IMI2 821513 – NEURONET

Efficiently Networking European Neurodegeneration Research

WP1– Projects & Impact Analysis

D1.7 Final report on impact of IMI neurodegeneration portfolio

Lead contributor	Fatima Salih (02 – NICE) Claire Hawksworth (02 – NICE) Dalia Dawoud (02 – NICE)
Other contributors	Kat Cresswell (02 – NICE) Lennert Steukers (04– JANSSEN) Carlos Diaz (01– SYNAPSE) Lewis Killin (01– SYNAPSE) Laurent Pradier (05-SARD) Manuela Rinaldi (04– JANSSEN)

Document History

Version	Date	Description
V0.1	06/07/2022	First draft
V1.3	13/07/2022	Comments
V1.4	09/08/2022	Draft
V1.5	18/08/2022	Final version for Consortium Review
V1.6	07/11/2022	Final version for IMI submission

Contents

Definitions and abbreviations

Partners of the NEURONET Consortium are referred to herein according to the following codes:

1. **SYNAPSE**: Synapse Research Management Partners SL
2. **NICE**: National Institute for Health and Care Excellence
3. **AE**: Alzheimer Europe
4. **JANSSEN**: Janssen Pharmaceutica NV
5. **LILLY**: Eli Lilly and Company Limited
6. **ROCHE**: F. Hoffman – La Roche AG
7. **TAKEDA**: Takeda Development Centre Europe LTD (*terminated partner*)
8. **SARD**: Sanofi-Aventis Recherche & Développement
9. **PUK**: Parkinson's Disease Society of the United Kingdom LBG
10. **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

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 this report details the second and final stage of the impact analysis including the conduct, reporting and results of two surveys: one to European Federation of Pharmaceutical Industries and Associations (EFPIA) organisations and another to 'non-EFPIA' organisations including academic institutions and small and medium sized enterprises.

Results showed that involvement in the IMI ND projects led to clear perceived benefits to the organisation, and for networking, collaborations and partnerships. This was true for both EFPIA and non-EFPIA respondents, and the key disadvantage was equally agreed upon. This was the extra administrative time and meetings associated with project involvement. Other areas of impact were more mixed such as the impact on the individual, policy, patient and public health impact. The scientific and economic impact were two key areas that were poorly answered with a lot of 'I don't know' answers.

Some areas of impact deemed key were analysed further according to project role (Project Lead, Work Package Lead and Task Lead) and hours worked on the project. There was no clear association between project role and perceived impact, although there was a clearer trend for higher perceived impact from those who spent more time each week working on the project.

1 Introduction

The Innovative Medicines Initiative (IMI), and its successor The Innovative Health Initiative (IHI), are the world's biggest public-private partnership (PPP) in the life sciences. IMI has been 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) and its work will be continuing under IHI.

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 the projects that form the IMI neurodegenerative disorders (ND) portfolio.

Assessing the impact of projects is one of the main objectives of NEURONET, and its Work Package 1 (WP1). To achieve this, WP1 carried out an impact analysis to assess the scientific and socio-economic impact of the IMI ND portfolio across the EU. The initial stage developed the scope of the project, impact indicators and defined measures, and was presented in 'First report on impact of IMI neurodegeneration portfolio' (deliverable 1.4[1]) which was completed in February 2021. This report details the second stage which further explored various measures of impact by conducting a survey with staff who were involved in IMI ND projects.

The projects are partnerships between different organisations including members of EFPIA and other organisations including academic institutions, and small and medium sized enterprises. Two surveys were administered: one to EFPIA organisations and one to other organisations involved in the IMI projects termed in this report 'non-EFPIA' organisations. The original focus of the impact assessment was to collect data on the perceived impact from EFPIA organisations, however it was then recognised that it would be valuable to survey people from non-EFPIA organisations too. Measuring assets produced by the projects was considered late during the first stage of the impact analysis and therefore the survey incorporated questions relating to project assets and their impact. This report presents results from both of these surveys which have been analysed and presented by type of impact to illustrate the impact of IMI ND projects on particular areas.

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

2 Methods

2.1 Impact on European Federation of Pharmaceutical Industries and Associations (EFPIA) partners

2.1.1 Data Collection

A questionnaire was developed with the aim of evaluating how IMI has impacted European Federation of Pharmaceutical Industries and Associations (EFPIA) companies and the neurodegeneration field and society at large. The questions were drafted by the Task 1.2 lead (Janssen) and refined following input from members of the NEURONET Executive Committee (ExCom). The draft survey was piloted by the WP1 lead (NICE) before being finalised for distribution.

The survey (see Annex I) was divided in 6 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

The questionnaire was conducted through an online survey of all staff from EFPIA partners (excluding contractors) that are or have been involved in one or more of the 18 IMI Neurodegenerative disease (ND) projects[2] that were part of the portfolio at the time of the survey. The survey was initially distributed to all staff involved in IMI ND projects from 2 Neuronet EFPIA partners (Janssen and Sanofi) to ensure a broad return and to bench test the survey. It was then sent to the remaining 29 EFPIA organisations that have participated in one or more of the IMI ND projects. The survey was distributed through the company's Strategic Governing Group (SGG) ND contact person and/or the IMI operational contact person of each EFPIA company. In case that this information was not available, the survey was distributed through the staff directly, working on one or several of the projects. To increase response rates from individual companies, a final reminder was sent by the IMI scientific officer on 13 August 2021.

The online survey was disseminated between 29th March and 13th August 2021 and remained live until 31st August 2021.

2.1.2 Data Analysis

To assess the impact of IMI on EFPIA, 9 areas of impact were defined. The 6 sections of the survey were then categorised and analysed according to these impacts:

- Organisational impact (e.g. organisational strategy, objectives, planning, processes, reputation etc)
- Economic impact (e.g. Return on investment)
- Capacity building (e.g. Professional development, attracting new staff)
- Collaborations, networks and partnerships

[2]ADAPTED, AETIONOMY, AMYPAD, EMIF, EPAD, EQIPD, IDEA-FAST, IMPRIND, IM2PACT, MOBILISE-D, MOPEAD, PD-MIND, PD-MITOQUANT, PHAGO, PHARMA-COG, PRISM, ROADMAP, RADAR-AD, RADAR-CNS

- Individual impact (e.g. personal development, collaborations and networks, ways of working)
- Scientific impact (e.g. impact on the drug development process e.g. awareness & visibility of IMI ND projects/assets and use assets in R&D and regulatory/HTA practice)
- Policy impact (e.g. impact on regulatory practice, decision makers)
- Patient impact (e.g. research that is generating outcomes and impacts that are relevant for patients/citizens)
- Health impacts (impacts on public health, e.g. life expectancy, prevention of illnesses, quality of life, and the health-care system)

See Annex II for which survey questions comprised which area of impact.

The results from the individual companies were collated in an Excel spreadsheet and analysed as a whole. Quantitative data were analysed using descriptive statistics (counts and percentages) and responses to the open-ended questions were thematically analysed. Correlations were explored between project roles, time spent on projects (selected independent variables) and key areas of impact. Questions representing key areas of impact included the themes of organisational impact, economic impact and collaborations, networks and partnerships. The correlations were not formally explored through hypothesis testing, but the data were stratified by the selected independent variables and graphs produced to show outcomes and results by these variables.

2.2 Impact on non-EFPIA partners

2.2.1 Data collection

The questionnaire used for EFPIA stakeholders was reviewed and adapted to make it more relevant for non-EFPIA partners, namely academic and small and medium enterprise (SME) staff involved in IMI ND projects. The questions were drafted by WP1 leads (NICE) and refined following input from the NEURONET ExCom. The survey (see Annex III) was divided in 6 different categories (different to those in the EFPIA survey):

- 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

The survey was disseminated through the NEURONET Scientific Co-ordination Board (SCB) and project managers of individual projects. The online survey was live from 3rd January to 1st March 2022.

2.2.2 Data Analysis

To assess the impact of IMI on non-EFPIA stakeholders, the results from the survey were categorised and analysed according to six areas of impact from the EFPIA survey that were deemed relevant:

- Organisational impact
- Collaborations, networks and partnerships
- Individual impact (e.g. professional development, career progression)
- Scientific impact (e.g. impact on research practices, research dissemination)

- Societal impact (e.g. research that is generating outcomes and impacts that are relevant for patients/citizens)
- Health impacts (impacts on public health, e.g. life expectancy, prevention of illnesses, quality of life, and the health-care system)

See Annex IV for which survey questions comprised which area of impact.

The individual responses were collated in an Excel spreadsheet and analysed as a whole. Quantitative data were analysed using descriptive statistics (counts and percentages) and responses to the open-ended questions were thematically analysed. Associations between variables were not explored for the non-EFPIA survey.

3 Results

3.1 EFPIA partners

3.1.1 Survey respondents

Overall, 91 responses were submitted from 24 out of the 31 companies that were invited to participate. The majority of responses were from Janssen and Sanofi. Five respondents indicated that they were not involved in any IMI project and therefore did not qualify for inclusion. The final analysis included 86 responses.

On average, the EFPIA survey respondents were involved in 2 IMI ND projects (minimum 1, maximum 5 projects) with 81% involved in 1 or 2, and the remaining 19% involved in 3-5. This is presented in Figure 1.

Of the respondents, 28% had been Project Leader on 1 project, with the majority (64%) not being Project Leader on any project. Half of respondents had been Work Package Lead on at least 1 project: 36% on 1 project, 12% on 2 projects and 1 respondent had been Work Package Lead on 5 projects. Results were similar for the number of projects where respondents had been a Task Lead: 37% on 1 project, 7% on 2 projects, and 4% on 3+ projects.

Figure 2 shows that the majority of EFPIA survey respondents (74%) worked on IMI ND projects for at least 2 hours per week, and of these 47% (n=64) spent more than 6 hours per week on IMI ND projects.

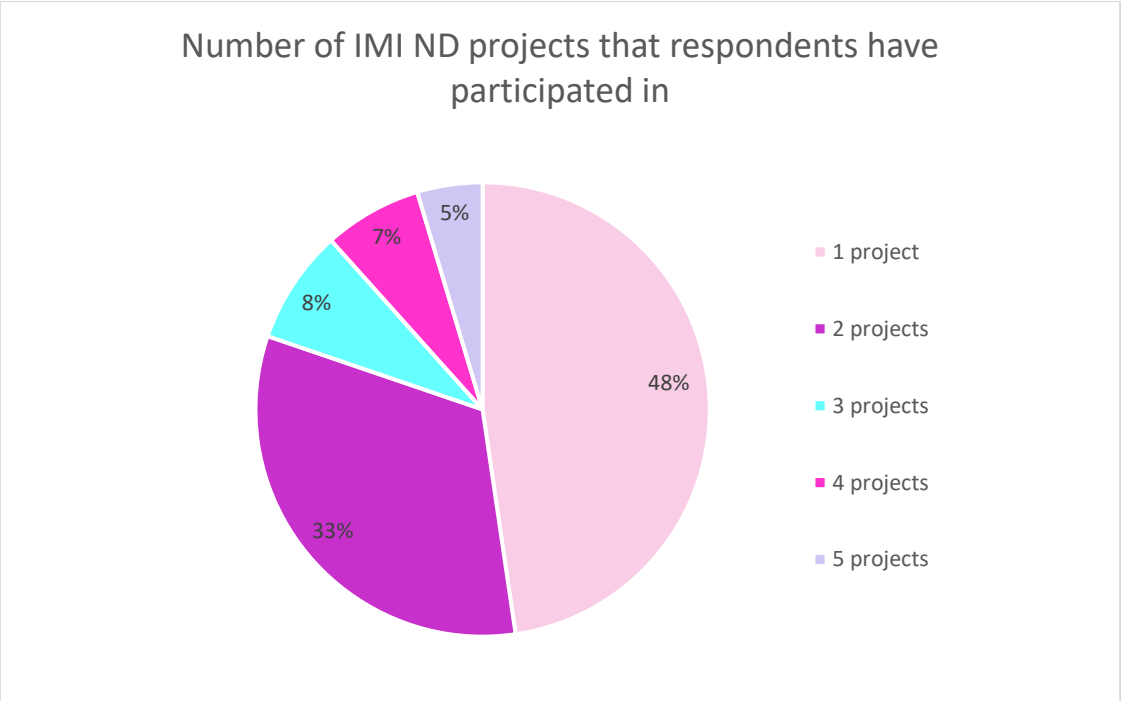


Figure 1. Number of IMI ND projects that EFPIA respondents have participated in

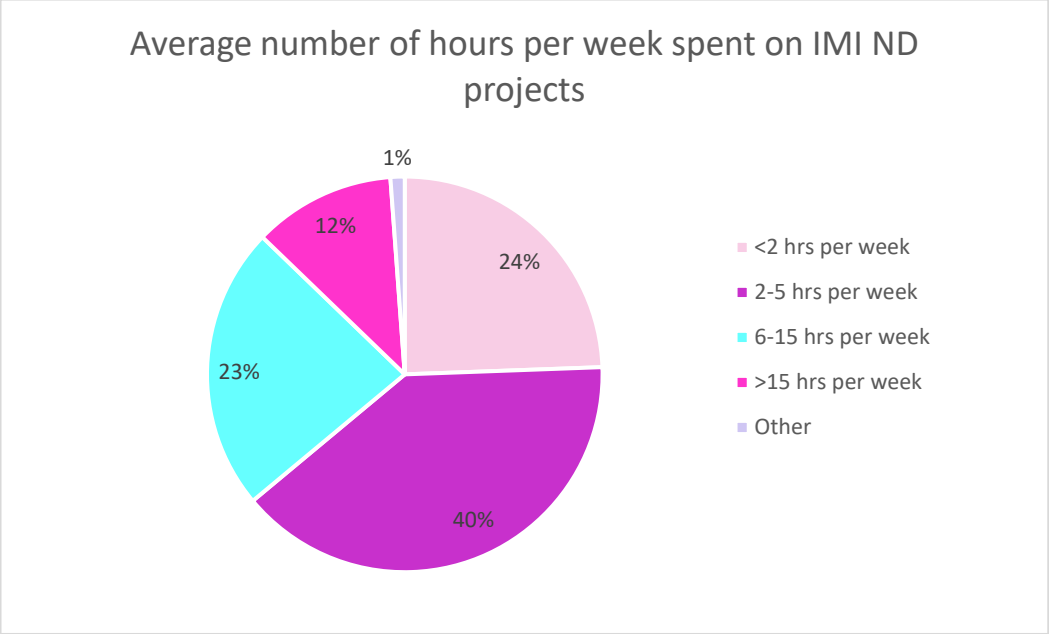


Figure 2. Average number of hours per week that EFPIA respondents spent on EFPIA projects

3.1.2 Organisational impact

In terms of organisational impact, a combined 37% of respondents rated the impact of IMI ND projects on the company's strategic objectives as moderate or high (Figure 3). 'Neutral impact' was the most popular answer (37% of respondents). The majority of respondents (66%) also thought that the IMI ND projects had an impact on the company's presence, visibility and public perception (Figure 4).

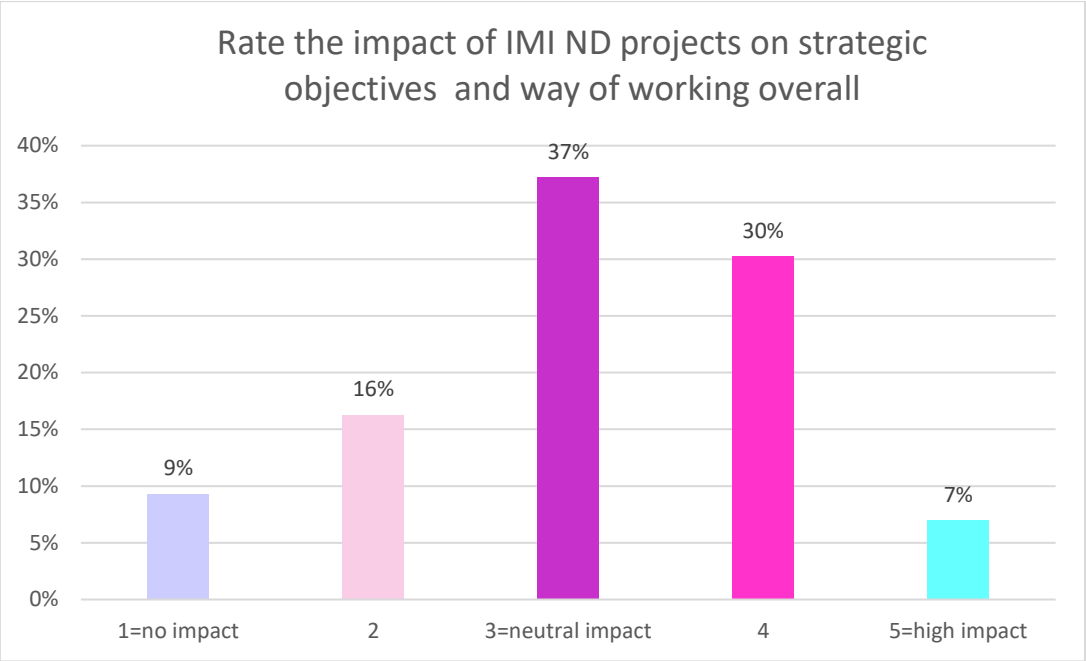


Figure 3. Perceived impact of involvement in IMI ND projects on company's and/or Therapeutic area (TA) Strategic Objectives and way of working overall

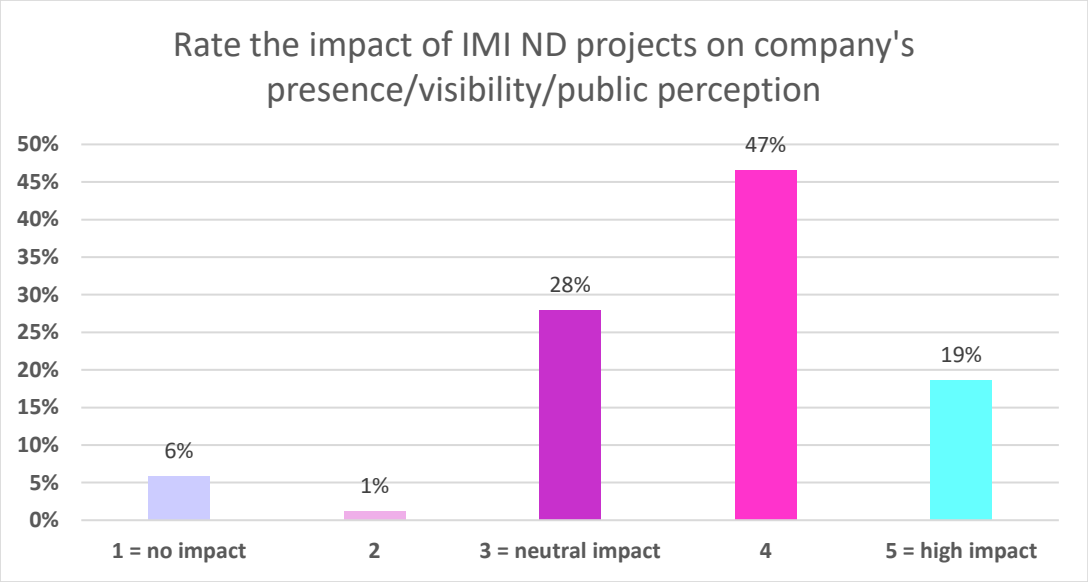


Figure 4. Perceived impact of involvement in IMI ND projects on company's presence/visibility/public perception

'I don't know' was the most popular answer when asked whether the company helps in creating awareness of project outcomes (43%) or helps in creating awareness on the impact of those outcomes (44%). Figure 5 shows that IMI was known within companies (100% of respondents said known to some degree) and Figure 6 shows that respondents thought there were aspects of R&D that are done differently due to IMI projects (58%).

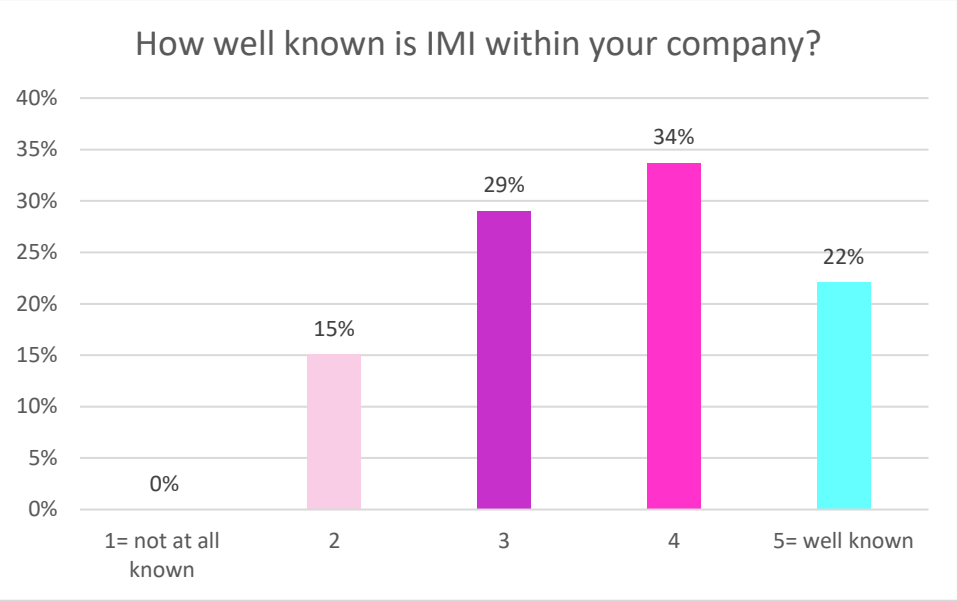


Figure 5. Knowledge of IMI within company

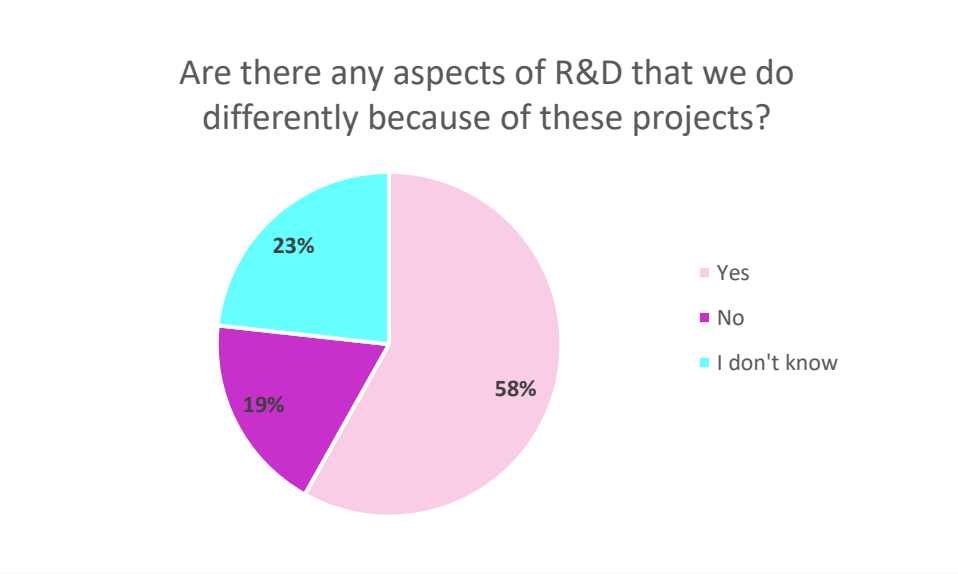


Figure 6. Aspects of research and development done differently due to IMI projects

3.1.3 Economic impact

When asked about the impact of IMI ND projects on return on investment (ROI), 50% of respondents selected 'neutral impact' (Figure 7). The survey prompted respondents to elaborate on which project outcomes triggered the ROI. Figure 8 shows these results with the most popular being outcomes around networking, knowledge and data sharing.

