Basic information

2009/0113(CNS) CNS - Consultation procedure Recommendation	Procedure lapsed or withdrawn
Joint programming of research activities: measures to combat neurodegenerative diseases, in particular Alzheimer's **Subject** 3.50 Research and technological development and space 3.50.01 European research area and policy 4.20.01 Medicine, diseases 4.20.02 Medical research	

Key players

Council of the European Union	**Council configuration**	**Meetings**	**Date**
	Competitiveness (Internal Market, Industry, Research and Space)	2982	2009-12-03
	Competitiveness (Internal Market, Industry, Research and Space)	2963	2009-09-24
European Commission	**Commission DG**	**Commissioner**	
	Research and Innovation	POTOČNIK Janez	

Key events

Date	Event	Reference	Summary
22/07/2009	Legislative proposal published	COM(2009)0379	Summary
24/09/2009	Debate in Council		
03/12/2009	Resolution/conclusions adopted by Council		Summary

Technical information

Procedure reference	2009/0113(CNS)
Procedure type	CNS - Consultation procedure
Procedure subtype	Legislation
Legislative instrument	Recommendation
Legal basis	Treaty on the Functioning of the European Union TFEU 181
Stage reached in procedure	Procedure lapsed or withdrawn

Documentation gateway

European Commission			
Document type	**Reference**	**Date**	**Summary**
Legislative proposal	COM(2009)0379	22/07/2009	Summary
Document attached to the procedure	SEC(2009)1039	22/07/2009	Summary

Additional information		
Source	**Document**	**Date**
National parliaments	IPEX	
European Commission	EUR-Lex	

Joint programming of research activities: measures to combat neurodegenerative diseases, in particular Alzheimer's

2009/0113(CNS) - 03/12/2009

The Council adopted **conclusions** welcoming the Commission communication on a European initiative on Alzheimer's disease and other dementias (see COM(2009)0380) and the recommendations by the Commission on the launch of the Joint Programming Initiative (JPI) on combating neurodegenerative diseases, in particular Alzheimer's.

On this basis, it 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, it also invites the Commission to offer support in the implementation of this initiative and avoid duplication in implementing the Framework Programme.

Member States are invited to:

1) 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.

2) Develop a Strategic Research Agenda 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 action, instruments and resources required for its implementation.

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

- identify and exchange information on relevant national programmes and research activities;
- reinforce joint foresight and technology assessment capacities at the level of basic, medical, health and social services research;
- 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;
- exchange information resources and best practices in areas such as the comparison of healthcare systems, including long term care and informal care settings;
- define the modalities for research to be undertaken jointly in the areas identified above;
- 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;
- development of new diagnostic tools particularly for early diagnosis;

- network centres dedicated to research on neurodegenerative diseases in areas such as clinical trials, standardisation of diagnostic criteria and diagnostic instruments;
- as appropriate, involve representatives of patient and care organisations and healthcare providers in this pilot initiative, including stakeholders from the private sector;
- identify effective measures to ensure the optimum dissemination and the use of research findings.

3) 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.

4) Jointly implement the Strategic Research Area, including through their national research programmes or other national research activities.

5) Cooperate with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda.

The Commission is invited to:

- 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;
- explore how best to contribute with complementary measures to the strategic research agenda and to its implementation plan via EU funding instruments;
- look into possible forms of consultation and cooperation on this subject with scientifically-advanced groupings at international level;
- regularly report to the Council and the European Parliament on the progress and results of this Joint Programme Initiative.

Joint programming of research activities: measures to combat neurodegenerative diseases, in particular Alzheimer's

2009/0113(CNS) - 22/07/2009 - Document attached to the procedure

In September 2008, the Competitiveness Council recognised the major societal impact of neurodegenerative diseases (ND), and in particular Alzheimer's disease (AD), in the context of an ageing society and adopted conclusions recommending the launching of a common European initiative in this field by bringing together Member States, the Commission and other stakeholders. Stock taking of existing initiatives at national and European level in this field is necessary for streamlining the use of Europe's public R&D funds through enhanced cooperation and coordination between national public R&D programmes.

