ALzheimer COoperative Valuation in Europe

The European Joint Action on Dementia
Public Health Programme 2008 - 2013
European Union

Core results and major indications from the Joint Action ALCOVE

Pierre Krolak-Salmon, French coordination of the JA

Nicola Vanacore, Italian coordinator of the WP Epidemiology

Unremembering eyes
A smile that barely ages
Distant yet so close

Herman Van Rompuy
President of the European Council

Italian Presidency of the Council of European union, 14th November 2014

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

100 authors & contributors
170 respondants

16 Associated Partners

HAS, France, WPL1
ISCIII, Spain, WPL2
NIU SAV, Slovakia, WPL3
ISS, Italy, WPL4
Worcester UNiversity, DoH, United Kigdom, WPL5
THL, Finland, WPL6
KBF, Belgium, WPL7
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UNIBS, Italy
RPNC Latvia
KMU, Lithuania
BIOEF, Spain
IKarolinska, Sweden

14 Collaborating Partners

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AA, Hungary
MoH, Lithuania
Vilnius University, Lithuania
MoH, Luxemburg,
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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.

ALCOVE organisation

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 Wellfare* (BPSD Support Systems) **Pr Harriet Finne-Soveri, Pr Pierre Krolak-Salmon, Pr Matti Mäkelä, Paivi Topo, Ulla Eloniemi-Sulkava**
- *Belgium King Baudoin Foundation* (Ethics)
  Gerrit Raws, Bénédicte Gombault,, Tom Goffin

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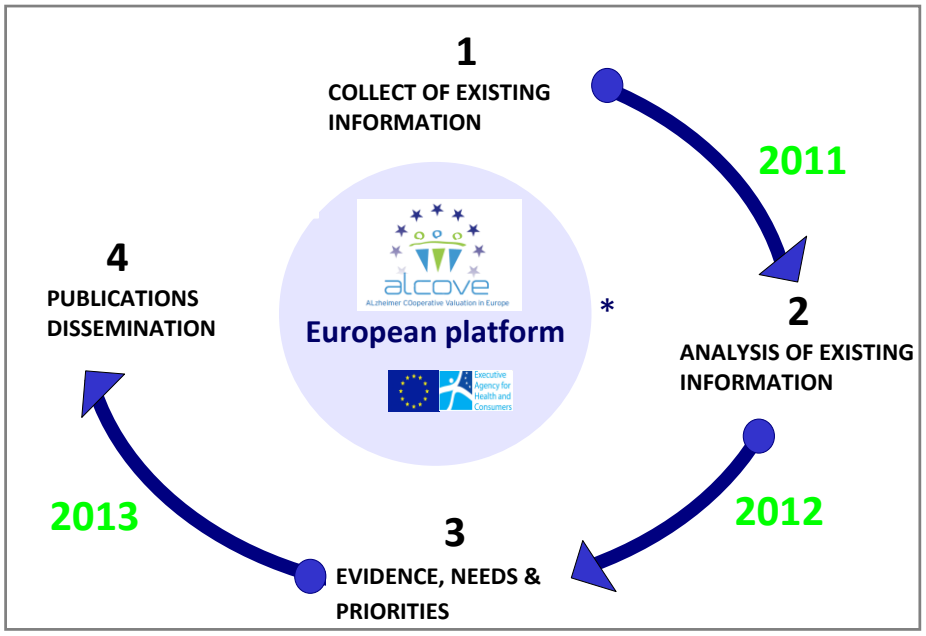
ALCOVE, a collaborative method



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

Archives of Public Health 2012, **70**:21

3 sources of work

(i) Questionnaires for European MS

(ii) Review & analysis of the literature

(iii) Exchanges 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

Collaborative – Independent
Scientific - Multidisciplinary

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UNDERSTANDING PREVALENCE & EPIDEMIOLOGICAL DATA ABOUT DEMENTIA

Prof. Nicola VANACORE et al.
Instituto Superiore di Sanita, Italy

Italian Presidency of the Council of European union, 14th November 2014

A quality score proposed by ADI 2009

Variability in prevalence of dementia by clinical criteria (Erkinjuntti et al 1997)

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.

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

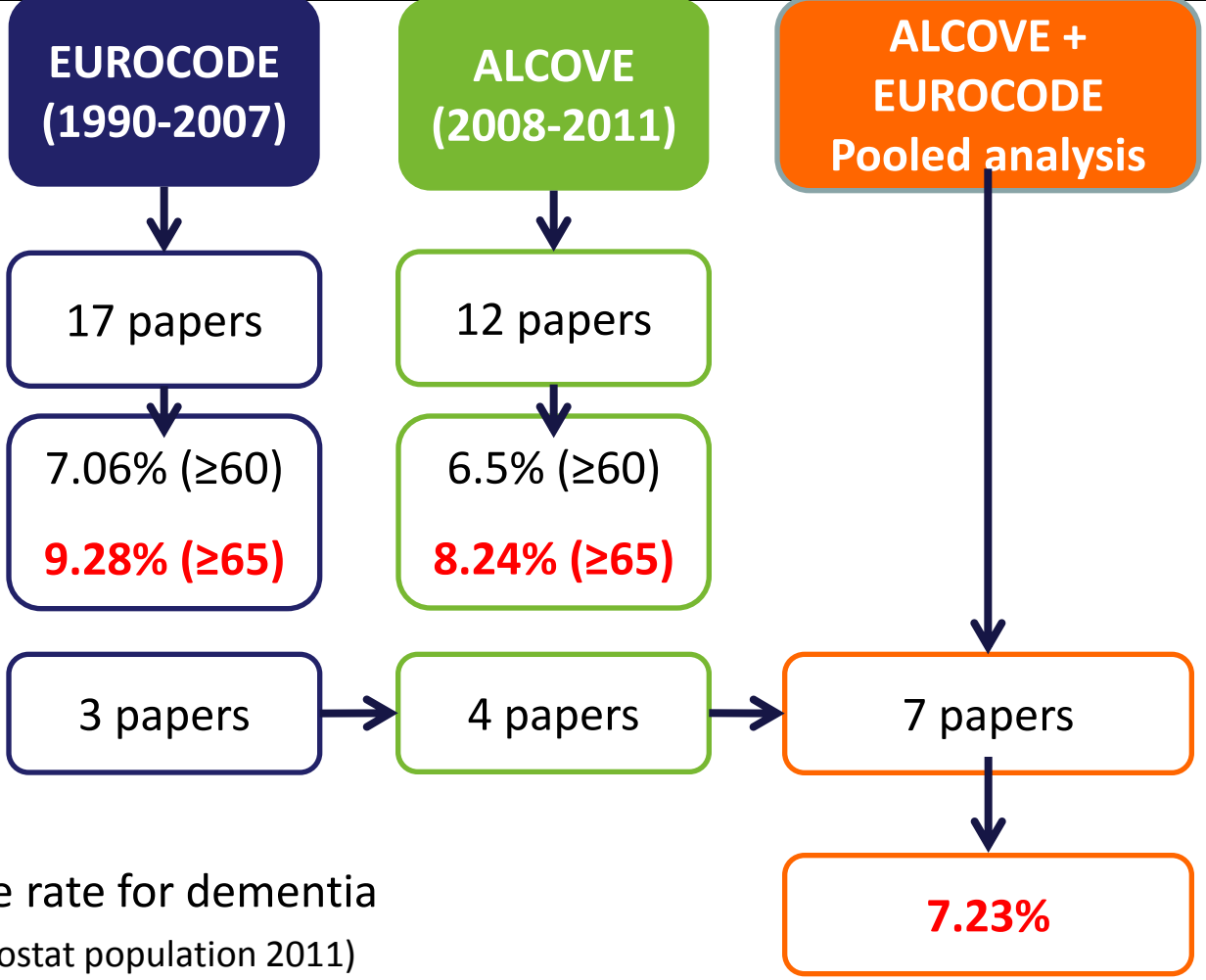
Two phase study with no sampling of screen negatives	0 points
Two phase study with sampling of screen negatives but no weighting back	1 point
One phase study or two phase study with appropriate sampling and weighting	2 points