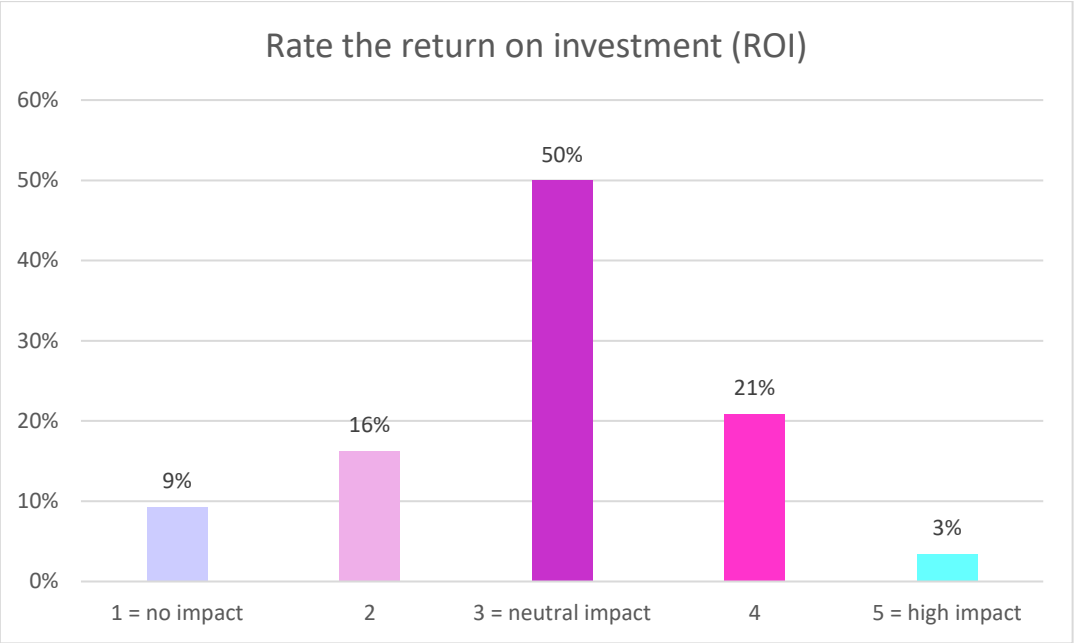


Figure 7. Perceived impact of involvement in IMI ND projects on return on investment in terms of increased efficiency, acceleration of processes, new knowledge

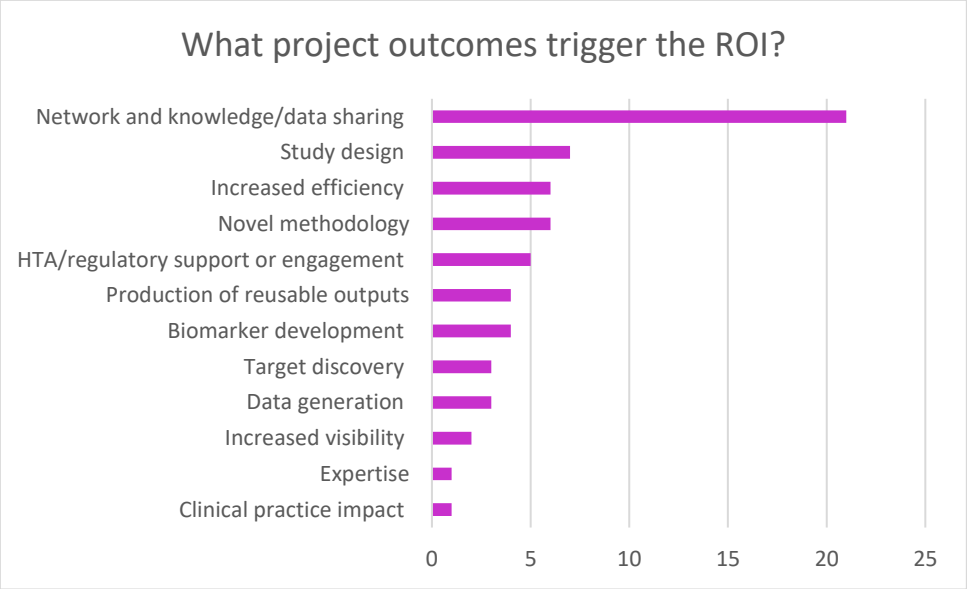


Figure 8. Projects outcomes that trigger the return on investment (ROI)

3.1.1 Capacity building

The responses showed that 31% of respondents thought the IMI ND projects had a neutral impact on attracting talent while a combined 41% rated the impact as moderate or high (Figure 9). Additionally, 45% of respondents reported that people had been hired specifically to work on the IMI ND project. 35% said none had been hired and the rest were unsure. The breakdown of the number of hires is shown in Figure 10. Nearly half (49%) of those who reported hires were aware of people who went on to receive a permanent position after being hired for an IMI ND project. Furthermore, 12% of respondents were aware of people who were hired from an IMI ND partner project to their company.

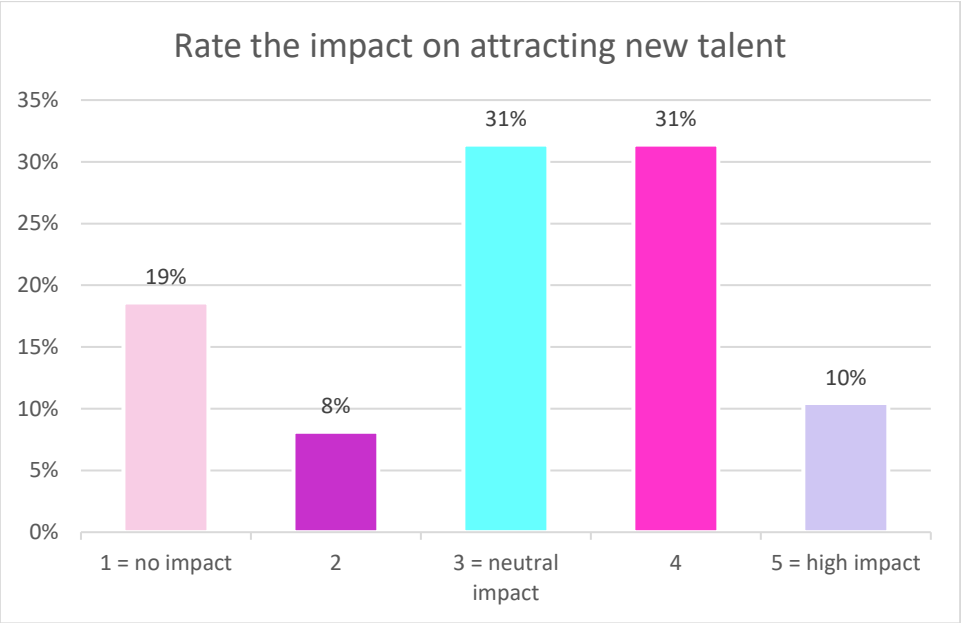


Figure 9. Perceived impact of IMI ND projects on attracting new talent to EFPIA companies

Figure 10. Number of new recruits to IMI ND projects. N=39; respondents that indicated there had been hires specifically for the IMI ND project.

3.1.2 Collaborations, networks and partnerships

Similar numbers of respondents selected neutral or some degree of impact when asked to rate the impact (1 to 5) on establishing strategic partnerships (38% and 41% of respondents respectively; Figure 11). However, when combining 'some' and 'high' impact (ratings of 4 and 5) nearly half of respondents (49%) thought that IMI project participation had impact compared to those who did not (13%, 1 and 2 combined). Figure 12 shows whether the respondents were

aware of any strategic partnerships formed between the company and other IMI partners, where 53% said they did not know.

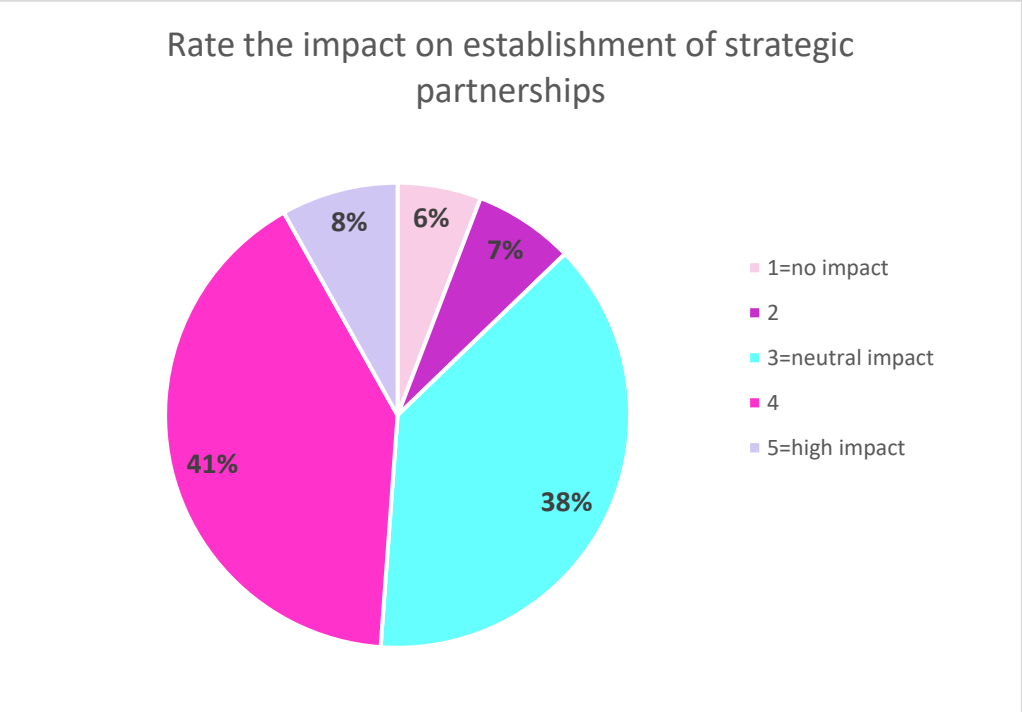


Figure 11. Impact on strategic partnerships

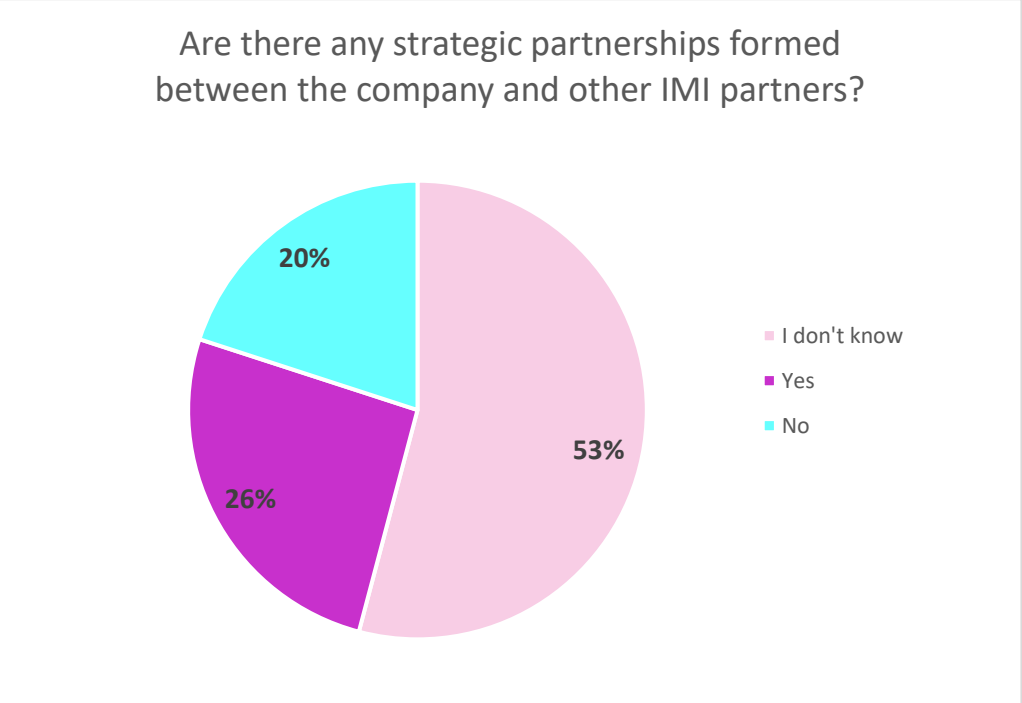


Figure 12. Knowledge of respondents of strategic partnerships formed between their companies and other IMI partners

However, most people (81%) did report meeting new people internally at their own company (Figure 13) and 93% reported meeting new people from different companies (Figure 14). The

'other' category in Figure 14 is primarily driven by people reporting that they had met more than 15 people. Respondents also reported establishing new long-term relationships with academic institutions, SMEs, Biotechs and patient organisations (Figure 15).

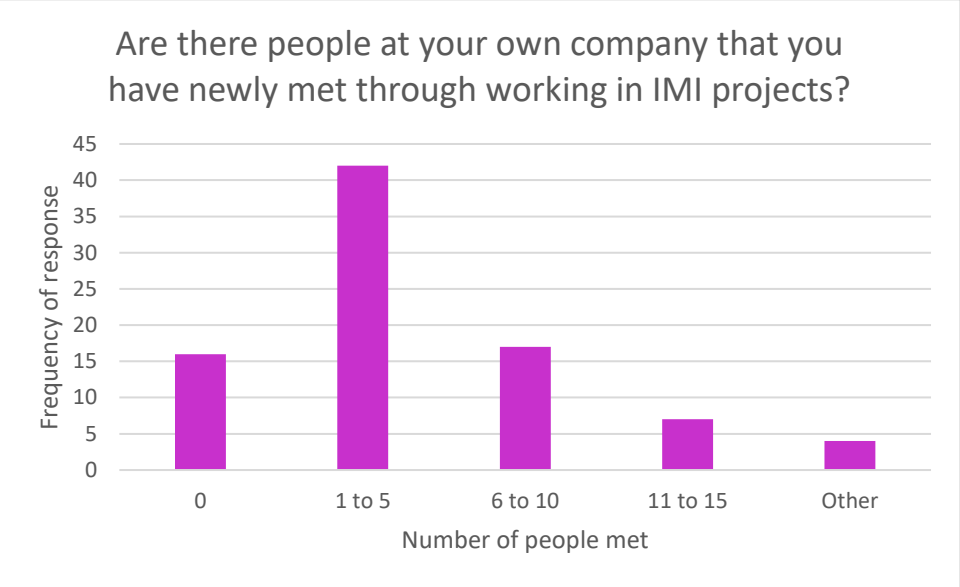


Figure 13. Frequency of number of new people met at own company through IMI projects

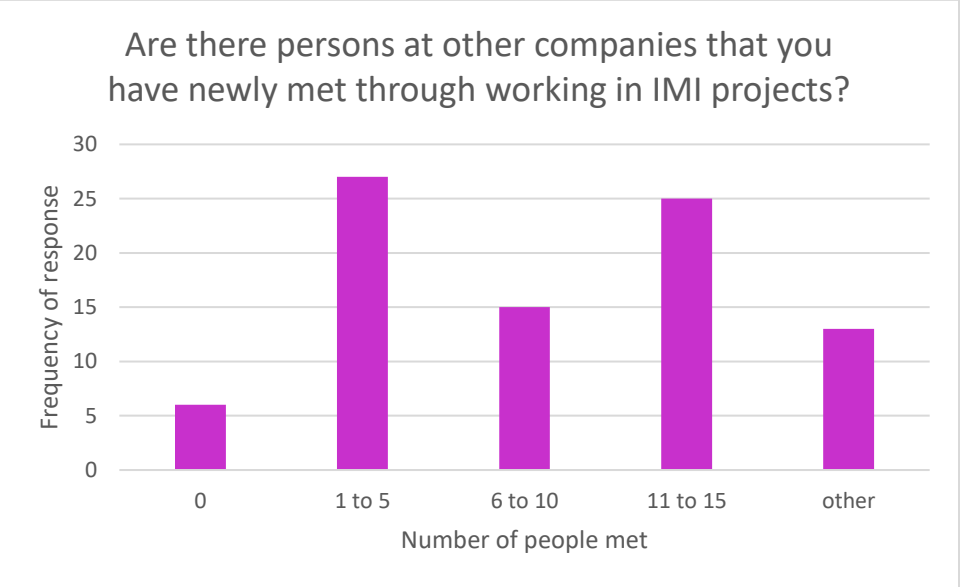


Figure 14. Frequency of number of new people met at other companies through IMI projects

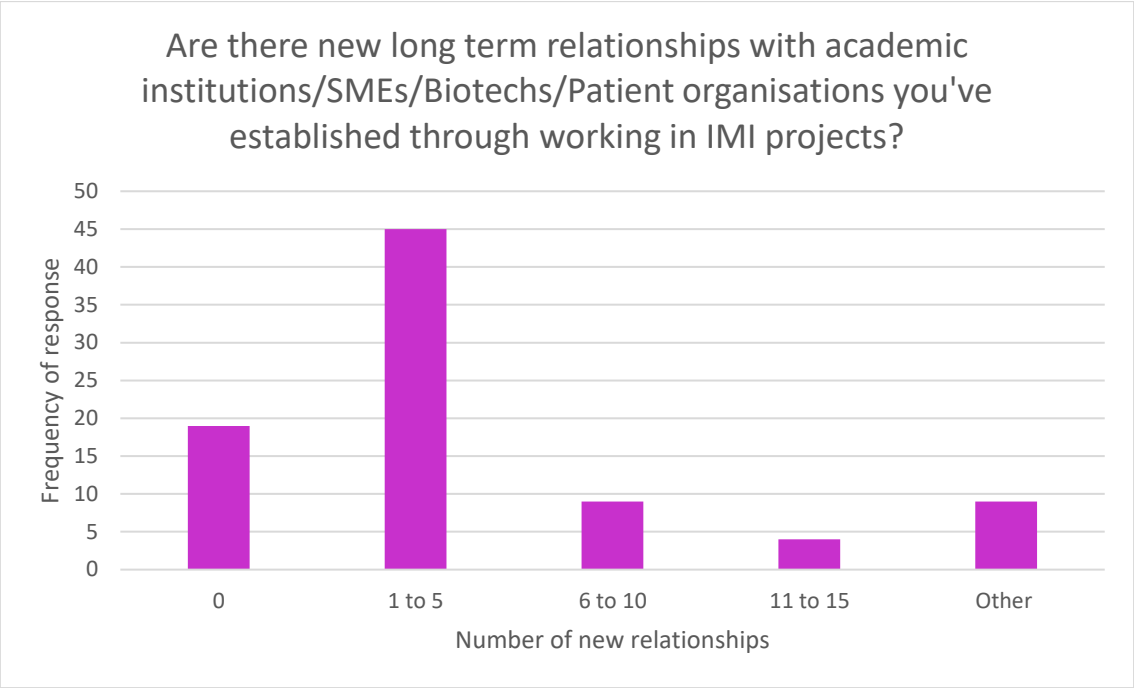


Figure 15. Frequency of numbers of new long-term relationships with academic institutions, SMEs, Biotechs and patient organisations

3.1.3 Individual impact

When asked to rate the impact of IMI on daily tasks, the results were mixed. Most respondents (34%) selected 'neutral impact', followed by a degree of impact (24%) and no impact (21%). (See Figure 16). Also, 60% of respondents said there are no tasks they do differently and nearly half said there are not new tools/datasets/knowledge generated through an IMI project that they use for their daily work, while 38% said there was and 14% said I don't know. 36% of respondents took the time to use free text to highlight and share the impacts on their daily tasks. These are summarised in Figure 17. This perhaps indicates a high level of engagement.

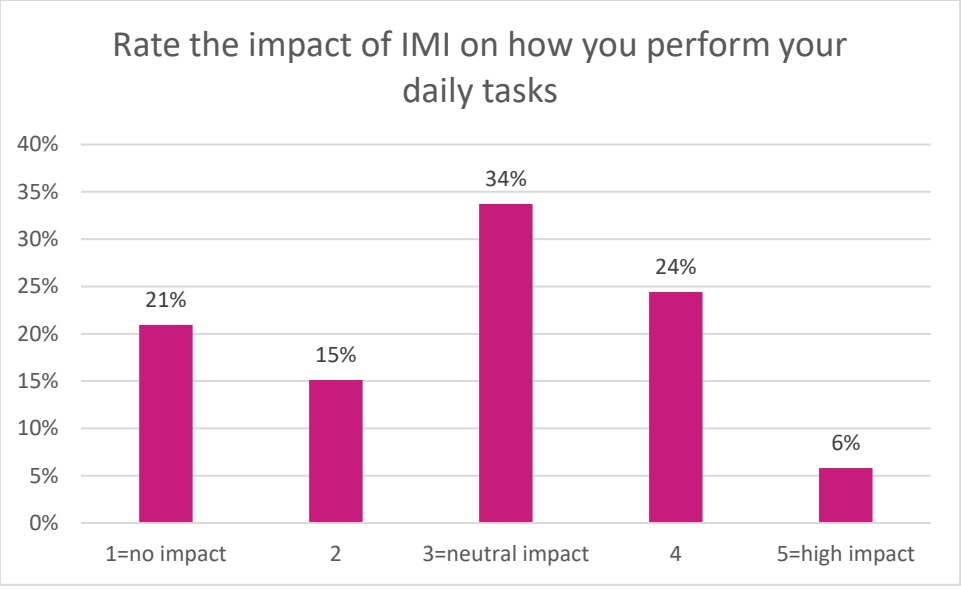


Figure 16. Impact of IMI on daily tasks

Impacts on daily tasks due to participation in Neurodegeneration IMI projects

Positives:

- Strategic insight provided by interaction with HTA and regulators
- Collaborative aspect- a different and fresh perspective, access to knowledge, common and improved protocols, learn things from others in the group
- Pay more attention to detail
- Increased awareness of platform trials
- Data collection- increased awareness of importance and collaborations there to help do it
- Expanding network and therefore awareness of things going on
- Better understanding of modus operandi of stakeholders outside of the manufacturing space
- Valuable interaction with SME, and gain intelligence on research activities
- Access to key opinion leaders
- Access to patient voice
- Access to scientific knowledge- easier to access non-published material
- Mixed group to learn new things and broader topics

Negatives:

- Higher administrative burden- more meetings, time reporting and some meetings have limited points of engagement
- Only indirect benefits- no dedicated resources, fragmented allocation and less internal coordination

Figure 17. Impacts on daily tasks

In relation to this, 76% of respondents said they get support from their manager. Respondents who selected 'other' (7%) could use free text to specify. Their answers ranged from 'the support included more senior people' to 'supportive in theory but no resource commitment or adjustment to other deliverables'. Additionally, 60% of respondents said they received appreciation from their employer for working on these projects and 48% said they had sufficient resources and time to fulfil their assigned tasks for the project. However, 40% of respondents selected 'no, mostly on top of my other activities'.

