Neuronet

Efficiently Networking European Neurodegeneration Research

How IMI projects have addressed the challenge & 'moved the needle'

NEURONET, Carlos Díaz

IMI impact on dementia - Event

15 June, 2021

www.imi-neuronet.org

innovative medicines initiative

efpia

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

IMI as paradigm for PPPs

- Overcoming cultural divide
- Clear needs-based focus
- Involving multiple stakeholders
- Wide range of projects

BUT isolation remains where projects are seen as silos

Science suffering from medieval organisation?

Neuronet

Can science provide today timely, actionable results commensurate with the scale of the challenges we are facing?

NEURONET as fragmentation ‘antidote’

Neuronet

CSA (**Coordination and Support Action**) for IMI neurodegeneration portfolio. 1.2 M€ IMI funding.

March 2019 - February 2022.

To set up an **efficient platform to boost synergy and collaboration across the IMI projects of the Neurodegenerative Disorders (ND) portfolio**, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide.

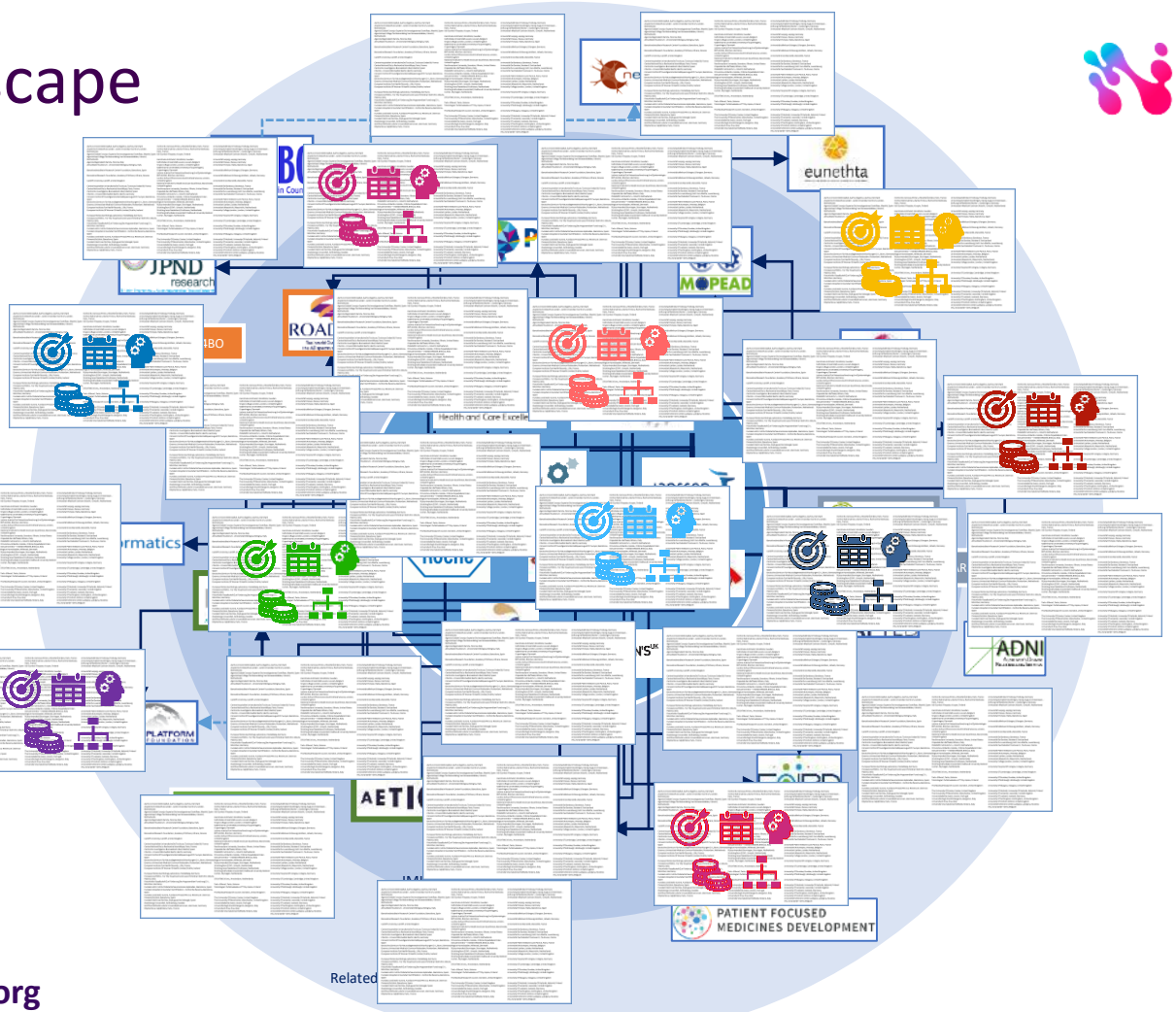
SYNAPSE RESEARCH MANAGEMENT PARTNERS
NICE National Institute for Health and Care Excellence
Alzheimer Europe

SME, public bodies and non-profit organizations

Janssen
Lilly
SANOFI
Takeda
Roche
PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

EFPIA and associated partner

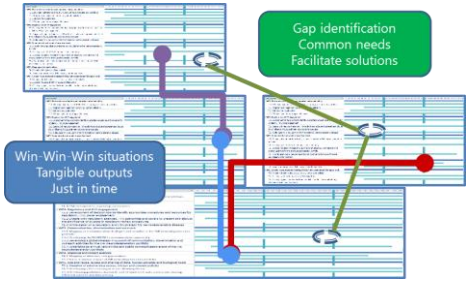
Our landscape

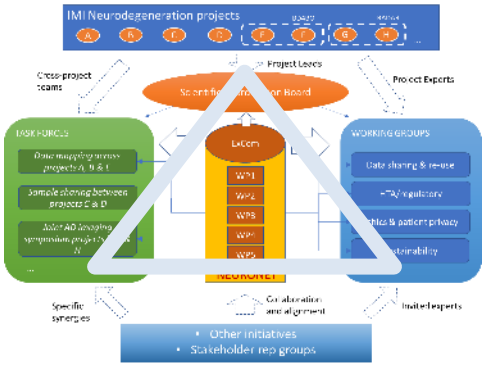


Neuronet

How do we harness this power?

