Basic information

2010/2084(INI) INI - Own-initiative procedure	Procedure completed
European initiative on Alzheimer's disease and other dementias **Subject** 4.20.01 Medicine, diseases 4.20.02 Medical research	

Key players

European Parliament

Committee responsible	Rapporteur	Appointed
ENVI Environment, Public Health and Food Safety	MATIAS Marisa (GUE/NGL)	18/05/2010
	Shadow rapporteur ANTONESCU Elena Oana (PPE) CHILDERS Nessa (S&D) RIES Frédérique (ALDE) HASSI Satu (Verts/ALE) YANNAKOUDAKIS Marina (ECR)	

Committee for opinion	Rapporteur for opinion	Appointed
ITRE Industry, Research and Energy	The committee decided not to give an opinion.	

European Commission

Commission DG	Commissioner
Health and Food Safety	DALLI John

Key events

Date	Event	Reference	Summary
22/07/2009	Non-legislative basic document published	COM(2009)0380	Summary
17/06/2010	Committee referral announced in Parliament		
30/11/2010	Vote in committee		Summary

09/12/2010	Committee report tabled for plenary	A7-0366/2010	
18/01/2011	Debate in Parliament		
19/01/2011	Decision by Parliament	T7-0016/2011	Summary
19/01/2011	Results of vote in Parliament		
19/01/2011	End of procedure in Parliament		

Technical information	
Procedure reference	2010/2084(INI)
Procedure type	INI - Own-initiative procedure
Procedure subtype	Initiative
Legal basis	Rules of Procedure EP 55
Other legal basis	Rules of Procedure EP 165
Stage reached in procedure	Procedure completed
Committee dossier	ENVI/7/01154

Documentation gateway

European Parliament

Document type	Committee	Reference	Date	Summary
Committee draft report		PE445.928	30/09/2010	
Amendments tabled in committee		PE452.652	11/11/2010	
Committee report tabled for plenary, single reading		A7-0366/2010	09/12/2010	
Text adopted by Parliament, single reading		T7-0016/2011	19/01/2011	Summary

European Commission

Document type	Reference	Date	Summary
Non-legislative basic document	COM(2009)0380	22/07/2009	Summary
Commission response to text adopted in plenary	SP(2011)2858	17/06/2011	
Commission working document (SWD)	SWD(2014)0321	16/10/2014	

European initiative on Alzheimer's disease and other dementias

2010/2084(INI) - 19/01/2011 - Text adopted by Parliament, single reading

The European Parliament adopted by 646 votes to 6, with 6 abstentions, a resolution on a European initiative on Alzheimer's disease and other dementias.

Parliament recalls that it is estimated that 35.6 million people worldwide will suffer from dementia in all its forms in 2010, and that this number is estimated to nearly double every 20 years, possibly reaching 65.7 million in 2030. The number of people suffering from dementia in Europe is

estimated to be 9.9 million, with Alzheimer's accounting for the vast majority of these. Europe accounts for over 28 % of the total number of persons suffering from dementia, placing it second only to Asia (with 35 %), while of all the world's regions western Europe has the highest proportion of sufferers (19 %).

According to certain estimates, the total direct medical and social care costs of Alzheimer's disease in Europe amount to USD 135.04 billion.

In this context, Parliament calls on the Council to **declare dementia to be an EU health priority**.

Welcoming the EU Joint Programming initiative promoted by the Member States in order to boost research on Alzheimer's and other neurodegenerative diseases, Members encourage the Commission to continue launching activities to tackle health-related, social, technological, and environmental challenges for the treatment of Alzheimer's and other neurodegenerative diseases.

Parliament calls on the Council and the Commission for the following measures:

As regards awareness raising:

- consider launching a European Year of Mental Health, complementing World Alzheimer's Day on 21 September;
- recognise the role of patients' associations in the area of neurodegenerative diseases and to involve them in information and prevention campaigns and support measures for dementia sufferers and in the preparation of research programmes;
- consider promoting a 'Carers Day' to raise awareness of and recognise the crucial role of formal and informal carers across Europe;
- raise public awareness in the Union concerning dementia, facilitating recognition of the early symptoms of dementia with a view to early diagnosis and the corresponding treatment and appropriate support.