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



ALCOVE confirms the high and increasing number of dementia cases in Europe

	Total rate	CI% 95 total rate	Pop Eurostat 2011	Total cases	CI 95% total cases
EUROCODE	9.28	8.95-9.61	88 074 340	**8 175 200**	7 882 700 – 8 463 900
ALCOVE	8.24	7.73-8.74	88 074 340	**7 262 700**	6 808 100 – 7 697 700
The high quality studies	7.23	6.74-7.72	88 074 340	**6 368 500**	5 936 200 – 6 799 300

A more robust estimation of dementia prevalence, based on shared quality criteria, will better inform policies and help planning services adapted to the needs

ESTIMATE OF DEMENTIA CASES IN ITALY AND FRANCE (1st Jan 2012)
ON THE BASIS OF THE HIGH QUALITY STUDIES IDENTIFIED IN ALCOVE

	Pop 2011 ≥ 65 yrs	Total cases 2012	CI 95% total cases
ITALY	12 370 822	**951 700**	887 200 - 1 016 200
FRANCE (without Overseas Territories and Departments)	10 968 525	**875 700**	816 300 - 935 000

ESTIMATE OF DEMENTIA CASES in EUROPE (27 member states, Eurostat projections)

	pop ≥ 65 yrs	rate dementia	Estimated dementia cases
2011	88074340	7,23	**6367775**
2020	103387503	7,23	**7474916**
2030	123272809	7,23	**8912624**
2040	140888254	7,23	**10186221**
2050	150927175	7,23	**10912035**

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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

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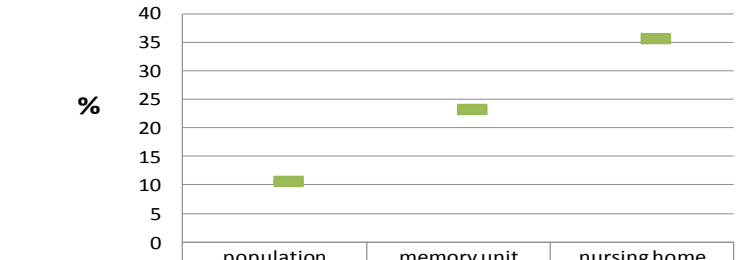
ALCOVE confirms the overexposure of people living with dementia to antipsychotics & its monitoring is recommended

Figure 1 Prevalence use of antipyschotics for settings (Europe 1994-2010)



	population	memory unit	nursing home
ULCI95%	10,8	24,2	36,6
prevalence rate	10,4	22,2	34,6
LLCI95%	10,6	23,2	35,6

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.

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Dementia National Programs

- 24 respondents
- 11 have a NP (starting from 2007)
- 5 will have in the short term
- 8 have not a specific plan dedicated to dementia

☆ 11/12 have been based totally or partially on the available national data.

Belgium Fi	Belgium Wa	Bulgaria	Cyprus	Czech Rep	Estonia	Finland	France	Germany	Greece	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Portugal	Slovakia	Spain	Sweden	UK England	UK N.Ir eland	UK Wales
Y	Y					Y	Y			Y					Y	Y				Y	Y	Y	Y
		N			N				N		N	N					N	N	N				
			D	D				D					D	D									

National Programs implementation

Since their approval

- ☆ 27.3% of NP have been fully implemented
- ☆ 54.5% partially implemented
- ☆ 18.2% not yet implemented

Reasons for partial implementation:

- ☆ Step by step implementation, program spread over several years
- ☆ Pilot experiment of new organization and system
- ☆ Different levels of local implementation
- ☆ Endorsement by sub-national level

Monitoring process

- ☆ 7/11 NP have a set of defined outcomes, standards and indicators that are measured on a regular monitoring basis

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The Quality and Timeliness of the Dementia Diagnosis

Professor Dawn BROOKER

Dr Karim SAAD

Italian Presidency of the Council of European union, 14th November 2014

Timeline of diagnostic opportunities

ALCOVE SURVEY in EUROPE

Missed diagnoses 50 – 60% or unknown

Stage of dementia at time of diagnosis

Most common: MMSE 10 - 20

Some: MMSE 21 – 26

Prince, M., Bryce, R. & Ferri, C. (2011) *World Alzheimer Report 2011: The Benefits of Early Diagnosis and Intervention.* Alzheimer's Disease International. Available online at http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

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Benefits & Risks of shifting diagnosis from T4 to T3

	Benefit	Risks
Person living with dementia	The right to know Time to adjust and plan Ability to make decisions Improved quality of life Access to treatment, intervention and services	Negative attitudes Misdiagnosis
Family	Understanding the changes Time to adjust Opportunity to build support. Access to services.	Negative attitudes Isolation
Health and social care economy	Social and fiscal benefits Support services for family carers	No services available or services are targeted at later stage. Without services to help those diagnosed the benefits to people and their families will be lost

Nuffield council on Bioethics, 2009: Banerjee & Wittenberg, 2009; Prince et al, 2011; Weimar & Sager. 2009; Bamford, 2011

Diagnosis is a key and beneficial intervention…. if risks are identified and managed!

5 ALCOVE recommendations on:

1. The diagnostic process
2. Workforce requirements
3. Managing complex diagnoses
4. Responding to early cognitive changes
5. Timely detection and screening

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ALCOVE Pyramids for Public health strategy for dementia diagnosis

5 Pyramids on 5 recommendations:

1. The diagnostic process
2. Workforce requirements
3. Managing complex diagnoses
4. Responding to early cognitive changes
5. Timely detection and screening

The same 4 Principles/Cornerstones for each pyramid:

- ☆ Timely & accessible:;
- ☆ Decrease fear & stigma:
- ☆ Rights & wishes:
- ☆ Diagnosis as a key intervention for person & family:

The Pyramids....

