



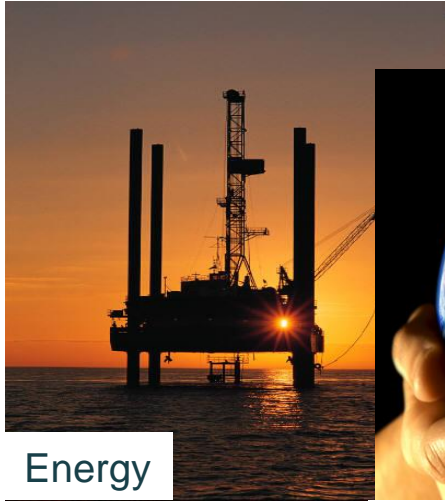
**JPND**  
research

EU Joint Programme – Neurodegenerative Disease Research

# Joint Programming in Neurodegenerative Disease Research (JPND)

**Prof. Thomas Gasser, MD**  
**Chair, JPND Scientific Advisory Board**

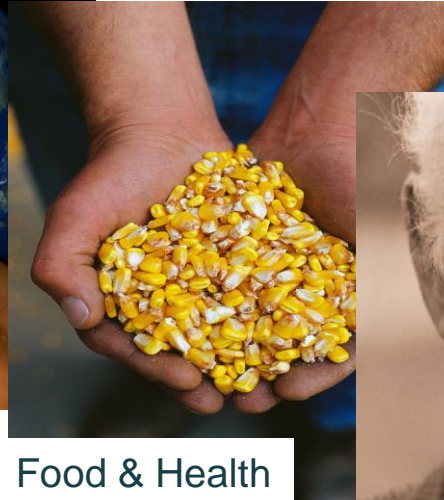
# A major societal “Grand Challenges”



