

WP3 – Tools & Services

D3.6 INKB web platform v2: The NEURONET Knowledge Base v2

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Document history

Version	Date	Description
V1	02/07/2020	First draft
V2	29/07/2020	Second draft
V3	28/08/2020	Final version

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*)
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.

KB: Knowledge Base

HTA: Health technology assessment

IMI: Innovative Medicines Initiative

ND: Neurodegenerative Disorders

WP: Work Package

GDPR: General Data Protection Regulation

SGG: Strategic Governing Group

Abstract

Deliverable D3.6 describes the updates made on the design and structure of the NEURONET Knowledge Base since the submission of deliverable D3.1 *INKB web platform v1* submitted in month 6.

The aim of the Knowledge Base is to provide a summary overview of the IMI ND programme, in the format of a dashboard, where users can find information about the portfolio of projects (e.g. work plan, deliverables, results, publications, tools developed, etc). It also includes a section with the contact details of project experts in six key areas (ethics, data sharing, regulatory interactions, sustainability, communication and project management). More recently, we have also included the first tools developed by NEURONET, namely the Asset map and the Regulatory and HTA engagement Decision Tool.

1. Background

The primary aim of the IMI Coordination and Support Action NEURONET is to set up an efficient platform to boost synergy and collaboration across the IMI projects of the ND portfolio, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives. NEURONET intends to be an eminently operational, pragmatic and agile instrument for efficient collaboration and communication among both present and future IMI ND projects.

WP3 *Tools & Services* aims to support projects by developing specific tools and services tailored to the context of IMI ND research. As part of this WP, the focus of task 3.1 *Setting up and maintaining an IMI Neurodegeneration Knowledge Base* (M1-M36) is to design, develop and maintain a user-friendly web platform that acts as a web portal for the IMI ND programme.

The aim of the Knowledge Base (KB) is to provide a summary overview of the IMI ND programme, in the format of a dashboard, where users can find information about the IMI ND projects (e.g. work plan, deliverables, results, publications, tools developed, etc) at a glance. It also includes a section with the contact details of project experts in six key areas (ethics, data sharing, HTA/regulatory interactions, sustainability, communication and project management). More recently, we have also included the first tools developed by NEURONET, namely the Asset map and the Regulatory and HTA engagement Decision Tool.

The IMI ND projects included in the KB are the following:

1. ADAPTED
2. AETIONOMY
3. AMYPAD
4. EMIF
5. EPAD
6. EQUIPD
7. IDEA-FAST
8. IM2PACT
9. IMPRiND
10. MOBILISE-D
11. MOPEAD
12. PD-MIND
13. PD-MITOQUANT
14. PHAGO
15. PRISM
16. RADAR-AD
17. RADAR-CNS
18. ROADMAP

IMI projects IDEA-FAST, MOBILISE-D and PD-MIND have recently joined NEURONET and the process of uploading data and information from these three projects to the KB is not concluded. We uploaded most information about PD-MIND, we have listed all MOBILISE-D publications and we will soon begin uploading data for IDEA-FAST.

As described in deliverable D3.1, we made a conscious effort for the KB to be usable and useful for projects, with appropriate interfaces and search capabilities enabling easy access to information and an efficient user experience. With this purpose in mind, we included a project filter and a search bar on most sections of the KB and also labelled all deliverables and publications with appropriate keywords (e.g. clinical study, Parkinson's disease, biomarkers, dementia, etc.)

The KB, which uses Laravel, a PHP framework, among other programming languages (e.g. JavaScript) was developed and is being technically maintained by SYNAPSE.

2. Target users

When we were designing the KB, there was an internal debate about who should be the target users of the tool. Some NEURONET members argued it should be public and freely accessible to anyone, including lay people, while others were of the opinion that access should be exclusive and therefore restricted to the project leaders and coordinators only. After careful consideration, it was decided that the tool would not be accessible to the wider public, at least in the beginning. The initial target users of the KB would be: IMI ND Project leadership teams, IMI staff and the members of the IMI Neurodegeneration Strategic Governing Group.

More recently, the KB access has been expanded to include members of the Communication experts group (WP4) and from the 4 NEURONET Working Groups (WP3). To date, there are 23 registered users to the KB, but we expect this number will go up in the coming months.

The external reviewers who evaluated the performance of NEURONET at the interim project review on 25 June 2020 advised that the KB should be made public for wider dissemination and for raising awareness about the IMI ND portfolio, its efforts and results. In response, NEURONET will engage in further discussions on widening access to the KB with the IMI ND projects represented in this resource. As requested by the reviewers, NEURONET will strive to make the tool as public as possible, taking into account data privacy requirements under the GDPR, and the need to retain control over user access to ensure compliance with this regulation.

3. Permission levels

The user permission levels have not changed. There are three permission levels for users:

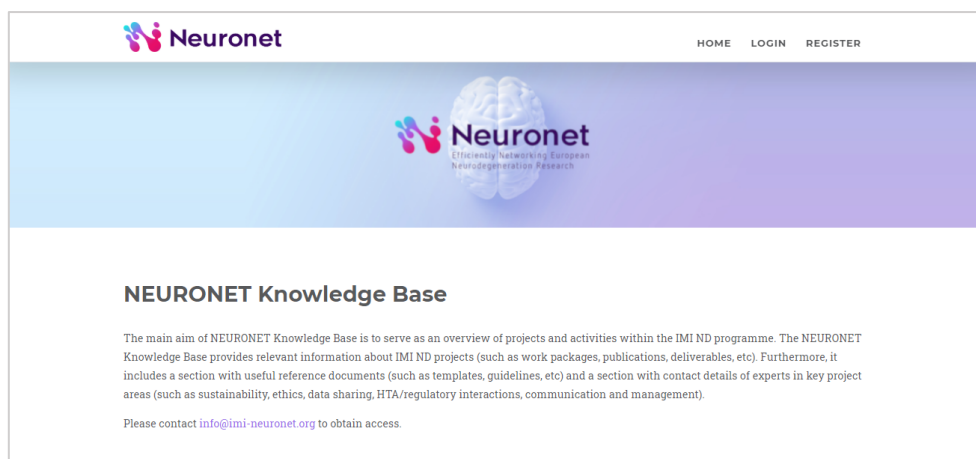
- Admin: Can list, create, read, update, download and delete all contents in the system, including users and user passwords.
- Editor: Can list, create, read, update, download and delete all contents.
- Subscriber: Can list, read and download contents.

The KB admins select the appropriate permission level for a user when validating the user request.

