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## **Milestone 4.2- Assessment of Current Approaches to Alignment:**

### **Case Study No.8- The Network of Centres of Excellence in Neurodegeneration (CoEN)**

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## ABSTRACT

This case study examines the key features, outputs and overall strengths and weaknesses of a specific modality that supports greater alignment of research activities across countries, namely the **Network of Centres of Excellence in Neurodegeneration (CoEN)**, which facilitates the launch of transnational calls for project proposals that are open to recognised national research institutes (i.e. Centres of Excellence) in the field of degenerative diseases. The alliance brings together organisations from nine countries, including large nationally mandated Centres of Excellence that have call funding resources as well as national funding organisations that provide funding to recognised Centres of Excellence if the latter have no funding capabilities. While focussing on the specific experience of CoEN, the case study also provides lessons for other public-to-public research networks wishing to develop a similar instrument to promote **collaborative research, institutional cooperation and coordination amongst European research funding and performing organisations**, and alignment more generally. The case study does however not aim to provide an in-depth assessment of CoEN nor of the instrument of the network of Centres of Excellence.

The study highlights CoEN's many benefits. By enhancing the **collaboration between some of the most influential research centres** working in neurodegeneration in participating countries, CoEN has allowed to establish new partnerships across Europe and North America. The initiative has facilitated the **implementation of high quality research** by leveraging on the critical mass, resources and expertise of existing national research centres, fostering operational alignment of research activities and implementing a common peer review process. Moreover, CoEN's strategic research focus on high risk/high impact research provides **high added value and complementarities to existing national and transnational research programmes and networks**, while developing several partnerships with related European and international initiatives in order to **benefit from higher visibility and political interest**. Regarding the operation of the alliance, CoEN members have adopted a **streamlined governance model, a central management structure and a flexible and sustainable country-driven funding mechanism** in order to effectively support the network's targeted membership and catchment of research centres and share the investment risk related to the type of research funded by CoEN.

Yet, the CoEN initiative has also been facing several limitations. In particular, it has been confronted with: (i) the challenging task of effectively reaching out towards the industry; and (ii) the need for more networking activities in order to keep members involved and achieve a common understanding of CoEN's research priorities and implemented activities among the research community.

The case study builds on the ERA-LEARN 2020 Task 4.1 ("Definition and Typology of Alignment"), and relies on a review of existing literature and targeted exchanges with a member of the Secretariat of the CoEN Oversight Group. The case is part of a series of nine short case studies that form the basis of the ERA-LEARN 2020 Task 4.2 "Assessment of Current Approaches to Alignment". The nine case studies that have been selected for this Task each rely on a different instrument (Member-State instrument or EC instrument, e.g. ERA-NET), cooperation mode (e.g. networking amongst researchers, programme integration, institutional cooperation, etc.) and approach (strategic, operational and/or financial) that promote alignment, and that are often put in place at different stages of the research programming cycle (planning, strategy, implementation, etc.).

## ACKNOWLEDGEMENTS

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## 1. Introduction

This case study examines the key features, outputs and overall strengths and weaknesses of a specific alignment modality, namely the **Network of Centres of Excellence in Neurodegeneration (CoEN)**, which consists of an alliance of national organisations with funding capabilities, including national research funding organisations (RFOs) and large national research performing organisations (RPOs). The alliance facilitates the development of a targeted joint research strategy and the management of joint calls for project proposals that are addressed to recognised national Centres of Excellence in the field of degenerative diseases. The study assesses in what context such a tool is best used for promoting greater alignment of national research programmes and activities. While focussing on the specific experience of CoEN, it also provides **lessons for other JPIs and public-to-public research networks** wishing to develop a similar instrument to promote collaborative research, institutional cooperation and coordination amongst European research funding and performing organisations, and alignment more generally.

This alliance is used in order to foster transnational research cooperation among designated research performing organisations. It mainly supports the implementation phase of the research programming cycle and allows for operational alignment. Participating members provide funding through a competitive bidding process to research groups from recognised Centres of Excellence. Thus, this research alliance also promotes alignment during the research funding phase.

