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COMMISSION STAFF WORKING DOCUMENT

**Implementation report on the Commission Communication on a European initiative on
Alzheimer's disease and other dementias**

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This document is a European Commission staff working document for information purposes. It does not represent an official position of the Commission on this issue, nor does it anticipate such a position.

1. Introduction

In July 2009, the Commission presented its Communication on a ‘European initiative on Alzheimer’s disease and other dementias¹’ (hereafter "the Communication"). The overall goal of this document was 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’. The Communication defined four strategic objectives for EU action and Member State cooperation:

- 1) Acting early to diagnose dementia and promote well-being with age;
- 2) A shared European effort to better understand dementia conditions: Improving epidemiological knowledge and coordination of research;
- 3) Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering dementia;
- 4) Respecting the rights of people with dementia.

This paper responds to the Commission's announcement in the Communication to produce an implementation report.

The report presents the key activities that have taken place since 2009 and summarises their main achievements. A wide range of activities have been implemented as part of the strategy, in the context of EU-health policy and of other EU-policy areas. The activities presented in this report include, among others, the Joint Action Alzheimer Cooperative Valuation in Europe (ALCOVE) (hereafter "Joint Action ALCOVE").

The Joint Action ALCOVE was a collaboration on dementia, implemented between 2011 and 2013 and co-financed by the EU Health Programme 2008-2013 and the participating Member States. The Joint Action was led by France (Haute Autorité de Santé) and involved 30 partners from 19 EU Member States). Through its work, the Joint Action ALCOVE has added upon existing knowledge and promoted the exchange of information on dementia in order to preserve the health, quality of life, autonomy, and dignity of people living with dementia and their caregivers in EU Member States². The results of the Joint Action were presented at its Final Conference on 28 March 2013 in Paris. They are available at: <http://www.alcove-project.eu/>

Besides the Joint Action ALCOVE, the report presents a number of further key activities that were linked to the strategy or contributed to its implementation, such as the European

¹ “Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer’s disease and other dementias.” Commission of the European Communities, 22 Jul. 2009. COM(2009) 380 final. Web. 20 May 2014. <http://ec.europa.eu/health/archive/ph_information/dissemination/documents/com2009_380_en.pdf>.

² ALCOVE included four thematic work packages: Epidemiological data on dementia (led by Italy); Timely diagnosis of dementia (United Kingdom); Support systems for behavioural and psychological symptoms of dementia (BPSD) (Finland); Rights, autonomy and dignity of people living with dementia (Belgium).

Innovation Partnership on Active and Healthy Ageing, EU-level activities in the fields of research (including the Joint Programming Initiative on Neurodegenerative Diseases [JPND]), eHealth, long-term care, and health statistics.

In order to give evidence about the extent to which the strategy has supported developments at national level, the report summarises the findings from a survey among the Member States. The report also refers to the initiative of the G8-Group to start up a “Global action against Dementia”, in which the Commission has been involved through its participation in the Summit of Ministers of Health launching the process in December 2013³ and the following series of high-level forums. In its final section, the report provides an outlook on a number of forthcoming Commission activities on dementia.

2. The implementation activities and their key achievements

2.1. Acting early to diagnose dementia and promote well-being with age

2.1.1. Early and timely diagnosis of dementia

A key concern underlying the Communication was that many people suffering from dementia never receive a diagnosis. In addition, where a diagnosis is made, it is frequently late in the course of the disease when clinical signs have progressed and daily activities, cognition, relationships and quality of life are already significantly challenged.

Activities and findings of the Joint Action ALCOVE

The Joint Action work package ‘Timely diagnosis of dementia’ found that many factors contribute to delays in diagnoses, including the stigma around dementia and the availability of diagnostic services and of interventions and support following diagnosis. Many countries report that up to 40% - 60% of dementia cases may be currently going undiagnosed and cite inadequate training of General Practitioners in diagnosing dementia and recognising its early symptoms as part of the problem. It is highly advisable to seek an early medical assessment when cognitive changes take place because many conditions can cause people to experience confusion and loss of memory and many of these conditions are treatable. On the other hand, undergoing an assessment for dementia predisposes the person and their family to face both fears concerning the disease and the fear of being stigmatised for having it.

Therefore, the Joint Action work package proposed that early diagnosis should also be timely diagnosis, occurring at a point when the person and their family are ready to undergo assessment. Based on this recommendation, the work package developed five different

³ UK G8 Dementia Summit of Health Ministers, 10-11 December 2013. More information under: <http://dementiachallenge.dh.gov.uk/category/g8-dementia-summit/>

strategy models, which explain how health policy can plan and benchmark service provision for the diagnosis of dementia at local or national levels.

EU-level work to improve diagnosis

The European Commission's Joint Research Centre (JRC) supported corresponding initiatives by professional organisations and Member States by developing quality assurance tools for enabling reliable measurements for the diagnosis of Alzheimer's disease. The JRC started in 2013 with the development of reference materials, in co-operation with the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) and the Alzheimer Association, e.g. for a peptide biomarker in cerebrospinal fluid of potential patients, aiming to support earlier diagnosis based on reliable measurement data. In addition, as part of its work on the role of nutrition in active and healthy ageing, the JRC considered the role of dietary components in the progression of cognitive decline and dementia⁴. An ongoing feasibility analysis on dietary recommendations for the elderly population may add further to this point.