On the issue of prevention:Parliament notesthat at present there is no specific policy on the prevention of Alzheimer's disease, and calls, therefore, for the establishment of such a policy, including at European level, to be based on the need to maintain an environment conducive to patients' physical and intellectual activity and a **diet** consistent with that recommended by the European Platform for Action on Diet, Physical Activity and Health and on the promotion of all policies to reduce smoking, both active and passive. They also call for:

- account to be taken of the concept of dementia when preparing future actions in the area of preventive health policy;
- early diagnostic tests to be carried out and for large-scale epidemiological and clinical studies on the basis of transnational cooperation to be conducted.

Parliament points out that (a) the increasingly ageing population and b) the mounting pressure on public finances and private productivity due to increased expenses for this ageing population will create a structural problem for the Member States. The European Union should therefore adopt in its long-term strategy the policy of firm promotion of the principle of prevention (in terms of medical practices as well as in terms of encouraging healthier lifestyles). Health indicators will contribute to significant improvement of the economic indicators.

Amongst the **proposed national actions**, Parliament outlines the following:

- the definition, development and implementation of common protocols for early diagnosis, to establish biomarkers with a view to building on the emergence of new therapies for both dementia and pre-dementia,and to define a common research agenda in the field of neurodegenerative diseases;
- the availability of **drugs** able to slow the onset of Alzheimer's to all patients suffering from the disease and not only patients who are diagnosed with severe cases of Alzheimer's;
- the setting up of **specialist centres** and to provide satisfactory medical equipment (including magnetic resonance imaging, whose contribution to dementia research is indisputable) nationwide;
- the development of policies for facilitating access to research funding in the field of dementia and Alzheimer's;
- the development of long-term policies and action plans in the field of care and prevention which anticipate and address social and demographic trends,
- the development of action plans aimed at improving the well-being and quality of life of patients suffering from Alzheimer's and other dementias, and that of their families;
- strengthened cooperation with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda;
- the development of action plans aimed at improving the well-being and quality of life of patients suffering from Alzheimer's and other dementias, and that of their families;
- drawing up common guidelines for the training of staff who work in whatever capacity with Alzheimer's patients (medical and paramedical professions);
- the development of healthcare and social services with the core principle of maximising coverage and ensuring equity of access and equality;
- the development of healthcare and social services with the core principle of maximising coverage and ensuring equity of access and equality in general;
- the development of personalised pathways for multiprofessional and multidisciplinary care and support coordinated by a single reference person from the moment the diagnosis is notified;
- the development of diverse, innovative and high-quality facilities to offer respite to carers, such as accommodation and temporary reception centres;
- the promotion, on a voluntary basis, the practice of free memory screenings for those population groups that according to scientific data have a high risk of developing Alzheimer's disease or other dementia illnesses.

Overall, the resolution calls for the setting up of measures to strengthen research, improving access to diagnosis and access to drugs (notably for new treatments). Member States are urged to improve public and professional awareness of dementia among healthcare skilled/semiskilled professionals, healthcare policy makers and media. Parliament stresses the importance of preventing Alzheimer's disease by encouraging a **healthy lifestyle**.

On a research basis, Parliament points to the importance of research into the connection as well as the distinction between the ageing process and dementia, between dementia and depression in older people, and between gender differences and the various types of dementia. It encourages the Member States, furthermore, to promote specific healthcare and research programmes that give great importance to patient choice and perspective, and to formulate recommendations centered on the core principles of dignity and social inclusion, thereby promoting the autonomy and self determination of patients.

Parliament underlines that research in health economies, social science and humanities, and non-pharmacological approaches is also needed to understand the psychological and social aspects of dementia.