- ☆ Can be used by each country to assess where they currently are on each pyramid – cornerstones to apex
- ☆ Can be used to map and plan national and EU strategy for improving timely diagnosis

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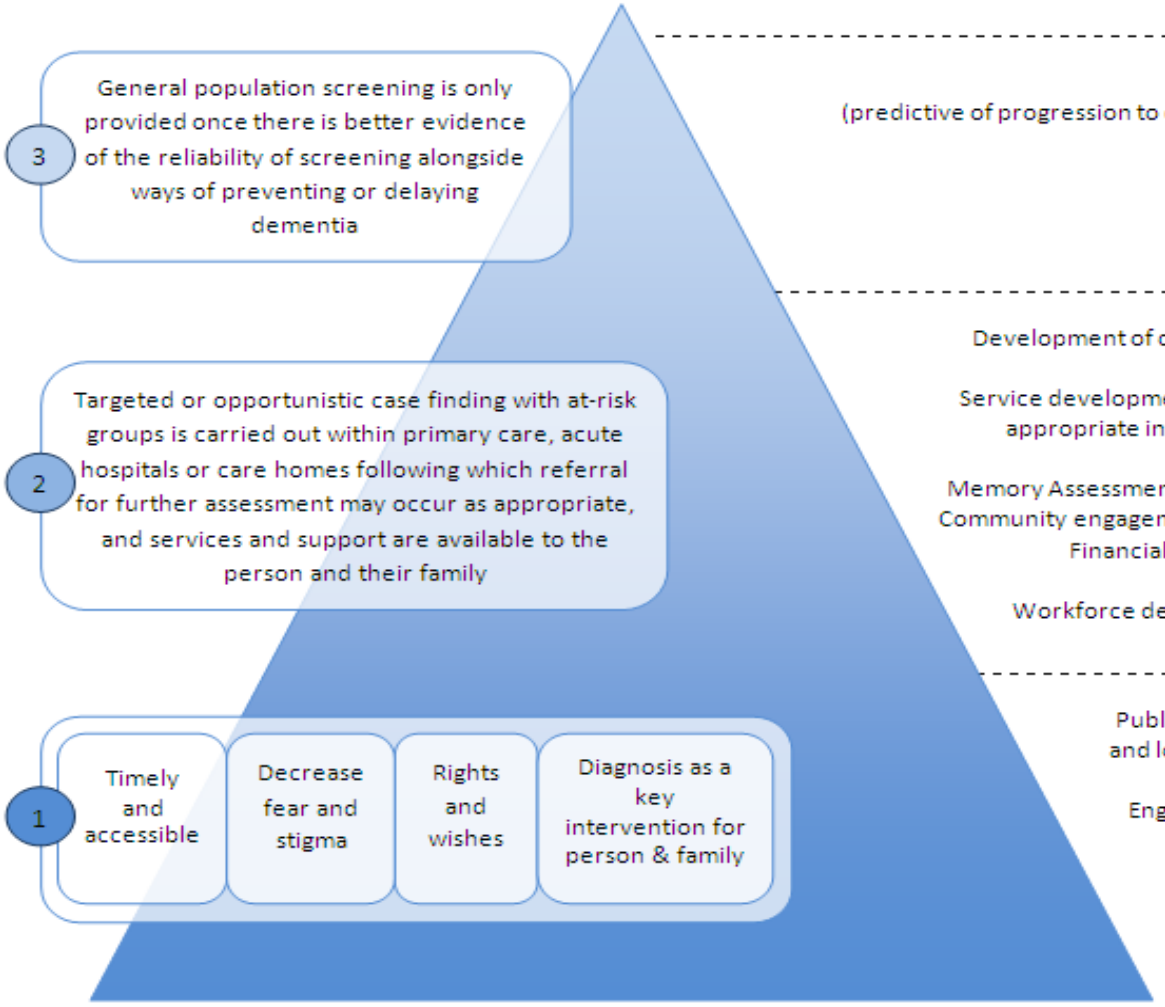
Timely detection

Recommendations for timely detection



Strategic actions required

Identification of evidence-based processes
Research evidence including reliable biomarkers (predictive of progression to dementia) combined with intervention programmes which can delay onset of dementia

Evidence-based decision support toolkits
Development of care pathways which facilitate equality of access and ongoing support to live well
Service development in partnership with local communities to provide appropriate interventions to the person and their family, including community engagement
Memory Assessment Clinics/Services and/or Early Intervention Services
Community engagement to support detection with hard to reach groups
Financial and resource planning including reimbursement for diagnosis and treatments
Workforce development – primary and secondary health care and community

Knowledgeable and informed communities
Public and professional awareness campaigns at national and local level to decrease stigma and fear and normalise the experience of dementia
Engagement with people living with dementia and their family members/carers as key agents of change and involvement in campaigning
Workforce development and education

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COMPETENCE ASSESSMENT & ADVANCE DIRECTIVES FOR PEOPLE WITH DEMENTIA :

ETHICAL AND LEGAL ASPECTS

Gerrit RAUWS, **Bénédicte GOMBAULT**
King Baudouin Foundation, Belgium

Herman NYS, University of Leuven, Belgium

Dianne GOVE, Alzheimer Europe

Italian Presidency of the Council of European union, 14th November 2014

Ethics in dementia care

- Human dignity, whatever the medical condition
- How to strike the right balance between the autonomy of the person with dementia and his protection?
- Can the assessment of competence & the drawing up of advance directives help persons with dementia in strengthening their autonomy, in protecting them ? Help the (family) carers & health professionals?
- 2 tools :
  - **Advance directives** as an instrument to facilitate the dialogue between the person with dementia and the caregivers
  - **Competence assessment** to support the presumption of competence of the person with a diagnosis of dementia and take into account the real capacity of the patient

Fondation Roi Baudouin

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alcove

Advance directives

- ☆ Written (or oral) statements regarding positive (consent) and negative (refusal) decisions
- ☆ Aim to clarify this person's wishes and will
- ☆ Anticipate the decline of the capacity to make decisions
- ☆ Anticipate the decline of the ability to express decisions towards others
- ☆ May or may not include end-of-life decisions

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ALCOVE key messages
Competence Assessment in dementia

- ☆ **Presumption of competence is crucial.**
- ☆ **Distinction between decision-making capacity (in a care and treatment context) and functional competence.**
- ☆ **Respect of the person's remaining capacities.**
- ☆ **Differentiating between competence and incompetence remains difficult.**
- ☆ **Repeated assessment on a case by case approach is necessary.**

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ALCOVE propositions for
Behavioral & Psychological Symptoms of Dementia
Support Systems
a holistic approach in 3 dimensions

Harriet Finne-Soveri
National Institute for Health and Wellfare, Finland

Armelles Leperre-Desplanques
HAS, France

Pierre Krolak-Salmon
French Federation of Clinical and Research Memory Centres
Lyon, France

Introduction

- **BPSD represent the main cause of a impairment of quality of life and of institutionalisation.**
  - Anxiety, depression and apathy are often observed at mild stages of the disease,
  - Agitation and aggressiveness, hallucinations, delusions, sleep and appetite disorders may occur at all stages,
  - Aberrant motor behaviour and resisting care and help tend to occur at moderate to severe stages.
- **Multiple sources:** degenerative processes, concomitant psychological or psychiatric conditions, like depression or psychoses, somatic illnesses and environmental influences.
- **Pharmacological interventions still far from efficient and not well-tolerated**

  → non pharmacological strategy crucial for both prevention and care.