Furthermore, the Innovative Medicines Initiative (IMI) Joint Undertaking, a public-private partnership between the EU and the pharmaceutical industry, published a call for proposals in December 2013, including the topic 'European platform to facilitate proof-of-concept for prevention of Alzheimer's Disease' (EPOC-AD) with dedicated funding of EUR 25 million from the EU and EUR 28 million of in-kind contribution from industry. The goal is to enable rapid cycling of learning from registries and longitudinal cohorts into adaptive clinical trials that shorten timelines, improve efficiencies and permit more rapid dissemination of knowledge.

2.1.2. Promoting well-being with age

The Communication underlined that health promotion and disease prevention, as well as the adoption of a "healthy brain lifestyle", can help to avoid cognitive decline and in particular vascular dementia. The Communication also emphasised the importance of mental activity and stimulation and the important support that elderly people with cognitive problems and mild dementia, and also their caregivers, can get from ICT solutions (e-Health).

The European Innovation Partnership on Active and Healthy Ageing

Improving the quality of life of older people in the EU, including those suffering from cognitive decline, is one of the objectives of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA). The Partnership was launched in 2011⁵ with the overarching

⁴ Ning Mak T, Caldeira S., "The Role of Nutrition in Active and Healthy Ageing." European Commission, 2014. Web. 1 Aug. 2014. <<http://bookshop.europa.eu/en/the-role-of-nutrition-in-active-and-healthy-ageing-pbLBNA26666/>>.

⁵ "Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. Europe 2020, Flagship Initiative. Innovation Union." Com (2010) 546 Final. European Commission, 6 Oct. 2010. Web. 21 May 2014. <http://ec.europa.eu/research/innovation-union/pdf/innovation-union-communication_en.pdf>.

target to increase the average healthy life years of EU citizens by two years by 2020. It brings together key stakeholders in the innovation cycle (end users, public authorities, industry) in a forum in which they cooperate and coordinate their work for innovation in health.

The Partnership includes activity strands that aim to develop solutions for people living with dementia⁶. One of these strands deals with “prevention of frailty and cognitive decline”. Through their work, the partners involved have identified good practices on cognitive decline, on functional decline and on frailty in general⁷. This collaborative work suggests that innovative organisational approaches and technical solutions for evidence-based interventions that target frail older people can result in a more efficient use of resources⁸.

The second dementia-related theme of work under the Partnership is innovation for “age-friendly environments”. Here, the partners explored effective and sustainable ways of creating supportive environments for people living with dementia, which enable improvements in the quality of life and help people with dementia to remain independent for longer. The focus was on improvements in communities, care settings, and homes⁹.

The EIP AHA activities have also highlighted cross-cutting issues of user empowerment, namely empowerment of persons with dementia and their carers in the development of ICT solutions through methods of co-design¹⁰ and in the area of integrated care highlighting the importance of responding to the needs of Alzheimer’s disease patients by coordinating different levels of health and social care services around the needs of the patient in community and home care settings.¹¹

The European Pact for Mental Health and Well-being

Two thematic conferences, of which the first one addressed measures to promote social inclusion and to combat stigma in mental health¹² and the second one dealt with promoting

⁶ More information on examples of Activities on dementia within the European Innovation Partnership on Active and Healthy Ageing (2012-2015) can be found here:
http://ec.europa.eu/health/major_chronic_diseases/diseases/alzheimer/index_en.htm

⁷ These solutions focus on: the improvement of screening methods to detect dementia early; the identification of predicting factors of Alzheimer’s disease and other forms of dementia; testing of new drugs; diffusion of new ICTs to support ageing better with cognitive impairments and to improve screening and diagnostic tools; and training of dementia patients to maintain and improve neuro-psychological functions.

⁸ “A Compilation of Good Practices. Prevention and Early Diagnosis of Frailty and Functional Decline, Both Physical and Cognitive, in Older People.” European Commission, 2013. Web. 21 May 2014. <http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/gp_a3.pdf>.

⁹ “A Compilation of Good Practices. Innovation for Age-Friendly Buildings, Cities and Environments.” European Commission, 25 Nov. 2013. Web. 21 May 2014. <http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/gp_d4.pdf>.

¹⁰ http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/c2_action_plan.pdf

¹¹ http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/b3_action_plan.pdf#view=fit&pagemode=none_action_plan.pdf

¹² Thematic Conference supported by the Belgian Presidency of the EU “Promoting Social Inclusion and Combating Stigma for better Mental Health and Well-being”, Lisbon / Portugal, 8th - 9th November 2010, more information: http://ec.europa.eu/health/mental_health/events/ev_20101108_en.htm

the mental health of older people¹³, helped the “dementia integration” into the European Pact for Mental Health and Well-Being. The events brought together policy makers, professionals and research experts to discuss principles and examples of good practices in policies and practices in Europe. Building on the results of these two conferences, and of three further conferences, a Joint Action on Mental Health and Well-being¹⁴ was launched in 2013. Its objective is to develop a common framework of action on mental health and well-being by 2016.

e-Health

New digital technologies have a strong potential to help face the challenges linked to dementia and neurodegenerative disorders. Some examples of eHealth-solutions for people with dementia are wearable, portable or implantable devices which are linked to appropriate platforms and services and promote the interaction between patients and doctors. Where necessary, they can also facilitate self-treatment and cognitive behavioural therapy. Other solutions, in-silico, are based on computer modelling of the diseases and offer decision support for diagnosis and treatment.

