

ACT ON DEMENTIA

FINAL REPORT



This document is part of the joint action '678481/DEM2' which has received funding from the European Union's Health Programme (2014-2020).

© Scottish Government, January 2020

This report has been developed by Gillian Barclay, Rona Tatler and Suzanne Kinross (the Scottish Government) on behalf of the European Union Joint Action Act on Dementia. The text was prepared by Alex Mathieson.

Statement of originality

The information in this document reflects only the authors' views and the European Community is not liable for any use that may be made of the information contained therein. The information in this document is provided as is, and no guarantee or warranty is given that the information is fit for any particular purpose. The user thereof uses the information at its sole risk and liability.

Contents

Act on Dementia	4
Work pages 4, 5, 6 and 7 – summary	5
Work package 4 (WP4): diagnosis and post-diagnostic support.....	5
WP5: crisis and care co-ordination	6
WP6: residential care.....	7
WP7: dementia-friendly communities	8
WP2 Dissemination	9
WP3 Evaluation	9
Final Reflections and Thoughts on Future Opportunities	10

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: <https://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 (<https://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.

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/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.

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

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

that GP–nurse co-operation is feasible and constitutes an efficient option for improving NCD detection and diagnosis.

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.

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.

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

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
- 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.

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;
- residential care units should have access to external support and supervision to support implementation;

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.

- 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.

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 (<https://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 to 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-based 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 Governemnt. 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 Governamental Experts on Dementia, some central themes emerged that seem worthy of further collabrative 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 destatisation 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.