



**COUNCIL OF  
THE EUROPEAN UNION**

**Brussels, 25 November 2009**

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**RECH 426  
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**NOTE**

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from: Permanent Representatives Committee  
to: Council

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Subject: Joint programming of research in Europe:  
a) The launch of the pilot joint programming initiative on combating neurodegenerative diseases, in particular Alzheimer's  
b) Progress in joint programming and the way ahead  
– *Adoption of Council conclusions*

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In its conclusions of 2 December 2008, concerning joint programming of research in Europe in response to major societal challenges, the Council considered the necessity to launch a pilot joint programming initiative (JPI) on combating neurodegenerative diseases, in particular Alzheimer's.

In addition it established a High Level Group on Joint Programming (GPC) with a view to identifying and substantiating the first list of a limited number of JPI themes in due time so that JPIs could be launched no later than 2010.

At its meeting of 18 November 2009, the Permanent Representatives Committee reached agreement on the launch of the pilot JPI on combating neurodegenerative diseases, in particular Alzheimer's, as well as on the progress made in joint programming, therefore, the Council is called upon to adopt the conclusions in the annex.

**DRAFT COUNCIL CONCLUSIONS****CONCERNING THE JOINT PROGRAMMING OF RESEARCH IN EUROPE**

THE COUNCIL OF THE EUROPEAN UNION,

RECALLING

- The Commission Green paper of 4 April 2007, entitled "The European Research Area: New Perspectives"<sup>1</sup> in which one of the core objective was to ensure the coherence of national and regional research programmes and priorities on issues of European major societal challenges or opportunities relevant to all or many countries which require a new approach as regards research efforts beyond individual national capacity;
- Its Key Issues Paper (KIP) of 25 February 2008<sup>2</sup>, in which the Member States and the Commission were encouraged to continue developing initiatives for joint programming of research in areas suited to such an approach, allowing a more strategic and better structured approach to the launch of new joint programmes and common calls for projects;
- The conclusions of the European Council of 13 and 14 March 2008<sup>3</sup>, which launched the new cycle of the Lisbon strategy for growth and jobs (2008-2010) and which, with the aim of fully developing the potential for innovation and creativity of European citizens, confirmed that particular attention should be given to further initiatives for joint programming of research;

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<sup>1</sup> 8322/07.

<sup>2</sup> 6933/08.

<sup>3</sup> 7652/1/08 REV 1.

- The Commission communication of 15 July 2008, entitled "Towards joint programming in research: Working together to tackle common challenges more effectively"<sup>4</sup>, which called for the implementation of a process led by the Member States to step up their cooperation in the R&D area in order to better confront major societal challenges of European or worldwide scale, where public research plays a key role.
- Its conclusions of 26 September 2008, entitled "A common commitment by the Member States to combat neurodegenerative diseases, particularly Alzheimer's"<sup>5</sup>, which recognised that R&D activities relating to Alzheimer's disease constitute a good example for testing innovative ways of pooling national expertise and resources on a voluntary basis as part of joint Europe-wide goals, and invited the Member States and the Commission to create a forum with a view to bringing together key players in European research, to take account of existing national plans to fight Alzheimer's disease and to explore proposals for a commitment by Member States to establish closer and stronger collaboration in this respect.
- Its conclusions of 2 December 2008 concerning joint programming of research in Europe in response to major societal challenges<sup>6</sup>, which established a dedicated configuration of CREST, the High Level Group for Joint Programming (GPC), with a view to identifying and substantiating the first list of a limited number of joint programming themes. In addition, it recognised neurodegenerative diseases as an area where Joint Programming would provide a major added value to the current, fragmented efforts of Member States in the field of research, and the necessity to launch a pilot Joint Programming Initiative on combating those diseases, in particular Alzheimer's disease, and invited the Commission to submit a proposal in preparation for its launch as soon as possible in 2009.

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<sup>4</sup> 11935/08.

<sup>5</sup> 13668/08.

<sup>6</sup> 16775/08.

**a) THE LAUNCH OF THE PILOT JOINT PROGRAMMING INITIATIVE ON COMBATING NEURODEGENERATIVE DISEASES, IN PARTICULAR ALZHEIMER'S**

1. TAKES NOTE that the number of people suffering from neurodegenerative diseases in Europe is estimated to be 8.6<sup>7</sup> million with Alzheimer's accounting for vast majority of these cases. Moreover, STRESSES that neurodegenerative diseases represent one of the main causes of disabilities of the elderly, and that the number of people suffering from these diseases is expected to rise drastically by 2020, due to the increased life expectancy and a decreasing ratio of working to retired populations;
2. Due to the fact that this will lead to a greater burden on patients, their families and caregivers and pose substantial challenges ahead for Member States' healthcare systems in terms of costs and organisation, ACKNOWLEDGES that Member States have recognised the need to adopt specific national plans and strategies for Alzheimer's disease and related disorders in order to alleviate the burden on society in general and on healthcare systems.
3. RECOGNISES, there is a growing awareness that the impact of neurodegenerative diseases on the population in Europe is of such a magnitude that no Member State is capable of resolving it alone. Member States would therefore benefit from coordinating their actions to develop a stronger, better coordinated and more effective response at the European level.