- Systems leadership approach – participative structure – overcome fragmentation
- Neutral positioning
- Move center of gravity from ‘project’ to ‘asset’
- Highlighting and generating actionable innovation



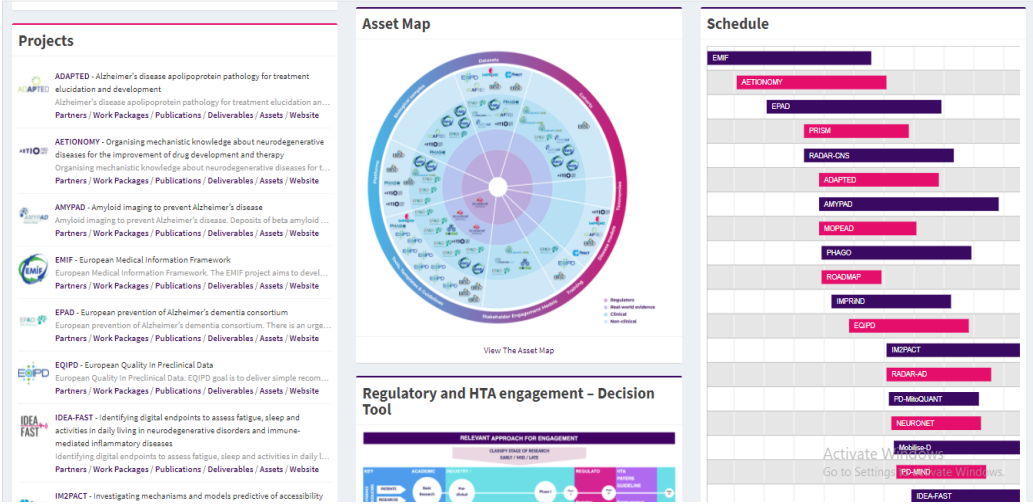


NEURONET leverages existing expertise + capacity through 3 pillars:

- ✓ Scientific Coordination Board (project leaders) – for overall strategy and direction
- ✓ Working Groups (project experts) – for specialised technical discussion
  - ✓ Data sharing
  - ✓ Ethics & privacy
  - ✓ Regulatory interaction
  - ✓ Sustainability
- ✓ Task Forces (small teams) – for targeted synergy implementation

Knowledge Base

- The public version of the Knowledge Base was launched on February 1st.
- Summary overview of the IMI ND programme in the format of a dashboard.
- Provides information about projects (e.g. deliverables, publications, tools, etc).
- Includes Asset Map, network diagrams and other useful tools

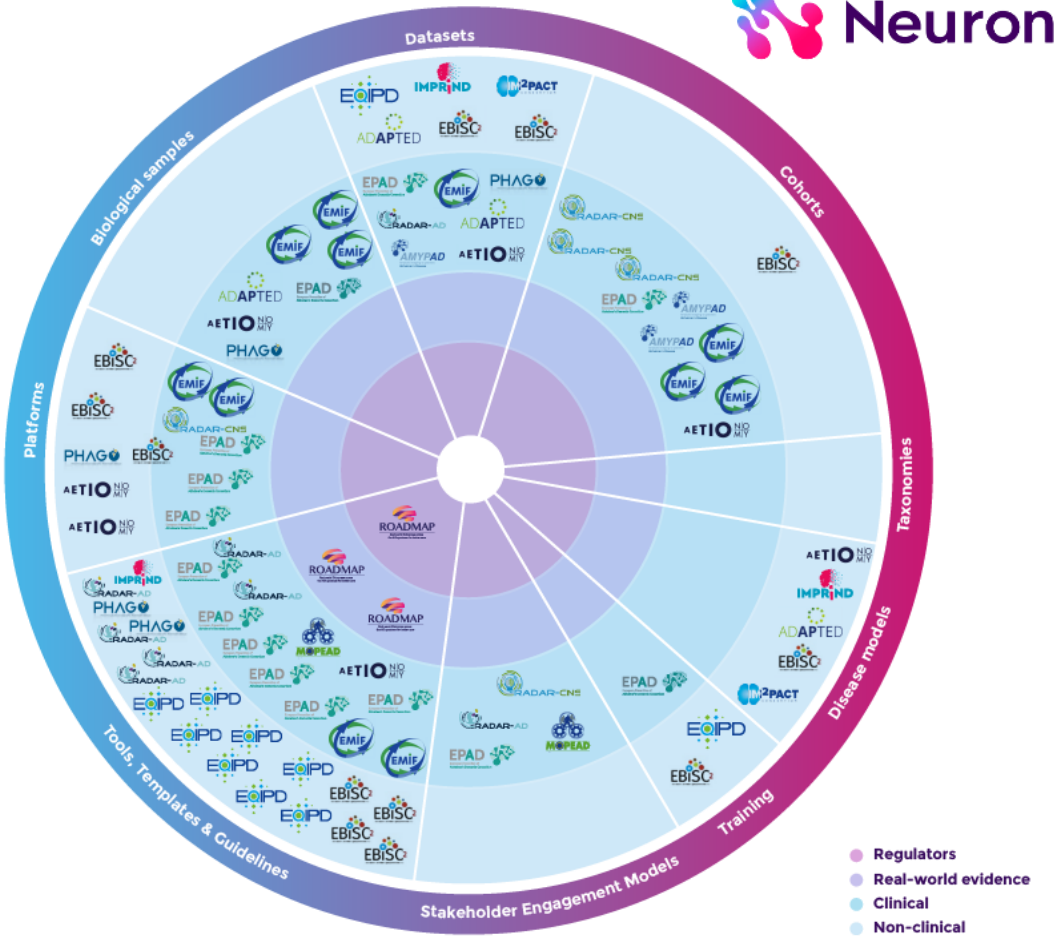


www.imi-neuronet.org

https://kb.imi-neuronet.org/

Asset Map

- ✓ Provides a **unified view** of the **richness** of IMI ND projects in terms **of assets delivered.**
- ✓ Provides summarised information and links to the respective projects and asset owners
- ✓ Allows to detect redundancies and gaps
- ✓ Enables collegiate discussion on priorities and innovations needed



