ALCOVE, Alzheimer Cooperative valuation in Europe: an Overview

Armelle Leperre Desplanques
ALCOVE Project Leader
No Health Industry Interests Relevant to Presentation
Why a European Joint Action on dementia?

Dementia is a priority for the European decision makers
☆ Impact on social & health systems (ageing population, social and medical cost, burden for carers and for active people…)
☆ Increase of the economical constraints in Europe

The need of an operational synthesis
☆ During the last past years, numerous therapeutic failures should not mask huge advances in the understanding of dementia: genetic and environmental mechanisms, natural history and investigation through clinical tests, genetic tests, brain imaging, biochemistry and neuropathology
☆ Several scientific projects and dementia initiatives in Europe

Alzheimer Cooperative Valuation in Europe 2011-2013

The ALCOVE project
☆ Sharing of experience & synthesis of knowledge for public health decisions in order to improve care and quality of life for individuals and their family
☆ Collaboration with other Eu projects & networks & experts
☆ Health public recommendations adapted to the continuous evolution of our knowledge, link between social issues, medical care and research

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme.
MANY THANKS TO ALL ALCOVE PARTNERS!!

19 countries committed in this joint action
30 organizations nominated by their government
7 countries serving as leaders of 7 workpackages

16 Associated Partners
HAS, France, WPL1
ISCIII, Spain, WPL2
NIU SAV, Slovakia, WPL3
ISS, Italy, WPL4
Worcester UNIniversity, DoH, United Kingdom, WPL5
THL, Finland, WPL6
KBF, Belgium, WPL7
EEAPHP, France
INSERM U897, France
AA ADRD, Greece
MINSAL, Italy
UNIBS, Italy
RPNC Latvia
KMU, Lithuania
BIOEF, Spain
IKarolinska, Sweden

14 Collaborating Partners
MoH, Cyprus
AA, Hungary
MoH, Lithuania
Vilnius University, Lithuania
MoH, Luxemburg,
MoF, Luxemburg,
MoH, Malta
MoH, Norway
MoH, Portugal
Ac.of Sciences, Slovakia
Sterling University,
UKingdom
AA, Czech Republic
MoH, Spain
MoH, Netherlands

*Collaborative partners, voluntary basis participation; others are associated partners with financial support from the European Commission

EC: DG SANCO  EAHC
Alzheimer Europe & Alzheimer Associations

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme.
Unremembering eyes
A smile that barely ages
Distant yet so close

Herman Van Rompuy
President of the European Council
**ALCOVE, a collaborative method**

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**1 COLLECT OF EXISTING INFORMATION**

2011

**2 ANALYSIS OF EXISTING INFORMATION**

**3 EVIDENCE, NEEDS & PRIORITIES**

2012

**4 PUBLICATIONS DISSEMINATION**

**European platform**

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**3 sources of work**

(i) Questionnaires for European MS

(ii) Review & analysis of the literature

(iii) Exchanges with European experts, projects & networks

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Overview of the situation in Europe & Level of evidence

Gap between real practices & Evidence/good practices

Operational health policy propositions for improvement

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**Collaborative – Independent Scientific - Multidisciplinary**

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ALCOVE, themes chosen for the production of recommendations

☆ The choice of focusing on some key issues
☆ Targeting situations or steps at risk all along the person pathway
☆ Aim: To improve quality of life of individuals and their family carers

1. Epidemiological data: better knowledge on dementia prevalence in Europe, antipsychotics use, health and social care services

2. Dementia diagnosis: for a Timely diagnosis for all

3. Behavioral & psychological symptoms of dementia: comprehensive strategy for BPSD, which support systems for those experiencing BPSD & for their carers?

4. Ethics: how to improve rights & dignity of people living with dementia?

5. Limitation of antipsychotics: reduction of adverse effects, promotion on non pharmacological approaches, improving quality & Safety
3 transversal workpackages led by

- **France Haute Autorité de Santé (Main partner)** Dr Armelle Leperre – Desplanques, Dr Nathalie Riolacci – Dhoyen, Christine Barr, Maggie Galbraith, ALCOVE coordination team

- **Spain Instituto de Salud Carlos III (Dissemination)** Pr Carlos Segovia, Tomás López-Peña Ordoñez, Gloria Villar Acevedo

- **Slovakia Neuro Immunology Institute (Evaluation)** Pr Michal Novak, Pr Rostislav Skabranova, Martina Jerzovicova

4 Core workpackages led by

- **Italy Istitute Superiore di Sanita (Epidemiology)**
  Pr Nicola Vanacore, Pr Francesca Galeotti, Pr Angela Giusti, Pr Fiorentino Capozzoli

- **UK Worcester’s University, Department of Health (Timely Diagnosis)**
  Pr Dawn Brooker*; Dr Karim Saad, Regional Clinical Lead for Dementia, Coventry; Dr Simon Evans, Dr Jerry La Fontaine, University of Worcester*; Jerry Bird, Prof. Alistair Burns, Department of Health, UK

- **Finland National Institute for Health and Welfare (BPSD Support Systems)** Pr Harriet Finne-Soveri, Pr Matti Mäkelä, Paivi Topo, Ulla Eloniemi-Sulkava, Dr Helka Hosia-Randel

- **Belgium King Baudoin Foundation (Ethics)**
  Gerrit Raws, Bénédicte Gombault, Tom Goffin
UNDERSTANDING PREVALENCE & EPIDEMIOLOGICAL DATA ABOUT DEMENTIA

Prof. Nicola VANACORE et al.
Istituto Superiore di Sanita, Italy
This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme.

