PROGETTO ALCOVE : UN'OCCASIONE PER LA DEFINIZIONE DELLA POLICY SULLA DEMENZA IN EUROPA

Nicola Vanacore, Angela Giusti, Paola Scardetta, Eleonora Lacorte, Francesca Meduri, Roberto Raschetti, Reparto Farmacoepidemiologia

VI Convegno Nazionale UVA

16 novembre 2012

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

alcove
ALzheimer COoperative Valuation in Europe

16 Associated Partners

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

14 Collaborating Partners

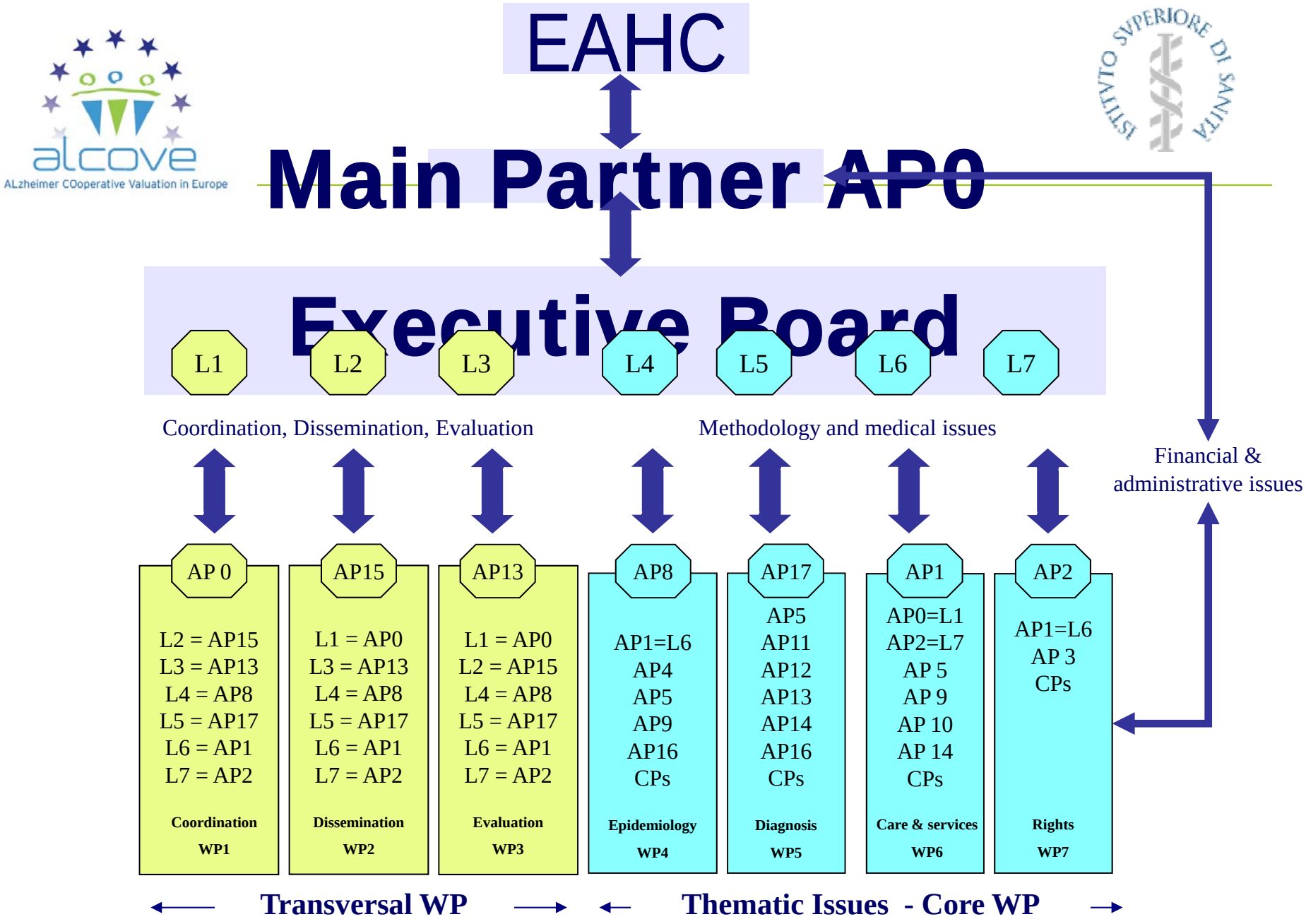
MoH, Cyprus
AA, Hungary
MoH, Lithuania
Vilnius University, Lithuania
MoH, Luxemburg,
MoF, Luxemburg,
MoH, Malte
MoH, Norway
MoH, Portugal
Ac.of Sciences, Slovakia
Sterling University, UKingdom
AA, Czech Republic
MoH, Spain
MoH, Netherlands

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

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

Executive Agency for Health and Consumers

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)



This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the Framework of the Public Health Programme (Grant Agreement 2008 12 13)

AP: Associated Partners, CP: Collaborating Partners, L: Leader

Why a European Joint Action on dementia ?

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

>> ALCOVE was born out of a need to share knowledge & experiences between European Member States, in order to make health policy recommendations to improve care for dementia in Eu

>> ALCOVE collaborates & exchanges with other Eu projects & networks

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ALCOVE Core Questions

1. How to improve data on prevalence?
2. How to improve access to early diagnosis?
3. How to improve care particularly for those with behavioural and psychological symptoms?
4. How to improve people's particularly with respect to advance declarations of will?
5. How to reduce the inappropriate use of antipsychotics in dementia?

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OPPORTUNITA'

Contribuire alla policy europea sulla demenza:

- **Aspetti epidemiologici (preventivi e descrittivi)**
- **Diagnosi pre-clinica, precoce / tempestiva**
- **Uso off-label degli antipsicotici**
- **Organizzazione dei servizi socio-sanitari**
- **Aspetti etici (Direttive anticipate, valutazione della competenza, consenso informato, fine-vita)**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

7 workpackages

3 transversal WP led by

- ***France*** ***Haute Autorité de Santé*** **(Main partner) Dr Armelle Leperre – Desplanques, Dr Nathalie Riolacci – Dhoyen, Christine Barr, Maggie Galbraith, ALCOVE coordination team, Haute Autorité de Santé, France**
- ***Spain*** ***Instituto de Salud Carlos III*** **(Dissemination) Tomás López-Peña Ordoñez, Carlos Segovia, Gloria Villar Acevedo, Institudo de Salud Carlos III, Spain;**
- ***Slovakia*** ***Neuro Immunology Institute*** **(Evaluation) Pr Michal Novak, Pr Rostislav Skabranova, Martina Jerzovicova, Slovenska Akademia Vied – Neuroimmunologicky Ustav, Slovakia;**

4 Core WP led by

- ***Italy*** ***Istitute Superiore di Sanita*** **(Epidemiology) Pr Nicola Vanacore, Pr Francesca Galeotti, Pr Angela Giusti, Pr Fiorentino Capozzoli, Istituto Superiore di Sanita, Italy;**
- ***UK*** ***Department of Health, Worcester's University*** **(Early 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 Wellfare*** **(Care & services) Pr Harriet Finne-Soveri, Pr Matti Mäkelä,, Paivi Topo, Ulla Eloniemi-Sulkava, Dr Helka Hosia-Randel, National Institute of Health and Welfare, Finland;**
- ***Belgium*** ***King Baudoin Foundation*** **(Ethics) Bénédicte Gombault, Gerrit Raws, Tom Goffin, King Baudoin Fundation, Belgium.**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

www.alcove-project.eu

Archives of Public Health

BioMed Central
The Open Access Publisher

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 doi:10.1186/0778-7367-70-21

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Nathalie Riolacci (n.riolacci@has-sante.fr)
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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. (Grant Number 2010 22 01)

ALCOVE final report : a statement for decision makers in march 2013

WP4: Recommendations to improve epidemiological data on AD & dementia w/ overview data & def. of best practices for data collection

WP5: Recommendations to improve early diagnosis of dementia in ambulatory and nursing home settings with an assessment of MS recommendations on Diagnostic Health Care Systems and their implementation

WP6: Recommendations to improve practices in ambulatory and nursing home settings with an assessment of practices and training, focus on BPSD

WP7: Recommendations to improve rights & dignity of people w/ dementia (ADW & good practices in assessing the CAD)

