

IMI2 821513 - NEURONET

Efficiently Networking European Neurodegeneration Research

WP4 – Dissemination & Outreach

D4.3 Interim report on dissemination activities

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Document history

Version	Date	Description
V0.1	10/08/2020	First draft
V0.2	20/08/2020	Review by WP4
V1.0	24/08/2020	Review by communication expert community (see Annex I
		Members of the Communication Expert's Community)
V1.1	28/08/2020	Consortium review
V2.0	31/08/2020	Final version – submission to IMI











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
- 8. SARD: Sanofi-Aventis Recherche & Développement
- 9. PUK: Parkinson's Disease Society of the United Kingdom LBG

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

As the coordination and support action (CSA) for IMI neurodegeneration projects, NEURONET identifies research synergies and overlaps, creating links between IMI projects as well as with other international research initiatives and enabling stronger and more fruitful collaborations. NEURONET also works to support scientists to enhance the visibility of their research, providing a platform that will act as a multiplier of impact.

The communication and dissemination activities of NEURONET have been designed with these objectives in mind, aiming to amplify the communications activities of the IMI ND projects, enhance interactions between project communications teams, and support dissemination at a portfolio level.

The present Interim Report on dissemination activities provides a detailed list of communications activities that have been carried out halfway through the CSA. These include the development of a Communications Experts Community and the creation and maintenance of NEURONET communications channels, as well as participation in two high-profile face-to-face events. The report assesses the impact of undertaken communication activities, analyses compliance with the initial plan and identifies future dissemination opportunities as updates to the communication strategy.









Introduction

The NEURONET Coordination and Support Action (CSA) kicked off in March 2019, supporting 15 projects in the Innovative Medicines Initiative (IMI) neurodegeneration (ND) portfolio. Since the beginning of 2019, NEURONET has expanded to include three further IMI ND projects, PD-MIND, Mobilise-D and IDEA-FAST. In addition, NEURONET has launched its Knowledge Base (KB; described in D3.1), a web platform that provides a summary overview of the IMI ND programme, and has compiled information on the assets of the IMI ND projects, depicted in the NEURONET asset map located within the KB. The four NEURONET working groups have published deliverables providing expert guidance on data sharing, patient privacy, regulatory & HTA interactions, and sustainability (Deliverables 3.2 to 3.5). Meanwhile, WP1 has performed a detailed programme analysis to obtain a first, integrated view of the IMI ND portfolio (D1.2), as well as mapping the global ND research landscape in D1.3.

The dissemination of these and other NEURONET activities has been the focus of WP4, the "Dissemination and Outreach" work package. WP4 efforts have also focused on supporting the communication and dissemination activities of IMI ND projects, aiming to act as an "ambassador" connecting IMI ND projects with the general public and other stakeholders.

The present Interim Report aims to describe the dissemination and outreach activities carried out during the first 18 months of the NEURONET CSA, in line with the NEURONET communication strategy (<u>D4.1</u>). In particular, this report analyses compliance with the communication strategy, assesses NEURONET communication activities, and identifies future dissemination opportunities as updates to this initial strategy.

1. NEURONET communication strategy

The NEURONET communication strategy (D4.1) was published in August 2019 in month 6 of the CSA, following consultation with consortium members and IMI ND project representatives. D4.1 identified communication objectives for NEURONET, also describing the tools, target audiences and activities to achieve these objectives. The communication strategy was structured around four pillars:

- (1) Definition of communication objectives
- (2) Identification of relevant target audiences
- (3) Identification of specific communication tools
- (4) Description of <u>communication activities</u>

In this first section of the Interim Report, we will analyse our compliance with the NEURONET communication strategy, focusing on the communication objectives and their associated measures of success.

1.1 Communication objectives

In the first pillar of the communication strategy, two interdependent communication objectives were identified:

(1) Internally-focused objective: to support communication activities at a portfolio level











(2) **Externally-focused objective:** to raise awareness of IMI ND project activities and findings in target audiences

The communication objectives and their associated outcomes were agreed in collaboration with the NEURONET consortium and Communication Expert's Community, and were reviewed and approved after the first year of the CSA.

1.1.1 Objective 1: supporting communication activities at portfolio level

NEURONET was founded on the principle of boosting synergy and collaboration between IMI ND projects. The operational and governance structures of NEURONET were designed with this principle in mind; the leaders of the IMI ND projects sit on the NEURONET Scientific Coordination Board and representatives from projects contribute to the four NEURONET Working Groups. The principle of boosting collaboration also extends to communication and led to the creation of a Communication Expert's Community (CEC). As outlined below, WP4 efforts over the last 18 months have ensured that a number of secondary outcomes have been met.

(1) Participation of IMI ND project representatives in CEC meetings

The CEC is composed of IMI ND project collaborators responsible for the communication and outreach activities of the projects they represent (see Annex 1 for a list of current CEC members). The CEC currently comprises 22 project collaborators, representing 17 projects of the IMI ND portfolio. A majority of CEC members are employed by Project Management SMEs, although academia, Industry and patient organisations are also represented. The CEC meets on a quarterly basis and discusses communication challenges, identifies common outreach opportunities and shares good practice. These meetings also enable NEURONET's communication and dissemination team to adapt the work of WP4 to meet the needs of individual IMI ND projects.

By August 2019, when the NEURONET communication strategy was published, a first teleconference of the CEC had been held, attended by 13 representatives of 12 IMI ND projects. Since the first CEC meeting, a further four teleconferences have been held, on 2 September 2019, 2 December 2019, 9 March 2020 and 12 June 2020. Minutes from each of these meetings have been distributed to all CEC members and are also stored on a central Sharepoint directory, accessible to NEURONET consortium members. **Table 1** below lists the IMI ND projects represented at each CEC teleconference.

Table 1. Representation of IMI ND projects at NEURONET CEC meetings

CEC meeting date	IMI ND projects represented		
2 September, 2019	ADAPTED, AMYPAD, EPAD, MOPEAD, PHAGO, PRISM, ROADMAP, NEURONET		
2 December, 2019	ADAPTED, AMYPAD, EPAD, EQIPD, PHAGO, RADAR-CNS, RADAR-AD, ROADMAP, NEURONET		
9 March, 2020	ADAPTED, AMYPAD, EPAD, IM2PACT, MOPEAD, PD-MITOQUANT, PHAGO, PRISM, RADAR-AD, RADAR-CNS, ROADMAP, NEURONET		
12 June, 2020	ADAPTED, AMYPAD, EMIF, EPAD, MOPEAD, PHAGO, NEURONET		









(2) Promote the exchange of best practices and challenges

The CEC was designed by NEURONET as a space for IMI ND project collaborators to share best practice and challenges encountered in their communications work. The CEC meetings generally start with a tour de table of participants, during which ongoing work and issues are discussed. This format will continue throughout the duration of the CSA. In addition, CEC members were invited to join the NEURONET Forum, which was established in December 2019 and provides an additional space for informal exchanges on communications challenges and best practice, in a specific area of the Forum dedicated to "Communication and Outreach".

Several recurring themes have emerged during CEC discussions, as detailed below:

Challenges

- Engaging with the general public
- o Involving consortium members in communications activities
- Ensuring ethical and privacy concerns are respected

Best practice

- o Involving more junior project collaborators in communications activities
- Using surveys and General Assembly meetings to engage with consortium members

Building on input provided during the CEC meetings and in the NEURONET Forum, WP4 intends to collate further examples of best practice and identify common challenges, to be summarised in D4.6 ("Final report on dissemination and outreach activities", M36).

(3) development of guidance on minimum standards for public information about the projects

To meet challenges in engaging with the general public as part of IMI ND project communications and to facilitate greater synergy of communications activities, a discussion was held between CEC members on minimum standards for public information about the projects. All projects have a dedicated website and logo, with many projects also publishing newsletters and regular news posts. In addition, certain projects disseminate their activities via social media channels (Twitter, LinkedIn, Facebook), while others focus primarily on print media and website updates (see **Table 2** below).

Table 2: NEURONET target audiences and communications formats

PROJECT	WEBSITE	SOCIAL MEDIA
ADAPTED	www.imi-adapted.eu	Twitter, LinkedIn
AETIONOMY	www.aetionomy.eu	
AMYPAD	www.amypad.eu	Twitter, YouTube
EMIF	<u>www.emif.eu</u>	
EPAD	www.ep-ad.org	Twitter, YouTube, Facebook
EQIPD	www.quality-preclinical-data.eu	Twitter, LinkedIn, Facebook
IDEA-FAST	www.idea-fast.eu	Twitter, LinkedIn
IM2PACT	www.im2pact.org	Twitter
IMPRIND	www.imprind.org	Twitter
Mobilise-D	www.mobilise-d.eu	Twitter, LinkedIn, Facebook









MOPEAD	www.mopead.eu	Twitter, YouTube, Facebook
Neuronet	www.imi-Neuronet.org	Twitter, LinkedIn, YouTube
PD-MIND	www.pd-mind.org	
PD-mitoQUANT	www.pdmitoquant.eu	
PHAGO	www.phago.eu	Twitter, LinkedIn
PRISM	www.prism-project.eu	LinkedIn
RADAR-AD	Www.radar-ad.org	Twitter, LinkedIn
RADAR-CNS	www.radar-cns.org	Twitter, YouTube, LinkedIn
ROADMAP	www.roadmap-alzheimer.org	Twitter, YouYube

Following discussions with CEC members, it was agreed that the group would focus on following guidance provided by the European Commission in the 'Grant Management' section of its Horizon 2020 manual. This manual, which is freely available online, provides guidance on science communication, tips for effective social media communications and an overview of best practices for disseminating and amplifying project activities, based on previous EU-funded projects. For example, it recommends clarifying the targets, audience and message before deciding on the communications tools to develop, and encourages the use of platforms such as Twitter and YouTube to disseminate short, high-impact messages to intended audiences. The manual is particularly relevant for IMI ND projects as it references Art.38 of the H2020 Annotated Model Grant Agreement, which lays out the obligations for funding beneficiaries to promote their projects, and identifies tools and platforms that can be used to fulfil these obligations.