Systematic review of the literature

Estimated prevalence rate for dementia (27 MS, Eurostat population 2011)

ADI High quality score + DSM IV diagnostic criteria + age groups (≥65 years)

Estimated ALCOVE prevalence rate for dementia (27 MS, in ≥65 years population, Eurostat population 2011)

A more robust estimation of dementia prevalence, based on shared quality criteria, will better inform policies and help planning services adapted to the needs.
ALCOVE confirms the high and increasing number of dementia cases in Europe

<table>
<thead>
<tr>
<th></th>
<th>Total case rate</th>
<th>CI 95% total case rate</th>
<th>Pop Eurostat 2011</th>
<th>Total cases 2012</th>
<th>CI 95% total cases</th>
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<tr>
<td>EUROCODE</td>
<td>9.28</td>
<td>8.95-9.61</td>
<td>88 074 340</td>
<td>8 175 200</td>
<td>7 882 700 – 8 463 900</td>
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<tr>
<td>ALCOVE</td>
<td>8.24</td>
<td>7.73-8.74</td>
<td>88 074 340</td>
<td>7 262 700</td>
<td>6 808 100 – 7 697 700</td>
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<td>The high quality studies</td>
<td>7.23</td>
<td>6.74-7.72</td>
<td>88 074 340</td>
<td>6 368 500</td>
<td>5 936 200 – 6 799 300</td>
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ESTIMATE OF DEMENTIA CASES IN ITALY AND FRANCE (1st Jan 2012)
ON THE BASIS OF THE HIGH QUALITY STUDIES IDENTIFIED IN ALCOVE

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<tr>
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<th>Pop 2011 ≥ 65 yrs</th>
<th>Total cases 2012</th>
<th>CI 95% total cases</th>
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</thead>
<tbody>
<tr>
<td>ITALY</td>
<td>12 370 822</td>
<td>951 700</td>
<td>887 200 - 1 016 200</td>
</tr>
<tr>
<td>FRANCE (without Overseas Territories and Departments)</td>
<td>10 968 525</td>
<td>875 700</td>
<td>816 300 - 935 000</td>
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ESTIMATE OF DEMENTIA CASES in EUROPE (27 member states, Eurostat projections)

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<th>pop ≥ 65 yrs</th>
<th>rate dementia</th>
<th>Estimated dementia cases</th>
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<tr>
<td>2011</td>
<td>88074340</td>
<td>7.23</td>
<td>6367775</td>
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<tr>
<td>2020</td>
<td>103387503</td>
<td>7.23</td>
<td>7474916</td>
</tr>
<tr>
<td>2030</td>
<td>123272809</td>
<td>7.23</td>
<td>8912624</td>
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<td>2040</td>
<td>140888254</td>
<td>7.23</td>
<td>10186221</td>
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<td>2050</td>
<td>150927175</td>
<td>7.23</td>
<td><strong>10912035</strong></td>
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This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme.
ALCOVE recommendations to improve data collection on estimates of dementia prevalence in Europe

[1] Future studies on dementia prevalence should be performed using the highest quality epidemiological studies as defined in the 2009 ADI report (Sample size: ≥3000 subjects; Design: One phase study or two phase study with appropriate sampling and weighting; Response proportion≥ 80%, Diagnostic assessment with Inclusion of multi-domain cognitive test battery, formal disability assessment, informant interview and clinical interview)

[2] Epidemiological studies on dementia using the DSM IV and NINCDS-ADRDA clinical criteria for dementia and Alzheimer’s disease should be promoted. These clinical criteria are the only ones that have been validated with post-mortem data

[3] At the same time, dementia prevalence and incidence studies using the new clinical criteria of the National Institute on Aging and the Alzheimer’s Association should be performed to promote new knowledge in this area

[4] Prevalence and incidence studies on people living with dementia aged ≤65 years should be promoted to define dementia frequency

[5] Studies in the same areas should be carried out over different decades to intercept any phenomenon of dementia decline as speculated by some evidence of literature
ALCOVE confirms the overexposure of people living with dementia to antipsychotics & its monitoring is recommended.

