

ACT ON DEMENTIA

FINAL REPORT



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Statement of originality

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Act on Dementia

Act on Dementia was a 44-month European Union Joint Action which began in March 2016 and ended on 31 October 2019.

The aim of the Act on Dementia Joint Action was to promote collaborative actions among European Union (EU) Member States to improve the lives of people living with dementia and their carers. It has provided practical guidance for policy-makers developing and implementing their national dementia plans, policies and strategies, and cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

Act on Dementia consisted of seven work packages:

- Work Package 1: Co-ordination
- Work Package 2: Dissemination
- Work Package 3: Evaluation
- Work Package 4: Diagnosis and Post-Diagnostic Support
- Work Package 5: Crisis and Care Co-ordination
- Work Package 6: Residential Care
- Work Package 7: Dementia-Friendly Communities

For further information on the work packages, reports and other resources, access: www.actondementia.eu.

Joint actions are a financial mechanism in the Health Programme to cover specific health-policy needs. They support EU cooperation with an important number of partners which are either competent health authorities in the Member States or other organisations designated by these competent authorities. Joint actions generate momentum for wider impact; gain for the Member States involved is substantial in terms of knowledge and experience exchanged. Joint actions are grants for actions co-financed with Member State authorities.

Work pages 4, 5, 6 and 7 – summary

The Joint Action set up work packages to carry out a series of evidence reviews and develop pilot programmes to explore best practice in the areas of **diagnosis and post-diagnostic support, crisis and care co-ordination, residential care and dementia-friendly communities**. Each work package produced a series of detailed reports which can be found on the Act on Dementia website (www.actondementia.eu/resources). The following provides a brief summary of some of their main findings.

Work package 4 (WP4): diagnosis and post-diagnostic support

WP4's main aim was to improve diagnosis and post-diagnostic support for people living with neurocognitive disorders (NCDs)¹ through:

- collective reflections, active collaborations and agreements among international experts from several European countries;
- a detailed analysis of the currently available scientific literature and recommendations in this field; and
- the coordination and implementation of multi-site pilot projects.

On the basis of collaborations with the WP4 expert group and the main results extracted from a WP4 European survey, three main themes were prioritized for the pilot work.

WP4.D2 Implementation Pilots

1. "ANTI-STIGMA" TRAINING PROGRAM FOR THE GPs



2. GPS/NURSES COOPERATION



3. TELEMEDICINE IN NURSING HOMES



Focused primarily on primary care & based on:

- ✓ Cross-disciplinary literature review
- ✓ Partners agreement on best practices & pilots experimentations
- ✓ ICHOM outcomes set for NCD/dementia

Goals defined during the last physical WP4 meeting (Paris, November 2017)

The anti-stigma project addressed misperceptions of NCD in primary care. WP4 developed an anti-stigma education programme mainly targeting GPs and medical residents. Versions of the programme were introduced to four testing areas – Limoges and Lyon (France), Lublin (Poland) and Sofia (Bulgaria).

Data were collected from 192 participants (135 GPs and 57 medical students) from the four sites. Results showed significant improvements in the sense of competence/

¹ Neurocognitive disorder is a general term that describes decreased mental function due to a medical disease other than psychiatric illness. It includes dementias.

confidence of attendees and significant reductions in their entrenched stereotypes regarding NCD after the anti-stigma training in Lyon, Sofia and Lublin. In Limoges, the pre- and post-test score difference did not reach significance due to the low number of attendees.