Following the first eHealth Action Plan 2004 – 2012, the Commission adopted in 2012 the Communication ‘eHealth Action Plan 2012 – 2020 Innovative healthcare for the 21st century’. The action plan supports research, development and innovation in the field of neurodegenerative diseases and the wider mental health field. Interdisciplinary research addresses the parallel development of technological solutions and new management of treatment models based on closed-loop approaches¹⁵. The research projects under the Action Plan aim at:

- 1) Objective and quantitative assessment of symptoms, patient condition, effectiveness of therapy and use of medication;
- 2) Decision support for treatment planning;
- 3) Provision of warnings and motivating feedback.

Although the implementation of this Action Plan is still in an early phase, the deployment of telemedicine and other eHealth tools is steadily picking up. The substantial base of evidence supporting the potential of eHealth services and the growing political importance of health systems reform in the context of the ageing European population have elevated eHealth on the political agenda and have also raised expectations as to what it can deliver.

The implementation of the eHealth Action Plans includes the funding of projects from the ‘ICT for Health’ Programmes. By 2012, three projects, which focused on using ICTs for the

¹³ Thematic Conference supported by the Spanish Presidency of the EU “Mental Health and Well-being in Older People – Making it happen”, Madrid, 28-29 June 2010. More information about the conference is available under the link: http://ec.europa.eu/health/mental_health/events/ev_20100419_en.htm

¹⁴ <http://www.mentalhealthandwellbeing.eu/>

¹⁵ An approach where a management system is designed to feed outcomes from the processes back into the system to allow for future improvements and changes in a patient’s course of care.

cognitive training of older people, were completed¹⁶. Further projects have been launched. These address the fields of disease management, quality of life, cognitive training and social activation¹⁷. Finally, a number of further projects are supported in the computer-based Virtual Physiological Human (VPH) framework, which models and simulates diseases and develops ICT solutions for the early and differential diagnosis of Alzheimer's disease and other dementias¹⁸.

The key achievements on this objective:

- The development of recommendations on timely diagnosis and strategy models for service provision and benchmarking in this field (Joint Action ALCOVE).
- Sets of innovative good practices on “prevention and frailty and cognitive decline” and building “age-friendly communities” were identified (European Innovation Partnership on Active and Healthy Ageing);
- The “dementia dimension” was integrated in the European Pact for Mental Health and Well-being;
- Funding of eHealth-projects that developed ICT-based in-silico solutions for diagnosing people with dementia (eHealth Action Plans 2004-2012 and 2012-2020).

2.2. A shared European effort to better understand dementia conditions: Improving epidemiological knowledge and coordination of research

The Communication stressed that reliable prevalence and incidence data on dementias¹⁹ are essential if Member States are to be able to make appropriate plans and provisions. Furthermore, the Communication referred to EU-research efforts in the areas of brain and ageing research, and plans to promote coordination of public research efforts into neurodegenerative diseases in order to overcome their fragmentation by setting up a pilot Joint Programming initiative on neurodegenerative diseases.

2.2.1. Improving epidemiological knowledge

Implementation activities were, firstly, carried out through the Joint Action ALCOVE and, secondly, through EU-level work on health statistics.

¹⁶ SOCIABLE “What is SOCIABLE?” Sociable, n.d. Web. 21 May 2014. <http://www.cognitivetraining.eu/?q=about-us>; “About.” Long Lasting Memories, n.d. Web. 21 May 2014. <http://www.longlastingmemories.eu/?q=content/about>; AGNES Successful Ageing in a Networked Society.” Agnes, n.d. Web. 21 May 2014. <http://agnes-aal.eu/site>.

¹⁷ “What is VERVE?” Verve Consortium, n.d. Web. 21 May 2014. www.verveconsortium.eu; Dementia Ambient Care: Multi-Sensing Monitoring for Intelligent Remote Management and Decision Support.” Dem@Care, n.d. Web. 21 May 2014. www.demcare.eu.

¹⁸ “From patient data to personalised healthcare in Alzheimer's disease”. PredictAD, n.d. Web. 31 Jul. 2014. <<http://www.predictad.eu/>>; “ PredictND, n.d. Web. 31 Jul. 2014. <<http://www.predictnd.eu/> VPH-DARE@IT, n.d. Web. 21 May 2014. <http://www.vph-dare.eu/index.php/project>.

¹⁹ A presentation of EU-level health statistics data on dementia can be found here: http://ec.europa.eu/health/major_chronic_diseases/diseases/alzheimer/index_en.htm

Activities and findings of the Joint Action ALCOVE

The Joint Action work package ‘Epidemiological data on dementia’ evaluated peer-reviewed articles and performed a systematic review on prevalence rates for dementia in Europe, using the same terms that the EuroCoDe project (2006-2008)²⁰ had adopted for systematic reviews.

On the basis of the highest quality epidemiological studies, the ALCOVE report estimated a dementia prevalence rate of 7.23% in the population aged 65 years or older, corresponding to an estimated number of 6.37 million cases (EU-27 countries, 2011). This estimation was 22.1% lower than the earlier estimates from the EuroCoDe review (prevalence rate: 9.28%, 8.3 million cases). Based on this work, the Joint Action identified a set of recommendations for future data collections on estimates of the prevalence of dementias in Europe.

In addition, the Joint Action estimated that antipsychotics are prescribed for 35.6% of people with dementia residing in nursing homes (ranging between 25.8% in Norway to 60% in Italy), while antipsychotics are taken by an estimated 10.6% of the general elderly population. Here, values range from 5.7% in France to 32.5% in Finland. The United Kingdom, Sweden and France have carried out campaigns to reduce the exposure to antipsychotics in the population living with dementia. In the United Kingdom, for instance, the rate was reduced by 52% between 2008 and 2011²¹.