4. Welcome page

The landing or welcome page of the Knowledge Base (<https://kb.imi-neuronet.org>) is the first page that people encounter. It includes:

- NEURONET logo
- Full project name
- Intro text
- Invitation to Log in / Register



5. Registration page

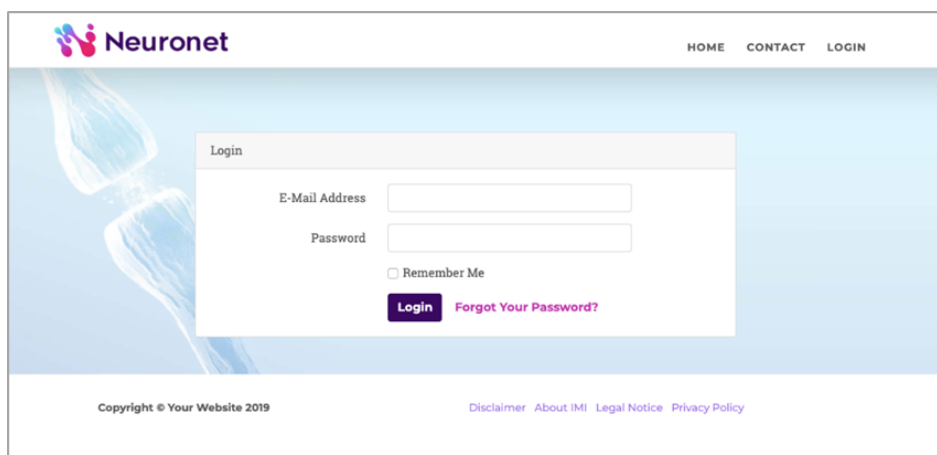
Following implementation of the General Data Protection Regulation (GDPR), and in order to have greater control over data access, a verification registration process for new users (manually moderated by site admins) has been implemented. New users are required to register by providing the following information:

- Name
- Email address
- Institution/Company
- IMI ND project/s he/she participates in.
- Professional category (e.g. Research assistant, Post-doc, Principal Investigator, etc.)
- Education (e.g. BSc, MSc, PhD, MD etc.)
- Country

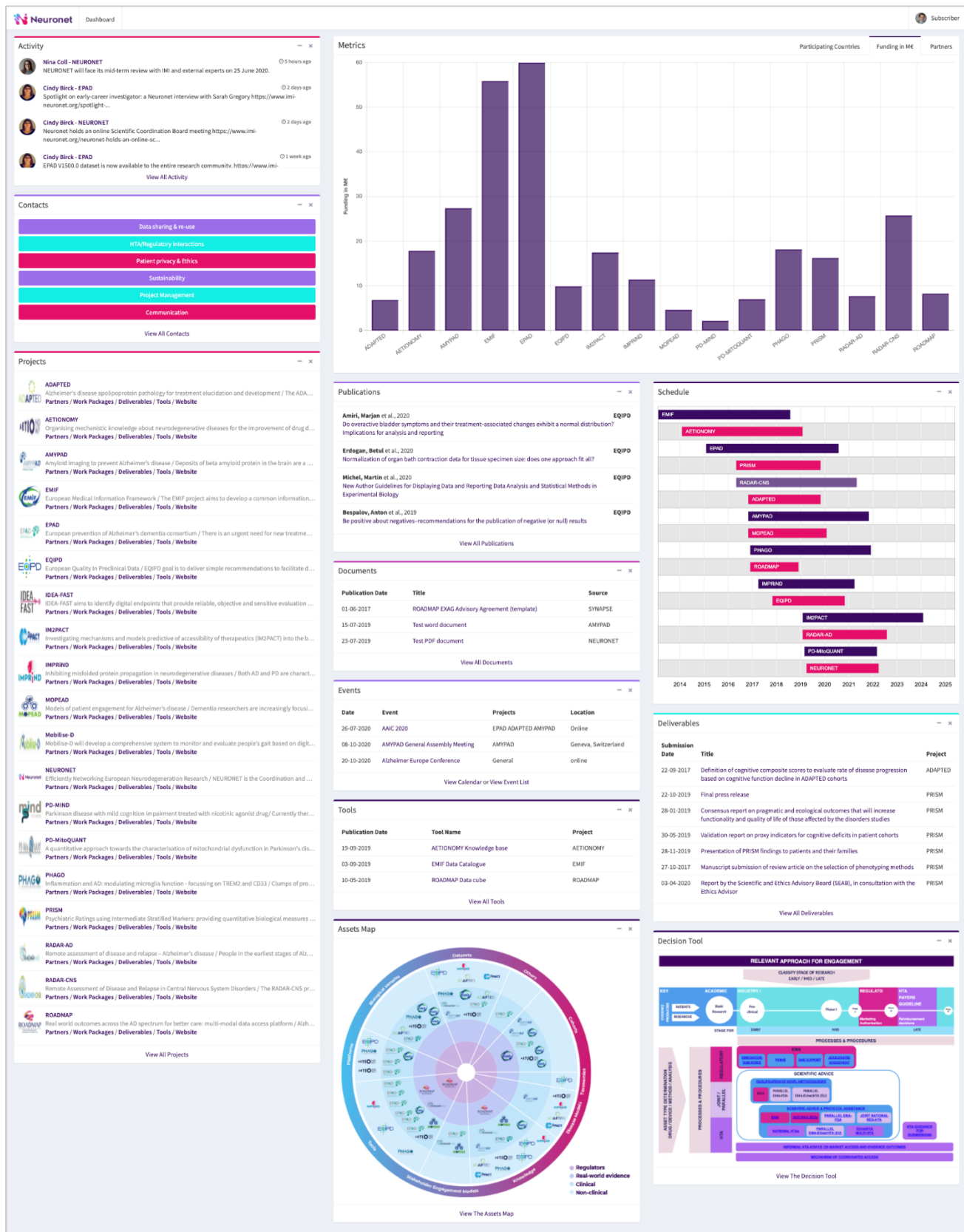
An automatic email is sent requiring the confirmation of the new user account as part of the verification process. Once the new user account is validated, the KB admins decide whether or not to accept the new user request in case of concerns about their identity. As described in D3.1, since institutional email accounts are generally more secure the use of an institutional email address may be requested to allow the professional identification of the individual.

6. Log in page

The log in page prompts registered users to complete the fields username and password for accessing the KB dashboard.



7. Dashboard



The dashboard provides an overview of the IMI ND programme at a glance. The website is designed in three columns to optimize visualisation and user experience. In the top right corner there is the user menu, with options to edit user details, change password, etc.

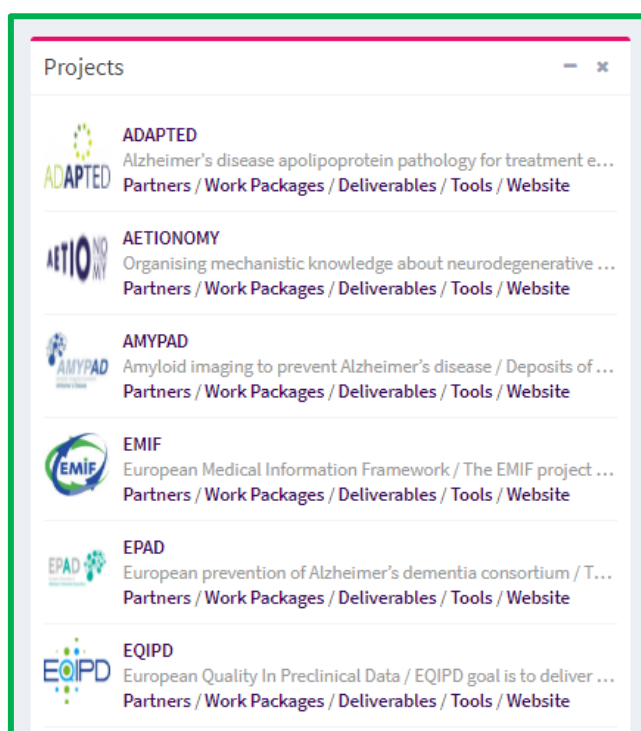
As mentioned previously, changes from the previous version include the addition of the first tools developed by NEURONET, namely the Asset map and the Regulatory and HTA engagement Decision Tool.