On the issue of **early detection**, Parliament encourages all the Member States to engage actively in the definition, development and implementation of common protocols for early diagnosis. It points to the importance of a multidisciplinary approach to ways in which cooperation and coordination in the field of research at European level can improve knowledge, diagnosis, treatment, prevention, and social research into the welfare of patients and their families and carers. It regards early diagnostic tests, research into risk factors and early diagnosis criteria as crucial.

On a budgetary level, Parliament recognises the current importance of the European Union's support, totalling EUR 159 million and considers it essential, in the context of the forthcoming 8th RDFP, to address the fragmented nature of research, particularly that on Alzheimer's. It calls on the Member States to devote suitable resources to healthcare for Alzheimer's patients. Members emphasise the scale of the medical costs entailed by Alzheimer's disease and other dementias and that it is important to find viable solutions which take into account: the direct medical costs (comprising health system costs: specialist costs, medicinal products, medical examinations and regular check-ups); the direct social costs (comprising the cost of formal services outside the medical system: community services, home care, provision of food, transport, and placement of patients in specialist residential centres for the care of the elderly, where they can receive medical assistance); and informal costs (comprising the costs associated with reduced productivity in the event of a prolongation of working life, and loss of output as a result of early retirement, leave for medical reasons or death).

Members call on the Commission, the Council and Member States to take into account the specific needs of women, who account for twice the number of sufferers and a disproportionate number of carers.

The resolution stresses the importance of **home help for patients** and for the elderly, and the vital contribution made by non-profit and voluntary organisations in the care of Alzheimer's patients and those suffering from other age-related diseases. It encourages the Member States to create forms of partnership with those organisations and support for their activities. Parliament calls on the Member States, in addition, to give due credit and recognition to the role played by the **informal care** provided by the relatives of those suffering from these diseases. Parliament emphasises that the dignity of people with Alzheimer's needs to be preserved and the stigma and discrimination against them needs to be eliminated.

Members call for recognition of **Alzheimer associations** as prime partners and for them to be involved in: (1) defining prevention recommendations and best practices and disseminating these at grass-root level; (2) providing much needed information and support to people with dementia and their carers; (3) presenting the needs of people with dementia and their carers to policy makers; (4) fostering partnerships with the medical profession to provide a holistic approach.

Lastly, the Council, the Commission and the Member States are called upon, in conjunction with Parliament, to foster the autonomy of persons with dementia and promote their dignity and social inclusion through the action plan in the field of health.

European initiative on Alzheimer's disease and other dementias

2010/2084(INI) - 22/07/2009 - Non-legislative basic document

PURPOSE: to propose a European initiative on Alzheimer's disease and other dementias

BACKGROUND: dementia is a decline in mental ability that usually develops slowly, causing impaired memory, thinking and judgement, and personality may deteriorate. It predominantly affects those aged over 60. The best available estimates indicate that, in 2006, 7.3 million Europeans between 30 and 99 years of age were suffering from different types of dementia (12.5 per 1 000 inhabitants). Within this group, more women (4.9 million) than men (2.4 million) are affected. With the increase in life expectancy, dementia's incidence has increased dramatically and some current forecasts project a doubling of the number of persons affected every 20 years. The total direct and informal care costs of Alzheimer's disease and other dementias in 2005 amounted to EUR 130 billion for the EU 27 region (EUR 21 000 per patient/year); 56% of costs were generated by informal care. However, Alzheimer's disease remains under-diagnosed in the EU. According to the available epidemiological data, only half of those suffering from the disease are currently identified.

The objective of this Communication is to set out actions providing support to Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for Alzheimer's disease and other dementias in Europe. For this a Joint Action between the European Commission and the Member States as defined in the Work Plan for the implementation of the Second Health Programme (2008-2013) will be launched in 2010. This will in turn contribute to the overarching goal - an improvement in health outcomes, and therefore a growth in Healthy Life Years, a key Lisbon Strategy indicator.