(4) identification and planning of common outreach and dissemination opportunities

To support communication at a portfolio level, opportunities for common outreach and dissemination activities have been identified in collaboration with the CEC. In particular, the CEC and NEURONET have worked together to develop a yearly social media campaign on Twitter, themed around a specific topic for each year. Twitter was chosen as the platform for the social media campaign as 14 of the 18 projects in the IMI ND portfolio have Twitter handles.

Each campaign is scheduled to take place during September and October, aligning with the timing of World Alzheimer's Month and the yearly NEURONET event, and is co-designed with the CEC. Further details and metrics from the social media campaign are presented in Section 2.5 below. The CEC has also played an integral part in planning the yearly NEURONET Public Event, a further platform for disseminating IMI ND project activities at a portfolio level, described in greater detail in Section 2.6 below.

Going forward, the CEC will continue to work with the NEURONET communications team on these joint outreach initiatives; at the time of writing, the twitter cards for the year 2 social media campaign are in preparation, and the 2020 Public Event is scheduled for 20-22 October (virtual NEURONET sessions).









1.1.2 Objective 2: raising awareness of IMI ND project activities

The second, externally-focussed communications objective for NEURONET is to raise awareness of IMI ND project activities in target audiences, increasing the visibility and raising the profile of the projects on an individual level and the IMI ND portfolio as a whole. To support this objective, the NEURONET communication strategy identified several target audiences, also proposing communications formats that could be used to reach each audience, summarised in **Table 3** below:

Table 3: NEURONET target audiences and communications formats

TARGET AUDIENCE	FORMAT
	Press releases
	Quarterly newsletter
NEURONET consortium & Scientific	Website
Coordination Board	SCB & Consortium meetings
	Knowledge Base
	Public events
ND comments forther	Social media
ND community (patient organisations, health & care	Quarterly newsletter
professionals, people living with ND)	Website
, and the state of	Public events
	Social media campaigns
Policymakers & regulators	Dementia in Europe magazine
	European Parliament lunch debate
	Social media
Academic researchers	Website
	Quarterly newsletter
	Public events
	Quarterly newsletter
	Alzheimer Europe Company Round
Industry & EFPIA	Table meeting
	Public events
	Press releases
	Social media
General public	Website
	News media
	Public events

Over the last 18 months, NEURONET has developed a coordinated and streamlined approach to raise awareness of IMI ND project activities in the target audiences identified in its communication strategy, outlined in the schematic below (**Fig.1**).

NEURONET uses several platforms to source information on project activities that could be highlighted; project social media streams are monitored on a daily basis, project websites are









checked for updates on a weekly basis (e.g new publications, news articles), and all project newsletters are evaluated as soon as they are released. NEURONET also uses Feedly, a news aggregator application, to identify online news content on IMI ND project activities. In addition, CEC members are encouraged to provide information on specific results or outputs they want NEURONET to highlight. Finally, NEURONET proactively engages with projects to obtain further information on project activities and on the involvement of project collaborators at different career stages.

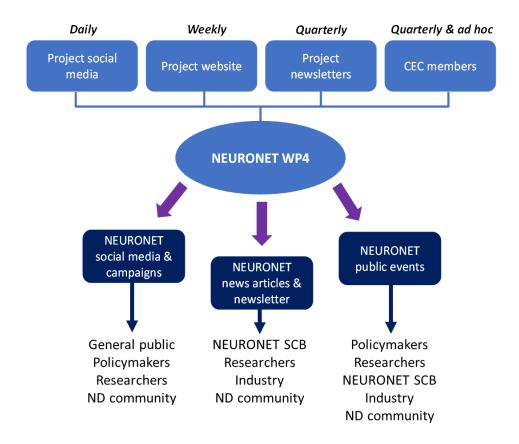


Figure 1: NEURONET approach for raising awareness of IMI ND project activities

To enhance the visibility of identified IMI ND project activities, NEURONET has developed several communications tools (described in greater detail in section 2). Briefly, NEURONET amplifies project social media content by retweeting items on twitter, sharing content on LinkedIN and linking to project videos via the NEURONET YouTube channel. Complementing these activities, and in its role as an ambassador for the IMI ND portfolio, NEURONET has generated social media content highlighting IMI ND project activities for World Alzheimer's Month in 2019 (WAM, September), and World Parkinson's Day (WPD, 11 April) and World Brain Day (WBD, 22 July) in 2020.

The NEURONET website acts as a go-to-point for project information, also providing links to project websites, project leader profiles and social media channels, thereby funnelling visitors towards IMI ND project websites and channels. Similarly, the quarterly NEURONET newsletter highlights notable project activities and profiles IMI ND project collaborators, whilst also providing links to the newsletters and news pages of the individual projects. NEURONET also leverages the communications channels of its consortium members, publishing articles on IMI









ND project activities in the Dementia in Europe magazine and Alzheimer Europe newsletter, which are circulated to policymakers and lawmakers at both national and EU levels.

Finally, NEURONET also reached policymakers and lawmakers through its public events, which have been covered in press releases on EU platforms such as CORDIS and the EU Health Policy Platform.

2. NEURONET communication tools & activities

In accordance with the NEURONET communication strategy, several tools and channels have been developed to communicate NEURONET and IMI ND project activities. These tools & channels include the NEURONET Knowledge Base, website, forum and social media channels, as well as our external newsletter, press releases and public events. In this section, we will provide an overview of the NEURONET communications activities that involve these tools & channels, describing how the channels have developed over the last 18 months and, where available, provide activity metrics. **Table 4** below lists the NEURONET communication tools & channels, identifying their target audiences and outlining their activity status at the time of writing.

Table 4. NEURONET communication tools & channels

Tools & channels	CONTENT	TARGET AUDIENCE	FORMAT	STATUS AS AT 07/2020
Knowledge Base	Links to publications & deliverables Information on project consortia, workpackages and collaborators	Project leadership team IMI staff IMI ND SGG members	Online portal (Dashboard)	Contains information on 18 IMI ND projects 330 publications 248 deliverables 24 registered users
NEURONET website	Project & programme summary Summary of ongoing work/ achievements Project & programme news Deliverables & publications Events	NEURONET consortium Intra-portfolio ND community Researchers and academics Industry representatives Regulators/HTA bodies, payers General public	Online, Plain text, links to partners and affiliated projects, PDF files, videos	Launched 22-07-2019 4,585 users 6,418 sessions 00:02:34 average session duration 15,385 page views
NEURONET forum	Discussion groups on different topics Links to job vacancies	Intra-portfolio NEURONET consortium	Online platform	Launched 15-01-2020 34 users 18 posts
Twitter account	Updates of ongoing work/achievements Project & programme news External events Internal meetings (past/present/upcoming) Links to news related to project, programme and external newsletter	Communication expert community ND community Researchers, academics and ECRs Industry representatives Policy makers at EU and international level General public	Online platform	Launched 01-03-2019 904 Followers 732 Following 2 social media campaigns 482 tweets 656,132 tweet impressions 5168 profile visits









Tools & channels	CONTENT	TARGET AUDIENCE	FORMAT	STATUS AS AT 07/2020
External Newsletter	Programme news (major achievements from the IMI ND projects) Tools & re-usable results Interviews with experts on different ND areas Information about events Job openings	NEURONET Consortium Intra-portfolio ND community Researchers, academics and ECRs Industry representatives Regulators/HTA bodies, Payers Policy makers at EU and international level General public	Mailchimp campaign introducing articles with links to news on project website	Launched 19-09-2019 4 issues: 19 September 2019 6 January 2020 10 March 2020 30 June 2020 146 current subscribers Average opens 36.1%
Conferences & events	Programme and projects summaries/objectives/ challenges/ results	Media NEURONET Consortium Intra-portfolio ND community Researchers, academics and ECRs Industry representatives Regulators/HTA bodies, Payers Policy makers at EU and international level Philanthropists and funding organisations	Yearly event NEURONET Flyer/leaflet and roll-up banners Project relevant presentations: • Posters • Symposia • Panel sessions	Neuronet sessions at #29 AEC, October 2019 4 sessions 14 speakers 11 projects represented Alzheimer Europe lunch debate, February 2020 "The IMI: advancing AD research through public-private partnerships"

2.1 Knowledge Base

The main aim of NEURONET Knowledge Base is to provide an overview or summary of the IMI Neurodegeneration portfolio. It acts as a repository for information on the IMI ND projects, including details on project objectives, partners, timelines and workpackages, as well as summary portfolio metrics such as participating countries and total funding.