This Commission Staff Working Document has been prepared as a background paper to the Commission's proposal for a Council Recommendation on Joint Programming in research on neurodegenerative diseases, in particular Alzheimer's disease. With the aim of clarifying the context of this proposal and to document and justify the added value of a joint European action in this field, it provides a first non-exhaustive picture of research on neurodegenerative diseases, in particular Alzheimer's disease, which is currently carried out or planned across Europe.

This first analysis illustrates the significant diversity of the research landscape on neurodegenerative diseases in Europe, in many of its aspects such as levels of investments, funding mechanisms, public-private involvement, priority themes, topics and approaches, etc, but it also highlights the potential for complementarity of current actions and initiatives.

The information – even though not exhaustive – provides a set of elements which outlines the reasons why a joint European approach in this area could contribute to increase the effectiveness of research on neurodegenerative diseases in Europe, open the path to potential therapies to the benefit of affected individuals and their families, and help to establish the rationale for the proposed Recommendation.

Joint programming of research activities: measures to combat neurodegenerative diseases, in particular Alzheimer's

2009/0113(CNS) - 22/07/2009 - Legislative proposal

PURPOSE: to adopt a common approach at European level through joint programming in research on neurodegenerative diseases, in particular Alzheimer's Disease.

PROPOSED ACT: Council Recommendation.

BACKGROUND: neurodegenerative diseases are hereditary or sporadic conditions which are characterised by progressive nervous system dysfunction. They are a heterogeneous group of age-associated, chronic illnesses of varying aetiologies. Alzheimer's Disease is the most prevalent neurodegenerative diseases, accounting for around 50 -70 % of all dementias, followed by Parkinson's disease. Around 7.3 million people are

estimated to suffer from Alzheimer's Disease and related disorders in Europe, a figure that is expected to double by 2020. Alzheimer's Disease is a devastating disorder for the patients themselves and a very heavy burden is placed on the shoulders of the patients' relatives. Family carers are often old and frail, with high levels of depression and physical illness. As a consequence, Alzheimer's Disease is extremely costly for society as a whole. It is estimated that the total direct and informal care costs of Alzheimer's and other dementias in 2005 amounted to EUR 130 billion for EU-27, 56 % of costs were for informal care. The proposal notes that a substantial research effort is needed. In 2008, the Council adopted conclusions recommending that a common European initiative be launched in this field through a joint programming approach.

CONTENT: the Recommendation **invites Member States** to develop a common vision on how cooperation and coordination in the field of research at the European level can improve prevention, diagnosis and treatment of neurodegenerative diseases, in particular Alzheimer's. Member States are asked to develop a **strategic research agenda** establishing medium to long term research needs and objectives in the area of neurodegenerative diseases, in particular Alzheimer's. The strategic research agenda should contain **an implementation plan establishing priorities and timelines** and specifying the actions, instruments and resources required for its implementation.

It is recommended that **certain actions should be undertaken as part of the implementation plan**. These include:

- identify and exchange information on relevant national programmes and research activities;
- reinforce joint foresight and technology assessment capacities at the level of basic, medical, health and social services research;
- identify research activities that would benefit from coordination or pooling of resources in areas such as the development of new prevention and treatment strategies, new imaging technologies and biomarkers;
- exchange information resources and best practices in areas such as the comparison of healthcare systems, including long term care and informal care settings;
- share existing research 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;
- network centres dedicated to research on neurodegenerative diseases in areas such as clinical trials, and diagnostic instruments;
- set up a common management structure in the field of neurodegenerative diseases, in particular Alzheimer's disease, mandated to establish common conditions, rules and procedures for cooperation and to monitor the implementation of the strategic research agenda;
- cooperate with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing the common research agenda.

The Commission is invited to provide 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. The Commission is also asked to explore how best to contribute with complementary measures to the strategic research agenda and to its implementation plan via Community funding instruments, and to look into possible forms of consultation and cooperation on this subject with scientifically-advanced groupings at international level.