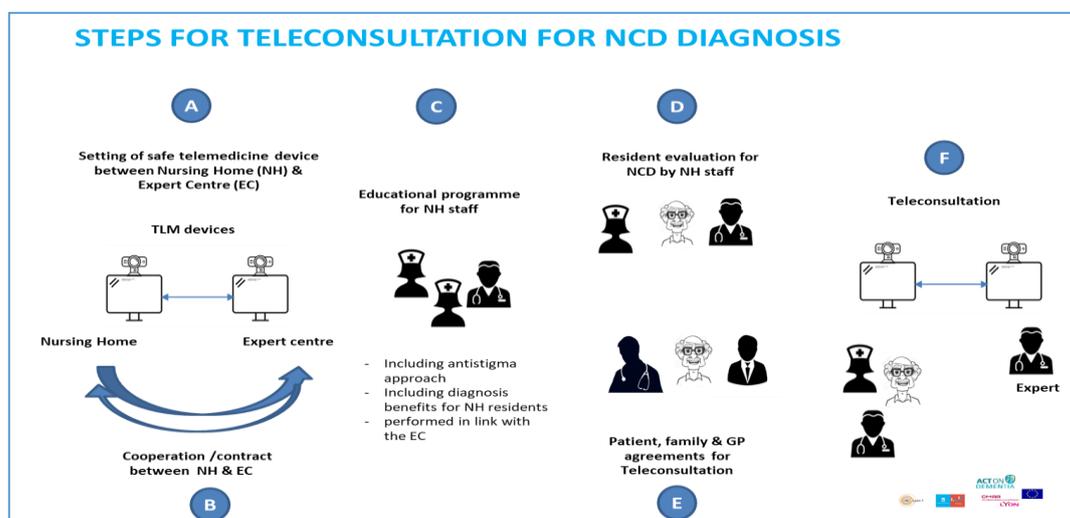
ANTI-STIGMA PROGRAMS - MAIN CONCLUSIONS	
Main message	GPs Stereotypes about disclosure are high Antistigma training reduces stereotypes /increases GPs confidence
Other messages	High satisfaction from GPs
Barriers	GP availability and motivation
Facilitators	Lectures/workshop combination Possible e-learning
Key messages	<p>1/ Disseminate anti-stigma training for GPs and nursing homes >> “ Anti-stigma” training is based on a bottom-up approach (WHY before HOW / ethics before science)</p> <p>2/ Harmonize practices in European countries >> Work with GPs National College in different countries</p> <p>3/ Special attention should be paid to diagnosis disclosure >> Suggest national recommendations for diagnosis disclosure</p> <p>4/ Use anti-stigma content for national campaigns >> Adapt checklist for the public</p>
Tools proposed by WP4	<ul style="list-style-type: none"> • WP4 diagnosis strategy • WP4 deliverable 1 on Benefice-risk of Diagnosis • WP4 evidence based tools selection • Shared educational content / efficient anti-stigma programme • Aims for training (checklist) • Inventory of stereotypes • French national recommendations for disclosure of a severe chronic disease
Pilot Impact indicators	<p>level 1 :</p> <ul style="list-style-type: none"> - Number of GPs attending the training ; - Satisfaction of participants <p>Level 2 :</p> <ul style="list-style-type: none"> - Evolution of stereotypes - Evolution of competences <p>Level 3 :</p> <ul style="list-style-type: none"> - Number of programmes - Number of agreements with GP associations - Number of recommendations/ national campaigns

The **GP–Nurse Cooperation** project aimed to improve NCD detection rates in primary care to improve diagnosis quality, reduce delay and improve patient management. The project involved sites in Bulgaria (Sofia), France (Lyon) and Italy (Rome/Modena). The pilot sites looked at the use of detection scales for assessing cognitive, behavioural and autonomy impairment (Bulgaria), a multidimensional assessment performed by an advanced practice nurse (France), and a case-finding tool for people with NCD in GPs’ daily clinical practice (Italy).

Sixty-two patients (31 in Bulgaria, 16 in Italy and 15 in France) were assessed. The multidimensional assessments performed in each site allowed GPs to formulate diagnosis hypotheses for some patients (Bulgaria and Italy) or nurses to signal proven risks for NCD and/or mood disorders (France). The pilot provides evidence that GP–nurse co-operation is feasible and constitutes an efficient option for improving NCD detection and diagnosis.

