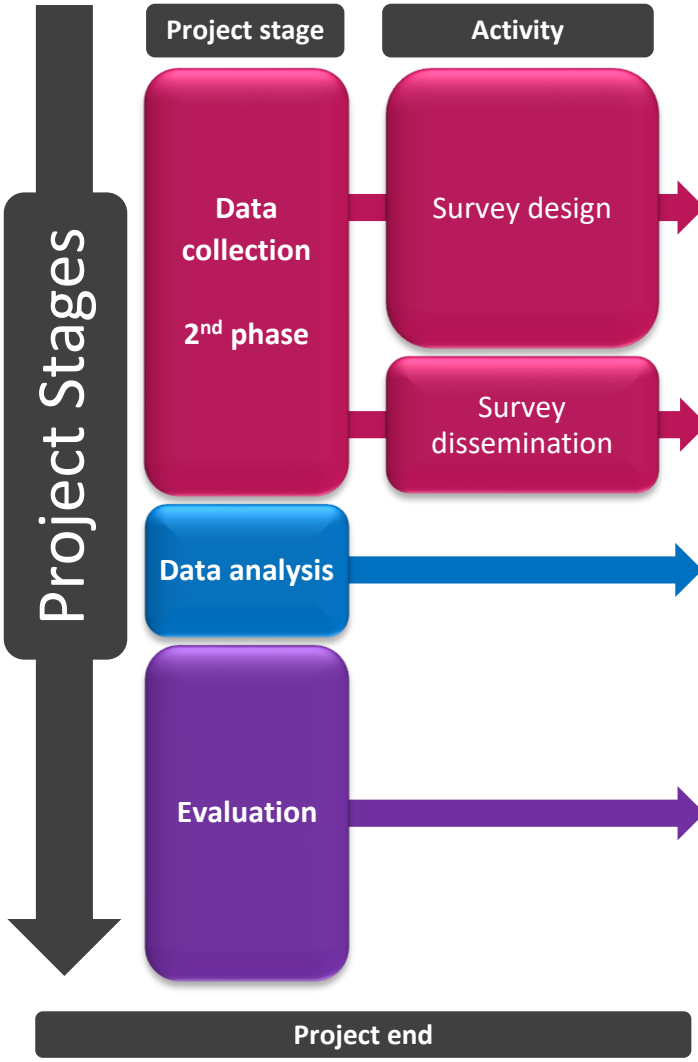

- Involve stakeholders with in-depth understanding of target groups to ensure the survey design is relevant and intuitive.
- Tailor surveys to the target audience.
- Pilot surveys prior to their roll-out to identify and resolve any issues with the data collection tool before distributing them.
- Include 'N/A' options where appropriate to limit free text answers requiring analysis time providing no additional insight.

- The timing of data collection activities is important and may impact the number of responses received.
- Include mechanisms to allow for the tracking of completion rates when disseminating surveys
- Follow-up with periodic reminders for completing surveys and direct interviews to foster contribution.

- Sufficiently resource for any thematic analysis of surveys.
- Have flexibility in surveys so that responders could opt-in to relevant questions based on their experience.
- Pilot data collection tools with people of differing roles to make data collection and analysis more efficient.

- Ensure that the methods/frameworks for evaluation are clear and transparent to all relevant partners and include them in early discussions and scoping decisions.
- Engage all partners in the evaluation. Discuss intermediary analysis with key stakeholders (Scientific Coordination Board for Neuronet) to confirm/refine main messages.
- Have a central decision log that is accessible to and is a reference point for all partners to avoid inefficiencies in project activities due to duplicative work.
- Have sufficient resources and capacity for undertaking the evaluation. Engage key members of the team with relevant skills and knowledge for particular tasks. Key members of the WP1 team with greater knowledge of the neurodegenerative disease field were involved with the qualitative analysis of publications against the key scientific priorities.

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1 Introduction

Neuronet is a Coordination and Support Action (CSA) aiming to support and better integrate projects in the Innovative Medicines Initiative (IMI)[2] Neurodegenerative Disorders (ND) portfolio. One of the objectives of Work Package 1 (WP1) of Neuronet is to assess the scientific and socio-economic impact of the IMI ND portfolio across the EU. An impact assessment is a means of measuring the effectiveness of activities and assessing the changes brought about by those activities. It is important to measure the impact of research, but particularly in disease areas where developing viable innovative technologies is challenging. It can provide valuable insight into factors that contribute to the difficulties faced in bringing new medicines to market. The IMI has a portfolio of different ND projects, and this impact assessment was conducted at this portfolio level allowing assessment of the overarching impact of these projects rather than assessing the project impact in silo. The goal of this exercise was to collate learnings and insights to develop a guide to support future portfolio impact assessment exercises.

