



Crisis and care  
coordination:  
Final report

EU Joint Action on  
Dementia  
2015-2018



This Joint Action (grant agreement No 678481) has received funding from the European Union's Health Programme (2014-2020)

## Disclaimer

This report was produced under the EU Joint Action on Dementia Programme (2014-2020) in the frame of a service contract with the Trimbos Institute acting under the mandate from the Dutch Ministry of Health.

The content of this report represents the views of the Trimbos Institute, Dutch Ministry of Health and Italian Health Institute; it can in no way be taken to reflect the views of the European Commission and/or related parts of the European Union's Health Programme.

The European Commission, the Trimbos Institute, Dutch Ministry of Health, and Italian Health Institute do not guarantee the accuracy of the data included in this report. Please cite the report if information from the report is used in third-party documents, presentations, and/or online.

## Acknowledgements

The authors would like to thank project leaders and staff at each of the pilot project sites. We would also like to thank and acknowledge the effort of other members of the Act on Dementia project, including their review and suggestions for improvement on the work of Work Package 5.

## Table of Contents

<b>1. Summary</b>	4
<b>2. Key terms</b>	4
<b>3. Ethics</b>	4
<b>4. Introduction</b>	5
4.1 Act on Dementia	5
<b>5. Introduction to Work Package 5</b>	6
5.1 Objective	6
5.2 Partners/Work Package 5 team	6
5.3 Defining care coordination and crisis management	7
5.4 Tasks and deliverables	8
<b>6. Development of recommendations for crisis and care coordination in dementia care</b>	9
6.1 Review of existing practices in care coordination and crisis in dementia	10
6.1.1 Literature review: care coordination for those with dementia and crisis in dementia	10
6.1.2 Literature review: updating the 2012 ALCOVE literature review	11
6.1.3 Survey of relevant organizations and EU Member States on dementia care strategies	13
6.2 Good Practices in dementia care	14
6.2.1 Selection criteria/mapping dementia care coordination	15
6.2.2 Collecting literature	15
6.2.3 Use of the criteria to develop guidance on good practices in dementia care	15
6.3 Recommendations	16
<b>7. Pilot project implementation planning and ongoing support</b>	18
7.1 General implementation planning and support (December 2017 – April 2019)	19
7.1.1 Intervention development and implementation support: December 2017	19
7.1.2 Intervention development and implementation support: March 2018	20
7.1.3 Intervention development and implementation support: July 2018	20
7.1.4 Intervention development and implementation support: February 2019	21
7.2 Tailored intervention development and implementation support	21
7.2.1 Bulgaria	22
7.2.2 France	27
7.2.3 Italy	36
7.2.4 Netherlands	44
7.2.5 Scotland	48
<b>8. Recommendations from pilot sites</b>	56
<b>9. Reflections on the five pilot projects</b>	58
<b>10. Limitations</b>	60
<b>11. References</b>	61

## 1. Summary

The Act on Dementia Joint Action: Crisis and Care Coordination Work Package 5 worked to improve crisis response services and care coordination for those with dementia in Europe. This was done through collecting pertinent academic literature and guidelines on dementia care, conducting a survey of relevant organizations in the EU, reviewing the collected literature using a standardized tool, and developing good practice recommendations based on the findings from literature review. These guidelines were shared with the larger Act on Dementia team to be used to improve care for those with dementia. As well, these guidelines were used, in part, to shape and improve care offered as part of pilot projects undertaken in five European countries (Bulgaria, France, Scotland, Italy, and the Netherlands). The development and implementation of the pilot projects was supported by experts from the Crisis and Care Coordination Work Package 5 using implementation science principles, existing materials, and customized implementation support tools. The pilot projects, which have been tailored to the needs and context of each setting, can serve as a model for using evidence-informed recommendations and implementation science guided support to improve crisis response services and care coordination for those with dementia.

## 2. Key terms

- Act on Dementia
- ALCOVE
- behavioral and psychological symptoms of dementia
- care coordination
- crisis response services
- dementia
- development of recommendations
- good practices
- Horizon 2020
- implementation science
- implementation support
- translation of knowledge

## 3. Ethics

The authors of this report have worked to respect the rights of all participants involved in the EU Act on Dementia, including those outlined by the Declaration of Helsinki and those described in the EU's General Data Protection Regulation. As such, no private or confidential data on individual patients was shared between the partners and projects involved in Work Package 5. In addition, no confidential data shared on the projects involved in Work Package 5. As all data was of a public or non-confidential nature, no ethical review was required.

Project leaders for the pilot projects undertaken in five European countries (Bulgaria, France, Scotland, Italy, and the Netherlands) were responsible for their own ethical review and ethical approval, if needed. The authors of this report can take no responsibility for the ethical review of the individual projects involved in this Work Package.

## 4. Introduction

Over 50 million people live with a form of dementia, with Alzheimer's disease representing the most commonly diagnosed type of the dementia.<sup>i</sup> As dementia can have long-lasting medical, social, and economic effects for people with dementia and their families, it is important that healthcare systems, including those in Europe, seek strategies to improve dementia care.<sup>ii</sup> In order to improve dementia diagnosis, care, and management in European Member States, the EU has funded a variety of initiatives, such as the Joint Action on Alzheimer Cooperation Valuation in Europe (ALCOVE) and its follow-up, the Act on Dementia.<sup>iii,iv</sup>

### 4.1 Act on Dementia

Initiated in March 2016, the overall aim of the EU Joint Action - Act on Dementia - was to promote the implementation of coordinated activities by Member States to improve the situation of people living with dementia and their carers. The coordination of Act on Dementia (work package 1) and dissemination of the JA projects (work package 2) was led by the Scottish Government; the evaluation of the Joint Action was led by the Catalan Agency for Health Information, Assessment and Quality (AQuAS) in Spain (work package 3). Content-related activities have been conducted through the remaining four work packages, focusing on diagnosis and post-diagnostic support (work package 4), crisis and care coordination (work package 5), quality of residential care (work package 6), and dementia friendly communities (work package 7).

## 5. Introduction to Work Package 5

Many healthcare systems are in need of guidance on effective, ethical, and evidence-based guidance on ways to care for those living with dementia, including guidance on crisis response services and care management programs. However, as research has shown, static guidance in the form of reports and articles is only part of the guidance needed for healthcare systems and care practices to make a change in the way that care is delivered. This is often understood as a knowledge/practice gap. More is needed, often in the form of resource sharing, education on implementation models, and tailored implementation support. Combining evidence-informed recommendations and implementation support has been shown to increase the use and sustainability of interventions in healthcare.

Work Package 5 of the Act on Dementia initiative supports the development of practical recommendations for healthcare system and through tailored implementation support for project leaders and staff conducting pilot projects in Bulgaria, France, Scotland, Italy, and the Netherlands, with special attention for the knowledge/practice gap.

### 5.1 Objective

The overall objective of Work Package 5 has been to provide “clear, evidence-based and tested information and recommendations on how to effect change and improvement in care coordination and crisis response services for people with dementia”.<sup>v</sup> This objective has been met through the development and dissemination of good practice recommendations for care coordination and crisis response services for those living with dementia, as well as through tailored, timely, and evidence-informed implementation support for pilot projects in Bulgaria, France, Scotland, Italy, and the Netherlands to improve how dementia care coordination and crisis response services for people with dementia is delivered.

This report describes the process of developing and disseminating the good practice recommendations, as well as the translation of aspects of these recommendations into pilot projects and the tailored implementation support given to the Work Package 5 pilot projects.

### 5.2 Partners/Work Package 5 team

Organizations from Italy and the Netherlands were in the lead of Work Package 5 of Act on Dementia. The Scottish Government, Bulgaria and France were involved as associated partner, while Greece (Dr. Antonio Politis), Alzheimer Europe (Jean George) and Italian Ministry of Health (Dr. Teresa Di Fiandra) were involved as collaborating partners. The Dutch Ministry of Health, Welfare and Sport (VWS) (Dr. Jacqueline Hoogendam), with the Trimbos Institute as a subcontractor, and the Italian National Health Institute (ISS) (Pr. Nicola Vanacore) were the main lead organization of this Work Package.

As its main mission, the ISS provides scientific EBM technical support in the field of public health. The departments and national centers of the ISS have the specific aim of promoting public health through scientific research, surveillance, and preventive interventions in the different fields of health sciences, including infectious and chronic diseases, environmental health, and food and drugs safety and quality control. The Unit of Promotion and Evaluation of Prevention Policies for Chronic Disease (Responsible: Nicola Vanacore), within the National Centre for disease prevention and health promotion of the Italian ISS, cooperates in promoting and assessing preventive strategies and specific

plans aimed at adopting integrated programs for the management of chronic diseases. Its activities include the participation in institutional working groups and public health research activities, and the production and assessment of scientific evidence. The ISS working group, lead by Nicola Vanacore, included 12 staff members (Ilaria Bacigalupo, Guido Bellomo, Marco Canevelli, Annamaria Confaloni, Alessio Crestini, Alessandra Di Pucchio, Giuseppe Gervasi, Eleonora Lacorte, Flavia Mayer, Monica Mazzola, Luana Penna, Paola Piscopo).

In the Netherlands, the Ministry of Health, Welfare and Sport (VWS) was the Dutch lead for this Work Package and subcontracted the Trimbos Institute. Jacqueline Hoogendam is the Work Package 5 leader from VWS.

The Trimbos Institute was contracted to research and develop recommendations for good practices in dementia care coordination and crisis management and to support implementation of pilot projects in care coordination and crisis response services in Bulgaria, France, Scotland, Italy, and the Netherlands. The Trimbos Institute is the Netherlands Institute of Mental Health and Addiction. The mission of the Trimbos institute is to improve mental health by generating and disseminating knowledge using a life course perspective as a starting point. For the care and support for those with dementia, specialists from the Trimbos Institute work in close collaboration with practice (care homes, carers, care professionals, case managers). The Trimbos team consists of researchers in care for those with dementia from the Elder Care department (Astrid van der Schot, PhD) and an implementation scientist from the International Department (Bethany Hipple Walters, PhD, MPH). Researchers from Trimbos worked in close collaboration with the Italian National Institute of Health and the Dutch Ministry of Health, Welfare, and Sport.

### *5.3 Defining care coordination and crisis management*

In order to improve care for those with dementia with regard to crisis response services and care coordination, it is crucial to have clear and shared definitions of these concepts. While many different definitions of care coordination exist, WP5 has defined care coordination as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care”.<sup>vi</sup> Further, crisis in the lives of those with dementia has been defined as “a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome and therefore crisis resolution”<sup>vii</sup>; in the case of dementia care, crisis resolution can be seen as crisis response services, as dementia is a chronic condition with no curative treatment or curative resolution.

The conceptualizations of crisis response services and of care coordination shaped the goals and all of the activities of Work Package. These definitions ensured that all parties involved had a consistent understanding of crisis response services and care coordination with regard to those with dementia, their families, their carers, and their healthcare providers.

#### 5.4 Tasks and deliverables

As part of Act on Dementia, the Work Package 5 team was commissioned to complete the following tasks and deliverables, as noted below:

- Report on the existing practices in care coordination and crisis response services
- Report on identified best practices
- Materials for implementation planning and support
- Report on the outcomes of the pilot projects

These activities were conducted by the Work Package 5 team, with support and collaboration of other members of the Act on Dementia Joint Action.

This report describes the process of developing and then implementing recommendations for crisis response services and care coordination; the recommendations focused, in part, on the behavioral and psychological symptoms of dementia (BPSD) as BPSD can influence both crisis response services and care coordination for those with dementia.