Asset Map

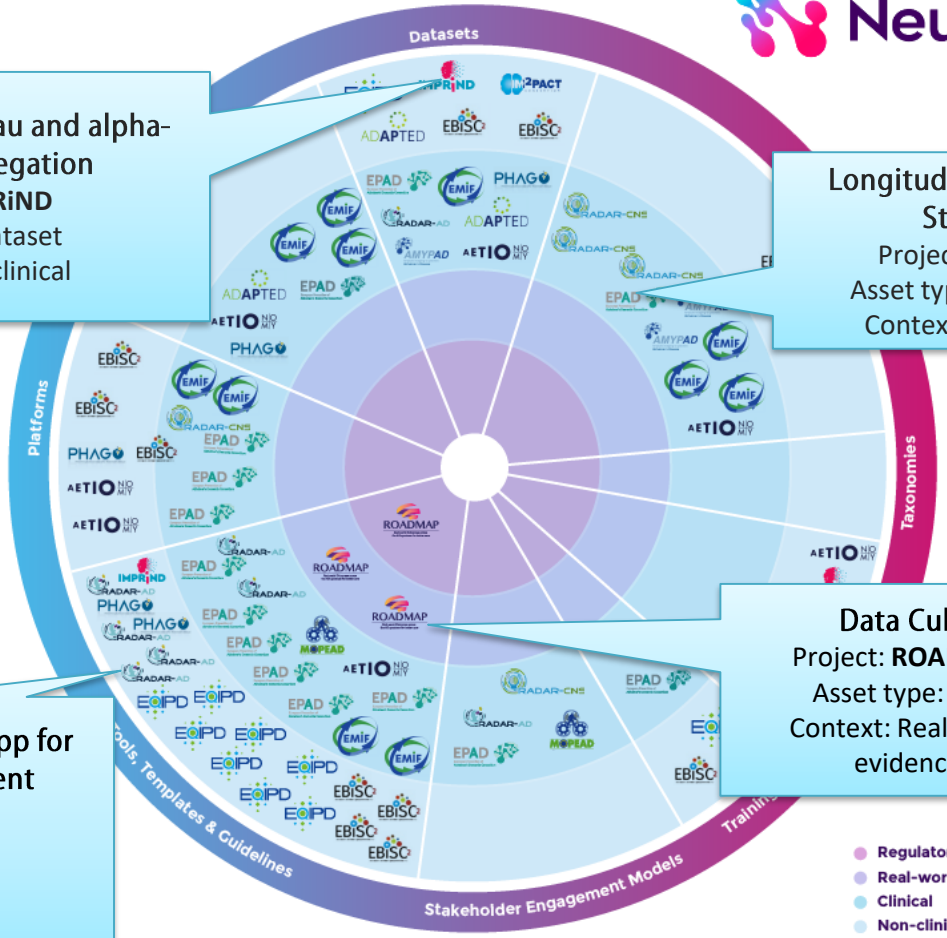
- ✓ Provides a **unified** the **richness** of IM projects in terms **delivered.**
- ✓ Provides summarised information and links to the respective projects and asset owners
- ✓ Allows to detect redundancies and gaps
- ✓ Enables coll on prioritie needed

Genetic screens for tau and alpha-synuclein aggregation
Project: **IMPRiND**
Asset type: Dataset
Context: Non-clinical

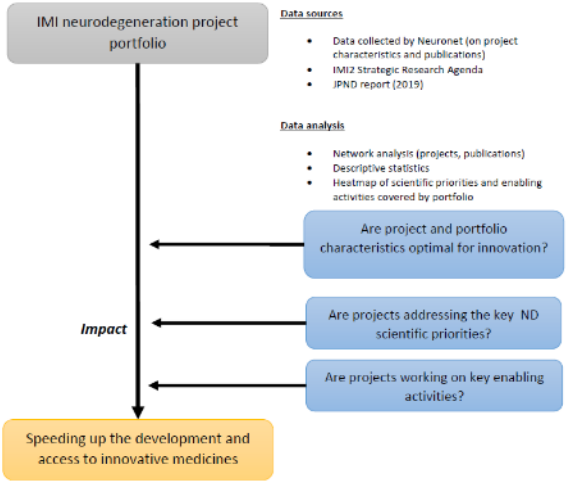
Longitudinal Cohort Study
Project: **EPAD**
Asset type: Cohort
Context: Clinical

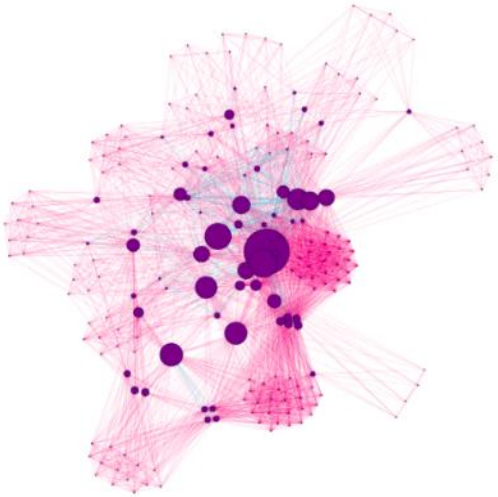
Data Cube
Project: **ROADMAP**
Asset type: Tool
Context: Real-world evidence

Daily life tasks monitoring app for cognitive status assessment (*Banking App*)
Project: **RADAR-AD**
Asset type: Tool
Context: Clinical

