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

NEURONET, Carlos Díaz

IMI impact on dementia - Event
15 June, 2021

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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?

Can science provide today timely, actionable results commensurate with the scale of the challenges we are facing?
NEURONET as fragmentation ‘antidote’

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


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.

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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
  - Data sharing
  - Ethics & privacy
  - Regulatory interaction
  - Sustainability

- **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.

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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

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Asset Map

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**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 collaborating organisations on publications

Network diagram of projects in the portfolio

Network diagram of organisations participating in the portfolio

IMI neurodegeneration project portfolio

Data sources:
- Data collected by Neuronet on project characteristics and publications
- IMI2 Strategic Research Agenda
- JPIO report (2015)

Data analysis:
- Network analysis (projects, publications)
- Descriptive statistics
- Identifying of scientific priorities and enabling activities covered by portfolio

Are project portfolio characteristics optimal for innovation?

Are projects addressing the key R&D scientific priorities?

Are projects working on key enabling activities?

Speeding up drug development and access to innovative medicines
Impact Analysis - industry

1. Experience in IMI
2. Impact on company
3. Impact on daily work
4. Impact on your professional career
5. Impact on your professional network
6. Impact on the field of large

Neuronet survey

• 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%)

Results taken from Sanofi and Janssen participants (n = 53)
Cradle for new ideas & innovations

European research site network?

High-level Summit?

European ‘parent cohort’?

Academy for early career researchers?

Virtual incubator for assets?
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

EPAD LCS:
1600 participants
Deep phenotyping
Trial readiness
30+ centres

6000 participants, 60 centres, research-oriented, ND disorders

Project A
Project B
Project C
Project D
Project E
Project F

Ease recruitment, engagement with centres, speed...
Contracting, project participation, visibility...

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**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.