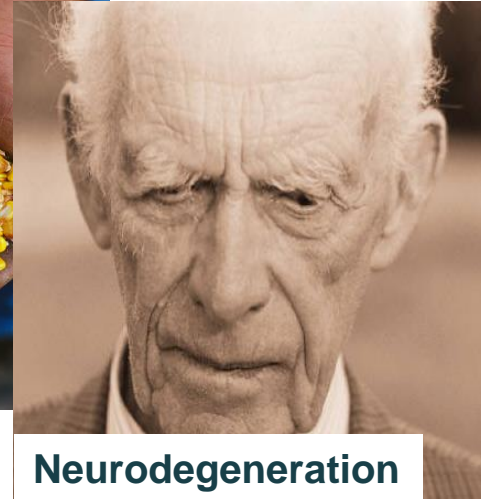
Energy



Climate Change



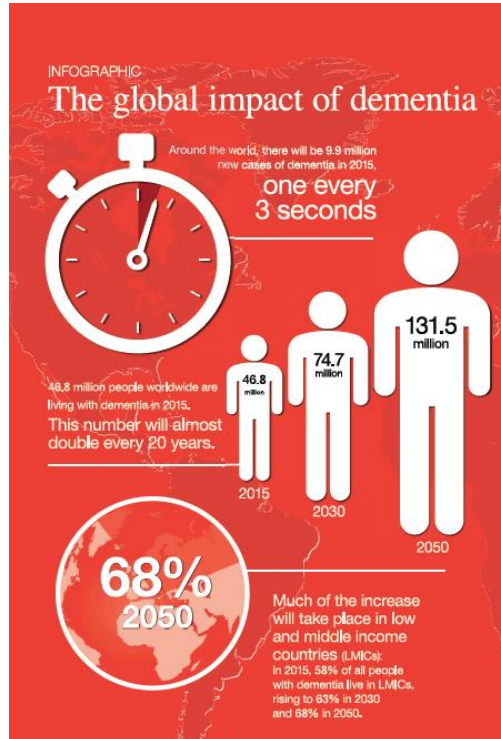
Food & Health



Neurodegeneration



# The global threat of neurodegeneration



World dementia report 2015

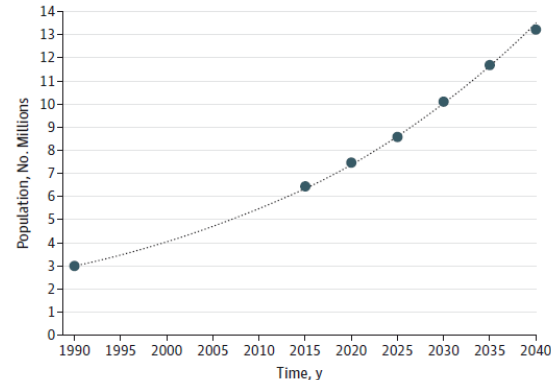
## VIEWPOINT

## The Parkinson Pandemic A Call to Action

JAMA Neurology



Figure. Estimated and Projected Number of Individuals With Parkinson Disease, 1990-2040



# Overcoming barriers in Europe



- Fragmented Research
- Non-concerted National Funding
- Duplication
- < 5% of total EU countries research budget shared (mainly through the European Commission)



# The Joint Programming Concept

Joint programming was originally created as a *Member States-led* initiative in Europe. It aims to address “grand challenges” to EU and global society by **coordinating national research programmes** to increase the impact and effectiveness of research efforts.

*Source : Communication from the Commission to the European Parliament, the Council, the European Economic and social committee and the Committee of the Regions toward Joint Programming in Research : Working together to tackle common challenges more effectively - COM(2008) 468 final, Brussels*



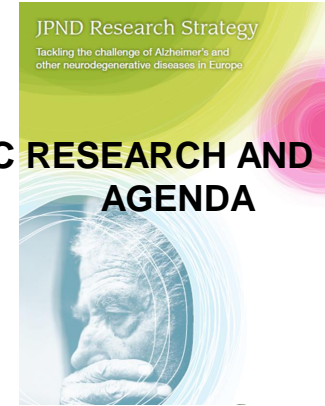
- **Immediate JPND goals:**
  - To add value to national investments through coordinated action
  - To encourage the development of national research strategies in ND
  - To engage in partnership to reach the full potential of research in JPND-affiliated countries