In addition, the Knowledge Base lists the publications and provides links to the publicly-available deliverables of each project in the IMI ND portfolio. Publication titles, first author, year of publication and keywords are provided alongside a DOI link to the article. Similarly, deliverable titles, project name and submission date are provided alongside direct links to the deliverables.

In total, 330 publications and 248 deliverables are currently listed in the Knowledge Base; 24 individuals are currently registered as users of the Knowledge base, although discussions are underway to widen access to this resource, as recommended by reviewers during the June 26 IMI Interim Review.

Further details on the Knowledge base are provided in deliverable <u>D3.1 INKB web platform v1</u> and D3.6 INKB web platform v2 (to be published in September 2020).











2.2 Forum

As part of WP3 Tools and services, NEURONET set up a Forum space to promote dialogue and participation across projects on different topics. The NEURONET Forum is intended as a space for free discussions, where people from different IMI ND projects and institutions can come together to share knowledge and learn from each other, as well as to reinforce the sense of community.

The Forum was launched in January 2020 and since then has enrolled 38 users (representing 11 IMI ND projects), with 18 posts. All members of the Communication Experts' Community have been invited to join the Forum and one of the topic categories is dedicated to Communications & Outreach. Going forward, it is hoped that the Forum will create new opportunities for informal interactions between the members of the Community, and promote communication between IMI ND project collaborators at a portfolio level.

2.3 Website

The project website (<u>imi-neuronet.org</u>) was launched on 22 July 2019. It has been designed to support and reinforce all of NEURONET's communication and dissemination activities, acting as the go-to point for project information, referenced by project tools and channels at all times.

Our first goal in designing the website was to inform audiences on the aims and activities of NEURONET itself. As such, the website provides information on the NEURONET governance structure and decision-making bodies (under the 'About' tab) as well as a repository of tools, deliverables, presentations and publications from NEURONET (under the 'Resources' tab). A second goal for the website was to provide information about the IMI ND projects in the NEURONET programme. The website therefore displays summary information about each project and links to its website, newsletters and news pages, providing visitors to the NEURONET website with a quick overview on each project and direct links to IMI ND project channels for more detailed information. IMI ND project information is displayed under two tabs: the 'Projects' tab and the 'Project News' page within the 'News' tab. Linked to the second aim of providing information about IMI ND projects, the third objective of the website is to keep audiences up-to-date on IMI ND project activities. NEURONET therefore regularly posts news items, which are then shared via the NEURONET social media channels and used as a foundation for the NEURONET newsletter.

Table 5. Google analytics data for the NEURONET website, July 2019 – July 2020

MONTH	USERS	PAGE VIEWS	SESSIONS	AVG. SESSION (h:min:sec)
July 2019	87	821	145	00:10:40
August 2019	269	1169	385	00:03:42
September 2019	499	1859	747	00:03:13
October 2019	513	1530	703	00:02:23
November 2019	373	1431	529	00:03:46
December 2019	517	1082	648	00:01:43
January 2020	401	1547	570	00:02:50









February 2020	243	931	347	00:04:03
March 2020	295	1009	438	00:02:57
April 2020	311	866	431	00:02:22
May 2020	412	1098	550	00:01:54
June 2020	382	1327	551	00:02:38
July 2020	283	713	366	00:01:47

Since it was launched in July 2019, the NEURONET website has attracted <u>4,585</u> users who have initiated <u>6,410</u> sessions, spending an average of 2-3 minutes on the website per session (see **table 5** above for a month-by-month breakdown of google analytics metrics). In total, there have been <u>15,383</u> page views over this period.

The two most-frequently tracked google Analytics metrics are user number (i.e the number of 'unique visitors' to the website) and session number (i.e the number of website visits). Analysis of the metrics for the NEURONET website shows a close relationship between these two metrics (Fig.2). Numbers of users and sessions were highest in September, October and December 2019, peaking at 647 sessions and 511 users in October. The 2019 NEURONET Public Event was held that month, with several news articles published and high levels of social media activity (83 tweets, 122,000 tweet impressions, 142 new followers; see section 2.5.1 below for further details). September 2019 was also an active month for NEURONET in terms of social media, with 40 tweets, 58,000 tweet impressions and 91 new followers, linked to the NEURONET social media campaign for World Alzheimer's Month. In December, videos from the 2019 NEURONET public event were posted on the website, attracting further traffic.

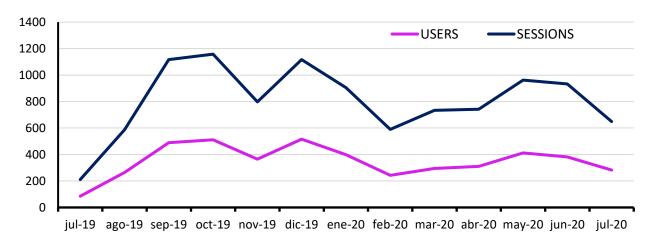


Figure 2. NEURONET website metrics, by calendar month

Since July 2019, as well as attracting larger numbers of visitors the website has also grown substantially in size, with new sections added and many sections expanded. Firstly, the sections devoted to NEURONET activities have expanded to include the following pages, with linked content and information:

• **NEURONET tools:** Knowledge Base, Asset Map and Forum









NEURONET deliverables: Downloadable versions of Public deliverables, publishable summaries of Confidential deliverables (D2.1, D4.1, D3.1, D5.1, D1.1, D3.3, D4.2, D3.4, D2.2, D1.3, D1.2, D3.2 and D3.5)

NEURONET presentations:

- Poster entitled "Regulatory and HTA Engagement in Neurodegenerative Disease Research: a Decision Tool" presented by NICE at ISPOR Europe, 2019
- o Oral presentation entitled "Neuronet effectively Networking European Neurodegeneration Research" presented by SYNAPSE at the Alzheimer Europe conference, 2019

Secondly, the section devoted to IMI ND project descriptions have been updated to include details of the three projects that have joined the portfolio since the start of NEURONET, and have expanded to include twitter handles (where relevant) and, if available, a short video describing the project. The 'Project News' page now contains links to each project newsletter and links to the 'News' pages of the IMI ND project websites. The 'Scientific Coordination Board' page has been expanded to provide brief biographies of the 18 IMI ND project leaders, with internal links to the project information page.

Thirdly, the NEURONET news section has grown extensively, currently displaying 99 news items (format shown in Fig. 3 below), which highlight notable project outputs and activities, as well as providing updates on NEURONET meetings, events and tools.

Spotlight on early-career investigators: a Neuronet interview with Sarah Gregory

17th June 2020



In this early-career researcher interview, we talk to Sarah Gregory who is a PhD student and study coordinator at the University of Edinburgh (UK). The main focus of her research is the hypothalamic-pituitary-adrenal axis (HPA), the stress response system, in cohorts of participants at risk of Alzheimer's

She started her PhD as a part-time student in October 2018 and is aiming to finish in October 2022. She has been working on the EPAD (European Prevention of Aizheimer's dementia) project for the last few

Can you tell us a bit about your PhD?

The focus of my PhD is to look at the HPA axis in mid- and later- life cohort studies to understand how it associates with Alzheimer's disease. The HPA axis, or the hypothalamic-pituitary-adrenal axis, is the

LATEST NEWS

The IMI IDEA-FAST project has joined the Neuronet programme 22nd July 2020

Support Action (CSA) aiming to support and better integrate projects Read More

IMPRIND researchers describe the structures of alph synuclein filaments in MSA and DLB Michel Goedert, a partner on the IMPRIND project, has recently published an article in Nature, Read

ADAPTED and AMYPAD to hold a Featured Research Session at AAIC2020

3rd July 2020
We are pleased to report that bo ADAPTED and AMYPAD project will hold a Featured Read More

RADAR-AD launches its biyearly newsletter 3rd July 2020 The RADAR-AD project (R Assessment of Disease And Relapse er's Disease), which aims

Fourth Neuronet newsletter 30th June 2020 Neuronet newsletter! We hope t newsletter finds you Read More

to Read More

Figure 3. NEURONET news item from website, with a sidebar listing the most recent website news items.

As illustrated in Fig. 4 below, the number of news articles published on the NEURONET website varies from month-to-month. This is partly linked to varying activity levels of IMI ND projects, as











well as what is happening in the NEURONET event calendar; for example, the NEURONET public event was held in October 2019 (10 news articles published, including 3 directly linked to the event), and the European Parliament Lunch Debate took place in February 2020 (11 news articles published, including 2 directly linked to the event). Interestingly, the amount of website activity as measured by Google analytics (**Fig. 2** above) does not appear to be associated with the number of news articles published each month. However it does appear to mirror the levels of social media activity (**Fig. 7** in Section 2.5.1 below), reinforcing the value of social media in driving users to the NEURONET project website.