## 2. Key features of CoEN

### 2.1 Overview

The Centres of Excellence in Neurodegeneration (CoEN) initiative is a network of national research funders (i.e. RFOs and nationally mandated Centres of Excellence with funding capabilities) that seeks to enhance collaboration among recognised research centres (i.e. Centres of Excellence) in the field of neurodegenerative disorders such as Alzheimer's and Parkinson's Disease, Multiple Sclerosis, Motor Neurone, Huntington's and Prion Disease. It was founded in 2010 by national research funders from Canada, Germany and the United Kingdom and now brings together nine countries<sup>1</sup>. It is aligned with the broader EU Joint Programme on Neurodegenerative Research (JPND)<sup>2</sup> and complements the research activities undertaken through this initiative, although CoEN operates as an independent entity (see Section 2.3). To date, CoEN has facilitated the joint launch of three transnational calls for project proposals in 2011, 2013 and 2015 and the development of a common strategic orientation focused on **high risk/high pay-off** research. Targeting **recognised research centres** has enabled the network to facilitate the implementation of high quality research based on a critical mass of expertise, standardised methodologies and procedures, and enhanced sharing of equipment and data. .

Age-associated neurodegenerative disorders represent a major public health issue at European level and worldwide. They are affecting a growing number of people as the population ages. Yet the causes and mechanisms of these diseases remain largely unknown. Existing treatments are hence limited and focus on the symptoms rather than on the origin and development of the disorders. <sup>3</sup> Support for neurodegeneration research is required in order to advance knowledge in this field and potentially trigger breakthroughs for innovative treatments. As a country-driven initiative, CoEN seeks to contribute to this overall objective by connecting leading research groups across Europe and Canada.

### 2.2 Mission and activities

The main aim of CoEN is to address the major challenges and barriers to progress for neurodegeneration research through innovative and progressive transnational collaborative science. CoEN also seeks to provide a mechanism for industry (e.g. the biopharmaceutical and diagnostic companies) to link to its Centres of Excellence, and to develop novel and effective industry partnerships in pre-competitive research.

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<sup>1</sup> Member countries are Canada, Flanders, France, Germany, Republic of Ireland, Italy, Slovak Republic, Spain and the United Kingdom.

<sup>2</sup> See Annex 1 for more information on JPND

<sup>3</sup> <http://www.neurodegenerationresearch.eu/about/why/>

The scientific scope covered by CoEN is broad. The network encourages researchers to advance knowledge of neurodegenerative mechanisms as well as to explore new ways of diagnosing and treating such diseases. Connectivity with research in related areas such as inflammation and sensory neuroscience, or vascular and mental health is encouraged, as is outreach to experts in the fields of physical and computational science.

Through the CoEN network, participating members commit national funding resources in order to **launch transnational calls for joint project proposals**. In particular, CoEN facilitates:

- 1) The scoping of the call;
- 2) The mutualisation of national funding resources;
- 3) The launch and management of the call, including joint agreement on proposals to be funded based on the recommendations of an international panel of experts;
- 4) The monitoring of selected projects;
- 5) Networking activities within the CoEN research community;
- 6) Dissemination of project outcomes, in particular via the CoEN website.

### **2.3 Governance structure of the network**

The network has adopted a clear governance model. The CoEN Oversight Group is the decision-making body of the network. In order to keep its size manageable, it consists of two representatives (i.e. scientific and administrative) per funding partner. It deals with all issues related to the development and management of the CoEN initiative, i.e.:

- the management process and procedures of joint calls;
- membership of the network;
- strategic partnerships with other related initiatives such as JPND;
- communication of the network and its projects' outcomes.

The Oversight Group is supported by a Secretariat which has been provided in-kind by the Medical Research Council (United Kingdom). The Secretariat coordinates the Oversight Group meetings and oversees the implementation of the Oversight Group's decisions.