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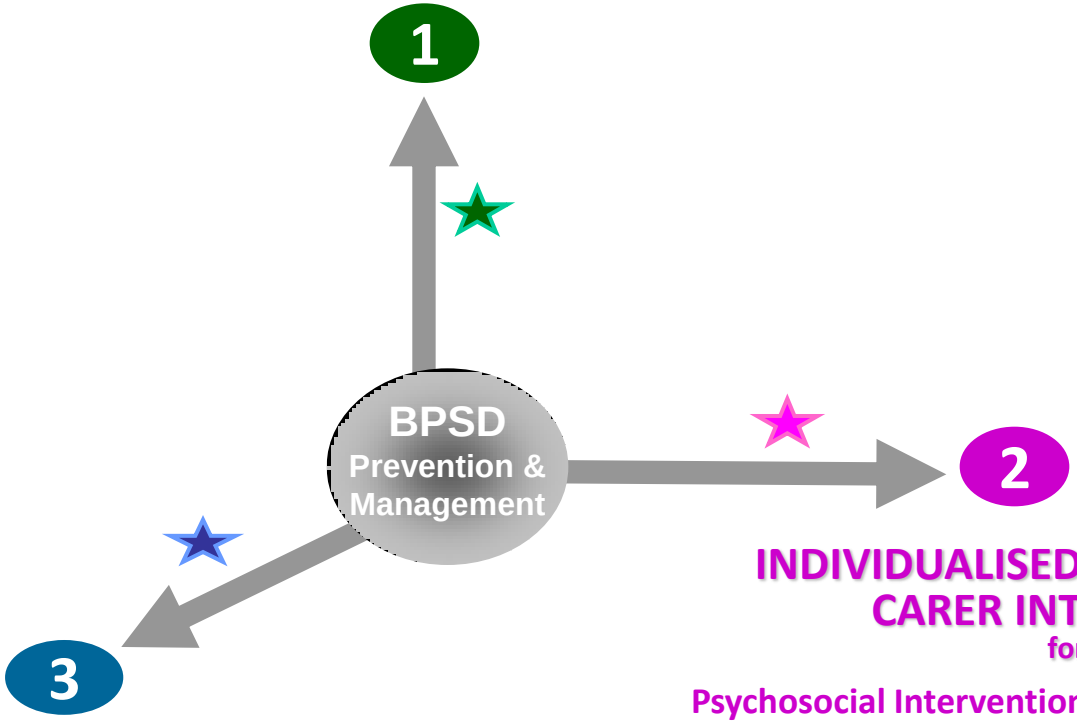
The « 3D » Support Systems Strategy

STRUCTURES & CARE ORGANISATIONS
for BPSD

Ambulatory, hospital and nursing home settings

(where are applied 2 & 3)



INDIVIDUALISED PATIENT & FAMILY CARER INTERVENTIONS
for BPSD

Psychosocial Interventions for Family Carer & Patient, Non Pharmacological Therapies for Patient, Pharmacological Therapies for Patient

(delivered within 1)

WORKFORCE & SKILLS
for BPSD

Education & Training , Clinical guidelines, Improvement programs for BPSD

(applied within 1)

the European Union in the framework of the Public Health Programme.

Structures & Care Organisations for BPSD

☆ What are Structures & Care Organisations for BPSD?

- Collaborative care, e.g. multidisciplinary teams
- Outpatient consultation services, home care, day hospitalisation units
- Mobile team dedicated to BPSD
- Respite care, i.e. temporary nursing home accommodation, day care units
- Telemedicine
- Specific hospital neuro-psycho-geriatric units
- Specific units within nursing homes
- …

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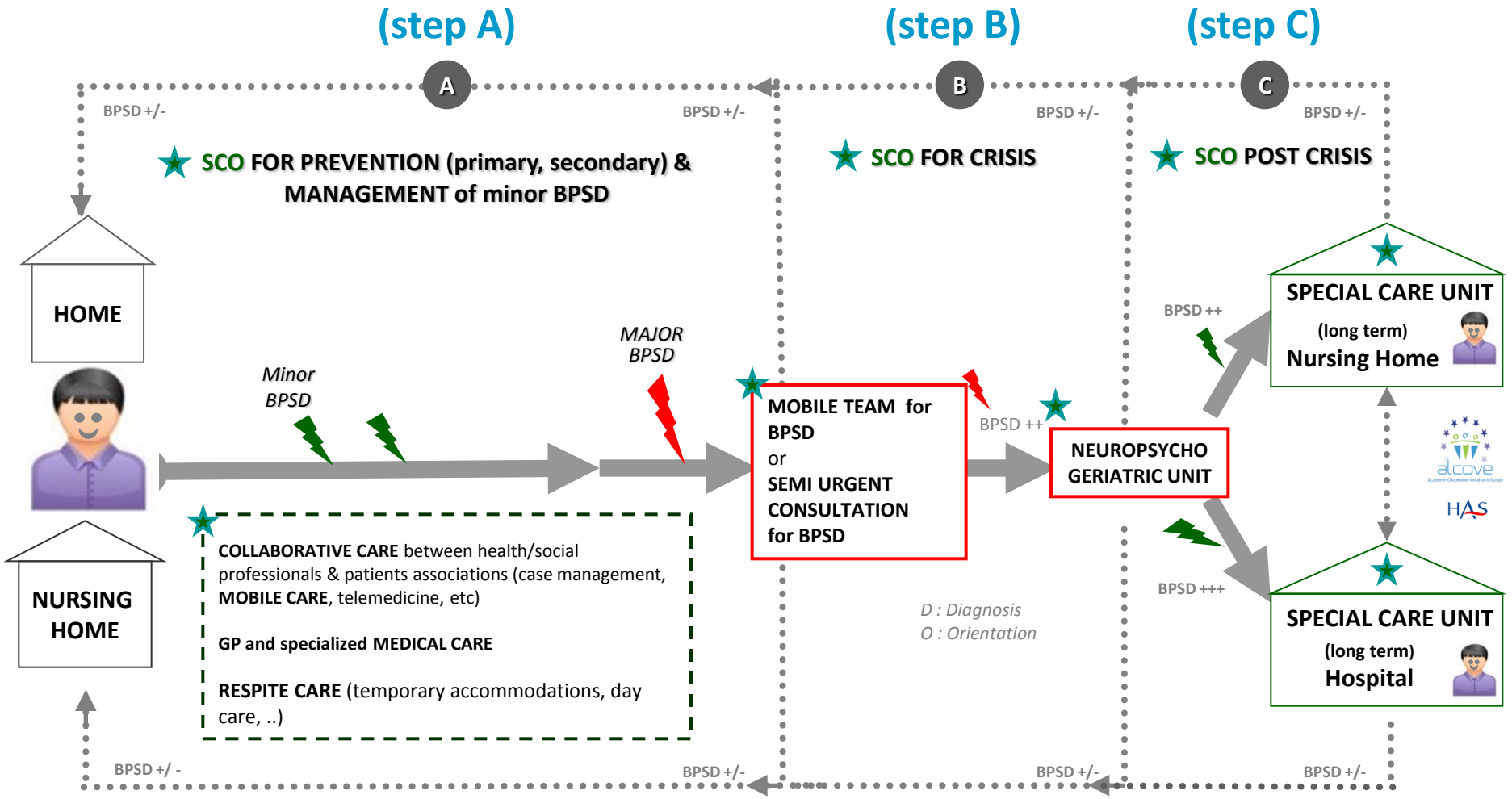
Structures & Care Organisations for BPSD
all along the Patient Pathway