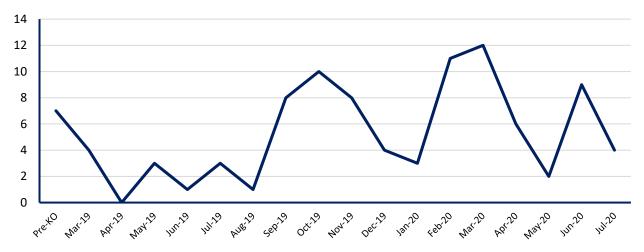


Figure 4. Number of news articles published on NEURONET website (KO = kick-off meeting)

2.4 Newsletters

The quarterly NEURONET newsletter highlights major achievements from the IMI ND projects, publicises tools, reusable results and interesting events, and holds interviews with experts on different ND areas. In addition, it increases the dissemination of IMI ND project newsletters, by providing links to all IMI ND project newsletters published in the preceding 3 months.

The publication of each newsletter (which is created and managed via the MailChimp platform) is announced on the NEURONET social media channels and via news articles on the NEURONET website. To further increase dissemination, a "subscribe to the newsletter" button is displayed prominently on the website homepage, linking to a "NEURONET newsletter" sub-page on the website, which acts as a respository for all newsletters published by NEURONET (**Fig. 5** below).

To date, NEURONET has published four newsletters, with the first issue published in September 2019. Each newsletter starts with an introduction from the NEURONET project leaders, and features an interview with an early-career researcher working on one of the IMI ND projects (a "Spotlight on early-career investigators" feature) alongside news highlights from IMI ND portfolio from the previous 3 months.









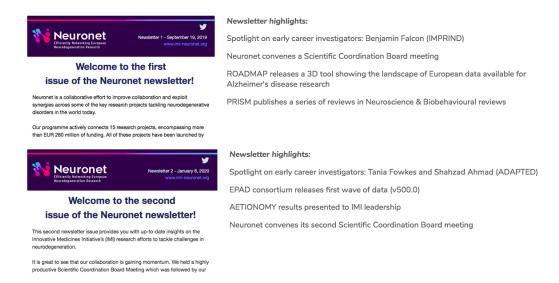


Figure 5. Screenshot of NEURONET newsletter webpage, displaying the outlines for the first two NEURONET newsletters.

To evaluate outreach performance, MailChimp, bit.ly and twitter metrics are collected for each newsletter:

- On 19 September 2019, the <u>first NEURONET newsletter issue</u> was sent to 106 recipients
 (254 total opens by direct recipients). An additional 75 visits were recorded via <u>bit.ly</u>
 <u>URL clicks</u>. Social media performance to support newsletter outreach marked 3,749
 tweet impressions.
- On 06 January 2020, the <u>second NEURONET newsletter issue</u> was sent to 125 recipients
 (133 total opens by direct recipients). An additional 66 visits were recorded via <u>bit.ly</u>
 <u>URL clicks</u>. Social media performance to support newsletter outreach marked 4,160
 tweet impressions.
- On 10 March 2020, the <u>third NEURONET newsletter issue</u> was sent to 135 recipients (154 total opend by direct recipients). An additional 51 visits were recorded via <u>bit.ly</u> <u>URL clicks</u>. Social media performance to support newsletter outreach marked 3,980 tweet impressions.
- On 30 June 2020, the <u>fourth NEURONET Newsletter issue</u> was sent to 144 recipients (97 total opened by direct recipients). An additional 30 visits were recorded via <u>bit.ly URL clicks</u>. Social media performance to support newsletter outreach marked 3,981 tweet impressions.

The next NEURONET newsletter will be published at the start of October; as well as highlighting IMI ND project achievements, it will feature several articles on the upcoming NEURONET Public Event, including "Meet the Speaker" interviews and details on the programme.











2.5 Social media

2.5.1 Twitter

Twitter is categorised as a "microblogging" platform, which enables individuals and organisations to share short posts (that can include images, gifs or hyperlinks) with a broad range of audiences, from the general public to patients, researchers, clinicians and policymakers. By creating tweets and retweeting existing content, NEURONET is able to raise awareness about the IMI ND Portfolio in many target audiences, and reach out to relevant stakeholders and initiatives worldwide.

NEURONET's Twitter handle (@imi2_NEURONET; **Fig. 6** below) was launched to coincide with the kick-off meeting, which was held in Madrid on 21 March 2019. The mandatory funding acknowledgement has been included in the NEURONET Twitter profile, in accordance with the guidelines in the H2020 manual and Model Grant Agreement.

All news posts on NEURONET's website are accompanied by tweets. These tweets are designed to enhance awareness of project and programme news, events and conferences in which IMI ND projects are participating, information on internal meetings as well as links to news related to NEURONET. Furthermore, conference proceedings and videos (including a follow-up on the annual public event) are shared through this channel, as well as key achievements of the IMI ND portfolio. Finally, NEURONET has organised specific campaigns around key Awareness Weeks (such as the World Alzheimer's Month and World Brain Day) for maximum outreach, as detailed in section 2.5.2 ("Social media campaigns") below.



Figure 6. The NEURONET twitter profile

To evaluate the performance of NEURONET social media activities, metrics are collected from the twitter platform on a monthly basis. At the time of writing, the @IMI2_NEURONET handle has 904 twitter followers and follows 732 other twitter handles. NEURONET has created 482









original tweets (with 819 retweets), amassing 656,132 tweet impressions and 5,168 profile visits since March 2019.

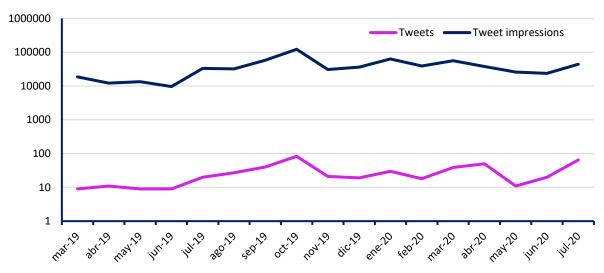


Figure. 7. Twitter metrics for @IMI2-NEURONET: tweets and tweet impressions (log scale)

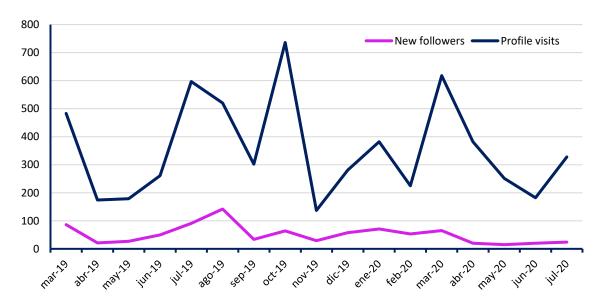


Figure. 8. Twitter metrics for @IMI2-NEURONET: new followers and profile visits

Analysis of 2019-2020 twitter metrics for the NEURONET handle shows that the number of tweets and tweet impressions vary slightly from month-to-month, with an average of 33 tweets and 38,596 tweet impressions per month (Fig.7 above). Overall, the number of tweets and tweet impressions follows a similar pattern to the number of website users quantified using Google Analytics (Fig.2, section 2.3 above), with a peak during the month of October, when the 2019 NEURONET Public Event was held.

Similarly, the number of profile visits peaked in October 2019 (Fig.8 above; 672 profile visits) Conversely, the number of new followers was highest in August, with 142 new followers; this may be linked to the relatively high number of twitter mentions the previous month (33 mentions in July, compared to an average of 21 mentions/month). We will continue to collect









metrics for the NEURONET handle to measure engagement with our social media content and to further enhance the visibility of NEURONET and IMI ND project activities.

2.5.2 Social media campaigns

As described in Section 1 above, the CEC and NEURONET have worked together to develop a yearly social media campaign on Twitter. Each campaign is themed around a specific topic:

- Year 1 (2019) programme introduction: "Why we do what we do campaign on the value of participating in research"
- Year 2 (2020) programme findings highlights: "The value of public-private collaboration"
- Year 3 (2021) programme impact analysis: "Where we are and where we need to go"

These topics are addressed on Twitter via tweets that include Twitter cards as images. The campaigns start in September each year, to capitalise on the increased public attention on neurodegenerative disease during World Alzheimer's Month. The social media campaigns conclude in the middle of October, in time to build up awareness towards NEURONET's yearly event.



Fig. 9 2019 social media campaign Twitter cards for ADAPTED and EPAD.

The 2019 campaign consisted of 35 individual cards with quotes from collaborators on 10 of the projects in the IMI ND portfolio (ADAPTED, AMYPAD, EMIF, EPAD, MOPEAD, PHAGO, PRISM, RADAR-AD, RADAR-CNS, ROADMAP; examples shown in **Fig.9** above). NEURONET purposefully









aimed to collect quotes from a broad range of different project collaborators, from project leaders to EFPIA members, postdoctoral researchers and clinical study participants. Each card displayed a personalized bit.ly link (e.g http://bit.ly/PHAGO-project) which directed users to the project website in question. Where available, the accompanying tweet referenced the project twitter handle (e.g @IMI_EPAD). In addition, a dedicated hashtag (#WeAreNeuronet) was created for the campaign, and was used throughout September and October for all tweets linked to the campaign and public event.

Metrics for the 2019 campaign demonstrated a very positive engagement with the tweets and associated links. Overall, the campaign generated 377 engagements and 105,157 tweet impressions. The @IMI2_NEURONET tweet impressions for the campaign period amounted to 130,600, demonstrating the impact of the campaign alone on public engagement with the NEURONET twitter handle. Metrics for individual tweets in the 2019 campaign are included in Annex II, and will be collected consistently for the upcoming 2020 and 2021 campaigns. The CEC is currently developing the content for the 2020 social media campaign, which will be launched in September 2020.