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

ALCOVE method

(i)
Questionnaires for European MS

(ii)
Review & analysis of the literature

(iii)
Exchange with European experts, projects & networks

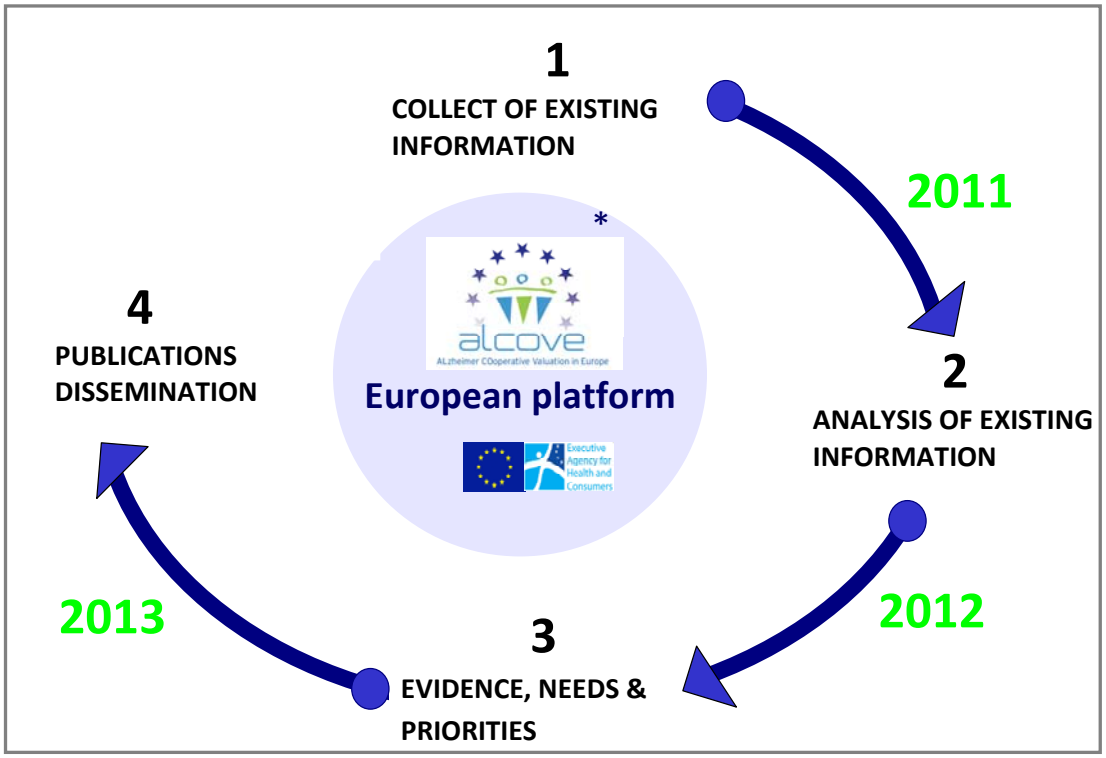
Overview of the situation in Europe <<<< >>>> Level of evidence

[gap between real practices & evidence/good practices]

Operational health policy propositions for improvement

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

ALCOVE, a collaborative method



Sharing knowledge to advance healthcare policies in Europe for people living with dementia and their carers: the ALCOVE project

Christine Barr[1*], Nathalie Riolacci-Dhoyen[1], Maggie Galbraith[1], Armelle Leperre-Desplanques[1] and the ALCOVE GROUP[2]

ARCHIVES OF PUBLIC HEALTH

Barr *et al. Archives of Public Health* 2012, **70**:21
http://www.archpublichealth.com/content/70/1/21

Collaborative - Independent
Scientific -Multidisciplinary

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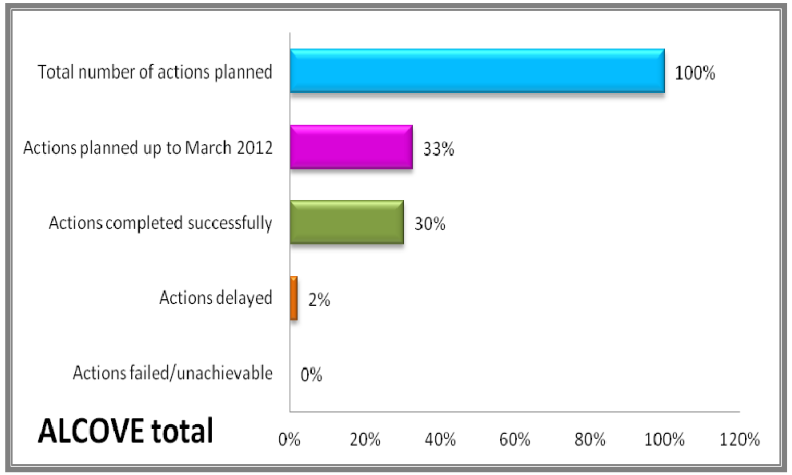
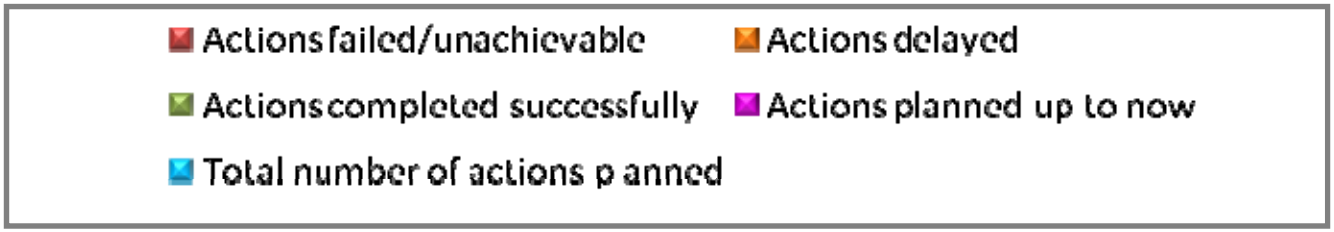
www.alcove-project.eu

WP 2 Spain



ALCOVE's monitoring



WP 3 Slovakia

Executive Agency for Health and Consumers

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ALCOVE Final Report

	What do we know about ?	How to improve ?
WP4 ***Epidemiology*** **Italy**	*Prevalence ?* *Available databases ?*	*How to improve the data notably for better knowledge regarding dementia prevalence*
WP5 ***Diagnosis*** **U Kingdom**	*Systems in place in Europe for the diagnosis?* *Evaluation of their effectiveness?*	*How to improve the access to dementia diagnosis as early as possible*
WP6 ***Care & Services*** **Finland**	*Care & supports systems dedicated to BPSD?* *Evaluation of their effectiveness?*	*How to improve the care for people living with dementia and particularly those with behavioural disorders*
WP7 ***Ethics*** **Belgium**	*Advance directives of will and their implementation ?* *Individuals' competence assessment?*	*How to improve the rights of people with dementia, particularly with respect to advance declarations of will*
WP4, WP5, WP6 & WP7 ***Risk reduction : Antipsychotics in dementia***	***Exposure to AP in dementia*** ***Early Ds & prevention of AP use*** ***Alternatives to AP for BPSD*** ***Ethical & legal aspects of AP use***	***Improve Knowledge about AP*** ***Measure the risk*** ***Improve knowledge of good practices for BPSD***

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Diagnosis across Europe

- **Most countries estimate they are missing diagnosis for 40 -60% of people**

- **When diagnosis does occur**

➢ **80% of countries report most usual at moderate stage (MMSE10-20)**

➢ **20% usual at Mild (MMSE 21-25)**

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Tentative recommendations process of diagnosis

- **Ensure the diagnostic process is managed to support good adjustment to the news such as promoting choice over whether to go forward for diagnosis and provision of information and interventions post diagnosis.**
- **<u>Recent criteria for diagnosis of dementia syndrome and its subtypes require further validation and possible revision but are recommended for use in clinical practice.</u>**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Revising the definition of Alzheimer's disease: a new lexicon

Bruno Dubois, Howard H Feldman, Claudia Jacova, Jeffrey L Cummings, Steven T DeKosky, Pascale Barberger-Gateau, André Delacourte, Giovanni Frisoni, Nick C Fox, Douglas Galasko, Serge Gauthier, Harald Hampel, Gregory A Jicha, Kenichi Meguro, John O'Brien, Florence Pasquier, Philippe Robert, Martin Rossor, Steven Salloway, Marie Sarazin, Leonardo C de Souza, Yaakov Stern, Pieter J Visser, Philip Scheltens

Lancet Neurol 2010; 9: 1118–27
Published Online
October 11, 2010
DOI:10.1016/S1474-4422(10)70223-4
See Reflection and Reaction page 1044

Pierre & Marie Curie University, Paris, Research Centre of the Institute of the Brain and Spinal Cord, Institute for Memory and Alzheimer's

Alzheimer's disease (AD) is classically defined as a dual clinicopathological entity. The recent advances in use of reliable biomarkers of AD that provide in-vivo evidence of the disease has stimulated the development of new research criteria that reconceptualise the diagnosis around both a specific pattern of cognitive changes and structural/biological evidence of Alzheimer's pathology. This new diagnostic framework has stimulated debate about the definition of AD and related conditions. The potential for drugs to intercede in the pathogenic cascade of the disease adds some urgency to this debate. This paper by the International Working Group for New Research Criteria for the Diagnosis of AD aims to advance the scientific discussion by providing broader diagnostic coverage of the AD clinical spectrum and by proposing a common lexicon as a point of reference for the clinical and research communities. The cornerstone of this lexicon is to consider AD solely as a clinical and symptomatic entity that encompasses both predementia and dementia phases.