CONTENT: there are four key issues that Community action could help to address:

- people can act to help prevent dementia, especially vascular dementia and in some extent also Alzheimer's disease. Early diagnosis can ensure that interventions take place while they are most effective. However, there is a lack of awareness of the importance of prevention and early intervention;
- there is a clear need for improved understanding of dementias, in particular of Alzheimer's disease and other neurodegenerative types. Yet there is very limited coordination of research, an issue with particular potential for European added value, and a lack of sufficient epidemiological data to help direct research and action in the future;

- there are good practices emerging in different places across the EU with regard to diagnosis, treatment and financing of therapies for these conditions, but they are not being shared throughout the Union. This is all the more important given that the EU is confronted with staff shortages of formal carers, and problems stemming from a lack of support for informal carers;
- insufficient attention is being paid to rights of people suffering from a cognitive deficit. There is also a lack of recognition of the mental capital of older people, lack of understanding by the general public of what Alzheimer's disease is, and a stigma associated with dementias that can influence the health of these patients.

Community action

Acting early to diagnose dementia and to promote well-being with age: promoting good physical and mental health (e.g. developing a healthy cardiovascular system, encouraging education and learning throughout life) can help to avoid cognitive decline leading to dementia. Furthermore, there is growing evidence that mental activity and stimulation (through lifelong learning as well as through social interactions) reduces the risk of developing dementia. The Commission proposes the following actions:

- to incorporate the 'dementia dimension' into the EU's ongoing and future actions on health prevention, especially those related to cardiovascular health and physical activity;
- to produce a set of recommendations, which would help citizens to prevent dementia diseases;
- to include the 'dementia dimension' in flexible European policies on retirement and in the framework for action on older people in the European Pact for Mental Health and Wellbeing. of 13 June 2008.

A shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research. Reliable prevalence and incidence data on dementias are essential if Member States are to be able to make appropriate provision. The Commission proposes:

- to improve epidemiological data on Alzheimer's disease and other dementias, implementing the conclusions of the European Collaboration on Dementia (EuroCoDe)" Project;
- to use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive deficiencies;
- to adopt a proposal for a Council Recommendation on a pilot Joint Programming initiative on combating neurodegenerative diseases as a pilot, in particular Alzheimer's disease. The purpose of this Recommendation is to develop a new approach, through cooperation and collaboration between national research programmes, for more effectively tackling common European challenges in the area of neurodegenerative diseases, hence making better use of Europe's limited public R&D funds.

Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering dementia: the Commission proposes:

- -to map good practices related to treatment and care for persons suffering from Alzheimer's disease and other forms of dementia and to improve the dissemination and application of such practices (using, when possible, the Structural Funds);
- to develop, by means of the Open Method of Coordination, quality frameworks for medical and care services for people with dementias;
- to use facilities provided for in the EU Disability Action Plan (DAP) 2003-2010 to support patients' organisations.

Respecting the rights of people with dementias: the image of Alzheimer's disease and other dementias in European society is a negative one, often associated with fear and helplessness that can influence the health of these patients. The Commission proposes to:

- establish, using the facilities provided by the Health Programme, a European Network for rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable adults and tackling patient abuse.

The Commission will use the different **legal instruments** at its disposal (Health Programme, FP7, EU Disability Action, Open Method of Coordination and Statistical Programme) in an integrated way that permits a high level of efficiency and coordination, and optimum use of resources. Community action can help to support the Member States in addressing the issue of dementias as European society ages, but success in meeting this challenge will mostly depend on the primary role of Member States and civil society.

The Commission will also support World Alzheimer's Day (21 September) through European and national initiatives, and will also foster cooperation at an international level with all interested countries and in close collaboration with the World Health Organisation. International cooperation is already an integral part of the Framework Programmes for Research.

Next steps: the Commission will produce by 2013 an implementation report on this Communication at the end of the Joint Action between the European Commission and the Member States implementing the actions of this Communication.