In terms of how IMI has improved their skill set, 84% of respondents (n=72) answered this and all with positive attributes. These were thematically analysed and the most frequent theme was collaboration for problem solving/networking/communicating externally/project management (Table 1).

Table 1. Themes and frequencies of answers given when asked how IMI had impacted skillset. N=72

Theme describing how IMI has improved their skill set	Frequency	Percentage of N=72 (%)
Collaboration for problem solving/networking/communicating externally/project management	45	63%
Improved understanding of neurodegenerative disease field/current data and issues	17	24%
Knowledge of and access to new techniques/tools/data analytical methods	11	15%
Understanding of current research activities	1	1%
Not applicable	14	19%
Total	**72**	**100%**

Additionally, 80% of respondents (n=69) said that IMI had expanded their (scientific) horizon and described how. Their answers were categorised as themes which are shown in Table 2.

Table 2. Themes and frequencies of answers given when asked how participation in IMI had expanded horizons. N=69

Theme describing how IMI has expanded horizons	Frequency	Percentage of N=69 (%)
Broader perspective and understanding alternative approaches by interacting with external colleagues	19	28%
Understanding research landscape	12	17%
Learning from experts in the field	9	13%
Expanding network	6	9%
Exposure and access to novel research techniques and technologies	5	7%
Knowledge of unpublished data	2	3%
Interaction with academic partners	1	1%
Total	**69**	**100%**

When all respondents were asked if any new opportunities came their way directly or indirectly through participation in an IMI project, the majority (53%) said no.

3.1.4 Scientific impact

On the whole there was greater internal company awareness of assets generated through IMI projects that respondents had been involved with, compared to assets from projects they were not involved with. See Figure 18 and Figure 19.

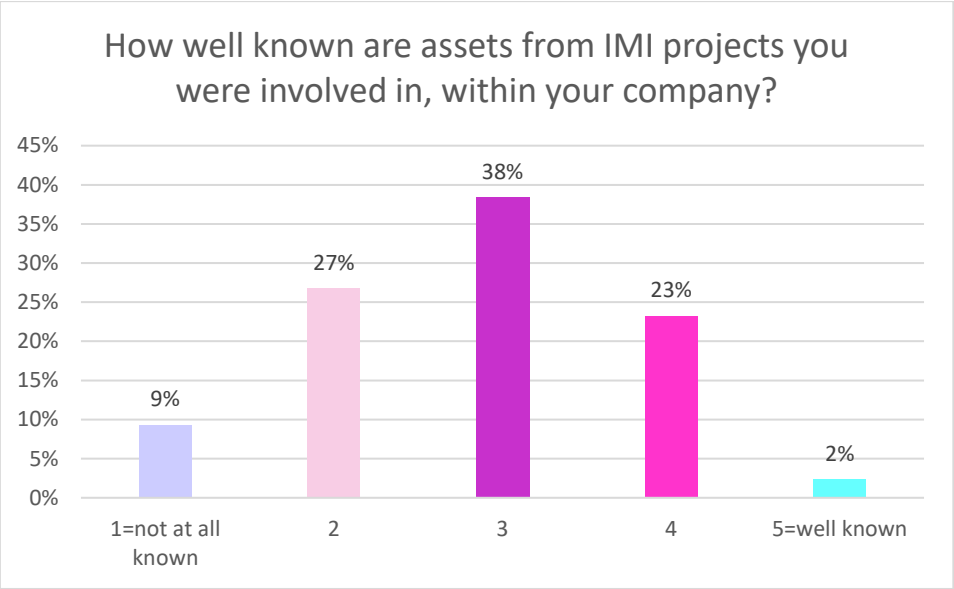


Figure 18. Company knowledge of assets generated through projects that the respondents had been involved with

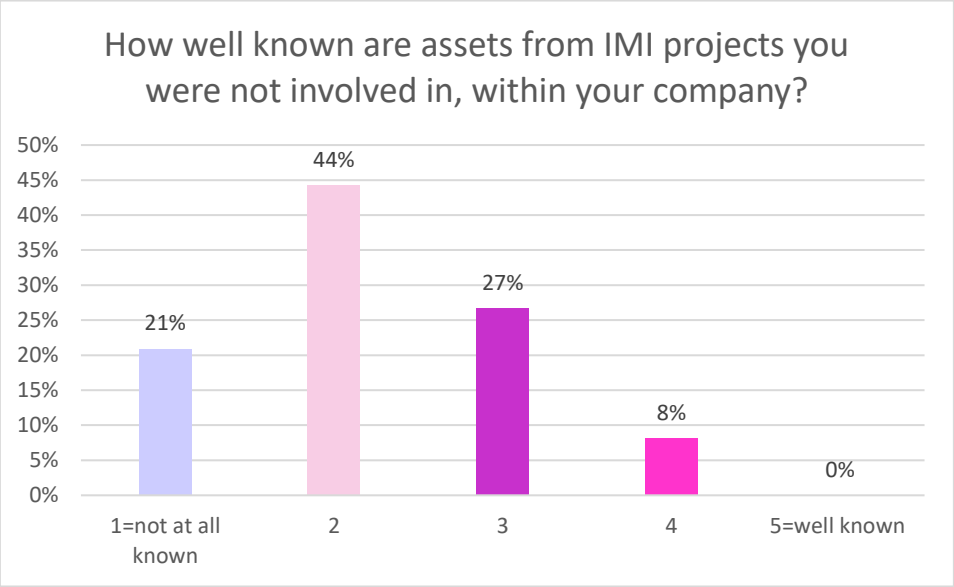


Figure 19. Company knowledge of assets generated through projects that the respondents had not been involved with

Respondents were not sure if assets were re-used within research and development or if their company helped in sustaining project assets with 45% and 69% respectively selecting 'I don't know'. Most respondents (53%) were not sure if there is a central database within their company that contains information of assets generated in Neurodegeneration IMI projects. Respondents (42%) were also not sure if results were changing the way that R&D is being conducted.

Overall, 56% of respondents provided insight into what is possible now, that wasn't possible before these IMI projects and the key themes are shown in Figure 20.

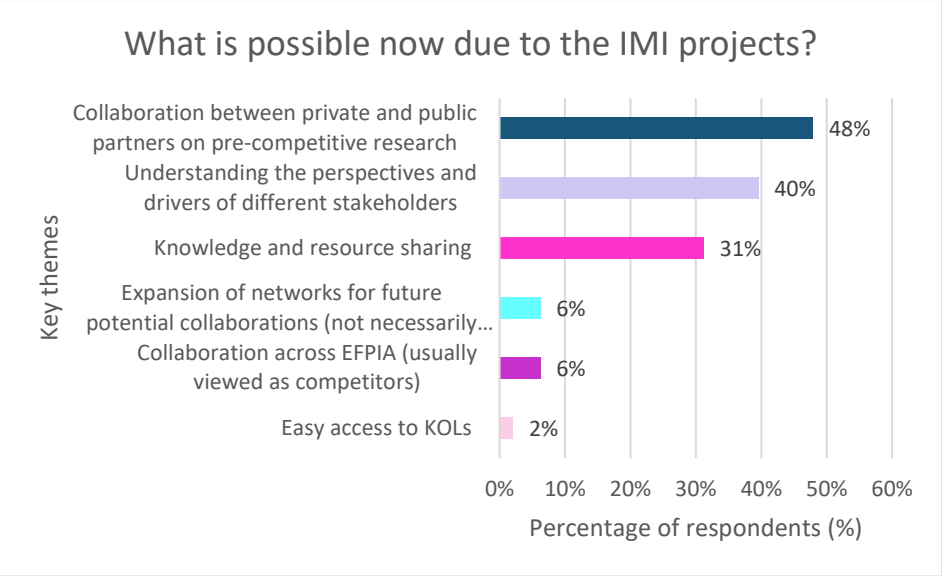


Figure 20. Frequency of key themes analysed from respondents answers to what is possible now that was not pssible before IMI projects

3.1.5 Policy impact

In terms of impact on policy, respondents were asked if the results of the projects had an impact on regulatory practice. The majority of respondents selected 'I don't know' (48%), with similar numbers of respondents selecting yes and no (26% and 27% respectively).

3.1.6 Patient impact

Respondents rated the societal impact (1-5). This included if the general public and participants had been involved in the research, if it had given them a voice, better informed the public on ongoing research and results and paved the way for new patient-relevant treatment modalities. On average people selected neutral impact or a degree of impact (Figure 21). An equal proportion of respondents (40%) selected 'yes' and 'I don't know' to whether these projects had brought science closer to patients and the general public (Figure 22).

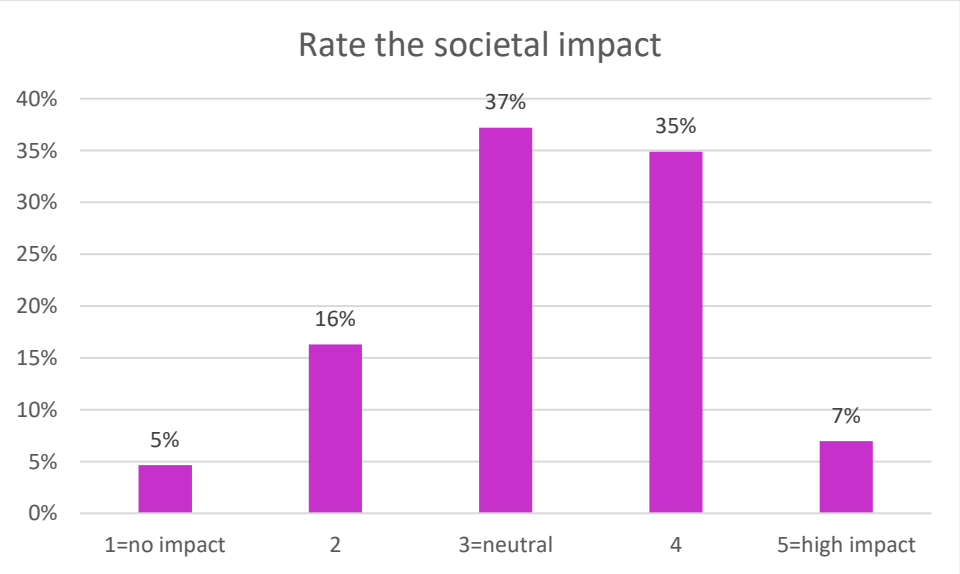


Figure 21. The societal impact of the IMI projects rated 1-5 with 1 being no impact and 5 being high impact.

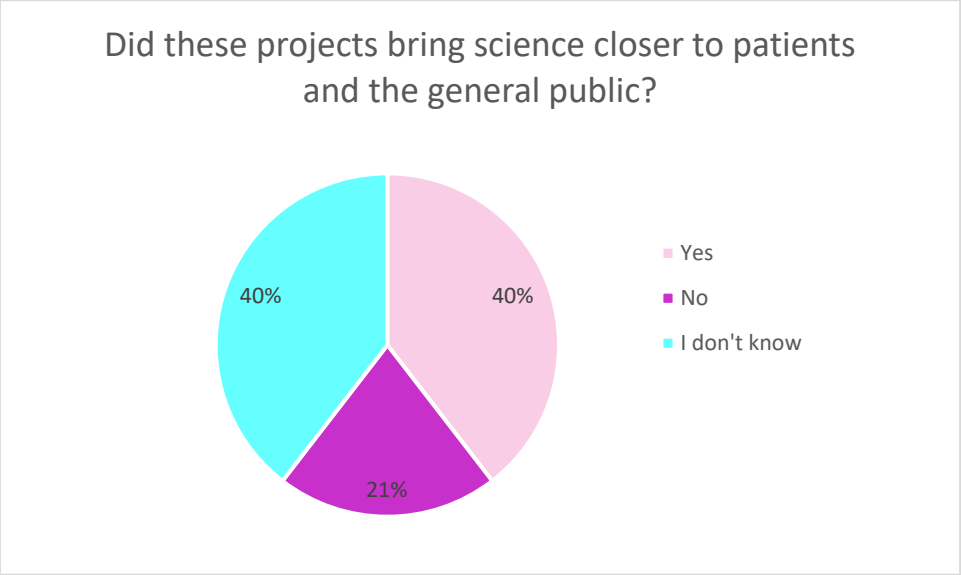


Figure 22. Whether the IMI projects brough science closer to patients and the general public.

3.1.7 Public health impact

The majority of respondents (55%) were not sure if the project had an impact on public health and more people selected 'no' than 'yes'. See Figure 23.

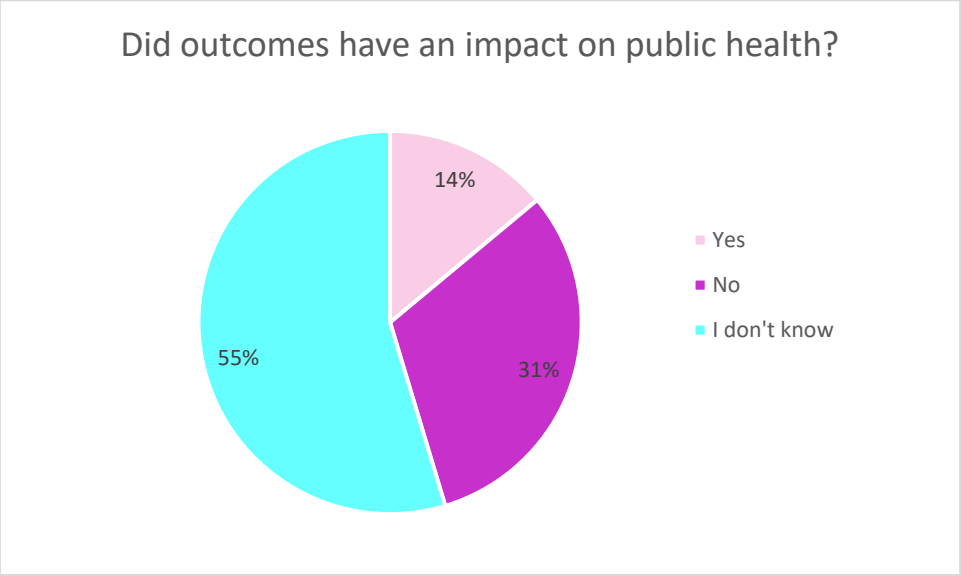


Figure 23. Whether project outcomes had an impact on public health.

3.1.8 Advantages of participation in IMI ND projects

Of the 86 respondents, 82 (95%) felt that there were advantages associated with being involved in IMI ND projects. The main advantages cited by the respondents are presented in Figure 24, with almost half (49%) citing "collaboration and networking" as an advantage closely followed by "access to knowledge or expertise or resources or tools" which was mentioned by 42% of respondents. Other advantages that were mentioned were "increased visibility of companies", "risk-sharing between with consortium partners" and "innovation".

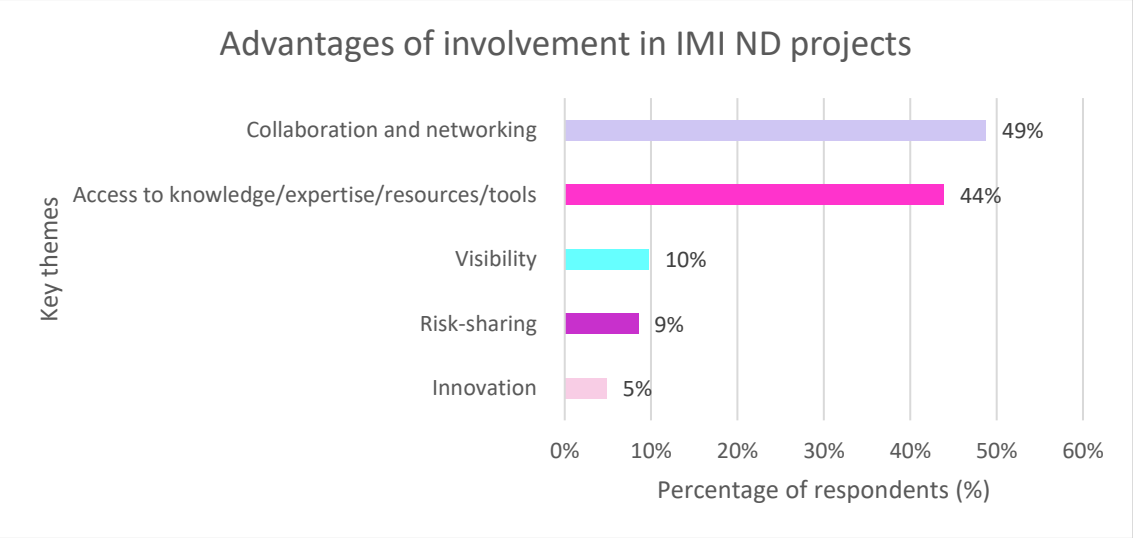


Figure 24. Main advantages of being involved in IMI ND projects

Examples of advantages respondents gave are:

"Acquiring and sharing knowledge and tools in a highly collaborative mindset." **EFPIA survey respondent**

"Improved networking; pre-competitive alignments and collaborations (reduce redundant R&D); boost company image for R&D." **EFPIA survey respondent**

"Discussions with experts in a specific field to solve rapidly existing experimental difficulties." **EFPIA survey respondent**

3.1.9 Disadvantages of participation in IMI ND projects

When asked about disadvantages of participation in IMI ND projects, 71% of responders cited the disadvantages presented in Figure 25, 19% stated they did not think there were any disadvantages, while 10% provided no response.

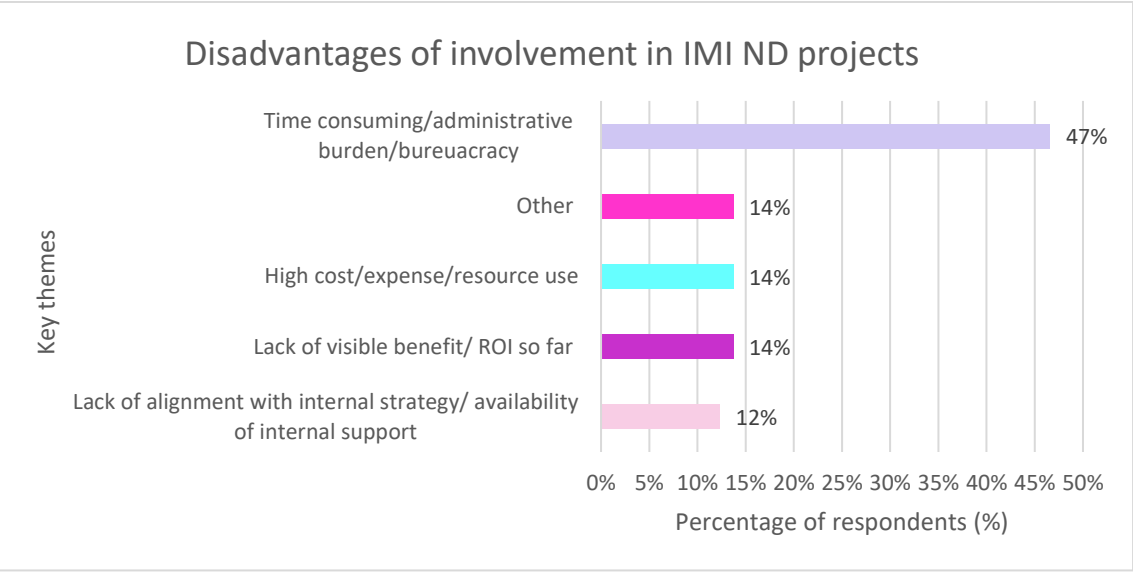


Figure 25. Main disadvantages of being involved in IMI ND projects

Examples of disadvantages respondents gave are:

"Deviation of original plan due to continuous negotiation with public consortium leading to dilute results after 5 years." **EFPIA survey respondent**

"Requires more effort and time than initially though it would take to positively contribute to the projects." **EFPIA survey respondent**

"Workload related to high documentation requirements." **EFPIA survey respondent**

3.2 Association between key areas of impact with job role and time on projects

Survey questions deemed key impact areas were the impact of the IMI ND projects on a company's presence/visibility/public perception and the establishment of strategic partnerships. The former is categorised as organisational impact and the latter as collaborations, networks and partnerships.

WP1 agreed that it would be interesting to determine if perceived impact in these areas differed by project role or time spent on project. Therefore, the impact ratings for both of these were stratified by project roles and average weekly hours spent on IMI projects.

The survey asked how many projects the respondent had been Project Lead, Work Package Lead and Task Lead. For the purposes of this analysis these were turned into binary variables either never had the role or had the role at least once. N=31/86 (36%) of respondents had been Project Lead at least once, n=43/86 (50%) had been Work Package Lead at least once and n=42/86 (49%) had been Task Lead at least once.

3.2.1 Organisational impact- Company's presence/visibility/public perception

Impact on the company's presence/visibility/public perception by whether the respondent had been Project Lead (Figure 26), Work Package Lead (Figure 27) and Task Lead (Figure 28) reveal a mixed association between impact rating and project role. In all cases more of those who had roles rated the impact a 4 compared to those without formal project roles. This was especially prominent among Work Package and Task Leads. However, only Task Leads gave more 'high impact' ratings with fewer Project Leads and Work Package Leads rating the impact a 5 compared to those without the roles. If anything, many more non-role respondents rated the impact as high compared to the Project and Work Package Leads.