Organising the language of Alzheimer's disease in light of biomarkers

Published Online
October 11, 2010
DOI:10.1016/S1474-4422(10)70246-5
e Position Paper page 1118

Criteria for Alzheimer's disease dementia have served clinicians remarkably well for the past 25 years despite the fact that they predate knowledge of biomarkers, quantitative neuroimaging, other dementias of late life, disease continuum; otherwise, a diagnosis of Alzheimer's disease cannot be made. Furthermore, according to these definitions, episodic memory impairment must be present as the clinical phenotype for typical Alzheimer's

Lon S Schneider
Departments of Psychiatry and Neurology, University of Southern California Keck School of Medicine, Los Angeles, CA, USA; and University of Southern California Alzheimer's Disease Research Center, Los Angeles, CA, USA

This presentation arises from the Joint Action ALCOVE which
Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Panel 2: Diagnostic criteria for AD

Probable AD: A plus one or more supportive features B, C, D, or E

Core diagnostic criteria

A. Presence of an early and significant episodic memory impairment that includes the following features:

1. Gradual and progressive change in memory function reported by patients or informants over more than 6 months
2. Objective evidence of significantly impaired episodic memory on testing: this generally consists of recall deficit that does not improve significantly or does not normalise with cueing or recognition testing and after effective encoding of information has been previously controlled
3. The episodic memory impairment can be isolated or associated with other cognitive changes at the onset of AD or as AD advances

Supportive features

B. Presence of medial temporal lobe atrophy

- Volume loss of hippocampi, entorhinal cortex, amygdala evidenced on MRI with qualitative ratings using visual scoring (referenced to well characterised population with age norms) or quantitative volumetry of regions of interest (referenced to well characterised population with age norms)

C. Abnormal cerebrospinal fluid biomarker

- Low amyloid β_{1-42} concentrations, increased total tau concentrations, or increased phospho-tau concentrations, or combinations of the three
- Other well validated markers to be discovered in the future

D. Specific pattern on functional neuroimaging with PET

- Reduced glucose metabolism in bilateral temporal parietal regions
- Other well validated ligands, including those that foreseeably will emerge such as Pittsburg compound B or FDDNP

E. Proven AD autosomal dominant mutation within the immediate family

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

ELSEVIER

Alzheimer's & Dementia ■ (2011) 1–7

Alzheimer's & Dementia

The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup

Guy M. McKhann[a,b,*], David S. Knopman[c], Howard Chertkow[d,e], Bradley T. Hyman[f], Clifford R. Jack, Jr.[g], Claudia H. Kawas[h,i,j], William E. Klunk[k], Walter J. Koroshetz[l], Jennifer J. Manly[m,n,o], Richard Mayeux[m,n,o], Richard C. Mohs[p], John C. Morris[q], Martin N. Rossor[r], Philip Scheltens[s], Maria C. Carillo[t], Bill Thies[t], Sandra Weintraub[u,v], Creighton H. Phelps[w]

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

In persons who meet the core clinical Criteria for probable AD dementia biomarker evidence may **increase the certainty that the basis of the clinical dementia syndrome is the AD pathophysiological process**. However, we do not advocate the use of AD biomarker tests for routine diagnostic purposes at the present time. There are several reasons for this limitation: (1) the core clinical criteria provide very good diagnostic accuracy and utility in most patients; (2) more research needs to be done to ensure that criteria that include the use of biomarkers have been appropriately designed, (3) there is limited standardization of biomarkers from one locale to another, and (4) access to biomarkers is limited to varying degrees in community settings. Presently, the use of biomarkers to enhance

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STUDI DIAGNOSTICI E VALUTAZIONI PROBABILISTICHE

Luigi Pagliaro,
Marco Bobbio
Agostino Colli.

LA DIAGNOSI IN MEDICINA
Raffaello Cortina Editore
2011.

Tabella 7.1 Architettura della ricerca diagnostica e fasi degli studi.

Fase	Disegno e popolazione	Oggetto dello studio	Risultato
Fase I	Popolazione normale	Distribuzione dei risultati	Definizione dei valori normali, ripetibilità e riproducibilità, influenza di età, sesso, BMI ecc.
Fase II			
a	Caso/controllo affetti/volontari sani	Discriminazione affetti/sani	Stima capacità discriminativa
b	Caso/controllo	Correlazione con gravità malattia	Stima capacità discriminativa
c	Coorte consecutiva prospettica di pazienti con sospetto clinico di malattia	Identificazione dei pazienti affetti e dei non affetti	Stima della accuratezza dell'index test (sensibilità e specificità)
Fase III	Trial clinico randomizzato	Effetto del test su outcome clinici	Efficacia della strategia diagnostica includente il nuovo test
Fase IV	Osservazionale in ampia coorte	Effetto del test su outcome clinici	Efficacia reale (effectiveness) della strategia diagnostica includente il nuovo test

This presentation arises from the Joint Action AL
Union in the framework of the Public Health Pro

STUDI DIAGNOSTICI E VALUTAZIONI PROBABILISTICHE (esempio)(a)

Nella fase III il disegno utilizzato è quello del trial clinico randomizzato (RCT). Il confronto avviene tra pazienti randomizzati all'esecuzione o meno del test in un predefinito percorso diagnostico.
I pazienti vengono randomizzati in due gruppi, uno solo dei quali esegue il nuovo test, mentre tutto il rimanente percorso diagnostico e terapeutico rimane invariato.
Si misurano gli esiti clinici (clinical outcomes) e quindi i benefici o i danni per il paziente (Sackett, Haynes 2002, Gluud, Gluud 2005).
Questo disegno è in grado di ridurre i fattori confondenti (confounders) che possono inficiare i risultati degli studi osservazionali.

Luigi Pagliaro, Marco Bobbio
Agostino Colli.

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

STUDI DIAGNOSTICI E VALUTAZIONI PROBABILISTICHE (esempio)(b)

Un esempio di trial clinico randomizzato recentemente condotto in Danimarca per valutare l'utilità delle stadiazioni delle neoplasie polmonari (non a piccole cellule) Con PET, rispetto a quella tradizionale con TC. Nei due gruppi, randomizzati a essere stadiati con TC o con PET, nonostante rilevanti difformità nella definizione dello stadio di malattia, non sono state dimostrate significative variazioni dei risultati clinici (mortalità e recidive)(Fischer 2009, NEJM). Quindi la maggiore accuratezza della stadiazione PET rispetto a quella con TC non sembra aver prodotto risultati clinicamente migliori.

Luigi Pagliaro, Marco Bobbio Agostino Colli.

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The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Preoperative Staging of Lung Cancer with Combined PET–CT

Barbara Fischer, Ph.D., Ulrik Lassen, Ph.D., Jann Mortensen, Dr.Med.Sci., Søren Larsen, Ph.D., Annika Loft, Ph.D., Anne Bertelsen, M.D., Jesper Ravn, M.D., Paul Clementsen, Dr.Med.Sci., Asbjørn Høgholm, M.D., Klaus Larsen, M.D., Torben Rasmussen, Ph.D., Susanne Keiding, Dr.Med.Sci., Asger Dirksen, Dr.Med.Sci., Oke Gerke, Ph.D., Birgit Skov, Dr.Med.Sci., Ida Steffensen, Ph.D., Hanne Hansen, M.D., Peter Vilmann, Dr.Med.Sci., Grete Jacobsen, Dr.Med.Sci., Vibeke Backer, Dr.Med.Sci., Niels Maltbæk, M.D., Jesper Pedersen, Dr.Med.Sci., Henrik Madsen, M.D., Henrik Nielsen, Dr.Med.Sci., and Liselotte Højgaard, Dr.Med.Sci.

Table 1. Characteristics of the Patients at Baseline.*

Characteristic	PET–CT (N=98)	Conventional Staging (N=91)	P Value
Patients			
Age (yr)			0.22
Mean	63	64	
Range	42–80	38–80	
Male sex (no. of patients)	53	49	0.97
Female sex (no. of patients)	45	42	

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group (P=0.05). There were no significant differences in survival between the two groups; median survival was 31 months in the PET–CT group and 49 months in the conventional-staging group (P=0.29). At follow-up, 56% of all patients had died (61% in the PET–CT group and 51% in the conventional-staging group, P=0.15). In most pa-

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ALCOVE preliminary results
All WP

	What do we know about ? Summaries of the situation in Europe and of the evidence	How to improve ? Propositions of different options with tools for implementation & evaluation
Safety issue	Exposure to antipsychotics (AP) in AD in Europe – **WP4** Earlier diagnosis & limitation of AP – **WP5** Outstanding programmes to limit overuse of AP – **WP6** Key ethical questions regarding the AP use – **WP7**	ALCOVE Tool box

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ALCOVE TOOL BOX

FOR LIMITING ANTIPSYCHOTICS IN DEMENTIA

ALzheimer COoperative Valuation in Europe

WHY SUCH A TOOL BOX?