The impact analysis was conducted in two stages: an initial stage developed the scope of the exercise, impact indicators and defined measures (deliverable 1.4[3]), and a second stage further explored various measures of impact by surveying staff involved on their perceived impact of the IMI projects (deliverable 1.7).

Measuring impact can be challenging in itself and it is important to take these learnings forward to help address or pre-empt challenges in future projects. There was extensive learning throughout the process of undertaking this evaluation, especially in the initial stage of the impact assessment where different approaches were explored to shape and finalise the analysis. These learnings and insights gleaned from this project can guide and be referred to when undertaking similar impact assessments in the future.

2 Learnings from the first stage of the impact assessment

2.1 Developing the Scope

2.1.1 Consensus on aims and objectives of project and tasks

The first stage for carrying out the impact assessment exercises involved discussions by WP1 to agree the scope of Neuronet as a whole (i.e., what conditions and projects would be included), and the scope and work plan for the individual tasks within WP1. This included extensive discussion to agree on how to implement what was set out in the Description of Action (DoA) of the Grant Agreement.

A critical step was clarifying and mutually agreeing the requirements (according to the DoA) between the partners, paying particular attention to the feasibility of the impact assessment within the project timeline and resources available.

[2] *The Innovative Medicines Initiative (IMI) is the world's biggest public-private partnership (PPP) in the life sciences. It is a partnership between the European Union (EU), (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations). The first phase of the IMI programme (IMI1) ran from 2008-2013, while the second phase (IMI2) ran from 2014-2020. The mission of IMI2 is to "improve health by speeding up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need." (https://www.imi.europa.eu/about-imi/mission-objectives)*

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Key learnings

- With consortium partners, agree the project's overall aims and objectives, including those for the individual tasks, before trying to identify measures to assess impact.
- Align with consortium partners on the most feasible approach to carry out an impact assessment based on time and resource available.

2.2 Defining the impact indicators and measures

2.2.1 Areas to be assessed and how impact measurement will be undertaken

Traditionally the evaluation of impact involves the assessment of the changes that can be attributed to a particular intervention or project, and whether outcomes would have changed if that intervention or project was not undertaken.[4] This would require comprehensive baseline data and information relating to those outcomes in order to assess the change from baseline. Unfortunately for Neuronet this was not an option as many of the projects in the portfolio had already started. The assessment of the impact of the project portfolio was further complicated because each project has different inputs (funding, partners etc.), timelines (see Table 1) objectives, outcomes and outputs. The projects also span across the two phases of IMI; IMI1 and IMI2[5], which each have their own respective research objectives.

Table 1. Projects in the IMI ND portfolio funded through IMI1 and IMI2 and included in the impact assessment

	IMI Project	Project dates		IMI Project	Project dates
1	PHARMA-COG	2010 - 2015	12	IMPRiND	2017 – 2021
2	EMIF	2013 – 2018	13	EQIPD	2017 – 2021
3	AETIONOMY	2014 – 2018	14	IM2PACT	2019 – 2023
4	EPAD	2015 – 2020	15	RADAR-AD	2019 – 2022
5	PRISM	2016 – 2019	16	PD-MitoQUANT	2019 – 2022
6	RADAR-CNS	2016 – 2021	17	MOBILISE-D	2019 - 2024
7	ADAPTED	2016 – 2020	18	PD-MIND	2019 – 2022
8	AMYPAD	2016 – 2022	19	IDEA-FAST	2019 – 2025
9	MOPEAD	2016 – 2019	20	PRISM 2	2021– 2024
10	PHAGO	2016 – 2021	21	EPND	2021– 2026
11	ROADMAP	2016 – 2018			

[4] *Nigel Simister. Impact Assessment.: Intrac; 2017*

[5] *https://www.imi.europa.eu/about-imi/history-imi-story-so-far*

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Key learnings
When developing an impact assessment:

- Outline the areas of impact that will be assessed and how these will be measured at the beginning of new projects
- Include milestones to assess change during a project. This removes the need to collect information and data retrospectively, particularly as information and data can be forgotten or lost, people and resources change thus the process of evaluation can take significant time and resources.