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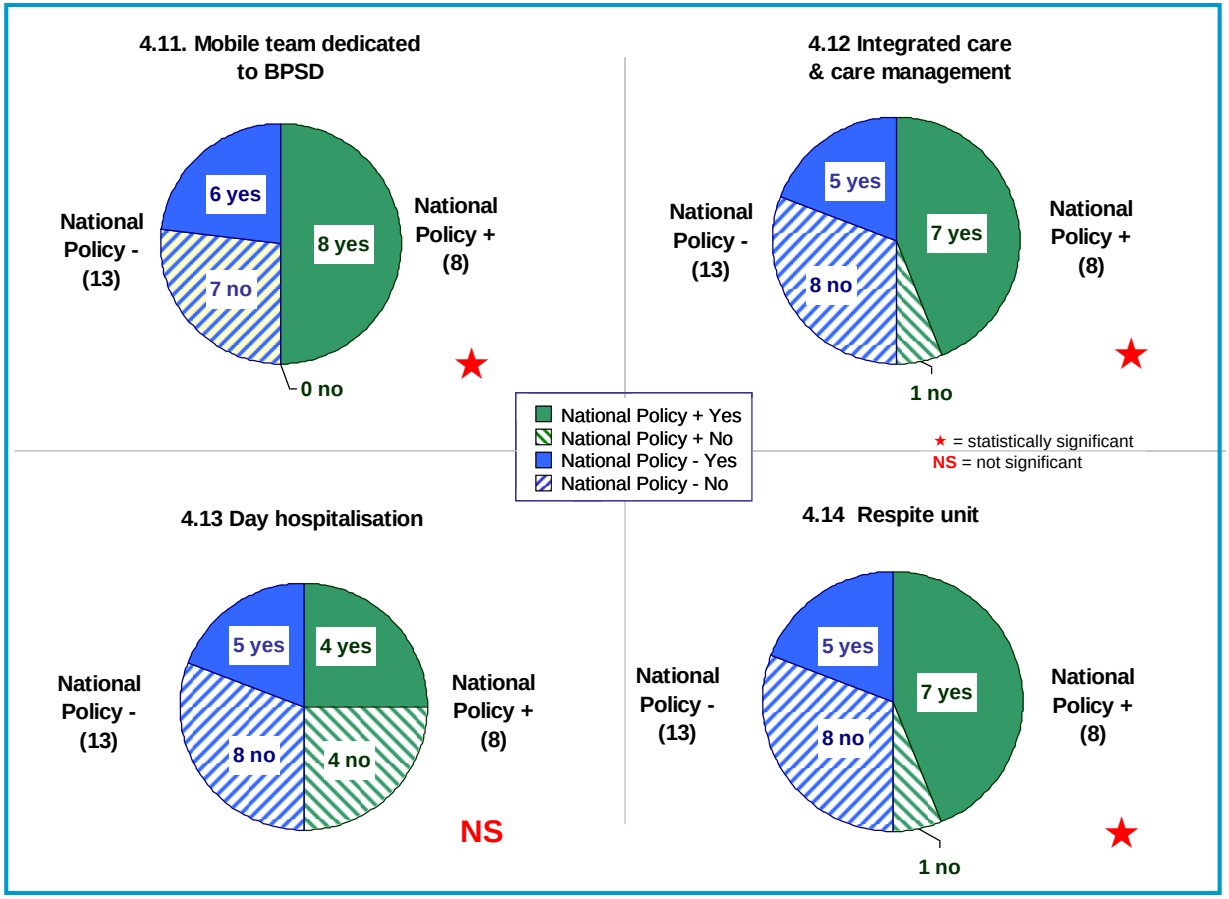
ALCOVE European Survey on SCO for BPSD ★

☆ SCO for the prevention & management of minor BPSD (step A)