GP/NURSES COOPERATION - MAIN CONCLUSIONS	
Main message	GP Nurse cooperation (or other health professionals) is an efficient option to improve NCD detection and diagnosis
Barriers	<ul style="list-style-type: none"> • Insufficient knowledge about neurocognitive disorders • No consensus in cognitive tools in primary care • Opposition of the medical profession • Funding of nurses • Legislation
Facilitators	<ul style="list-style-type: none"> • Respond to a shortage of physicians • Respond to a changing demand for care and promoting high quality of care • Respond to growing health costs • Promote scientific research into primary care
Key messages	<ol style="list-style-type: none"> 1) <i>Formation of the GPs and Nurses on cognitive assessment and management</i> 2) <i>Legislative and regulatory changes to validate Advanced Practice Nursing activity</i> 3) <i>Funding the nurse assessment in the detection of neurocognitive disorders</i> 4) <i>Develop an algorithm decision for the management of neurocognitive disorders detected in primary care (same tools to detect, to assess,...)</i> 5) <i>Involve health care authorities in this model of cooperation</i>
Tools proposed by WP4	<ul style="list-style-type: none"> • WP4 diagnosis strategy • WP4 deliverable 1 on Benefice-risk of Diagnosis • WP4 evidence based tools selection • Best practice model from the 3 projects within the pilot
Pilot impact indicators	<p>level 1 : Mean rates of detection/diagnosis performed by a nurse/other professional or by a GP</p> <p>Level 2 : GP's diagnosis performance (sensitivity, specificity, positive/negative predictive value) in primary care</p> <p>Level 3 : Number of trainings and programmes for GP/Nurses (other professionals)</p>

The **telemedicine pilot project** included Bulgaria (Sofia), France (Bordeaux) and Greece (Athens) and aimed to increase NCD detection and diagnosis rates through telemedicine in nursing homes. The project in Greece involved three nursing homes, Bulgaria one and France two. The WP4 team leader shared a set of common tools and a range of project activities was arranged, including a workshop and systematic literature review.



The pilot projects revealed challenges at structural and health-system levels, and also at clinical level, where NCD diagnosis benefits were not well understood by participants. WP4 has provided recommendations to overcome the challenges, which include setting up telemedicine devices in nursing homes and developing an anti-stigma education programme on NCD diagnosis benefits.

Telemedicine for NCD diagnosis in Nursing Home - Main conclusions	
Main message	NCD detection and diagnosis in nursing homes is feasible and would be favored by telemedicine with a combination with behavioral disorders management
Barriers	Legal and ethics requirements/confidentiality of data Budget Time consuming Lack or insufficient training of GPs and nurses on NCD detection Lack or insufficient knowledge on NCD etiological diagnosis benefits for NH residents
Facilitators	Health system policies/support/decision
Key messages	<p>1- <i>NCD detection and diagnosis in nursing homes would be favored by Telemedicine with a combination with BPSD evaluation; if telemedicine is performed for BPSD a diagnosis process should be apply</i></p> <p>2- <i>Educational programmes on the diagnosis benefits should be proposed to GP and nursing home staffs in order to give them arguments for diagnosis</i></p> <p>3- <i>The Act On Dementia WP4, 5 and 6 groups should share their experiences to better support each other conclusions</i></p>
Tools proposed by WP4	WP4 diagnosis strategy WP4 evidence based tools selection WP4 anti-stigma programmes statistically efficient on stereotypes and on competences WP4 dedicated table on etiological diagnosis benefits in nursing home WP4 deliverable 1 on Benefits and risks on NCD diagnosis
Pilot Impact indicators	level 1: satisfaction of participants to TLM projects for NCD Level 2: nb of NH teleconsultations for NCD diagnosis/behavioral disorders Level 3: nb of European NH with TLM for NCD diagnosis/ behavioral disorders

WP5: crisis and care co-ordination

The WP5 team was commissioned to collaborate with other members of the Joint Action to:

- report on existing practices in care co-ordination and crisis-response services;
- report on identified best practices;
- develop materials for implementation planning and support; and
- report on the outcomes of the pilot projects.

The process began by reviewing the literature and guidelines on existing practices in dementia care. WP5 thereafter devised recommendations for health-care centres to support the development and implementation of programmes focusing on crisis-response services and care co-ordination, especially related to behavioural and psychological symptoms of dementia (BPSD). WP5 then developed and disseminated an online survey among EU Member States and relevant organisations in 29 countries (20 completions). The survey data provide an overview of the current status of national dementia policies and information on how services for people with dementia are organised.

Pilot projects were set up in:

- Bulgaria (reducing inappropriate referrals and use of emergency departments by GPs);
- France (two projects: using a multidisciplinary mobile team to address BPSD in Lyon; and the INFIMEGE project to improve detection and diagnosis rates of NCD through multidimensional assessment by a nurse and medical investigation leading to diagnosis by a GP);
- Italy, focusing on implementation of a management system for emergencies in patients with dementia in the local health unit of Modena;
- the Netherlands, as part of a national programme on dementia focusing on care management and support around difficult behaviour at home; and
- Scotland, through a post-diagnostic support in primary care project in GP clusters² in three parts of the country.