# Aligning to defragment: what JPND is all about



## STRATEGIC RESEARCH AND INNOVATION AGENDA



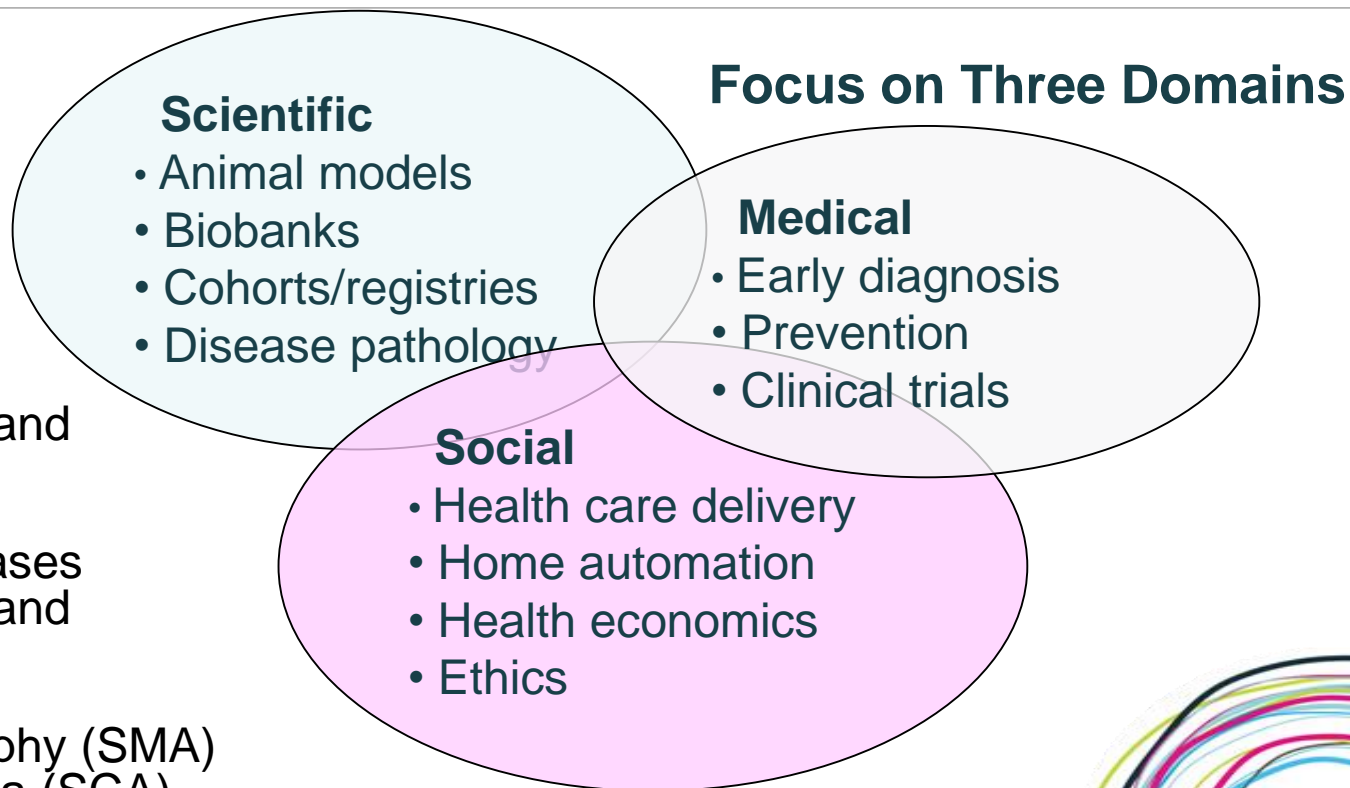
## ALIGNMENT OF COUNTRIES ON COMMON RESEARCH GOALS



# Scope of the JPND initiative

## Disease areas

Alzheimer's disease and other dementias  
Huntington's disease  
Motor Neurone Diseases  
Parkinson's disease and PD-related disorders  
Prion disease  
Spinal muscular atrophy (SMA)  
Spinocerebellar ataxia (SCA)





# JPND brings together

- Researchers (Basic, Clinical, Healthcare/Social)
- National Funding Bodies
- National Research Strategies and Investments
- Industry



# Internationalisation: Europe and beyond

JPND is the largest global ND research initiative led by EU countries, with 30 participating

**23 EU member states**

**5 Associated countries**

**2 Partner countries**



Albania  
Australia  
Austria  
Belgium  
Bulgaria  
Canada  
Croatia  
Czech Republic  
Denmark  
Finland  
France  
Germany  
Greece  
Hungary  
Ireland  
Israel  
Italy  
Luxembourg  
Netherlands  
Norway  
Poland  
Portugal  
Romania  
Slovakia  
Slovenia  
Spain  
Sweden  
Switzerland  
Turkey  
United Kingdom

# Forging new international links

- New collaboration with USA NIH in 2018
- Exploring potential for future collaboration with
  - Brazil
  - China
  - India
  - Japan
  - Singapore
  - South Korea



# **A common Strategic Research and Innovation Agenda**



# 2012: The Strategic Research Agenda

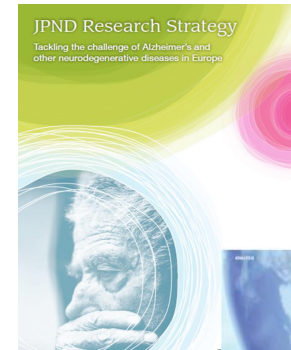
- **A roadmap for research agreed by all Member States + Assoc. Countries + Partners Countries**
- **Thematic priorities for future research:**
  - The origins of neurodegenerative disease
  - Disease mechanisms and models
  - Disease definitions and diagnosis
  - Developing therapies, preventive strategies and interventions
  - Health and social care



# The Strategic Research Agenda – Enablers

## Enabling activities

- Research funding capability (fully engaging JPND MOs)
- Supportive infrastructure / platforms (cohorts, models, imaging)
- Industry partnership
- Regulation
- Global partnership
- Building capacity in research (people)
- Education and practitioner training
- Connection to policy makers
- Communication and outreach to patients and public