- Antipsychotics for behavioral disorders in dementia represent a crucial safety & ethical issue
- ALCOVE, the European Joint Action on dementia, has benchmarked between European MS 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

To know more

RISK MEASUREMENT

- Risk exposure in Europe
  The results of ALCOVE SURVEY
- Examples of monitoring of AP in dementia
  - The UK audit
  - The French survey
  - The Swedish registry
- ALCOVE recommendations & tools to support data collection

To know more

DIAGNOSIS

- Why & how an earlier diagnosis contributes to Antipsychotics limitation?
- Examples of outstanding projects
  - XX
  - XX
- ALCOVE Check-list: elements to accompany diagnosis & reduce behavioral disorders & antipsychotics

To know more

ETHIC IN PRACTICE

- The key questions regarding to the use of antipsychotics
- What do we know about antipsychotics & competence assessment?
- Tool for ethic in practice
- Legal and ethical aspects of the use of antipsychotics

To know more

Key points for success

Xx
Xx
Xx
Xx
Xx
Xx
Xx

RISK REDUCTION

- ALCOVE survey on strategies for risk reduction in Europe
- Outstanding projects
  - The UK Call for Action
  - The French AMI programme
  - xxxx
- Tools for risk reduction strategy

To know more

Behavioral & Psychological Symptoms of Dementia

PREVENTION & CARE

- ALTERNATIVES TO AP
  Non pharmacological interventions & level of evidence
- TOOLS FOR GOOD PRACTICES
  - What to do, what not to do?
  - Bath & toilets
- ALCOVE CLINICAL INDICATORS of good practice

To know more

SUPPORT SYSTEMS

- What are Care Support Systems (CSS) for BPSD ?
- Outstanding projects of CSS for BPSD
- ALCOVE quality criteria for CSS

To know more

EDUCATIONAL PROGRMMES (EP)

INFORMAL CAREGIVERS
- Key messages 1 communication
- ALCOVE survey on EP in Europe
- ALCOVE recommendations for EP
- ALCOVE criteria for EP

HEALTH PROFESIONALS
- Key messages
- ALCOVE survey on guidelines and EP in Europe
- ALCOVE recommendations for EP
- ALCOVE criteria for EP

To know more

www.alcove-project.eu

Executive Agency for Health and Consumers

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Work Package 4

Prevalence: Cohorts, Epidemiology and Registration Network

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Associated Partners

- **ISS, Italy, WP4 leader;**
- **National Institute of Health and welfare (THL), Finland**
- **Institut National de la Sante et la Recherche Medical (INSERM), France**
- **Karolinska Institute (IK), Sweden**
- **Athens Association of AD and Related Disorders (AAADRD), Greece**
- **Ministero della Salute (MINSAL), Italy**

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Collaborating Partners

- **Haute Authorite de Sante (HAS), France;**
- **Institudo de Salud Carlos III (ISCIII), Spain;**
- **Slovenska Akademia Vied – Neuroimmunologicky Ustav (NIU SAV), Slovakia**

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Specific objective

Recommendations to improve epidemiological data on AD and other dementia with an overview of available data and definition of best practices for data collection.

Milestone 1. Publication of a systematic review of available population-based epidemiological studies on dementia

Milestone 2. Publication of a survey on available data on exposure to psychotropic drugs in people with dementia

Milestone 3. Publication of survey on available data on health and social care services for all other information in people with dementia

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Methods (a)

Identification of the studies to be included in the systematic review

and definition and application of the following inclusion criteria as

those defined in the Eurocode project:

- **a. Community based study**
- **b. Minimum sample size 300**
- **Study survey date including 2006 or thereafter.**
- **Use of standardized diagnostic criteria**
- **Participation rate over 50 %**

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Inclusion Criteria:

1. Community based study
2. Minimum sample size 300
3. Study survey date including 1990 or thereafter.
4. Use of standardized diagnostic criteria
5. Participation rate over 50 %
6. Available raw prevalence data

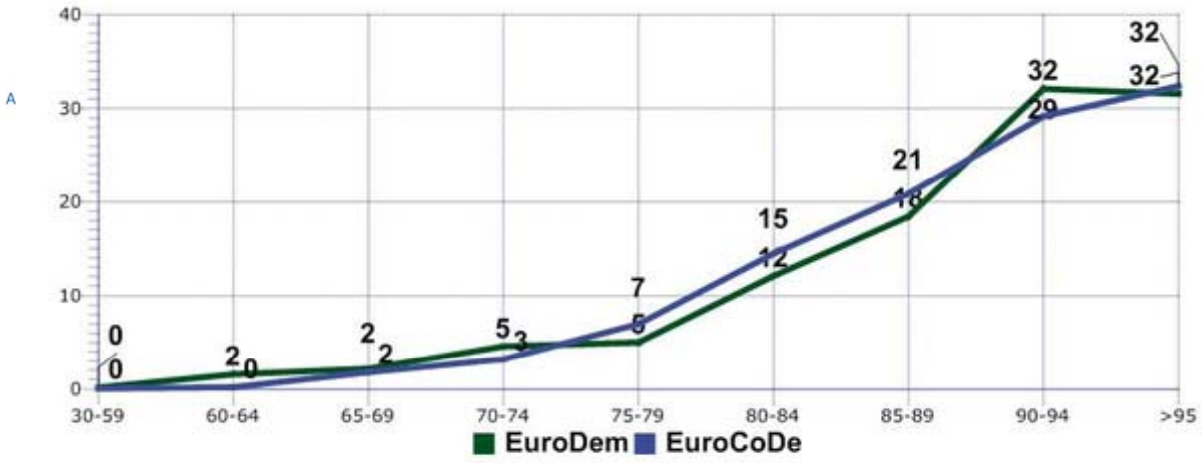
A total of 194 articles were identified from the literature search. 31 studies were identified as possible for inclusion in collaborative analysis and they were invited to submit data. Raw data was obtained from 17 studies and used in the collaborative analysis of dementia prevalence rates in Europe ■

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Author	Country	Number of participants	Age range	Prevalence of dementia (%)
Gabryelewicz	Poland	893	65-84	5.7
Ravaglia	Italy	1016	?65	5.9
Tognoni	Italy	1600	?65	6.2
Ott	Netherlands	7528	>55	6.3
De Ronchi	Italy	7930	?61	6.5
Bdzan	Poland	1000	?60	6.7
Andersen	Denmark	3346	65-84	7.1
Prencipe	Italy	968	?65	8
Gascon-Bayarri	Spain	1754	?70	9.4
Ferini-Strambi	Italy	673	?60	9.8
Gostynski	Switzerland	465	?65	10.1
Strauss	Sweden	1424	77-84	13
Vilalta-Franch	Spain	1460	?70	16.3
Manubens	Spain	1127	>70	17.2
Riedel-Heller	Germany	1265	?75	17.4
Helmer	France	1461	?75	17.8
Azzimondi	Italy	727	>74	21.9

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Prevalence of dementia (men)



2006-2008: European Collaboration on Dementia (EuroCoDe)

Prevalence of dementia (women)

This presentation arises from the joint Action A2SD V2 which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Preliminary results (a)

- **The systematic review on prevalence rates for dementia in Europe using the same terms used by Eurocode systematic review (as reported in their web-site) in the period January 1, 2008 to September 15th 2011, both as MeSH terms and as free text in title and abstract in the most recent period has allowed to identify the 14 papers**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Preliminary results (a) – Prevalence studies that adopted DSM IV clinical criteria(n=8)

Author	65-69			70-74			75-79			80-84			>=85		
	pop	cases	rate (%)	pop	cases	rate (%)	pop	cases	rate (%)	pop	cases	rate (%)	pop	cases	rate (%)
Fernandez 2008	511	10		572	30		395	31		251	34		202	70	
Fish 2008	500	4		590	23		457	43		117	18				
Gavrila 2009	339	1		285	10		194	13		111	13		88	19	
Bermejo-Pareja 2009	1647	17		1411	32		959	42		739	85		522	130	
Spada 2009	66	1		75	3		45	4		41	11				
Numes 2010	258	4		237	10		165	12							
Mathillas 2011													430	114	
Mathillas 2011 bis													465	173	
Virues-Ortega 2011							216	7		165	17		165	25	
total	3321	37	1,11	3170	108	3,41	2431	152	6,25	1424	178	12,5	1872	531	28,4

Total population

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Special Article

THE EFFECT OF DIFFERENT DIAGNOSTIC CRITERIA ON THE PREVALENCE OF DEMENTIA

TIMO ERKINJUNTTI, M.D., PH.D., TRULS ØSTBYE, M.D., M.P.H., RUNA STEENHUIS, PH.D., C.PSYCH., AND VLADIMIR HACHINSKI, M.D., D.SC.(MED.)