8. Modules in the dashboard

8.1. Projects

This module lists the 18 IMI ND projects that are currently part of NEURONET. Besides their project logo, acronym and full title, the following additional project information is also available:

- Partners: List with partner institution names and countries.
- Work Packages: List of project Work Packages.
- Deliverables: List of project deliverables. Only public deliverables (and/or those confidential deliverables they wish to provide) are listed. The deliverables are linked to the actual reports that might be available from the respective projects' websites or on CORDIS.
- Tools: List of project developed tools, databases, cohorts, etc. Whenever possible, details about the team or organization sustaining the tools (i.e. acting as gate keepers) plus an overview of the type of data available in them are provided.
- Website: Link to the project website.



By clicking *View all projects* a new window opens, showing the complete list of IMI ND projects and including a search bar in the top right corner.

Neuronet

Dashboard

Subscribed








Projects

All | Trash

List

Show 100 entries

Search:

Name	Description	Website	Date	Duration	Logo	
EPAD	European prevention of Alzheimer's dementia consortium	http://ep-ad.org/				View
ADAPTED	Alzheimer's disease apolipoprotein pathology for treatment elucidation and development	https://www.imi-adapted.eu/				View
AMYPAD	Amyloid imaging to prevent Alzheimer's disease	https://amypad.eu/				View
IMPRIND	Inhibiting misfolded protein propagation in neurodegenerative diseases	https://www.imprind.org/				View
MOPEAD	Models of patient engagement for Alzheimer's disease	https://www.mopead.eu/				View
EQIPD	European Quality In Preclinical Data	https://quality-preclinical-data.eu/				View
NEURONET	Efficiently Networking European Neurodegeneration Research	http://imi-neuronet.org/				View


Showing 1 to 7 of 7 entries

Previous

1

Next

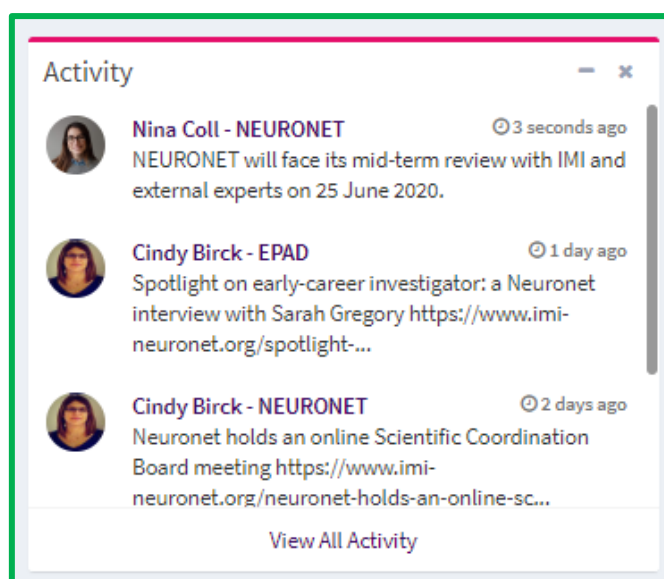
By clicking the *View* button we obtain further details about the project, including a general description, the main objectives, and start date and end date.

Projects	
View	
Name	EPAD
Description	European prevention of Alzheimer's dementia consortium / There is an urgent need for new treatments for Alzheimer's disease. The number of people affected worldwide is expected to reach over 100 million by 2050, yet despite intensive efforts over many years, there is still no cure for Alzheimer's and little in the way of treatments. Today, research increasingly focuses on ways to prevent the onset of Alzheimer's in the first place. The EPAD project is pioneering a novel, more flexible approach to clinical trials of drugs designed to prevent Alzheimer's dementia. Using an 'adaptive' trial design should deliver better results faster and at lower cost.
Objectives	1. Defining an accurate set of criteria for identifying Alzheimer's pathology early in the course of disease in people who have no or minimal associated symptoms. 2. Identifying these individuals from population and clinical cohorts or registers. 3. Developing a large longitudinal cohort study including these individuals with clinical, cognitive and biomarker assessments to ease identification for trial inclusion, provide trial run-in data and generate high quality data for updating these disease models, including defining risk for developing AD or evaluating efficacy. 4. Establishing a protocol and infrastructure for a standing, double-blind, adaptive, proof of-concept clinical trial for secondary prevention of Alzheimer's dementia. (Source EPAD DoW)
Website	http://ep-ad.org/
Start date	01-01-2015
End date	30-06-2020
Logo	

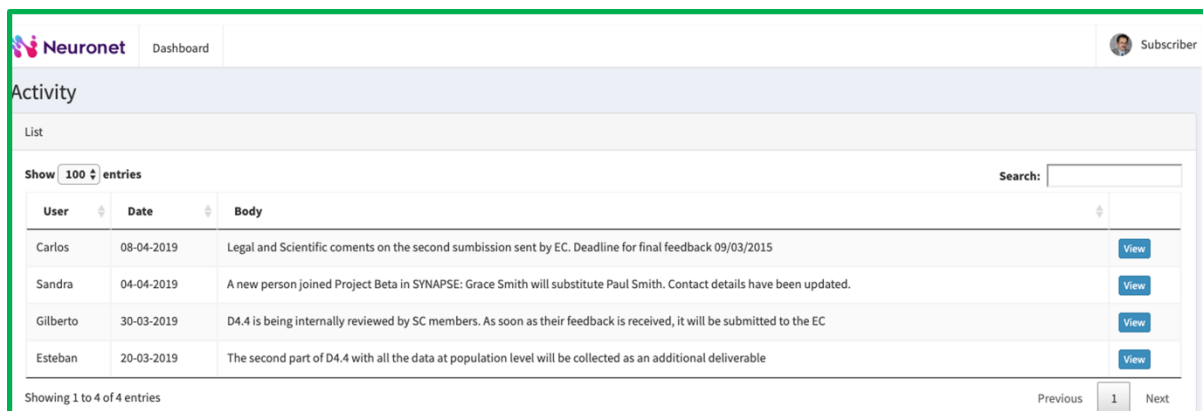
8.2. Activity

This module contains short project updates, in a Twitter-style format. The aim is to offer a space for communication between projects where they can post updates or make comments and requests.

All messages display the user name, project acronym and date of publication.