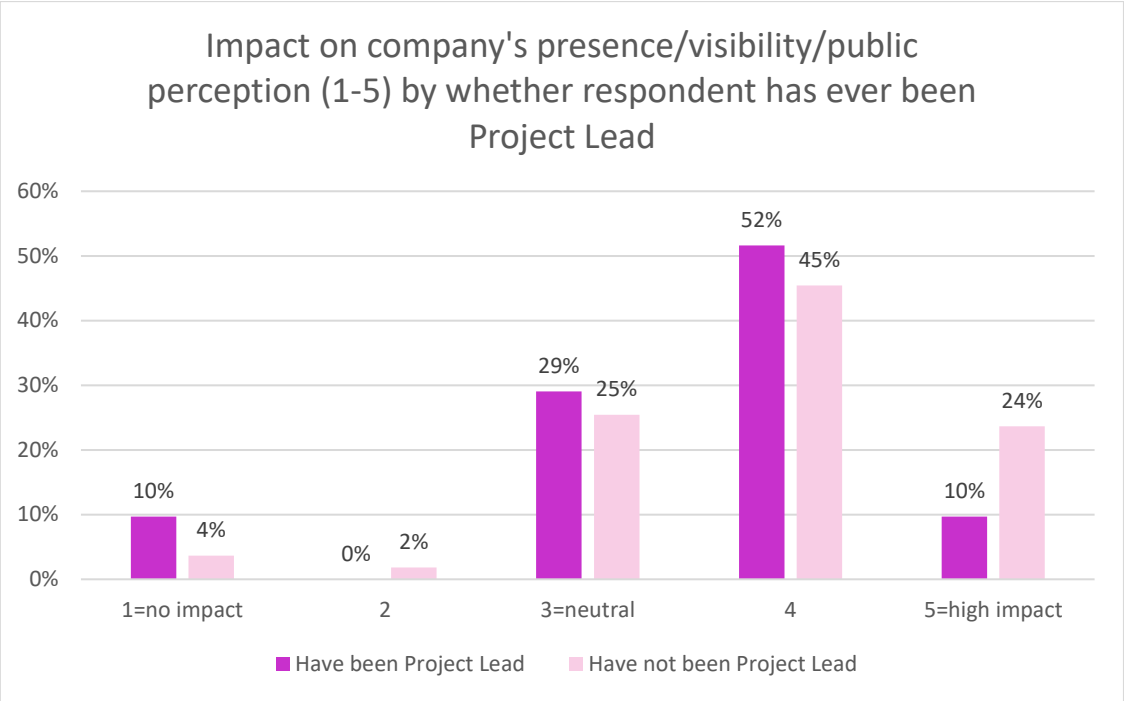


Figure 26. Impact on the company's presence, visibility, and public perception by whether the respondent had been Project Lead

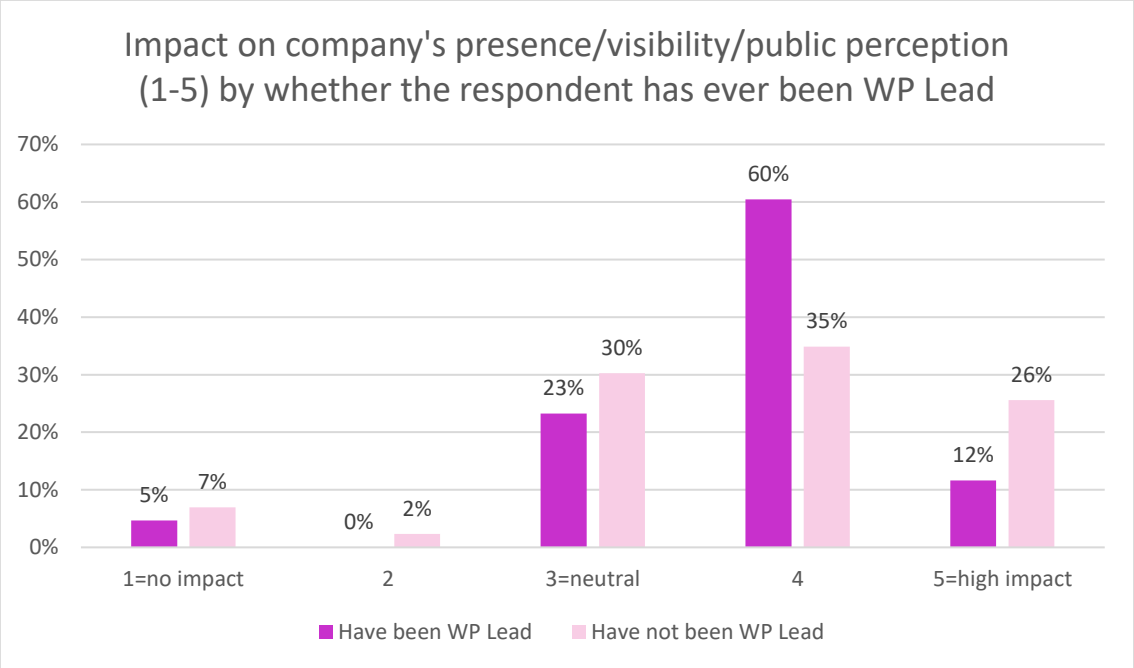


Figure 27. Impact on the company's presence, visibility, and public perception by whether the respondent had been Work Package Lead

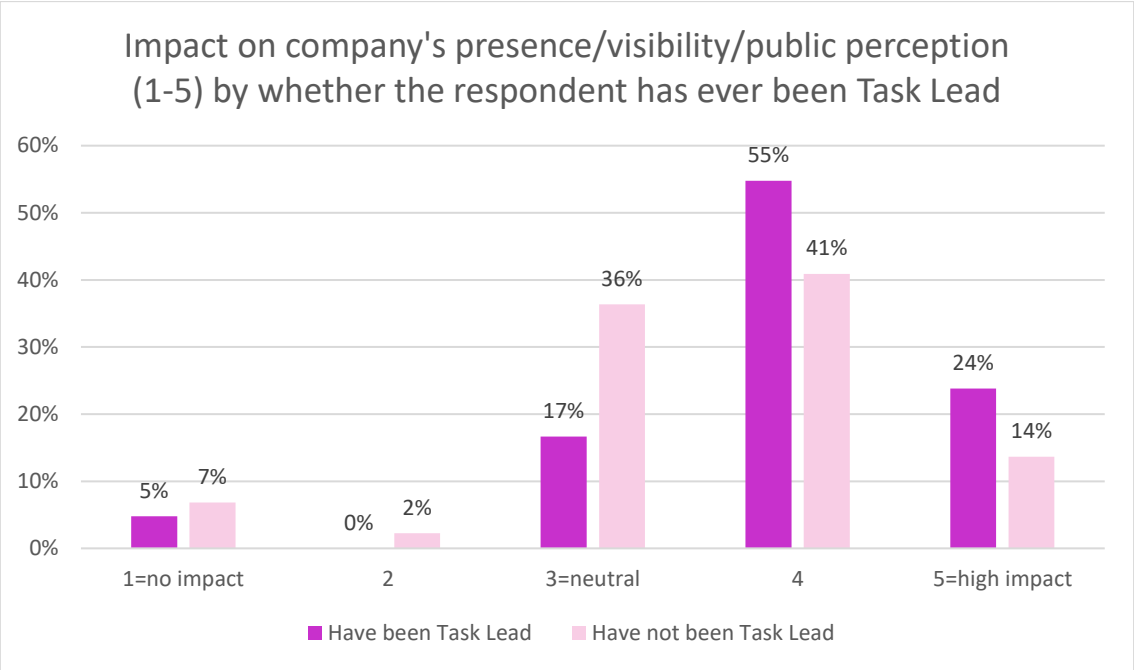


Figure 28. Impact on the company's presence, visibility, and public perception by whether the respondent had been Task Lead

This was explored further by looking at the perceived impact by average weekly hours worked on the project. Ratings of 1 (no impact), 2 and 5 (high impact) were similar regardless of hours worked. However, neutral impact was more common among those who worked less than 2 hours a week on the project and a rating of 4 was more common among those who worked more than 2 hours a week.

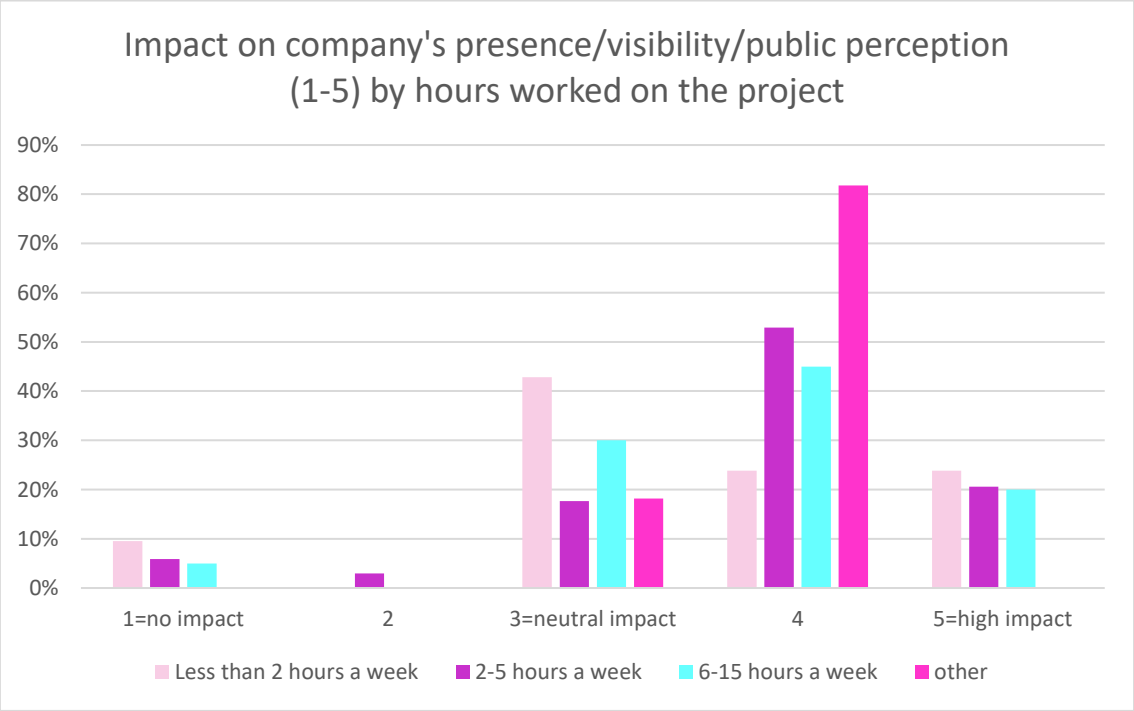


Figure 29. Impact on company's presence, visibility, and public perception by average weekly hours worked on the project

The results reflect a loose trend that those who had formal roles and those who spent more time each week working on the project thought there was a higher perceived impact on the company's presence/visibility/public perception.

3.2.2 Collaborations, networks and partnerships- Establishment of strategic partnerships

There was no great difference in perceived impact on establishing strategic partnerships by whether a respondent had been Project Lead (Figure 30), Work Package Lead (Figure 31) or Task Lead (Figure 32). For Project Lead there was a slight skew towards less impact. Ratings of 4 and 5 were slightly more common among Work Package Leads compared to those who had not been, and results were very similar between those who had and had not been Task Lead.

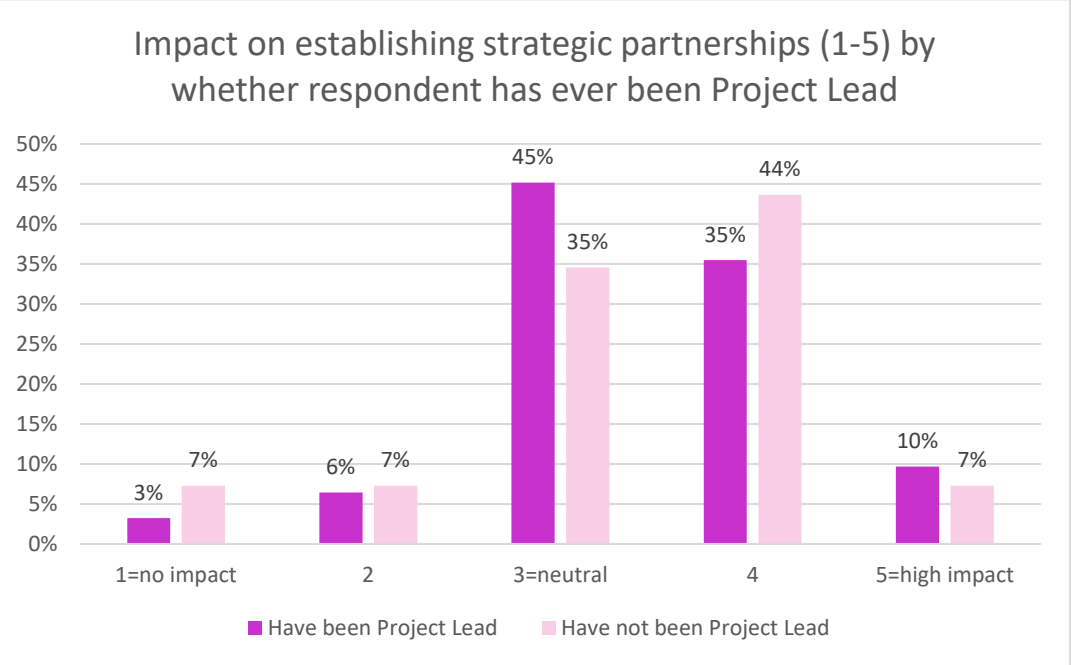


Figure 30. Impact on establishing strategic partnerships by whether the respondent had been Project Lead

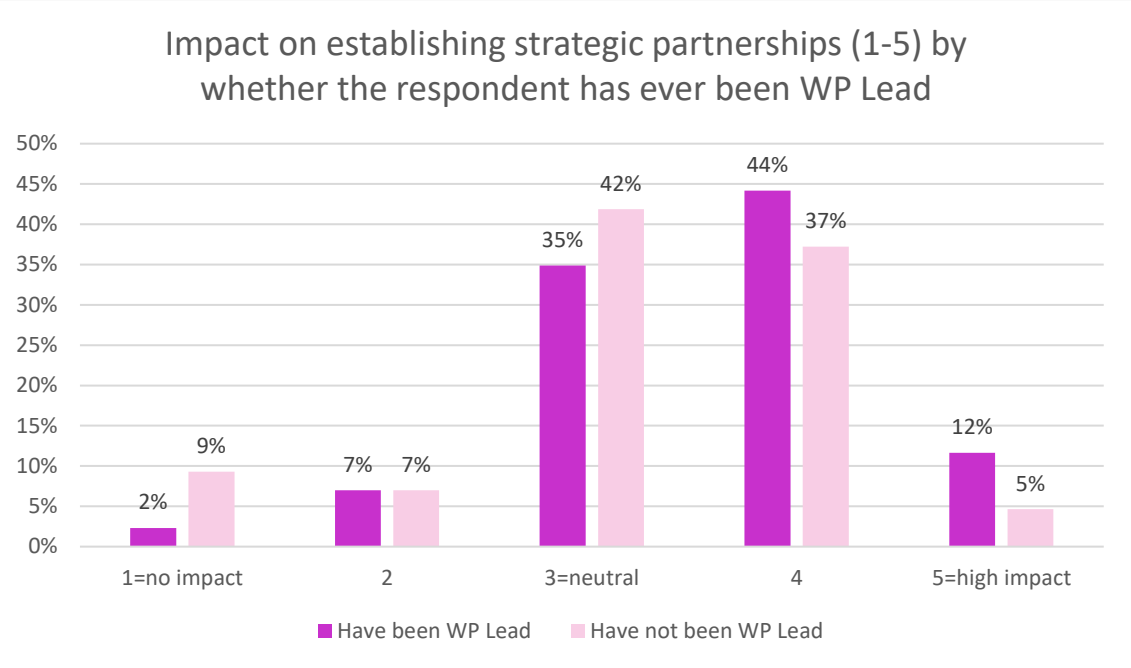


Figure 31. Impact on establishing strategic partnerships by whether the respondent had been Work Package Lead

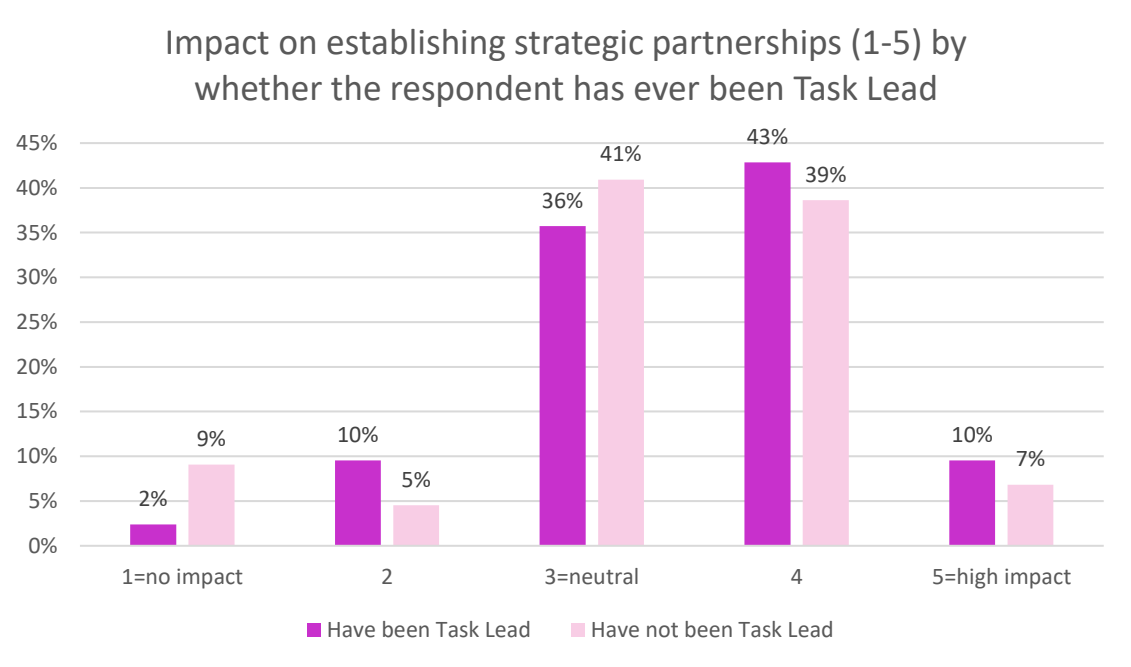


Figure 32. Impact on establishing strategic partnerships by whether the respondent had been Task Lead

Higher impact ratings were more common among those who spent more time working on the project (Figure 33). Over half of those who worked less than 2 hours a week rated the impact as neutral compared to over half of those who worked 6-15 hours a week rated the impact as moderate.

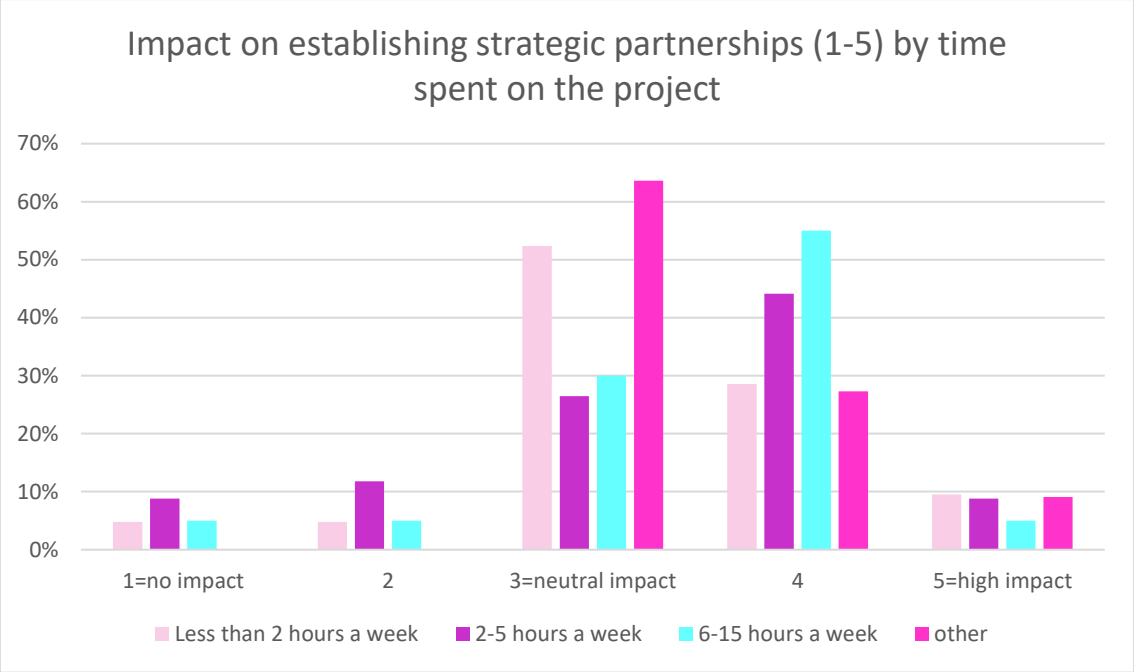


Figure 33. Impact on establishing strategic partnerships by average weekly hours spent on project

3.2.3 Economic impact- return on investment

There was no difference in perceived return on investment by whether someone had been Project Lead or not. There were slight differences in impact ratings by those that had been Work Package and Task Lead with results skewed to slightly higher impact ratings for Work Package Leads (compared to non-Work Package Leads) and slightly lower for Task Leads (compared to non-Task Leads). Overall there was no clear association. All graphs are in Annex V, section 8.5.2.

There was also no clear trend between increasing weekly time spent on project and greater perceived impact on ROI. Graph in Annex V, section 8.5.2.

3.3 Non-EFPIA survey

3.3.1 Survey respondents

A total of 43 responses were received and 42 were included in the analysis, since one responder stated that they were from an EFPIA partner organisation and therefore the questions were not suited to them. The 42 respondents to the non-EFPIA survey were from a range of roles, see Figure 34. The highest number of responses were from Principal Investigators (38%), followed by PhD students and Project Managers (both 19%). A smaller number of post-doctoral researchers/researchers and clinicians also responded (10% and 7% respectively). An additional 7% of respondents provided an 'Other' job role; the individual job titles have not been reported here to maintain anonymity. There was an even split in the time non-EFPIA survey respondents spent working on IMI ND projects across the three categories presented to them (see Figure 35). A third of respondents spent 5-10% of their time, another third spent 10-50% of their time, and the final third spent more than 50% of their time working on IMI ND projects.

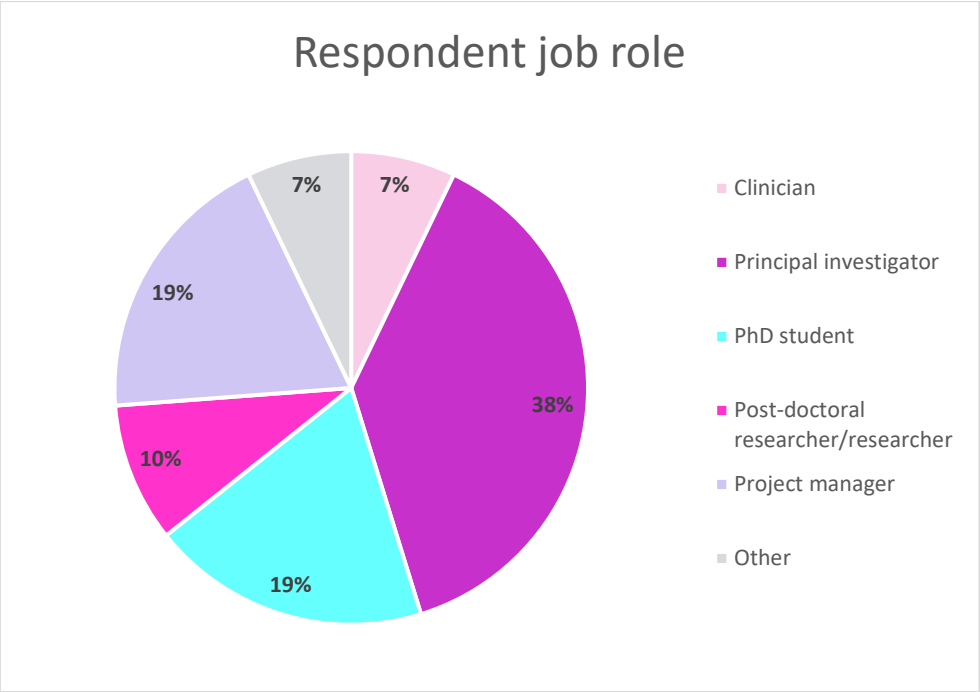


Figure 34. Survey respondent job roles.