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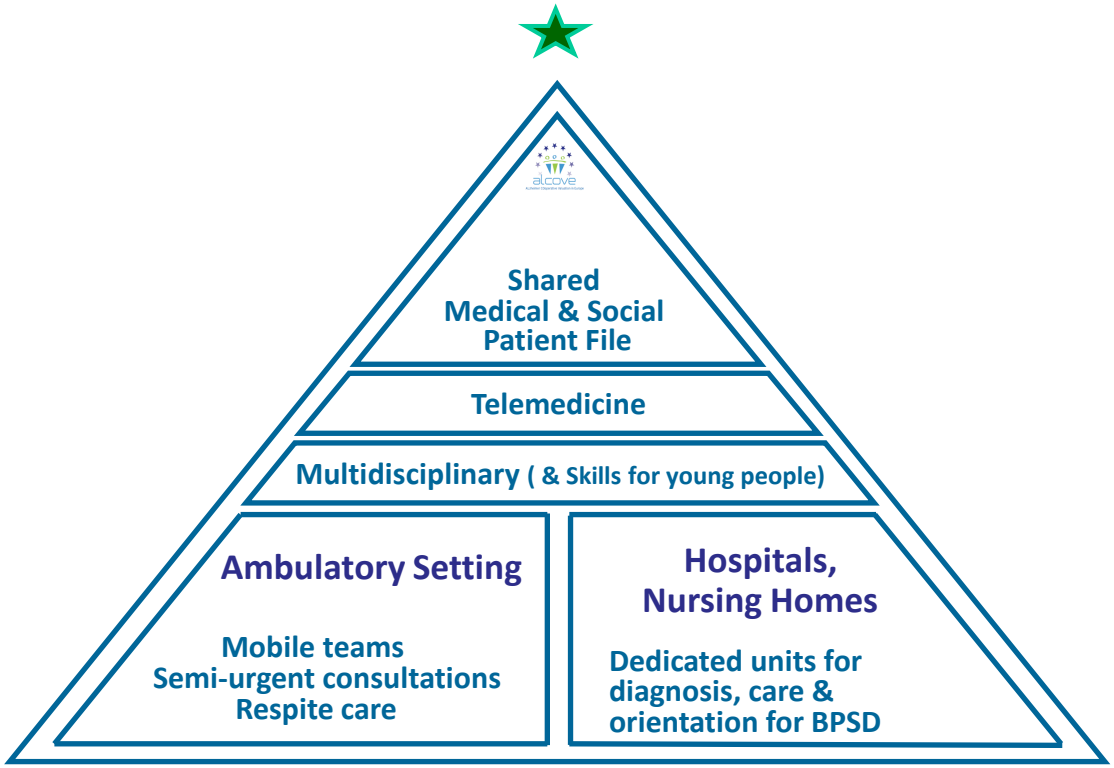
ALCOVE recommendations for SCO for BPSD

- ☆ Ambulatory SCO for persons experiencing BPSD
- ☆ Dedicated units for BPSD in Nursing homes and Hospitals
- ☆ A shared medical and social patient file as an optimal tool, key to an indispensable multidisciplinary approach
- ☆ Quality and impact indicators collected in all SCO to evaluate new programs



The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

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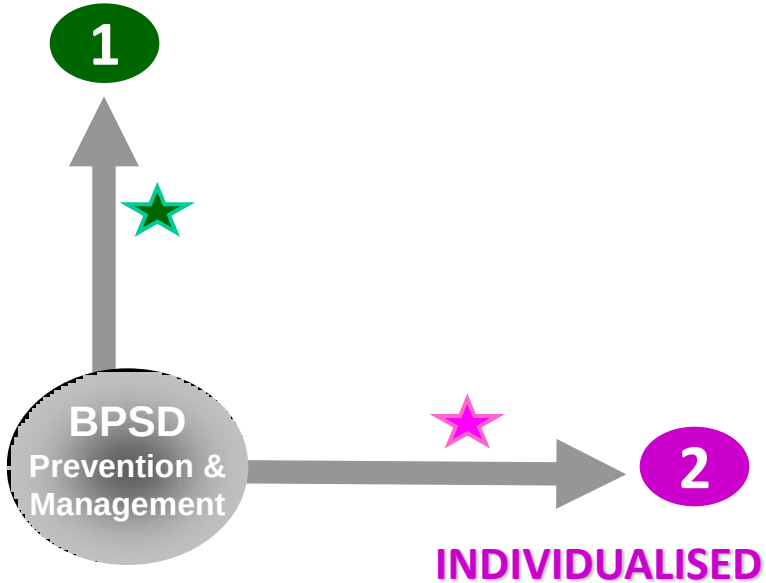
The « 3D » Support Systems Strategy

STRUCTURES & CARE ORGANISATIONS
for BPSD

Special care unit, Respite care, Mobile care for BPSD Prevention & Management

(where are applied 2 & 3)



INDIVIDUALISED PATIENT & FAMILY CARER INTERVENTIONS
for BPSD

Psychosocial Interventions for Family Carer & Patient, Non Pharmacological Therapies for Patient, Pharmacological Therapies for Patient

(delivered within 1)

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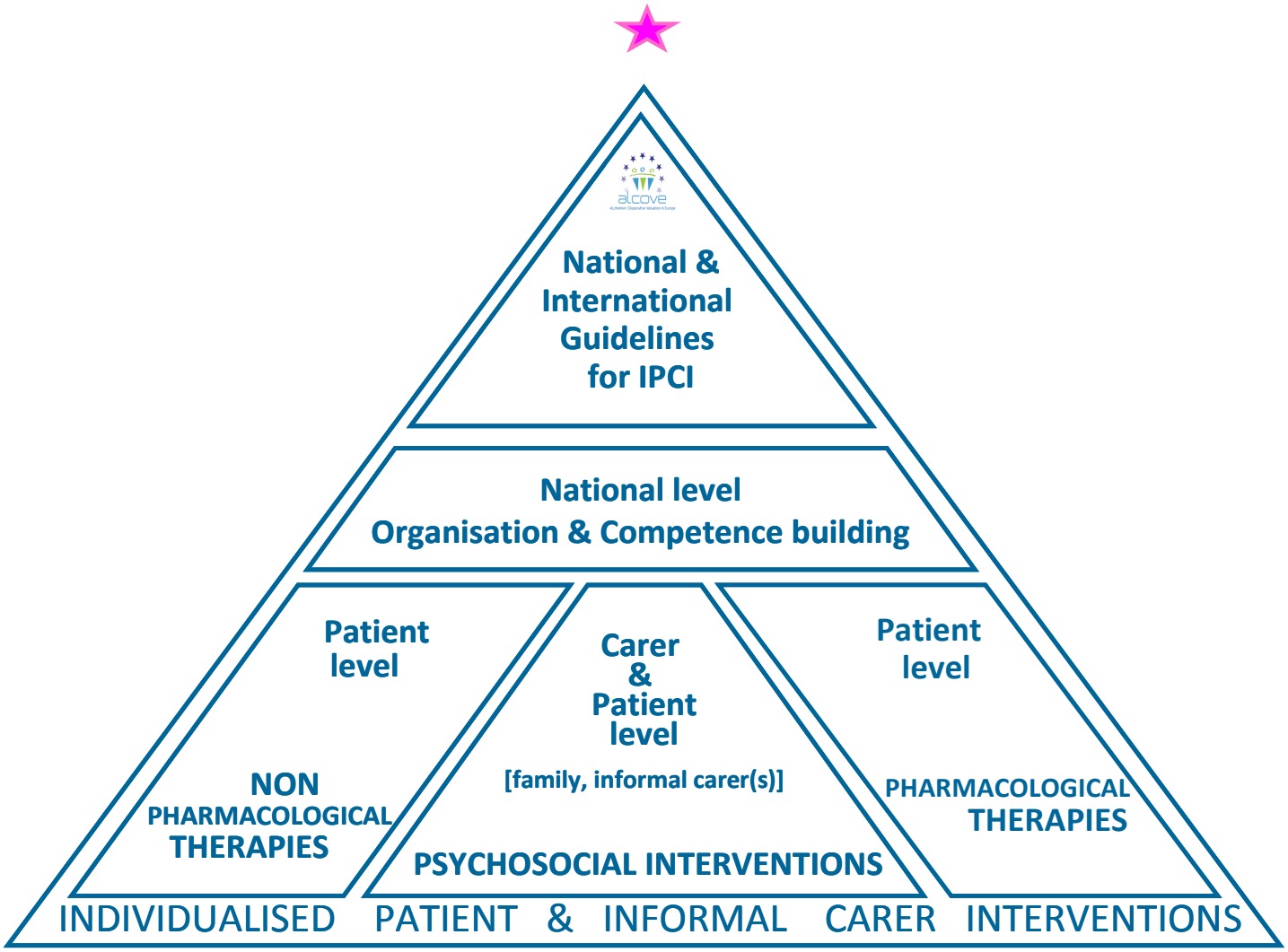
Recommendations for all Individualised Patient & Family Carers Interventions