An international peer review panel is temporarily established during each call in order to assess submitted proposals and recommend the projects that are suitable for funding. The ranked list obtained is validated by all CoEN members without any other evaluation at national levels and funded projects are selected from this list according to available national funding.

In addition, as mentioned above, the CoEN network is aligned with the development of the JPND initiative. There is an overlap of membership and of persons involved in governing bodies of both initiatives, which facilitates the latter's interaction and complementarity and avoids duplicative calls.<sup>4</sup> For instance, national representatives for United Kingdom within the Oversight Group are also part of the decision-making body of JPND (i.e. the JPND Management Board). This ensures an efficient communication flow and coordination between both initiatives when scoping CoEN and JPND calls. However, as mentioned in Section 2.1, CoEN operates independently from JPND, which means that there is no structural link between CoEN and JPND governing bodies.

### **2.4 Approximate resources and time needed for implementation**

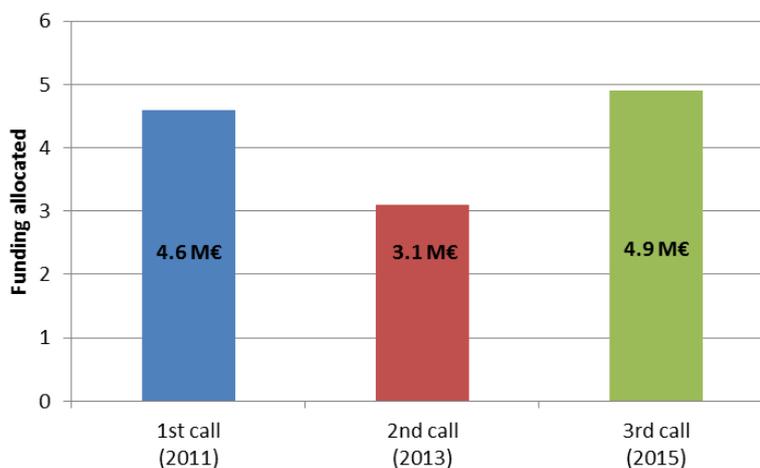
The funding of the three CoEN joint calls relied on a **virtual common pot**, which means that each participating national funder provided in-cash funding for the research activities undertaken by the Centres of Excellence within its country. As explained in Section 2.1, national funders involved in the CoEN network can include national funding organisations as well as nationally mandated Centres of Excellence with funding capability. In the first case, national funding organisations commit funding to be distributed to the Centre(s) of Excellence within the concerned country that participate in selected CoEN research projects. In the second case, nationally mandated Centres of Excellence secure funding for their own research activities under CoEN projects. CoEN calls

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<sup>4</sup> Network of Centres of Excellence in Neurodegeneration (CoEN) – Oversight Group, 1<sup>st</sup> meeting (December 2010)

are only open to Centres of Excellence that have been recognised by the network. Each funder administers the grants according to their respective policies and procedures, and assumes all costs related to the administration of these grants. Costs for peer review of the applications (e.g. travel, accommodation and panel meeting costs) are shared equally between each participating CoEN partner. As mentioned above, the Secretariat is supported as an in-kind contribution.

**Figure 1. Funding commitment towards CoEN joint research projects**



Source: 9<sup>th</sup> CoEN Oversight Group Meeting Report

So far, CoEN joint calls have been launched every two years. The funding cycle and strategic direction adopted by the CoEN Oversight Group has been developed and revised over time. The timeline below (Fig. 2) gives the evolution of CoEN's activities to date.