Crisis and care coordination - Care model



In general, the work of the pilot projects showed the desire and need to:

- connect primary-care providers to external support from dementia care specialists;
- train primary-care providers in the tools and techniques needed for people with dementia;
- co-ordinate care between primary-care providers and dementia specialists;
- develop dementia care pathways in primary-care settings through, for example, care co-ordination by nurses or other care providers;
- reduce carer burden and stress, especially in relation to care for people with dementia and BPSD;
- provide support for people with dementia so they can live longer at home;
- tailor dementia care approaches and improvement strategies to each pilot site context; and

² GP clusters typically are groups of 5–8 GP practices in a close geographical location.

- conduct ongoing evaluation of care to improve care co-ordination and crisis-response services for people with dementia.

WP6: residential care

The purpose of WP6 was to provide EU Member States with clear, evidence-based and tested information and recommendations on how to make changes and improvements in quality of care for people with dementia in residential care.³ It had six projects:

- projects on translating, adapting and further developing BPSD models and testing their feasibility and usefulness in residential care homes in Bulgaria, Greece and Romania;
- projects on promoting larger-scale implementation of recommended models for BPSD in the Netherlands and Norway; and
- a project to evaluate an e-learning programme about palliative care in nursing homes in Norway.

The projects in Bulgaria, Greece and Romania were considered pilot projects, while those in the Netherlands and Norway were about promoting larger-scale implementation of existing initiatives.

Pilot project	Type of project	Target group
Bulgaria IMPACT	Adapting a model Testing of acceptance and feasibility	All staff at the included institutions
Romania TIME inspired		
Greece ARIS		
Norway Train the trainer in TIME	Implementation after testing of TIME	Key staff, superusers, BPSD coaches (train the trainer)
Netherlands GRIP – less is more	Process evaluation of implementation	Stakeholders in implementing GRIP

Based on results from the projects, WP6 made the following recommendations:

- countries should develop evidence-based teaching and training programmes for approaching BPSD in residential care, including methods for mapping and analysing staff knowledge and attitudes and residents' needs, a theoretical introduction to person-centred care and BPSD, and activities and actions to prevent BPSD;
- owners of residential care settings and their managers and leaders should commit to implementing the programmes;
- programmes should be piloted in a few sites and adapted appropriately;

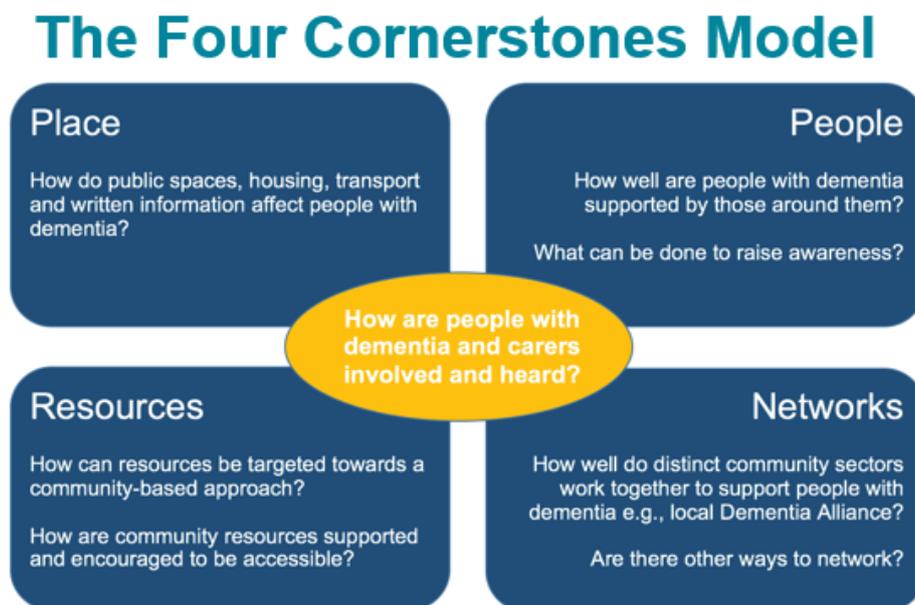
³ Residential care refers to all facilities providing a 24-hour service that people move to or are hospitalized in due to cognitive, mental or physical needs.