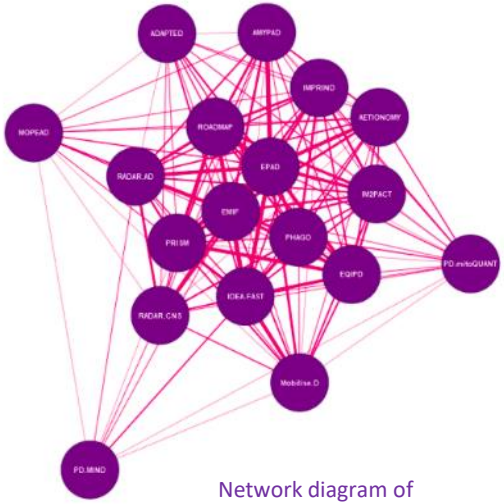


Impact Analysis

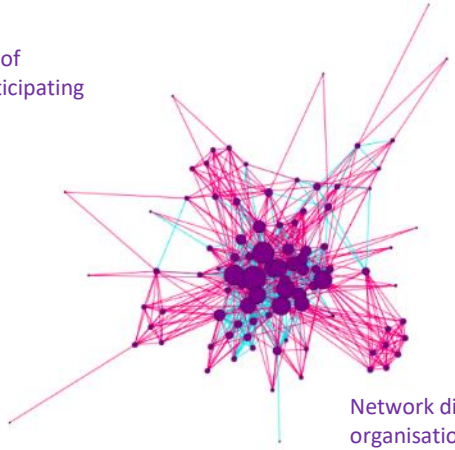




Network diagram of organisations participating in the portfolio

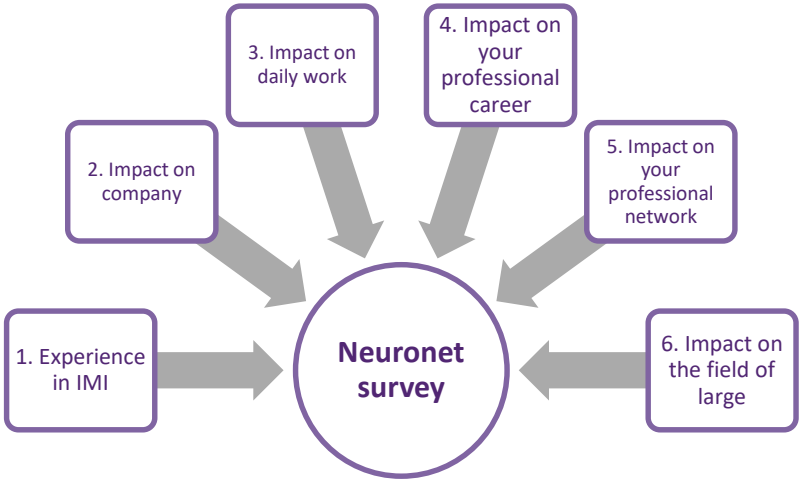


Network diagram of projects in the portfolio



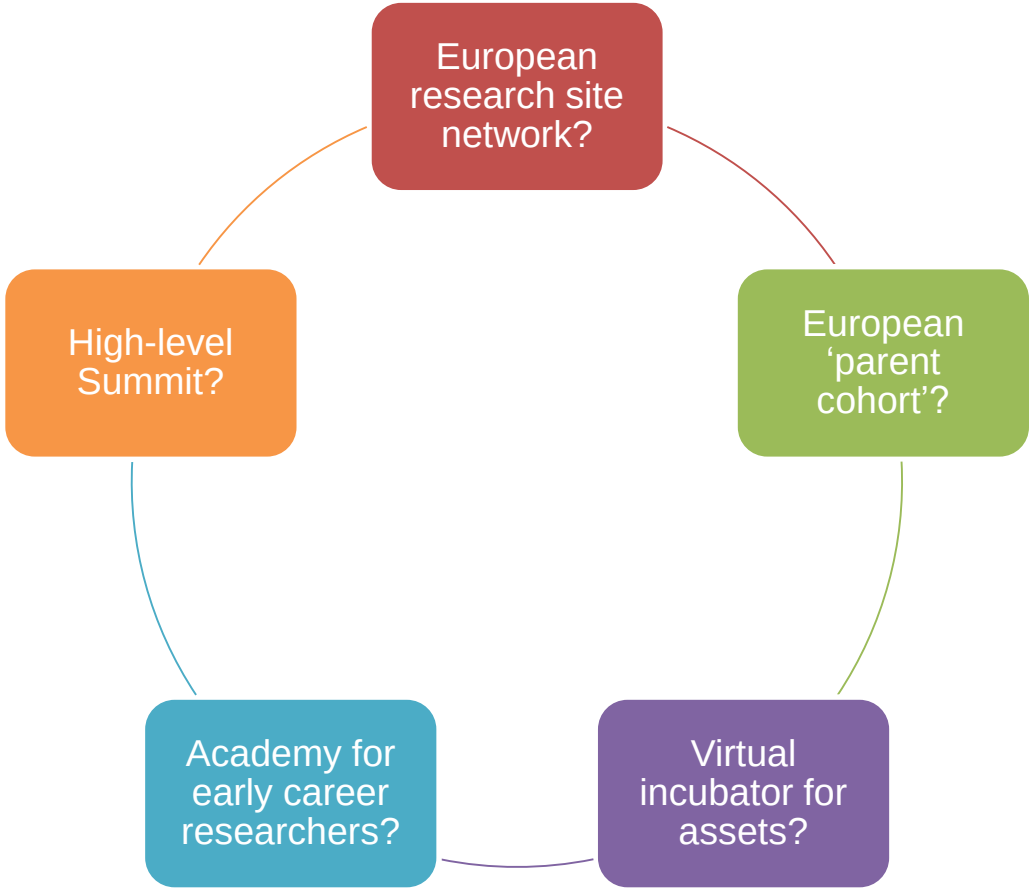
Network diagram of collaborating organisations on publications

Impact Analysis - industry



- Interim results - percentage of respondents who felt that IMI had a **moderate-to-high impact** on their company's:
  - strategic objectives for their therapeutic area (*34%*)
  - establishment of strategic partnerships (*51%*)
  - presence, visibility or image (*62%*)