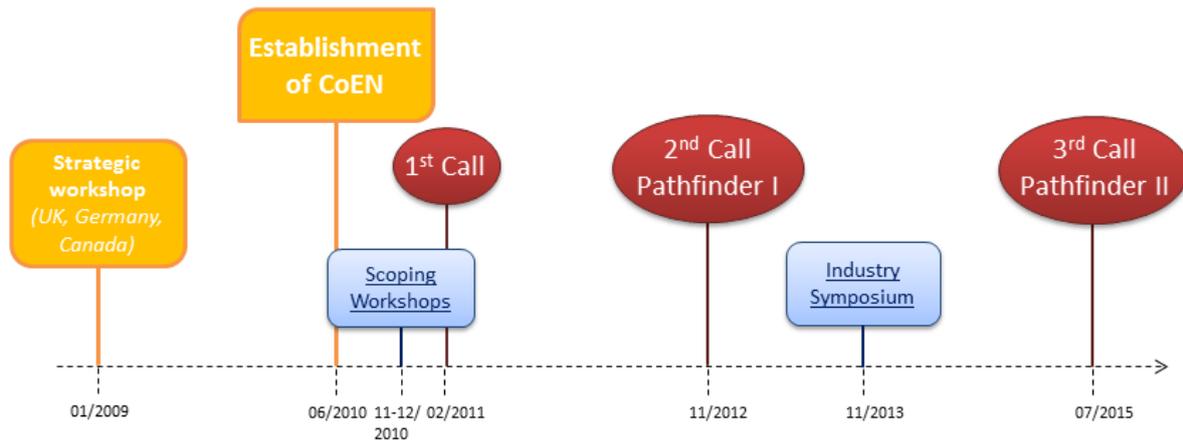
As a first step towards the set-up of the CoEN network, the Medical Research Council (MRC; UK) convened a trilateral workshop in January 2009 to help identify areas for potential cross-border collaboration which formed the basis of the CoEN initiative. After the official establishment of the network in June 2010, founding members signed a Memorandum of Understanding in September 2010.

Initially CoEN adopted a traditional approach and defined priority research areas to be addressed through the joint call. Scoping workshops took place before launching the call in order to identify specific research needs. The first call for proposals involved six CoEN partners and addressed bottlenecks in infrastructure and resource.

Following this first call, the 'Pathfinder' concept was developed and has been the basis for the subsequent calls in 2013 and 2015, involving seven and six national funders respectively (CoEN members do not all participate in each call). Future calls will also rely on this strategic concept (e.g. in 2017). Pathfinder calls set out to encourage the community to think 'outside the box', to stimulate new and unconventional approaches and creative solutions to the challenges of neurodegeneration research by undertaking high-risk / high-payoff research, which, if successful, will provide a step change in neurodegeneration research. The scientific remit for Pathfinder awards is broad in scope, and projects may include studies to illuminate our understanding of neurodegenerative mechanisms, or create technological advances to support novel diagnostic or therapeutic approaches.

In addition to calls for proposals, CoEN organised a Symposium in November 2013 with stakeholders from the pharmaceutical industry in order to present the achieved and expected project outcomes and to understand how CoEN research can benefit commercial organisations.

Figure 2. Timeline for implementation



Source: Own compilation

### 3. Principal outputs to date

CoEN has contributed to advancing knowledge on neurodegenerative processes and therapeutic approaches. So far, the network has:

- Launched three joint calls that enabled the implementation of 24 transnational research projects (i.e. 8 projects for the 1<sup>st</sup> call, 5 projects for the 2<sup>nd</sup> call and 11 projects for the 3<sup>rd</sup> call);
- Invested national financial resources amounting to over 12.5 M€ over the three joint calls;
- Organised a workshop with the pharmaceutical industry, including Pfizer, Sanofi, GSK, MSD, Lilly and others, to foster its involvement in CoEN projects and to discuss first project results and expected outputs.

Joint research projects that had been selected through the first and second CoEN calls have now been completed and have led to the development of innovative models on disease mechanisms and new opportunities for elaborating potential treatments. In particular, projects from the first CoEN call focus on various research questions including the development of new disease models, the identification of biomarkers and the harmonisation of methodologies for clinical studies. The projects brought together a wealth of resources and expertise from a number of large research institutes in different countries to tackle scientific questions that are key to advancement within the field.