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
The variability of clinical criteria adopted

TABLE 3. PREVALENCE OF DEMENTIA IN THE CSHA COHORT AS DIAGNOSED BY VARIOUS CLASSIFICATION SYSTEMS, ACCORDING TO AGE GROUP.*

AGE GROUP	No.	DSM-III	DSM-III-R	DSM-IV	ICD-9	ICD-10	CAMDEX	CLINICAL CONSENSUS
yr				number of subjects (percent)				
65–74	391	85 (21.7)	41 (10.5)	43 (11.0)	17 (4.3)	8 (2.0)	7 (1.8)	57 (14.6)
75–84	931	245 (26.3)	149 (16.0)	114 (12.2)	41 (4.4)	28 (3.0)	49 (5.3)	184 (19.8)
≥85	557	216 (38.8)	136 (24.4)	100 (18.0)	36 (6.5)	22 (3.9)	36 (6.5)	152 (27.3)
Total	1879	546 (29.1)	326 (17.3)	257 (13.7)	94 (5.0)	58 (3.1)	92 (4.9)	393 (20.9)

*CSHA denotes the Canadian Study of Health and Aging.

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
The variability of clinical criteria adopted

- **Out of 14 studies identified in ALCOVE two (De Pedro Cuesta 2009, Renvoize 2010) have been excluded because the first is a review and the second regarding the epidemiology on young onset dementia (45-64 yrs).**
- **Out of remaining 12 , 10 have adopted the DSM IV clinical criteria, one the CAMDEX criteria and one the DSM III.**
- **In the Eurocode out of 17 studies, 10 have adopted the DSM III R clinical criteria, 3 the DSM IV, two ICD 10, one CAMDEX and one DSM III criteria.**

The adoption of clinical criteria DSM III R entails probably an overestimation of about 26% of dementia prevalence rate compared to those of the DSM IV (see Erkinjuntti 1997)

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Methods (b)

- **Identification of the best epidemiological methods to perform accurate and valid estimates of dementia prevalence in Europe.**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Preliminary results (b)

- **The following principal characteristics influence the quality and the variability of prevalence studies in dementia:**

- **Sample size**
- **Design**
- **Response proportion**
- **Diagnostic assessment**
- **Clinical criteria adopted**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 1
Preliminary results (b)
The adoption of a quality score (ADI 2009)

An overall quality score was derived by summing scores for the following elements:

Sample size

<500	0.5 points
500-1499	1 point
1500-2999	1.5 points
>=3000	2 points

Design

Two phase study with no sampling of screen negatives	0 points
Two phase study with sampling of screen negatives but no weighting back	1 point
One phase study or two phase study with appropriate sampling and weighting	2 points

Response proportion

<60%	1 point
60-79%	2 points
>=80%	3 points

Diagnostic assessment

Inclusion of multidomain cognitive test battery, formal disability assessment, informant interview and clinical interview	1 point each

Alzheimer's Disease International
World Alzheimer Report
2009

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Esempio

Neuro
epidemiology

Original Paper

Neuroepidemiology 2007;28:224–234
DOI: 10.1159/000108597

Published online: September 19, 2007

Prevalence of Dementia Subtypes in El Prat de Llobregat, Catalonia, Spain: The PRATICON Study

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J.M. Ramón[b] J.M. Manubens[d†] C. Sánchez[a] M. Hernández[a] J. Estela[a]
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Abstract

Background: Studies on dementia subtypes show a wide variation in the prevalence of Alzheimer's disease (AD) and vascular dementia (VD) worldwide. However, studies reporting on Lewy body dementia (LBD) and frontotemporal dementia (FTD) are sparse. ***Aims:*** To describe the prevalence of dementia and subtypes. ***Method:*** A 34% sample of 5,150 subjects aged 70 years and over in El Prat de Llobregat (Barcelona) were screened by the Mini-Mental State Examination. When scoring <24, participants were assessed to establish a diagnosis. ***Results:*** There were 165 subjects diagnosed with dementia (prevalence of 9.4%). Subtypes of dementia were: AD 69.1%, VD 12.7%, LBD 9.1%, FTD 3% and secondary dementia 1.8%. Prevalences were: AD 6.5%, VD 1.2%, LBD 0.9% and FTD 0.3%. ***Conclusions:*** AD and VD were the most common type of dementia. Prevalence of dementia, AD and FTD were similar to those reported, while prevalence of VD and LBD were lower.

=186/1754

Prevalenza nei screened negative = 3/162=2%

Casi fra i screened negative = 0.018*1133=21

Prevalenza = 186/1754 =10.6%

This presentation arises from the Joint Action ALCOVE which has r
Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Table 1.3
Study characteristics, by region (for those regions within which meta-analyses were conducted), and by country income level
HIC = high income countries LAMIC = low and middle income countries

	Europe	North America	Latin America and Caribbean	Asia Pacific High Income	Austral-asia	Asia, East	Asia, South	Asia, South East	HIC	LAMIC	All regions
Number of studies [1]	51	13	15	20	4	34	7	5	93	64	157
Year of research											
1980-1989	13 (26%)	3 (23%)	0	7 (35%)	2 (50%)	5 (15%)	0	1 (20%)	25 (27%)	8 (13%)	33 (21%)
1990-1999	34 (67%)	9 (69%)	3 (20%)	10 (50%)	1 (25%)	25 (74%)	4 (57%)	2 (40%	59 (63%)	32 (50%)	91 (58%)
After 2000	4 (8%)	1 (8%)	12 (80%)	3 (15%)	1 (25%)	4 (12%)	3 (43%)	2 (40%)	9 (10%)	24 (38%)	33 (21%)
Sample size											
<500	16 (31%)	0	0	3 (16%)	2 (50%)	0	1 (14%)	1 (20%)	21 (23%)	3 (5%)	24 (16%)
500-1499	19 (37%)	4 (31%)	5 (36%)	7 (37%)	2 (50%)	10 (29%)	3 (43%)	4 (80%)	34 (37%)	24 (38%)	58 (37%)
1500-2999	9 (18%)	5 (39%)	8 (57%)	5 (26%)	0	10 (29%)	2 (29%)	0	21 (23%)	22 (34%)	43 (28%)
>=3000	7 (14%)	4 (31%)	1 (7%)	4 (21%)	0	14 (41%)	1 (14%)	0	16 (17%)	15 (23%)	31 (20%)
Outcome (Dementia criterion)											
ICD-10	1 (2%)	0 (0%)	0	1 (5%)	0	1 (7%)	1 (14%)	0	3 (3%)	2 (5%)	5 (4%)
DSM-IV/IIIR	37 (73%)	9 (69%)	8 (53%)	17 (85%)	2 (67%)	10 (71%)	4 (57%)	4 (80%)	69 (75%)	25 (60%)	94 (70%)
GMS/AGECAT	2 (4%)	1 (8%)	0	0 (0%)	0	0	0 (0%)	1 (20%)	3 (3%)	1 (2%)	4 (3%)
CAMDEX	6 (12%)	0 (0%)	0	0 (0%)	0	0	0	0	6 (7%)	1 (2%)	7 (5%)
Other	5 (10%)	3 (23%)	7 (47%)	2 (10%)	1 (33%)	3 (21%)	2 (29%)	0	11 (12%)	13 (31%)	24 (18%)
Design											
One phase	16 (31%)	2 (15%)	10 (67%)	3 (15%)	3 (75%)	3 (21%)	3 (43%)	0	25 (27%)	16 (36%)	41 (30%)
Two or more phases	36 (69%)	11 (85%)	5 (33%)	17 (85%)	1 (25%)	11 (89%)	4 (57.%)	5 (100%)	69 (73.%)	20 (46%)	97 (70%)
Multiphase design applied and analysed correctly [2]	22%	55%	20%	12%	100%	9%	0%	0%	25%	11%	21%
Response proportion											
<60%	5 (10%)	0	0	0	0	0	0	0	5 (5.3%)	1 (2%)	6 (4%)
60-79%	16 (31%)	6 (46%)	2								
(13%)	3 (15%)	2									
(50%)	4 (29%)	1 (14%)	1 (20%)	29 (31%)	8 (18%)	37 (27%)					
80-100%	28 (54%)	5 (39%)	10 (67%)	10 (50%)	2 (50%)	10 (71%)	5 (71%)	1 (20%)	48 (51%)	26 (59%)	74 (54%)
Not specified	3 (6%)	2 (15%)	3 (20%)	7 (35%)	0	0	1 (14%)	3 (60%)	12 (13%)	9 (21%)	21 (15%)
Assessment quality											
Comprehensive diagnostic assessment [3]	28 (55%)	5 (39%)	11 (73%)	2 (10%)	0	4 (31%)	3 (43%)	1 (20%)	36 (39%)	21 (51%)	57 (43%)
Overall quality score [4]											
Mean (SD)	8.2 (1.8)	8.2 (1.7)	9.7 (2.0)	6.6 (1.6)	8.3 (0.9)	8.0 (1.9)	8.4 (2.2)	5.5 (0.7)	7.8 (1.8)	8.3 (2.5)	7.9 (2.0)

World Alzheimer Report 2009

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

SOURCE OF VARIABILTY IN PREVALENCE RATES OF ALHEIMER'S DISEASE (Corrada et al.1995)