2.2.2 Defining and measuring impact

Within research, impact is defined as the contribution that excellent research makes to health, the economy, environment or wider society. To address the need to operationalise this definition into measurable elements, a conceptual framework was initially developed based on IMI's key objectives, identifying six core concepts and measures for impact assessment.

As per the DoA, Neuronet is not positioned to act as an auditor or evaluator of individual projects or of the impact of specific deliverables against project aims. Therefore, it was agreed within WP1 **that impact should be assessed in terms of the combined value of the IMI ND programmes, going beyond the key performance indicators (KPIs) and socio-economic impact measures currently collected by IMI and taking into account the perspectives of and added value for key stakeholder groups** (e.g., pharmaceutical industry, academic organisations, patients etc.). It was also agreed within the consortium that the impact measures selected should take into account the feasibility of collecting the required data given the resource and time available, and the expectations of IMI Neuronet. Finally this was discussed with its Scientific Coordination Board (SCB)[6] representing all IMI project Principal Investigators (PIs) (those who will be filling survey) to align on the expected goals. The SCB are a group of project representatives and are therefore almost participants as they were providing data for the impact analysis. It was critical to have them on board, and as a key stakeholder they were consulted throughout to appreciate the value of the effort they were putting in and the exercise as a whole.

WP1 began by identifying an extensive range of KPIs to be prioritised according to different stakeholder preferences and the feasibility of their collection. This identified metrics and indicators to assess impact. This short list of KPIs was then discussed with the SCB to finalise the list.

Once WP1 identified a list of KPIs and data that IMI routinely collects to monitor projects, there were discussions within the WP to align these based on the relevance to the impact assessment task (as well as to the other tasks within WP1). The IMI clarified that it could not grant access to KPI data for individual projects from the IMI office due to confidentiality considerations, and that Neuronet should aim to define its own methodology for measuring impact. The goal was not to duplicate individual project review by the IMI and the focus should be on additional value, therefore some standard measures (such as publications) were deemed not novel enough to be included.

The feasibility of data collection and accessibility of data were a key consideration in determining which indicators would be collected. The concepts of impact and related KPIs were presented to the SCB for discussion and validation, in terms of their suitability for measuring impact in a novel way. The

[6] *The SCB is a pivotal body in Neuronet's governance structure. Its 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, whilst also highlighting gaps in the portfolio or specific areas that require concerted action. Each IMI ND project nominated one representative for the Neuronet SCB.*

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SCB commented that the scope of the data suggested for collection was too extensive and the use of KPIs and indicators may be too burdensome on the individual projects. The SCB also felt that the development of a conceptual framework for impact was not helpful. Instead, it was agreed that the focus should be on project variables that would be collected following a stepwise approach, starting with data from publicly available sources and reaching out to the projects for any information not available via other sources.

Key learnings

- Involve key stakeholders from the outset in determining the scope of the impact assessment and in defining the indicators and measures of impact to optimise efficiency and resources at the beginning of the project and avoid unnecessary steps (or worse, not having to take revert steps already taken).
- When identifying indicators for impact, ensure that the measurement of each indicator is feasible and relevant to what is being measured, and that data is accessible.
- Have regular touch points with key stakeholders and include a standing item for any general changes in the landscape eg staff, policy, processes etc.

2.3 Data collection

2.3.1 Approach to data collection

Prior to data collection, WP1 set out all the variables with their definitions, descriptions and data sources. This included data for both the impact analysis and for the integrated programme analysis (deliverable 1.2[7] and the updated analysis in deliverable 1.5[8]).

To support data collection, a standardised form was developed in Excel to capture data in a structured way. A sub-group of WP1 formed the 'data collection team' who took charge in collecting mostly publicly available data and contacted the projects for further information if required. The data collection form was piloted by a few members of the data collection team and then amended to ensure it was fit for purpose.

It was agreed that data would be collected using a step-wise approach. The chronological steps were:

- Data from publicly available sources (e.g., IMI website, project websites, the European Commission's Community Research and Development Information Service (CORDIS))
- Members of Neuronet partners that are directly involved in the projects in the portfolio were contacted for additional information not available from public sources (e.g., projects' DoA, project newsletters, project final reports)
- Contacting the projects directly for any further information
- The Neuronet project leaders then carried out interviews with some of the projects to explore the facilitators and barriers faced by IMI projects and to gain an in-depth understanding of their objectives, activities and results (this primarily informed the integrated programme analysis).

