EU Joint Action on Dementia 2015-2018

Background and Overview
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Joint EU Action on Dementia - Summary

- The Scottish Government is finalising a proposal for approval by the European Commission to lead the next phase of joint EU action on dementia on behalf of the UK from 2015-18. It is expected that approval to be given by early autumn at the latest.
- The project will involve 15 organisations from 13 countries. Scotland will be responsible for leading and coordinating the project, with work streams led by France, Italy, Netherlands, Spain, UK (DoH) and Norway (the only non EU Member State involved in the Joint Action).
- The overall aim of the Joint Action is to promote the implementation in Member States of coordinated actions to improve the situation of people with dementia and their carers, building on the outcomes of the ALCOVE Joint Action.
Key Objectives for 2015-18

- The key objectives of the project (subject to approval by the EU) will be:
  - to provide evidence on how to improve outcomes for people with dementia and their carers;
  - to enhance and strengthen EU collaboration on improving dementia services and support, including early diagnosis;
  - to add value to existing activity across Europe and globally on improving diagnosis and the quality of services and supports for people with dementia and their carers.
Work package 1: (Coordination) and 2: (Dissemination) - Scotland

- Both led by Scotland for UK
- Coordination including secretariat support, with 2 new dedicated policy posts
- Dissemination plan will include targeting key EU bodies and decision-makers; plus positioning messaging in post-G7 global dementia context
Work package 3:
Evaluation of the Joint Action - Spain

- To be led by Spain (Agència de Qualitat i Avaluació Sanitàries de Catalunya, AQuAS)
- All partners are actively involved.
- **Aim:** Actions undertaken to verify if the Joint Action on Dementia project is being implemented as planned and reaches the objectives.
Work package 3: Evaluation of the Joint Action - Spain

• The key WP3 objectives are:
  – To assess the initial and on-going WP activities, with a view to improve the work in progress, and to evaluate the Joint Action on Dementia project (process evaluation).
  – To assess the quality and impact (short term effects) of the implementation of the Joint Action on Dementia activities/actions, and to verify the achievement of the project’s goals (effect evaluation).
  – To contrast and crosscheck predetermined deliverables and outcomes with the final products of the Joint Action on Dementia project.

• A three-year plan:
  – Year 1: draft report on evaluation and evaluation plan.
  – Year 2: report on data collection and analysis for 1st interim internal evaluation.
  – Year 3: report on data collection and analysis for 2nd and final internal evaluation (confidential). Final evaluation report (public).
Work package 4: Diagnosis and post-diagnosis support - France

- To be led by France (University Lyon 1 and Ministry of Health)
- Supported by WP partners:
  - Bulgaria Luxembourg
  - Croatia Norway
  - Finland Poland
  - Greece Spain
  - Italy

- Aims
  - Identify and test evidence-based examples of best practice in key aspects of diagnosis and post-diagnostic support
Work package 4: Diagnosis and post-diagnosis support - France

Key WP4 objectives:
- To define the benefits/risks of the diagnosis of dementia (and related diseases) according to:
  • patient/carer needs and wills
  • stage of the disease in terms of cognitive, behavioural and functional impairment
- To define an optimized (reasonable) diagnosis strategy according to:
  • patient/carer needs and wills
  • stage of the disease in terms of cognitive, behavioural and functional impairment
- To define post-diagnosis support goals to propose an adaptation of structures and care organizations in European countries

Milestones to be reached

Year 1
- Literature synthesis report
- First meeting of the expert groups from scientific, medical, pharmacology, humanities and social, ethics, primary care, patients and families
- Publication of evidence report
- Surveys dedicated to governmental organisations and family carer organisations

Year 2
- Agenda of meetings and web conferences of experts (minutes and synthesis reports)

Year 3
- Toolbox for primary care
- Synthesis report and recommendations on “Diagnosis and post diagnosis supports”
- Publication of WP report and implementation agenda
Work Package 5: Crisis and Care Coordination - The Netherlands

• To be led by: The Netherlands (Ministry of Health, Welfare and Sport) and Italy (National Institute of Health)
• Work package partners: Bulgaria, France, Scotland, UK
• Aim: to improve the level of coordination of care towards a one stop shop and to provide appropriate care in crisis situations
Work Package 5: Crisis and Care Coordination - The Netherlands

The key WP5-objectives are:

- Identify evidence-based examples of best practice in key aspects of crisis and care coordination for dementia.
- Test evidence-based examples of best practice in key aspects of crisis and care coordination for dementia, including application of improvement science methodologies.

A three year plan:
1. Mapping of relevant research on and practices of dementia care coordination and the prevention of crisis/BPSD.
2. Identify the best practices and test them in pilots.
3. Implement the best practices in participating countries.
Work Package 6: Quality of Residential Care - Norway

The work package on residential care will target improvement for people who are currently living in residential care or nursing home establishments.

- This WP will seek to pilot improvements in at least one area in each of the five participating partner states. In each, at least one district (hospital district; local authorities; municipality) that deliver specialized services for people with dementia and/or at least one residential care unit in that area.
- Actions undertaken to identify best evidence and testing the evidence in localities to demonstrate improvement and how it was achieved

The work will be done parallel in the five main areas

1. Physical environment
2. Organizational issues
3. Use of medication
4. Psychosocial intervention
5. End of life issues
Actions:
First we will describe the evidence of best practice regarding the five areas by...

...perform a literature review with focus on review papers, state of the art papers and consensus reports.

...go through the different national guidelines within the five areas (not only from the participating countries but from all European countries that have such guidelines available).

...identify and describe examples of good practice in the participation countries
Then each partner contact relevant hospital districts and residential care venues aiming to make plans for the interventions within the five areas. In addition will the partners identify and describe good examples from their own country.
At last we will to try out a model of best care practice for persons with dementia in residential living, in a small scale and to evaluate these tests by performing several small interventions (pilot studies)
Work package 7: Dementia friendly communities - UK

- To be led by England (Department of Health)
- Supported by WP partners:
  - Bulgaria
  - Greece
- Aim: To help empower people with dementia to continue to be able to actively participate in society and remain independent for as long as possible through reducing stigma, isolation and fear through increased community awareness and understanding
Work package 7: Dementia friendly communities - UK

• **The key WP7 objectives are:**
  – To identify evidence-based examples of best practice in key aspects of promoting, nurturing and sustaining dementia-friendly communities;
  – To test evidence-based examples of best practice in key aspects of promoting, nurturing and sustaining dementia-friendly communities, including application of improvement science methodologies where possible.

• **A three-year plan:**
  – Year 1 – collect and collate evidence on best practice, use that to inform development of toolkit, design pilots and identify pilots sites.
  – Year 2 – run pilots, making adaptations in-year as necessary.
  – Year 3 – evaluate pilots to inform development of final toolkit to be published and shared with all MSs.