The process began by reviewing the literature and guidelines on existing practices in dementia care, developing and using a method of selecting good practices from the reviewed literature on existing practices, and a summary of the recommendations. These activities are described in detail in the *Evidence and recommendations* report, *Overview of best practice recommendations* report, and in the *Implementing programs in healthcare systems: Tips and Tools* materials. These reports and materials have been included as appendices to this report; the WP 5 activities have been summarized from the relevant deliverables in the following section. Additional information on the implementation support provided to each pilot project is also described in the following sections.

## 6. Development of recommendations for crisis and care coordination in dementia care

Many healthcare systems are in need of synthesized, clear, and tailored recommendations in order to make changes in care, including changes in care related to dementia care. However, many healthcare practices do not have the resources needed to develop such guidelines on their own, as they are lacking time, staff skilled in synthesizing and analyzing research, and access to the latest evidence from journals. As well as being necessary for deciding which changes to make in systems (often in the form of programs in healthcare practices and clinics), evidence-based recommendations are needed to guide effective, sustainable, and feasible implementation of changes in care at the care provision level. The lack of such recommendations adds to the knowledge/implementation gap in healthcare systems; this gap is evident in dementia care, such as in the implementation of programs for crisis response services and care coordination in dementia care.

To support the implementation of evidence-informed care for those with dementia, the activities of WP5 of the Act on Dementia Joint Action included the development of recommendations for healthcare centers to support the development and implementation of programs focusing on crisis response services and care coordination. As can be seen in the *Evidence and recommendations* report, these recommendations were developed through an in-depth review of existing practices and through the development of an evidence and recommendation selection criteria. This work resulted in the development of a set of recommendations for good practices in dementia care in care coordination and crisis response services. These recommendations were used, in part, to develop and implement pilot projects in Bulgaria, France, Scotland, Italy, and the Netherlands.

## 6.1 Review of existing practices in care coordination and crisis in dementia

Expert staff from ISS (Ilaria Bacigalupo, Guido Bellomo, Marco Canevelli, Annamaria Confaloni, Alessio Crestini, Alessandra Di Pucchio, Giuseppe Gervasi, Eleonora Lacorte, Flavia Mayer, Monica Mazzola, Luana Penna, Paola Piscopo) and from VWS (Jacqueline Hoogendam), with the support from all associated partners, performed two quasi-systematic literature review. The first review was aimed at updating the evidence supporting the recommendations on behavioral and psychological symptoms of dementia (BPSD) from the previous ALCOVE Joint Action. The second review included all literature on best practices for the management of crises in people with dementia and the best models for care coordination for people with dementia. Further information on models for crisis response and care coordination was collected through a survey involving several representatives from EU Member States.

### 6.1.1 Literature review: care coordination for those with dementia and crisis in dementia

All published and grey literature reporting data on best practices and models of crises response and care coordination was collected through structured bibliographic searches on selected databases (PubMed, Web of Science), by searching guidelines and policy databases such as the NHS Evidence Tool, and by reviewing the websites of public health institutions in Europe. As noted in the *Evidence and recommendations* report, the literature was classified into the following four main areas:

- 1) models of care coordination or care organization (n=63)
- 2) management of crises and access to emergency care or acute care (n=33)
- 3) models for the management of advanced dementia care and palliative care, including end-of-life care (n=17)
- 4) elements characterizing models of care for patients with dementia and their families and/or carers (n=29)

A summary of each of these themes is below.

The primary conclusions from the literature on models of care coordination reported in *Evidence and recommendations* were:

“a multi-component intervention based on antipsychotic review, social interaction and exercise in conjunction with person-centered care reduced significantly the antipsychotic use, in nursing home; moreover, antipsychotic review plus the social interaction intervention significantly reduced mortality (Ballard 2016).

A collaborative care model improve the quality of care and behavioral and psychological symptoms of dementia among primary care patients and their carers. These improvements were achieved without significantly increasing the use of antipsychotics or sedative-hypnotics (Callahan 2006).

Multicomponent intervention program conducted in people with dementia and their spouse carers significantly reduced long-term institutional care admissions. (Eloniemi-Sulkava 2009).

Care consultation, a multi-component telephone intervention, which points to a collaboration among patients and carers to improve the family and community resources, decrease

utilization of managed care services and improve psychosocial outcomes, hospital

admissions and emergency department visits during the one-year study period. (Clark 2004)<sup>viii</sup>

From these findings, a set of recommendations relating to models of care coordination were developed; these recommendations included the:

- adoption of a case management model of care for those with dementia,
- use of guideline-based disease management strategies and programs, and
- use of multicomponent interventions in dementia care.<sup>ix</sup>

A full description and justification for these recommendations can be found in the *Evidence and recommendations* report.

The *Evidence and recommendations* report uncovered 33 relevant articles related to the management of crises and access to emergency care or acute care for people with dementia. From these articles, the report recommended, in part, that healthcare professionals in the acute care setting should be trained in care management of people with dementia, that physical therapeutic rehabilitation services should be offered to people with dementia who have fractured a hip, that specialized care units for people with dementia may improve the patient's quality of life, and that implementing complex assessments and interventions in acute care may reduce the behavioral and psychological symptoms of dementia (BPSD).<sup>x</sup>

Seventeen articles were found to be related to models for the management of advanced dementia care and palliative care, including end-of-life care. The review of this literature found, in part, that: "The delivery of end of life care plans cannot disregard the multidimensionality and multidisciplinary nature of the intervention as well as the need for a case coordination."<sup>xi</sup> Further findings can be found in the *Evidence and recommendations* report, including an in-depth description of findings from a study on motor stimulation, activities of daily living, and cognitive stimulation (MAKS) therapy.

The report identified a number of articles related to elements characterizing models of care for patients with dementia and their families and/or carers. These included articles on antipsychotic and psycho-social interventions, nutrition, sleep, falls, institutionalization, communication and information support, staff training, and quality of care. As recommended by the report, it is important to address nutrition issues for those with dementia and to make nutritional care and support a standard aspect of care for people with dementia.<sup>xii</sup>

The full methodology, findings, and general recommendations from the literature review on the management of crises in people with dementia and on care coordination in dementia care literature review is available in the report in the **appendix 1**.

#### 6.1.2 Literature review: updating the 2012 ALCOVE literature review

To update the recommendation from the previous ALCOVE Joint Action, a systematic review was performed on PubMed adopting the same methodology as from the 2012 ALCOVE literature

review. As noted in the report, 50 studies were included in the qualitative summary. Full methodological details can be found in the **appendix 1**.

The recommendations developed from this review of the literature include, in part, the use of a multidisciplinary approach for those with complex, persistent dementia systems, the use of mobile teams to avoid and/or reduce behavioral issues, and that psychosocial interventions should be used as a first line approach for prevention and management at the public health level.<sup>xiii</sup>

Further recommendations noted that:

- “interventions that aim to communicate with people with dementia, helping staff to understand and fulfil their wishes, reduce symptomatic and severe agitation”
- “all Psychosocial Interventions should be double targeted, individualized, and regularly revised - PSI must implicate both the carer and the patient and they must be tailored to the needs of both the patient and the carer, because the dynamics in their relationship can be a source of BPSD, and therefore, key to BPSD management”
- “dedicated units for BPSD in nursing homes and hospitals should be developed”<sup>xiv</sup>

The complete update of the ALCOVE recommendations, as based on the literature review, can be read in the report in the **appendix 1**.

### 6.1.3 Survey of relevant organizations and EU Member States on dementia care strategies

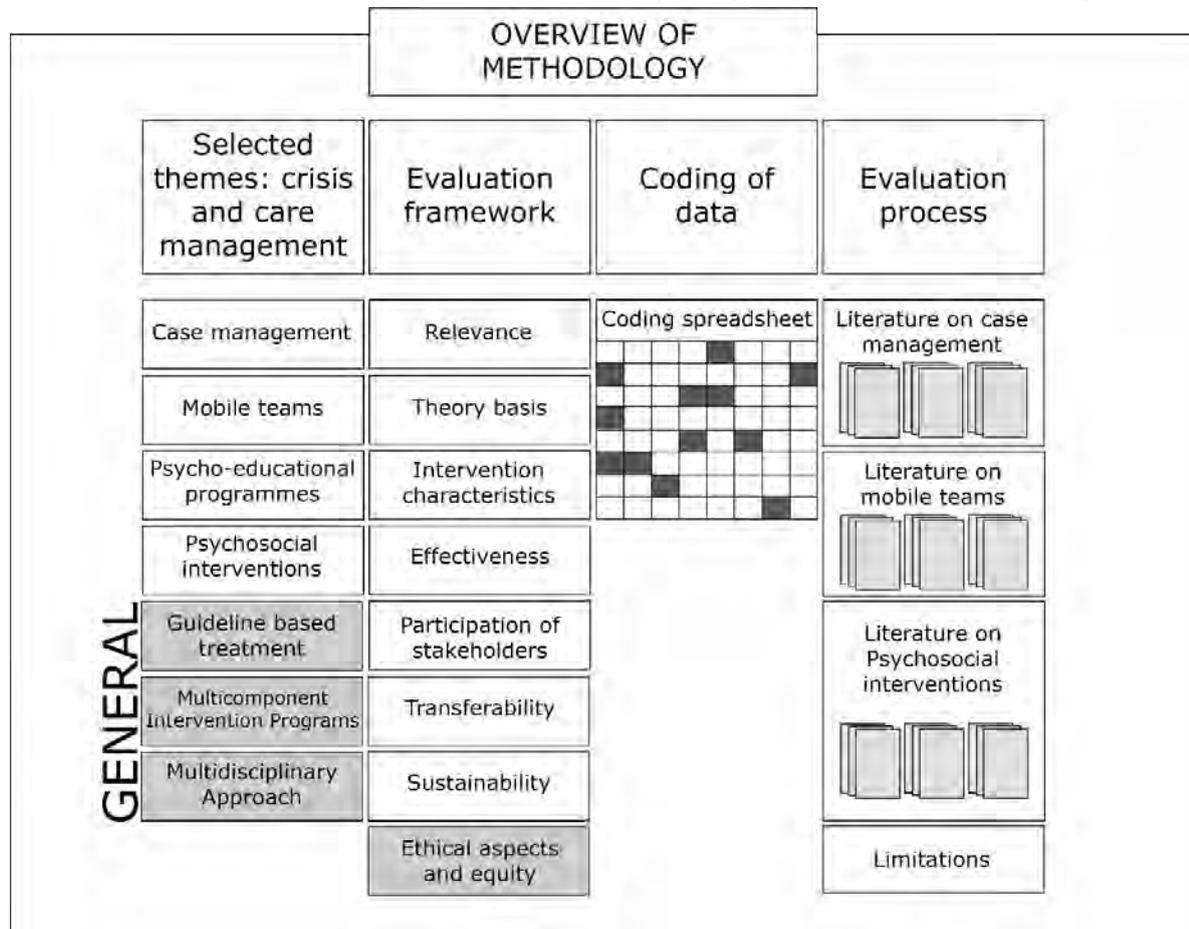
In addition to reviewing literature related to existing practices in care coordination and crisis management in dementia care, a survey was developed and disseminated to EU Member States and relevant organizations. The online survey was sent to experts on dementia in 29 countries; representatives from 20 countries completed the survey.

The self-administered survey focused on national dementia policies, on the implementation of ALCOVE recommendations, and on the use care pathways and multidisciplinary care teams to care for people with dementia. The survey found that of the countries completing the survey, 15 countries have a national dementia policy; in 11 of these countries, the policy has been at least partially implemented.<sup>xv</sup> The number of countries with such a policy has increased since the previous ALCOVE Joint Action survey. According to survey respondents, the most common aspects of a national dementia policy or strategy included care pathways and strategies related to improving the quality of care for those with dementia. Survey data also shows that seven countries have implemented the ALCOVE recommendations related to BPSD. As noted in the *Evidence and recommendations* report, the survey data provides an overview of the current status of national dementia policies and information on how services for people with dementia are organized.