1. Inclusion of mild cases of dementia
2. Inclusion of instituzionalized subjects
3. Use of CT scans in diagnosing AD
4. Use of laboratory blood test in diagnosing AD
5. Use of Hachinski Ischemic Score (HIS) to diagnose vascular dementia
6. Type of sample (random sample, versus total population ascertainment)
7. Rate adjustement for false negative in studies that used a two stage procedure
8. Type of community (urban, rural or mixed urban/rural)

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
Methods

- **The aim of the literature search is to find published data on the proportion of people with dementia to whom antipsychotics are prescribed in European countries. Only studies that use large databases and only studies that have the assessment of the proportion of drug use among their primary aims will be assessed. The literature search will be divided between ambulatory care (community setting) and residential care (institutionalized setting)**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
PREVALENCE USE OF ANTIPYSHCOTICS IN DEMENTIA PATIENTS IN GENERAL POPULATION

Author	Year	Country	Pts with dementia	Pts with AA exposure	%
Giron et al. 2001	1994-6	Sweden	188	34	18.1%
Hartikainen et al. 2003	1998	Finland	77	25	32.5 %
Jedenius et al. 2011	2005	Sweden	815	n.a.	2.9% *
Shah et al. 2011	2008-9	England and Wales	627	63	10.1%
Guthrie et al. 2010	2007	Scotland	10.058	1.865	17.7%
HSD	2010	Italy	21.500	2.282	9.4%

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
PREVALENCE USE OF ANTIPYSHCOTICS IN DEMENTIA PATIENTS IN SPECIALISTIC CENTRES

Author	Year	Country	Pts with dementia	Pts with AA exposure	%
Prudent et al 2008	2001-2	French	543 *	94	17.3%
Haw et al 2008	2006-7	UK	60	28	46.7%
Musicco et al. 2011	2002-8	Italy	4369	1093	25.5%

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
PREVALENCE USE OF ANTIPYSHCOTICS IN DEMENTIA PATIENTS IN NURSING HOMES

Author	Year	Country	Pts with dementia	Pts with AA exposure	%
Hosia-Randell et al. 2005	2003	Finland	1380	597	43.3%
Nijk et al. 2009	2003	Netherlands	1322	606	46%
Martinez-Romero et al. 2010	n.a.	Spain	219	n.a.	18.5% *
Selbaek et al. 2008	2005-6	Norway	933	241	25.8%
Larrayadieu et al. 2011	2008	French	1948	591	30.3%
Nobili et al. 2009	2003	Italy	349	209	60%

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
Preliminary results (a)

- **The prevalence use of antipsychotics seems increase for the specific setting (although some data are conflicting) (community , home care, memory clinic, nursing home)**
- **The ratio between conventional and atypical antipsychotics is probably different for the specific setting (higher in nursing home and home care than memory clinic)**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 2
Preliminary results (b)

- **The difference between prevalence use of antipsychotics in dementia patients are probably also due to the methodological issues of the studies (retrospective, cross-sectional and cohort studies; definition of exposure to antipsychotics – at least one prescriptions or not)**

- **From descriptive data available shows a large inappropriate use of antipsychotics: chronic use, concomitant use of two antipsychotics or with benzodiazepines , absence of use as second-line after a non-pharmacological approach.**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

The use of antipsychotic medication for people with dementia:

Time for action

NHS choices

Antipsychotic prescriptions for people with dementia have reduced by 52 per cent in three years, according to an audit carried out by the NHS Information Centre.

The audit collected data from more than 3,800 GP practices in England, with information about nearly 197,000 people with dementia. The 52 per cent reduction is between 2008 and 2011.

It was also found that there were strong regional variations, with rates of prescribing of antipsychotic drugs up to six times higher in some areas than others.

Executive Agency for Health and Consumers

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Agenzia Italiana del Farmaco
AIFA
Ufficio Segreteria Organi Collegiali

Roma, 21 luglio 2005

COMUNICATO

IL TRATTAMENTO FARMACOLOGICO DEI DISTURBI PSICOTICI IN PAZIENTI AFFETTI DA DEMENZA

La Commissione Consultiva Tecnico Scientifica dell'A.I.F.A., nella seduta del 27 giugno 2005, valutato le premesse di carattere scientifico e le evidenze di farmacovigilanza relative agli antipsicotici di prima e di seconda generazione, nonché il ruolo svolto nella terapia dei disturbi psicotici e comportamentali in pazienti affetti da demenza, ha ritenuto necessario ed urgente la definizione di un programma di farmacovigilanza attiva, allo scopo di aumentare le conoscenze a disposizione su tale argomento.

Facendo seguito a tale richiamata decisione, l'A.I.F.A. dispone quanto segue.
Le disposizioni qui di seguito riportate riguardano sia gli antipsicotici di prima generazione sia quelli di seconda generazione (categoria ATC N05A).

2) L'AIFA istituisce un data-base dei trattati con demenza assuntori di farmaci antipsicotici, sulla base delle schede di monitoraggio compilate dai suddetti Centri Specialistici.

3) Le visite di monitoraggio devono avere usualmente cadenza bimestrale. Pertanto, la dispensazione degli antipsicotici usualmente non deve superare i 60 giorni di terapia, in base alle disposizioni adottate dalle Regioni.

Executive Agency for Health and Consumers
This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Per i medici che operano nell'ambito dei Centri Specialistici, viene individuato il seguente percorso clinico per giungere alla prescrizione degli antipsicotici nella demenza.

1. Valutare attentamente il disturbo da trattare. Nei malati di demenza, infatti, non tutti i disturbi del comportamento richiedono un trattamento con antispicotici. Tale trattamento deve essere, infatti, riservato al controllo dei disturbi comportamentali gravi che non abbiano risposto all'intervento non farmacologico (modifiche ambientali, counseling, ecc.)

AL2

2. Iniziare la terapia con una dose bassa e raggiungere gradualmente il dosaggio clinicamente efficace.

3. Se il trattamento è inefficace, sospendere gradualmente il farmaco e prendere eventualmente in considerazione un diverso composto.

4. Se il trattamento è efficace, continuare a trattare e monitorare il soggetto per un periodo di 1-3 mesi e poi, una volta che il soggetto sia asintomatico, tentare di sospendere gradualmente il farmaco. Gli alti tassi di risposta al placebo in tutte le sperimentazioni effettuate (mediamente attorno al 40%) ci ricordano infatti che siamo in presenza di sintomi per loro natura fluttuanti nel tempo e che tendono a risolversi spontaneamente nel breve periodo.

5. Evitare di somministrare due o più antipsicotici contemporaneamente. Questa pratica che dovrebbe essere eccezionale è in realtà troppo diffusa: da stime nazionali a circa il 2% dei dementi nella popolazione generale e a circa il 14% di quelli istituzionalizzati vengono somministrati due o più antipsicotici contemporaneamente.

6. Evitare l'uso concomitante di antipsicotici e benzodiazepine. Una percentuale variabile tra l'1 e il 5% dei dementi nella popolazione generale e circa il 17% di quelli istituzionalizzati vengono trattati con antipsicotici e ansiolitici/ipnotici contemporaneamente. A più del 4% dei dementi in istituzione vengono somministrati contemporaneamente tre o più tra antipsicotici e ansioliti/ipnotici! Anche questa associazione andrebbe fortemente limitata, soprattutto alla luce della dichiarazione dell'EMEA che riporta l'uso concomitante di benzodiazepine e olanzapina tra i fattori predisponenti associati all'aumento di mortalità.

7. Monitorare attentamente sicurezza ed efficacia dei antipsicotici e segnalare tempestivamente tutti gli effetti indesiderati.

8. Somministrare con estrema cautela gli antipsicotici a soggetti con fattori di rischio cardiovascolare dopo attenta valutazione dello stato clinico e con rivalutazione dei parametri vitali (e in particolare della pressione in clino e in ortostatismo) a distanza di una settimana dall'inizio della terapia.

Executive Agency for Health and Consumers

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

OPEN ACCESS Freely available online

PLoS one

How Are the Interests of Incapacitated Research Participants Protected through Legislation? An Italian Study on Legal Agency for Dementia Patients

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CURRENT OPINION

Drugs Aging 2012; 29 (8): 1-8
1170-229X/12/0008-0001/$49.95/0

How Legislation on Decisional Capacity Can Negatively Affect the Feasibility of Clinical Trials in Patients with Dementia

Francesca Galeotti,[1] Nicola Vanacore,[1] Sabina Gainotti,[1] Fabio Izzicupo,[2] Francesca Menniti-Ippolito,[1] Carlo Petrini,[1] Flavia Chiarotti,[1] Rabih Chattat[3] and *Roberto Raschetti[1] and the AdCare Study Group*

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Executive Agency for Health and Consumers

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

IL CONSENSO INFORMATO NEI SOGGETTI INCAPACI

Il riferimento normativo sul consenso informato in soggetti "incapaci" è il D.lgs 24 giugno 2003, n. 211 ("*Attuazione della direttiva 2001/20/CE relativa all'applicazione della buona pratica clinica nell'esecuzione delle sperimentazioni cliniche di medicinali per uso clinico*").