By clicking *View all activity* a new window opens showing the full list of messages available. It also includes a search bar in the top right corner to allow users to search messages by project, by user, etc.

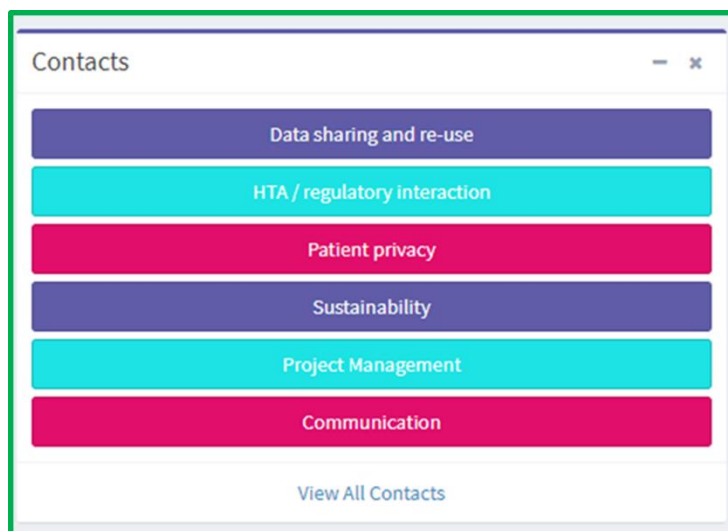


8.3. Contacts

This module is similar to the 'yellow pages' as it provides the contact details of experts in the following six categories or interest areas:

1. Data sharing & re-use
2. HTA/Regulatory interactions
3. Patient privacy & Ethics
4. Sustainability
5. Project management
6. Communication

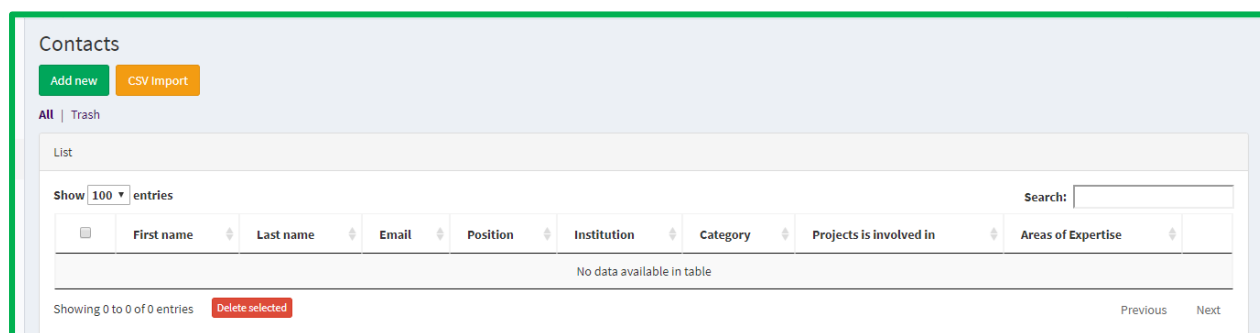
The idea is that the KB users can contact experts for advice when needed and communication is enhanced throughout the programme.



By clicking on one of these categories, a new window will open displaying a list with the contact details of experts in that area, including:

- Name
- Email
- Position (i.e. Head of Department X, Project Manager, etc)
- Institution
- Names of IMI ND project/s he/she is involved in
- Areas of expertise

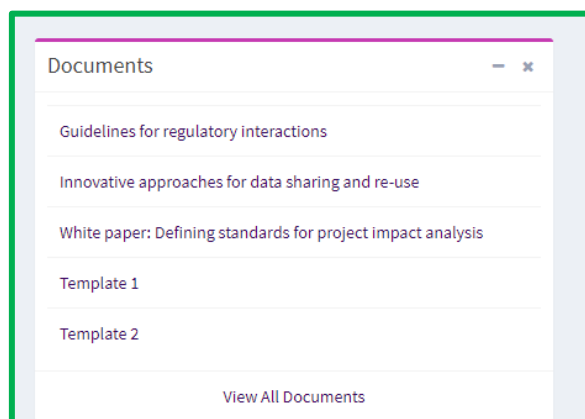
The page also includes a search bar in the top right corner to allow users to search the contact details of experts by project, name, area of expertise, etc.



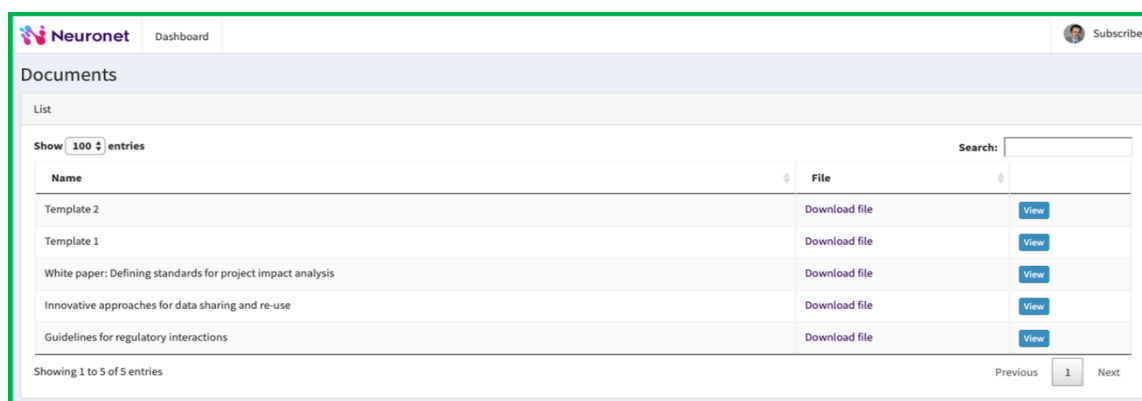
If the KB were to be made public and opened up for wider use this section would to be protected as it contains personal data.

8.4. Documents

This module contains a list of documents that might be helpful or interesting for IMI ND projects, such as guidelines, templates, white papers, etc. The documents could come from NEURONET, from the IMI ND projects or from other external sources.



By clicking *View all documents* a new window opens, displaying the complete list of documents available. This page also includes a search bar to allow users to search documents containing specific keywords (e.g. biomarkers, dementia, etc.). Users are able to download a copy of the documents through the download link provided.



8.5. Publications

This module displays publications from IMI ND projects containing the required IMI JU acknowledgement. In principal, all publications identified on the project website and/or the CORDIS portal will be included in this section.

Publications

Tochel et al., 2019
ADAPTED

What outcomes are important to patients with mild cognitive impairment or Alzheimer's disease, their caregivers, and health-care professionals? A systematic review.

Molinuevo et al., 2016
EPAD

Ethical challenges in preclinical Alzheimer's disease observational studies and trials: results of the Barcelona summit

Mortamais et al., 2017
EPAD

Detecting cognitive changes in preclinical Alzheimer's disease: A review of its feasibility

View All Publications

By clicking *View all publications* a new window opens, displaying the complete list of publications available. The list of publications shows:

- Title
- First author surname
- Year of publication
- Project
- Link to publication (DOI)
- Keywords

The page includes a search bar to allow users to search publications by project, author, year, etc.