### 4. Overall strengths of this tool, including key achievements

The CoEN initiative has adopted a strategic focus on enhancing collaboration between recognised Centres of Excellence and provides high added value to existing national and transnational research. CoEN has succeeded in **fostering new partnerships across Europe and North America that previously did not exist**<sup>5</sup>, and in providing a suitable mechanism for promoting transnational research collaborations between some of the most influential laboratories working in neurodegeneration in participating countries.

#### 4.1 Implementation of high quality research thanks to operational alignment of research activities and a common peer review process

A key advantage of the CoEN structure is that it **leverages on already existing national centres** selected as a result of stringent peer review processes. CoEN research projects can therefore be launched rapidly and benefit from resources that are appropriately targeted towards researchers who can deliver high quality science. Large centres and institutes have the necessary critical mass to focus resources and expertise on key barriers to progress in neurodegeneration. In addition, an effort to **'cluster' national centres of excellence** offers longer-term possibilities to both attract recognised scientists/clinicians, provide access to cutting-edge technologies and enhance interdisciplinary approaches, and to help create a high quality platform for training and capacity building.

<sup>5</sup> 4<sup>th</sup> CoEN Oversight Group Meeting (December 2011)

Furthermore, CoEN has implemented a joint procedure for assessing and selecting project proposals that ensures the funding of high quality projects. A peer-review panel composed of leading international experts from academia and industry is convened to assess the submitted proposals according to predefined criteria. Those scoring over a certain quality threshold are qualified as fundable and ranked. Funding is allocated using a virtual common pot model and following the ranked list with no jumping, hence ensuring the high quality of funded research projects. The CoEN Oversight Group has noted that **the quality of submitted proposals has significantly increased** with subsequent Pathfinder calls.

#### **4.2 Development of a transnational research network with a unique research approach**

CoEN's strategic approach supports the principle of **avoiding unnecessary duplication of research efforts and providing added value and complementarities to existing research programmes and networks** at national and transnational levels<sup>6</sup>). Hence, CoEN members have launched three joint calls in order to fund research that would not have been funded otherwise. Indeed, the Pathfinder scheme has been deemed an appropriate niche for CoEN and has allowed the organisation to be distinct from other transnational funding calls focusing on the same research area such as JPND and the European public-private Innovative Medicines Initiative (IMI)<sup>7</sup>, and for many countries, distinct from national grant schemes. By demonstrating to national funding providers the uniqueness of the research financed through the CoEN initiative, CoEN members are more effectively **ensuring continued financial support**, thereby contributing to the long-term sustainability of the network.<sup>8</sup>

#### **4.3 Sustainable financial alignment thanks to a country-driven and nationally funded transnational research initiative**

Launching a transnational call allows member countries to pool together national financial resources. This is particularly valuable for the CoEN network as it funds scientifically riskier research. Thus, CoEN's transnational approach enables the **sharing of investment risk** among participating countries. In addition, the launch of a joint call focusing on Centres of Excellence indirectly facilitates the mobilisation of valuable in-kind resources across these national research centres (e.g. equipment, new technologies, leading researchers, etc.).

Furthermore, the CoEN network only relies on the engagement of participating countries and committed national financial resources. Although call budgets could be increased with co-funding from the European Commission (e.g. through an ERA-NET Cofund), CoEN's strategy is to rely on a flexible and independent agenda. Indeed, **the network's current governance and funding mechanism can easily take into account national constraints and requirements**. It allows for more flexibility regarding funding commitments and application, management and reporting requirements, in contrast to complex procedures related to EC co-funding. This makes the network more accessible to applicants as well as to CoEN member countries.<sup>9</sup> **CoEN members are committed to supporting a long-term initiative that is self-sustainable** without the need for EC co-funding.