In conclusion, the Joint Action underlined that the overprescribing of antipsychotics for the behavioural disorders in dementia represents a major worldwide safety and ethical issue. Therefore, the Member States in the Joint Action ALCOVE developed a shared Toolbox for Antipsychotics Limitation in Dementia²².

EU-level work on public health statistics and dementia

The activities in the context of EU-public health statistics in the field of dementia were founded on the legal basis for EU statistical data collection in the field of public health, as established by Regulation²³ (EC) No 1338/2008 of the European Parliament and of the Council of 16 December 2008 on Community statistics on public health and health and safety at work.

The implementation process featured two main developments relevant to data on dementia:

- Firstly, the Joint Action on European Community Health Indicators Monitoring (ECHIM) has developed more precise definitions of the indicators. It delivered a shortlist of 88 health indicators classified by policy areas, including a specific indicator

²⁰ <http://www.alzheimer-europe.org/Alzheimer-Europe/Our-work/Completed-AE-projects/2006-2008-EuroCoDe>

²¹ http://www.alcove-project.eu/images/pdf/ALCOVE_SYNTHESIS_REPORT_VF.pdf

²² http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_Toolbox.pdf

Examples of European Projects from the Toolbox of the Joint Action ‘Alzheimer Cooperative Valuation in Europe (ALCOVE)’ can be found here: http://ec.europa.eu/health/major_chronic_diseases/diseases/alzheimer/index_en.htm

²³“Regulation (EC) No 1338/2008 of the European Parliament and of the Council of 16 December 2008 on Community statistics on public health and health and safety at work.” Web. 6 Oct 2014. < <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2008:354:0070:0081:EN:PDF>>.

on dementia and other health services indicators where dementia is one of the diseases monitored. The European Core Health Indicator on Dementia is currently being developed.

- Secondly, the Commission supported 16 Member States which participated in pilot projects aiming to assess the feasibility of the proposed data collection method. A Eurostat Task Force on morbidity statistics analysed the pilot projects and released a report²⁴ on 15 April 2014 with recommendations on how to identify the best estimates for the measurements presented in the European shortlist, including disease-specific recommendations. As regards specifically “mental and behavioural disorders, including Alzheimer’s disease and other types of dementia”, the report concluded that getting more reliable and comparable estimates on the prevalence of dementia would require the use of multiple data sources. Standards for definitions, data collections and algorithms for linking data from different sources should be developed and agreed in the short-term before starting regular data collections at EU level in view of an implementing regulation on morbidity statistics.

In parallel to the ECHIM process and the piloting phase on morbidity data collection methodology, an implementing Regulation²⁵ on Community statistics on causes of death was adopted in 2011, obliging Member States to transmit to the Commission “statistics in the domain of ‘causes of death’ [which] shall concern all registered deaths [...] occurring in each Member State”. The Commission publishes these statistics according to the European shortlist of 86 causes of death²⁶ which includes dementia and Alzheimer's disease. The Commission has put in place a Taskforce on Satellite Lists and foresees in 2014 the dissemination of “satellite lists”²⁷ of causes of death with specific diseases grouped together. One selected list is “Deaths related to dementias including Alzheimer’s disease”.

The Commission also supported the development and implementation of an automated coding system for the standardisation of the selection of the underlying cause of death (IRIS, 2009 - 2011) in the Member States to improve comparability through a multiple causes of death approach. This would benefit data on dementia where morbidity can be complex and not adequately represented by the causes of death statistics as such. Finally, the Commission is currently supporting projects on electronic certification of causes of death which are paving the

²⁴ “Morbidity statistics in the EU. Report on pilot studies.” Eurostat, n.d. Web. 11 May 2014.
<http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-TC-14-003/EN/KS-TC-14-003-EN.PDF>

²⁵ “Commission Regulation (EU) No 328/2011 of 5 April 2011 implementing Regulation (EC) No 1338/2008 of the European Parliament and of the Council on Community statistics on public health and health and safety at work, as regards statistics on causes of death.” Web. 21 May 2014.
<<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:090:0022:0024:EN:PDF>>.

²⁶ “European Shortlist for Causes of Death, 2012.” *ec.europa.eu/Eurostat*. Eurostat. n.d. Web. 13 May 2014
http://ec.europa.eu/eurostat/ramon/nomenclatures/index.cfm?TargetUrl=LST_NOM_DTL&StrNom=COD_2012&StrLanguageCode=EN&IntPcKey=&StrLayoutCode=HIERARCHIC

²⁷ The satellite lists contains data on specific public health themes which are of high political relevance, such as amenable and preventable deaths, transport accidents, infant deaths, deaths related to dementias and Alzheimer’s disease, and deaths related to infectious diseases. Thus, they provide complementary information to the statistics according to the standard European shortlist on causes of death.

road for more timely and better quality statistics on causes of death and possibly to a comprehensive approach in the context of e-Health.

2.2.2. Improving coordination of research

The understanding of dementia conditions is still very limited. A key objective of the strategy was to support further European research in this field and to strengthen the coordination of Member States' research efforts through a pilot Joint Programming initiative on combating neurodegenerative diseases.