Neuronet's project coordinator and project leader carried out the interviews at face-to-face meetings including the second face-to-face SCB meeting and the Neuronet Annual Event at the Alzheimer

[7] *https://www.imi-Neuronet.org/wp-content/uploads/2020/04/Neuronet_D1.2_Final-3.pdf*
[8] *https://www.imi-Neuronet.org/wp-content/uploads/2022/03/Neuronet_D1.5-Final-Version.pdf*

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Europe Conference. Follow up interviews were then carried out if needed. They found the conference setting to be particularly good in engaging participants.

Key learnings

- Have a dedicated team who is responsible for data collection and gathers all publicly available data to avoid duplication at the project level.
- Use a standardised data collection form to ensure that team members are clear about what data to collect and in what format.
- Design the data collection form to support data analysis (e.g., collating figures relating to funding etc).
- Consider the burden of translating information between different MS programs eg from an excel form to word. This issue was encountered when Neuronet requested a dossier from each project (in MS Word) to inform interviews with project leaders and was time consuming.
- Identify different sources of information and methods for collecting data, particularly if data is missing from primary sources.
- Perform interviews to engage more active participants such as Principal Investigators (conference setting worked well)

2.3.2 Efficiency of data collection

Through this exercise Neuronet collected a vast amount of information about the projects and portfolio. Much of the data collected was used to inform other tasks in WP1 (i.e., programme analysis) and to populate the Neuronet Knowledge Base which brings together key information about the various projects in the IMI ND portfolio. The formatting of the Knowledge Base was refined based on input from SCB (a couple steps were conducted). However, some of the data collected has not been used and further data was later required when carrying out the impact assessment.

Key learnings

- Be clear from the outset on what you want to evaluate and what data is needed to measure that change. In this exercise data was collected but not used. This ensures data is not collected unnecessarily and that further data is not required later in the process. It also helps to hone questions in any interviews conducted.
- Showcase the output regularly to key stakeholders to valorise their contribution and show usefulness of the data collection.

2.4 Evaluation

2.4.1 Identifying links between projects and scope for sharing and disseminating knowledge

In undertaking the first stage of the impact assessment, a framework (figure 1) was developed based around two clear aspects of impact:

- The structure and characteristics of the IMI ND project portfolio (network analysis)
- The outputs of the project portfolio and the extent to which these addressed key scientific priorities

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A network analysis (informed by the work carried out by van Rijnsoever et al.[9]) was performed to analyse the structure and characteristics of the portfolio. This was done through examining publicly available sources of information, extracting data from DoAs, newsletters and project reports, and conducting interviews (described in deliverable 1.2). The aim was to show how partners and projects were linked together and thus how and to what extent knowledge might be shared and disseminated. The group felt analysing and interpreting the concepts and results associated with this approach were complex and required extensive discussion within the WP. This was in part due to the volume of data gathered.

2.4.2 Choosing project outputs and measuring their impact

Publications were chosen as a measure of project output early on, mainly because other key assets resulting from projects (including datasets, biological samples, cohorts, disease models, taxonomies, platforms and tools) were potentially going to be covered within another deliverable. However, IMI was already collecting publications and they flagged this as being too limited in scope. Neuronet needed to use more novel parameters and it was decided that looking at assets and public deliverables would be a better way of assessing impact. An overview of the number of assets that had been developed by each project was included in the initial stage of the assessment and the impact of these was assessed in the second stage of the impact assessment.

2.4.3 Assessment of how key scientific priorities were addressed by projects

A framework was developed (see figure 1) to analyse project publications against key scientific priorities for neurodegenerative disease research. The overarching themes were drawn from the EU Joint Programme – Neurodegenerative Disease Research (JPND) Research and Innovation Framework. The IMI Strategic Research Agenda (SRA) priorities for neurodegenerative disease were mapped against the relevant themes and included as sub-categories in the framework in addition to several other sub-categories identified from the JPND Research and Innovation Framework. Framework development is described in deliverable 1.4.