#### **4.4 Development of strategic partnerships with related European and international initiatives**

Neurodegenerative disorders represent a major public health issue that is a strong political priority on the international agenda. CoEN has benefited from its **alignment with the EU Joint Programme on Neurodegenerative Research (JPND)**, which has been a valuable intermediary for showcasing CoEN's work at the strategic level, especially as JPND has a close relationship with the European Commission and the Global Alliance against Dementia. Also, CoEN benefited from the support of the United Kingdom's Government for the CoEN Industry workshop which was held in the context of the G8 Dementia Summit hosted by the UK in December 2013.<sup>10</sup> The workshop was then highlighted during following G7 meetings on dementia.<sup>11</sup>

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<sup>6</sup> <https://www.imi.europa.eu/>

<sup>7</sup> <https://www.imi.europa.eu/>

<sup>8</sup> 4<sup>th</sup> CoEN Oversight Group Meeting Report (December 2011)

<sup>9</sup> CoEN Call for Proposals – Allocation of Funds Meeting and CoEN Oversight 3<sup>rd</sup> Group Meeting (July 2011)

<sup>10</sup> 7<sup>th</sup> CoEN Oversight Group Meeting (May 2013)

<sup>11</sup> P. Amouyel, Presentation on Joint Programming in Neurodegenerative Disease Research (JPND), 3<sup>rd</sup> Global Dementia Legacy meeting, Tokyo, 6 November 2014; <https://www.nia.nih.gov/about/events/2015/g7-dementia-research-coordination-and-collaboration-meeting>

#### **4.5 Simple governance model and targeted membership for efficient operational alignment**

The governance structure of the CoEN network relies on a **single governing and decision-making body** (i.e. CoEN Oversight Group), which allows for a more manageable operation, especially with the support of its Secretariat. As such, procedures and requirements for the call launch and management, applications, evaluation and monitoring are collectively agreed amongst CoEN members. The network's governance also facilitates efficient decision-making as strategic decisions are provided by CoEN members only. In addition to its independence from the EC (see Section 4.3 above), the simplicity of CoEN's governance model also contributes to enabling CoEN to provide a flexible coordination support that can adapt to member's needs and requirements. In particular, it is most suitable for effectively supporting a targeted catchment of research centres and associated researchers.

In addition, CoEN membership is open to national funding organisations linked to one or several identified Centres of Excellence, or nationally mandated Centres of Excellence with funding capability.<sup>12</sup> This facilitates a peer-to-peer collaboration within the network and a balanced decision-making process where partners equally have the capability to provide funding towards CoEN joint calls.

#### **5. Overall limitations with this tool, including difficulties encountered during implementation**

The CoEN network has been confronted with challenges regarding the implementation of efficient outreach towards the industry, community building within the network and well-known limitations of the virtual common pot mechanism.

##### **5.1 Challenging outreach towards the industry**

As indicated in Section 3, CoEN organised a workshop with stakeholders from the industry in order to showcase CoEN's research activities and results and identify the added value of a partnership between CoEN and industry. Industry representatives highlighted that the innovative and collaborative research supported through the CoEN initiative was precisely the type of activity needed to provide novel insights and the pathways to explore potential solutions to dementia.<sup>13</sup> However it was noted that communication could be improved between members of the CoEN research community and industry to better highlight the added value of CoEN's research.

Industry has limited resources for discovery science and needs access to basic and preclinical studies before committing to the development of a specific therapy or diagnostic agent. In addition, industry could benefit from the cutting-edge technology available in laboratories of CoEN partners. A recognised network of centres of excellence provides a single point of contact through which significant interest from industry to promote, translational science and the rapid implementation of new therapies and public health interventions. An ambition is that activities driven by networked Centres of Excellence will provide the platform of choice for collaboration with industry and global partners on large-scale projects. Aligning CoEN's research agenda with the needs of industry may provide a route for translational science and the rapid implementation of new therapies and public health interventions. In return, a partnership with the industry would give CoEN partners access to industry data (e.g. on early drug-development). This could provide valuable inputs for discovery research (e.g. on potential disease mechanisms) and potentially guide CoEN's research strategy.<sup>14</sup> JPND is developing a strategy for interaction with industry and the niche for CoEN will be part of the discussion.