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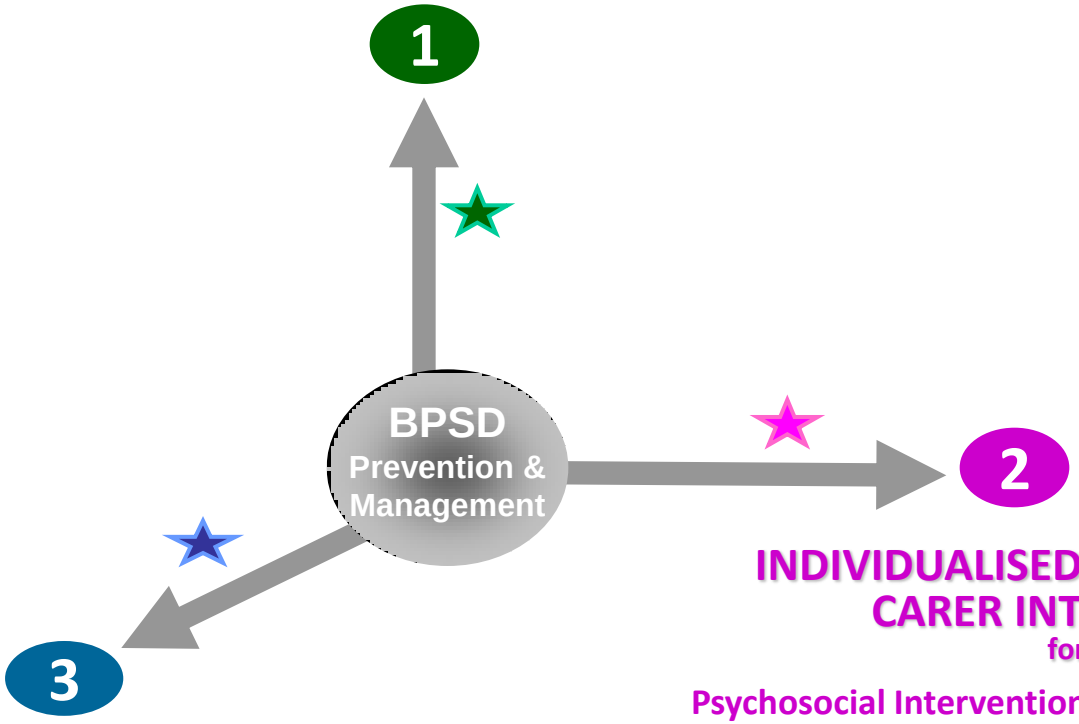
The « 3D » Support Systems Strategy

STRUCTURES & CARE ORGANISATIONS
for BPSD

Special care unit, Respite care, Mobile care for BPSD Prevention & Management

(where are applied 2 & 3)



INDIVIDUALISED PATIENT & FAMILY CARER INTERVENTIONS
for BPSD

Psychosocial Interventions for Family Carer & Patient, Non Pharmacological Therapies for Patient, Pharmacological Therapies for Patient

(delivered within 1)

WORKFORCE & SKILLS
for BPSD

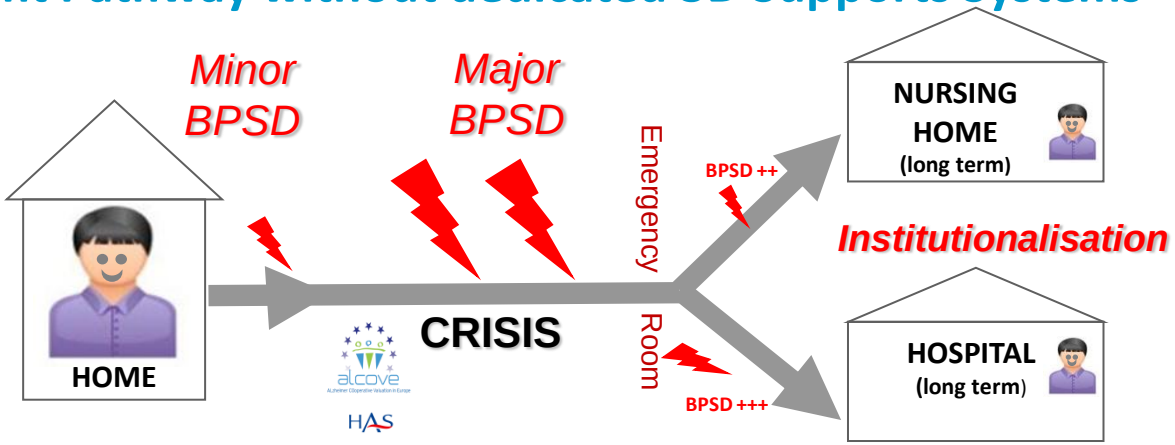
Education & Training , Clinical guidelines, Improvement programs for BPSD

(applied within 1)

the European Union in the framework of the Public Health Programme.