## 6.2 Good Practices in dementia care

The data, recommendations, and references reported in *Evidence and recommendations* were used to develop good practices in dementia care, especially as related to care coordination, crisis response services, and the management of the behavioral and psychological symptoms of dementia (BPSD). In order to compile and develop these recommendations, the *Evidence and recommendations* report was first read and reviewed to gain an initial understanding of issues related to dementia care. This information shaped the comprehensive process of selecting, developing, and dissemination good practice recommendations for dementia care.

As described in detail in the *Overview of best practice recommendations* report, crafting good practice recommendations was a team effort involving experts in dementia care, implementation science, public health, and psychology from multiple organizations.<sup>xvi</sup> This teamwork was done in order to explore the multi-faceted, complex, and ongoing nature of dementia care at the patient, carer, professional caregiver, healthcare organization, and national healthcare system levels. Recommendations were developed through the creation of an evidence-informed selection criteria, through an exploration of the findings from literature (including but not limited to the literature in the *Evidence and recommendations* report) using the selection criteria, and through the development and dissemination of good practice recommendations in the *Overview of best practice recommendations* report. The process of developing recommendations can be seen in the Overview of Methodology figure. The process and recommendation are also summarized in the section that follows; further details can be found in the *Overview of best practice recommendations* report.



### 6.2.1 Selection criteria/mapping dementia care coordination

In order to uncover and disseminate evidence-informed good practices in dementia care, experts from the Trimbos Institute developed a selection criteria to be used to systematically review relevant literature, including the literature described in the *Evidence and recommendations* report, existing guidelines and recommendations in dementia care, and additional academic literature. As noted in the *Overview of best practice recommendations* report, the selection criteria was based on the EU Good Practices in Mental Health and Well-being criteria and was further influenced by the European best practices in health promotion and chronic disease prevention evaluation criteria from DG Santé and by a systematic review on selecting best practices in public health.<sup>xvii,xviii,xix,xx</sup> The criteria was tailored to factors associated with dementia care in Europe, to the aims of Act on Dementia, to the needs of the pilot practices, and to the specific aims of Work Package 5. The criteria was developed primarily by dementia experts and implementation scientists at the Trimbos Institute but was shared, as needed, with Act on Dementia partners.

While the development of the criteria was evidence-informed, pragmatism was a key consideration in the development process. The criteria was developed as an Excel file to be used as a deductive qualitative coding framework as well as a screening criteria. Using the criteria, literature was analyzed along eight themes related to good practices in healthcare. The themes are:

- 1) Relevance of the intervention or program
- 2) Theory basis of the intervention or program
- 3) Intervention characteristics of the program
- 4) Effectiveness of the program
- 5) Participation of stakeholders (care providers, families, clients/patients, policymakers)
- 6) Sustainability of the program
- 7) Ethical aspects and equity of the program
- 8) Transferability (ability of the program to be moved to a new setting) of the program

Further information about the development of the criteria can be found in the full *Overview of best practice recommendations* report.

### 6.2.2 Collecting literature

Literature on crisis and care coordination in dementia care was collected for analysis to be used to develop good practice recommendations. Selected articles from the *Evidence and recommendations* report were reviewed; when additional information was needed, the experts from the Trimbos Institute collected and analyzed additional sources of information, such as dementia care guidelines, white papers, and journal articles. A complete literature list can be found in the *Overview of best practice recommendations* report.

### 6.2.3 Use of the criteria to develop guidance on good practices in dementia care

Three experts from the Trimbos Institute used the selection criteria Excel spreadsheet to collect and later analyze literature on care management/coordination and crisis. Data from the articles was directly copied into the relevant fields of the criteria. The completed criteria was then used to create recommendations related to good practices in dementia care.

### 6.3 Recommendations

The WP5 team developed concrete, practical recommendations related to crisis and care coordination for people with dementia. A few of the general recommendations from the *Overview of best practice recommendations* report are shared below:

“Care for people with dementia (and their carers) requires complicated clinical, sociobehavioral and caregiving skills. All care and/or support programs should have a focus on patient centered care, contain multiple components and have a multidisciplinary approach.

The gold standard of care for people with dementia and their carers require teams integrating, coordinating, and manage between and across disciplines. Collaboration with the carers and integration within primary care is important, as is collaboration and coordination with other members of the multidisciplinary care team.”

The full recommendations can be read in the report in the **appendices 2 and 2bis**. The recommendations were disseminated to the WP5 team, including with project leaders at the pilot implementation sites.

However, several recommendations from the WP5 milestone 1 in the mapping report were selected by the implementing countries. In particular, recommendations concerning the three topics as listed in the box below :

**RECOMMENDATION a 1** The adoption of a **Case management** model of care organization.

**RECOMMENDATION e 2** [WP6.5.1 - Alcove Recommendation] **Mobile teams** with specific skills for the caring of BPSD, both in the home and nursing home setting. The mobile team for dementia allows to avoid hospitalization and may help to reduce behavioral disorder.

**RECOMMENDATION e 4** [WP6.9 - Alcove Recommendation] In terms of public health, the first line in BPSD prevention and management should be **Psychosocial Interventions (PSI)**, and in particular, the first level should be psycho-educational programmes.

**RECOMMENDATION e 5** [WP6.10- Alcove Recommendation] All **Psychosocial Interventions (PSI)** should be double targeted, individualised & regularly revised - PSI must implicate both the carer and the patient and they must be tailored to the needs of both the patient and the carer.

In addition, several recommendations from the WP5 milestone 1 in the mapping report, are more general and important for all care aspects of people with dementia and their carers, namely:

**RECOMMENDATION a 2 Dementia guideline-based disease management programs** improve care quality, community agency assistance, patient health-related quality of life, overall quality of patient care, caregiving quality, social support, and level of unmet caregiving assistance needs. (Vickrey 2006, Sivananthan 2013, Brody 2013)

**RECOMMENDATION a 3 Multicomponent intervention programs** can improve the quality of care, psychosocial outcomes and reduce the antipsychotic use. (Ballard 2016, Callahan 2006, Eloniemi-Sulkava 2009, Clark 2004)

**RECOMMENDATION e 1 [WP6.4 – Alcove] A multidisciplinary approach in all dimensions of Support Systems for BPSD** should be promoted for older people who have complex, persistent symptoms associated with dementia (INESSS 2012)

## 7. Pilot project implementation planning and ongoing support

Too often, healthcare systems attempt to improve care through disseminating guidelines and policies without additional support. These policies and guidelines, while often based on strong evidence, often cannot be implemented 'as is'. Clinicians and healthcare practices need support to implement changes in practice, to move the best care from theory to practice, and to tailor improvement plans to real-world settings.

The good practices recommendations helped shape the content and direction of the work of the five pilot programs, which were conducted in care settings in Bulgaria, France, Scotland, Italy, and the Netherlands. While each of the pilot programs focused on improving crisis and care coordination for those with dementia, the aims, methods, and target populations of the pilot programs were unique, tailored to the context, to the needs of the target populations, and to the skills and experience of the project leaders. In order to successfully meet their goals and objectives, each pilot program needed both general implementation guidance and tailored implementation support. The following section describes how and in what ways project leaders in the pilot sites engaged with the implementation planning and support offered by the WP5 team.

### 7.1 General implementation planning and support (December 2017 – April 2019)

Both general and tailored implementation planning and support were offered to project leaders in the pilot sites. The general guidance was tied to the development and implementation of programs for crisis and care coordination, as well as to implementation science literature. This general guidance aimed at equipping all project sites with the basic skills and tools needed to develop and implement programs related to crisis and care coordination in dementia care.

The WP5 team regularly reached out to project leaders from each of the pilot practices to offer both general and tailored support and assistance with implementation. This outreach came in the form of routine emails, offers to have one-on-one and group meetings, and sharing of resources. The WP5 team also invited the project leaders to contact them with questions or requests; when relevant, these questions and answers were shared with all of the pilot project leaders.

General guidance was provided to all project leaders. This general guidance occurred primarily through meetings, presentations, emails, and resource materials. When possible and relevant, existing materials were shared, such as tools from the RE-AIM framework (**appendices 3-7**), and a SMART goal setting template (**appendix 8**). When existing materials did not meet the needs of the pilot projects and/or of the WP5 aims, the implementation scientist from the Trimbos Institute developed clear, easy-to-use materials customized for Act on Dementia.

The general guidance provided to pilot project leaders is described below. Relevant WP5 implementation support materials are available in the **appendices 2, 9 and 10**.

#### 7.1.1 Intervention development and implementation support: December 2017

In December 2017, the good practice recommendations for improving dementia care were disseminated by email to pilot project leaders and other members of the Act on Dementia team. The email contained materials developed by the WP5 team for the pilot projects; these materials included the *Dementia Care Implementation Framework*, the *Overview of best practice recommendations*, and the *Framework Example*. These materials are available in the **appendices 2, 9 and 10**; a short description of these materials is described below:

- the Dementia Care Implementation Framework provides information, tools, and guidance on how to develop and evaluate dementia care programs (appendix 9).
- the Overview of best practice recommendations (appendix 2) contains evidence and guideline-based information about how to care for those with dementia, specifically on crisis and care management in dementia, and
- the Framework Example (appendix 10) uses tips and recommendations from the Dementia Care Implementation Framework and care recommendations and program suggestions from the Overview of best practice recommendations to outline two potential programs in the care for those with dementia.

These materials were designed to support project leaders at each of the pilot sites as they developed program protocols and implementation strategies. The *Framework Example* focused on concrete guidance for project leaders; the framework tied care improvement recommendations to actions to improve care, provided relevant examples and illustrations, and shared potential measures. The *Implementation Development Framework* described how the RE-AIM model and tools could be used to guide dementia care programs step-by-step, while sharing links to additional RE-AIM tools,

training, and techniques; the email also contained RE-AIM templates that the project leaders could also use. These implementation planning and support tools were developed to be used in conjunction with the *Overview of best practice recommendations* report. Project leaders were encouraged to review the materials and guidance when developing their plans with an eye to develop uniform protocols between projects.

In addition to the materials provided by email, project leaders were made aware that support was available from the Trimbos Institute and that experts from Trimbos would reach out in January 2018 to offer assistance in developing program plans and implementation strategies.

#### 7.1.2 Intervention development and implementation support: March 2018

To further support the development of dementia care programs and their implementation in the pilot sites, experts from the Trimbos Institute gave a presentation on implementation strategies at the Act on Dementia meeting in Rome in March 2018 (**appendix 11**). The presentation focused on:

- developing realistic implementation strategies through clear documentation, goal setting, and a timeline of actions
- creating SMART goals
- matching the implementation plans to the real-world settings of care
- testing the desired intervention and its implementation strategy through PDSA cycles
- measuring the impact of new interventions

The presentation also gave the representatives from other Work Packages and from the pilot sites the opportunity to ask questions about implementation and sustainability strategies for their programs. Additional materials, such as implementation science tools and articles were shared via USB drive with those who were in attendance and interested. These materials had been curated to the needs of Act on Dementia and were of a practical, rather than a theoretical, nature.

The implementation strategies presentation was an opportunity for pilot project leaders, other members of WP5, and other Act on Dementia partners to ask questions, share experiences, and reflect on their own pilot project. As developing, implementing, and managing a pilot project is frequently time-consuming and complex, the implementation scientist from the Trimbos Institute worked to increase each pilot project leader's motivation and confidence in their ability to implement their pilot project. Pilot project leaders were encouraged to reach out to the Trimbos Institute for further support and assistance. The dementia specialist and the implementation scientist continued to reach out to practices on a regular basis between March and July 2018.