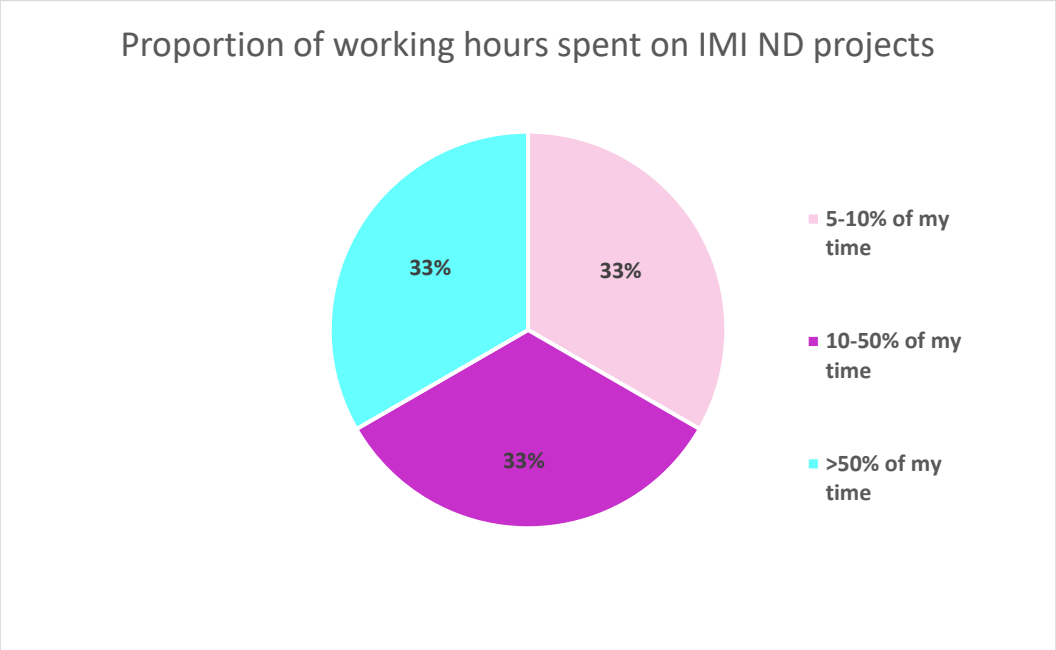


Figure 35. Proportion of working hours spent on average on IMI neurodegeneration projects

3.3.2 Organisational impact

The majority (88%) of non-EFPIA survey respondents felt that involvement in IMI ND projects has resulted in some level of organisational impact, see Figure 36. Most felt that there had been a 'slight' (45%) or a 'moderate' change (33%) to their department or organisation. A smaller number saw either a 'radical' change or no impact at all (10% and 12% respectively).

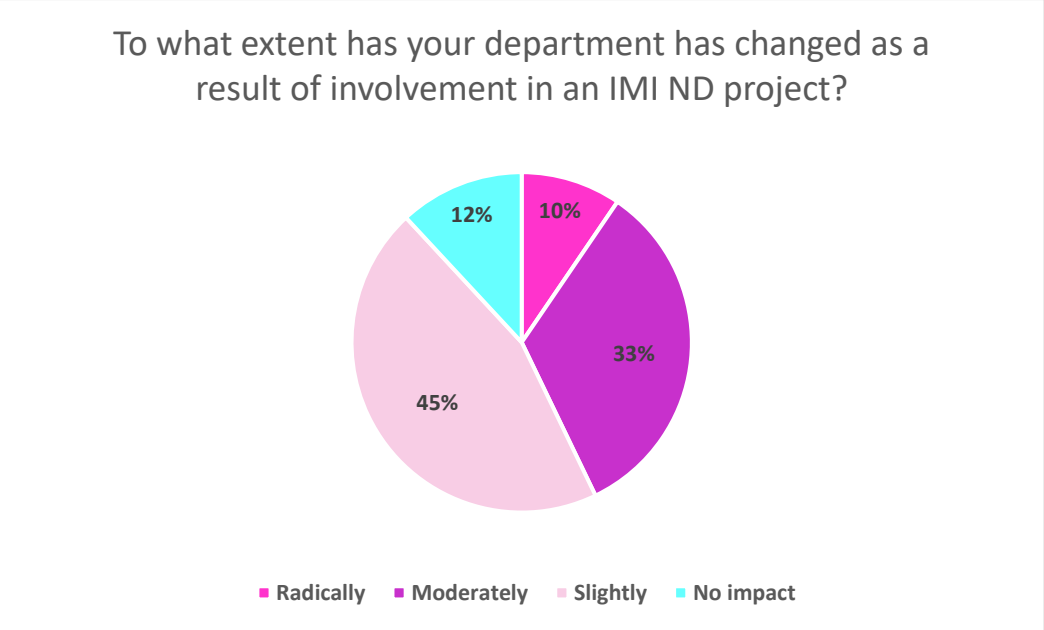


Figure 36. Extent department has changed (e.g. size, structure) as a result of involvement in an IMI ND project.

Nearly two-thirds of respondents reported an increase in the number of staff and/or an expansion to current research lines, see Figure 37. While nearly half of respondents reported that involvement had led to the creation of new research lines (45%) and/or an improvement in global positioning (43%). Over a third (38%) also saw new contracts or funding opportunities in their organisation as a result of being involved in IMI ND projects.

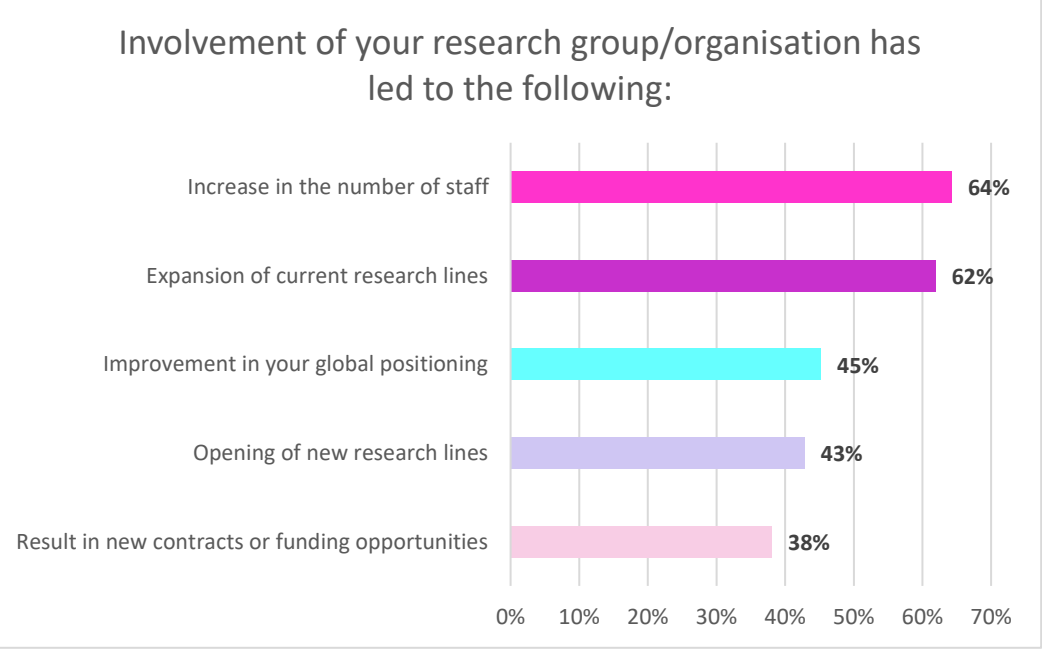


Figure 37. What the involvement of research group or company in IMI neurodegeneration projects has led to

Other organisational impacts described by respondents include being able to finance staff locally and diversify the staff involved in projects.

3.3.3 Collaborations, networks and partnerships

All survey respondents reported meeting new people from other organisations as a result of working on IMI ND projects, and nearly half also met new people in their own organisations, see Figure 38. Collaborations and networking were seen a key advantage of being part of an IMI ND project see Figure 49.

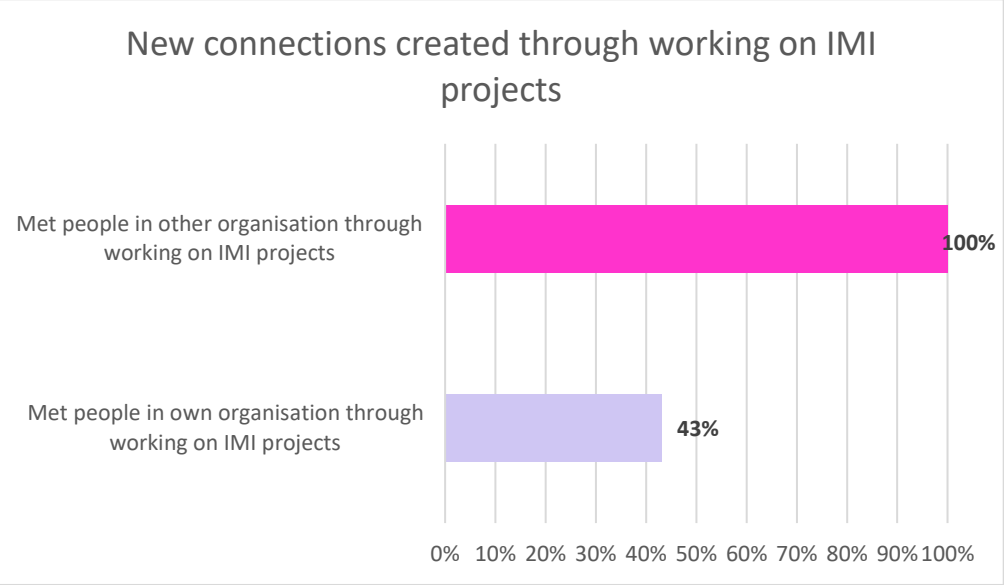


Figure 38. New connections created through working on IMI projects

Figure 39 summarises some of the impacts these new connections have resulted in. The most common type of collaboration has been with academic partners, followed by EFPIA partners and then SMEs.

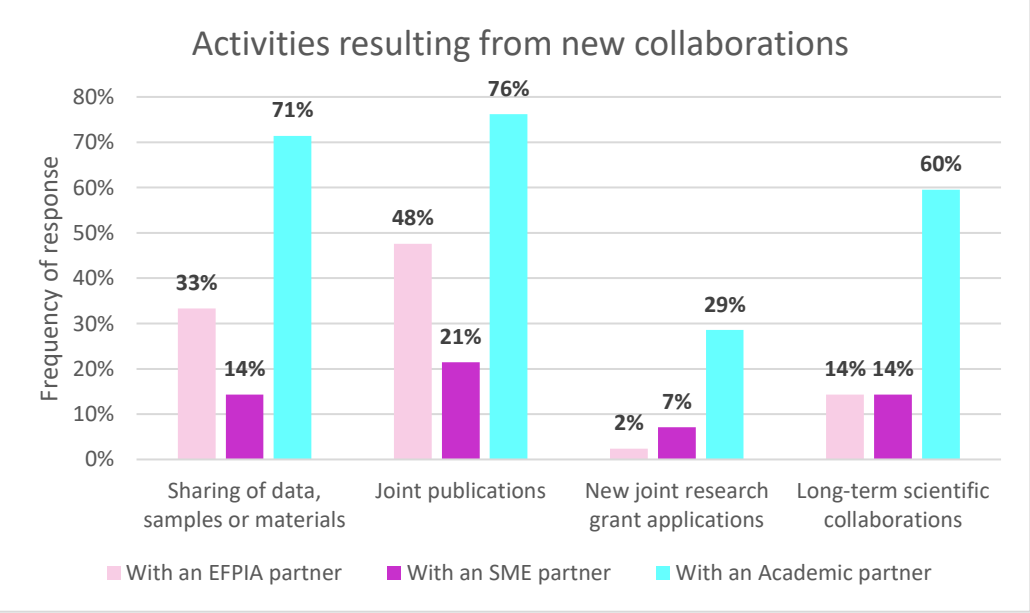


Figure 39. Types of new collaborations with Academic, SME or EFPIA partners

Around three quarters of respondents had shared data, samples or materials and/or had joint publications with academic partners and nearly two thirds (60%) had developed long-term

scientific collaborations. Nearly a third of respondents (29%) had also been involved in a new joint research grant application with an academic partner.

A third of respondents (31%) had some form of interaction with a regulatory or health technology assessment body in relation to IMI ND research, see Figure 40.

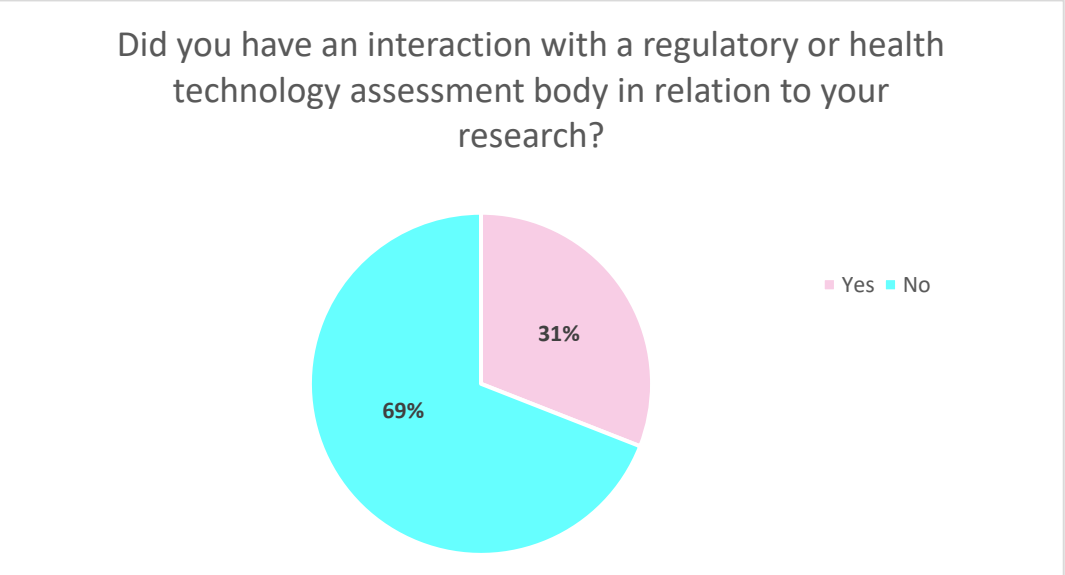


Figure 40. Interaction with a regulatory or health technology assessment body in relation to research

3.3.4 Individual impact

The majority of respondents felt that involvement in IMI ND projects has resulted in a beneficial impact on their career, see Figure 41. Over half of respondents had presented at scientific conferences, published peer-reviewed publications or had new professional opportunities as a result of involvement in an IMI ND project, see Figure 42. Additionally, 29% of respondents had also worked on a new product or using a new technique through their involvement.

Qualitative findings suggest that the benefit of being involved in am IMI ND project may have been particularly useful for early career researchers who, as described by one respondent, were provided with a ‘unique scientific and networking opportunity’.

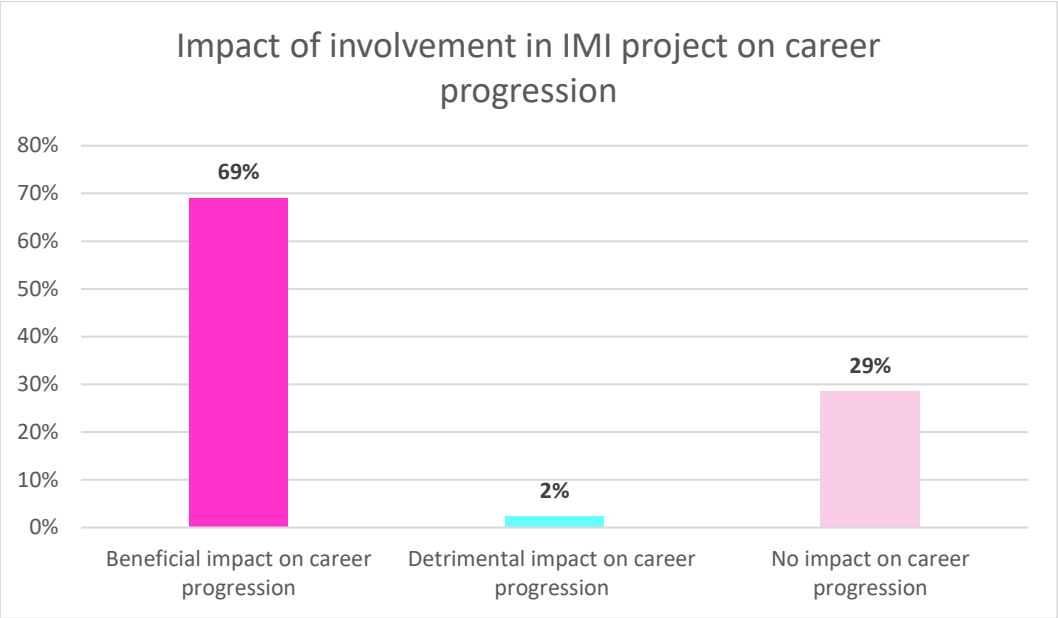


Figure 41. Impact of involvement in IMI project on career progression

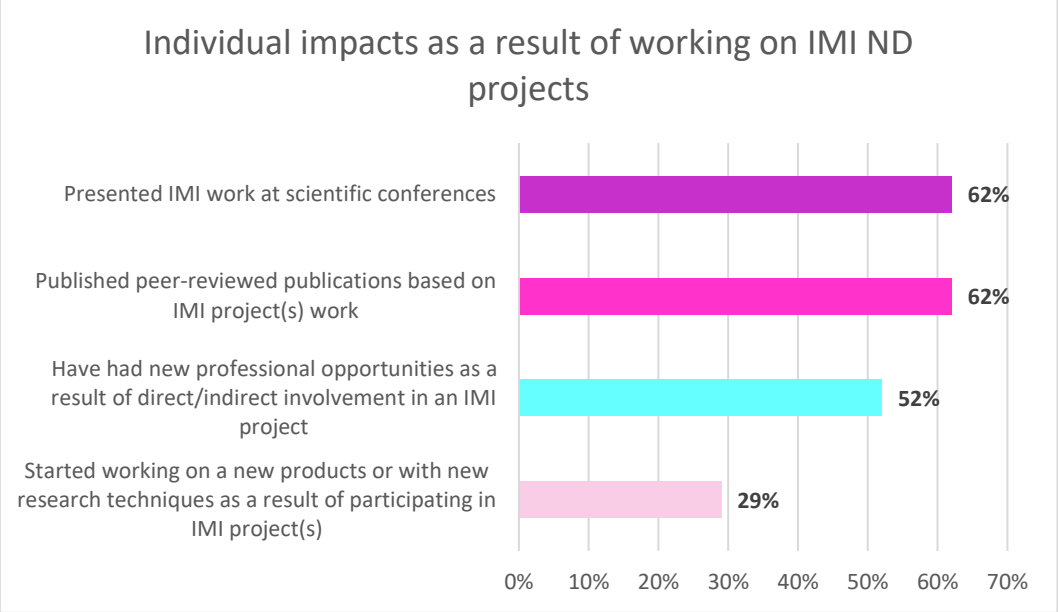


Figure 42. Impacts on individuals as a result of working on an IMI ND project

Approximately a third of respondents felt that being involved in IMI projects had no impact on their career, and one respondent reported their involvement having a negative detrimental impact on their career, see Figure 41.

3.3.5 Scientific impact

A quarter of respondents (26%) felt that results of the IMI ND projects had impacted the way science/drug development is being conducted, see Figure 43. A further quarter (24%) felt it had no impact on this and half were not sure.

Examples given of the changes to Science/drug development due to the results of IMI projects included:

- Advances to and implementation of new technologies e.g. IDEA-FAST
- More focused work e.g. focus on a digital biomarker, or greater focus on multiple targets
- More rigorous processes
- More integrated approaches
- Higher level and more global thinking
- Highlighted challenges in using multiple technologies with physically impaired samples
- Project results will be used to inform future work

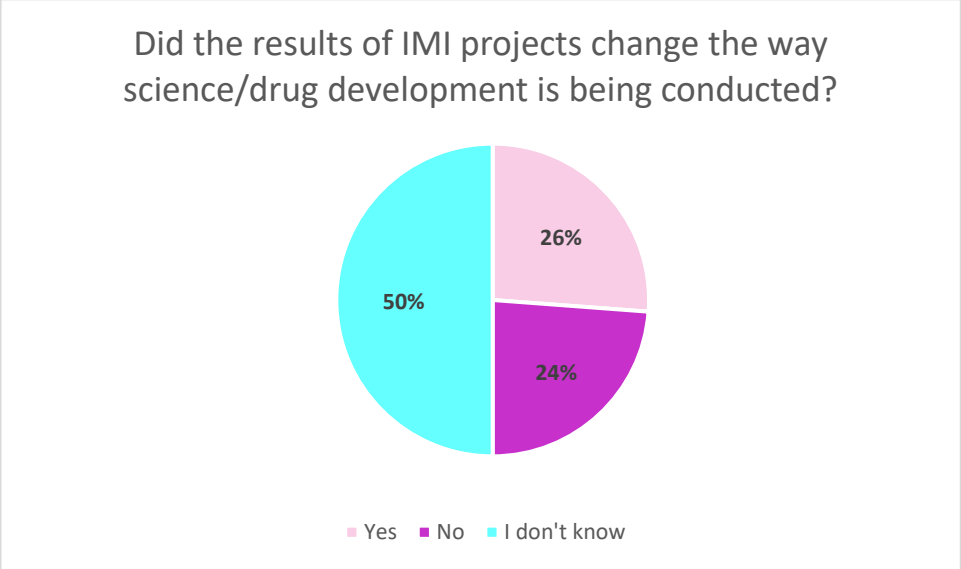


Figure 43. Whether the results of IMI ND projects have impacted the way science/R&D is being conducted

The majority of respondents were aware of project assets from other projects as well as their own, see Figure 44. 60% were aware of 'a few' assets from other projects, while 14% were aware of 'many' assets from other projects. Only a quarter of respondents were unaware of other projects' assets.