Cradle for new ideas & innovations



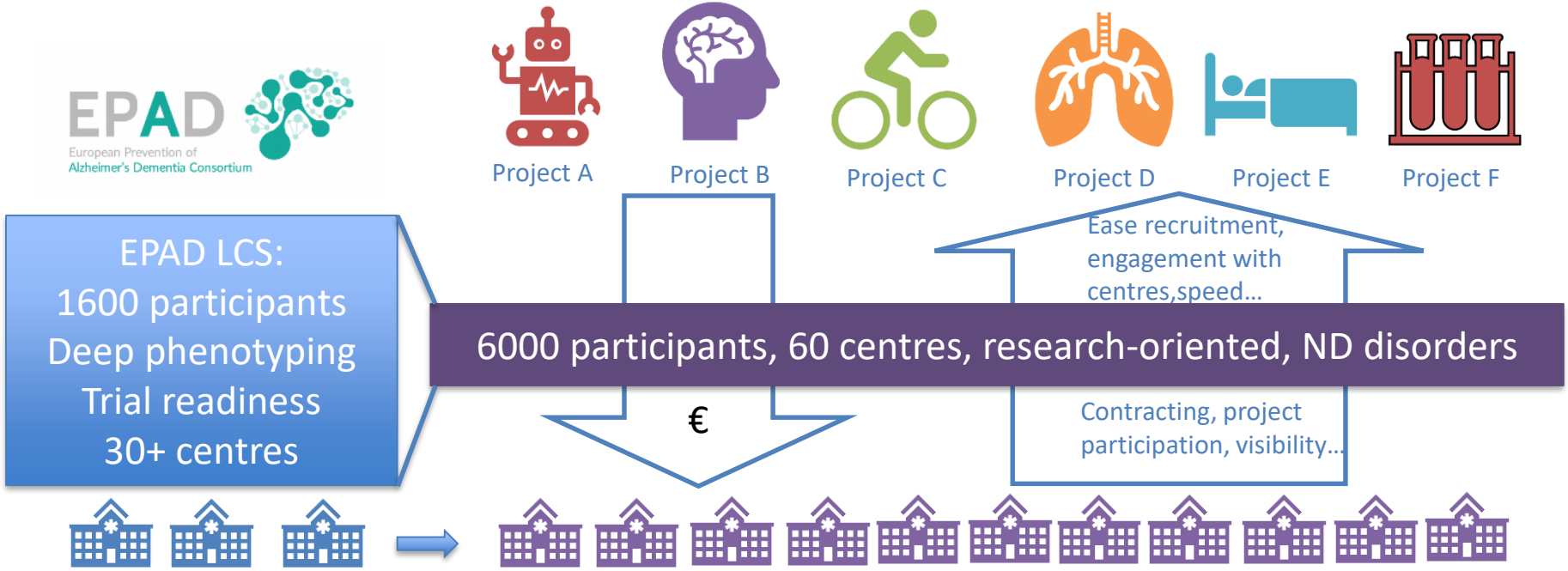
NEURONET Academy

- Leveraging EPAD Academy into a NEURONET Academy, providing a framework for Early-Career Researchers development across IMI ND projects.

COMPONENTS:

- **NEURONET Academy community**: provide to the Academy fellows the latest news on neurodegeneration research, job vacancies, online forum.
- **Short-term exchanges**: promote international and interdisciplinary collaboration through short-term exchanges of early career researchers.
- **Neuronet Academy webinars**: online trainings by thought leaders on current topics in neurodegenerative disease, with the potential to integrate training platforms and materials developed by e.g. EQIPD, EHDEN, etc.
- **Focus on ECR**: specific sessions at meetings, calls for presentations at events (e.g. Alzheimer's Europe annual conference), etc.

NEURO Cohort



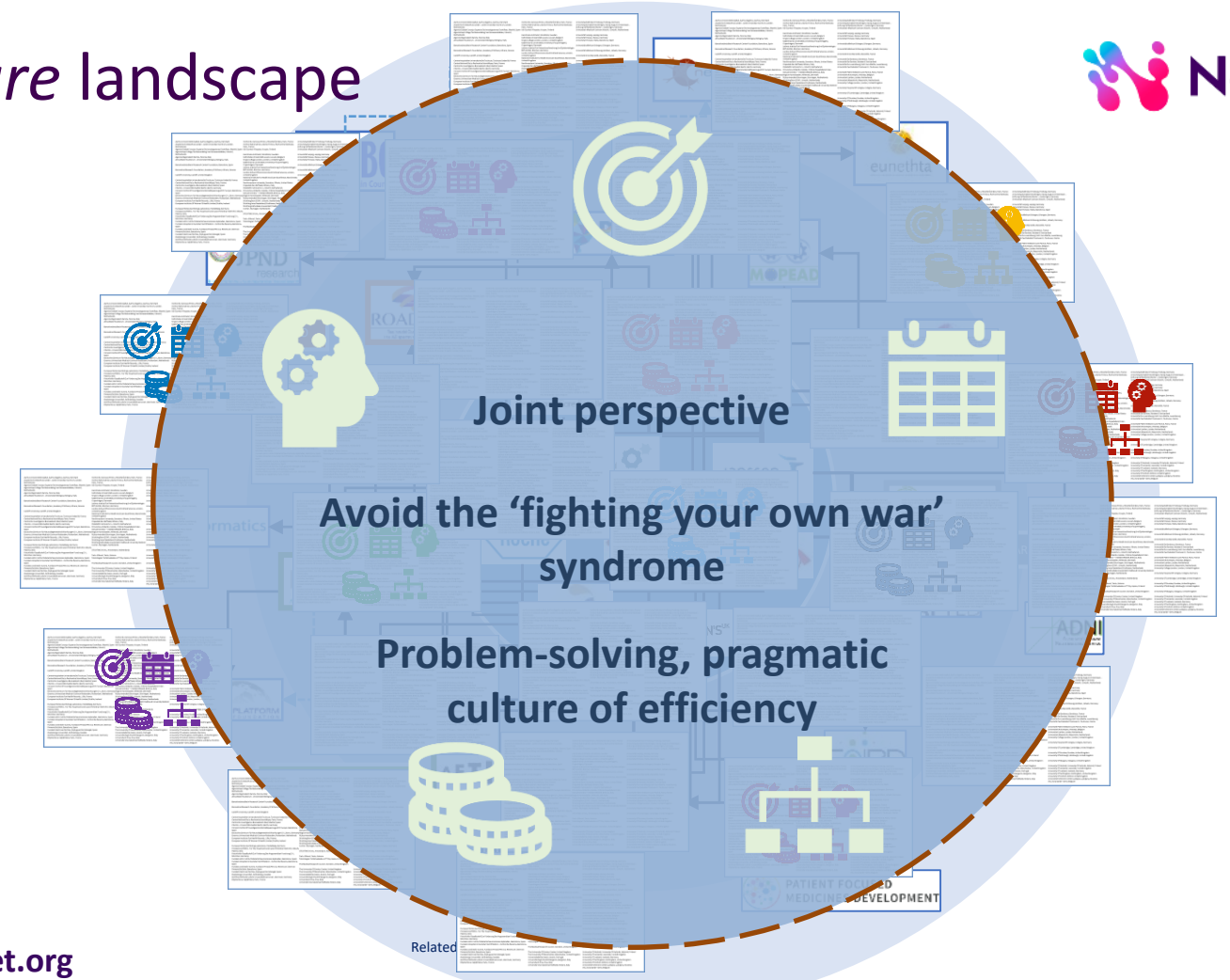
NEURO Cohort status

- To date, **39 centers from 13 countries** participating in the NEURO Cohort proposal, encompassing 25,000 potential participants.
- Pilot underway. Active outreach to stakeholders and potential funders.

