

A GENERAL PRESENTATION OF ALCOVE



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ALCOVE'S GENERAL OBJECTIVES

- **Dementia, the most common form being Alzheimer's disease, concerns more than 7 million Europeans living with it as well as their estimated 20 million family carers.** Alzheimer's disease is characterised by progressive memory and cognitive problems as well as the occurrence of disturbing behaviour disorders. The current absence of curative treatment for Alzheimer's disease does not translate to an absence of care. Today in Europe, citizens, families, and health professionals are mobilised to provide better care and services all along the progression of dementia, from timely diagnosis to home or institutionalised care.
- **ALCOVE was born out of a need to share knowledge and experiences about Alzheimer's disease and related disorders in health policy between European Member States:** ALCOVE aims to capitalise on the European experience and knowledge on this disease and its consequences and to reflect together on the best means of preserving quality of life, autonomy and the rights of people living with dementia. Major cognitive disorders, with Alzheimer's disease and related disorders (AD) as a major cause, represent a challenge for our societies in terms of care organisation as well as in terms of social support and innovation to preserve quality of life, both for individuals living with the disorder as well as their family carers. The general objective of this Joint Action was to establish an independent and scientific European network to inform and advise decision-makers, health care professionals, carers, individuals living with dementia, and other European citizens through convergent operational recommendations from a health policy perspective.

ALCOVE PARTNERS & COOPERATION

- **Nineteen countries were committed to this 2-year Joint Action, and were represented by thirty organizations which were appointed by their respective governments:** Among these partners, 7 of the countries served as leaders of 7 Work Packages. Three transversal Work Packages were devoted to the **Coordination** of the Joint Action (WP1), led by the Main Partner, France's Haute Autorité de Santé, its **Dissemination** (WP2), led by Spain's Instituto de Salud Carlos III, and its **Evaluation** (WP3), led by Slovakia's Neuro Immunology Institute. Four Core Work Packages were led by Italy's Istituto Superiore di Sanità (**Epidemiological Data**, WP4), the UK's Department of Health in conjunction with the University of Worcester (**Timely Diagnosis**, WP5), Finland's National Institute for Health and Welfare (**Support systems for Behavioural and Psychological Symptoms of Dementia**, WP6), and Belgium's King Baudouin Foundation (**Rights, Autonomy and Dignity**, WP7). Besides these 4 core ALCOVE themes, the safety issue that is the overuse of antipsychotics in dementia, as well as solutions on how to limit it, was collaboratively examined by all the ALCOVE partners. In total, more than 100 people contributed to the ALCOVE work, and in addition about 170 respondents from 24 European countries participated in the different ALCOVE surveys. (see Chapter ALCOVE Partners p. 8).
- **ALCOVE and its collaboration with other European projects and networks in the field of dementia:** ALCOVE is a network which is made up of representatives from Member States within the framework of a public health mission. More than 10 previous or current European projects and networks related to dementia exist. ALCOVE acted in order to position and synergise its public health missions with respect to these other initiatives and research projects. Meetings and exchanges with other projects such as the Joint Programming on Neurodegenerative Disease or the European Alzheimer Disease Consortium were conducted. In particular, a formal, close, and fruitful cooperation was established with Alzheimer Europe, a patient and family umbrella association which includes all national Alzheimer associations. This collaboration permitted ALCOVE to avoid redundancy and allowed it to capitalise on Alzheimer Europe's expertise and previous work, such as its Eurocode project and its experience in analysing ethical issues.

ALCOVE METHOD

- **The aims of the ALCOVE Method were to identify good practices, gaps between real practices and evidence in the literature, and to propose public health options to support improvement in the ALCOVE targeted topics:** To generate an operational synthesis of these complex and evolving questions, with respect to already-existing European projects and the 10 new public health plans for dementia implemented since 2008, ALCOVE has chosen a method with 3 approaches. Besides literature reviews and the subsequent analyses of the texts identified therein and exchanges with European experts and networks, questionnaires were created and sent to holders of information in European Member States in order to access data and

analyse effective practices and care. The collection, analysis and comparison of information collected both in the field and in the literature reviews led to the drafting of ALCOVE recommendations which address public health needs. (Figures 1 & 2).

- **To ensure that it would meet its objectives within the 2-year time frame, as well as to guarantee project management that was both collective and transparent, ALCOVE developed its own project management method and self evaluation process:**
 - A collaborative method based on consensual decisions made by the members of the ALCOVE Executive Board. All Executive Board members participate in regular meetings and conference calls and receive minutes of the decisions taken.
 - A global and coherent work plan including the specific work plan for each Work Package as well as systems for regular monitoring and assessment of progress.
 - A strong project management strategy with specialised leadership tools for both internal communication and evaluation (see Chapter ALCOVE Evaluation p. 96).