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<sup>7</sup> Number of European patients affected by the four most prevalent neurodegenerative diseases (Alzheimer's disease, Parkinson's disease, Amyotrophic Lateral Sclerosis, and Huntington's disease).  
Sources: AD: [http://ec.europa.eu/health/ph\\_information/dissemination/echi/docs/dementia2\\_en.pdf](http://ec.europa.eu/health/ph_information/dissemination/echi/docs/dementia2_en.pdf); PD: Von Campenhausen S. et al, European neuropsychopharmacology 2005, vol. 15, no 4, pp. 473-490; ALS: Orphanet web site: <http://www.orpha.net/consor/cgi-bin/index.php>; and Logroscino G et al, J Neurol Neurosurg Psychiatry 2009 Aug 25 [E-pub ahead of print]; HD: Orphanet web site: <http://www.orpha.net/consor/cgi-bin/index.php>.

4. WELCOMES the Commission communication on a European initiative on Alzheimer's disease and other dementias<sup>8</sup> and the recommendations by the Commission on the launch of the Joint Programming Initiative (JPI) on combating neurodegenerative diseases, in particular Alzheimer's<sup>9</sup>, and, on this basis, EMPHASISES that Joint Programming in research on neurodegenerative diseases will contribute to the reduction of fragmentation of research efforts of Member States in this field and encourage the pooling of skills, knowledge and resources, with a view to advancing research on the prevention, diagnosis and treatment and to alleviating the burden of neurodegenerative diseases on patients, their carers and society. In this context, also INVITES the Commission to offer support in the implementation of this initiative and avoid duplication in implementing the Framework Programme;
5. INVITES the Member States to:
- i. Develop a common vision, based on a multidisciplinary approach, on how cooperation and coordination in the field of research at the European level can improve knowledge, prevention, diagnosis and treatment of neurodegenerative diseases, in particular Alzheimer's, in order to ensure the efficiency of the joint efforts of Member States in fighting neurodegenerative diseases.
  - ii. Develop a Strategic Research Agenda (SRA) establishing medium to long term research needs and objectives in the area of neurodegenerative diseases, in particular Alzheimer's. The strategic research agenda should be further developed towards an implementation plan establishing priorities and timelines and specifying the actions, instruments and resources required for its implementation.

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<sup>8</sup> 12392/09.

<sup>9</sup> 12382/09.

ii.1. The following actions could be considered, subject to the needs of the Strategic Research Agenda, as part of an implementation plan:

- (a) identify and exchange information on relevant national programmes and research activities;
- (b) reinforce joint foresight and technology assessment capacities at the level of basic, medical, health and social services research;
- (c) identify areas or research activities that would benefit from coordination or joint calls for proposals or pooling of resources in areas such as the development of new prevention and treatment strategies, new imaging technologies and biomarkers;
- (d) exchange information resources and best practices in areas such as the comparison of healthcare systems, including long term care and informal care settings;
- (e) define the modalities for research to be undertaken jointly in the areas identified above;
- (f) share, where appropriate, existing research studies and infrastructures or develop new ones in areas such as coordinated registries, biobanks for blood samples and tissues or the development of animal models for the study of these diseases;
- (g) development of new diagnostic tools particularly for early diagnosis;
- (h) network centres dedicated to research on neurodegenerative diseases in areas such as clinical trials, standardisation of diagnostic criteria and diagnostic instruments;

- (i) as appropriate, involve representatives of patient and care organisations and healthcare providers in this pilot initiative, including stakeholders from the private sector;
- (j) identify effective measures to ensure the optimum dissemination and the use of research findings.

- iii. Actively support the work of the newly established management structure in the field of neurodegenerative diseases, in particular Alzheimer's disease, mandated to establish common conditions, rules and procedures for cooperation and coordination and to monitor the implementation of the strategic research agenda.
- iv. Jointly implement the SRA, including through their national research programmes or other national research activities.
- v. Cooperate with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda.

6. INVITES the Commission to:

- i. Act as a facilitator by providing ad-hoc and complementary measures to support the pilot Joint Programming initiative. Those measures should include support to the management structure and the establishment of the strategic research agenda, the provision of data, information and analysis on the state of the art in this field in Member States and at European level.
- ii. Explore how best to contribute with complementary measures to the strategic research agenda and to its implementation plan via EU funding instruments.

- iii Look into possible forms of consultation and cooperation on this subject with scientifically-advanced groupings at international level.
- iv. Regularly report to the Council and the European Parliament on the progress and results of this JPI.

**b) PROGRESS IN JOINT PROGRAMMING AND THE WAY AHEAD**

1. WELCOMES the progress made in the High Level Group on Joint Programming (GPC) by identifying and substantiating the first wave of themes for JPIs with a view to the adoption of JPIs by the Council in due time. These are the following three themes:
  - Agriculture, food security and climate change
  - Health, food and prevention of diet related diseases
  - Cultural heritage, climate change and security;
2. STRESSES the importance of further continued process of the identification of JPI themes within the GPC, and, in this context, ENCOURAGES Member States to continue with the joint efforts to identify common and concerted responses to societal challenges on other themes as well as to work on the framework conditions during the development and implementation of JPIs;
3. REAFFIRMS that joint programming is a process led by Member States, with the Commission acting as a facilitator, and EMPHASISES that this should be reflected in the decision-making process in preparation of the launch of joint programming;

4. In this context, AGREES, in relation to Council conclusions concerning joint programming for research in Europe in response to major societal challenges<sup>10</sup>, on the new modalities as regards the decision-making process to launch joint programming initiatives, and, therefore, INVITES the Commission, within the remit of its competence, to contribute to the preparation of the joint programming initiatives which correspond to the themes identified and substantiated by the GPC, together with the state of play of research in the field of each of these themes, on the basis of which the Council will agree on joint programming initiatives.
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<sup>10</sup> 16775/08.