Key learnings

- Ensure that the methods/frameworks for evaluation are clear and transparent to all relevant partners and include them in early discussions and scoping decisions.
- Engage all partners in the evaluation. Discuss intermediary analysis with key stakeholders (SCB for Neuronet) to confirm/refine main messages.
- Have a central decision log that is accessible to and is a reference point for all partners to avoid inefficiencies in project activities due to duplicative work.
- Have sufficient resources and capacity for undertaking the evaluation. Engage key members of the team with relevant skills and knowledge for particular tasks. Key members of the WP1 team with greater knowledge of the neurodegenerative disease field were involved with the qualitative analysis of publications against the key scientific priorities

[9] *Frank J. van Rijnsoever, Jesse van den Berg, Joost Koch, Marko P. Hekkert. Smart innovation policy: How network position and project composition affect the diversity of an emerging technology,Research Policy,Volume 44, Issue 5,2015,Pages 1094-1107*

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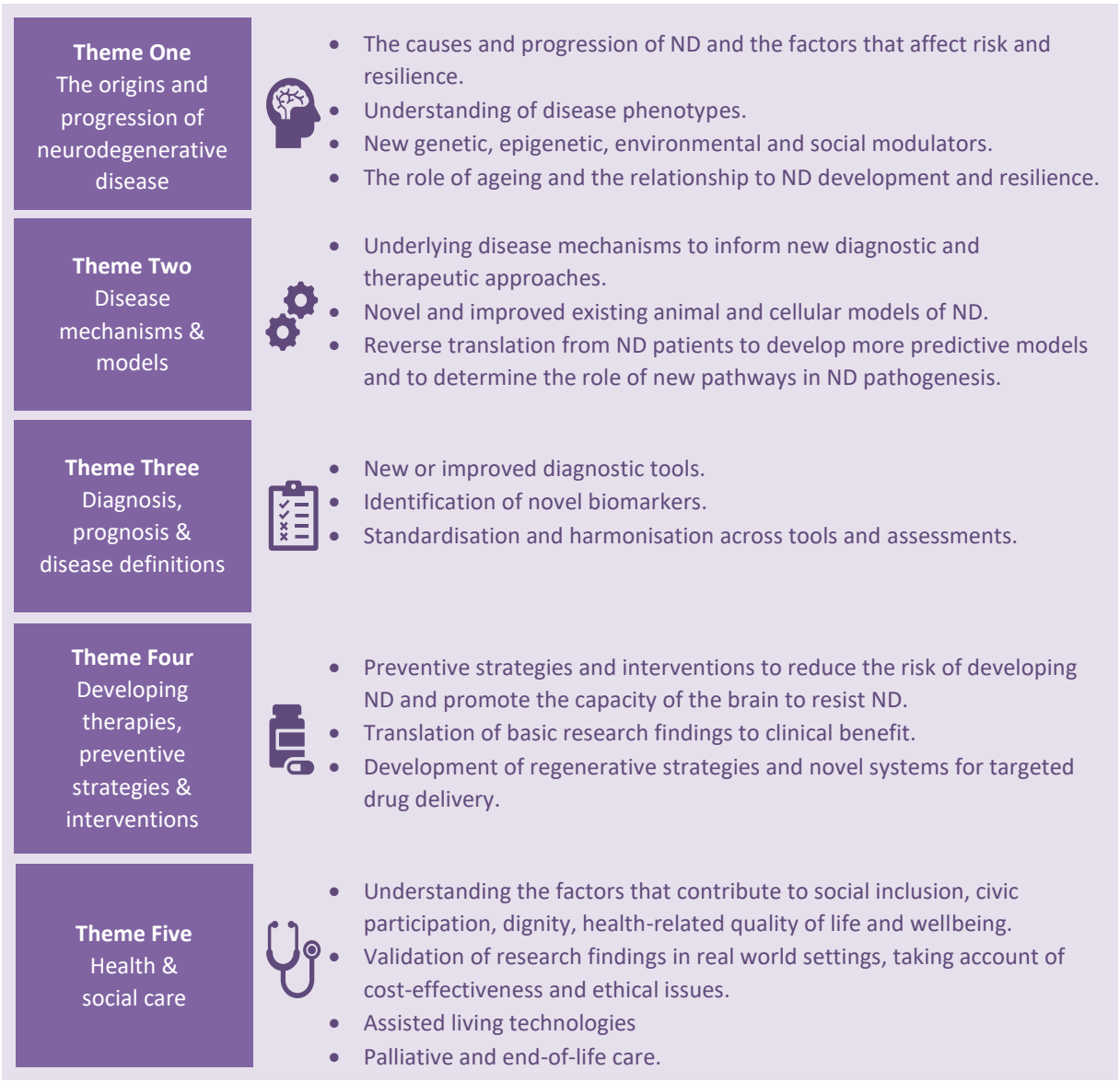