Seventh Framework Programme for Research and Technological Development 2007-2013

Research on dementia and neurodegenerative diseases was a priority in the Seventh Framework Programme for Research and Technological Development (FP7) 2007-2013, which allocated more than EUR 555 million in funding for this purpose. EUR 327 million of this total went specifically to supporting research on Alzheimer's disease. This considerable funding has translated into approximately 300 projects contributing towards the overall goal of improving the quality and timeliness of the diagnosis, treatment, and quality of life of people with dementia and their caregivers.

Furthermore, the FP7-funded Human Brain Project²⁸, which started in 2013, works on aggregating existing data and generating new knowledge in neuroscience with the overarching objective of delivering models for human brain functioning. The Human Brain Project is a 10-year Flagship initiative with foreseen funding of around EUR 100 million per year. Eventually, this will allow developing new in-silico approaches to design and test treatments for brain diseases.

In addition, research on Alzheimer's disease benefited from the support of the Innovative Medicines Initiative (IMI) Joint Undertaking²⁹, a public-private partnership between the EU and the pharmaceutical industry launched in 2008. For example, the EUR 56.4 million European Medical Information Framework (EMIF) project³⁰ endeavours to facilitate access to medical and research data, including data on Alzheimer's disease, by creating an information framework of patient-level data.

Joint Programming Initiative on Neurodegenerative Diseases

Further to promoting research on neurodegenerative diseases and dementia, the European Union has supported better coordination of national research efforts through the launch in 2008 of the Joint Programming Initiative on Neurodegenerative Diseases (JPND). The JPND is a Member States-led initiative striving for a common research strategy and alignment of

²⁸ "Overview." Human Brain Project, n.d. Web. 20 May 2014. <<https://www.humanbrainproject.eu/>>.

²⁹ "Mission." The Innovative Medicines Initiative, n.d. Web. 20 May 2014. <<http://www.imi.europa.eu/>>.

³⁰ "European Medical Information Framework. Summary." Innovative Medicines Initiative, n.d. Web. 20 May 2014. <<http://www.imi.europa.eu/content/emif>>.

national programmes. Comprising 28 countries, including non-EU countries such as Canada, it is the largest global research initiative in the field of neurodegenerative diseases. The JPND approved a common Strategic Research Agenda on neurodegenerative disorders. It highlights as priorities: finding causes, developing cures, and improving care and structures for those with neurodegenerative diseases in a more strategic and effective way. Since 2011, approximately EUR 68.5 million have been committed for actions, mainly joint translational calls.

In December 2013 the JPND published a call for proposals on 'Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases' and on 'Pilot Studies on Preventive Strategies related to Neurodegenerative Diseases'. The outcomes of the resulting projects are expected to contribute significantly to the goals of the EU initiative by providing more insight into the pathophysiological mechanisms of neurodegenerative diseases.

Horizon 2020, the EU Framework Programme for Research and Innovation

Building on the results of FP7, the new EU Framework for Research and Innovation - Horizon 2020 will offer a range of opportunities to address dementia as a societal and health challenge. With an indicative budget close to EUR 1.2 billion, the Work Programme for 'Health, demographic change and wellbeing' 2014-2015 includes calls such as 'Understanding health, ageing and disease: determinants, risk factors and pathways', 'New therapies for chronic, non-communicable diseases', and 'Comparing the effectiveness of existing healthcare interventions in the elderly', all of which are of direct relevance for research on dementia. The Work Programme also calls for the development of innovative treatments and technologies and opens new opportunities for exploring ICT-based approaches to self-management of health.

Always under the 'Health, demographic change and wellbeing' 2014-2015 Work Programme, support will be provided to the European Innovation Partnership on Active and Healthy ageing, with a topic calling for proposals that would coordinate support for the action plans and promote the development of new ones.

Other parts of Horizon 2020 may provide further opportunities. The 'Excellent science' priority offers support for research on technologies and ways to improve the autonomy of people with dementia as well as support to individual researchers through the European Council Research grants and the Marie Skłodowska-Curie actions. The 'Industrial leadership' priority calls for the development of technologies, e.g. ICT, nanotechnologies, biotechnology, that would help implement solutions to societal challenges, including those of health and care.

Furthermore, under the second Innovative Medicines Initiative³¹ (IMI2), neurodegenerative diseases have been identified as one of the health areas most urgently needing academia-industry partnering. The main research axes identified are: target validation and biomarker

³¹ "IMI2." Innovative Medicines Initiative, n.d. Web. 22 May 2014. <<http://www.imi.europa.eu/content/imi-2>>.

development, adoption of innovative clinical trial paradigms, innovative medicines and patient-tailored adherence programmes³².

The key achievements on this objective:

- An improved estimate of the prevalence of dementia in the EU-population and the development of a Toolbox for Antipsychotics Limitation in Dementia (Joint Action ALCOVE) and progress in integrating dementia into the EU-public health statistics;
- Major investments into research on dementia under the Seventh Framework Programme for Research and Technological Development (FP7) 2007-2013; Setting up in 2008 of the Joint Programming Initiative on Neurodegenerative Diseases (JPND), which agreed on a common Research Strategy.

2.3. Best practices for care of people with dementia

Some of the overarching objectives of the Communication were to support the exchange of best practices between Member States on issues related to the care given to people with dementia, to develop quality frameworks for medical and care services for people with dementias, and to empower patient organisations.

Activities and findings of the Joint Action ALCOVE

The Joint Action work package ‘Support systems for behavioural and psychological symptoms of dementia (BPSD)’ analysed the availability and efficacy of organisational structures and service models for BPSD management at home, in hospitals and care homes.