In particolare all'art. 5 la norma stabilisce che:

(...) *la partecipazione ad una sperimentazione clinica degli adulti incapaci che non hanno dato o non hanno rifiutato il loro consenso informato prima che insorgesse l'incapacità e' possibile solo a condizione che:*
sia stato ottenuto il consenso informato del rappresentante legale;

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Publication of a survey on available data on exposure to psychotropic drugs in people with dementia (September 2012)

Milestone 2

TASK 2.3; 2.4

Development and collection of a questionnaire for identification of available data on psychotropic drug (antidepressant, antipsychotics, BDZ) prescriptions in dementia

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

ALzheimer COoper

ALzheimer COoperative Valuation in Europe

Available data about prescriptions of psychotropic medications in dementia

Questionnaire

Dear Colleague,
The aim of the following questionnaire is to collect data on prescriptions of psychotropic medication in dementia. We ask you to fill it as key person involved in Dementia care and/or planning. Thank you in advance for your time!

Institution responsible for filling out this questionnaire:

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

1. Are the medications prescribed paid by the Health System?

☐ Yes ☐ No ☐ Partly

2. Is it possible to collect specific information about prescriptions of cholinesterase inhibitors and/or memantine?

☐ Yes ☐ No

3. If the answer to question (2) is **yes**, are pharmacoepidemiological indicators available?

☐ Yes ☐ No

4. If the answer to question (3) is **yes**, please specify both qualitative and quantitative data (i.e. DDD, prevalence of use, etc.)

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

5. Are these data:

- Census based (population based) ☐Yes ☐No
- Sample data (based on defined sample methodology) ☐Yes ☐No

What percentage of the total population is covered?_____

If the coverage is incomplete, are the data extrapolated to reach 100% coverage?

☐Yes ☐No if yes please specify:

6. Are there data available on the prescriptions of psychotropic medications in these specific settings?

- Outpatient clinic ☐Yes ☐No if yes please specify:

  _____

  _____
- Hospitals ☐Yes ☐No if yes please specify:

  _____

  _____
- Nursing home ☐Yes ☐No if yes please specify:

  _____

  _____
- Population ☐Yes ☐No if yes please specify:

  _____

  _____

7. Is it possible to ascertain if a prescription for a psychotropic medication is made for a person affected by dementia? ☐Yes ☐No

If yes please specify for the following categories:

- Antidepressants (ATC N06A):

  _____

  _____
- Benzodiazepines (ATC N05B):

  _____

  _____
- Antipsychotics (ATC N05A):

  _____

  _____

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

TASK 2.5

Description of the possibility to identify subjects with a clinical diagnosis of dementia exposed to psychotropic drugs in countries included in WP4 of ALCOVE project

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Methods: possible approaches in the identification of AD patients

A pilot study using a record linkage procedure

- Patients treated with acetylcholinesterase inhibitors (AChEI)
- Hospitalised patients (with primary or secondary diagnosis of AD)
- Patients followed by neurological centres involved in the diagnosis and treatment of AD
- Patients (with diagnosis of AD) followed by GPs
- Patients in residential care centres

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 3
Methods

- **Survey for characterization of National programs dedicated to dementia in Europe**
- **Survey on available data on dementia, strenghts and waknessess of data collection systems**

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

DH Department of Health

Living well with dementia:
A National Dementia Strategy

A network of memory clinics: when and how?

The first stage of an ambitious plan to transform dementia services in England over the next 5 years, a consultation on a National Dementia Strategy (NDS), opened for public discussion on June 19. In a country struggling to cope with the health and social care needs of more than 500 000 patients with dementia—a number expected to at least double by 2040—this is undoubtedly a much-needed approach. Neurologists, psychiatrists, geriatricians, and dementia researchers should not miss the opportunity to shape the future of dementia health services.

patients with memory complaints referred by their family doctors would receive a prompt diagnostic assessment.

The provision of memory assessment clinics as referral points for diagnosis is a key recommendation of the 2006 National Institute for Health and Clinical Excellence guidelines on the management of dementia, and has also been recommended by the European Dementia Consensus Network. The model of multidisciplinary memory clinics proposed by the NDS has been successfully evaluated in the Croydon Memory Service, a pilot clinic in south

www.thelancet.com/neurology Vol 7 August 2008

n ALCOVE which has received funding from the European
h Programme. (Grant Number 2010 22 01)

Plan « Alzheimer et maladies apparentées » 2008-2012

Funding summary

1.6 billion euros over 5 years

300 million euros in 2008

The medico-social aspect **over 1.2 billion euros**

Spending will amount to 254 million euros in 2008.
Funding will be provided by the health insurance system and the National Fund for the Autonomy of Elderly and Disabled People (Caisse nationale de solidarité pour l'autonomie des personnes âgées et des personnes handicapées, CNSA).

The health aspect **over 200 million euros**

Health spending will represent 23 million euros in 2008, most of which will come from the health insurance system.

The research aspect **200 million euros**

The creation of a Foundation for Scientific Research will make it possible to stimulate and coordinate research into Alzheimer's disease in France and to attract public and private resources to the issue.
In 2008, 29 million euros of spending are planned (including an initial capital subsidy from the state for the Foundation for Scientific Cooperation of €14.4 million).

Th… pean Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

1. Context and issues

A major effort has been made in recent years to ensure that each health district (territoire de santé) has its own memory unit (consultation mémoire).

On 31 December 2006 there were 366 memory units located in short-stay institutions throughout the country, of which 234 were recognised by regional hospitalisation agencies (agences régionales d'hospitalisation, ARH). A large degree of regional diversity remains. This is why it is necessary to **create 38 memory units** to enable each region to reach a satisfactory level of facilities.

6. Funding

- ***Funding amount***

  A memory unit requires a multidisciplinary team including practitioners in neurology, geriatrics or psychiatry , a psychologist or speech therapist and secretarial provision.

  Creation of 38 memory units over the term of the plan: **€6.68 million over 5 years**

  For 2008: **creation of 24 memory units, i.e. €4.224 million for new measures and additional funding for the memory units created in 2007 (€2.7 million)**

- ***Sources of funding***

  Health insurance system: national targets for health insurance spending (Objectif national des dépenses d'assurance maladie, ONDAM), health establishments, missions of public interest and support for contracting (Missions d'intérêt général et d'aide à la contractualisation, MIGAC)

7. Evaluation

- Monitoring of activity figures for new memory units six months after they open: number of active patients, unit opening times
- Number of memory units

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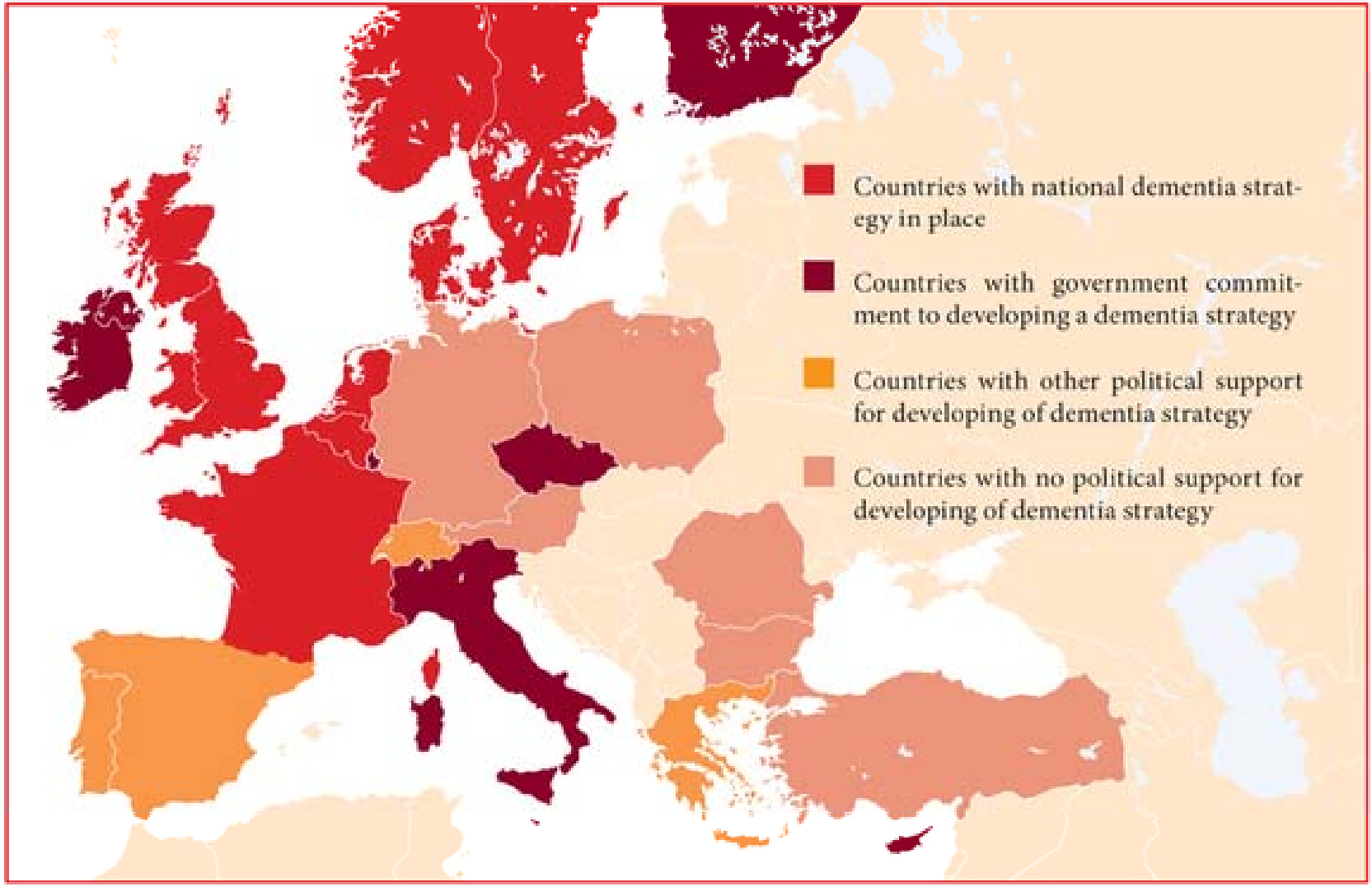
Last Updated: Thursday 15 March 2012