Figure 1. ALCOVE Method: Timeline



Figure 2. ALCOVE Method: 3 approaches



ALCOVE TOPICS

- **What do we know in scientific terms? What is the situation in Europe?** Each of the five topics - the four core questions and the shared question on antipsychotics - has been analysed while using these two questions to contextualise ALCOVE's work. In answering these questions, ALCOVE's aim is to make concrete recommendations which propose avenues for improvement.
 - **From an epidemiological perspective**, what data is available in Europe on Alzheimer's disease prevalence, the characteristics of persons living with dementia, and how they are taken care of medically and socially? What minimum body of knowledge and what good practices for data collection could be proposed to improve this knowledge? (see Chapter Epidemiological data p. 26).
 - **As concerns an Alzheimer's disease diagnosis**, what systems are in place to make such a diagnosis and how are they evaluated? What are the different options available for offering a timely Alzheimer's disease diagnosis and how can it best be paired with appropriate care for persons living with dementia and their family carers? (see Chapter Timely diagnosis p. 38).
 - **As concerns care for persons experiencing BPSD**, what are the options for the organisation of care and the subsequent evaluation of different options? How can we improve care for persons living with dementia and their carers? (see Chapter Support Systems for BPSD p. 54).
 - **As concerns both advance directives and competence assessment**, what are the current legislative and legal practices in Europe? How can we improve them so that the rights and autonomy of individuals living with dementia are better respected? (see Chapter Rights, Autonomy & Dignity p. 74).
 - **What is the risk of exposure to antipsychotics for persons living with dementia and how can it be limited?** What risk reduction programmes have been implemented to reduce this safety and ethical issue? During the course of the project, this issue was the common ground for the four thematic work packages. Together, along with WP1 and WP2, they constructed a Toolbox which contains information about outstanding projects which have supported the implementation of good practices in the field of antipsychotic risk prevention (see Chapter ALCOVE Toolbox p. 84).

ALCOVE RESULTS

- **ALCOVE's recommendations have been generated based on updated knowledge about scientific evidence and after having identified the needs and current situations in Europe:** ALCOVE's propositions target key decision-makers and seek to enlighten them about health policy as concerns Alzheimer's disease and related disorders. At the same time, these recommendations are designed to be useful for health and social professionals, researchers, and individuals living with dementia and their family.

The knowledge on Alzheimer's disease has been undergoing a rapid and huge evolution, even as concerns the definition of dementia and major cognitive disorders themselves. At the same time, due to an ageing population, the urgent needs for persons living with dementia and their carers in Europe are dramatically increasing. ALCOVE proposes strategies with different levels of action which address the diverse current realities in European healthcare systems while proposing high level objectives for the near future for systems that may be ready to advance (see Chapter ALCOVE Recommendations p. 18).

- **ALCOVE's recommendations will be made public at the ALCOVE Final Symposium which is scheduled to take place in Paris on the 28th of March 2013 and will be further disseminated on the ALCOVE website (www.alcove-project.eu) which is to be sustained beyond the formal term of the project:** More than 23 countries will be represented by government officials and key actors in the field of dementia at the ALCOVE Symposium. This will include stakeholders, political figures, decision-makers and patients' and citizens' organisations. This ALCOVE Synthesis Report has been prepared and published so that it may be disseminated at the event (see Chapter ALCOVE Dissemination p. 90).

CONCLUSIONS

ALCOVE's partners' involvement and dynamism were key during the two years' of collaborative work between 2011 and 2013. As a result of this work, ALCOVE is able to present operational proposals in this Synthesis Report for several key aspects for improving, from a public health standpoint, care pathways and the quality of life for persons living with dementia as well as their carers: improve knowledge about dementia prevalence so as to be able to better anticipate needs; propose a diagnosis as early as possible, such a diagnosis should be accessible and accompanied by a long-term care cycle for persons living with dementia and their carers; design a public health strategy for the disturbing behaviours related to BPSD, and in doing so reducing burn-out among carers and allowing the person to stay in his or her home for the longest period possible; improve the respect of the rights and dignity of people living with dementia by encouraging good practices in advance directive and competency assessment use.

Due to its expected impact on health systems and society, dementia represents a serious threat to medical-social systems and intergenerational solidarity. At the same time, this collaborative approach which promotes benchmarking and sharing between European Member States is an opportunity to reform and to innovate. ALCOVE's proposals aim to improve care and quality of life for persons living with dementia and their family carers in Europe.

REFERENCES

- [1] ALCOVE Collaborative Method, available on www.alcove-project.eu
- [2] ALCOVE Global Work Plan, available on www.alcove-project.eu
- [3] Sharing knowledge to advance healthcare policies in Europe for people living with dementia and their carers: the ALCOVE project. Archives of Public Health 2012, 70:21-
<http://www.archpublichealth.com/content/70/1/21>