##### **5.2 Need for more networking activities in order to keep members involved and achieve a common understanding among the research community**

The CoEN Oversight Group aims to organise a symposium that is targeted towards CoEN members and researchers.<sup>15</sup> The objective of this event is to foster networking amongst researchers and synergies amongst CoEN joint research projects, which would help develop community building and a common understanding of research priorities and implemented activities both by researchers and funding providers.

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<sup>12</sup> 9th CoEN Oversight Group Meeting, 18th March 2016

<sup>13</sup> In particular, industry representatives commented that CoEN was "an important piece in the global pipeline of innovation needed to face this paramount public health challenge".

<sup>14</sup> 8th COEN Oversight Group Meeting, Tuesday 17th June 2014

<sup>15</sup> 9th CoEN Oversight Group Meeting, 18th March 2016

### **5.3 Limits of the virtual common pot**

The most significant and well-known limitation of the application of a virtual common pot for the funding of a transnational call is the potential inability to exactly follow the ranked list of selected joint project proposals. Indeed, the virtual common pot mechanism is limited by dependence on national budget availability and the distribution of applicants from member countries on each proposal. Once the point was reached in the ranking list where a Sponsor Group has insufficient funds remaining from their budget the allocation of funding to projects cease. Thus, national funding gaps may not allow the funding of high quality joint research projects. This can be avoided by using more flexible funding models (e.g. through the implementation of a funding reserve at national level or the adoption of a real common pot).

In addition, the virtual common pot triggers time-consuming bureaucracy at national level in order for transnational research proposals and consortia to comply with national eligibility criteria. Harmonising the latter among network member countries is however challenging and can be impossible in certain countries. Despite that, CoEN has not encountered any major issues related to the application of national criteria and procedures when administrating grants.

## 6. Conclusions: Suitability and key factors of success

The set-up of a network of recognised Centres of Excellence is most suitable for building on existing cutting-edge infrastructure, high quality expertise and significant national funding resources, the latter being especially valuable to share the investment risk related to “high-risk” research. This allows to maximise the added value of transnational research and also provides an opportunity for capacity building. Moreover, such a network facilitates the cooperation amongst most influential research centres in a given research area, which ensures high impact of the network’s scientific results.

Establishing a small network that focuses on a narrow scientific scope provides greater flexibility to modify and even shift the network’s joint research strategy, ensures a more manageable operation and contributes to higher impact in its specific field of research (i.e. niche).

*Key factors of success:*

*1) At strategic level:*

- **Develop a common strategic vision and agenda among network members:** in particular, this strategy should be aligned with related national and international initiatives to ensure complementary and avoid duplications. This hence allows to provide high added value to existing national and transnational research and contributes to enhancing long-term support from members.
- **Carefully manage the network’s membership:** targeting a specific group of potential members allows for peer-to-peer collaboration and balanced decision-making processes. Strict criteria should be applied in order to maintain a small sized-network and ensure scientific excellence.
- **Develop strong interactions with highly visible and more political initiatives** in order to ensure high impact on the concerned international agenda and related political strategies.

*2) At financial level:*

- **Develop a flexible mechanism for the funding of joint projects:** this funding mechanism should take into account national funding and monitoring constraints and requirements, while enhancing investments in selected Centres of Excellence and facilitating the funding of best joint research projects (i.e. by following the ranked list of proposals for instance thanks to national funding reserves or a real common pot approach).
- **Enhance the willingness of network members to support the operation of the network** thanks to an adapted financial mechanism (e.g. costs of peer review shared among participating partners, costs for the administration of awards shared or subsumed by respective funding agency, provision of in-kind resources from members).

*3) At operational level:*

- **Build a streamlined governance model** that gives the network flexibility and efficiency in strategic and operational/financial decision-making.
- **Set up a management structure** (e.g. Secretariat) to coordinate and provide a day-to-day support for the launch and management of calls and other activities related to the operation of the network.
- **Develop a robust peer-review procedure** undertaken by international expert panel in order to ensure the scientific excellence of funded research projects.
- **Actively disseminate scientific outcomes**, for instance through a website but also and more importantly through the collaboration with end-users for an efficient uptake and application of results.