# Joint calls: Funding process

1. JPND member countries decide on a topic
2. Countries that want to participate earmark a dedicated budget
3. Once enough funding has been collected, an MoU is signed
4. A joint program call is launched



# Implementing transnational and additional joint calls

**Total investment €200 M**

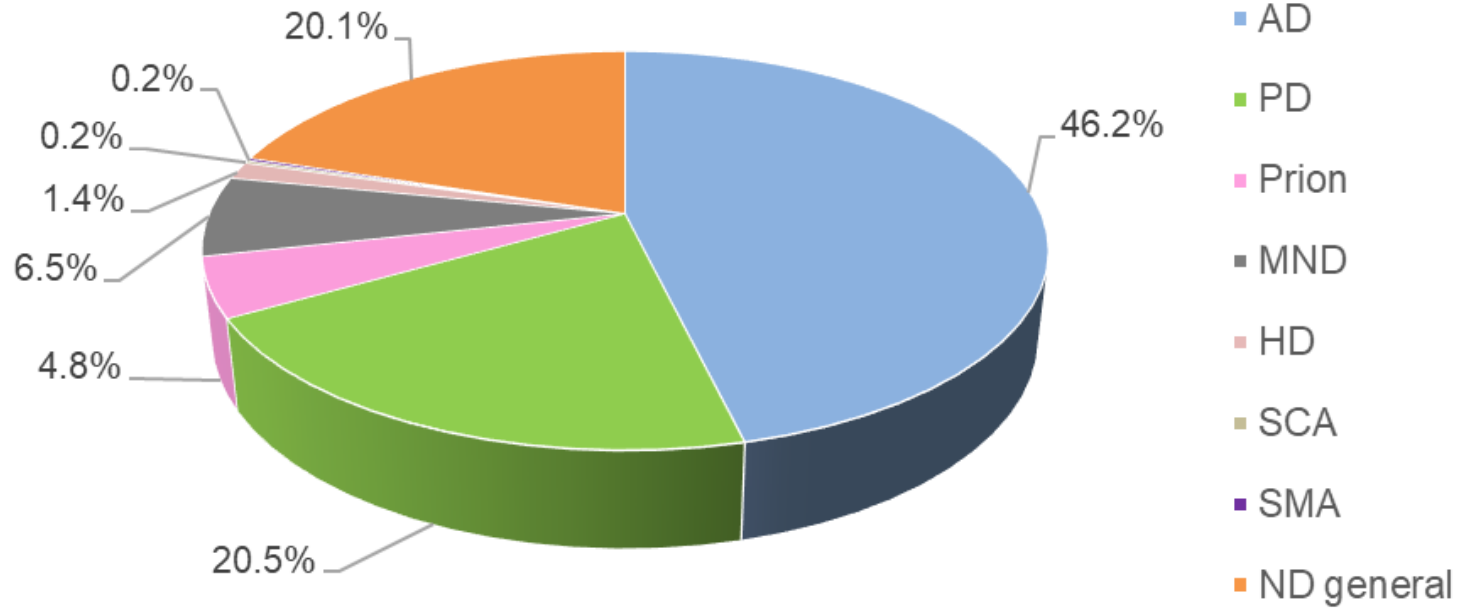
## Joint Transnational Calls:

- Between 20 and 189 proposals per call
- 125 projects supported including 24 projects in the Center of Excellence Network program

Year	Total fund	Research Area	No. of Projects
2011 (pilot)	€16M	Optimization of biomarkers + harmonization of their use	4
2012	€18M	Risk and Protective Factors	5
2012	€11M	Evaluation of Healthcare	6
2013	€12M	Cross-Disease Analysis	10
2013	€11M	Preventive Strategies	5
2014	€0.5M	Working Groups Cohort Studies	10
2015	€36M	Longitudinal Cohort Approaches; Advanced Experimental Models; Risk and Protective Factors.	21
2016	€0.6M	Working Groups on Harmonisation and Alignment in Brain Imaging Methods	10
2017	€14.4M	Cross-Disease pathways	10
2018	€18-19M	Health and Social Care	9/10
2019	#30M	Personalised medicine	In progress
2011	€6M	CoEN common resources and meth. approaches	8
2013	€8M	CoEN Phase II : “Pathfinder” projects	5
2016	€4,9M	CoEN Phase II : “Pathfinder” projects	11