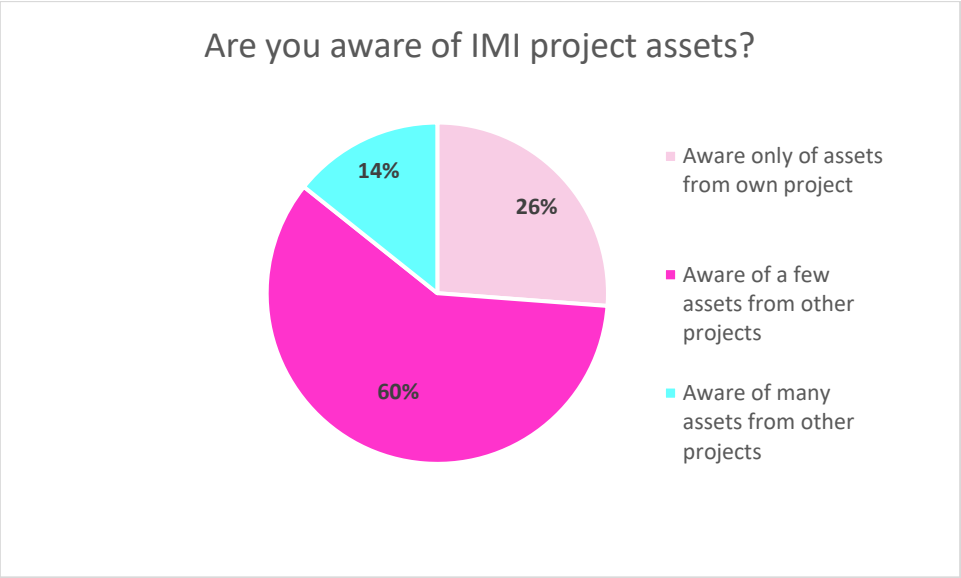


Figure 44. Awareness of IMI project assets from own or other projects

The majority (93%) of respondents had not received requests for assets from other organisations, see Figure 45.

Figure 45. Received request for assets from other organisations

3.3.6 Patient impact

Overall, 43% of respondents felt that the IMI ND projects they had worked on had successfully brought science and patients and the public closer together, see Figure 46.

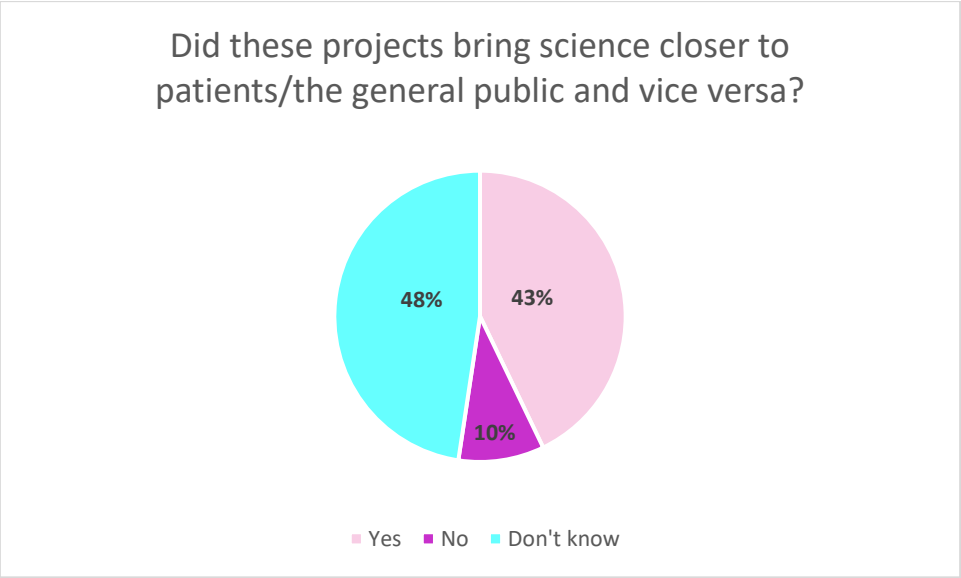


Figure 46. Impact of IMI ND projects on brining science and patients/the public closer together

Those who felt that the IMI ND projects had brought science and patients and the public closer together, felt it did so through:

- Putting Patient and Public Involvement and Engagement (PPIE) at the core of activities, including study design and communication
- Having high levels of contact with patients and patient representatives
- Ongoing and wide dissemination of results
- Outreach activities such as small group meetings, newsletters, conferences, public discussions and seminars

One respondent noted that they did not feel the project had brought science and the public together yet, but there was a vision to do so once more solid results were available.

3.3.7 Societal Impact

Around 78% of respondents rated the level of societal impact they felt IMI ND projects had as a 4 or 5, where 5 meant high impact. Only 4% of respondents rated the societal impact as 1 or 2, where 1 meant no impact, see Figure 47.

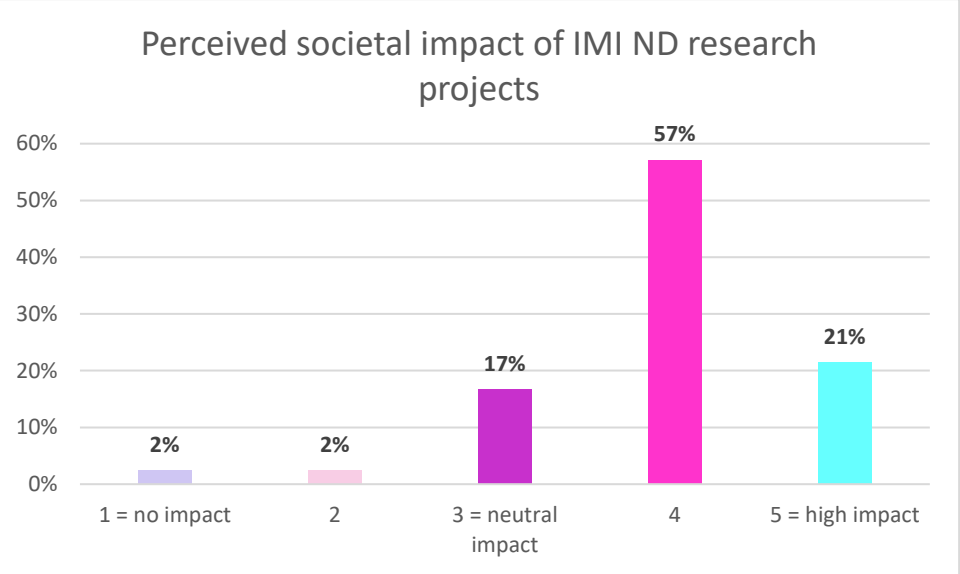


Figure 47. Perceived societal impact of IMI ND research projects

3.3.8 Health impact

The majority of respondents (60%) were not sure if the outputs from the IMI project(s) they worked on had an impact on public health, see Figure 48, while 17% felt they had not had an impact and 24% felt they had. This included two respondents who thought that though they hadn't had an impact on public health yet, they would in the future.

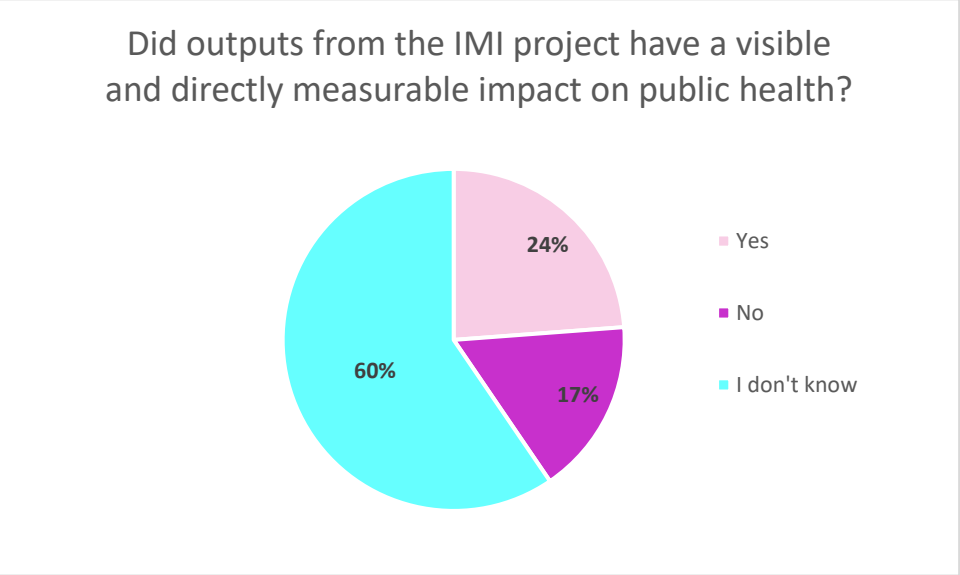


Figure 48. Impact of outputs of IMI ND projects on public health

Examples of impact on public health included:

- Amyloid PET becoming routine in clinic
- Possible new guidelines for application of digital health tools in mobility
- A new hypothesis based on IMI findings currently being tested clinically
- Increased outreach, interest and knowledge including a number of peer-reviewed publications

3.3.9 Advantages of participation in IMI ND projects

Opportunities for networking and collaborations was the most commonly cited advantage of being part of an IMI ND project, see Figure 49. Survey respondents stated that they welcomed the chance to build global relationships, have greater exposure to industry and regulatory bodies and strengthen intra-institute relationships.

Figure 49. Perceived advantages of participating in an IMI ND project. Larger font size indicates more frequent mentions

Respondents mentioned a series of other advantages on the theme of collaboration including being able to work with or have access to world leading experts and key opinion leaders on topics, share knowledge, increase experience, and innovate.

A further area that respondents reported advantages in was within research practices and processes. Involvement in IMI projects was seen to provide access to larger sample sizes, image and data sets, and help improve research structures through sharing of best practice.

3.3.10 Disadvantages of participation in IMI ND projects

Only a small proportion of respondents (n= 11, 26%) reported disadvantages of participating in an IMI ND project, and several respondents said they felt there were no disadvantages to being involved.

Figure 50 illustrates the main disadvantages highlighted by respondents. Bureaucracy, increased workload and complex co-ordination were the most commonly cited disadvantages. Respondents spoke of the large volume of additional administration required including significant reporting requirements:

"HUGE amount of reporting required by IMI, well above and beyond other H2020 funding schemes." **Non-EFPIA survey respondent**

One respondent noted that the work was particularly demanding on SMEs, with no or very low profit.

Figure 50. Perceived disadvantages of participating in an IMI ND project. Larger font size indicates more frequent mentions

Co-ordination of projects was felt to be complex due to the large number of partners involved. Respondents reported that not only did co-ordination of projects require time and effort, but that at times it made delivery difficult because partners were not aligned. Tight timeframes added to this issue, and also made it hard to leverage learnings from data. Though some respondents stated the large size of the consortium/projects as an advantage due to the experience and exposure it gave, others saw it as a disadvantage:

"If too big, these projects become a series of silo projects. My experience with smaller IMI projects is much better than with larger ones." **Non-EFPIA survey respondent**

A small number of respondents commented on what they considered uneven workloads within projects, and one noted the impact of funding allocation on this:

"EPFIA contributions not clear or not very significant at times (Academic partners seem to be the most involved and put the majority of the effort)." **Non-EFPIA survey respondent**

"Some partners do much more to advance the project than others but this is not reflected in the amount of funding. So when partners delay progress due to lack of effort, it is difficult to reallocate funding to a more motivated partner." **Non-EFPIA survey respondent**

4 Discussion

4.1 Summary of key findings

4.1.1 Survey respondents' characteristics

Overall, 86 responses were included in the EFPIA analyses and 42 in the non-EFPIA analyses. The majority of EFPIA respondents were from Janssen and Sanofi and were involved in an average of 2 projects. The majority had not been Project Leader but half had been Work Package Lead. On average people spent 2-5 hours per week on IMI projects.

The 42 non-EFPIA respondents included Principal Investigators, PhD students, Project Managers, post-doctoral researchers/researchers and clinicians. A third of respondents spent more than 50% of their working time on IMI projects which is a larger time commitment than the cohort of EFPIA respondents.

4.1.2 Organisational impact

Both EFPIA and non-EFPIA respondents felt that involvement in the IMI ND projects resulted in some level of organisational impact. This included a change in the organisation, impact on strategic objectives and ways of working overall. Most EFPIA respondents thought that the projects had an impact on the company's presence, visibility and public perception, although they were unsure whether the company helped in creating awareness of project outcomes.

4.1.3 Capacity building and economic impact

Both surveys indicated a clear impact on capacity and the IMI projects led to an increase in the number of staff. Most EFPIA respondents thought that the projects had an impact on attracting talent and they were aware of people who had gone on to receive a permanent position.

The economic impact was less clear. Half of EFPIA responders thought the economic impact was neutral, with similar numbers thinking there had and had not been an impact on the return on investment. There was no clear association between project role or hours worked and perceived impact on ROI for EFPIA respondents. Approximately a third of non-EFPIA responders saw new contracts or funding opportunities in their organisation as a result of being involved in IMI ND projects.

4.1.4 Collaborations, networks and partnerships

This was a clear area of impact and both groups of respondents cited networking and collaborations as the key advantage of IMI projects. They thought the projects had impact on strategic partnerships and resulted in new long-term relationships with a variety of organisation including academic institutions and SMEs. Three quarters of non-EFPIA respondents had shared data, samples or materials within projects and/or had joint publications with academic partners. In addition, nearly all respondents reported meeting lots of new people at different organisations and within their own. For non-EFPIA respondents the new collaborations reported were mainly with academic institutions.

4.1.5 Individual impact

The impact of IMI projects on individuals was mixed. On the whole people said they didn't do tasks differently and nearly half don't use any new tools generated through the projects. Most EFPIA respondents felt being involved in IMI projects had improved their skill set and expanded their scientific horizon. However, people gave mixed responses on whether it had resulted in professional opportunities or benefitted their career. A substantial proportion of people stated

that they did not have sufficient time for the IMI projects and were doing it on top of their daily activities.

4.1.6 Scientific impact

This area of impact attracted the most 'I don't know' answers with this being the majority answer for numerous questions including any re-use of assets within R&D, companies sustaining project assets, presence of centralised databases at companies detailing assets and whether project results were changing the way R&D was being conducted (true of non-EFPIA responders too). Many respondents were aware of assets including some from other projects. The awareness is was potentially greater among non-EFPIA respondents, although this may have been due to how the question was asked. A large proportion of the non-EFPIA respondents reported an expansion to research lines and the creation of some new ones. Very few non-EFPIA responders had received requests for assets from other organisations. This suggests a need to further publicise outcomes and tools resulting from the projects.

4.1.7 Patient impact

An equal proportion of respondents (approximately 40%) chose 'yes' and 'I don't know' when asked about whether the IMI projects they had worked on had successfully brought science, patients and the public loser together. This was mirrored across both surveys. This indicates a mixed perception on whether the IMI projects have had an impact on patients in terms of giving them a voice, better informing the public on ongoing research and results and paving the way for new patient-relevant treatment modalities. Some respondents did note that they planned to do this in the future.

4.1.8 Societal and policy impact

The majority of respondents thought the IMI ND projects did have an impact on society. The EFPIA audience was asked about policy impact, particularly in terms of regulatory practice and this had a mixed response with most stating they didn't know and only small numbers of people saying yes or no.

4.1.9 Health impact

Health impact wasn't a clear area of success with the large majority of both EFPIA and non-EFPIA respondents saying 'I don't know' for whether the IMI projects had an impact on public health. More EFPIA respondents selected no than yes, with the reverse being true among non-EFPIA responders. This may be due to the long timelines required for bringing a new drug to market.

4.1.10 Advantages and Disadvantages

The unanimous key advantage of participating in IMI projects was the networking and collaboration. This was cited by both audiences. A close second for the EFPIA respondents was "access to knowledge or expertise or resources or tools".

Not all respondents reported disadvantages, but the most common in both groups was around the administrative burden including bureaucracy, increased workload and complex co-ordination.

4.1.11 Associations between key areas of impact with project role and time spent on project

The perceived impact on the company's presence/visibility/public perception by project role was mixed. More of those who had been Project Lead, Work Package Lead and Task Lead rated

the impact as moderate, but it was those who had not been Project Lead or Work Package Lead who rated the impact as high. This pattern wasn't seen for Task Lead. Those who spent more hours on the project did appear to rate the impact higher.

There was no real difference in perceived impact on establishing strategic partnerships by different project roles. However, it did seem that those who spent more time working on the project each week rated the impact as higher.

There was no difference in perceived impact on ROI by project role or hours spent on the project.

4.2 Commentary

The results indicated clear advantages and disadvantages to being involved in the projects, and these were the same for both EFPIA and non-EFPIA audiences. The overwhelming advantage was networking and collaboration. This is not surprising as the projects bring together people from different organisations and require cross-team working. This is supported by the fact that nearly all of the respondents reported meeting new people, both internally and externally. The key disadvantage to being involved in the projects was the burden of extra meetings, admin, increased workload and complex coordination. This is perhaps an area that should be considered in future projects.

The new non-EFPIA collaborations were mainly with academic institutions. Absence of the same question in the EFPIA survey prevents any direct comparison, but the majority of EFPIA respondents reported establishing 1-5 new long-term relationships with academic institutions, SMEs, Biotechs and patient organisations and nearly half of respondents said that collaboration between private and public partners on pre-competitive research was something possible now that wasn't before the IMI projects. This suggests that academic institutions were a focus of new collaborations for EFPIA respondents too, although it is hard to say in relative terms how many academic collaborations were made compared to collaborations with other organisations. There are more academic partners in IMI projects so making new collaborations with academic institutions could be expected. However, it would be interesting to know whether the majority of new collaborations for EFPIA respondents were with academic institutions (and could be explained by reason stated above) or if not, why not, and why this should differ to non-EFPIA respondents.

In terms of perceived scientific impact and specifically asset awareness, a combined 74% of non-EFPIA respondents were aware of assets from other projects. When EFPIA respondents were asked about their project's asset awareness within their company only a combined 25% thought they were fairly well known. This dropped to 8% when asked about the awareness among their company of assets from projects they had not been involved with. This could suggest that asset awareness was greater among non-EFPIA respondents, or it may have been the phrasing of the question. Non-EFPIA respondents were asked about their personal awareness of different assets whereas EFPIA respondents were asked about the awareness among their company. Even so, the EFPIA awareness of assets appeared to be low. This was supported by the fact that over half of EFPIA respondents were not sure if there was a central database within their company that contains information of assets generated in Neuroscience IMI projects. This suggests that more could be done to publicise the outcomes of projects including a more widespread awareness of the Neuronet Knowledge Base which had just been expanded at the time of the survey. This is a platform that brings together key information and is designed to promote collaboration and inform and facilitate similar new projects.

A difference to note between the respondents of the EFPIA and non-EFPIA surveys were the average project hours worked. On the whole non-EFPIA respondents worked a greater number of weekly hours on the projects with a third ticking 'over 50% of my time'. This is in contrast to 12% of EFPIA respondents who worked over 15 hours a week on an IMI project. This may have impacted the results and should be taken into consideration when comparing answers between the EFPIA and non-EFPIA respondents.

The projects had really clear impact in some areas. These included collaborations, networking and partnerships, capacity building, and organisational impact. Organisational impact covered organisational strategy, objectives, planning, process, and reputation. In the EFPIA survey, the only aspect of organisational impact that was unclear was whether the company helped in creating awareness of project outcomes, and the impact of those outcomes. This generated a majority of 'I don't know' answers and it isn't clear if this lack of awareness was due to the respondent's project role, or because the company did not put concerted effort into raising awareness. This is in line with the fact that over half of EFPIA respondents were not aware of a central database detailing project assets (discussed previously). Organisational impact was also a clear area of impact for the non-EFPIA survey. This included a change in their department, creation of new research lines and new funding opportunities. However, questions on awareness and impact of project outcomes were not included and therefore it is not possible to comment on whether this area of impact was also unclear for the non-EFPIA respondents. As previously discussed, non-EFPIA respondents did appear to have good awareness of project assets, and this could provide insight into project outcome awareness for this audience.

The analyses by project role for the EFPIA respondents revealed mixed results. For perceived impact on the company's presence/visibility/public perception, more of those who had been Project Lead, Work Package Lead and Task Lead rated the impact as moderate, but it was those who had not been Project Lead or Work Package Lead who rated the impact as high. However, there appeared to be a clearer association for hours worked and those who spent more hours on the project did appear to rate the impact on company presence/visibility/public perception as higher.

The pattern of results was similar when examining strategic partnerships. There didn't appear to be any great difference by project role, although it did seem that those who spent more time working on the project each week rated the impact on establishing strategic partnerships as higher. This can be expected as those who spend more time working on a project understand its potential impact. One might expect project role and hours to correlate, but perhaps in this instance they do not. Time spent on project is arguably a better indicator of involvement and commitment and whilst the lack of correlation between project role and hours spent on project may be surprising, the correlation of perceived impact and hours spent working on the project is less so. More formal statistical testing would be required to confirm this hypothesis.

The direction of impact on the individual was mixed. People felt that involvement with the projects did beneficially improve their skill set and scientific horizons but did not change their ways of working and people did not greatly utilise the assets. On the whole respondents did not feel they had sufficient time to dedicate to the projects. This aligns with the finding that the key disadvantage is an administrative burden. One recommendation would be to ensure that people have dedicated or ring-fenced time to perform their work and ideally their other deliverables should be adjusted. A widespread comment was that even in cases where their manager or employer were supportive of their involvement, their normal workload was not adjusted.

The perceived impact on patients, society and policy was also mixed across both EFPIA and non-EFPIA respondents. A substantial proportion of people said that the projects did have an impact on bringing patients and science closer together, but an equal proportion of people were not sure. Similarly, people felt that the projects did have an impact on society, but when the EFPIA audience was asked about policy impact in terms of regulatory practice most stated they didn't know. This could be linked to the types of projects that respondents were working on. The IMI ND projects span the whole pre-reimbursement pathway and whilst there are examples of projects focused on the HTA and regulatory end of the pipeline, many projects are pre-clinical and would not be expected to achieve a high impact on regulatory practice.

However, whilst an immediate aim of NEURONET is to facilitate collaboration between projects in the ND disease space, the overarching goal is to enable faster patient access to new technologies in this area. Therefore, involvement of patients is relevant at all stages of the pipeline and to all projects. The mixed findings for this area of impact suggest that either the projects are not having the desired outcome in terms of patient impact, or the perceived impact does not reflect reality. More could be done to include patients, ensure that the impact for patients is apparent and highlight the value of involving, engaging and communicating with patients at all stages of the pipeline.

Some areas of the survey were poorly answered with lots of "I don't know" answers. This included the economic impact (return on investment) and the scientific impact covering the impact on the drug development process (awareness & visibility of IMI ND projects/assets and the use of assets in R&D and regulatory/HTA practice). This may be due to the respondent's level of involvement in the project and the strategic nature of their role. ROI impact was looked at by project role, but there was no difference in impact according to project role. However, these analyses were post hoc and whilst provide insight, should not be used to draw conclusions. More research is needed to understand why this area of impact was poorly answered.

5 Limitations

There were a few limitations in conducting this piece of work. First of all, it was not possible to calculate a response rate because the number of people sent the survey was not recorded.

Secondly, the original ambition was to directly compare responses from the EFPIA and non-EFPIA surveys to understand differences in perceived impact between the two audiences. However, in tailoring the non-EFPIA survey to be appropriate for the audience, the questions that assessed the same areas of impact became different and it was not possible to perform a descriptive comparative analysis. Broad interpretations could be made, but not direct comparisons.