The status of national dementia strategies in Europe



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Vol. 12, N. 3, Luglio-Settembre 2011

Qual è l'effetto dei programmi di gestione integrata nel ritardare l'istituzionalizzazione delle persone affette da demenza? I risultati di una revisione sistematica della letteratura

Chiara Rivoiro[1], Francesca Galeotti[2], Nicola Vanacore[2]

[1]*AReSS Piemonte;* [2]*Centro Nazionale di Epidemiologia, Sorveglianza e Promozione della salute, Istituto Superiore di Sanità*

Riassunto. Il problema della demenza sta assumendo una rilevanza crescente in termini di sanità pubblica. In Italia si stima che vi siano circa 1.000.000 di persone affette da demenza e 3.000.000 di familiari coinvolti nell'assistenza. La letteratura internazionale evidenzia gli effetti positivi di un approccio di gestione integrata a tale patologia sulla salute, l'organizzazione ed i costi diretti ed indiretti. Questa review nasce con l'intento di determinare l'efficacia del modello di gestione integrata della malattia per i pazienti con demenza e per i loro caregiver nel ritardare il momento dell'istituzionalizzazione. Solo nove studi sono stati selezionati per la valutazione finale nella revisione. Tutti gli studi hanno confrontato gli esiti di un intervento di gestione integrata su un gruppo costituito da coppie di malati/caregiver con un gruppo di controllo a cui venivano offerte le cure standard. I pazienti che hanno ricevuto l'intervento sperimentano una riduzione variabile del tasso di istituzionalizzazione rispetto ai controlli. I caregiver coinvolti nei gruppi sperimentali hanno mostrato un sollievo nel loro carico di cura soggettivo e oggettivo. Emergono dunque evidenze che la gestione integrata della malattia può essere efficace per la presa in carico delle persone affette da demenza, ma il grado di questo effetto è lieve e non è ancora chiaro quale tipo di intervento risulta più utile per i malati ed i caregiver ed in quale stadio della demenza.

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Regione Lombardia

ASL Brescia

PERCORSO DIAGNOSTICO-TERAPEUTICO-ASSISTENZIALE DECADIMENTO COGNITIVO/DEMENZA

Settembre 2011

This presentation arises from the Joint Action ALCOVE which has received funding from the European Union in the framework of the Public Health Programme. (Grant Number 2010 22 01)

Milestone 3
Methods

- **Review of the grey literature: National Plans, Programs, Policies, Guidelines on dementia care available in English in Europe**
- **Definition of the questionnaires main themes and categories based on the standards of care outlined in the literature**
- **First draft shared with Alcove partners and pre test**
- **Questionnaire administration via email to all Alcove partner, then to all Collaborative Partners and Member States**
- **Data collection via email or fax**
- **Data analysis with EpiInfo and Nvivo (qualitative data)**

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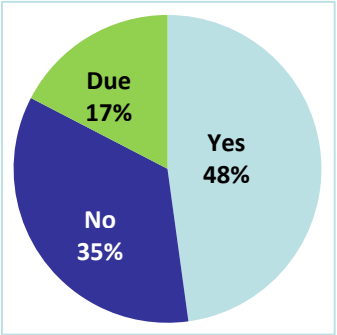
Milestone 3
Preliminary results – Survey on National Plans (NP)

- **Response rate AP and CP 100%, other MS 37.5%**
- **EU Countries with a National Plan or Policy →**
- **NP totally or partially based on national data 92%**
- **9/11 NP have a set of defined outcomes, standards and indicators**
- **7/11Have a system to measure indicators on a regular basis**



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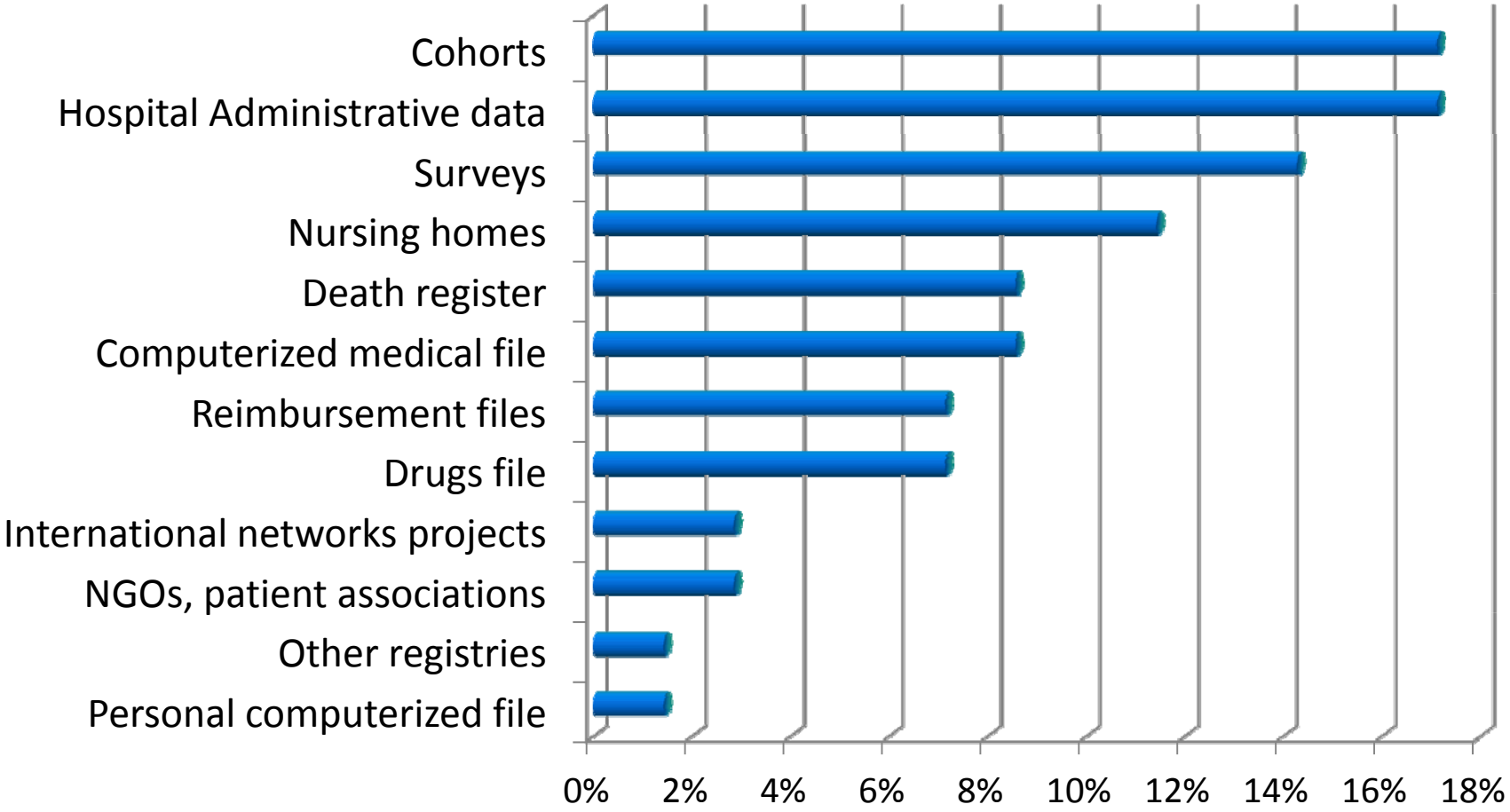
Milestone 3
Preliminary results – Survey available data

Classes of data sources (82 different sources identified)



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ALCOVE Final Event
28th March 2013

PALAIS de IENA
PARIS

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