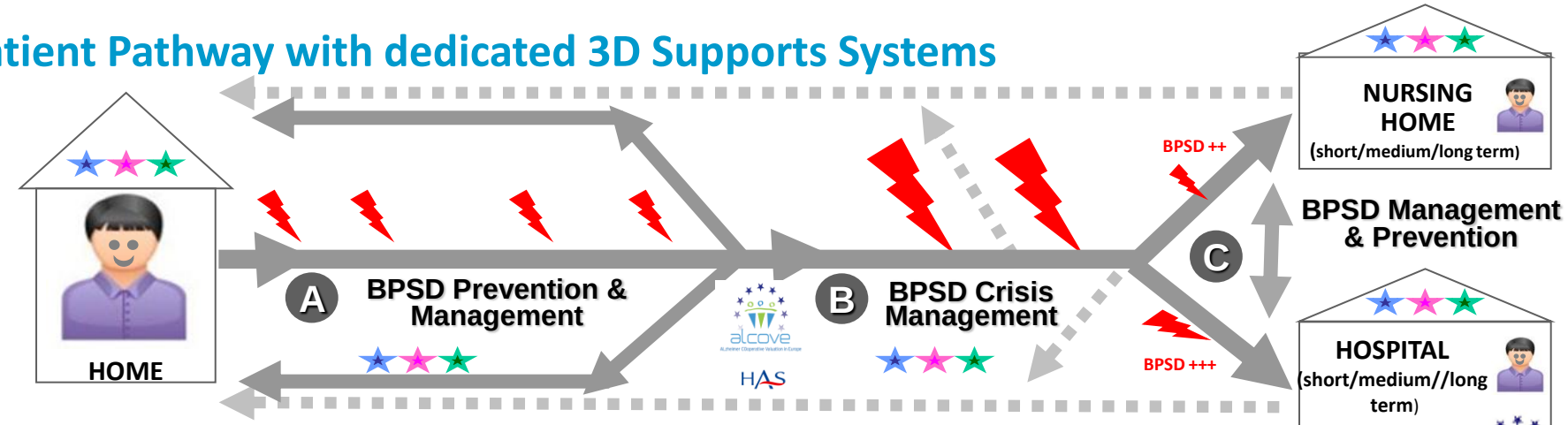
Patient Pathway & 3D Support Systems for BPSD

Patient Pathway without dedicated 3D Supports Systems



- STRUCTURES & CARE ORG.
- INDIVIDUALISED INTERV.
- WORKFORCE & SKILLS

Patient Pathway with dedicated 3D Supports Systems



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ALCOVE recommendations for BPSD Support Systems Strategy

☆ BPSD →
- family carer burden and depression
- increased rate of institutionalisation

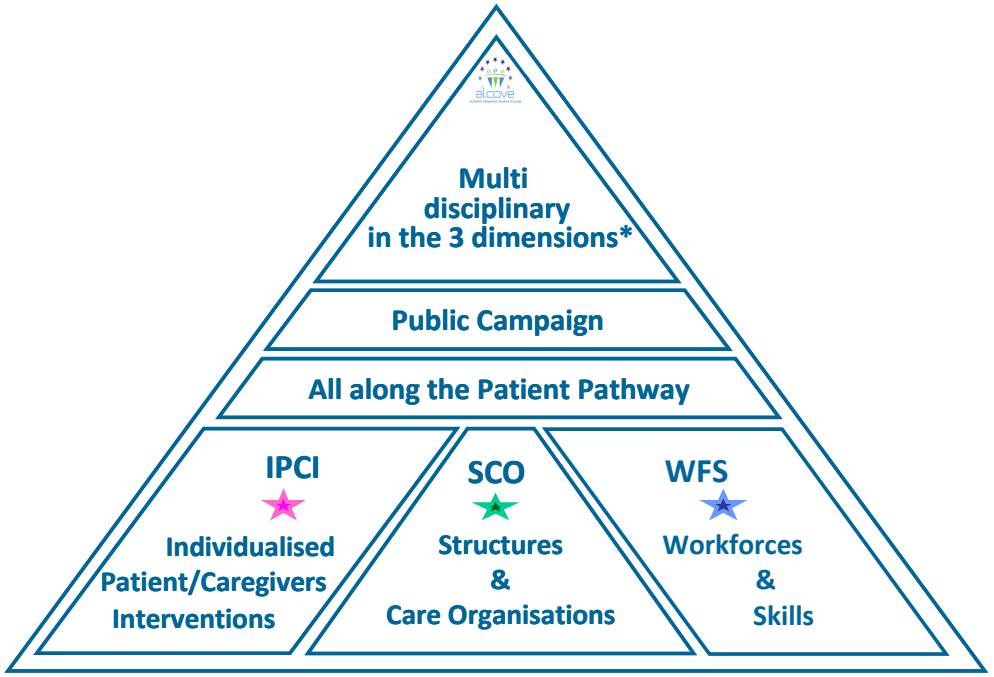
→ All nations should develop a 3-dimensional holistic strategy SCO – IPCI - WFS

☆ At each step of the patient pathway
- prevention and management of minor BPSD
- major BPSD crisis events
- post crisis phase

☆ Public information on :
- BPSD prevention and management
- Antipsychotic risks

→ General awareness campaigns for decreasing fear and stigma about dementia.

☆ A multidisciplinary approach



The recommendations at the bases of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

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ALCOVE PROJECT

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.

GENERAL PRESENTATION OF ALCOVE >>

(WP4) Epidemiological data on dementia

For a better knowledge on dementia: prevalence in Europe, available data & best practices for data collection

Instituto Superiore di Sanitá, Italy.

KEY MESSAGES >>

(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

KEY MESSAGES >>

(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

KEY MESSAGES >>

(WP6) Support Systems for BPSD

For better knowledge on their availability & efficacy for BPSD management at home, in hospitals & care homes

Terveyden ja Hyvinvoinnin Laitos, Finland

KEY MESSAGES >>

ALCOVE Synthesis Report

ALCOVE Recommendations

ALCOVE in various languages

ALCOVE Brochure

The ALCOVE TOOLBOX for Antipsychotics limitation in Dementia

A worldwide shared safety issue

EXECUTIVE SUMMARY | KEY MESSAGES >>

(WP3) Evaluation of the ALCOVE Joint Action

Slovenska Akademia Vied, Slovakia

EXECUTIVE SUMMARY | KEY MESSAGES >>

Dissemination of the ALCOVE Joint Action

EXECUTIVE SUMMARY | KEY MESSAGES >>

ALCOVE Key Messages presented by the Work Package Leaders

ALL THE VIDEOS >>

The European Joint Action on Dementia

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ALzheimer COoperative Valuation in Europe

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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TOOLBOX

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ALCOVE TOOLBOX

FOR LIMITING ANTIPSYCHOTICS IN DEMENTIA

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.

5 PARTS

- ANTIPSYCHOTICS RISK MEASUREMENT IN EUROPE 1
- ANTIPSYCHOTICS RISK REDUCTION PROGRAMMES 2
- TIMELY DIAGNOSIS & ANTIPSYCHOTICS 3
- & ANTIPSYCHOTICS 4
- SYCHOLOGICAL SYMPTOMS OF DEMENTIA 5

In each part:

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

All the tools

ALCOVE Key figures

7.23%, a new prevalence rate

3D strategy for BPSD all along the Patient Pathway

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 adressed BPSD in EU Member States

35.6% prevalence rate for antipsychotic use in people living with dementia residing in nursing homes. That's why ALCOVE has developped a TOOL BOX for anitpsychotics limitation.

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

30 tools for antipsychotic limitation in the ALCOVE Tool box

40-60% of theoretical dementia diagnoses are missed

22 EU Member States recognise legal validity of advance directives

5 pyramids & **4** corners stones for timely diagnosis detection

This presentation arises from the Joint Action ALCOVE