Recommendations to improve data collection on antipsychotics in dementia:

- Prospective and systematic data collection on people living with dementia in specific settings (community, home care, memory clinic, nursing home) in all Member States
- A list of antipsychotics used in each Member States, underlining the off-label use for the specific drug contained therein
- The collection of data on the use of antipsychotics in people living with dementia characterized to allow for prescription analysis
- Use of antipsychotics in conjunction with other quality indicators (e.g., physical restraints)
- A European database on the use of antipsychotics in people living with dementia to monitor the efficacy of national programmes for antipsychotic use risk reduction.
ALCOVE recommendations to improve data collection on health & social care services for dementia

[1] A minimum data set, shared among different Member States, should be adopted for administrative, clinical, epidemiological and other relevant data sources. The dataset should include general data on chronic diseases and specific data on dementia.

[2] A predefined set of operational diagnosis criteria for dementia for data collection purposes

[3] Optimise existent data sources by providing an efficient system of record linkage

[4] A unique, depersonalised identifier for record linkage. Privacy concerns addressed at the European level to assure the person’s ownership of the data
All ALCOVE Recommendations & tools available

☆ www.alcove-project.eu
Healthy life expectancy has dramatically increased in Europe over the past 50 years. At the same time, there has been a corresponding increase in diseases linked to aging, particularly dementia. Alzheimer’s disease and related dementias are an EU public health priority given their high prevalence and cost as well as the profound impact they have on society. The ALCOVE project was co-financed by the European Commission and over the past two years it has built a sustainable network which includes 30 partners from 19 EU Member States. Through its work, ALCOVE has aimed to improve knowledge and to promote 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 carers in EU Member States.

(WP4) Epidemiological data on dementia
For a better knowledge on dementia prevalence in Europe, available data & best practices for data collection
Instituto Superiore di Sanità, Italy.

(WP5) Timely diagnosis of Dementia
Operational criteria for dementia timely diagnosis & health care systems for dementia diagnosis in ambulatory and nursing home settings.
Association for Dementia Studies, Worcester, United Kingdom

(WP7) Rights, Autonomy & Dignity of People living with Dementia
Improving the rights, autonomy & dignity of people living with dementia, with a focus on advance declarations of will & competence assessment.
Fondation Roi Baudouin, Belgium

(WP6) Support Systems for BPSD
For better knowledge on their availability & efficacy for BPSD management at home, in hospitals & care homes
Terveyen ja Hyvinvoinnin Laitos, Finland

The ALCOVE TOOLBOX for Antipsychotics limitation in Dementia
A worldwide shared safety issue

(WP3) Evaluation of the ALCOVE Joint Action
Slovenska Akademia Vied, Slovakia

Dissemination of the ALCOVE Joint Action

ALCOVE Key Messages presented by the Work Package Leaders

ALCOVE Synthesis Report

ALCOVE Recommendations

ALCOVE in various language

ALCOVE Brochure
# The European Joint Action on Dementia

## Synthesis Report 2013

### Unremembering eyes
A smile that barely ages
Distant yet so close

Herman Van Rompuy
President of the European Council

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*Behavioural & Psychological Symptoms of Dementia*
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In each part:

- Issue
- Situation in Europe (ALCOVE surveys, literature)
- European projects (sharing of experience)
- ALCOVE Recommendations & Available tools

**ALCOVE TOOLBOX**

FOR LIMITING ANTIPSYCHOTICS IN DEMENTIA

1. ANTIPSYCHOTICS RISK MEASUREMENT IN EUROPE
2. ANTIPSYCHOTICS RISK REDUCTION PROGRAMMES
3. TIMELY DIAGNOSIS & ANTIPSYCHOTICS
4. PSYCHOLOGICAL SYMPTOMS OF DEMENTIA
5. ALCOVE RECOMMENDATIONS & AVAILABLE TOOLS

Why such a Toolbox?

- The prescribing of antipsychotics for behavioural disorders in dementia represents a crucial safety & ethical issue.

ALCOVE, the European Joint Action on dementia, has benchmarked between European Member States in order to propose concrete tools and supports to tackle this safety issue.

- Several countries have already set up dedicated strategies to limit the antipsychotics in dementia.
ALCOVE PROJECT

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ALCOVE Key figures

7.23%, a new prevalence rate

6,367,526 people are living with dementia in Europe, the new prevalence rate projects more than 10 million in 2040

Only 6 clinical guidelines addressed BPSD in EU Member States

30 tools for antipsychotic limitation in the ALCOVE Toolbox

53 ALCOVE recommendations (www.alcove-project.eu)

3D strategy for BPSD all along the Patient Pathway

5 pyramids & 4 corners stones for timely diagnosis detection

35.6% prevalence rate for antipsychotic use in people living with dementia residing in nursing homes. That's why ALCOVE has developed a Toolbox for antipsychotics limitation

40-60% of theoretical dementia diagnoses are missed

7.23% a new prevalence rate

EU Member States recognise legal validity of advance directives

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Herman Van Rompuy
President of the European Council

Thanks you for your attention!

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