The resulting recommendations stressed that it is crucial to develop ambulatory structures and care organisations in order to prevent and manage BPSD at an early stage and thus enhance the person’s possibilities to live at home as long as possible. Such structures could be mobile teams with specific skills for the caring of BPSD and semi-urgent consultation for BPSD at the hospital or via telemedicine to ensure a quick response and prevent hospitalisation. Furthermore, it has been demonstrated in several countries that dedicated units for diagnosis, care and orientation for BPSD in nursing homes and hospitals are helpful to dementia patients. Their development should be continued.

In terms of individualised patient and carer interventions, it was found that psychosocial interventions are essential as they are effective when dealing with behavioural disorders and safer than antipsychotic drugs. In particular psycho-educational programmes and multicomponent interventions are effective in preventing BPSD and delaying institutionalisation.

³² “The right prevention and treatment for the right patient at the right time. Strategic Research Agenda for Innovative Medicines Initiative 2.” Innovative Medicines Initiative, n.d. Web. 22 May 2014. <http://www.imi.europa.eu/sites/default/files/uploads/documents/IMI2_SRA_March2014.pdf>.

These findings of the Joint Action show that patients, family members who provide care for persons with dementia and health professionals need to have access to education on dementia care and its psychological aspects. Guidelines on BPSD management and the side effects of antipsychotic medication should be available and disseminated. Quality and safety programmes focused on the limitation of antipsychotic drugs would be beneficial and complementary to the management of BPSD. In conclusion, the Joint Action ALCOVE encouraged Member States to develop public health approaches for behavioural and psychological symptoms of dementia.

EU-policy activities on long-term care

As a chronic condition, dementia requires long-term care. As a strand of social protection, long-term care provision is a Member State responsibility. While EU countries set their own level of ambition in long-term care provision, they have also agreed in the context of the Open Method of Coordination common objectives on the accessibility, quality and financial sustainability of long-term care. The objectives guide the collaboration between Member States on long-term care issues, which takes place in the Social Protection Committee.

A report entitled "A good life in old age? Monitoring and Improving Quality in Long-term Care", published by the OECD in June 2013 and co-financed by the Commission, supports this work with Member States and focuses on three aspects generally accepted as critical to quality care: effectiveness and care safety, patient-centredness and responsiveness, and care co-ordination. The report concludes that having external regulatory controls is the best approach for having assurance of quality, while market-based and care co-ordination approaches are more appealing options for providing incentive for consumers, providers and payers.

Empowerment of patient organisations

On the basis of its annual open calls for proposals under the second EU-Health Programme 2008-2013, the Commission has provided co-funding to the patient organisation Alzheimer Europe³³ through operational grants and financial support for annual conferences. The annual conferences³⁴ have further promoted the active participation of civil society in health policy work on dementia.

The key achievements on this objective:

- Development of recommendations on the organisation of care and structures for persons experiencing behavioural and psychological symptoms of dementia (BPSD) (Joint Action ALCOVE);
- Development of a common understanding on the quality of social services through the adoption by the Social Protection Committee of 'A Voluntary European Quality

³³ <http://www.alzheimer-europe.org/>

³⁴ <http://www.alzheimer-europe.org/Conferences>

Framework for Social Services'. The Quality Framework also covers social services for persons with dementia and their carers. Its implementation is voluntary.

- Empowerment of patient organisations through co-funding of Alzheimer Europe from the Second EU-Health Programme 2008-2013.

2.4. Respecting the rights of people with dementia

Activities and findings of the Joint Action ALCOVE

The Joint Action ALCOVE stressed the principle from an ethical perspective that the right balance must be struck between the autonomy of the person living with dementia and the protection of that person and his or her environment. In order to achieve this, it identified a set of recommendations for the assessment of the competence of people with dementia and the drawing up and use of advance directives by persons living with dementia. Four different models for the competence assessment are presented. Advance directives are statements intended to govern healthcare and related decision-making, should their authors lose decisional capacity in the future. Fifteen Member States have specific legislation regarding advance directives. Ten of them were approved after 2005. The Joint Action ALCOVE developed specific recommendations regarding the context of such advance directives, their content, validity and applicability.

Implementing the UN Convention on the Rights of Persons with Disabilities (CRPD)

The EU ratified in 2010 the UN Convention on the Rights of Persons with Disabilities (CRPD)³⁵. Most EU Member States are also party to the Convention. The Convention recognises that disability is a diverse and evolving concept and results from the interaction between a person with impairments, including those linked to chronic conditions like dementia, and barriers that hinder the full and effective participation of people in society on an equal basis with others. It thus marks a paradigm shift from a medical model of disability to a distinct human rights-based approach.

Its purpose is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. In particular Article 19 of the Convention recognises the right of people with disabilities to live independently and be included in the community. It thus obliges state parties to ensure that people with disabilities, including those resulting from dementia, have access to a range of in-home, residential and other community support services, including personal assistance, necessary to support living and inclusion in the community, and to prevent isolation or segregation.

³⁵ “United Nations Convention on the Rights of Persons with Disabilities”. European Commission, n.d. Web. 5 Aug. 2014 <http://ec.europa.eu/justice/discrimination/disabilities/convention/index_en.htm> and the Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union, SWD(2014) 182 final available at: http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf

The Commission actions to tackle the existing barriers and promote the effective implementation of the Convention are set out in the European Disability Strategy 2010-2020³⁶, adopted in 2010 as the successor of the Disability Action Plan 2003-2010. The actions cover areas as diverse as accessibility, participation, employment, education, social protection and health.