# Research Funding: By disease



# JPND Alignment Actions, working together



Alignment of  
National Strategies



Alignment of  
National Activities



Industry Partnership



Assisted Living  
Technologies



Longitudinal Cohorts



Animal and Cell  
Models



Palliative Care



Patient + Public  
Involvement



Optimisation of  
biomarkers

# Mapping Database

<http://www.neurodegenerationresearch.eu/search-our-database-new/>



# JPND Global Cohort Portal

## The first global database of cohorts for ND

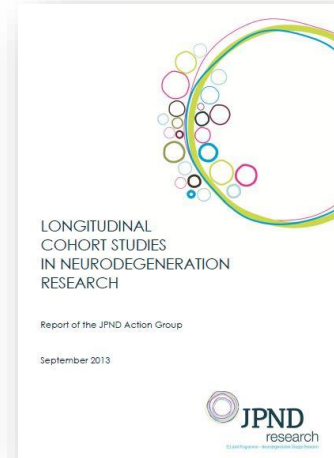
**Why cohorts?** Linking and comparing longitudinal cohort studies could lead to important insights and statistically more powerful conclusions about ND. But researchers face hurdles:

- Information on cohort studies is often difficult to find
- Identifying and connecting with the right contacts from each cohort can be challenging

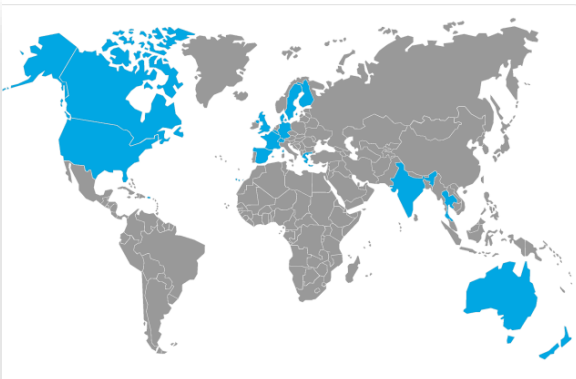
**Main objective:** to facilitate information exchange, greater use of cohorts and new collaborations to help promote:

- A larger volume of ND research
- Increased efficiency
- Greater scientific impact

More info:  
[cohorts@jpnd.eu](mailto:cohorts@jpnd.eu)



# How does the JPND Global Cohort Portal work?



Country All

Next Search

Learn how to use this search function can be found on the [How to use the Portal page](#)

Advanced search options

**SEARCH**

RECRUITMENT PERIOD	SEX	SAMPLE SIZE	DISEASE SPECIFIC	AGE	COGNITIVE	FUNCTIONAL RATING SCALES	ANTHROPOMETRIC	PHYSICAL	BIOLOGICAL SAMPLES	GENOTYPING	BRAIN IMAGING
<b>AGEING IN WOMEN AND MEN: A LONGITUDINAL STUDY OF GENDER DIFFERENCES IN HEALTH BEHAVIOUR AND HEALTHY AMONG ELDERLY</b>											
1994	MF	0 to 4,999	✓	69-80	✓	✓	✓	✓	✓	✓	✗
<input type="checkbox"/> Compare cohort											
<b>BRAINS FOR DEMENTIA RESEARCH</b>											
Unlimited	MF	0 to 4,999	✓	65	✓	✓	✓	✓	✓	✗	✗
<input type="checkbox"/> Compare cohort											
<b>THE BUSSELTON HEALTHY AGEING STUDY</b>											
Phase 1: 2010-15	MF	5,000 to 9,999	✓	46-69	✓	✓	✓	✓	✓	✓	✗
Phase 2: 2016-21											
<input type="checkbox"/> Compare cohort											
<b>THE CAMBRIDGE CITY OVER-75S COHORT STUDY</b>											
1985-87	MF	0 to 4,999	✓	>75	✓	✓	✗	✓	✓	✗	✗
<input type="checkbox"/> Compare cohort											
<b>COGNITIVE FUNCTION AND AGEING STUDIES WALES</b>											
2011	MF	0 to 4,999	✓	>65	✓	✓	✓	✓	✓	✗	✗
<input type="checkbox"/> Compare cohort											
<b>COLAU/PSYCOLAUS</b>											
2003-06	MF	5,000 to 9,999	✓	35-75	✓	✓	✓	✓	✓	✓	✓
<input type="checkbox"/> Compare cohort											