Principal Investigator	Site	Country
Giovanni Frisoni	Centre de la Memoire of Geneva University Geneva University Hospital	Switzerland
Rik Vandenberghe	University of Leuven	Belgium
Nikolaos Scarmeas	National and Kapodistrian University of Athens	Greece
Craig Ritchie	University of Edinburgh and Brain Health Scotland	United Kingdom
Bruno Vellas	CHUT – Hospital Center University Toulouse	France
Lucilla Parnetti	Università degli Studi di Perugia	Italy
Audrey Gabelle	Université de Montpellier	France
Miia Kivipelto	Karolinska Institute	Sweden
Félix Viñuela	Andalusian Institute of Neurology. Hospital Victoria Eugenia. Seville	Spain
Mercè Boada	Fundació ACE	Spain
Florence Pasquier	University Hospital de Lille	France
Pablo Martinez-Lage	Fundación CITA - Alzhéimer Fundazioa	Spain
Silke Kern	University of Gothenburg, Sahlgrenska University Hospital	Sweden
Vanessa Raymont	University of Oxford and Dementias Platform UK	United Kingdom
Sebastiaan Engelborghs	UZ Brussel - VUB Centre for Neurosciences	Belgium
Daniel Blackburn	University of Sheffield	United Kingdom
Paresh Malhotra	Imperial College London	United Kingdom
Bernard Hanseeuw	Cliniques Universitaires Saint-Luc, Brussels, Belgium	Belgium
Johannes Kornhuber	Friedrich-Alexander-University of Erlangen-Nuremberg	Germany

Principal Investigator	Site	Country
Robert Perneczky	University Hospital LMU Munich	Germany
Ross Dunne	University of Manchester	United Kingdom
Bruno Dubois	Salpétrière University Hospital, Paris	France
Frank Jessen	University of Cologne	Germany
Philip Scheltens	Stichting VUMC	Netherlands
Karine Fauria	Fundació BarcelonaBeta Brain Research Center	Spain
Elizabeth Coulthard	North Bristol NHS Trust	United Kingdom
Stefan Teipel	DZNE Rostock/Greifswald and Univeristy Medicine Rostock	Germany
Annalena Venneri	Brunel University London	United Kingdom
Julien Dumurgier	Lariboisiere Hospital, Paris	France
Claire Boutoleau-Bretonnière	CHU Nantes	France
Pascual Sánchez-Juan	University Hospital Marqués de Valdecilla	Spain
Mario Riverol Fernández	Clínica Universidad de Navarra	Spain
Oliver Peters	Charité Berlin	Germany
Samantha Galuzzi	IRCCS Centro San Giovanni di dio Fatebenefratelli – Brescia	Italy
Lutz Froelich	Central Institute of Mental Health (CIMH), Medical Faculty Mannheim, University of Heidelberg,	Germany
Mircea Balasa	IDIBAPS, Hospital Clinic Barcelona	Spain
Konrad Rejdak	Medical University of Lublin	Poland
Luiza Spiru	Clinical Department Elias University Hospita	Romania
Görsev G. Yener	Izmir University of Economics, Faculty of Medicine, Izmir	Turkey

Our *future* landscape



Neuronet

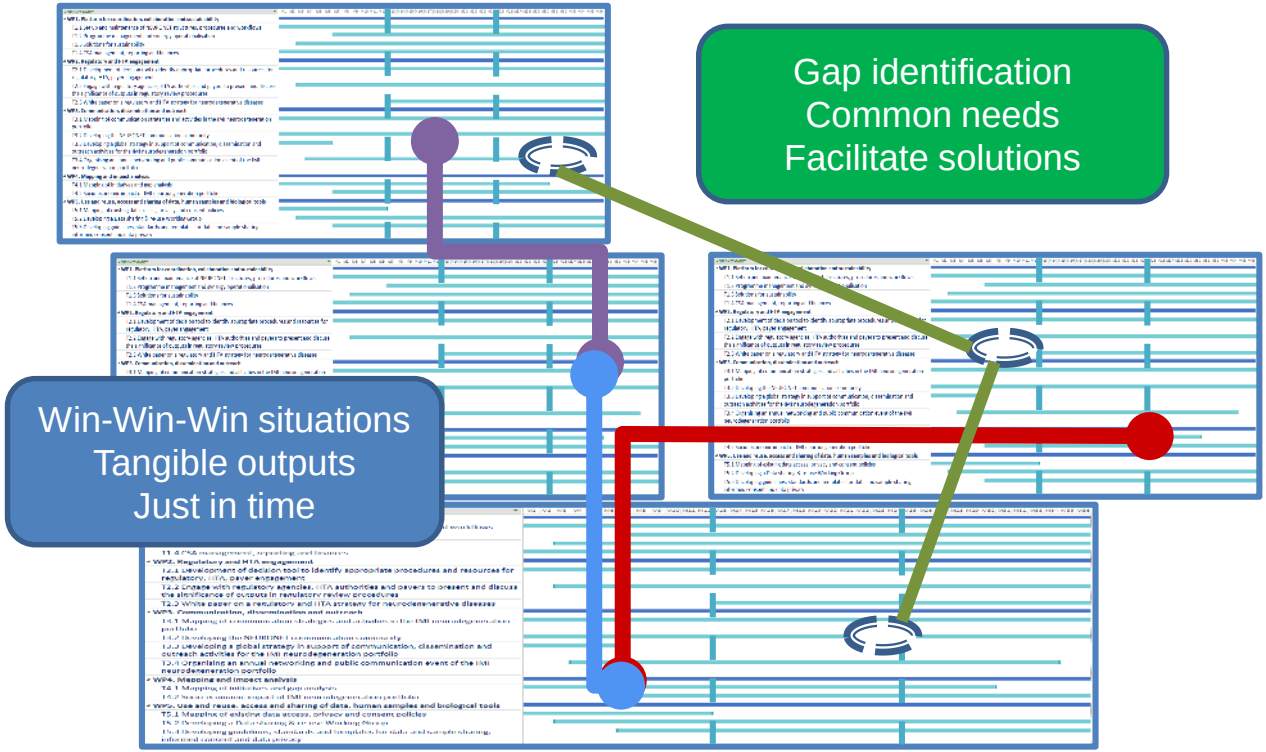
Efficiently Networking European Neurodegeneration Research