Preventing elder abuse

Further activities were carried out in the field of prevention of elder abuse, particularly concerning elderly citizens in need of long-term care and assistance. Two calls for proposals originally initiated by the European Parliament, on Preventing Elder Abuse were launched in 2009 and 2010.³⁷ The overarching aim was to improve the understanding of the problem, to look at existing mechanisms and tools for prevention, and to develop options for improving their implementation. Key deliverables from the projects included proposals for a reference framework³⁸ of measures and instruments for effective prevention of elder abuse, proposals for a monitoring framework³⁹ to recognise and assess elder abuse in long-term care, and for a framework⁴⁰ for long-term care services designed to implement the existing recommendations and charters at national and European level on the rights of older people in need of long-term care and assistance.

Creation of a European network for the rights and dignity of people with dementia

In 2009, the patient organisation Alzheimer Europe established the European Dementia Ethics Network⁴¹ as a European network for the rights and dignity of people with dementia. Its creation was funded through an initial grant from the German Ministry of Health, and its following activities were funded as part of the operating grants which Alzheimer Europe had received from the EU-Health Programme 2008-2013.

With the help of working groups and based on literature reviews, the network developed consensus statement positions on:

- The use of assistive technology in 2010
- The ethics of dementia research in 2011
- The ethical issues linked to restrictions of freedom of people with dementia in 2012

³⁶ COM/2010/0636 final, available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1401271644100&uri=CELEX:52010DC0636> and the list of actions for 2010-2015 SEC(2010) 1324 final, available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:en:PDF>

³⁷ Call for proposals VP/2009/014 and Call for proposals VP/2010/015

³⁸ <http://www.forumseniorov.sk/Leaflet - How to prevent elder abuse.pdf>

³⁹ <http://www.milcea.eu>

⁴⁰ <http://www.wedo-partnership.eu/>

⁴¹ <http://www.alzheimer-europe.org/Ethics>

- The ethical issues linked to the perceptions and portrayal of dementia and people with dementia in 2013.

The findings of the literature review and the consensus statements were published on an annual basis.

The key achievements on this objective

- Based on existing models in Member States, the development of recommendations for the assessment of the competence of people living with dementia and for advance directives (Joint Action ALCOVE);
- The development of activities to implement the UN Convention on the Rights of Persons with Disabilities and the EU Disability Action Plans 2003-2007 and 2010-2020;
- The creation of the European Dementia Ethics Network as a European network for the rights and dignity of people with dementia (Alzheimer Europe)

3. Developments in Member States' activities in the field of dementia

The implementation actions at EU level described in this report have ultimately aimed to support Member States in their efforts to improve the health and quality of life of dementia sufferers and their families by ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for Alzheimer's disease and other dementias. When the EU initiative was adopted in 2009, only one Member State, France, had a national plan on dementia while currently there are seven - Belgium, the Czech Republic, Denmark, Finland, France, Luxembourg, the United Kingdom (and Norway)⁴². In order to obtain a better understanding of the extent to which the EU initiative has positively influenced and supported developments at national level, a survey was undertaken by Member States' Ministries of Health in the spring of 2014.

According to the survey results, several Member States, including Cyprus, Greece, Ireland, Italy, Malta, Portugal, Slovenia, Spain and Sweden are currently working on strategies dedicated to dementia and are in various stages of their development. For example, a public consultation is currently running on the 'National Dementia Strategy Malta 2015 - 2023' and the strategy is expected to be published in October 2014. At the same time, Sweden has just started to work on what is foreseen to be a national plan on dementia and neuro-degenerative diseases covering 2015 - 2018.

Certain countries – such as Croatia, Estonia, Germany, Latvia, Netherlands and Sweden - have no dedicated national strategies in place but dementia is included in other relevant strategies and plans. For example Estonia has an 'Active Ageing Development Plan 2013 - 2020' striving to relieve the burden on people who are looking after their elderly family members. In addition, an Estonian national plan on 'Special Care Services 2014 - 2020' is currently being developed

⁴² According to Member States responses to the survey and information from Alzheimer Europe.

with the goal to improve the care services, including specific actions on services for elderly people with dementia.

Member States priorities

The dedicated national strategies/plans already in place, as well as the ones currently in development, strive for a global and integrated approach to the patient pathway looking at both health and social services. Specific operational objectives vary from one national context to another, but they generally cover prevention and early diagnosis; improvement of treatment, institutional and home care; post-diagnostic support for dementia sufferers; support for formal and informal caregivers and respect for the rights of dementia patients.

Examples of national priorities aiming at the convergence of dementia services and support range from creating a network of relevant state and private institutions in the Czech Republic, to the elaboration of a “two-level diagnosis” standard in Luxembourg (consisting of a level one diagnosis at the GP level and a more thorough level two diagnosis with neuropsychological, radiological and biological assessment) and the possible introduction of a “night guard” service to support family caregivers, to the “[pooled] efforts for all neurodegenerative diseases” in France. The UK explicitly mentions improving research on dementia as a priority, in line with the objectives of the ‘Global action against dementia’ process launched at the G8 summit in December 2013.

The influence of the European initiative on Member States’ policies

It is difficult to measure the extent to which the EU initiative has influenced and supported activities at national level. However, the fact that 16 Member States have adopted national plans or strategies on dementia (which in some cases also cover other neurodegenerative disorders) or are developing them since the adoption of the Commission’s Communication in 2009 suggests that the European initiative on Alzheimer’s disease and other forms of dementia had an influence on policy actions in this field in a significant number of countries.