Publications Add new

List

Show 100 entries

Search:

<input type="checkbox"/>	Title	First author last name	Year	Project	Link	Keywords	
<input type="checkbox"/>	The European medical information framework: A novel ecosystem for sharing healthcare data across Europe	Lovestone	2020	EMIF	https://doi.org/10.1002/lrh2.10214	catalogue, EMIF, EMIF-AD, EMIF-MET, use case	<div>View</div> <div>Edit</div> <div>Delete</div>
<input type="checkbox"/>	Patient's experience of wearing multimodal sensor devices intended to detect epileptic seizures: A qualitative analysis	Simblett	2020	RADAR-CNS	https://doi.org/10.1016/j.jyebh.2019.106717	Epilepsy, Acceptability, Feasibility, Qualitative analysis, Wearables, Seizure detection	<div>View</div> <div>Edit</div> <div>Delete</div>
<input type="checkbox"/>	Novel tau filament fold in corticobasal degeneration	Zhang	2020	IMPRIND	https://doi.org/10.1038/s41586-020-2043-0	Cryoelectron microscopy, Neurodegeneration	<div>View</div> <div>Edit</div> <div>Delete</div>
<input type="checkbox"/>	Differential Membrane Binding and Seeding of Distinct α -Synuclein Fibrillar Polymorphs	Shrivastava	2020	IMPRIND	https://doi.org/10.1016/j.bpj.2020.01.022		<div>View</div> <div>Edit</div> <div>Delete</div>

8.6. Events

This module displays information about events, conferences and meetings that might be relevant for the NEURONET community. The list includes the following details:

- Event name
- IMI ND project involved (if applicable)
- Location
- Dates
- Type of event
- Link to event website (if available)

By clicking *View events list* a new window opens, displaying the complete list of events. The page includes a search bar to allow users to search by project name, event location, etc.

Events Add new								
Showing: Current and future events Click here to see all events								
Show <input type="text" value="100"/> entries Search: <input type="text"/>								
<input type="checkbox"/>	Event	Projects	Location	Start date	End date	Type of event	Link	
<input type="checkbox"/>	AAIC 2020	EPAD ADAPTED AMYPAD	Online	26-07-2020	30-07-2020	Conference, Congress, Symposium, etc.	https://www.alz.org/aaic	View Edit Delete
<input type="checkbox"/>	AMYPAD General Assembly Meeting	AMYPAD	Geneva, Switzerland	08-10-2020	09-10-2020	Internal project events (General Assembly, Consortium meeting, etc.)		View Edit Delete
<input type="checkbox"/>	Alzheimer Europe Conference		online	20-10-2020	22-10-2020	Conference, Congress, Symposium, etc.	https://www.alzheimer-europe.org/Conferences/30AEC-2020	View Edit Delete

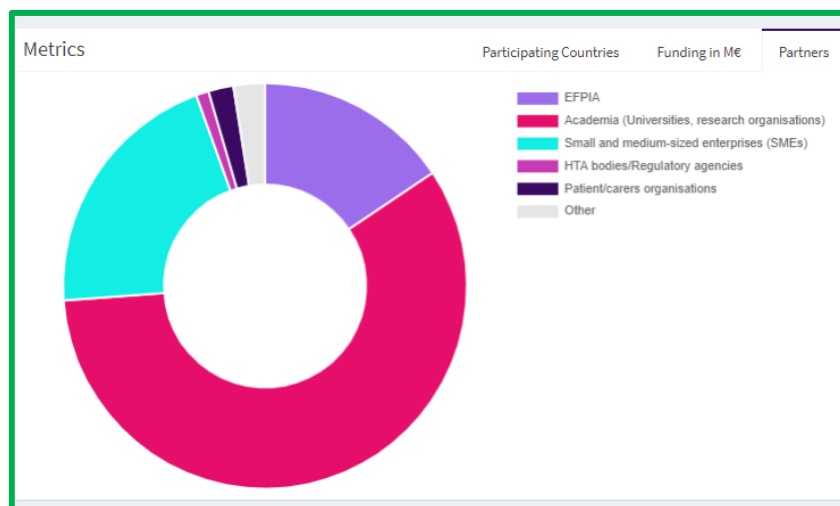
There is also the option to display the same information in the format of a calendar by clicking *View Calendar*.

Calendar						
July 2020						
Sun	Mon	Tue	Wed	Thu	Fri	Sat
28	29	30	1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
GENERAL - FENS 2020 Virtual Forum						
GENERAL - FENS 2020 Virtual Forum						

8.7. Metrics

The contents of this module have been updated following the data collection exercise carried out by WP1. The summary metrics provided include:

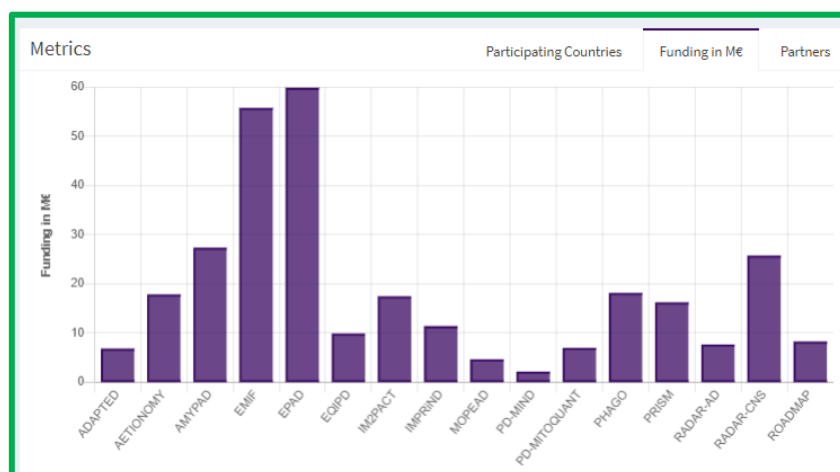
Number of organisations involved, by type of partner