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- CoEN (2011). 4<sup>th</sup> CoEN Oversight Group Meeting, 1 December 2011.
- CoEN (2012). 5<sup>th</sup> CoEN Oversight Group Meeting, 19 June 2012.
- CoEN (2013). 6<sup>th</sup> CoEN Oversight Group Meeting, 25 January 2013.
- CoEN (2013). 7<sup>th</sup> CoEN Oversight Group Meeting, 15 May 2013.
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- CoEN (2016). 9<sup>th</sup> CoEN Oversight Group Meeting, 18 March 2016.

### Presentation

- Amouyel, P. (2014). Presentation at the 3rd Global Dementia Legacy meeting “*Joint Programming in Neurodegenerative Disease Research (JPND) – Coordinating approaches to research across Europe*”, November 2014. Available at:  
[http://eulachealth.eu/wp-content/uploads/2014/11/3\\_JPND\\_EU\\_LAC\\_Madrid\\_Amouyel.pdf](http://eulachealth.eu/wp-content/uploads/2014/11/3_JPND_EU_LAC_Madrid_Amouyel.pdf)

### Consulted websites

- EC – Public Health – Brain and neurological diseases:  
[http://ec.europa.eu/health/major\\_chronic\\_diseases/diseases/brain\\_neurological/index\\_en.htm](http://ec.europa.eu/health/major_chronic_diseases/diseases/brain_neurological/index_en.htm)
- CoEN: <http://www.coen.org/home.html>
- IMI: <https://www.imi.europa.eu/>
- JPND: <http://www.neurodegenerationresearch.eu/>

## ANNEX 1. JOINT PROGRAMME ON NEURODEGENERATIVE RESEARCH<sup>16</sup>

The Centres of Excellence in Neurodegeneration (COEN) Initiative operates as a parallel research initiative under the umbrella of the EU Joint Programme on Neurodegenerative Research (JPND). JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. It has identified through its Research Strategy common research goals that would benefit from joint action between countries in order to accelerate progress on solutions that can alleviate the symptoms, and lessen the social and economic impact for patients, families and health care systems.

There are three main components to this work:

- Improve the scientific understanding of the disease;
- Improve the medical tools available to doctors to identify and treat the disease;
- Improve the social care and structures available to assist patients, their families, and health service providers so that patients can receive optimum care at all stages of their illness.

The neurodegenerative diseases (ND) that JPND focuses on are:

- Alzheimer's disease (AD) and other dementias;
- Parkinson's disease (PD) and PD-related disorders;
- Prion disease;
- Motor neurone diseases (MND);
- Huntington's Disease (HD);
- Spinocerebellar ataxia (SCA);
- Spinal muscular atrophy (SMA).

JPND's goals are:

- To add value to national investments through coordinated action;
- To encourage the development of national research strategies in ND;
- To engage in partnership to reach the full potential of JPND.

***JPND VISION:*** *To find cures for neurodegenerative diseases and to enable early diagnosis for early targeted treatments.*

***JPND MISSION:*** *To bring together researchers, existing research evidence and national funding bodies to investigate the key research questions and barriers to progress in this area; To increase coordinated investment in neurodegenerative disease research aimed at finding causes of disease, developing cures, and identifying appropriate ways to care for those with neurodegenerative disease.*

### **JPND IMPLEMENTATION PROCESS:**

JPND's implemented activities are presented in Fig.1 below. An important first objective of JPND was the drafting of a Strategic Research Agenda (SRA), which defines the strategic and scientific priorities that would benefit from co-ordination at the European level.

JPND executes its strategy through an implementation plan that is agreed to every three years. The plan consists of a number of major activities, including:

- Annual Calls for proposals launched in priority research areas;
- Alignment Actions to promote alignment of research activity across Europe and focus on emerging scientific themes;
- The CoEN initiative, which operates independently and in alignment with JPND.

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<sup>16</sup> <http://www.neurodegenerationresearch.eu/>

Figure 1. JPND's implementation process



Source: Own compilation