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 821513. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and Parkinson's UK.

www.imi-neuronet.org

NEURONET as a ‘switchboard’

NEURONET collects information from projects (e.g. results, resources, tools…) and establishes just-in-time connections among project components.



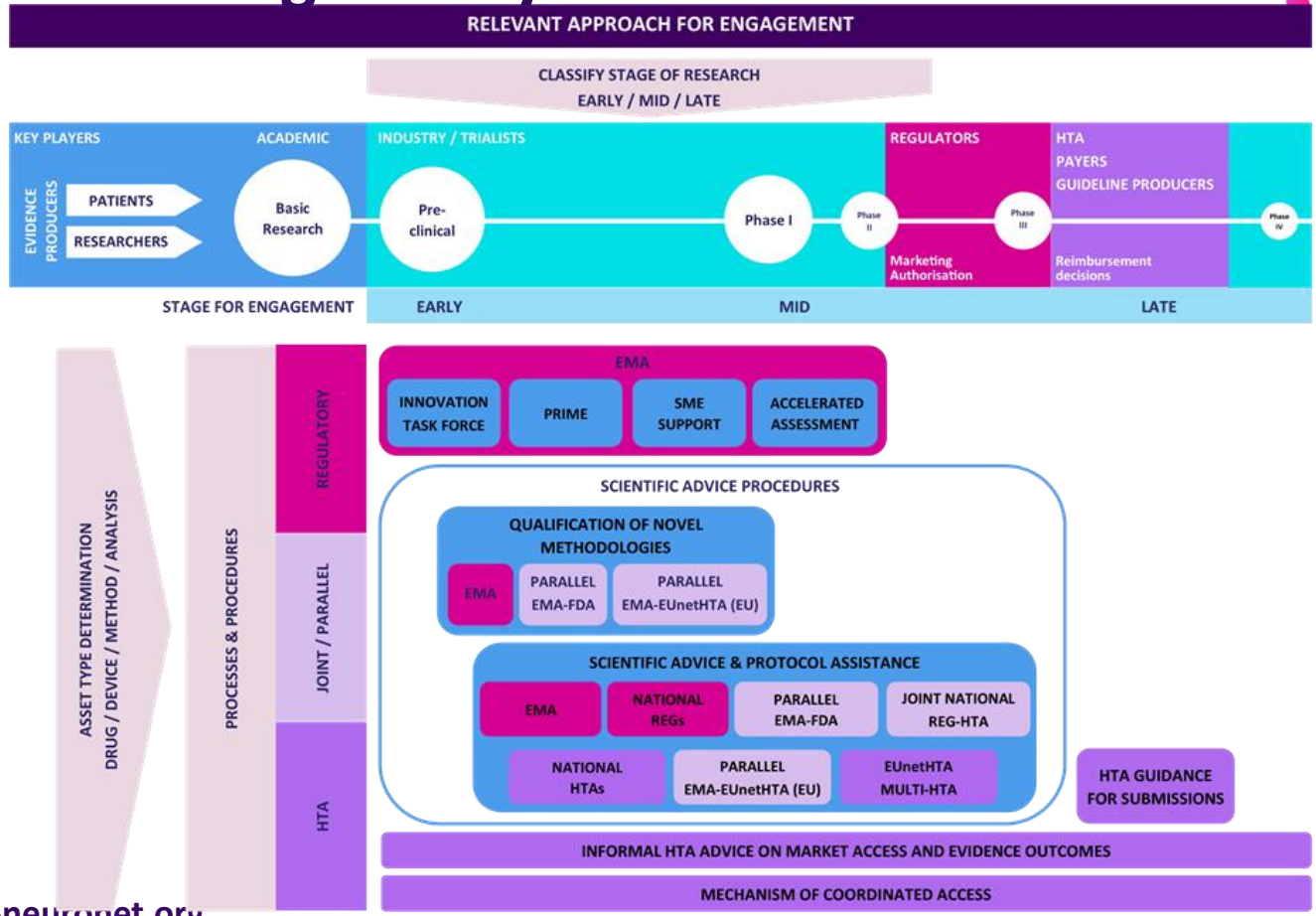
Connecting:

- Tools
- Technologies
- Methodologies
- Expertise
- Data
- Other results

Asset definition

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

WG HTA & Regulatory interactions



NEURO Cohort: initial overall principles

- **Systems leadership approach** and coalition of the willing. No explicit hierarchy or top-down control. NEURONET acts as a global facilitator rather than a prescriptive sponsor.
- 'Grassroots' initiative based on **trust** and **collaboration** across sites according to jointly agreed protocols, policies and procedures.
- Focus on serving IMI, other projects, researcher-driven studies. **Breadth** rather than depth.
- Enhance **visibility and participation** for sites. **Dovetailing** with future cohorts and initiatives.
- Minimise bureaucracy and pain, but offer **transparent** and **clear** procedures.
- Absence of baseline funding -> leverage cost efficiencies and what already exists.

An initiative BY THE SITES and FOR THE PATIENTS.

Update – June 2021

- Taken together, the interest in NEURO Cohort reflects:
  - 11 different European countries
  - 44 different protocols
  - Potentially 25,000 participants

- Most sites have taken part in EPAD, but not all. Open to new sites willing to join.