Number of organisations involved, by country

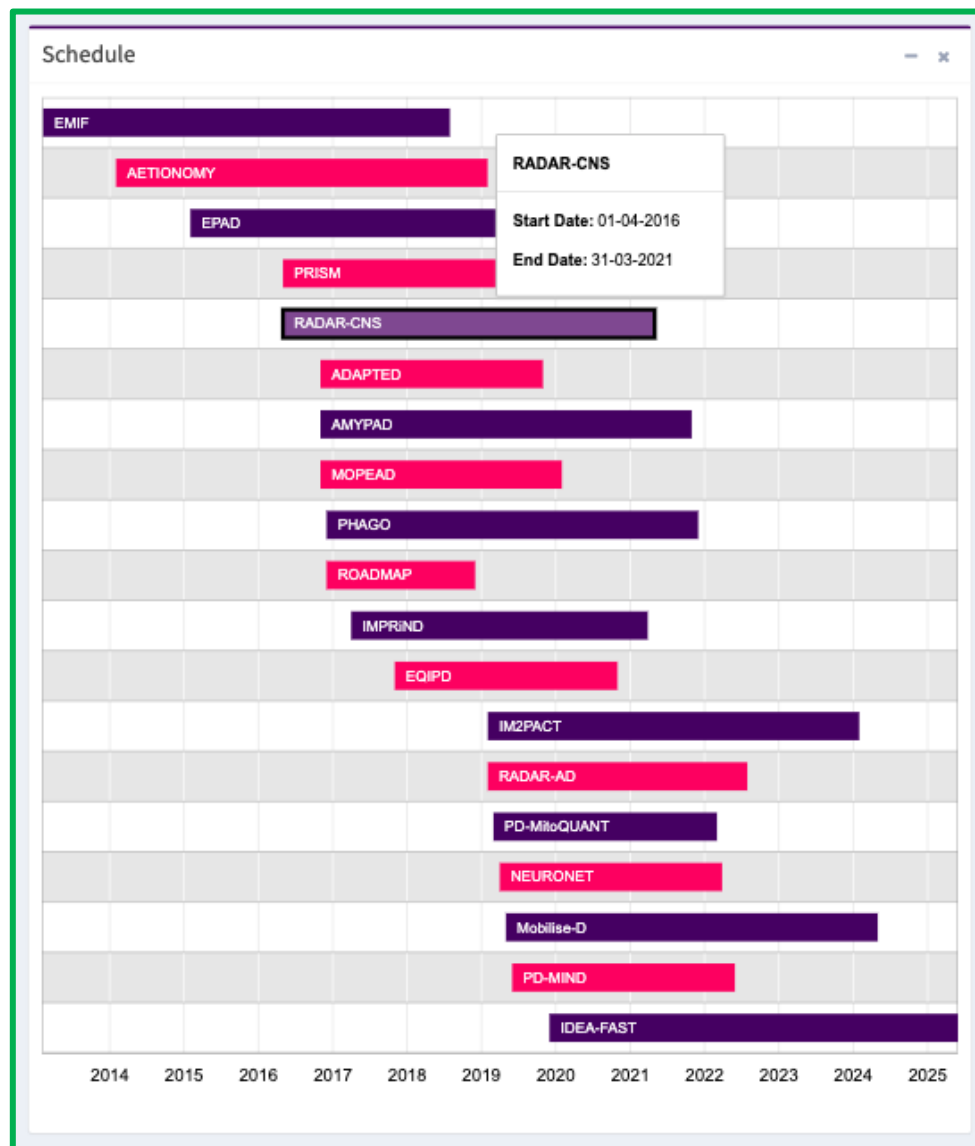


Funding in M€ per project



8.8. Schedule

This provides a meta-Gantt chart showing the timelines for the 18 IMI ND projects. By clicking on the bar, a pop-up window is displayed with the start date and end date of the project.



8.9. Tools

This module contains a list of project developed tools, including databases, cohorts, etc. Whenever possible, details about the team or organization responsible for the tools (i.e. acting as gate keepers) plus an overview of the type of data available is provided.

Tools		
Publication Date	Tool Name	Project
01-06-2020	EPAD LCS (longitudinal cohort study) Research Access Process	EPAD
19-09-2019	AETIONOMY Knowledge base	AETIONOMY
03-09-2019	EMIF Data Catalogue	EMIF
10-05-2019	ROADMAP Data cube	ROADMAP
View All Tools		

By clicking *View all tools* a new window opens providing more details about:

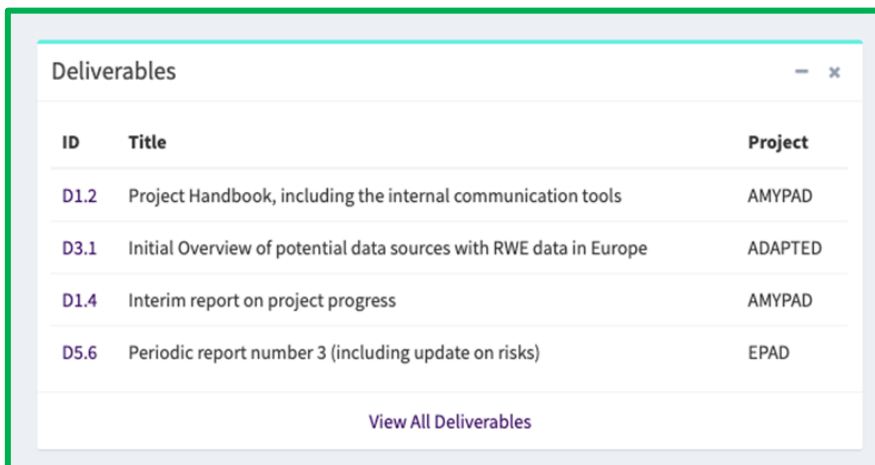
- Tool name
- Project
- Publication date
- Type of data available
- Description
- Keywords
- Tool URL (if applicable)

The page also includes a project filter and a search bar to allow users to search tools by keywords, name, etc.

Tools Add new							
Filter by project ▼							
Show 100 entries Search: <input type="text"/>							
<input type="checkbox"/>	Name	Project	Publication date	Type of data available	Description	Keywords (comma separated)	Link
<input type="checkbox"/>	ROADMAP Data cube	ROADMAP	10-05-2019	Overview of availability of European real-world data on Alzheimer's disease.	The Data Cube can be seen as a three-dimensional 'heat map' to interactively visualise how European data sources capture relevant AD-related outcomes. It also provides an overview of the relevance of such outcomes for different types of stakeholders. ROADMAP's Interactive Data Cube does not provide access to any underlying data for any of the different data sources. Its aim is to only provide high-level information about availability of such data, as provided by the data sources themselves. ROADMAP does not represent in any way any of the data sources included herein. Actual availability of the data, the extent of such availability and procedures to gain access pertain to the applicable policies, rules and regulations of each of the data sources. Interested parties should contact data sources directly.	real-world data, Alzheimer's disease	https://datacube.roadmap-alzheimer.org/