2.5.3 LinkedIn

LinkedIn is an online platform that is primarily used for professional networking and career development. Although initially developed as a tool for private sector users, in recent years it has expanded to include a substantial audience of academic and public sector stakeholders and Institutions. Similar to Facebook and Twitter, users can engage with LinkedIn content by 'liking' it, and can reshare it through their feeds. In addition, LinkedIn uses hashtags, with a "follow hashtag" feature enabling users to personalise their LinkedIn feeds with tailored content.

To reach professional audiences, a LinkedIn page for NEURONET was launched in January 2020, to coincide with the release of the January NEURONET newsletter. The LinkedIn page summarises the key goals of NEURONET, providing links to the website, newsletter, twitter and YouTube feeds. It is populated with news items from the website, with 54 items displayed in total, and has accumulated 84 followers to date. **Table 6** below outlines the summary metrics for the first 7 months of the NEURONET LinkedIn page.

Table.6 NEURONET LinkedIn metrics

Month	Number of updates	Total page views	Total unique visitors
Jan-20	10	41	23
Feb-20	11	11	5
Mar-20	12	36	12
Apr-20	6	30	9
May-20	2	9	5
Jun-20	9	14	7
Jul-20	4	4	2









Two additional measures of engagement with individual LinkedIn posts not listed in the table above are "organic impressions" (the number of times content is displayed to users) and "likes". An interim, preliminary analysis of the NEURONET LinkedIn posts from January to July 2020 found the highest levels of engagement for a post on the launch of the Fraunhofer SCAI knowledge space for COVID-19, based on work carried out during the AETIONOMY and PHAGO IMI ND projects (524 organic impressions, 20 likes; Fig.10 below) and a post on the effect of COVID-19 on dementia research at Fundacio ACE (398 organic impressions, 20 likes).

More detailed analysis of LinkedIn metrics are required to draw firm conclusions, however it is tempting to speculate that the use of the #COVID19 hashtag (which currently has over a million LinkedIn followers) in both posts may have contributed to the greater engagement with these posts. Going forward, LinkedIn metrics will be collected and collated with Twitter metrics and Google Analytics, to facilitate more in-depth analysis of NEURONET communications reach and audience engagement across these channels.



Figure 10. NEURONET LinkedIn post

2.5.4 YouTube

A NEURONET YouTube channel has been created, which can also be accessed via a link on the project website. The channel currently hosts the 14 videos filmed as part of the 2019 NEURONET public event, as indicated in the NEURONET Grant Agreement - Description of Action (DoA). In addition, the NEURONET YouTube channel features the channels of EFPIA, the IMI and all IMI ND project channels (at the time of writing, EPAD, AMYPAD, ADAPTED, EMIF, MOPEAD, MobiliseD, RADAR-CNS), to showcase the activities of these projects and the links between projects and their partner funders.









In total, the 14 NEURONET videos have attracted 395 views, with an average of 28 views per video. Although the viewer metrics for the NEURONET videos are fairly low, it should be emphasised that each video is between 15-20 minutes in length; several studies show that the ideal video length for optimal engagement is 2 minutes or under, which may account for the low number of views. For comparison, a 2-minute video describing the first three years of the EPAD project has accumulated over 1,000 views since it was published 2 years ago. Moreover, the NEURONET video content is very specialised, targeted primarily to research and professional audiences, which may also partly account for the low number of video views.

Going forward, to increase engagement with NEURONET and the IMI ND portfolio via YouTube WP4 and the CEC hope to generate short videos that engage with the public in the form of brief, 2-minute presentations, with lay language used throughout. Since video recordings will be integrated into the NEURONET public events, the development of these 2-minute videos could be organised at this time; unfortunately the 2020 public event will be held online, due to the COVID-19 pandemic, however we will explore the potential to film these brief videos at the final Neuronet public event in 2021.

2.6 Public events

2.6.1 NEURONET sessions at #AEC29

One of the key dissemination activities (both in terms of generating content to disseminate and as a route for dissemination) is the annual NEURONET public event, organised by WP4 with the support of the CEC. The primary goal of the NEURONET public event is to comprehensively showcase the work of IMI projects on neurodegeneration, as a legacy to the 2017 IMI event on "Collaboration in Alzheimer's disease & beyond".

To achieve this goal WP4 involves all IMI ND projects, aiming to disseminate NEURONET and IMI ND project activities to an audience of policy makers, scientists, researchers, representatives of industry, payers, regulators and HTA bodies. To reach this broad audience and engage with the ND community, the NEURONET public events are integrated into the Annual Alzheimer Europe Conference. In order to maximise the long-term visibility of the event, as well as disseminating information about the event via the NEURONET social media channels and website, proceedings of the public-facing part of the event are published as part of the Dementia in Europe Magazine, and presentations from the event are filmed and uploaded to the NEURONET youtube channel (as outlined in Section 2.5.4 above).

Each year, the agenda for the event is based on on priorities and gaps detected in WP1 and discussed in WP2, so that all activities across the NEURONET programme are as tightly integrated as possible. For the first NEURONET event in 2019 (Year 1), the theme was "Collaboration in Alzheimer's Disease and Beyond", retaining the title of the 2017 IMI event to emphasise the connection to this event. Deliverable 4.2 "Public Event Proceedings and Videos" provides a detailed overview of the 2019 Public Event and related outreach activities, including publication of a "Dementia in Europe" magazine article on the public event and associated news items and press releases.

Briefly, the year 1 NEURONET public event featured speakers from the IMI, as well as representatives of IMI ND projects, presenting in four parallel sessions on 24 and 25 October during the Alzheimer Europe Conference in The Hague. The finalised programme was made











public on the NEURONET website <u>here</u>, also linking to videos of the presentations and providing brief abstracts describing the session contents. A brochure (**Fig. 11** below) designed specifically for the event was included in all conference bags, which were distributed to the >900 attendees of the Alzheimer Europe Conference, thereby ensuring broad dissemination to conference attendees who were not present during the NEURONET sessions.

Organisation of the 2020 NEURONET public event is currently underway. During this event, again hosted as part of the Alzheimer Europe annual conference (to be held online between 20-22 October), members of the data sharing, ethics & patient privacy and regulatory Working Groups have been invited to present their work on these key priority areas for IMI ND projects. In addition, NEURONET SCB members (IMI ND project leaders) will hold a roundtable discussion on the topic "Public-Private Partnership research in the post-COVID era", aiming to address the challenges of PPP research during the COVID pandemic and aspirations for how PPP research should evolve in the post-pandemic period. Finally, NEURONET will host an early-career researcher (ECR) session, during which project collaborators who are ECRs (defined as graduate students or researchers within 10 years of completing their graduate studies) will showcase their work on IMI ND projects.



Figure. 11: 2019 NEURONET event brochure cover

Together, these sessions will amplify the voices of IMI ND project collaborators at many different career stages, provide a platform for discussions on the actions required to overcome the obstacles to research caused by COVID-19, and highlight efforts to resolve ethical, regulatory and data sharing issues – to ensure that the work of IMI ND projects ultimately benefits patients and citizens.









2.6.2 European Parliament Lunch Debate

In the first 18 months of the CSA, NEURONET has held two public events. As well as the conference sessions in October 2019, NEURONET co-hosted a European Parliament lunch debate with Alzheimer Europe. This debate took place on 18 February 2020, aiming to raise the profile of NEURONET and the IMI neurodegeneration portfolio at the European level. The lunch debate was hosted by Christophe Hansen MEP (European Peoples' Party; Luxembourg) and was attended by 70 people including representatives from national member organisations, government experts on dementia, academics, industry representatives and policymakers. The lunch debate featured presentations by Carlos Diaz (Project Coordinator for Neuronet), Bart Vannieuwenhuyse (Co-Lead of EMIF) and Pierre Meulien (Executive Director of IMI)(Fig.12 below).

The event had originally been planned for year 3 of NEURONET, but was brought forward by one year due to the ongoing negotiations regarding the multiannual financial framework (MFF), Horizon Europe and the Innovative Health Initiative (the putative successor to the IMI). To frame the discussions around the importance of public-private partnerships for neurodegenerative disease research, the lunch debate was entitled "The Innovative Medicines Initiative (IMI): Advancing Alzheimer's research through private-public partnerships". A <u>detailed overview</u> of the lunch debate was published on the NEURONET website and disseminated via LinkedIn and Twitter.

During the lunch debate, Carlos Diaz outlined the work of the project in supporting the neurodegeneration portfolio of the IMI, as well as the opportunities to identify gaps and potential synergies between the different projects. Bart Vannieuwenhuyse then described how EMIF had established a foundational information framework supporting dementia research throughout Europe and beyond. Drawing the lunch debate to a close, Pierre Meulien provided an overview of the public-private partnerships (PPP) in relation to neurodegeneration research, also discussing how the new PPP programme in Horizon Europe may be shaped.