Some responses to the survey which the Commission undertook provided concrete examples of the positive influence of the EU initiative. For example, Malta has pointed out that the EU actions in the field “have made it possible for the Maltese government to increase its interest in the health and social aspects of dementia”. Latvia has commissioned educational material and organised training for health professionals in line with the Joint Action ALCOVE recommendations. Furthermore, the Latvian participant in the Joint Action used ALCOVE recommendations in his meeting with the Public Health Commission of the Latvian Parliament, resulting in the adoption of an updated list of reimbursed medications for people with dementia.

4. Global dimension of EU action on dementia

On 11 December 2013, the UK Presidency of the G8-Group organised a Summit of Health Ministers on Dementia. European Health Commissioner Tonio Borg participated in the event.

In the resulting declaration⁴³, the G8-Ministers of Health committed themselves to, inter alia: call for greater innovation; to strive to identify a cure or a disease-modifying therapy for dementia by 2025 and to increase the amount of collective funding for dementia research; to work together, to share information about the funded research and to identify strategic priority areas.

A series of high-level forums were announced for 2014 as part of the “Global action against dementia’ initiative, in partnership with the OECD, WHO, the European Commission, the EU Joint Programme on Neurodegenerative Disease (JPND), and civil society⁴⁴.

5. Conclusions

The Commission’s Communication on a ‘European initiative on Alzheimer’s disease and other dementias’ has prompted a significant number of activities on dementia at EU-level and in Member States.

The Communication set out four strategic objectives concerning the early diagnosis of dementia, the need to build upon epidemiological knowledge and coordinate research, best practices for caring for people with dementia and respecting the rights of people with dementia.

Key to implementing the initiative was the Joint Action ALCOVE, carried out between 2011 and 2013 under the leadership of France, with support from the EU-Health Programme. The Joint Action addressed all four objectives of the initiative. It promoted the coordination and cooperation between the participating Member States on these issues. All participating countries could benefit from the Joint Action, and smaller Member States could benefit from pooling their resources with other countries. The Joint Action has led to the creation of networks, which can be expected to continue their activities. Most importantly, the Joint Action has delivered findings, recommendations and toolkits that will provide concrete guidance for future actions in the field of dementia at EU and Member States level.

The Commission’s initiative has also inspired the development of actions on dementia across the various EU’s own policy areas:

The European Innovation Partnership on Active and Healthy Ageing (EIP AHA), which brings together key stakeholders to work collectively towards innovation in health, has identified and disseminated good practices in preventing frailty and cognitive decline and in building environments that are “friendly” to ageing and dementias.

EU research and eHealth policies have made action on dementia one of their priorities and have provided major financial resources into research projects and improving the coordination

⁴³https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_DementiaSummitDeclaration_acc.pdf

⁴⁴ The first such Legacy Event on ‘Finance and Social Impact Investment in Dementia’ took place on 18-19 June 2014 in London, organised by the United Kingdom.

of national research efforts. The model of the Joint Programming initiative on Neurodegenerative Disorders (JPND) is now being considered by the G7-Group as one of the possible models for strengthening research coordination at the global level.

Finally, there is evidence that the EU initiative has had an impact on Member States, for instance by prompting more than half of them to adopt national plans or strategies on dementia or to start work on them.

The European initiative has helped to counter the stigmatisation of dementia: it is now established as one of the biggest challenges that European societies face in the context of demographic change.

Building on the successes and achievements of these activities since 2009, the Commission has launched action to:

- Maintain its coordination role⁴⁵ in the development of the EU policy on dementia and to support Member States in their activities at national level
- Take forward action at EU level by launching a second Joint Action on dementia under the Work Plan 2014⁴⁶ of the Health Programme. It will build on the results of the Joint Action ALCOVE, and focus on post-diagnostic support, improvement of care pathways, the use of medicinal products and specifically psychotropic substances, care for family carers, workforce skills, and the quality of residential care.
- Provide further opportunities to support research under Horizon 2020⁴⁷
- Stimulate the development and use of e-Health solutions⁴⁸ in the field of dementia
- Continue playing a global role and collaborate with international stakeholders, particularly in the context of the initiative ‘Global action against dementia’ launched by the G8 Declaration⁴⁹.

⁴⁵<http://ec.europa.eu/transparency/regexpert/index.cfm?do=groupDetail.groupDetail&groupID=2984&NewSearch=1&NewSearch=1>

⁴⁶Point 2.2.1.3 of Annex I. Public Health Programme – Work Programme for 2014. Web. 7 Oct 2014
<http://ec.europa.eu/health/programme/docs/wp2014_annex_en.pdf>.

⁴⁷“Health, Demographic Change and Wellbeing.” Horizon 2020, n.d. Web. 7 Oct. 2014
<<http://ec.europa.eu/programmes/horizon2020/en/h2020-section/health-demographic-change-and-wellbeing>>.

⁴⁸“Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions ‘eHealth Action Plan 2013 – 2020 – Innovative healthcare for the 21st century’.” 6 Dec. 2012. COM (2012) 736 final. Web. 7 Oct. 2014
<http://ec.europa.eu/health/ehealth/docs/com_2012_736_en.pdf>.

⁴⁹G8 Dementia Summit Declaration Global Action Against Dementia, 11 Dec. 2013. Web. 7 Oct 2014
<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_DementiaSummitDeclaration_acc.pdf>.