Other limitations relate to exploring associations between variables. Some areas of impact were looked at according to job role, however stratifying the data decreased the sample size and for example the sample size for those who had been Project Leader was n=31. This decreases the reliability of the results. It is for this reason that associations were not explored for the non-EFPIA survey as the overall sample size was smaller to start with. In addition, the associations were post hoc analyses and no formal hypothesis testing was done to assess any statistical differences between groups.

6 Recommendations

Based on our findings from these two surveys, the following recommendations can be made to ensure the success of future IHI NDD projects in achieving their objectives.

1. **Development of key performance indicators at baseline**
2. **Co-ordination of activities across projects**
    - Communication
    - Sharing of outputs
    - Exchange and reuse of assets /sustainability of assets
    - Awareness of project assets- only 15% of EFPIA respondents were aware of a central database of project assets
3. **Reduction of administrative burden**
    - Decrease the number of deliverables, focus on a few targeted deliverables
    - Allocation of sufficient resource for projects
    - Increase efficiency within projects to increase ROI
4. **Alignment of project activities to needs of different stakeholders**
5. **Engagement with stakeholders at earlier stages**
    - Patients and Patient associations
    - Researchers
    - HTA and Regulatory bodies
6. **Linking project activities to impact and ensuring that project staff are aware of impact on field/public health/patients /societal impact**

7 Conclusion

Overall, these surveys provided rich insight into the perceived impact of being involved in IMI ND projects. They revealed clear areas of impact and key advantages and disadvantages. Lots of these were universal across both EFPIA and non-EFPIA audiences such as the benefit to collaborations and networking and the organisational impact. The unanimous disadvantage to being involved in the IMI projects was the extra administrative burden and time in meetings. There were also some noticeable differences between the EFPIA and non-EFPIA respondents in terms of their characteristics (namely weekly hours spent on the project) and in areas of perceived impact such as asset awareness. On the whole the non-EFPIA respondents appeared to be more aware of project assets that had been generated although the phrasing of the question was different in each survey which prevents direct comparison. A more widespread access to the ND project Knowledge Base should help growing the understanding and breadth of assets available.

The survey results also generated further areas of research. This would be to understand the cause of such mixed perceived impact in areas including impact on individuals, on policy, patients, society and public health. It would also be useful to understand the reason behind the large volume of 'I don't know' answers for the economic and scientific impact of IMI ND projects. Exploratory analyses examined the economic impact by project role and hours worked, and there wasn't a clear association between project role and degree of perceived impact. The same exploratory analyses were conducted for aspects of organisational impact and networking and collaboration. Again, there did not seem to be a clear relationship between project role and perceived impact but there did appear to be a clearer association between perceived impact and hours worked on the project. However, these analyses were post hoc and did not include

formal statistical testing. A suggested area of research would be to explore these more thoroughly.

Resulting recommendations from the impact assessment include promoting the output of projects and publicising project assets. Also, to highlight the value in including patients at every step of the product pipeline and ensure the impact on patients is recognised. In terms of addressing the key disadvantage of involvement in the IMI ND projects it is recommended that the associated administrative burden is reduced. This could be through reducing the number of deliverables, sufficiently allocating time and resource to projects and overall increasing the efficiency within projects – particularly reducing the burden related with Grant Agreement amendments whenever a change in the workplan and/or beneficiaries is needed. A positive consequence of this would hopefully also be an increase in the ROI for those involved in the projects.

8 Annexes

8.1 Annex I - Impact analysis – EFPIA – survey questions

IMPACT analysis EFPIA

Questions 1-5 are about your experience in Innovative Medicines Initiative (IMI)

1 How many Neuroscience IMI Projects have you personally participated in (past and ongoing Projects)?

2 In how many Neuroscience IMI Projects have you personally been involved as Project Leader?

3 In how many Neuroscience IMI Projects have you personally been involved as Work Package Lead?

4 In how many Neuroscience IMI Projects have you personally been involved as Task Lead?

5 How much of your time did you work on Neuroscience IMI projects on average (number of hours/ week)?

Question instructions: *Select one answer*

☐ Less than 2 hours per week ☐ 2-5 hours per week ☐ 6-15 hours per week

☐ If other, please specify ☐

Questions 6 up to 28 are about the **IMPACT on Company. Please answer these questions by sharing your own perspective.**

6 Rate impact on the company's and/or Therapeutic area (TA) Strategic Objectives and way of working overall: Did the IMI projects you were involved in contribute to achieving Strategic Objectives or influence these (e.g. faster compound development, data sets and tools developed, expanding to new research areas/modalities etc.)? Did IMI change or influence the way the company is operating (e.g. increased external collaborations, co-development opportunities, collaborative/IIS studies, etc.)?

Question instructions: *1= No Impact, 3= Neutral, 5= High Impact*

☆☆☆☆☆ ☐ / 5

7 Are there any aspects of R&D we do differently because of these projects (e.g. having a stronger patient voice, more research through external collaborations, use of certain tools/methodologies/algorithms, knowledge that was internalised)?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes - Please describe ☐

8 Rate the impact on Company's presence/visibility/public perception (e.g. Did these projects contribute to a positive company image? Did it improve the image of the company as a trustworthy partner?)

Question instructions: *1= No Impact, 3= Neutral, 5 = High Impact*

☆☆☆☆☆ ☐ / 5

9 Rate the return on investment in terms of increased efficiency, acceleration of processes, new knowledge, etc.

Question instructions: *1= No Impact, 3= Neutral, 5= High Impact*

☆☆☆☆☆ ☐ / 5

10 If possible, could you elaborate on what project outcomes trigger the return on investment (ROI)?

11 Rate the impact on attracting new talent.

Question instructions: *1= No Impact, 3= Neutral, 5= High Impact*

☆☆☆☆☆ ☐ / 5

12 How many persons (e.g. post-docs) did the company hire specifically to work on an Neuroscience IMI Project you have worked on?

13 How many of these persons received a permanent position within the company, either during the Neuroscience IMI project or after completion of the Neuroscience IMI project?

14 How many persons did the company hire through IMI projects, who were initially working on a Neuroscience IMI Project affiliated to another Project Partner?

15 Rate the impact on establishment of strategic partnerships.

Question instructions: *1= No Impact, 3= Neutral; 5= High Impact*

☆☆☆☆☆ ☐ / 5

16 Are there any strategic partnerships formed between the company and other IMI partners? E.g. Academic partners/SME (small and medium-sized enterprises) /European Federation of Pharmaceutical Industries (EFPIA partners)?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes - Please describe ☐

17 Describe the main advantage of your company participating as EFPIA partner in IMI.

18 Describe the main disadvantage of your company participating as EFPIA partner in IMI.

19 How well known is IMI within your company?

Question instructions: *1= Not at all known, 5 = Well Known*

☆☆☆☆☆ ☐ / 5

20 How well known are assets (e.g. tools, datasets…) generated through Neuroscience IMI projects you were involved in, within your company?

Question instructions: *1= Not at all known, 5 = Well Known*

☆☆☆☆☆ ☐ / 5

21 Briefly describe a couple of assets if any (relates to the previous question)

22 How well known are assets (e.g. tools, datasets…) generated through Neuroscience IMI projects you were not involved in, within your company?

Question instructions: *1= Not at all known, 5= Well known*

☆☆☆☆☆ ☐ / 5

23 Briefly describe a couple of assets if any (relates to the previous question)

24 Are you aware of any (re)use of the assets in R&D?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes - Please describe ☐

25 Does your company help in sustaining project assets from Neuroscience IMI Projects?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

26 Does your company help in creating awareness on (outcomes of) Neuroscience IMI projects?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

27 Does your company help in creating awareness on the impact of (outcomes of) Neuroscience IMI projects?*

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

28 Is there a central database or knowledge base within your company that contains (descriptive) information of assets generated in Neuroscience IMI projects?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

Questions 29-35 are about the IMPACT on your daily work

29 Rate the impact of IMI on how you perform your daily tasks

Question instructions: *1= No Impact, 3= Neutral, 5= High Impact*

☆☆☆☆☆ ☐ / 5

30 Are there tasks you do differently?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

31 Are there new tools/datasets/knowledge you use for your daily work (created/known via an IMI project)?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

32 Any impact on your daily tasks by participation in Neuroscience IMI projects, you want to highlight?

33 Did you get any support from your employer (supervisor) for your assigned tasks in these Neuroscience IMI projects?

Question instructions: *Select one answer*

☐ Yes ☐ No

☐ If other, please specify

34 Did you receive any appreciation from your employer (supervisor) by working on these Neuroscience IMI projects?

Question instructions: *Select one answer*

☐ Yes ☐ No

☐ If other, please specify

35 Did you have sufficient resources/time to fulfill your assigned tasks in these Neuroscience IMI projects?

Question instructions: *Select one answer*

☐ Yes ☐ No, mostly on top of my daily activities

☐ If other, please specify

Question 36-38 are about the IMPACT on your professional career

36 Describe how IMI has improved/impacted your skillset.

37 Did participation in IMI expand your (scientific) horizon?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

38 Did any new opportunities come your way directly/indirectly through participation in an IMI project? Any personal development opportunities as a result?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe

Questions 39-41 are about the IMPACT on your professional network

39 Are there persons at your own company that you have newly met (e.g. from other departments, divisions) through working in IMI projects?

Question instructions: *Select one answer*

☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11-15

☐ If other, please specify

40 Are there persons at other companies that you have newly met through working in IMI projects?

Question instructions: *Select one answer*

☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11-15

☐ If other, please specify

41 Are there new longterm relationships with Academic Institutions/ SMEs/ Biotechs/ Patient Organisations/ Regulators/… (long term alliances, enacted collaborations, more possibilities to outsource) you've established through working in IMI projects?

Question instructions: *Select one answer*

☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11-15

☐ If other, please specify

Questions 42- 47 are about the IMPACT on the field at large

42 What is possible now, that wasn't possible before these IMI projects?

43 Rate the Societal impact (e.g. have the general public/participants more involved in research/give them a proper voice, inform public better on ongoing research/results of research, pave the way for new patient-relevant treatment modalities, etc)

Question instructions: *1= No Impact, 3= Neutral, 5= High Impact*

☆☆☆☆☆ ☐ / 5

44 Did results have an impact on regulatory practice?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe ☐

45 Did results change the way science/R&D is being conducted?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe ☐

46 Did these projects bring science closer to patients/general public and vice-versa?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe ☐

47 Did outcomes have a visible and directly measurable impact on public health?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes- Please describe ☐

8.2 Annex II – EFPIA survey questions by area of impact

Organisational impact:

Questions: 6, 7, 8, 17, 18, 19, 26, 27

Economic impact:

Questions: 9, 10

Capacity building:

Questions: 11, 12, 13, 14

Collaborations, networks and partnerships:

Questions: 15, 16, 39, 40, 41

Individual impact:

Questions: 29, 30, 31, 32, 33, 34, 35, 36, 37, 38

Scientific impact:

Questions: 20, 21, 22, 23, 24, 25, 28, 42, 45

Policy impact:

Question: 44

Patient impact:

Questions: 43, 46

Health impact:

Question: 47

8.3 Annex III- Impact analysis – Non-EFPIA – survey questions

IMPACT analysis- Academic and SME partners

Dear colleague,

Many thanks for taking the time to fill in this survey. The survey will take 10 mins of your time and your feedback will allow us to assess the impact of IMI neurodegeneration projects.

Involvement in Innovative Medicines Initiative (IMI) projects

1 Please select from below the option that describes your role

Question instructions: *Select one answer*

◯ Principal investigator ◯ Post-doctoral researcher ◯ Clinician ◯ PhD student ◯ Project manager

◯ Technician

◯ Other (please specify) ☐

2 What proportion of your working hours do/did you spend on average on IMI neurodegeneration projects?

Question instructions: *Select one answer.*

◯ 5%-10% of my time ◯ 10%-50% of my time ◯ >50% of my time

Impact on research group or department and personnel

3 To what extent has your department changed (e.g. structure, size) as a result of its involvement in an IMI neurodegeneration project?

Question instructions: *Select one answer*

◯ Slightly ◯ Moderately ◯ Radically ◯ No impact

4 The involvement of your research group or company in IMI neurodegeneration projects has led to (tick all that apply)

Question instructions: *Select one or more answers*

- ☐ Expansion of current research lines
- ☐ Opening of new research lines
- ☐ Increase in the number of staff
- ☐ Improvement in your global positioning
- ☐ Result in new contracts or funding opportunities
- ☐ Other impact, please specify

5 Did any new professional opportunities come your way directly/indirectly through participation in an IMI project?

Question instructions: *Select one answer*

- ◯ Yes
- ◯ No

6 Your involvement in IMI projects has had (choose one)

Question instructions: *Select one answer*

- ◯ A beneficial impact on your career progression
- ◯ A detrimental impact on your career progression
- ◯ No impact on your career progression

7 From your experience, what were the main advantages and disadvantages of participating in an IMI project?

Impact on research

8 Have you started working on any new products or with new research techniques as a result of participating in IMI project(s)

Question instructions: *Select one answer*

- ◯ No
- ◯ Yes, please explain

9 Have you published any peer-reviewed publications based on your work in IMI project(s)?

Question instructions: *Select one answer*

◯ Yes ◯ No

10 Did you present any of your IMI project work at scientific conferences?

Question instructions: *Select one answer*

◯ Yes ◯ No

Impact on collaborations

11 Are there persons at YOUR organisation that you have newly met through working in IMI projects?

Question instructions: *Select one answer*

◯ Yes ◯ No

12 Are there persons at OTHER organisations that you have newly met through working in IMI projects?

Question instructions: *Select one answer*

◯ Yes ◯ No

13 Did these new collaborations result in

Question instructions: *Select one or more answers in each row*

	With an EFPIA partner	With an SME partner	With an Academic partner	There was no type of collaboration
Sharing of data, samples or materials	☐	☐	☐	☐
Joint publications	☐	☐	☐	☐
New joint research grant applications	☐	☐	☐	☐
Long-term scientific collaborations	☐	☐	☐	☐

14 Please provide details of other collaboration activities not covered in previous question

Broader impacts on society, research and innovation

15 Rate the Societal impact (e.g. have the general public/participants more involved in research/give them a proper voice, inform public better on ongoing research/results of research, pave the way for new patient-relevant treatment modalities, etc) of IMI neurodegeneration research projects.

Question instructions: *1= No impact, 3=Neutral impact, 5=High impact*

☆☆☆☆☆ / 5

16 Did the results of IMI projects change the way science/R&D is being conducted?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes, please describe

17 Did these projects bring science closer to patients/general public and vice-versa?

Question instructions: *Select one answer*

☐ I don't know ☐ No

☐ Yes, please describe

18 Did you have an interaction with a regulatory or health technology assessment body in relation to your research?

Question instructions: *Select one answer*

○ No

○ Yes, please describe

19 Did outputs from IMI projects have a visible and directly measurable impact on public health?

Question instructions: *Select one answer*

◯ I don't know ◯ No

◯ Yes, please describe

Impact of assets

Table 1 below summarises the key assets from IMI projects, with the name of the project in bold and the corresponding project assets under it.

Table 1. List of assets produced by the IMI Neurodegenerative projects

ADAPTED
Multi-omics data from iPSC and ApoE mouse models
CSF and plasma -omics data from MCI patients
Biosamples from people with AD, MCI, or healthy individuals
iPSC-derived cell models of ApoE risk alleles
AETIONOMY
NeuroMMSig Server
Knowledge Base/ AData(Viewer)
Stratification algorithms
In silico model of neurodegenerative disease mechanisms
AMYPAD
Diagnostic and Prognostic study (DPMS)
Prognostic and Natural History study (PNHS)
Neuroimaging datasets from the AMYPAD PNHS and DPMS studies
EBiSC2
Disease relevant cohorts of hiPSC lines
Data on hiPSC lines and donors
Personal Data through DAC
HiPSC lines derived from different disease backgrounds
EBiSC public catalogue
EBiSC Data Access Committee
Human pluripotent stem cell registry (hPSCreg)
EBiSC template PIS and ICF
Protocols on use of hiPSC lines
hPSCreg nomenclature tools
Ethical and legal framework
Training videos on use of hiPSC lines

EMIF-AD
90+ study
Living systematic review
PreClinAD study
Clinical, neuroimaging and -omics datasets from EMIF-AD MBD, 90+ and PreClinAD studies
Blood and CSF from the EMIF-AD PreclinAD study
Blood samples, CSF and skin biopsies from the EMIF-AD 90+ study
Plasma, DNA and CSF from the EMIF-AD Multimodal biomarker discovery study (MBD)
Data Catalogue
Tools for federated EHR analysis
Risk factors for amyloid pathology, predictors for cognitive decline: clinical biology of AD
Procedures for federated data management
EPAD
Longitudinal Cohort Study (LCS)
Clinical, biomarker and neuroimaging data from the EPAD LCS study
Longitudinal Cohort Study biosamples
Trial delivery centre network
Register
Proof of Concept Trial Platform
Participant Registry in EPAD (PREPAD) tool
DerIDIOM tool
VElocity for EPAD (VEEPAD) tool
Subject Enrolment in EPAD (SEEPAD) tool
Research Participant Panel
Academy
EQIPD
Animal data from multi-site experiments
Tissue samples & DNA/RNA from in vivo and in vitro studies
Training Platform
Quality System
Variables in preclinical AD research that influence outcomes
Living systematic review
IM2PACT
-omics data on patient tissue and cellular disease models
In vitro and in silico models of the blood-brain barrier
IMPRIND
iPSC-based and organotypic cultures , neuronal models and animal models of alpha-synuclein or tau aggregation or propagation
Tools for isolating and characterising Tau & a-Synuclein, including aggregation assays
MOPEAD
Protocols for patient engagement
PHAGO

Neuroimaging data from the KCL neuroimaging study
CSF samples from TREM2 cohort KCL
Data and Knowledge Platform from Fraunhofer
Tools and assays for targeting and analysing TREM2 & CD33
RADAR-AD
Real-world data from RADAR-AD study of multiple wearable and digital devices
Patient Advisory Board
Advanced augmented reality monitor for assessing the risk of Alzheimer and Dementia
Advanced data management dashboard for monitoring of data continuity from remote sensors
Advanced passive remote monitoring (pRMT) application for user behavior modelling.
Daily life tasks monitoring app for cognitive status assessment (Banking App)
Manual data upload tool for remote monitoring sensors data acquisition files.
Mezzurio - A smartphone app supporting active participation in research studies and clinical trials
RADAR-CNS
MS Cohort
Epilepsy Cohort
Depression Cohort
Radar Base platform
Patient Advisory Board
ROADMAP
Data cube
Relevant functional outcomes for different stakeholder groups
EXAG Advisory Agreement Template

20 Looking at the summary of assets produced by IMI projects in Table 1 above, could you please indicate if you are aware of

Question instructions: *Select one answer*

◯ Only assets from your project ◯ A few assets from other projects ◯ Many assets from other projects

21 Have you received requests for assets from other organisations?

Question instructions: *If yes, please provide details*

◯ No

◯ Yes, please provide details

8.4 Annex IV- non-EFPIA survey questions by area of impact

Organisational impact:

Questions: 3, 4

Collaborations, networks and partnerships:

Questions: 11, 12, 13, 14, 18

Individual impact:

Questions: 5, 6, 8, 9, 10

Scientific impact:

Questions: 16, 20, 21

Patient impact:

Question: 17

Societal impact:

Question: 15

Health impact:

Question: 19

8.5 Annex V- Associations between variables for EFPIA survey

One of the survey questions asked how many times the respondent had been Project Lead, Work Package Lead or Task Lead. This was turned into a binary have they/have they not been a particular project role and used to examine the results of other questions deemed key areas of impact.

The same was done using the question that asked respondents the average number of weekly hours that they spent on the project.

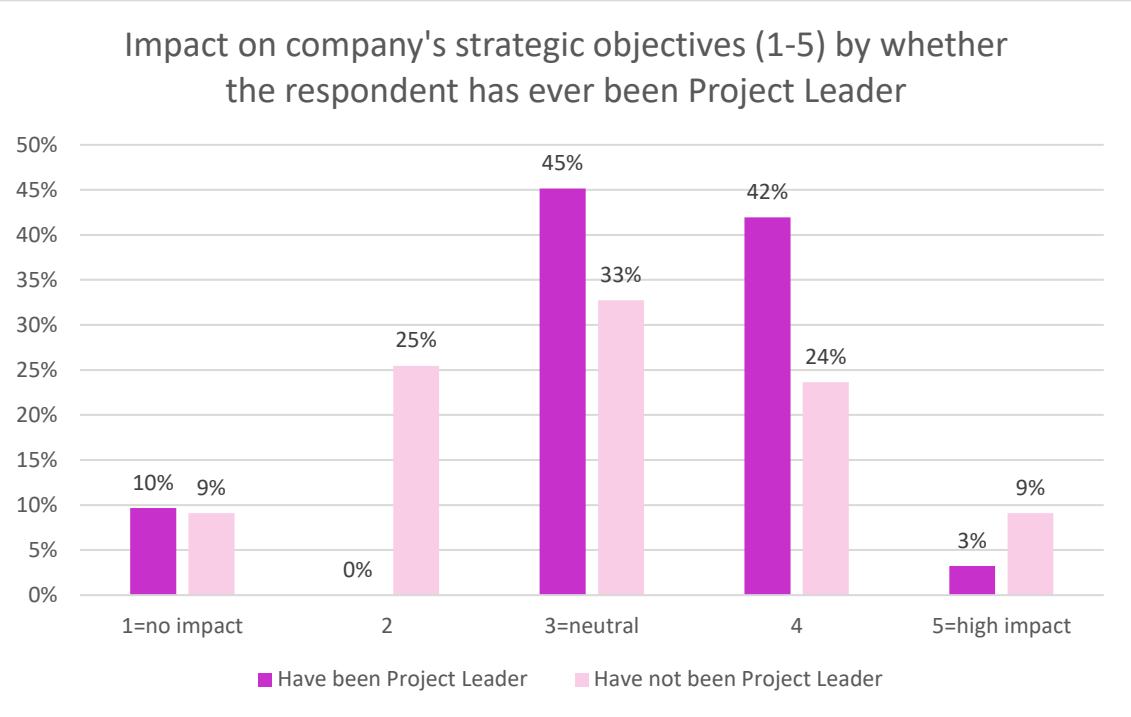
For project roles 36% (n=31/86) had been Project Lead, 50% (n=43/86) had been WP Lead and 49% (n=42/86) had been Task Lead.

For hours spent on projects 24% (n=21/86) spent less than 2 hours a week, 40% (n=34/86) spent 2-5 hours a week, 23% (n=20/86) spent 6-15 hours a week and 13% (n=11/86) spent 'other'.