Figure 12. Speakers at the NEURONET-Alzheimer Europe lunch debate (L-R Pierre Meulien, Bart Vannieuwenhuyse, Christophe Hansen, Jean Georges [Executive Director of Alzheimer Europe] and Carlos Diaz)









2.7 Print and news media

2.7.1 Dementia in Europe magazine

Alzheimer Europe publishes the <u>Dementia in Europe magazine</u> three times per year with a distribution that varies between 3,000 and 3,500 copies. It is delivered to all the Members of the European Parliament (MEPs) and many high-level decision makers in the European Commission. It also reaches lawmakers and politicians in the countries of Alzheimer Europe's member associations, who receive and further distribute numerous copies of each issue. In addition, the magazine is read by research professionals from public and private bodies, such as the JPND and the 2nd EU Joint Action on Dementia. Finally, the magazine is distributed to academic and scientific partners who work together with Alzheimer Europe in various projects.

As described in section 2.6.1 above, conference proceedings from the NEURONET public event were featured in <u>Issue 32</u> of the Dementia in Europe magazine. In addition, the lunch debate co-hosted by NEURONET was featured in <u>Issue 33</u> of the magazine. During the final half of the CSA, a 16-page special supplement will be produced to provide a high-level introduction to the NEURONET programme, drawing special attention to programme findings/highlights while underlining the value IMI has brought through its innovative concept.

2.7.2 Press & news releases

NEURONET issues press releases addressed to different stakeholders to communicate major updates. The <u>first NEURONET press release</u> was published during the project's kick-off meeting at the end of March 2019 on the Newsweaver platform, and was delivered to <u>7,772</u> individuals (Alzheimer Europe news subscribers, including policymakers, regulators, researchers, clinicians, people with dementia & caregivers, and the general public). The press release email was opened by <u>2,032</u> recipients, of whom <u>178</u> clicked on the link to the NEURONET website. NEURONET also featured prominently in the <u>final Alzheimer Europe press release</u> on their 29th Annual Conference in The Hague. Target audiences for these press releases were the ND research community and IMI ND projects to raise awareness about the launch and ongoing work of NEURONET.

As well as publishing press releases via Newsweaver, NEURONET has regularly updated CORDIS with news releases on its activities. CORDIS (Community Research and Development information Service) is the European Commission's primary source of information, results and outputs from EU-funded projects. At the time of writing, NEURONET had published four updates on CORDIS:

- The IMI launch a public-private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects (21 March 2019)
- Scientific Coordination Board meeting assembles project leaders from IMI neurodegenerative disease portfolio, encompassing €260 million in funding (2 July 2019)
- The Neuronet Coordination and Support Action on neurodegeneration research launches its website (3 August 2019)











<u>260 million EUR Research Programme on Neurodegeneration Featured at Alzheimer</u>
 <u>Europe Conference</u> (27 September 2019)

Finally, NEURONET published several news articles highlighting important events and results on science and science policy websites, such as ScienceX, Health Europa, EAN pages (European Academy of Neurology), EU Monitor and Phys.Org, as well as on the EU Health Policy Platform, a collaborative online communications tool that facilitates interactions between European Commision services, health-related interest groups and other stakeholders. These and other external dissemination activities are listed in the NEURONET dissemination tracker (Annex IV).

Going forward, NEURONET will continue to highlight important activities using press and news releases. For example, discussions are currently underway to broaden access to the Knowledge Base (KB). Once these discussions have concluded, NEURONET will publish a press release and news articles describing this resource.

2.8 Changes from the initial communication plan

This section highlights specific changes from the initial communication plan.

Due to the COVID-19 pandemic and the associated lockdown measures, the Year 2 NEURONET public event (see section 2.6.1) will now be held online, as part of the virtual Annual Conference of Alzheimer Europe. As a result, the schedule of the event has been amended: conference sessions have been shortened slightly, and WP4 will no longer produce any brochures or printed media to publicise the event. To maintain the desired interactiveness of the NEURONET sessions, WP4 is currently exploring the possibility of hosting a virtual conference booth for NEURONET.

As indicated in section 2.6.2, although it was initially planned to feature NEURONET as part of a Lunch Debate with MEPs in year three of the CSA, participation in the event was shifted to the first 2020 lunch debate due to the ongoing negotiations over the budget and scope of the Horizon Europe programme. The event was a timely opportunity to highlight the achievements of the IMI in supporting neurodegeneration research and to discuss the continued support of PPPs in Horizon Europe.

3. Challenges & mitigation strategies

Over the last 18 months, WP4 has identified a number of dissemination challenges: on the one hand, internal challenges that directly affect NEURONET channels & activities, and on the other hand, challenges experienced by the IMI ND projects that NEURONET will help mitigate.

- Due to lockdown measures imposed in response to the COVID-19 pandemic, the vast majority of face-to-face meetings have been cancelled, or have had to move online. From an internal communications perspective, this has meant that consortium and SCB meetings are now taking place via Zoom or GoToMeeting. From an external communications perspective, this has meant that the yearly NEURONET public event (see Section 2.6 above) will no longer take place in Bucharest as originally planned.
 - NEURONET has retained the planned periodicity of face-to-face meetings, moving meetings to teleconferencing platforms. Attendance at meetings has











generally been good, although the virtual format of these meetings has precluded one-to-one conversations or e.g interviews with SCB or consortium members. Going forwards, WP4 will schedule online interviews and use transcripts of meetings to develop content for the NEURONET website describing the meetings and actions. It is hoped that some face-to-face meetings will resume in 2021, in time for the year 3 public event.

- The 2020 NEURONET public event will be hosted online, as part of the Alzheimer Europe virtual conference. Instead of being filmed, conference presentations will be recorded as webinars, which will then be shared with stakeholders via the website and YouTube. Speakers will be asked to tailor their presentations to a lay audience, to increase engagement with the content.
- ➤ To maintain interactivity during the public event, NEURONET is exploring the possibility of hosting a virtual meeting room, which could be an area that assembles information about NEURONET and the IMI ND portfolio whilst also allowing visitors to ask informal questions of NEURONET representatives.
- Not all projects maintain a social media presence (Twitter, Facebook, LinkedIn), instead using their websites, newsletters or public events to disseminate information about their activities.
 - To raise awareness and visibility of these projects within the ND community on social media, NEURONET has created content and featured news items on these projects on its own Twitter, LinkedIn and YouTube channels, supporting outreach of the projects' public identity and communications.
 - The CEC underlined that it would be useful to have a social media recommendations guideline: This will be developed as part of WP4 and will also include recommendations on best practice from the projects.
- A frequently-reported issue for IMI ND projects is low website traffic and engagement, or low engagement with social media channels.
 - ➢ Based on a bi-annual benchmarking exercise, NEURONET is working to identify ways to increase traffic. Metrics have been provided from most projects on website and social media traffic for March 2019 − December 2019; metrics on the period between January − June 2020 are currently being collected. An interim analysis of these metrics will guide the development of best practice recommendations by WP4.
 - As described in the previous point, NEURONET social media activities will aim to guide target audiences towards IMI ND project websites; for example, NEURONET and the CEC will continue to work together on common outreach activities such as the annual public events and social media campaigns.











Annexes

Annex I Members of the Communication Expert's Community

Name	Institution	Project
Alex Schubert	ECNP	PRISM
Alexander Duyndam	Lygature	RADAR-AD
Angela Bradshaw	Alzheimer Europe	NEURONET
Annette Dumas	ASDM consulting	MOPEAD
Bridget Glaysher	Modus Ltd.	ADAPTED
Caroline Schuster	Arttic	PHAGO
Cindy Birck	Alzheimer Europe	AMYPAD, EPAD, NEURONET
Claudia Pfander	Arttic	PHAGO
Cora Meyer	Concentris	PRISM
David Dexter	Parkinson's UK	PD-MitoQUANT, PD-MIND
Gabriele Wagner	Arttic	PHAGO
Isabel Rodríguez	Fundacio ACE	MOPEAD
Jelle Praet	Modis Ltd.	EMIF
Kirsten Leufgen	SCIPROM	IMPRIND
Mara Diaconu	NTNU	Mobilise-D
Beatrix Vereijken	NTNU	Mobilise-D
Philippe Rocolle	Sanofi	IM2PACT
Sara Stoeber	Concentris	EQIPD
Stefanie Schütte	Arttic	PHAGO
Veronique Gobry	SCIPROM	IMPRIND
Yoanna Daskalova	Lygature	RADAR-CNS, RADAR-AD
Daniel Schmidtmann	EMPIRICA	IDEA-FAST