- In planning the workflows, a Task Force has progressed across four strands of work:
  - Scientific rationale
  - Technical infrastructure
  - Financial, Legal and Governance
  - Marketing and Communication

NEURO Cohort: Targets

- **Pilot exercise** completed (workflows defined, infrastructure ready) by June 2021.
- 25,000 potential participants from local cohorts - **10,000 enrolled during 2021-22** into NEURO Cohort from all **37 sites** covering **11 European countries**.
- Minimum dataset - yearly per participant (complemented by historical data when shareable):

Demographic information	Age
	Gender
	Diagnosis
Biomarkers	Amyloid status (if known)
	APOE status (if known)
Rating scales	Clinical Dementia Rating
	EQ-5D
	RUD-Lite
	Zarit Burden Inventory
	MMSE

- Proceeding to secure initial investment (preferential stakeholders).

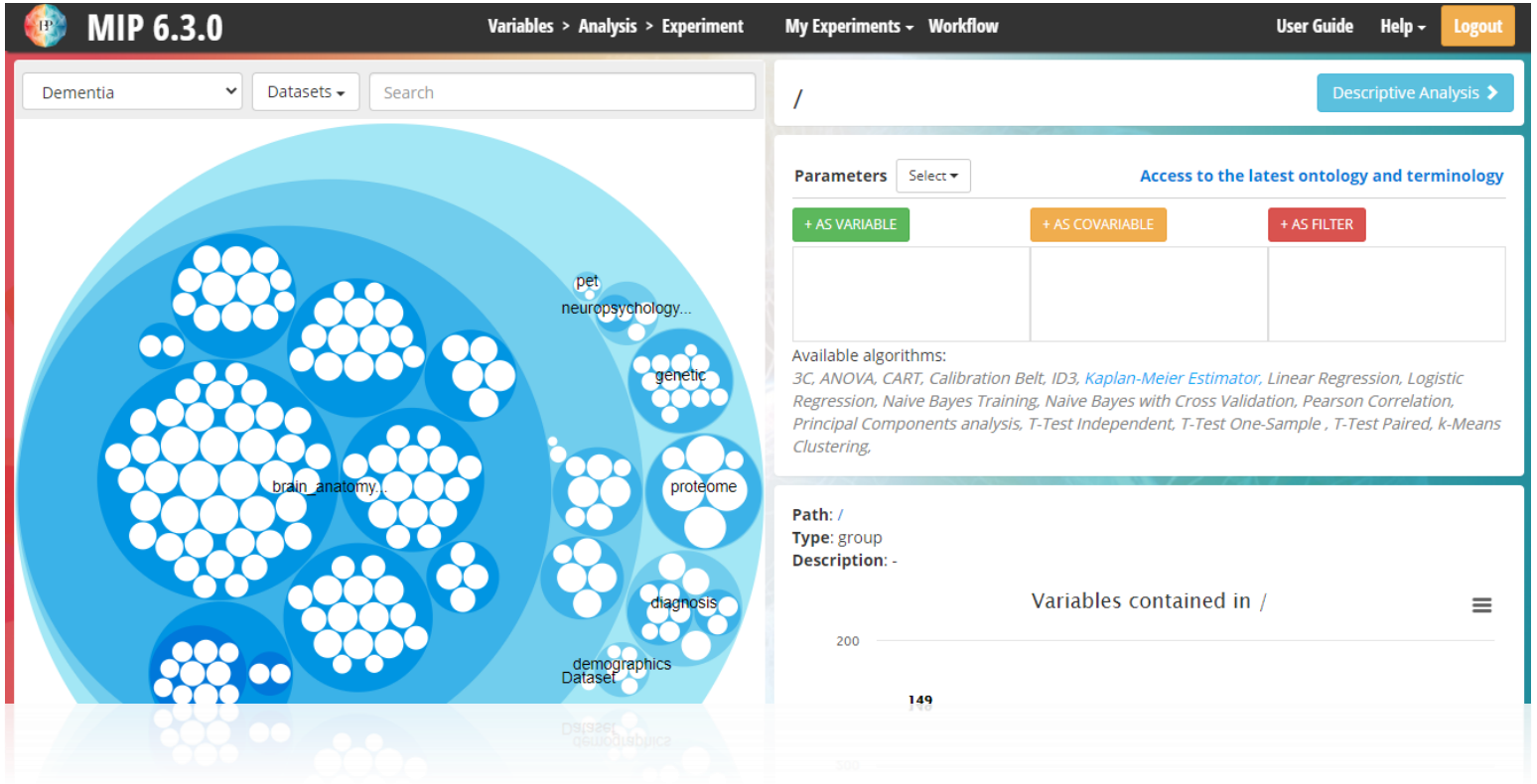
Scientific Rationale: Assessment plan

- This minimum dataset represents:
  - The scales that are **most commonly collected** across sites
  - The scales that have relevance for a Phase IV or post-license evidence base, but **are not commonly collected** across sites
  - Assessments and data that can facilitate pre-screening and recruitment
  - Assessments that can be conducted virtually or by phone
- We propose that data collection is longitudinal, possibly yearly, embedded into existing protocols where feasible.

Assessments across site protocols

MMSE (91.3%), CDR (73.9%), QoL scales (21.7%), caregiver scales (17.4%), health resource utilisation (13%).

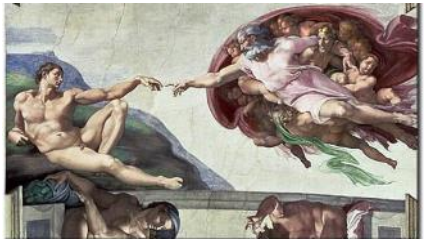
Technical infrastructure - MIP



The value of NEURONET – for whom?

imi innovative medicines initiative	Portfolio management service with emphasis on monitoring and impact measurement. Facilitating synergies and collaboration. NEURONET as a “template” for other research areas.
efpia SGG	Portfolio management service with emphasis on efficiency and synergy across projects. Inspirational force to devise areas where further research needs to be prioritised.
Projects	Support layer saving time, increasing speed and multiplying delivery of results/impact. Useful tool to influence future research priorities and to facilitate sustainability of assets that may be otherwise difficult to sustain.
Agencies/ Institutions	Overarching initiative representing relevant European research capacity and/or through leveraging specific assets.
Researchers	Integration of research capacities, positioning, community building, visibility/events, etc.

An H^3 paradigm for a new Renaissance?



Heads
Hands
Hearts