#### 7.1.3 Intervention development and implementation support: July 2018

While most of the pilot project leaders had shared a protocol and project materials by this point in the Joint Action, many of the protocols lacked key information about the projects and their implementation. Experts from the Trimbos Institute developed an implementation reporting template in order to collect consistent information on each of the pilot projects and to support their further implementation. It included questions from the *EU Good Practices in Mental Health and Well-being* criteria<sup>xxi</sup> and from the Consolidated Framework for Implementation Research.<sup>xxii</sup>

The template focused on collecting information on:

- the project's host organization
- project staff
- the background of the project
- characteristics of the project
- participation by the target population
- project metrics
- project support needs
- outcomes of the project
- project ethics and equity

The template was shared with all project leaders from the pilot project. It served as a tool to collect consistent information on each project, as a means of understanding what support each project needed, and as an opportunity for each project leader to reflect on their work, the successes of their project, and the areas in need of improvement. The implementation reporting template built upon the initial intervention development and implementation support guidance.

Project leaders were encouraged to copy/paste information into the template from existing protocols to reduce effort and ensure consistency. Once the template had been completed to the best of their abilities, project leaders were asked to return the document to the Trimbos Institute.

Experts from the Trimbos Institute reviewed the completed templates and offered suggestions for clarification and additional information. In cases in which necessary information on the project was missing, experts from Trimbos worked with pilot project leaders to find and/or create the needed project information for both themselves. Project leaders were encouraged to be as thorough as possible in order to have an accurate report of their pilot project's activities. A blank copy of the template is in the **appendix 12**.

#### 7.3.4 Intervention development and implementation support: February 2019

At the February 2019 Act on Dementia meeting in Edinburg, an implementation scientist from the Trimbos Institute presented the implementation reporting template. The presentation focused on how principles and questions from implementation science (as used in the template) could improve project development, implementation, sustainability, and reporting. The presentation described how implementation science principles could inform the development of implementation plans and strategies, giving examples from the implementation reporting template, and highlighted the need to make goals and project aims explicit. Each aspect of the template was described with examples given. The implementation scientist was available to answer questions before and after the presentation, including questions from other work packages. The presentation is available in the **appendix 13**.

## 7.2 *Tailored intervention development and implementation support*

Intervention development and implementation support that addresses the individual needs of each pilot project site was needed to improve each project's ability to effectively, efficiently, and feasibly address crisis and care coordination in dementia. In addition to the general support offered, each project leader was offered one-on-one support. This support came through in-person meetings, phone/Skype meetings, through emails, comments on project plans, and through shared materials.

While project leaders were routinely reminded by email of the support available to them, they availed themselves of this support at different times and in different ways. Based on the information provided by each project leader through the completion of the implementation reporting template, each pilot project has been summarized below. Please note, in many cases, this information has been copied directly from the completed template with small editorial changes.

Each project leader was offered customized support based on their needs and the needs of the projects. One of the underlying objectives when offering support was to enhance motivation and confidence as well as to provide more concrete support through providing materials and answering questions. This enhancement of motivation and confidence is intangible but can be of great value to project leaders. The section below contains an outline of both the tangible and intangible support offered to pilot project leaders.

### 7.2.1 Bulgaria

Professor Latchezar Traykov of the Bulgarian Society of Dementia oversaw an Act on Dementia pilot project on crisis in dementia care. The Bulgarian population is ageing and faces a high risk for an increased number of people with dementia. Usual care for people with dementia relies on care from family at home. There is a great need to introduce and disseminate evidence-based interventions for coping with neuropsychiatric symptoms and problematic situations. Information about BPSD in dementia and management for primary care professionals as well as for carers is highly needed.

#### Crisis in dementia care and Good Practice Recommendations

In order to improve the lives of people with dementia and their carers, general practitioners are in need of support and education on the behavioral and psychological symptoms of dementia (BPSD). As stated in the *Overview of best practice recommendations* report, “delivering better care in the treatment of BPSD is a shared and high level priority”.<sup>xxiii</sup> As noted in the report, psycho-educational programs are the first line care for BPSD prevention and management. The *Overview of best practice recommendations* report recommends the implementation of psychosocial interventions, including educational programs for carers of those with dementia. The Bulgarian project on crisis in dementia care aligns with these recommendations through educating GPs on management techniques for BPSD and through educational and support groups for carers of people with dementia.

#### Management system for emergencies in patients with dementia

The management of severe behavioral and psychological symptoms of dementia in those with dementia in Bulgaria usually involves the referral of patients to emergency psychiatric units by their GP. This pilot study aimed to have a relevant impact on the existing GP practices in Sofia by reducing inappropriate referrals and use of emergency departments. In line with *Deliverable 5.2 Overview of best practice recommendations*, the pilot project activities work to improve dementia care:

- at the GP level by reducing/avoiding unnecessary hospitalizations through improving their competences and networking in out-patient care structures; and
- at the carer level by supporting them to improve communication with people with dementia to understand their unmet needs and to reduce/manage BPSD.

#### Project aims

The project was designed with aim to improve the efficiency of management, treatment and support of people with dementia with BPSD. The project aims to:

- increase the knowledge of GPs about BPSD and how to cope with the challenging behavior in people with dementia
- detect the number of cases of BPSD managed by GPs
- detect the number of cases of cooperation of GP-specialist for those with severe BPSD
- reduce the number of inappropriate use of emergency departments
- improve the knowledge and self-confidence of carers about BPSD and how to cope with the challenging behavior in people with dementia
- to improve coordination between carer/GP/specialist regarding BPSD treatment and management
- create a caregiver/GP/specialist network related to the treatment and management of BPSD

Pilot project approach

The project focuses on the implementation of a psycho-educational training program for the management of crisis related to BPSD in people with dementia through the training of GPs in Sofia and the implementation of psychosocial interventions and psycho educational program with groups of carers of people with dementia in Sofia.

Two pilot sub-studies within approximately three months period were designed and implemented:

- Education/training of GPs in coping with BPSD in people with dementia:
  - Two educational sessions were organized, with the first meeting in May 2018 with 23 GPs and the second meeting with 15 GPs in October 2018.
  - Pre-training and post-training questionnaires were provided (Dementia knowledge, Self-confidence to cope with challenging behavior in people with dementia).
- Carer education and support groups for coping with BPSD in people with dementia. Sessions were planned with frequency of twice per month.
  - Two support groups were organized. Ten carers had 6 meetings in October, November, and December 2018; ten carers had 6 meetings in February, March, and April 2019.
  - Pre-training and post-training questionnaires were provided (Dementia knowledge, Self-confidence to cope with challenging behavior in people with dementia).

The pilot projects targeted GPs from Sofia and carers of their patients with dementia and BPSD who participated in face-to-face sessions.

The planning and organization of the education/training and support sessions were coordinated and provided by the Bulgarian Society of Dementia team with collaboration of partners, including Medical University-Sofia, University Hospital "Alexandrovska", and the Bulgarian organization "Living with Dementia".

The three months implementation period was designed for GPs to evaluate and manage/cope with BPSD in people with dementia referred to them by families. The GPs assessed BPSD in people with dementia using Neuropsychiatric Inventory (NPI), helped those with dementia and their carers cope with mild symptoms applying non-pharmacological interventions, and provided consultations with a specialist of the expert center in cases of people with more severe BPSD. Follow-up assessment of BPSD with NPI was planned and performed within one month after evaluation.

The core components of the project include:

- Emails and phone contacts with GPs and GPs association/carers
- Design of pre- and post-training questionnaires for GPs and carers
- Provide education/training sessions for GPs and for carers
- Provide pre- and post-training questionnaires in GPs
- Initial and follow-up assessment of neuropsychiatric symptoms in patients by GPs
- Provide pre- and post-training questionnaires in carers
- Design of data collection file
- Analysis of data
- Preparation of reports

## Measures and metrics

To evaluate the implementation and impact of the pilot project, several types of data were collected and analyzed:

- information about GPs and carers, such as proportion of contacted and attended participants and the number and demographic characteristics of attended GPs and carers
- information about people with dementia and BPSD, including the number of cases detected by GPs, number of cases of cooperation between GPs and specialists in cases with more severe BPSD, number of cases managed by GPs with non-pharmacological treatment approaches, number of inappropriate uses of emergency departments
- information from pre- and post-training questionnaires through the Dementia Knowledge and Self-confidence in managing BPSD surveys
- information about level of GPs' and carers' satisfaction with the educational/training programs

An excel data collection file was created to gather basic patient's information (age, gender, living status), carer's information (age, gender, status), dates of intervention, and questionnaires.

The Dementia Knowledge Questionnaire consists of 20 statements regarding dementia and care of a person with dementia. The respondent was asked to agree or disagree with these 20 statements and to rate the answer according to rating scale from 0 (totally disagree) to 4 (totally agree). The questionnaire has three sub-scales: general knowledge about dementia, knowledge about BPSD and knowledge how to manage the problematic symptoms/behaviour.

The Dementia Self-confidence Questionnaire asked GPs to rate how confident they feel about their competence in evaluating those with dementia and providing care and support in 12 different situations related to people with dementia and BPSD.

Satisfaction level was considered as an important factor for successful implementation and maintenance of the targeted activities. At final meetings approximately three months after starting the pilot, questionnaires about satisfaction level of GPs and carers with regard to the education and training provided as part of the pilot project. Using a scale from 1 (poor) to 4 (very good), GPs were asked to answer six questions concerning sign-up, organization, speakers, discussions, and the usefulness overall training course. Using a 10 point scale, carers were asked to answer 15 questions about general satisfaction, understanding and management of BPSD, and usefulness of the support and training sessions.

## Results

Data analysis revealed following results:

- Both target groups have insufficient knowledge, skills, and competence related to dementia, BPSD, person-centered care approaches, and non-pharmacological treatment approaches for coping.
- Training and education increased knowledge and self-confidence of GPs on BPSD and non-pharmacological approaches for coping. Feedback from GPs was very positive concerning detection and assessment of neuropsychiatric symptoms through NPI. They reported feeling more competent to introduce non-pharmacological treatment approaches to manage mild and moderate BPSD.
- Carer support groups increased dementia knowledge, knowledge of psychological symptoms, and non-pharmacological approaches for coping with BPSD.
- Both GPs and carers reported relatively high levels of satisfaction. The education programs were seen as very useful by both target groups, especially case presentations and discussion of practical issues.
- People with dementia and BPSD were successfully helped by GPs (13 out of 18 patients, 72%). The patients were with mild and moderate psychological symptoms. Non-pharmacological treatment approaches had been introduced to carers.
- Formal and informal communication with GPs revealed their willingness to continue with applying their knowledge on BPSD and coping skills in future in their everyday practice.
- Five patients with severe BPSD were referred to the specialists of the project team; in these cases, collaboration and care coordination between GPs and specialists occurred.

Reflections and potential areas of improvement

- There is a great need for more information about BPSD in dementia and best practices for coping with it for primary care.
- Carer support and information on BPSD is highly needed.
- GPs and carers are more satisfied when more practical information is introduced and shared. Case discussions are of key importance.
- Training programs and case discussions with a number of participants was a challenge.
- GPs were concerned about the time and costs of new ways of care; funding for education and training is of key importance.

Next steps

- Planned follow-up communication with GPs and carers
- Preparation of dissemination materials, such as publications, presentations, meetings, leaflets, and websites
- Development of a proposal for inclusion of educational programs on BPSD and crisis interventions for GPs
- Development of a proposal for continuing education to Professional Associations of GPs
- Development of a National Dementia Strategy with included results from Bulgarian pilot studies. The Working Group was established in May 2019, with meetings in summer 2019.

#### Tailored implementation support

To support the Bulgarian crisis in dementia care project, the implementation scientist and the dementia specialist from the Trimbos Institute met with the Bulgarian project team, reviewed project protocols, shared tools and educational materials on crisis management in dementia care, and provided assistance completing the implementation reporting template. The dementia specialist provided content-related assistance, including sharing links, materials, and suggestions for program improvement. The implementation scientist provided guidance on developing intervention protocol and implementation plans.