Annex II Social media campaign metrics

Date	Project	Bit.ly	Clicks	Impressions	Likes	Retweets
13/09/2019	RADAR-CNS	http://bit.ly/RADAR-CNS-survey+	24	2069	4	4
13/09/2019	NEURONET	bit.ly/WeAreNeuronet-campaign+	14	4782	19	16
16/09/2019	EPAD	http://bit.ly/EPAD-story+	30	3920	14	11
17/09/2019	AMYPAD	http://bit.ly/AMYPAD-Interview+	13	3143	22	7
18/09/2019	ROADMAP	http://bit.ly/ROADMAP-Findings+	11	3317	12	10
19/09/2019	MOPEAD	http://bit.ly/MOPEAD-survey+	18	3657	10	7
20/09/2019	NEURONET	http://bit.ly/Neuronet-project	7	2856	4	6
20/09/2019	ADAPTED	http://bit.ly/ADAPTED-Interview1+	7	2922	6	7
23/09/2019	EPAD	http://bit.ly/EPAD-study+	31	4676	13	11
23/09/2019	PHAGO	http://bit.ly/PHAGO-project+	18	2769	7	7
24/09/2019	RADAR-AD	http://bit.ly/RADAR-project+	15	4006	8	9
25/09/2019	RADAR-CNS	http://bit.ly/RADAR-CNS-survey+		2980	1	3
26/09/2019	EMIF	http://bit.ly/Neuronet-EMIF-catalogue+	47	4429	16	16
27/09/2019	PRISM	http://bit.ly/PRISM_IMI+	9	3537	8	6
28/09/2019	RADAR-CNS	http://bit.ly/RADAR-CNS-survey+		3120	7	5
30/09/2019	ADAPTED	http://bit.ly/ADAPTED-Interview3	5	2138	4	2
01/10/2019	NEURONET	http://bit.ly/Neuronet-projects+	15	3940	7	6
01/10/2019	EPAD	http://bit.ly/EPAD-study+		5323	9	19
03/10/2019	AMYPAD	http://bit.ly/AMYPAD-Interview2+	11	3776	13	7
04/10/2019	ROADMAP	http://bit.ly/ROADMAP-Interview+	26	5028	25	26
07/10/2019	MOPEAD	http://bit.ly/MOPEAD-Interview+	14	3725	16	9
08/10/2019	PHAGO	bit.ly/PHAGO-project+		2427	6	8
08/10/2019	ADAPTED	http://bit.ly/ADAPTED-Interview2+	4	2043	6	8
09/10/2019	RADAR-AD	http://bit.ly/RADAR-project+	15	2229	8	3
10/10/2019	RADAR-CNS	http://bit.ly/RADAR-CNS-project+	3	1476	4	0
11/10/2019	EMIF	http://bit.ly/Neuronet-EMIF-catalogue+		2682	9	7
11/10/2019	EPAD	http://bit.ly/EPAD-study+		3357	11	11
14/10/2020	PRISM	http://bit.ly/PRISM_IMI+		1372	2	2
15/10/2020	NEURONET	http://bit.ly/Neuronet-projects+		1313	1	3
15/10/2020	MOPEAD	http://bit.ly/MOPEAD-project+	19	1814	3	6
16/10/2020	EPAD	http://bit.ly/EPAD-story+		2089	10	7
17/10/2020	AMYPAD	http://bit.ly/AMYPAD-Interview3+	6	2307	11	10
18/10/2020	ROADMAP	http://bit.ly/Data-Cube+	15	2362	6	10
21/10/2020	ADAPTED	http://bit.ly/ADAPTED-Publications+ http://bit.ly/ADAPTED-Interview4+		1174	10	7
22/10/2020	EMIF	http://bit.ly/Neuronet-EMIF-catalogue+		1631	10	5
22/10/2020	NEURONET closing tweet			768	16	2









Annex III NEURONET dissemination tracker

ID	Title	Type of activity	Date (dd/mm/year)	Reference (e.g. website)
		menu		
1	The Innovative Medicines Initiative launches a public- private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/03/2019	http://alzheimereurope.newsweaver.com/ConferenceAnnouncement/8w4ryiy1ssc1 4p7eu75tbl?email=true&a=11&p=54726438
2	IMI launches NEURONET to develop an operational platform for its neurodegeneration platforms	Press release	21/03/2019	https://www.modis.com/en-be/insights/press-release/imi-launches-a-public-private-coordination-and-support-action-Neuronet/
3	The Innovative Medicines Initiative launches a public- private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/03/2019	https://phys.org/wire-news/314611875/the-innovative-medicines-initiative-launches-a-public-private-co.html
4	The Innovative Medicines Initiative launches a public- private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/03/2019	https://cordis.europa.eu/news/rcn/130950/en
5	The Innovative Medicines Initiative: tackling neurodegenerative diseases for its neurodegeneration projects	Website for general public	22/03/2019	https://www.healtheuropa.eu/innovative-medicines-initiative-neurodegenerative-diseases/90872/
6	The Innovative Medicines Initiative launches a public- private coordination and support action	Website for general public	21/03/2019	https://www.flanders.bio/en/news/flandersbio-member-news/2019/march/the-innovative-medicines-initiative-launches-a-public-private-coordination-and-support-action/



7	From innovation to better treatments	Website for general public	27/05/2019	https://medium.com/parkinsons-uk/from-innovation-to-better-treatments-838dd17f78b9
8	Neuronet CSA introduction	Other	21/05/2019	-
9	Article on BBRC participation in Neuronet	Website for general public	24/05/2019	https://www.barcelonabeta.org/en/news/news/Neuronet-will-boost-synergy-and-collaboration-across-imis-projects-neurodegenerative?utm content=92649120&utm medium=social&utm source=twitter&hss channel=tw-219289844
10	Alzheimer Europe collaborates in a new coordination and support action of the Innovative Medicines Initiative	Website for general public	01/05/2019	https://www.eanpages.org/2019/05/01/news-from-alzheimer-europe-3/
11	La colaboración público-privada como impulsora de la I+D+i	Website for general public	05/07/2019	https://www.diariomedico.com/investigacion/la-colaboracion-publico-privada- como-impulsora-de-la-idi.html
12	Scientific Coordination Board meeting assembles project leaders from IMI neurodegenerative disease portfolio, encompassing €260 million funding	Website for general public	14/07/2019	https://cordis.europa.eu/event/rcn/147301 en.html?WT.mc id=email-Notification
13	Scientific Coordination Board meeting assembles leaders from IMI neurodegenerative projects, encompassing € 260 million	Website for general public	12/07/2019	https://phys.org/wire-news/324371615/scientific-coordination-board-meeting-assembles-leaders-from-imi.html
14	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	https://synapse-managers.com/the-Neuronet-coordination-and-support-action-on-neurodegeneration-research-launches-its-website/
15	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	https://www.alzheimer-europe.org/News/EU-projects/Wednesday-31-July-2019- The-Neuronet-Coordination-and-Support-Action-on-neurodegeneration-research- launches-its-website
16	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	02/08/2019	https://cordis.europa.eu/news/rcn/131709_en.html



17	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	https://phys.org/wire-news/326000987/the-Neuronet-coordination-and-support-action-on-neurodegeneratio.html
18	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	06/08/2019	https://www.prlog.org/12782938-the-Neuronet-coordination-and-support-action-on-neurodegeneration-research-launches-its-website.html
19	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	06/08/2019	http://www.free-press-release.com/news-the-Neuronet-coordination-and-support-action-on-neurodegeneration-research-launches-its-website-1565091375.html
20	Collaboration in Alzheime's disease and beyond	Participation in activities organised jointly with other projects	23- 25/10/2019	https://www.imi-Neuronet.org/2019-event-the-hague/
21	NEURONET website launched	Website for general public	01/08/2019	https://imprind.org/news/?post_id=36&title=Neuronet-website-launched
22	Collaboration kick-starts at NEURONET first Scientific Coordination Board	Website for general public	03/07/2019	https://www.imi-adapted.eu/single-post/2019/07/03/Collaboration-kick-starts-at- NEURONET-first-Scientific-Coordination-Board
23	The Innovative Medicines Initiative launches a public- private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/04/2019	https://www.imi-adapted.eu/single-post/2019/03/25/The-Innovative-Medicines- Initiative-launches-a-public-private-coordination-and-support-action-NEURONET-to- develop-an-operational-platform-for-its-neurodegeneration-projects
24	IMI launches public-private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/04/2019	https://roadmap-alzheimer.org/news/the-innovative-medicines-initiative-launches-a-public-private-coordination-and-support-action-Neuronet-to-develop-an-operational-platform-for-its-neurodegeneration-projects/



25	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	https://roadmap-alzheimer.org/news/Neuronet-launches-website/
26	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	http://ep-ad.org/2019/07/31/the-Neuronet-coordination-and-support-action-on-neurodegeneration-research-launches-its-website/
27	The Neuronet Coordination and Support Action on neurodegeneration research launches its website	Website for general public	31/07/2019	https://amypad.eu/news/recent-news/the-Neuronet-coordination-and-support-action-on-neurodegeneration-research-launches-its-website/
28	The Innovative Medicines Initiative launches a public- private coordination and support action (NEURONET) to develop an operational platform for its neurodegeneration projects	Press release	21/04/2019	https://amypad.eu/news/recent-news/imi-launches-public-private-coordination-and-support-action-Neuronet-to-develop-an-operational-platform-for-its-neurodegeneration-projects/
29	Neuronet Scientific Coordination Board meeting	Website for general public	07/08/2019	https://prism-project.eu/en/Neuronet-scientific-coordination-board-meeting/
30	NEURONET website launched	Website for general public	30/07/2019	https://imprind.org/news/?post_id=36&title=Neuronet-website-launched
31	The Neuronet Coordination and Support Action on Neurodegeneration research launches its website	Website for general public	21/08/2019	https://www.radar-ad.org/newsroom/Neuronet-coordination-and-support-action-neurodegeneration-research-launches-its-website
32	REGULATORY AND HTA ENGAGEMENT IN NEURODEGENERATIVE DISEASE RESEARCH: A DECISION TOOL	Poster presentation at a scientific meeting	11/06/2019	
33	Neuronet Newsletter Issue I	External newsletter	19/09/2019	https://mailchi.mp/02e6ec71a7f7/Neuronet-newsletter-1
34	Benjamin Falcon discusses his research in Neuronet's first newsletter	Website for general public	20/09/2019	https://www2.mrc-lmb.cam.ac.uk/news-and-events/lmb-in-the-news/?y=2019



