

# Future initiatives the EU-level perspective

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## **Dementia: a challenge for EU-Member States**

All 28 Member States are concerned:

- 6.37 million people were living with dementia in the EU in 2011 (JA ALCOVE-report, 2013)
- Economic costs of €105 M in 2011 (J. Olesen et al., 2012)
- A diversity of situations and of health and social welfare systems.



## European Initiative on Alzheimer's disease and other dementias (2009)

Developed under French EU-Presidency to launch European collaboration on dementia.

### **Priorities:**

- Early (timely) diagnosis of dementia and promoting well-being with age;
- Better understanding dementia, epidemiological knowledge and coordination of research;
- Best practices in care for people with dementia;
- Respecting the rights of people with dementia.

Implementation report published on 16 October 2014.



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Some key implementation activities:

- Joint Action ALCOVE (2011 2013);
- European Innovation Partnership Active and Healthy Ageing (2011);
- EU Reseach Framework Programmes and eHealth Action Plans



## Joint Action ALCOVE (2011-2013)

- Led by France and involving 19 Member States;
- Funded by Member States and EU-Health Programmes.

Developed recommendations and toolkits on:

- Timely diagnosis of dementia;
- Epidemiology of dementia;
- Support systems for Behavioural and Psychological Symptoms in Dementia (BPSD);
- Advance Declarations of Will;
- Limitation of antipsychotics use.



## **ALCOVE Toolkit Timely Diagnosis of Dementia**

<ul> <li>Timely diagnosis has 4 sequential stages, each of which may be delivered by different professionals but needs to be coordinated at the individual person/family level</li> <li>Initial detection of cognitive difficulties</li> <li>Assessment to decide whether symptoms are due to dementia or not, referral on where complex presentation</li> <li>If dementia is present, to achieve diagnosis of subtype and relevant co-morbidities</li> <li>Care planning to address current and future needs</li> </ul>	Strategic actions required Evidence-based toolkits for detection and management Integrated care coordination and patient navigation systems Service delivery processes including care pathway development and identification of referral pathway for complex diagnosis Multidisciplinary involvement in assessment, diagnosis and intervention, Education and skills development of workforce across health and social care, including family doctors, primary and secondary health care staff and community staff
<ul> <li>Recent clinical criteria<sub>1</sub> for diagnosis of dementia syndrome and its subtypes are used in clinical practice, recognising that this is a changing area and that further validation and revisions will occur</li> <li>Information, advice and interventions are offered to the person and their family following diagnosis</li> <li>The diagnostic process is managed in a way that supports good adjustment to the news</li> <li>The provision of pre-assessment counselling</li> <li>Where and who should be present for diagnostic feedback</li> </ul>	Further research for validation of criteria Systems need to be in place so that professionals are informed and stay up to date with clinical criteria Evidence-based imaging and assessment processes are available Workforce education and skills development Identify who provides which interventions and at what point, involving dementia-friendly communities Evidence base for which interventions to offer Workforce education and skills development Research/evidence base for process Accessible to all at whatever stage of dementia Development of guidelines for person-centred diagnostic process Financial and Resource planning Workforce education and skills development
A sensitively delivered process of disclosure of the diagnosis      Timely     and     accessible     Stigma     Rights     and     stigma     Stigma	Assessment of specific needs and challenges to service, e.g. lack of specialist provision, rurality and need for tele- healthcare Public and professional awareness raising induding



## Second EU- Joint Action on dementia (2015-2018)

- To be led by United Kingdom (Scotland);
- Good interest among Member States in participation.

### Proposed focus themes:

Postdiagnostic support, improvement of care pathways, use of medicinal products and psychotropic substances, care for family carers, workforce skills, quality of residential care.



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## European Innovation Partnership Active and Healthy Ageing

- This EU-flagship initiative was launched in 2011. It is mobilising one thousand European regions and municipalities, involving 3000 partners and 300 leading organisations.
- All relevant actors involved in ageing are involved: industry, research, healthcare providers, NGOs,...
- The objective is to increase the average healthy life years of EUcitizens by two years by 2020 by identifying European good practices and scaling them up;
- The Partnership includes two activity strands relevant for dementia: one on "prevention of frailty and cognitive decline" and a further one on "innovation for age-friendly environments".



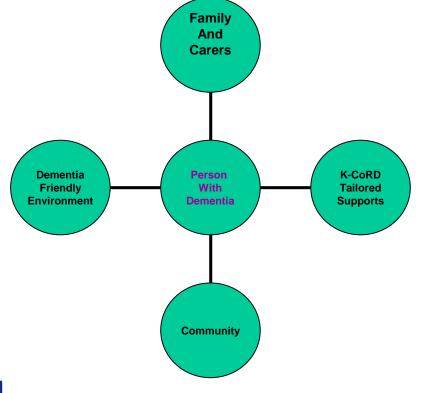
## **Reaching Scale**



# prevention of cognitive decline (21 identified)

- Create a Circle of Care around the person with dementia
- Collaborating with, enhancing and Coordinating existing services
- Delivering to the clients a package tailored to their individualised needs
- Introducing the benefits of Assisted Technology
- Develop Kinsale as a Dementia Friendly Environment







## Good practice "Age-friendly environment" Cumbria County Council Investment in Residential Care (2010)

### **Activties:**

Simple changes such as different colours on walls and door frames, plain carpets that are similar in colour and texture and clear signage on rooms and cupboards help reduce stress and anxiety levels of people with dementia, and provide a safer environment by reducing the risk of slips, trips and falls.

### **Outcome:**

A reduction in slips ,trips and falls (reduction from 22 in a 4 month period to 0 in the 4 months after refurbishment). Evidence of a reduction in antipsychotic medication, improved food intake (half a pound additional intake per person per day).

The first scheme at Elmhurst, Ulverston was awarded the University of Stirling Gold Standard for dementia design.



## **Completed eHealth projects (further ones ongoing)**

### **PredictAD**

Aimed to identity a biomarkger and develop a software allowing the GP to assess the risk of dementia

### **SOCIABLE**

Personalized cognitive training interventions for senior citizens including cognitive intact elderly, older adults with Mild Cognitive Impairment, as well as patients suffering from mild Alzheimer's disease.

### VERVE

Games modelling everyday scenarios and instances where anxieties might occur.



## **Dissemination**

- Implementation report on the Commission Communication on a European Initiative on Alzheimer's Disease and other Dementias (16.10.2014);

- Dissemination activities as part of the programmes and projects including the new EU-Joint Action on Dementia;

- Italian EU-Presidency conference "Dementia in Europe: A challenge for our common future", Rome, 14 November 2014;

- Group of Governmental Experts on Dementia (second meeting: Rome, 13 November 2014).



## Conclusions

Building on the activities and achievemtns since 2009, the Commission has launched action to:

- Maintain its coordinating role in the development of EU-policy on dementia and in supporting Member States in their actions;
- Launch the second Joint Action;
- Provide further opportunities to support research under the 'Horizon 2020'-EU Research Framework Programme;
- Stimulate the development and use of e-Health solutions in the field of dementia;

- Continue playing a global role and collaborating with international stakeholders, in particularly in the context of the initiative "Global Action Against Dementia".



## **Does EU-action make a difference?**

### We believe, it does:

- It supports the collaboration between large EU-countries;
- It enables smaller countries with more limited resources and infrastructure to liaise with work in other countries and to contribute to these.

### **Evidence of change:**

- 2009: only one EU-country had a National Action Plan on Dementia (France);
- 2016: 16 EU-Member States have a National Dementia Action Plan or are working on it.