Details about the support provided are listed below:

- In 2018, the WP5 team provided information on different types of caregiver programs in order to support the development of caregiver programs in Bulgaria.
- In December 2018, the WP5 team met with the Bulgarian project team by phone to discuss their plan and advise needed. Following this call, online tools for carers were shared for inspiration (STAR, Isupport).
- In February 2019, the WP5 implementation scientist met with the project team. Together, they reviewed the pilot projects and discussed next steps.
- In April 2019, the WP5 team assisted in the completion of the implementation reporting template.

### 7.2.2 France

Prof. Pierre Krolak-Salmon at the Clinical and Research Memory Centre of Lyon oversaw two pilot projects in France. The Alzheimer's Disease Mobile Team (EMMA) and a collaboration pilot project between a nurse and GPs (INFIMEGE).

Intervention description: The Alzheimer's Disease Mobile Team (EMMA)

The primary Act on Dementia pilot project in France focused on mobile teams. In the Alzheimer's Disease Mobile Team (EMMA) project, the mobile team works closely with general practitioners (GPs), neurologists, geriatricians, and other healthcare professionals to provide clinical expertise as well as practical support to people living with BPSD at advanced stages and their carers. During the intervention at the patient's home or nursing home upon request of one of the above mentioned healthcare professionals, the multidisciplinary team performs a clinical evaluation including the BPSD inventory and an evaluation of the factors contributing to BPSD. Based on the patient's assessment and/or interviews of the healthcare professional(s) caring for the patient as well as carers if relevant, the EMMA provides recommendations such as non-pharmacological interventions, pharmacological therapies or/and medico-social therapies in agreement with the patient's GP.

The mobile team actively cooperates in the crisis and care coordination pilot project in the Lyon metropolis to facilitate the access to care and structures/organizations dedicated to BPSD, propose at home and nursing home specific interventions and explore the main BPSD inducing a mobile team call. This team specialized in BPSD acted as an interface between the hospital and primary care.

EMMA and Good Practice Recommendations

As noted in earlier ALCOVE Joint Action, the Act on Dementia WP5 literature review, and in the good practice recommendations, mobile teams can be an effective, useful, and patient-centered approach to dementia care. As described in the *Overview of best practice recommendations* report, mobile teams allow people with dementia to continue living at home while received needed care from a multidisciplinary team of professionals. Mobile teams are especially useful for people with dementia with concerns related to the behavioral and psychological symptoms of dementia.

The EMMA pilot project uses a mobile team to address BPSD, as recommended by the *Overview of best practice recommendations* report. The EMMA project takes a multidisciplinary approach, in line with the good practice recommendations. The EMMA project's mobile team conducts clinical evaluations and offers a variety of types of therapies, as recommended by the *Overview of best practice recommendations* report.

Project aims:

- facilitate access to care and structures/organizations dedicated to BPSD to avoid the emergency room and inappropriate hospitalizations
- propose at home and nursing home specific interventions
- explore the main BPSD inducing a mobile team call
- reduce the carers' anxiety level
- disclose the mobile team's efficiency in terms of NPI decline and spared hospitalizations

### Pilot project approach

EMMA is made up of a geriatrician and psychiatrist, psychologist, coordinating nurse, research officer and secretary. It collaborates with coordinated services for the elderly such as home for autonomy and integration of people living with Alzheimer's disease (MAIA), home care nursing services (SSIAD) and home help and support services (SAAD).

The mobile team may be reached by phone or email by any healthcare professionals. Once it has gathered information about the patient's current situation and symptoms, it goes to the patient's home or in his/her nursing home throughout the Lyon metropolis. At home, a physician discusses with the cared-for person while a nurse or psychologist converses with his/her carer. The healthcare professionals strive to comfort, explain the origins, symptoms and signs of the disorders and provide tools to the cared-for person and his/her carer to better respond to crisis episodes. The NPI behavioral scale is assessed to evaluate the frequency, severity and occupational disruptiveness of the carer of 12 symptoms related to Alzheimer's disease and related diseases.

EMMA takes an educational approach including the patient data collection, communication of challenges, understanding of the elderly person refusal to seek help and care and essential principles of know-how and soft skills. The mobile team spends time with the elderly person and his/her family if it is available to listen to their needs and opinions and briefly assess their cognitive and behavioral abilities. Within the framework of the diagnosis approach of behavioral disorders, the EMMA recommends therapeutical and non-therapeutical care to the patient and his or her carer (Behavioral Psychological Support in Care Situations (BPSCS), educational psychology for the carer). The mobile team then proposes post-diagnostic support to the person needing help and his/her carer (personalized allowance for autonomy, home care, psychological support). Finally, the NPI scale is assessed once again two months after the initial assessment to compare the evolution and back up EMMA's actions.

### Measures and metrics

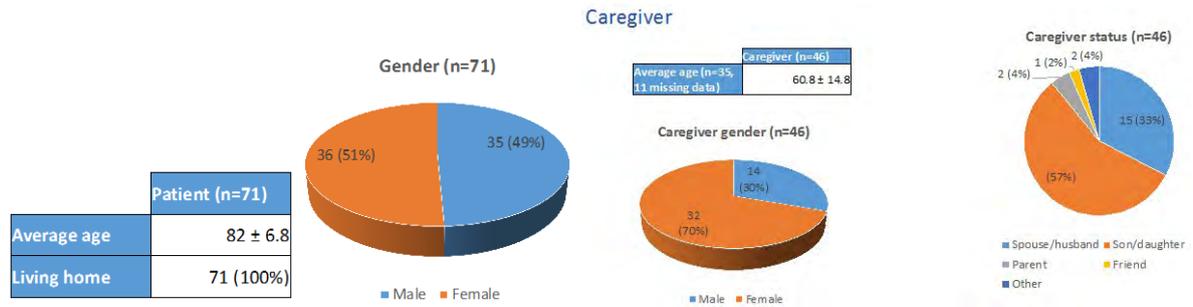
In order to evaluate the caregiver distress prior and after the intervention of the EMMA, it was decided to use the forms Y-A and Y-B of the State-Trait Anxiety Inventory (STAI) self-administered questionnaire for the carer. The assessment by the carer of the 20 state and 20 trait questions will enable the implementation team to evaluate the EMMA's intervention on the caregiver distress.

To assess the patient's behavioral and psychological symptoms, the implementation team assesses the Neuropsychiatric Inventory (NPI-NH) with the help of the carer during the intervention and 60 days after the EMMA intervention.

In addition, to increase the healthcare professionals' easiness and self-confidence to detect BPSD and the accessibility of the diagnosis pathways dedicated to BPSD, the project officer asks three questions by phone to the requesting healthcare professional before and 15 days after the EMMA intervention. These questions deal with their level of knowledge of BPSD detection, their level of knowledge of appropriate BPSD institutions and their level of confidence to provide care and support to patients living with BPSD.

Finally, an excel data collection file was created to gather basic patient's information (age, gender, living status), carer's information (age, gender, status), dates of intervention and questionnaires (STAI Y-A and STAI Y-B, short questionnaires for the requesting healthcare professionals and NPI-NH).

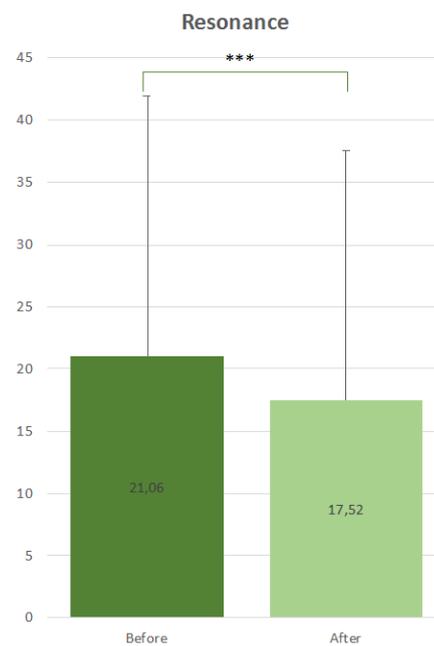
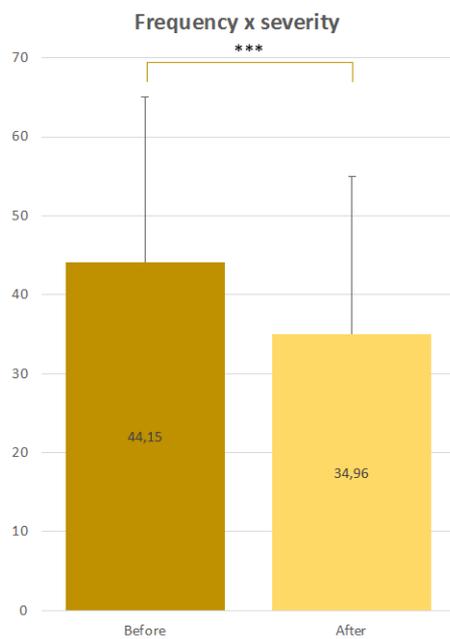
## Results



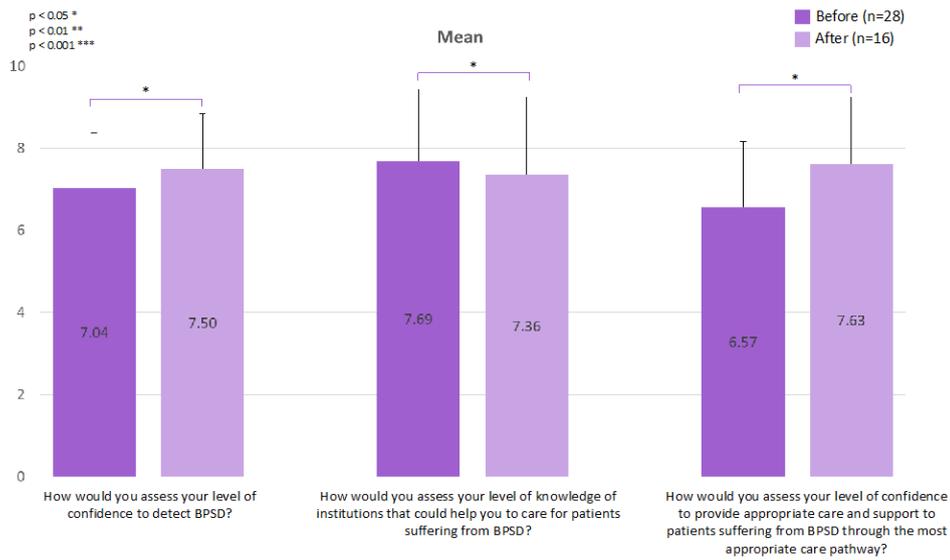
## NPI – total score

p < 0.05 \*  
p < 0.01 \*\*  
p < 0.001 \*\*\*

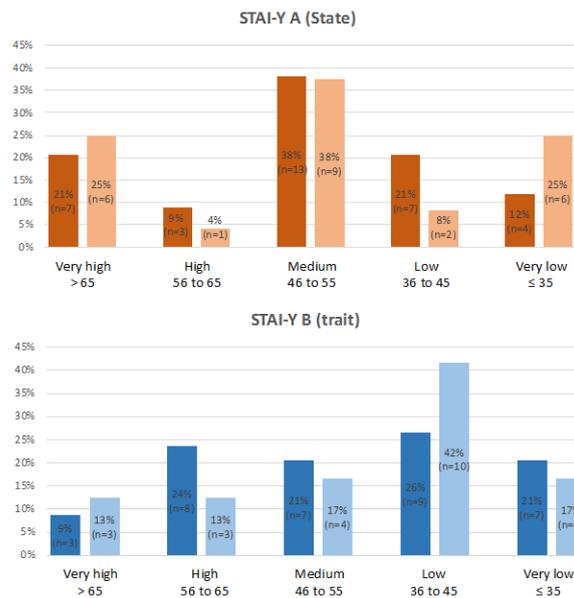
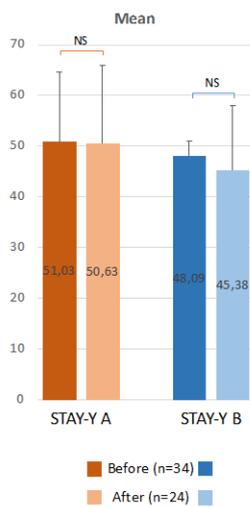
■ Before (n=65, 6 missing data) ■  
■ After (n=48, 23 missing data) ■