## Longitudinal Ageing Study in India

[EXPORT AS PDF](#)

### Cohort type

General population-based cohort

### If disease-specific

Alzheimers disease, Parkinsons disease

### Participant type

No diagnosis

### Profile

Start Date

2016-2017

Sample size at start or planned sample size if still recruiting

50,000 to 99,999

Estimated Current Sample Size

Age at Recruitment

40 to 59

Gender

Male and Female

### Abstract

The main objective of LASI is to provide comprehensive longitudinal evidence base on health, social and economic wellbeing of elderly population in India. 60,250 participants will be recruited between 2016-2017 from Delhi, Kolkata, Mumbai and Chennai.

Country

India

### Contact details

Institution name

University of Southern California (USC)|Harvard T. H. Chan School of Public Health (HSPH)|International Institute of Population of Sciences (IIPS)

Website

[http://iipsindia.org/research\\_lasi.htm](http://iipsindia.org/research_lasi.htm)

Principal Investigator (PI)

Professor Jinkook Lee|Professor David Bloom|Professor Perianayagam Arolkiasamy

Contact email

[jinkook@usc.edu](mailto:jinkook@usc.edu)

Search the database



Choose how your results display



Obtain high-level overview and cohort contacts

# 2018: From SRA to Scientific Research and Innovation agenda (SRIA)

2012



SAB  
review  
2016

Key areas identified

Expert workshops

Recommendations  
to SAB

NHP Consultation  
(Dec 2017-Jan 2018)

SRA

Updates to SRA text

Draft SRIA

SAB Meeting to discuss updates (29 Nov 2017, MS11)

Stakeholder Consultation

September 2018 (3 wks)



SAB/MB consulted

SRIA

Provisional launch Q1 2019

2018



current status

SAB = Scientific  
Advisory Board



# 2018: General updates

- Included techniques or developments in scientific understanding that have become important:
  - *New gene editing technologies*
  - *Organoids*
  - *Neuroinflammation and metabolism across diseases*
  - *Single cell analysis and systems analysis of brain tissue*
  - *Digital technologies / wearable devices*
  - *Computational modelling and analysis (ML / AI)*
- Modified some of the language to make it more lay friendly and bring out PPI aspects



# 2018: Example updates

- *Advance knowledge on the relationship between ND with vascular and metabolic systems and the role of infection and inflammation in the context of early and late-life comorbidity (SP1)*
- *Cohorts studies in susceptible groups including underrepresented populations (SP1)*
- *Examine ND mechanisms involving microglial and astroglial responses (SP2, also links to biomarkers in SP3 and imaging in SP4).*
- *Identify mechanism(s) that account for the effect of lifestyle factors on either promotion of resilience or neurodegeneration (SP2)*
- *Conduct studies to determine how to improve access to care and to reduce the unmet needs of individuals outside the formal care system and their carers.(SP5)*





# 2019: Pre-call Announcement

## “Multinational research projects on Personalised Medicine for Neurodegenerative Diseases” (~ 30 Mio €)

Joint call (JPND and EC) will focus on Precision Medicine in the following research areas:

- **Diagnosis** e.g. biomarkers, imaging data, omics approaches, big data analyses
- **Prevention** e.g. biomarkers for studying novel treatments and interventions, co-morbidities, digital technologies, stratification within cohort studies and clinical trials
- **Care** e.g. improvement of social and health care systems, molecular profiling, imaging, lifestyle data