Figure 1. Overarching framework for scientific priorities in neurodegenerative diseases

3 Learnings from the second stage of the impact assessment

For the second stage of the impact assessment, two surveys were conducted to collect data on perceived impact of projects and awareness of and uptake of assets from European Federation of Pharmaceutical Industries and Associations (EFPIA) and non-EFPIA (Academic and SME) partners to gain a broad perspective of perceptions of impact across these different groups.

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3.1 Data collection

3.1.1 Survey design

The survey for the EFPIA partners was designed to gain a deeper understanding of impact resulting from their participation in IMI ND projects on various fronts, from impact on company strategy & business conduct to public/societal impact and personal development. The definition of impact included both 'hard' metrics (e.g., return on investment and asset uptake) as well as 'soft' metrics (e.g., job opportunities, knowledge/network expansion, public perception). It had to be designed to avoid confidentiality issues. The key impact for consideration when designing the survey was the individual perspective of EFPIA representatives in Neuronet who had been involved on IMI projects. It was bench tested with two partners who distributed survey to their colleagues, from bench scientists to project leads, legal support and finance. A total of 47 questions were included in the EFPIA survey with both close-ended and open-ended questions to collect data. See Annex 5.1.1 for full survey. It was particularly helpful to have WP1 members from EFPIA partner organisations lead the design of the survey given their in-depth understanding of EFPIA organisations.

The survey was divided into these different categories:

- Experience in Innovative Medicines Initiative (IMI)
- Impact on company
- Impact on daily work
- Impact on professional career
- Impact on professional network
- Impact on the field at large

For the non-EFPIA survey (see Annex 5.1.2), the questions used in the EFPIA survey were revisited and those that were not relevant (e.g., questions around return on investment) were removed, while some questions were reworded to ensure that they were relevant to the target groups. Similarly, having members of WP1 from small and medium enterprises (SMEs), patient organisations, HTA bodies and members with a background in academia was very helpful in designing the non-EFPIA survey since they provided feedback on questions and typical metrics that would be of interest in these organisations. Furthermore, to reduce the burden on responders, the questions were streamlined for the non-EFPIA survey to facilitate their completion and there was a lower proportion of open-ended questions compared to the EFPIA survey. The total number of questions included in the non-EFPIA survey was 21 and they were divided into these categories:

- Experience in Innovative Medicines Initiative (IMI)
- Impact on research group or department and personnel
- Impact on research
- Impact on collaborations
- Broader impact on society, research and innovation
- Impact of assets

Both surveys were developed in the Survio platform and were piloted by members of WP1 and then amended as necessary prior to rolling them out. This was an important step to ensure that they were designed to capture the data needed and were clear to responders.

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Key learnings

- Involve stakeholders with in-depth understanding of target groups to ensure the survey design is relevant and intuitive.
- Tailor surveys to the target audience.
- Pilot surveys prior to their roll-out to identify and resolve any issues with the data collection tool before distributing them.
- Include 'N/A' options where appropriate to limit free text answers requiring analysis time providing no additional insight (see Data Analysis)

3.1.2 Survey dissemination

For the EFPIA survey both project leads/Strategic Governing Groups representatives as well as operations offices were approached to distribute the survey within their companies. The non-EFPIA survey was distributed by asking SCB members and project managers of IMI ND projects to share it with academic and SME partners. The EFPIA survey was disseminated between 29th March and 13th August 2021 and remained live until 31st August 2021 and the non-EFPIA survey was live from 3rd January 2022 to 1st March 2022.

Completion reminders were sent at different timepoints when the surveys were live to increase response rate, and there was an observed increase in number of responses received in periods following reminders. There were a total of 91 responses and 43 responses received for the EFPIA and non-EFPIA surveys, respectively. Given the approach taken for disseminating the surveys, the completion rate could not be calculated since it was not possible to track the number of people who received the survey. Furthermore, the timing of undertaking the surveys may not have been ideal as they coincided with a period of transition from the IMI to the Innovative Health Initiative (IHI) framework, which may have impacted completion rate. Another challenge that was encountered was that a survey was carried out for another Neuronet deliverable in the month prior to the roll-out of the non-EFPIA survey that also targeted IMI ND researchers so there may have been an issue with "survey fatigue". Additionally, the non-EFPIA survey was live for two months only to allow time for analysis of data and reporting prior to the closing of the Neuronet project in August 2022.