## BPSD Care by the General Practitioner



## STAY-Y

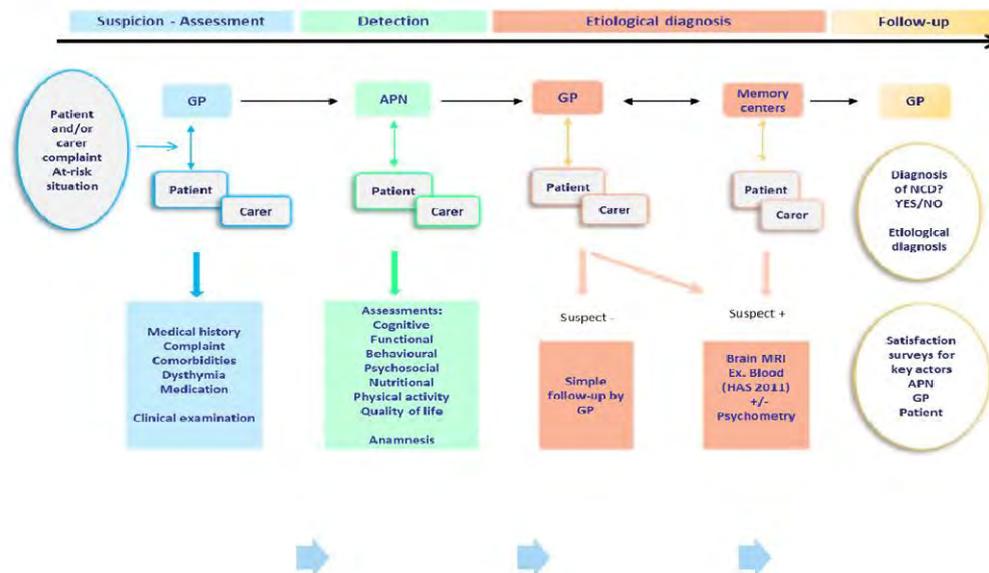


Intervention description: Collaboration pilot project between a nurse and GPs (INFIMEGE) In order to create an enhanced coordinated care pathway for patients living with NCD, a collaboration pilot project between a nurse and GPs entitled INFIMEGE was created to improve the detection and diagnosis rates of NCD.

## Pilot project approach

This pilot project led within the work package on diagnosis and post-diagnostic support (WP4) encompasses a multidimensional assessment by a nurse followed by medical investigation leading to a diagnosis by the GP. In addition to assessing cognitive disorders thanks to a clinical examination and detection and diagnosis scales, a nurse assesses behavioral disorders with the help of appropriate tests (NPI-NH, Mini-GDS, CMAI, Apathy Inventory) in order to identify at risk situations such as driving, preparation of hot meals or handling finances. After assessing the patients, the nurse may propose to the patients' GPs to contact the EMMA for the care and follow-up of their patient.

### ■ Description of the project

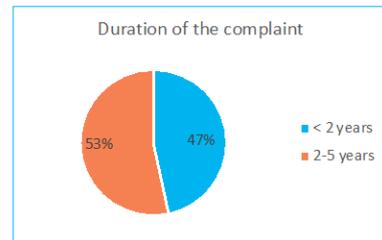
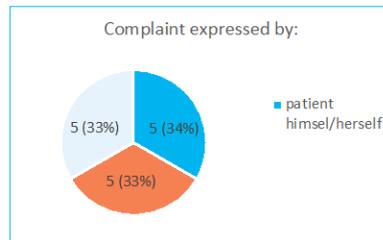
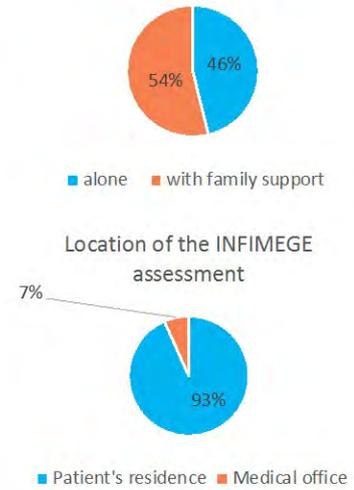


## Main Results

### Population characteristics

	Assessed parameters	FRANCE	
MAIN DEMOGRAPHICS	Number of subjects assessed	15	
	Mean age ( $\pm$ SD)	79.2 $\pm$ 7.6	
	Gender	13 F / 2 M	
	Education level	Primary education	5 (33%)
		Secondary education	4 (27%)
		Higher education	4 (27%)
	Living at home	Alone	6 (46%)
With family support		7 (54%)	

current living status : at home



REASON FOR RECOURSE	Nature of the complaint	Cognitive complaint only	12 (80%)
		Behavioral complaint only	-
		Cognitive AND behavioural complaint	3 (20%)
	Complaint duration	< 2 years	7 (47%)
		2 – 5 years	8 (53%)
		5 - 10 years	-
	Complaint expressed by	Subject himself	5 (33%)
		Subject with someone else	5 (33%)
		Someone else (family members, GPs, ...)	5 (33%)
	Decrease of daily-life activities		6 (40%)

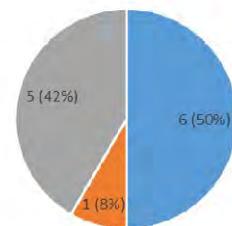
- Duration of the multidimensional assessment : 1h30

Multidimensional assessment (main scores collected for the assessed subjects)									
	COGNITION				BEHAVIOUR		AUTONOMY		Other
	MMS (n=15)	Mac Nair (n=15)	GP-Cog patient (n=15)	GP-Cog informant (n=9)	GDS 15 (n=15)	NPI (n=15)	ADL (n=15)	I-ADL (n=15)	Fried criteria (n=14)
Mean score	21.0	25.3	3.9	1.3	7.6	32.3	5.3	5.6	2.4
Standard deviation	5.5	5.7	3.0	1.4	4.0	24.1	0.9	2.2	1.2
Minimum	10	18	0	0	0	4	3	0	0
Maximum	30	40	9	4	14	95	6	8	5

### Recommendation & care proposition

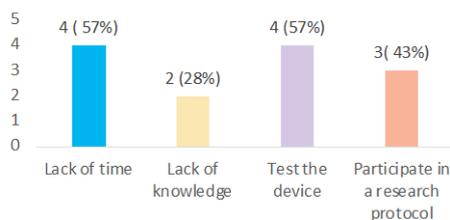
n=15	Hypothesis after assessment
Risk of neurocognitive disorders (NCD)	6 (40%)
Risk of NCD and mood disorder	5 (33%)
Risk of mood disorder	1 (7%)
Loss of autonomy	8 (53%)
Social or family isolation	7 (47%)
Loss of self-esteem	1 (7%)
Risk of falls	1 (7%)
Diagnosis already done	1 (7%)

Hypothesis (n=12)



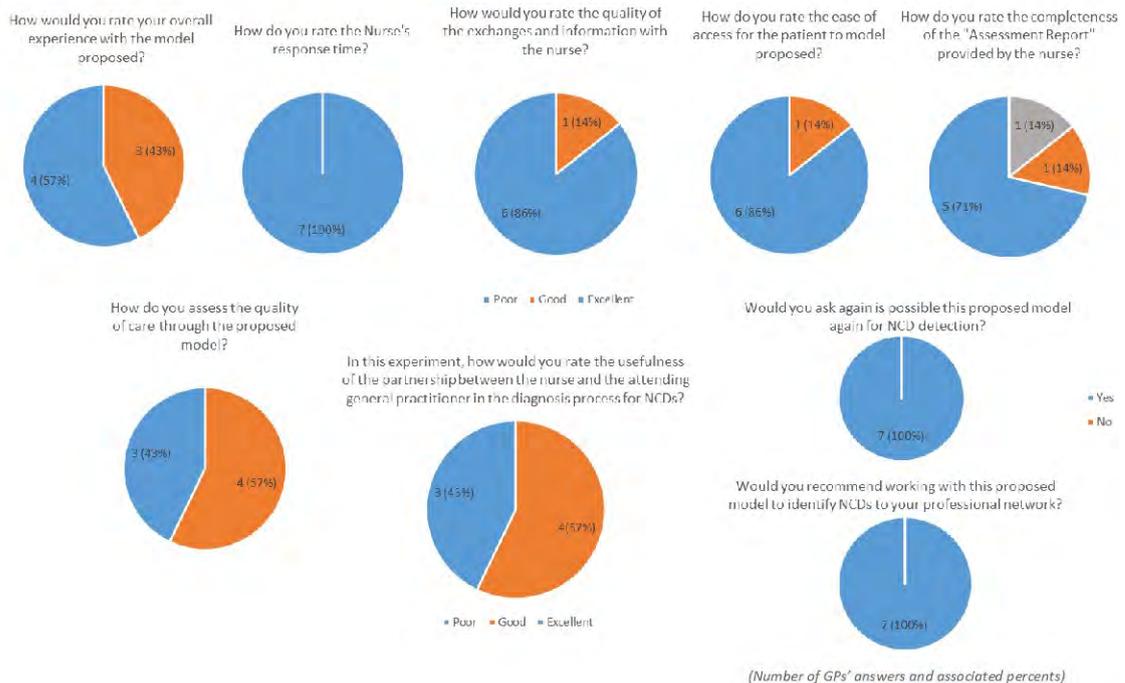
■ Risk of neurocognitive disorders ■ Risk of thymic disorder ■ Both

Reason for requesting a nurse for this assessment by the GPs



n=15	Care proposal
Day hospital check-up (Memory check-up, falls, cognitive and/or diagnostic procedure) and/or specialized consultation	15 (100%)
Nurse, domestic help	9 (60%)
Cognitive stimulation, memory group	6 (40%)
Health education	6 (40%)
Personalized autonomy allocation	6 (40%)
Day care in nursing home or other, social link	5 (33%)
ESAD implementation	4 (27%)
Kinesitherapy / Physical therapy / Tailored physical activity	3 (20%)
Speech and language therapy	2 (13%)
Support by a specialized mobile team (EMMA)	1 (13%)

## Main Results : satisfaction of the collaborating GPs



\* To date, 1 GP has not yet answered to the satisfaction questionnaire.

### Preliminary Results

- GP-Nurse collaboration may help to better detect BPSDs in primary care
- GP-Nurse collaboration may help GPs to better deal with patients with BPSDs
- GP-Nurse collaboration may help to better organize diagnosis and care pathways
- GP-Nurse collaboration may help to better detect BPSD in primary care
- Overall positive feedback from all collaborating GPs (usefulness of Nurse/GP collaboration for detection of NCD and/or behavioral disorders)
- To date: additional exams (brain imaging, neuropsychological testing..) performed after the initial assessment corroborate the nurse conclusions for 2 of the 15 subjects (on-going assessment for other subjects)
- 80% of the recommendations were validated with the patient's adherence to the care plan
- Direct coordination by the nurse with the care network

### Reflections and potential areas of improvement

- Prior and complete training of the nurse is required
- Collaboration with the GP difficult to implement, tedious recruitment (lack of time of GP, reception by doctors for a new autonomous nursing profile, etc.)
- On average GPs response time is 23 days, up to 58 days (implementation of processes to improve this time).