- residential care units should have access to external support and supervision to support implementation;
- a named employee in each residential care unit should be given the role of “superuser”, BPSD Care Coach or supervisor, to assume special roles in relation to follow-up of the implemented methods;
- the programmes should be made part of wider dementia plans, national standards, regulations or other guidance that lay obligations on residential care providers in relation to BPSD; and
- e-learning delivery options to complement and augment practical training, discussion of concrete cases and supervision should be explored.

WP7: dementia-friendly communities

The overarching objective of WP7 was to provide EU Members States with clear, evidence-based and tested information and recommendations on how to effect change, improvement and support for people with dementia to live at home through the development and promotion of dementia-friendly communities (DFCs).

The WP7 co-ordinating centre, the Department of Health and Social Care, England, commissioned an evidence review of DFCs that proposed a model (the “four cornerstones model”) identifying four aspects of DFCs: people, place, networks and resources. WP7 then tested the model in two pilot sites (Bulgaria and Greece), a collaborator site (Italy) and a partner site (England), where the DFC programme has been running for a number of years.



The WP7 team synthesised findings from implementation of the DFC model in the pilot sites, concluding that:

- a robust network of key organisations, with good levels of engagement and buy-in from local stakeholders (including local authorities and politicians), is essential;

- the success of the DFC depends, to a large extent, on the development of the site itself, in relation to levels of stigma, resources available and existing networks;
- a one-year pilot scheme is not enough time to demonstrate real change: the highest impacts were seen in Italy, which to some extent was related to the DFC site having been established over a number of years; and
- a thriving network of volunteers grouped around a strong charitable sector is essential.

Recommendations

<p>People</p> <ul style="list-style-type: none"> • Caregivers schools or support groups • Involvement of people with dementia and their caregivers • Education of service and community staff • Improve health and social care staff's knowledge of dementia 	<p>Places</p> <ul style="list-style-type: none"> • Improve accessibility to community spaces • Adapt physical layout of town, for example roads and pavements, to improve accessibility • Establish centres for PWD to attend and socialise
<p>Networks</p> <ul style="list-style-type: none"> • Signing of local agreements and memoranda • Establishing an online network and social media presence 	<p>Resources</p> <ul style="list-style-type: none"> • Use volunteers throughout all activities to minimise cost and maximise involvement • Train healthcare professionals and personnel in the initial stages, to maximise early intervention and increase sustainability of the DFC

WP7 found that the DFC model can work in a variety of contexts across the EU, as demonstrated in the pilot sites. The model must, however, reflect local culture, levels of resources and networks, and existing levels of stigma.

DFCs may not demonstrate measurable change in the short term, particularly in sites that have less robust networks, fewer resources and higher levels of stigma. The levels of improvement and impact varies dependent on the context, but DFCs have been shown to be effective and to have had a positive effect across the pilot sites.

WP2 Dissemination

Dissemination was the key focus of WP2 and aimed to ensure that key stakeholders (including Member State governments, health and care professionals, academics, people living with dementia and their carers, and the voluntary sector) were aware of the Joint Action and that learning from the Joint Action was shared widely. WP2 was led by the Scottish Government.

A Dissemination Advisory Group (DAG) that included people living with dementia and their carers was established. Three full meetings of the DAG were held via teleconferencing (reflecting the geographic spread of the group), with bilateral meetings taking place as necessary.

A dissemination communication strategy was developed following a stakeholder analysis, followed by a questionnaire on stakeholder mapping. The Act on Dementia website was the focal point of the strategy (www.actondementia.eu), supported by members of the Joint Action being encouraged to make presentations, attend national and international events and promote their findings through the Act on Dementia and institutional websites. Some video clips were made available to the Joint Action, many of which came from participants' resources and were seen as being extremely relevant to the messages the Joint Action promoted.