8.10. Deliverables

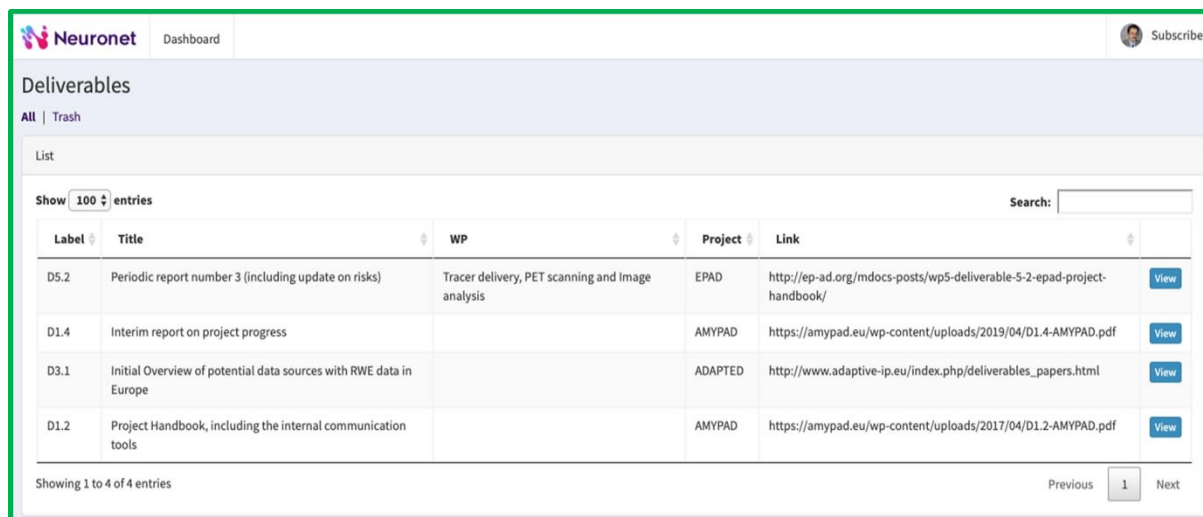
This module contains information about, and links to the public deliverables listed on the project websites or on the CORDIS portal. For some projects, confidential deliverables could also be shared if we receive the approval from the project team.



ID	Title	Project
D1.2	Project Handbook, including the internal communication tools	AMYPAD
D3.1	Initial Overview of potential data sources with RWE data in Europe	ADAPTED
D1.4	Interim report on project progress	AMYPAD
D5.6	Periodic report number 3 (including update on risks)	EPAD

[View All Deliverables](#)

By clicking *View all deliverables* a new window opens, displaying all submitted public deliverables from the IMI ND projects supported by Neuronet. Whenever available, a link to the actual reports that might be available from the respective project websites or through CORDIS is provided. The page also includes a project filter and a search bar to allow users to search deliverables by keywords, title, etc.



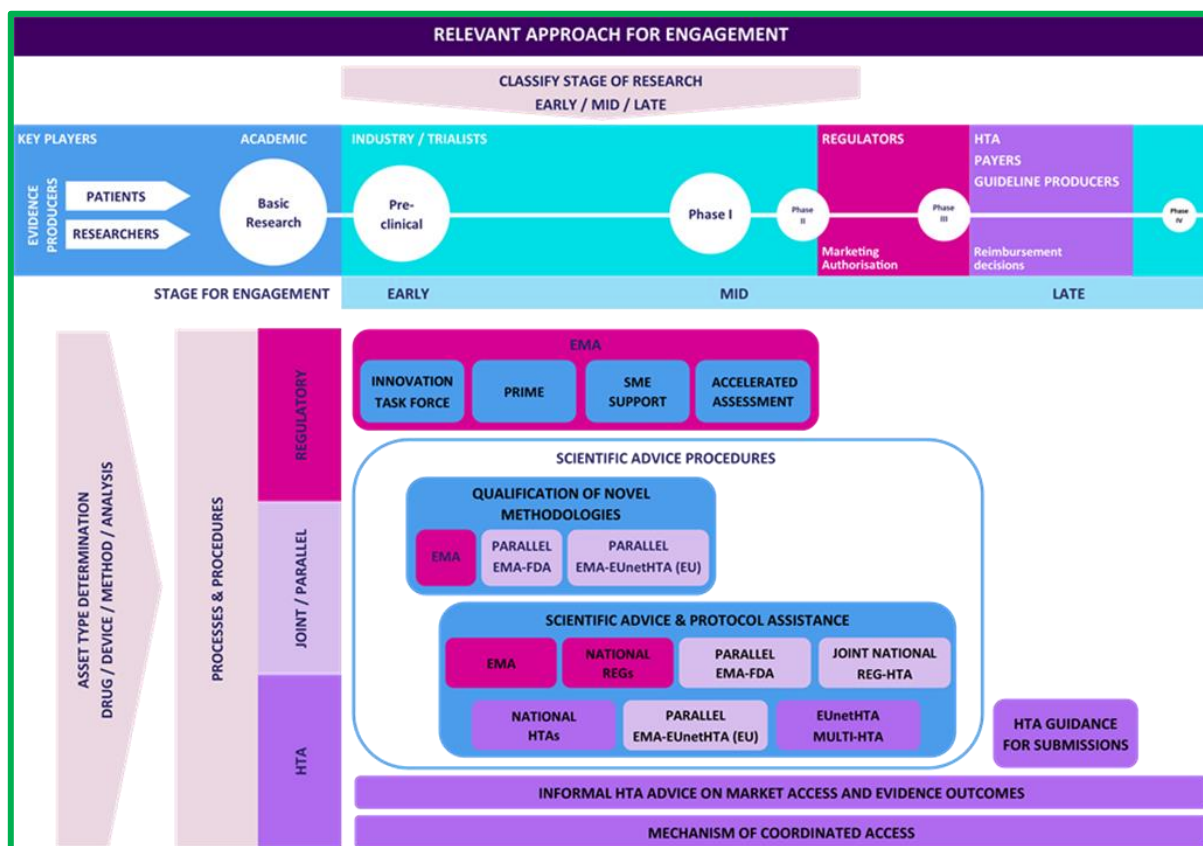
Label	Title	WP	Project	Link	
D5.2	Periodic report number 3 (including update on risks)	Tracer delivery, PET scanning and Image analysis	EPAD	http://ep-ad.org/mdocs-posts/wp5-deliverable-5-2-epad-project-handbook/	View
D1.4	Interim report on project progress		AMYPAD	https://amypad.eu/wp-content/uploads/2019/04/D1.4-AMYPAD.pdf	View
D3.1	Initial Overview of potential data sources with RWE data in Europe		ADAPTED	http://www.adaptive-ip.eu/index.php/deliverables_papers.html	View
D1.2	Project Handbook, including the internal communication tools		AMYPAD	https://amypad.eu/wp-content/uploads/2017/04/D1.2-AMYPAD.pdf	View

Showing 1 to 4 of 4 entries

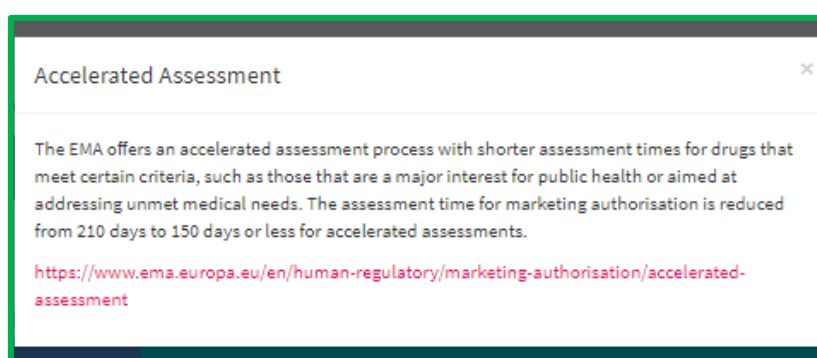
8.11. Regulatory and HTA engagement - Decision Tool

This is a new section of the KB. The Decision Tool was delivered as D3.3, and aims at identifying the key processes and procedures for engagement with regulatory, HTA bodies, and payers at key points in the development of an asset. The tool helps the IMI ND projects in identifying the most appropriate procedures and ways in which

they can interact with regulators, HTA bodies, and payers along the medicines development, approval, and reimbursement pathway.