### Next steps

The project team will try to disseminate these pilots in France and in European countries since the results are positive, convince French authorities to widespread this model in France

### Tailored implementation support

Both the Alzheimer's Disease Mobile Team (EMMA) and the collaboration pilot project between a nurse and GPs (INFIMEGE) were supported by the WP5 team. This support included meetings on the phone, in person, reviews of the project protocol, assistance completing the implementation reporting template, and sending needed and requested academic materials to the project leader.

Both the implementation scientist and the dementia specialist from the Trimbos Institute supported the development of the pilot projects' protocols, the initial implementation of the projects, and their ongoing support. The implementation scientist took the lead on supporting implementation, while the dementia specialist provided content-related assistance, especially as related to mobile teams for dementia care.

Details about the support provided are listed below:

- In May 2018, the WP5 team met Pr Pierre Krolak-Salmon in the Netherlands. They discussed the progress of the pilot project and implementation framework. Pr Krolak-Salmon briefly presented the pilot projects and described the next steps for the projects. Plans were made for future supportive activities from the WP5 team.
- In July 2018, the dementia specialist and the implementation scientist on the WP5 team reviewed and made suggestions to the project plan, especially as related to adding concrete details and steps to the programs and their evaluation.
- In February 2019, the WP5 implementation scientist met with Pr Pierre Krolak-Salmon in Edinburg. Together, they reviewed the pilot projects and discussed next steps.
- In March 2019, the WP5 team, using the project proposal and resources found online, completed the implementation reporting template. The completed template was shared with Pr Pierre Krolak-Salmon for his review, edits, and additional information.
- In March 2019, the WP5 implementation scientist met with Pr Pierre Krolak-Salmon by phone. Pr Pierre Krolak-Salmon discussed the need for assistance with qualitative data analysis. The implementation scientist shared references and articles related to coding, analyzing, and documenting qualitative data.

### 7.2.3 Italy

Dr. Nicola Vanacore oversaw the implementation of a management system for emergencies in patients with dementia in the local health unit of Modena as the local implementation team. The local implementation team was lead by Andrea Fabbo, included three health professionals (Lucia Bergamini, Luigi de Salvatore, and Barbara Manni).

#### Intervention description

The project was based on ALCOVE and *Overview of best practice recommendations*. Using these recommendations, a specific management model was designed to improve cooperation between GPs and the specialists within the Centers for Cognitive Disorders and Dementias in the Local Health Authorities of Modena. The model, which is similar to the mobile teams described in the ALCOVE and the *Overview of best practice recommendations report*, aims at improving the efficiency and effectiveness in the management of people with dementia, including those with behavioral and psychological symptoms of dementia.

Management system for emergencies in patients with dementia and Good Practice Recommendations  
The treatment, management, and support of patients with Behavioral and Psychological Symptoms of Dementia (BPSD) is crucial to improving the lives of those with dementia, to reducing carer burden, and reducing stress in healthcare providers who care for people with dementia. As noted in the *Overview of best practice recommendations report*, “agitation [a symptom of BPSD] should be viewed as a symptom of a problem, rather than a separate issue”.<sup>xxiv</sup> Well-trained GPs work with people with dementia, their families, and other healthcare professionals to effectively address behavioral and psychological symptoms of dementia.

The Modena pilot management system for emergencies in patients with dementia was directly informed by ALCOVE and the *Overview of best practice recommendations*. In line with these recommendations, the Modena pilot project works to improve dementia care at the GP level to reduce unnecessary hospitalizations and improve care for those with dementia through home visits for those who were housebound and through referral to outpatient care with a specialist at the Centers for Cognitive Disorders and Dementias. As recommended by the *Overview of best practice recommendations*, the Modena pilot project sought to improve care structures and the organization of care to reduce and manage behavioral and psychological symptoms of dementia and to help people with dementia avoid unnecessary hospitalizations and institutionalization

#### Project aims

The management system worked to address the very urgent needs expressed by both GPs and carers of people with dementia with severe BPSDs. The cooperation between GPs and specialists was also formalized in official agreements, thus the model was structured to have higher chances to have a long-term impact. As the management of BPSDs usually involves referring patients to emergency departments, this model aims to have a relevant impact on the existing structure of the local health unit of Modena by reducing inappropriate accesses to emergency departments, as well as the overuse of resources in terms of personnel and structures. As noted in the pilot project’s protocol, the project has the following objective: to implement a management system for BPSD episodes occurring in people with dementia.

Pilot project approach

The project was implemented in the local health unit of Modena through a 5-steps study from January 2018 to May 2019. The study was conducted in the area of Modena where nearly 3400 dementia<sup>xxvii</sup> cases have been estimated. It was expected that nearly one third of this population, approximately 1000 cases<sup>xxviii</sup>, presented moderate-to-severe BPSD, which represents an important epidemiological data in order to better frame the findings and the implications of the project.

The phases of project are outlined below:

- phase 1: Background and gathering of data on current practice (from January to May 2018);
- phase 2: Training on the management of BPSD (from May to November 2018);
- phase 3: Implementation of the management of BPSD (from July to November 2018);
- phase 4: Data collection and statistical analyses (from November 2018 to January 2019);
- phase 5: Final report (from January to May 2019).

During the first phase, information on current practice of BPSD management in the area of Modena were collected. Prior to the project, the LHA had adopted a specific protocol for the coordinated care and management of people with dementia and BPSDs, which involved both GPs and specialists. GPs, when having specific issues regarding the management of people with dementia with severe BPSDs, were offered the opportunity to refer to a specialist within the Centers for Cognitive Disorders and Dementias (CCDD) and together decide whether the issue required an urgent visit, or could be managed via usual care.

The formalized network between GPs and specialists provides people with dementia with outpatient visits or home visits within 7-10 days from the call. Outpatient visits were provided exclusively to patients with severe BPSDs that were not already in charge in any mental health structure, and for which the GP excluded any type of infection, uncontrolled pain, and other disorder unresponsive to behavioral therapy. Home visits were reserved for bedridden patients, patients with severe aggressive BPSDs, and/or with severe depressive symptoms.

In the second phase (training phase), GPs were trained on the management of BPSD by participating to two-phase training course. The training included a face-to face course, aimed at explaining the objectives of the project and providing the most important information on management of BPSD (**Italian appendices A-N**), and an e-learning-course targeted to all the GPs (n=138) who already participated in face-to-face course. The planning and organization of the training was coordinated by the National Institute of Health staff, who also defined a protocol for the whole implementation project. A short questionnaire was administered to GPs on management BPSD (**Italian appendix short questionnaire**). The e-learning course lasted four hours and was structured as two modules:

- a legislative module, including the Italian National Dementia Plan, a guidance on Integrated Care Pathways and Information Systems on Dementia, two power point presentations on the Joint Action and on the implementation of Integrated Care Pathway and Information Systems (**Italian appendices 1- 5**);
- an operative module specific to BPSD with a tutorial on the identification and management of BPSD in clinical practice and 3 clinical cases specific to the management of BPSD in people with dementia (**Italian appendices 6- 13**); .

Phase 3 was dedicated to the implementation and monitoring of the best practice. The implementation plan strengthened this already existing network and formalized it into a protocol. The monitoring of GPs was performed via phone calls by the National Institute of Health and by the LHAS of Modena. GPs received at least two phone calls as support in the management of people with dementia with BPSDs. Moreover, LHA Modena administered a structured interview aimed at evaluating the obstacles to the participation in the distance-learning course, and subsequently helped GPs to improve their participation to the course.

Phase 4 was dedicated to the data collection and analysis. The data source of this phase included collecting data on people with dementia, on the e-learning course registration and participation, on user satisfaction with the e-learning course through a questionnaire, and on phone calls with the dementia care specialists of the CCDDs.

Phase 5 was dedicated to the draft of the final report. The final report will include the final evaluation of the indicators, the strengths and limitations of the implementation process, and planning of new potential implementations.

#### Measures and metrics

To evaluate the qualitative impact of the project, a pilot study was carried out; the pilot study used a SWOT analysis approach, involving a sample of 20 GPs and 10 specialists from CDCDs. Moreover, a short questionnaire was also administered to all GPs that participated in the project to assess their satisfaction with respect to the current management system for emergencies in patients with dementia and BPSDs within the LHU of Modena.

Additional data has been collected on the number of GPs that attended the face-to-face course, on the number of GPs that attended and concluded the e-learning course, on the number of telephone calls between GPs and specialists, and the number of inappropriate use of the emergency department.

Data were gathered using the already existing databases covering the years 2016 and 2017 and the four-month period from January 2018 to April 2018 on the current system of management of emergencies for BPSDs within the local health unit of Modena. Data on the accesses to the emergency department were also collected.

Statistical analyses were performed using the software STATA. Descriptive analyses were made for all data sources. Linear correlation analysis was performed for the answer to the short questionnaire of the phase II. Chi-squared test for paired data was performed to detect any statistical difference between the period time before the implementation practice (2017) and the period time after the implementation practice (2018).

#### Results

Data on the accesses to the emergency department (Table 1) and to territorial psychiatric services (table 2) in the city of Modena were also collected. During the period time from January 1<sup>st</sup> 2017 to December 31<sup>st</sup> 2017, 162 patients (i.e. 46 from Policlinico and 116 from Baggiovara) were referred to emergency departments and 46, of which only one caused by BPSD, to psychiatric services.

ED 2017	Dementia	CNS neurodegen.	Total
<b>Policlinico</b>	<b>26</b>	<b>20</b>	<b>46</b>
<i>Discharge</i>	11	2	13
<i>Admission to other department</i>	15	18	26
<b>Baggiovara</b>	<b>80</b>	<b>36</b>	<b>116</b>
<i>Discharge</i>	49	25	74
<i>Admission to other department</i>	33	11	44

Table 1: Patients referring to emergency departments (Policlinico, Baggiovara) during the period time from January 1st 2017 to December 31st 2017.

Psychiatric Service 2017	Subjects aged between 50 and 64 years	Subjects aged > 65 years	Total
<i>Patients with Dementia</i>	3	42	45
<i>BPSD</i>	0	1	1
<b>Total</b>	<b>3</b>	<b>43</b>	<b>46</b>

Table 2: Patients referring to psychiatric service, during the period time from January 1st 2017 to December 31st 2017

During the face-to-face course, a short questionnaire was administered to all GPs that participated in the project (n=138) to assess their satisfaction with respect to the current management system for emergencies in patients with dementia and BPSDs within the LHA of Modena.

- Most of the 135 respondent GPs indicated a moderate/moderate-high confidence in managing BPSD episodes, without any correlation with the years of experience.
- The GP's level of confidence in informing and supporting caregivers; similar results for the previous topic, as most of the 136 respondent GPs indicated a moderate/moderate-high confidence in informing and supporting carers in case of BPSD episodes.
- Most of the 137 respondent GPs (around 70%) had managed at least one episode of BPSD in the 6 month before the training phase. Interestingly, only 6/137 GPs (4.4%) managed the BPSD by themselves, while almost half of the 137 GPs declared that they referred the patients to the CCDDs for an urgent visit.
- Almost 99% of the BPSD cases referred to the CCDDs after the activation by GPs were resolved (i.e. totally in around the 55% and partially in around the 45%), with less than 5% of cases that were not resolved after referral to the CCDDs.
- Possible improvements area (figure 7); in particular, the 51 respondent GPs identified, as the main area of improvements, the need of further reinforcing the cooperation with CCDDs, increasing the staff, and more appropriate integration between staff.

Moreover, a focus group interview was carried out in order to evaluate the qualitative impact of the project. The focus group interview used a SWOT analysis approach, involving a sample of 11 GPs. Most of GPs recognized as a useful opportunity the possibility to enhance the cooperation with specialists in the management of BPSD, in spite of the probable increase of the workload, considered as a weakness. Furthermore, the knowledge of the patient, their environment, history, and family were indicated as an important resource.