Full reports from WP 4–7 were posted on the website, along with short “layman” versions setting out key findings. WP2 made a short video on each of the subjects covered by the work packages and the evaluation of the Joint Action. An agency was selected to carry out this work, using the Scottish Government procurement framework. The agency worked with each work package over a number of weeks to plan/storyboard the films, which were created over September and October 2019.

WP3 Evaluation

The evaluation of the Act on Dementia Joint Action was led by the Agency for Health Quality and Assessment of Catalonia (AQuAS). The purpose of the WP3 was maximise the methodological quality of the outputs of the Joint Action (JA) (evidence and testing of best practices reports) and the impact of the Joint Action using appropriate qualitative and quantitative measures. WP3 was supported by the Evaluation Advisory Group (EAG) that included a representative of each Work Package and Alzheimer Europe as a representative of people living with dementia and carers.

The methodological approach of WP3 allowed the promotion of a quality culture of the products that includes the implementation of evidence-based best practices in the field of dementia. The evaluation of methodological quality is relatively innovative in the context of Joint Actions and those that include evidence-base of best practice models and their implementation; this approach also goes beyond the standard monitoring of accomplishment of tasks and processes. Evaluation, within Act on Dementia, has been a participatory process throughout the project, helping members to reach common understanding and agreement on quality standards.

A set of measures with high level of consensus among a wide range of stakeholders across Europe has been defined to assess impacts of Act on Dementia at short, medium and long term. The most relevant and feasible measures include among other aspects, the tracking of how key recommendations from Act on Dementia are included in strategic regional or national plans, training activities for professionals, and the improvement of information systems to collect in a systematic way the health status and use of services for both people living with dementia and their caregivers. In the qualitative study on impact, informants considered that the global goals of Act on Dementia were partially achieved. For example, they perceived an increase in the evidence of collaboration between Member States with regard to dementia, a reasonable provision of evidence-based and tested information and recommendations on how to effect change and improvement in the four key areas (diagnosis and post-diagnostic support, crisis and care coordination, quality of residential care and dementia-friendly communities). They perceived also some evidence of an intention to put key recommendations into practice in their context. Nevertheless, in spite of the JA's emphasis on the need for the continued prioritization of dementia at regional and national level, this has not been the case at European level according to participants. Finally, and in addition to perceiving benefits such as improving collaborations among regions, learning processes and the validation of dementia plans (including those in the process of implementation) were found to be common impacts at very short term.

To sum up, the evaluation and the project as a whole has generated a collective body of knowledge on key aspects in need of improvement in the field of dementia.

Final Reflections and Thoughts on Future Opportunities

Co-ordinating the Joint Action - Act on Dementia has been a hugely rewarding experience for Scottish Government. It was gratifying to attend each of the final meetings from of the work packages to experience the depth of innovation and collaboration that had taken between a wide range of experts in their fields.

From the conversation and debates that took place during these final meetings, alongside the full policy discussion that took place in Brussels at the European Group of Governmental Experts on Dementia, some central themes emerged that seem worthy of further collaborative efforts:

- Person-centred approaches and respecting the human rights of persons living with dementia/ neurodegenerative disorders must be a central component for all local and national government policy makers.
- Stigma concerning the attitudes and cultural behaviours of society across Europe is well expressed and documented – but we often overlook that it also applies professional health and care workers as well as clinicians. It is important for initial and ongoing professional development to tackle destigmatisation of dementia / NCD.
- Training – Dementia / NCD specific educational programs are central to equipping a range of professionals and lay-persons with the confidence to recognise and support persons with dementia / NCD to live their best lives.

- Behavioural and psychological symptoms of dementia – (or stress/ distress) is a significant factor in crisis situations that often result in poor outcomes for PWD living in their community, or in residential care settings. Investment in training for community based professionals and residential care staff in managing BPSD is critical in reducing or avoiding crisis situations.
- Greater collaboration between primary care providers and NCD specialists is needed to increase the confidence and ability of general practitioners and practice nurses in managing the needs of persons with dementia/ NCD who are living at home and experience a crisis.
- The central role of General Practitioners and Nursing practitioners in early detection and diagnosis of dementia/ NCDs is important to give patients and their carers the optimal opportunities to live well and plan their advance care preferences.
- Developing strong community networks and supports is important to destigmatise and strengthen solidarity for persons living with dementia and their carers.