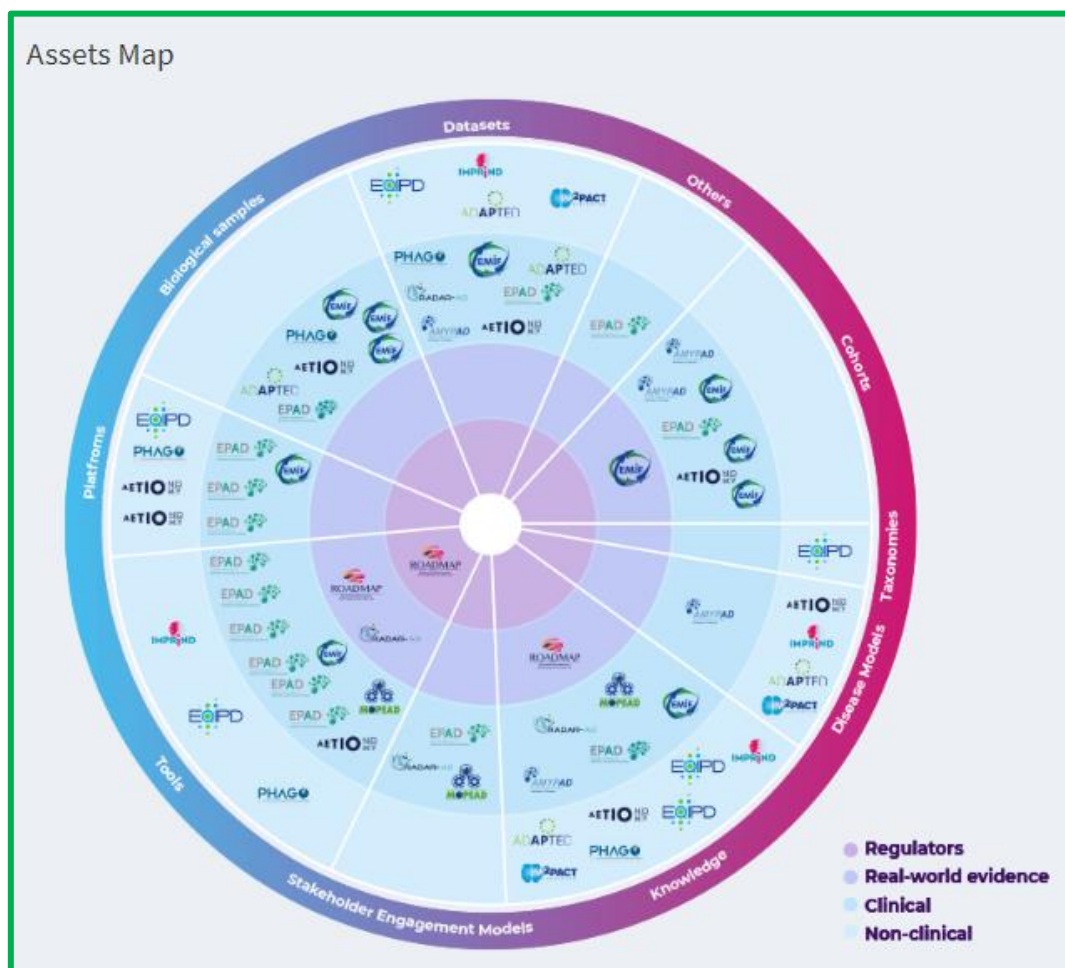
The tool is interactive, allowing users to click on the different boxes to obtain additional information on relevant informal and formal processes and procedures for engagement.



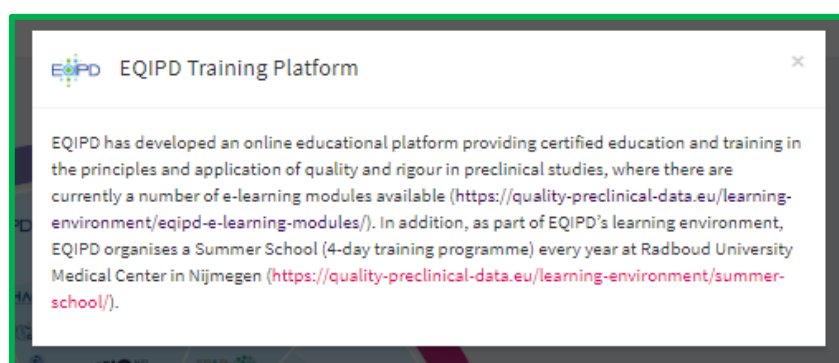
For more information on the decision tool, please read D3.3 *First version of regulatory/HTA/payer interaction decision tool*.

8.12. Asset map

The Asset map is also a new addition to the KB. It is one of the main outputs resulting from the data collection exercise carried out by WP1 that provides a comprehensive view of the different assets resulting from IMI ND projects.



The interactive Asset map allows users to click through the different project logos to obtain more detailed information about the asset the logo represents.



For more information on the Asset map, please read D1.2 *Integrated programme analysis*.

8.13. Periodic updates to the Knowledge Base

The KB aims to provide an up-to-date, summary overview of the IMI ND programme, including all public deliverables, publications, assets and other outputs. To ensure that the information contained in the KB is up-to-date, WP3 partners perform regular scans of the IMI ND project websites and the CORDIS portal, updating the KB information on existing projects on a 6-monthly basis. The KB is also updated when new projects join the NEURONET portfolio, using information collected from projects, their websites and CORDIS following signature of the NEURONET Memorandum of Understanding.

9. Conclusion

Since the submission of D3.1 *INKB web platform v1* in month 6, the structure, design and contents of the KB have been refined and updated by NEURONET partners. To date, there are 23 registered users to the KB. Details of 329 scientific publications as well as 247 project deliverables have been uploaded and the contacts section includes contact details of 45 experts across the different interest areas abovementioned. In addition, data from three new IMI ND projects (IDEA FAST, MOBILISE-D, PD-MIND) has also been uploaded. Two new modules have been added.

The KB is now advertised on the NEURONET website as a platform developed by the project (see <https://www.imi-neuronet.org/neuronet-tools/>). Moreover, the KB has been presented to the members of the NEURONET Scientific Coordination Board, IMI staff and also to the external reviewers evaluating NEURONET at the interim project review. The feedback received has generally been very positive, with suggestions to make the tool public and available to a wider audience.

NEURONET partners, with the help and collaboration of each IMI ND project, will update the information on the KB at least every six months until the end of NEURONET in February 2022. The sustainability strategy for NEURONET tools and results is currently under discussion, and it is likely that the KB will be one of the important assets to sustain beyond the project end.