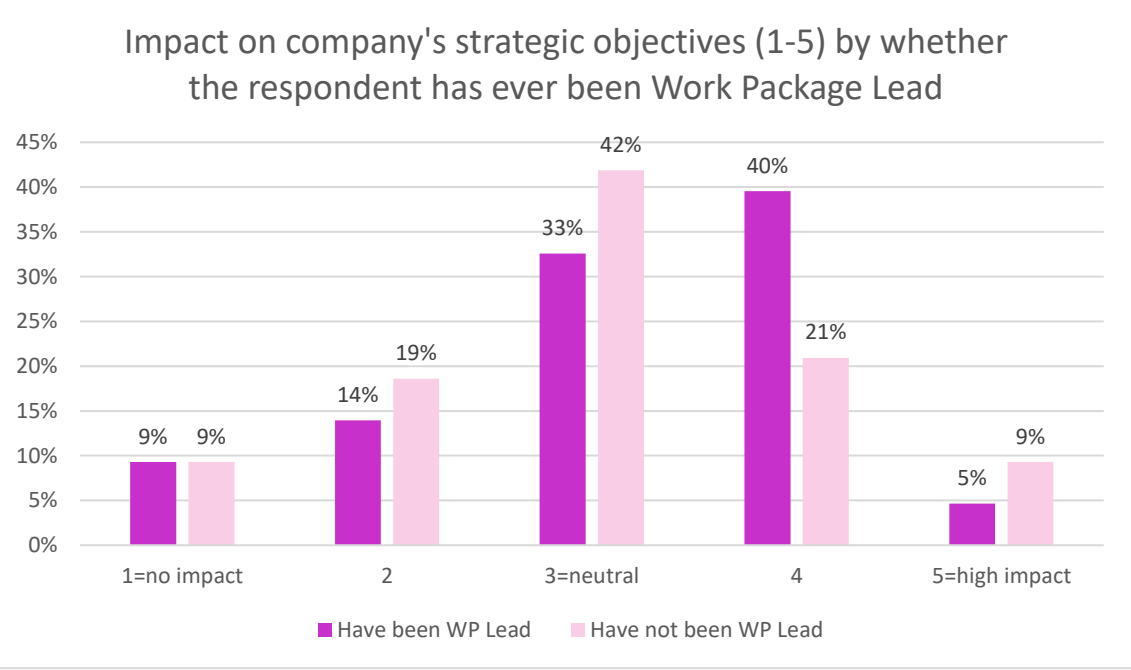
Following sections show areas of impact by job role and hours spent on project.

8.5.1 Impact on strategic objectives

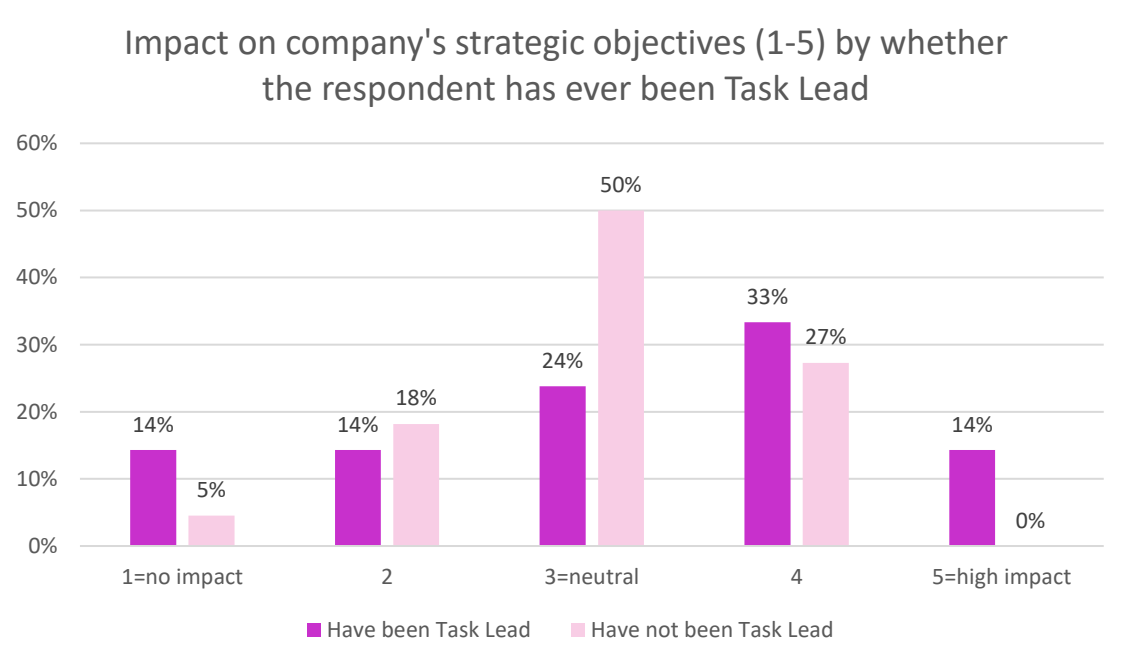
Project Leader

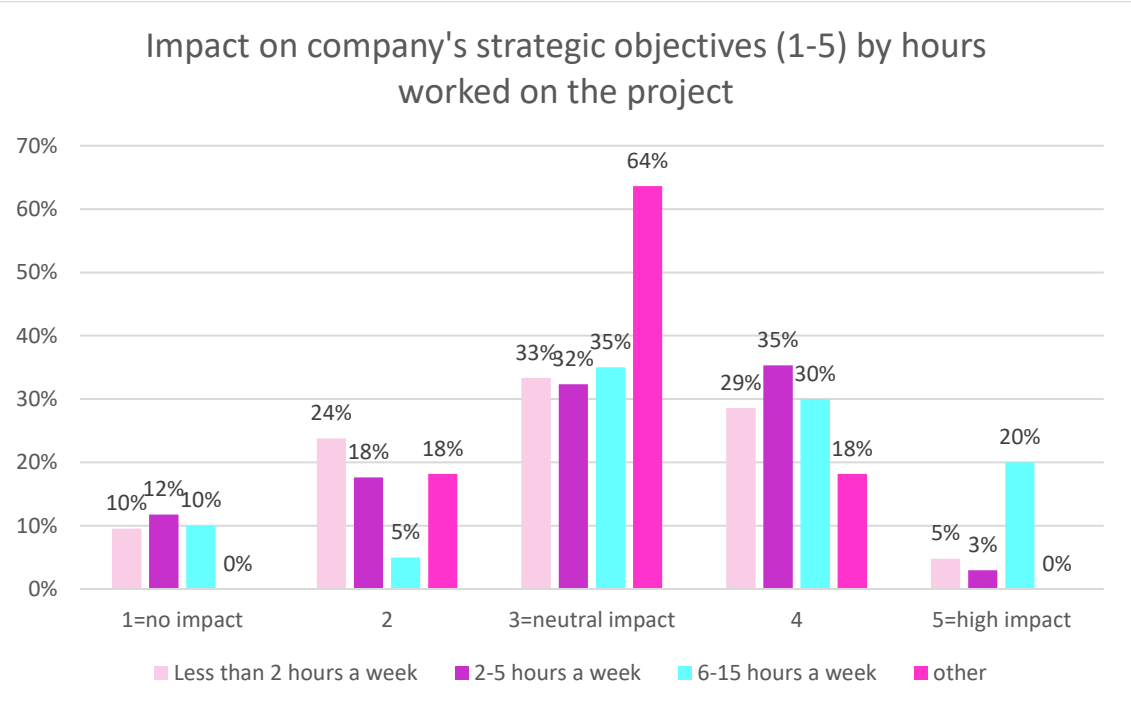


WP Lead

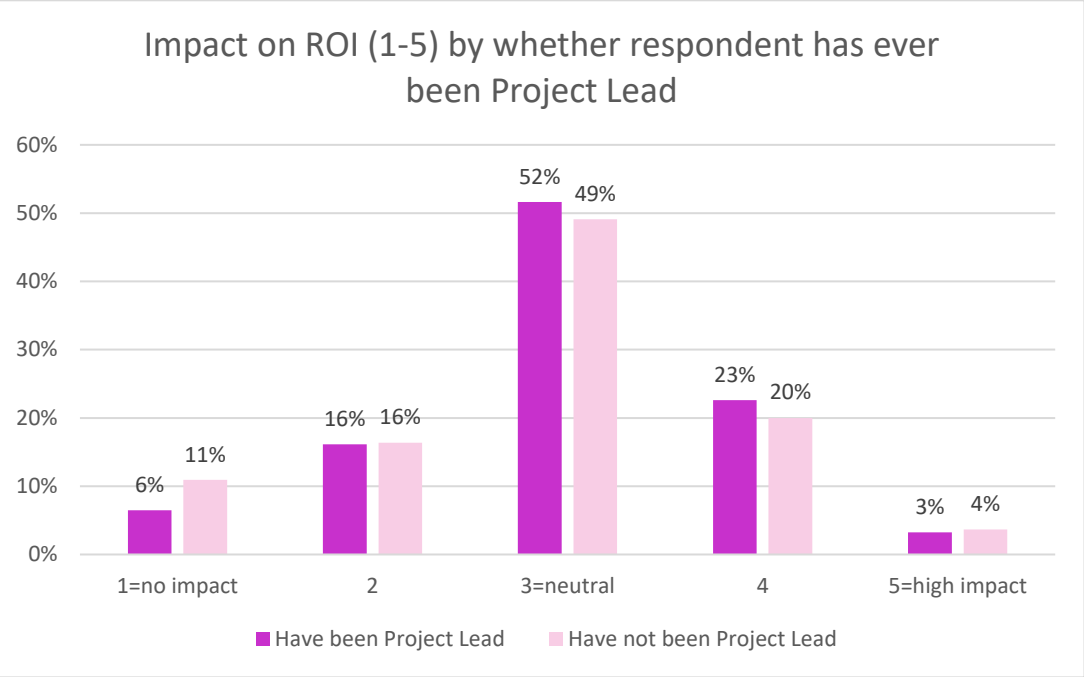


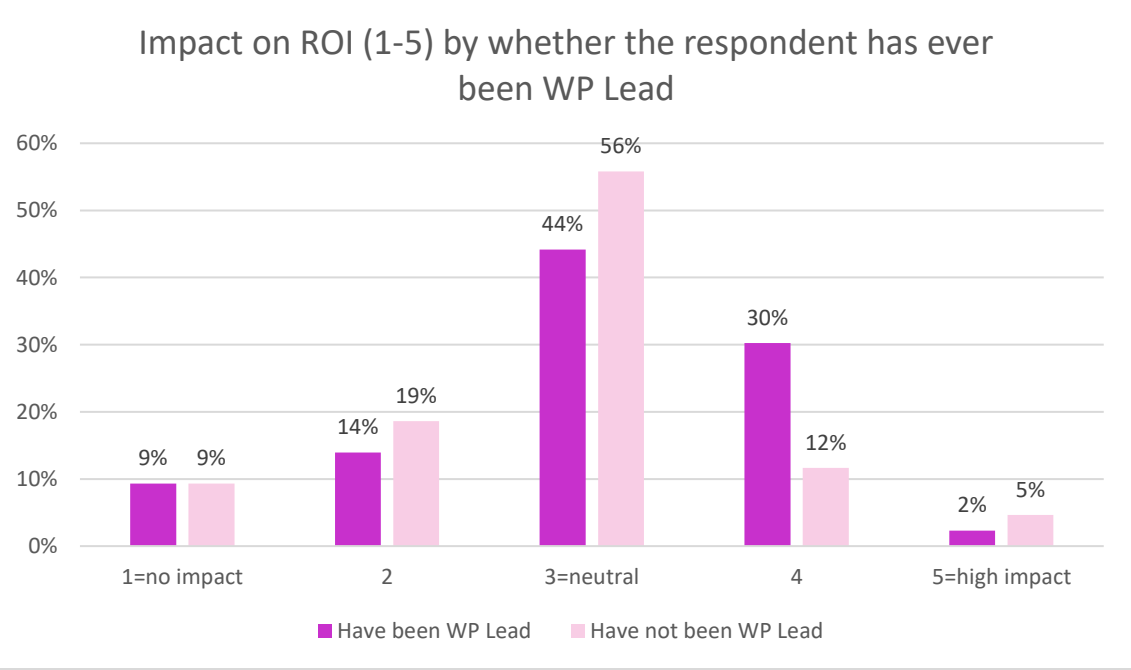
Task Lead


Impact on company's strategic objectives (1-5) by whether the respondent has ever been Task Lead
60%
50%
40%
30%
20%
10%
0%
14%
5%
14%
18%
24%
50%
33%
27%
14%
0%
1=no impact
2
3=neutral
4
5=high impact
Have been Task Lead
Have not been Task Lead

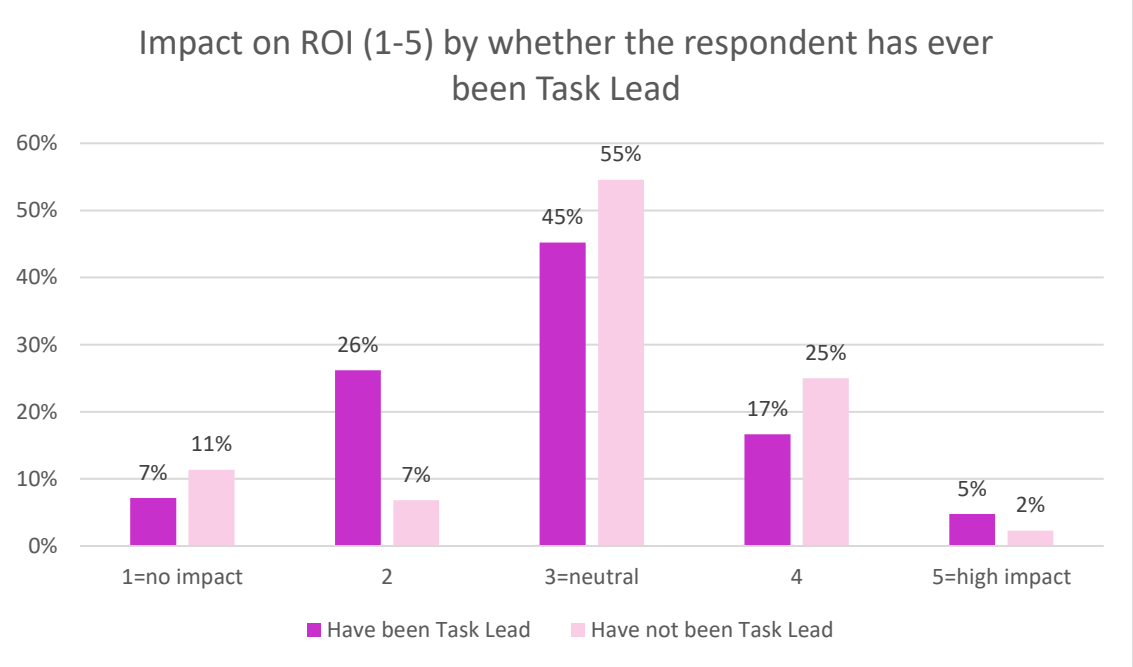

Impact on company's strategic objectives (1-5) by hours worked on the project
70%
60%
50%
40%
30%
20%
10%
0%
10%
12%
10%
0%
24%
18%
5%
18%
33%
32%
35%
64%
29%
35%
30%
18%
5%
3%
20%
0%
1=no impact
2
3=neutral impact
4
5=high impact
Less than 2 hours a week
2-5 hours a week
6-15 hours a week
other

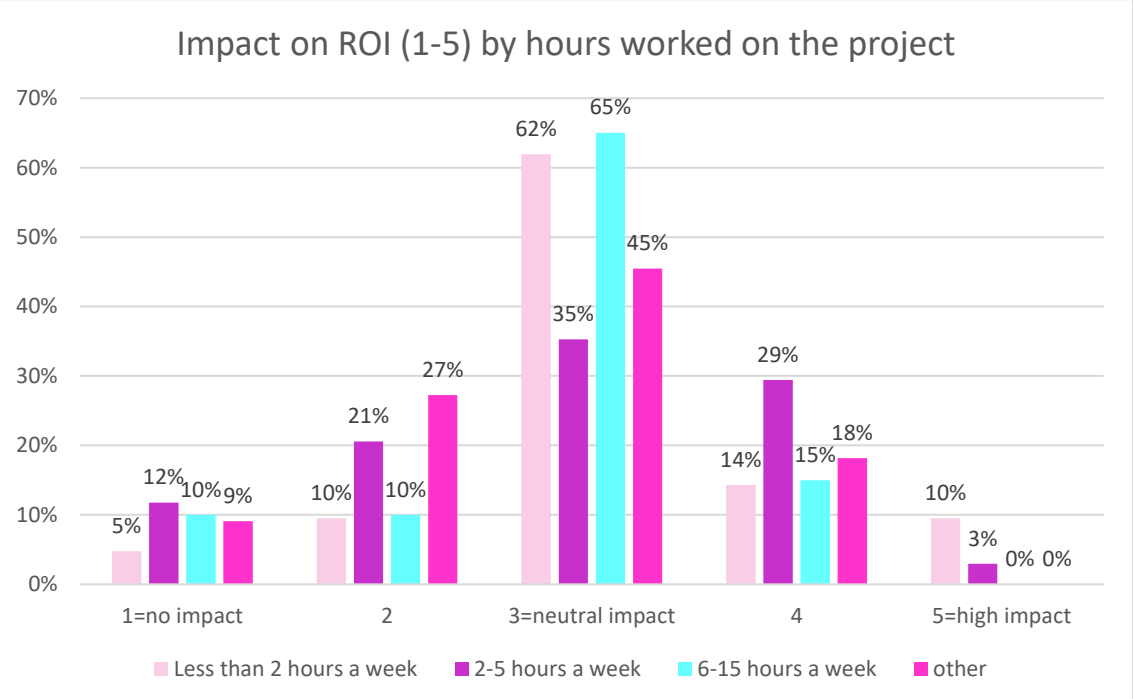
8.5.2 Impact on ROI





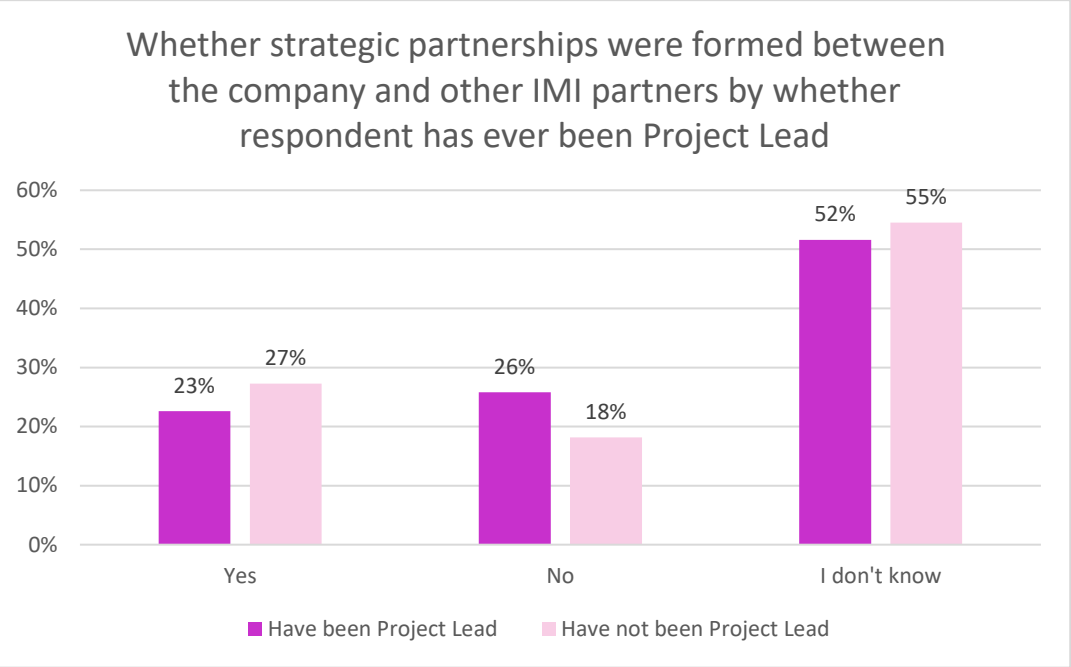
Task Lead


Impact on ROI (1-5) by whether the respondent has ever been Task Lead
60%
50%
40%
30%
20%
10%
0%
7%
11%
26%
7%
45%
55%
17%
25%
5%
2%
1=no impact
2
3=neutral
4
5=high impact
Have been Task Lead
Have not been Task Lead

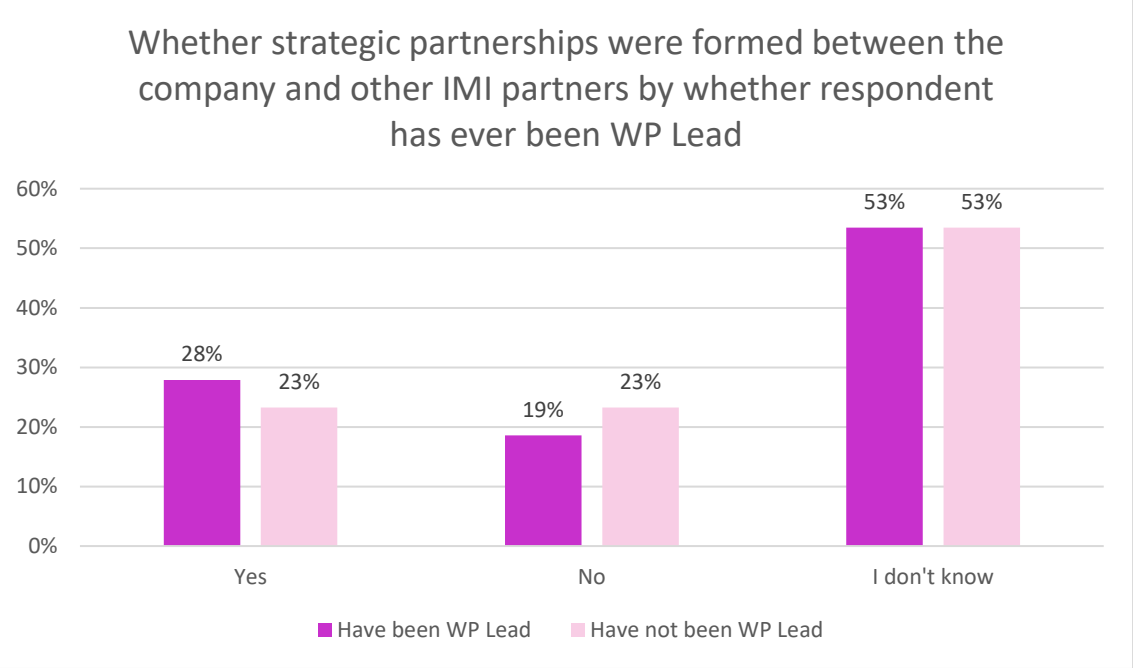

Impact on ROI (1-5) by hours worked on the project
70%
60%
50%
40%
30%
20%
10%
0%
5%
12%
10%
9%
10%
21%
10%
27%
62%
35%
65%
45%
14%
29%
15%
18%
10%
3%
0%
0%
1=no impact
2
3=neutral impact
4
5=high impact
Less than 2 hours a week
2-5 hours a week
6-15 hours a week
other

8.5.3 Impact on formation of strategic partnerships between company and other IMI partners

Project Leader



WP Lead



Task Lead