35	Spotlight on early-career investigators: an interview with Benjamin Falcon	Website for general public	20/09/2019	https://phys.org/wire-news/330418603/spotlight-on-early-career-investigators-an-interview-with-benjam.html
36	Neuronet launches social media campaign – Why we do what we do	Website for general public	13/09/2019	https://roadmap-alzheimer.org/news/Neuronet-launches-social-media-campaign-why-we-do-what-we-do/
37	ROADMAP Data Cube featured in Neuronet newsletter	Website for general public	19/09/2019	https://roadmap-alzheimer.org/news/roadmap-data-cube-featured-in-Neuronet-newsletter/
38	Neuronet launches its first newsletter issue and a social media campaign – Why we do what we do	Website for general public	23/09/2019	https://www.alzheimer-europe.org/News/EU-projects/Wednesday-31-July-2019- The-Neuronet-Coordination-and-Support-Action-on-neurodegeneration-research- launches-its-website
39	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference	Website for general public	26/09/2019	https://www.prlog.org/12791004-250-million-eur-research-programme-on-neurodegeneration-featured-at-alzheimer-europe-conference.html
40	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference	Website for general public	26/09/2019	https://phys.org/wire-news/331020005/250-million-eur-research-programme-on-neurodegeneration-featured.html
41	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference	Website for general public	26/09/2019	https://cordis.europa.eu/event/rcn/147484/en
42	Interview of Benjamin Falcon on Neuronet	Website for general public	26/09/2019	https://imprind.org/news/?post_id=37&title=interview-of-benjamin-falcon-on- Neuronet
43	CAEBi to present ADAPTED at Alzheimer Europe Conference 2019	Website for general public	15/10/2019	https://www.imi-adapted.eu/single-post/2019/10/15/CAEBi-to-present-ADAPTED-at-Alzheimer-Europe-Conference-2019
44	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference, Den Haag	Website for general public	26/09/2019	https://www.montesquieu-institute.eu/9353000/1/j9vvj72dlowskug/vl2e7kdk74zt



45	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference, Den Haag	Website for general public	26/09/2019	https://www.europa- nu.nl/id/vl2e7kdk74zt/agenda/250 million eur research programme on?ctx=vh6 ukzb3nnt0&s0e=vifdl6zl7txx
46	Showcasing IMI projects - Neuronet at #29AEC	Press release	25/10/2019	http://alzheimereurope.newsweaver.com/ConferenceAnnouncement/1sy5ob68ev9 17bovvbl73l?email=true&a=11&p=55862477
47	250 Million EUR Research Programme on Neurodegeneration Featured at Alzheimer Europe Conference, Den Haag	Website for general public	29/10/2019	https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vl2e7kdk74zt?ctx=vh72m a0flbwg&tab=1&start_tab1=5
48	Alzheimer Europe Newsletter October 2019	External newsletter	31/10/2019	alzheimereurope.newsweaver.com/Newsletter/pqjyt0c2e2o17bovvbl73l?i=2&a=5& p=55890736&t=29416949
49	PD-MitoQUANT joins Neuronet consortium of IMI- supported research projects	Website for general public	15/11/2019	https://www.pdmitoquant.eu/2019/11/pd-mitoquant-joins-Neuronet-consortium- of-imi-supported-research-projects/
50	Neuronet convenes annual event on European research collaboration in Alzheimer's disease and beyond	Website for general public	25/10/2019	https://www.alzheimer-europe.org/News/EU-projects/Friday-25-October-2019-Neuronet-convenes-annual-event-on-European-research-collaboration-in-Alzheimer-s-disease-and-beyond
51	Neuronet Scientific Coordination Board meeting brings together project leaders in The Hague	Website for general public	23/10/2019	https://www.alzheimer-europe.org/News/EU-projects/Wednesday-23-October-2019-Neuronet-Scientific-Coordination-Board-meeting-brings-together-project-leaders-in-The-Hague
52	Neuronet Scientific Coordination Board meeting brings together project leaders in The Hague	Website for general public	23/10/2019	https://roadmap-alzheimer.org/news/Neuronet-scientific-coordination-board-meeting-brings-together-project-leaders-in-the-hague/
53	ROADMAP presents at Neuronet's annual event on European research collaboration in Alzheimer's disease and beyond	Website for general public	25/10/2019	https://roadmap-alzheimer.org/news/roadmap-presents-at-Neuronets-annual- event-on-european-research-collaboration-in-alzheimers-disease-and-beyond/



54	RADAR-AD's project leader Dag Aarsland talks at the 29th Alzheimer Europe Conference in The Hague "Making valuable connections"	Website for general public	30/10/2019	https://www.radar-ad.org/newsroom/radar-ad%E2%80%99s-project-leader-dag-aarsland-talks-29th-alzheimer-europe-conference-hague-%E2%80%9Cmaking
55	AMYPAD features at the 29th Alzheimer Europe Conference	Website for general public	30/10/2019	https://amypad.eu/news/recent-news/amypad-presents-at-the-29th-alzheimer- europe-conference/
56	Neuronet team meeting focuses on the key assets and collaborations of IMI neurodegeneration projects	Website for general public	20/11/2019	https://www.alzheimer-europe.org/News/EU-projects/Wednesday-20-November-2019-Neuronet-team-meeting-focuses-on-the-key-assets-and-collaborations-of-IMI-neurodegeneration-projects
057	Neuronet convenes annual event on European research collaboration in Alzheimer's disease and beyond	Website for general public	25/10/2019	http://ep-ad.org/2019/10/25/Neuronet-convenes-annual-event-on-european-research-collaboration-in-alzheimers-disease-and-beyond/
058	Neuronet' interviews PRISM early career researcher Lianne Reus	Website for general public	09/12/2019	https://prism-project.eu/en/prism-study/
059	Neuronet team meeting focuses on the key assets and collaborations of IMI neurodegeneration projects	External newsletter	12/02/2019	http://alzheimereurope.newsweaver.com/Newsletter/1372p9um0b017bovvbl73l?e mail=true&a=11&p=56076706
060	Neuronet convenes third Scientific Coordination Board meeting in Madrid	Website for general public	28/01/2020	https://www.alzheimer-europe.org/News/EU-projects/Tuesday-28-January-2020- Neuronet-convenes-third-Scientific-Coordination-Board-meeting-in-Madrid
061	Neuronet convenes third Scientific Coordination Board meeting in Madrid	External newsletter	28/01/2020	https://www.alzheimer- europe.org/content/download/194663/1451775/file/2020%20January.pdf https://www.alzheimer-europe.org/News/EU-projects/Tuesday-28-January-2020- Neuronet-convenes-third-Scientific-Coordination-Board-meeting-in-Madrid
062	European research collaboration in Alzheimer's disease and beyond #29AEC	Non- scientific and non-	17/02/2020	http://bit.ly/DementiaInEuropeMagazine2020



		peer reviewed publications		
063	The Innovative Medicines Initiative (IMI): Advancing Alzheimer's research through private-public partnerships	Participation in activities organised jointly with other projects	18/02/2020	https://www.alzheimer-europe.org/News/Alzheimer-Europe/Tuesday-18-February-2020-Alzheimer-Europe-holds-lunch-debate-examining-European-research-collaborations
064	"Neuronet holds Consortium meeting in Brussels" & "Alzheimer Europe holds lunch debate examining European research collaborations"	External newsletter	03/02/2020	alzheimereurope.newsweaver.com/Newsletter/5aarwyi9dvn17bovvbl73l/external? email=true&i=2&a=5&p=56545038&t=29416949
065	Alzheimer Europe holds lunch debate examining European research collaborations	Website for general public	18/02/2020	https://www.alzheimer-europe.org/News/Alzheimer-Europe/Tuesday-18-February-2020-Alzheimer-Europe-holds-lunch-debate-examining-European-research-collaborations
066	Neuronet holds Consortium meeting in Brussels	Website for general public	18/02/2020	Not online yet (check projects section)
067	Neuronet convenes a meeting of its Working Group on sustainability	Website for general public	18/05/2020	https://www.alzheimer-europe.org/News/EU-projects/Monday-18-May-2020-NEURONET-convenes-a-meeting-of-its-Working-Group-on-Sustainability/(language)/eng-GB
068	Neuronet convenes a meeting of its Working Group on Patient Privacy and Ethics	Website for general public	03/06/2020	https://www.alzheimer-europe.org/News/EU-projects/Wednesday-03-June-2020- Neuronet-convenes-a-meeting-of-its-Patient-Privacy-and-Ethics-Working- Group/(language)/eng-GB
069	Neuronet holds an online Scientific Coordination Board meeting	Website for general public	05/06/2020	https://www.alzheimer-europe.org/News/EU-projects/Friday-05-June-2020-Neuronet-convenes-an-online-meeting-of-its-Scientific-Coordination-Board/(language)/eng-GB