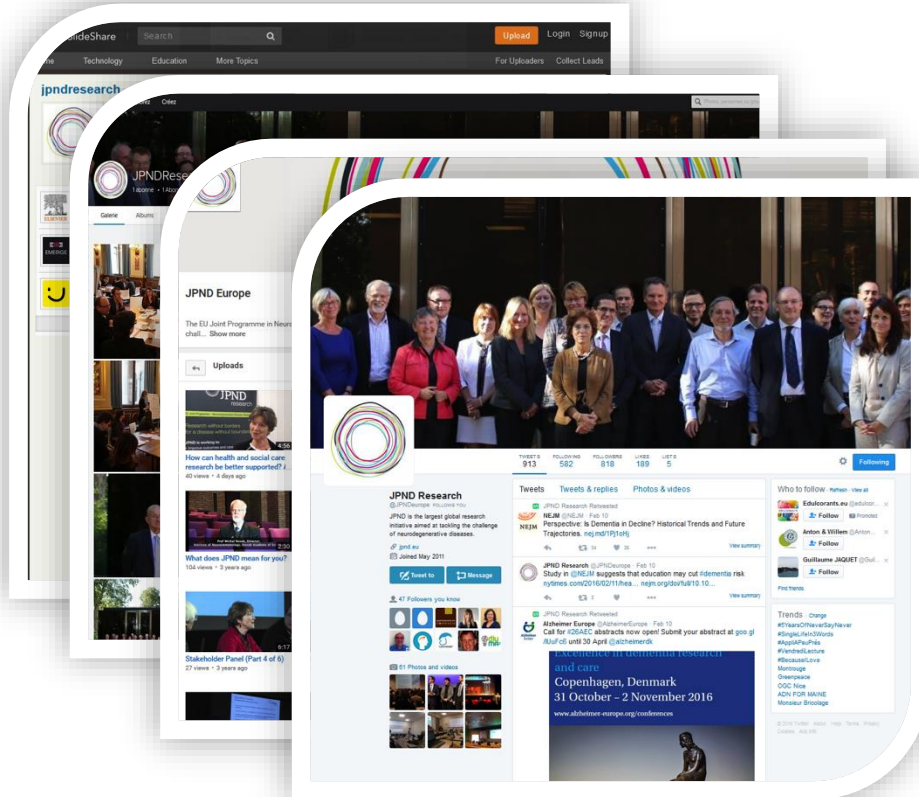


# How to improve collaboration with academia and industry

- **Organizing events**, such as the workshop, in other venues and bigger partnership meetings (e.g. BioEurope and others).
- Organizing **focused meeting** on specific results of JPND scientists;
- Support **science exchange programs and sharing of infrastructures** (such as the Global Cohort and Experimental models portals)
- Involve scientists working in companies in the **board of reviewers** of Joint calls
- Reserve a **JPND call for scientists** who had developed promising products suitable for further development to enable them to interact with SMEs specialized in validations.

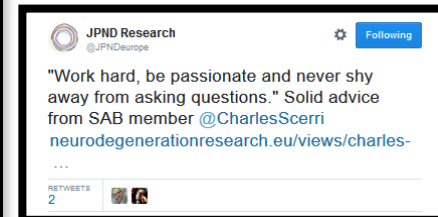
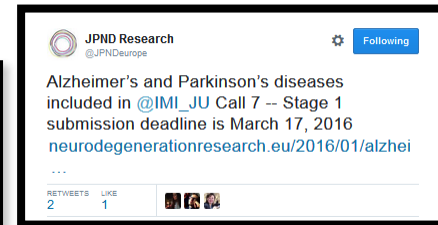


# Active Social Media Conversation



The JPND website reaches a wide range of stakeholders. In 2017:

- 96,279 users
  - 126,452 sessions
  - 250,993 pageviews
- Twitter
  - YouTube
  - Flickr
  - SlideShare



# Keep up to date

- Visit the JPND website:
  - <http://www.jpnd.eu>
- Sign up to the JPND News Feeds
- E-mail us: [secretariat@jpnd.eu](mailto:secretariat@jpnd.eu)



**@JPNDEurope**



#### Keep updated on JPND

Subscribe to JPND News update feed or receive email up dates.



#### JPND Progress

Click here for the latest progress and updates from ongoing JPND activities.



#### JPND Newsletter

The JPND Newsletter is a bi-annual "look back" at JPND activities and highlights.



# Creating a Global ERA for Neurodegenerative disease research