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<thead>
<tr>
<th>Principal Investigator</th>
<th>Site</th>
<th>Country</th>
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<tbody>
<tr>
<td>Giovanni Frisoni</td>
<td>Centre de la Memoire of Geneva University Geneva University Hospital</td>
<td>Switzerland</td>
</tr>
<tr>
<td>Rik Vandenberghe</td>
<td>University of Leuven</td>
<td>Belgium</td>
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<tr>
<td>Nikolaos Scarmeas</td>
<td>National and Kapiodistrian University of Athens</td>
<td>Greece</td>
</tr>
<tr>
<td>Craig Ritchie</td>
<td>University of Edinburgh and Brain Health Scotland</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Bruno Vellas</td>
<td>CHUT – Hospital Center University Toulouse</td>
<td>France</td>
</tr>
<tr>
<td>Lucilla Parnetti</td>
<td>Università degli Studi di Perugia</td>
<td>Italy</td>
</tr>
<tr>
<td>Audrey Gabelle</td>
<td>Université de Montpellier</td>
<td>France</td>
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<tr>
<td>Mia Kvileptlo</td>
<td>Karolinska Institute</td>
<td>Sweden</td>
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<tr>
<td>Félix Viñuela</td>
<td>Andalusian Institute of Neurology. Hospital Victoria Eugenia. Seville</td>
<td>Spain</td>
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<tr>
<td>Mercé Boada</td>
<td>Fundació ACE</td>
<td>Spain</td>
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<tr>
<td>Florence Pasquier</td>
<td>University Hospital de Lille</td>
<td>France</td>
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<tr>
<td>Pablo Martinez-Lage</td>
<td>Fundación CITA - Alzheimer Fundación</td>
<td>Spain</td>
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<tr>
<td>Silke Kern</td>
<td>University of Gothenburg, Sahlgrenska University Hospital</td>
<td>Sweden</td>
</tr>
<tr>
<td>Vanessa Raymont</td>
<td>University of Oxford and Dementias Platform UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Sebastiaan Engelborgh</td>
<td>JZ Brussel - VUB Centre for Neurosciences</td>
<td>Belgium</td>
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<tr>
<td>Daniel Blackburn</td>
<td>University of Sheffield</td>
<td>United Kingdom</td>
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<tr>
<td>Paresh Malhotra</td>
<td>Imperial College London</td>
<td>United Kingdom</td>
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<tr>
<td>Bernard Hanseeww</td>
<td>Cliniques Universitaires Saint-Luc, Brussels</td>
<td>Belgium</td>
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<tr>
<td>Johannes Kornhuber</td>
<td>Friedrich-Alexander-University of Erlangen-Nuremberg</td>
<td>Germany</td>
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<tr>
<td>Robert Perneckzy</td>
<td>University Hospital LMU Munich</td>
<td>Germany</td>
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<tr>
<td>Ross Dunne</td>
<td>University of Manchester</td>
<td>United Kingdom</td>
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<tr>
<td>Bruno Dubois</td>
<td>Salpêtrière University Hospital, Paris</td>
<td>France</td>
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<tr>
<td>Frank Jessen</td>
<td>University of Cologne</td>
<td>Germany</td>
</tr>
<tr>
<td>Philip Scheltens</td>
<td>Stichting VUMC</td>
<td>Netherlands</td>
</tr>
<tr>
<td>Karine Fauria</td>
<td>Fundació BarcelonaBeta Brain Research Center</td>
<td>Spain</td>
</tr>
<tr>
<td>Elizabeth Coughard</td>
<td>North Bristol NHS Trust</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Stefan Teipel</td>
<td>DZNE Rostock/Greifswald and Univeristy Medicine Rostock</td>
<td>Germany</td>
</tr>
<tr>
<td>Annalena Venneri</td>
<td>Brunel University London</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Julien Dumurgier</td>
<td>Lariboisiere Hospital, Paris</td>
<td>France</td>
</tr>
<tr>
<td>Claire Boutoleau- Bretonnière</td>
<td>CHU Nantes</td>
<td>France</td>
</tr>
<tr>
<td>Pascual Sánchez-Juan</td>
<td>University Hospital Marqués de Valdecilla</td>
<td>Spain</td>
</tr>
<tr>
<td>Mario Riverol Fernández</td>
<td>Clinica Universidad de Navarra</td>
<td>Spain</td>
</tr>
<tr>
<td>Oliver Peters</td>
<td>Charité Berlin</td>
<td>Germany</td>
</tr>
<tr>
<td>Samantha Galuzzi</td>
<td>RCCS Centro San Giovanni di dio Fatebenefratelli – Brescia</td>
<td>Italy</td>
</tr>
<tr>
<td>Lutz Froelich</td>
<td>Central Institute of Mental Health (CIMH), Medical Faculty Mannheim, University of Heidelberg,</td>
<td>Germany</td>
</tr>
<tr>
<td>Mircea Balasa</td>
<td>DIBAPS, Hospital Clinic Barcelona</td>
<td>Spain</td>
</tr>
<tr>
<td>Konrad Rejdak</td>
<td>Medical University of Lublin</td>
<td>Poland</td>
</tr>
<tr>
<td>Luiza Spiru</td>
<td>Clinical Department Elias University Hospital</td>
<td>Romania</td>
</tr>
<tr>
<td>Görsev G. Yener</td>
<td>Izmir University of Economics, Faculty of Medicine, Izmir</td>
<td>Turkey</td>
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Our future landscape

Joint perspective

Avoid the ‘fighting your own war’ syndrome

Problem-solving, pragmatic culture of efficiency
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.

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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

Win-Win-Win situations
Tangible outputs
Just in time

Gap identification
Common needs
Facilitate solutions

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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.
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):

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<th>Biomarkers</th>
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<td>APOE status (if known)</td>
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<td>Zarit Burden Inventory</td>
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- Proceeding to secure initial investment (preferential stakeholders).

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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%).

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Technical infrastructure - MIP
The value of NEURONET – for whom?

Portfolio management service with emphasis on monitoring and impact measurement. Facilitating synergies and collaboration. NEURONET as a “template” for other research areas.

Portfolio management service with emphasis on efficiency and synergy across projects. Inspirational force to devise areas where further research needs to be prioritised.

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.

Overarching initiative representing relevant European research capacity and/or through leveraging specific assets.

Integration of research capacities, positioning, community building, visibility/events, etc.
An $H^3$ paradigm for a new Renaissance?