Key learnings

- The timing of data collection activities is important and may impact the number of responses received.
- Include mechanisms to allow for the tracking of completion rates when disseminating surveys
- Follow-up with periodic reminders for completing surveys and direct interviews to foster contribution.

3.2 Data analysis

The survey data were analysed quantitively and thematically in Excel. Analysing the EFPIA survey data was time-consuming given the number of questions that allowed for free-text responses and the number of responses received. These needed to be analysed thematically. However, it did allow for more in-depth understanding of perceived impact from responders and allowing this via free text did

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not pre-empt or direct any answers. For some free text answers this was not necessary and upon reflection it could have been pragmatic to include an 'N/A' option to filter out these responses and limit the time required for analysis. This is learning relating to survey design rather than data analysis.

One issue was that depending on the level of seniority and involvement of the employees some questions were not relevant and could not be easily answered by all responders. Therefore, the design of the survey could have allowed for more flexibility in responding to questions as there were many responses of "I don't know" for some key areas of impact like "impact on strategic partnerships" and "return on investment". This may be a reflection of the role of the respondent within the project and this issue was anticipated but it felt the breadth of questions should still be included.

Key learnings

- Sufficiently resource for any thematic analysis of surveys.
- Have flexibility in surveys so that responders could opt-in to relevant questions based on their experience.
- Pilot data collection tools with people of differing roles to make data collection and analysis more efficient.

4 Discussion

This paper outlines the lessons learned from undertaking the Neuronet project impact analysis. Key learnings emerged throughout the process of both phases. These spanned consensus on project aims and objectives, defining the impact measures, data collection, evaluation and analysis. **Main findings relate to the importance of achieving agreement among the wider group, tailoring data collection tools and ensuring a diverse range of perspectives and roles for group membership**.

Carrying out an impact assessment is an iterative process and it is important to be clear on certain aspects from the beginning to guide this. One important area was agreeing on the aims of tasks, areas of impact and the scope of the impact assessment as this fed into deciding upon which measures were appropriate and their definitions. After determining the measures, it was important to agree that the measurement of each indicator was feasible with accessible data. Consensus on these helps prevent shelving, duplicating or carrying out unnecessary work as this was sometimes a result of a change in steer from the oversight group.

Another iterative aspect of an impact analysis is the regular touch points with key stakeholders. It can be useful to include a standing item for noting changes in the general landscape of the project. This can help alleviate the need to retrospectively collect information and data that has been forgotten or lost due to changes in people or resources. The iterative aspect is reminiscent of agile project management methodology[10], and it may have been useful to more formally integrate this.

Several Neuronet members were active participants in the individual IMI projects and were useful in disseminating Neuronet information and championing this effort within their respective projects to facilitate data collection. Neuronet was seen as a group of IMI project insiders (knew most projects already) trying to perform an analysis at a global portfolio level and not trying to mimic the IMI bureaucratic evaluation of individual projects. This was of utmost value to get active participation from the SCB and it was a success.

[10] https://www.apm.org.uk/resources/find-a-resource/agile-project-management/

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The value of having different perspectives represented within the Neuronet consortium and WP1 was clear across the two stages of the impact assessment. In the first phase of the impact analysis key members were engaged for particular tasks according to relevant skills and knowledge, for example those with greater knowledge of the neurodegenerative disease field were involved with the qualitative analysis of publications against the key scientific priorities. In the second phase having people with different perspectives allowed optimal survey design which made the data collection and analysis more efficient for the respondents and project team respectively. A key learning from this step was to distinguish between the content of a question in terms of what it was asking, and its format. This enabled the correct data to be collected in the most usable format and ensured the surveys were tailored to the target audience. This useful learning resulted from the multi-disciplinary oversight group, who added further value by piloting the data collection tools.

Overall the experience of Neuronet undertaking an impact assessment generated many learnings that should hopefully help those undertaking similar processes do so in a more efficient manner.

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5 Annexes

5.1 Survey questions

5.1.1 EFPIA

Survey questions_impact EFP

5.1.2 Non-EFPIA

Survey question (non-efpia).pdf

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