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.