Additional data has been collected on the number of GPs attending the face-to-face course, on the number of GPs that attended and finished the e-learning course, on the number of telephone calls between GPs and specialists, and the number of inappropriate use of the emergency department. The distance-learning course was considered as relevant/high relevant by most of participating GPs.

The e-learning course was attended by 59/138 GPs. All of the 59 GPs completed the distance-learning course. The optional satisfaction form was produced by only 25 GPs who attended the e-learning course, with 22/25 GPs (88%) indicating as relevant or highly relevant the entire e-learning course, especially for contents, supporting method, and acquisition of skills.

In Phase 4 the process and outcome indicators have been evaluated. The expected result for the process indicator has not been achieved since the 42.8% of the invited GPs participated to the distance-learning course, instead of the 60%. The GPs invited to the distance-learning course were 138 and the GPs participating to the e-learning course were 59.

Following, the results of outcome indicators have been reported:

- The number of calls by GPs was 123 before the implementation phase (January-September 2017) and 173 by the end of the implementation phase (January-September 2018). Then, the prefixed value of 20% increase in the number of calls by GPs to specialists in the CCDDs by the end of the implementation phase has been achieved with a +40.2% of calls by GPs to specialists in the CCDDs.
- The prefixed 10% increase in the number of GPs calling specialists in the CCDDs for the management of BPSD has been achieved as showed by the increase of 13.8% in GPs calling specialists, with the 56.5% before the implementation phase and 70.3% by the end.
- An increase of 5.3% of the proportion of calls between GPs and specialists that led to solve non-urgent crises through a phone call has been registered, respect to the 5% proposed for the indicator, with the 39.8% and 45.1% before and by the end of implementation phase respectively.
- Finally, the number of accesses to the EDs decreased by the end of the implementation phase, as set by the outcome indicator (from 161 access to EDs in 2017 to 153 in 2018) with a decrease of -5.5%.

A total of 178 call were registered, with a prevalence of requests for female patients (F/M ratio of 1.6), a mean age of  $86.16 \pm 6.72$ , and a prevalence of patients with a confirmed diagnosis of dementia (100/173). The most frequent reason for calling was a BPSD episode in 122 of 173 calls (70.5%), followed by other request (e.g. certificate, information, or organizational) in 35 calls (20.3%), and in 17 cases (9.8%) the call was regarding delirium episodes. Compared to 2017, calls in 2018 revealed a significant increase in calls related to aggressive BPSD (from 33 calls to 75 calls) and a reduction in calls related to delirium (from 26 calls to 17 calls).

Reflections and potential areas of improvement

The process of the pilot project, as well as the outcomes of the project, highlighted some important general observations:

- The management of subjects with BPSD is a very complex task, as it requires the activation of several specialized experts in different areas and for specific activities.
- The multidisciplinary nature of the management of BPSDs makes it difficult to adequately quantify the frequency of BPSDs.
- Improving and supporting the management at home of BPSDs could decrease the burden they determine on emergency departments.

The management of people with BPSDs is a very complex challenge, in particular when quantifying the phenomenon. Adequate management of BPSDs is essential for the national health system, as it could decrease the number of inappropriate uses of emergency departments and thus reduce overcrowding.

The main objective of the project was to identify the actual pattern of use of healthcare services by people with BPSD, including use of emergency departments, psychiatric community services, and/or nursing homes or residential care services. After a thorough analysis of the background, the use of healthcare services by people with BPSD within the territory of the LHA of Modena have been clearly identified and analyzed. This analysis helped to better understand the phenomenon and, consequently, to plan the implementation of the best practice program. Another key aspect regards the improvement of the cooperation between GPs and specialists in order to establish a long-term and fruitful cooperation. It is important to underline the key role of GPs in an adequate and appropriate management of BPSDs.

Furthermore, the technical and scientific phone support to GPs who participated to the distance learning could be considered as an important and useful tool in order to evaluate the difficulties encountered by GPs, both before and after the training. The implementation of a formal and sustainable (phone call) interaction system between GPs and specialists and an epidemiological perspective on the BPSD frequency in the city of Modena can be considered the strengths of this project in spite of partial involvement of GPs in distance learning (<50%) and a care coordination pathway which is not yet implemented. Finally, the project reveals the need for a harmonized information system in order to be able to characterize in a standardized way the phenomenon of BPSDs and the procedures for management within the national health system.

A notable barrier was the low use of the e-learning course by GPs. Reasons for this low use were uncovered through 75 follow-up phone calls: 4 GPs were not interested in completing the implementation project; 2 GP were close to retirement; and 54 GPs did not answer to the phone. In particular, the pilot team found an important communication gap between institutional actors (namely LHA professionals and NIH researchers) and GPs, mainly caused by a lack of clear definition of the roles.

The team planned an extensive communication effort, in cooperation with Modena authorities, to increase the low GPs participation at the training courses. In particular, the pilot team transferred the monitoring process from NIH researchers to LHA professionals, and confirmed the role of

technical (for the web platform) and scientific (for the e-learning course contents) supervisors. After the clear definition of the roles, the pilot team registered an increased participation of GPs to the e-learning courses.

#### Next Steps

The positive outcomes of the implementation process have informed the future implementation of this training project to all the Italian local health authorities as “best practice” in management of BPSD. However, the barriers encountered during the implementation process in LHA of Modena have given feedback which can be used to tailor the training program. In particular, the main concern of GPs was the period time needed for completing the e-learning course, especially in relation to their excessive workload. Future steps include better tailoring the two phases of the training process in order to provide a widespread diffusion of this best practice aimed at improving the good management of BPSD, with the intention of having an important impact on public health burden in terms of reducing inappropriate use of emergency departments and psychiatric services.

### Tailored implementation support

The implementation scientist and the dementia specialist from the Trimbos Institute supported the development and implementation of the management system for emergencies in patients with dementia in the local health unit of Modena project. This support included meetings, emails, suggestions based on the *Overview of best practice recommendations* report, reviews of the project protocol, and assistance completing the implementation reporting template. The dementia specialist provided content-related assistance, especially as related to evaluation measures and mobile teams and BPSD. The implementation scientist provided guidance on the development of a clear, detailed intervention protocol and concrete implementation strategies.

Details about the support provided are listed below:

- In March 2018, the Modena project leader shared their study protocol, which was reviewed by the implementation scientist.
- In July 2018, the dementia specialist and the implementation scientist on the WP5 team reviewed and made suggestions on the project plan, especially as related to adding concrete details and steps to the programs and their evaluation.
- In February-March 2019, the WP5 team helped the Modena pilot project leader complete the implementation reporting template.
- In February 2019, the WP5 implementation scientist met with the pilot project leader and a project staff member. Together, they reviewed the pilot projects and discussed next steps.

#### 7.2.4 Netherlands

While the Netherlands has made great effort in improving dementia care, there is still room for improvement with regard to care coordination, roles, the responsibilities of care professionals, and/or help with regard to difficult behavior at home.

The multidisciplinary care group manager in North Limburg ('Hulp bij dementie') oversaw the Dutch pilot project. The Dutch pilot project was part of the national program on dementia in the Netherlands focusing on care management and support around difficult behavior in the home. The North Limburg multidisciplinary care group consists of three regions (Venlo, Venray, and Peel en Maas) in which the GP has a central role. The care for people with dementia in the region starts with a referral from the GP and stops when the GP is no longer involved. The multidisciplinary care group is an active network in which case managers have a key role in the multidisciplinary collaboration in supporting people with dementia and their carers. The case manager is the link between the GP and multidisciplinary care.

In addition, a multidisciplinary team is closely involved in organization and supportive care as part of the Diagnostic Expertise Center (DEC). A few years ago, a number of case managers were thoroughly trained in supporting people with dementia and their carers when there is difficult behavior at home. The DEC team consists of five professionals, including an elder care specialist, an elder care mental health professional, a psychologist, a psychiatrist, and case manager(s).

The Diagnostic Expertise Team in North Limburg offers diagnostic help at dementia. Each DEC team has a weekly meeting. The case managers work closely with the other professionals of the DEC team. Depending on the problem and background, the teams develop a (treatment) plan and the route/steps of support are determined. The GP and DEC professional jointly determine whether there is an emergency situation. The waiting list manager examines who is connected to the GP practice and the case manager that is connected to that practice contact within 24 hours.

Evaluation of the Diagnostic Expertise Team in North Limburg and Good Practice Recommendations  
Multidisciplinary team care coordinated by a care manager is one of the recommended methods of providing care for those with dementia, especially those with the Behavioral and Psychological Symptoms of Dementia (BPSD) and/or difficult behavior. As described in the *Overview of best practice recommendations* report, case managers help to coordinate care between the person with dementia, their family, and their healthcare providers. Case managers also help those with dementia live at home through providing and coordinating home-based and out-patient care. The Diagnostic Expertise Team in North Limburg project, in accord with recommendations from *Overview of best practice recommendations* report, employs a case management approach to care for those with dementia.

### Project aims

After working with the DEC team for a number of years, the pilot project aims to evaluate the current role and functioning of this team and the given and experienced support around difficult behavior at home. The project aims to evaluate:

- how support around difficult behavior is experienced by carers,
- the support given by case managers and whether they feel sufficiently equipped to be able to offer appropriate support, and
- the current role of the DEC team.

The evaluation data will be used to improve DEC care and case management for those with dementia.

### Pilot project approach

The project team consist of the multidisciplinary care group manager and three delegate members of the three DEC teams, an expert on difficult behavior from the Trimbos Institute and two advisors from the national program on dementia. The pilot project has been divided in three phases. First, an evaluation of the current situation around difficult behavior at home in the North of Limburg was conducted; this evaluation was done through semi-structured online questionnaires and interviews with informal carers, case managers, and members of the DEC teams. The results of these steps were discussed with the multidisciplinary team manager, the project team, and DEC team members. During these meetings, the group discussed areas in need of improvement and developed an implementation plan. Future efforts will include an additional short questionnaire and implementation of improvements in practice.

### Reflections and potential areas of improvement

Evaluation data from interviews, from focus groups with DEC teams, from meetings with representatives of DEC, and from discussions with the multidisciplinary care group manager showed that:

- case managers need more tools and knowledge about analyzing difficult behavior at home and about how to explain (difficult) behavior to those with low literacy, as well as tips for helping those with low literacy manage difficult behavior at home
- DEC team members need more education on difficult behavior in those with a psychiatric condition
- the roles, ways of working, connection, and possible support from and with the DEC team was not clear and visible/known by relevant professionals, such as GPs
- work processes and workflow differs between the three DEC teams

With regard to setting up dementia care improvement programs, the project team learned that:

- Case managers should be facilitated in working on points of improvement as part of their work, not in addition to their current tasks.
- Evaluation and gaining insight into the current situation was necessary part of project to set up point of improvement.
- Local contexts can differ even within one pilot region; this can result in different suggestions for improvement.

- Ensure that resources are available for implementing points of improvement, such as the training of the case managers or developing easy to understand material about difficult behavior.

#### Next steps

As of June 2019, the project team will focus on improvement activities. The exploratory evaluation has led to insight and improvement activities related to:

- how the carers experience support in the event of challenging behavior
  - Evaluation data showed that carers are positive about the accessibility and a permanent contact person in the form of a counselor
  - Evaluation data also revealed that they experience positive tips and advice from the counselor as positive
  - Carers revealed that clear information about challenging behavior is needed
- how the case managers feel comfortable in the guidance of challenging behavior
  - Data from the evaluation showed that the case managers feel sufficiently equipped to offer guidance in the event of challenging behavior. Experience and previous training has contributed to this.
  - Case managers noted that there is a need to pay more attention to the analysis phase in the "problem exploration" of challenging behavior
  - A point of attention is appropriate information for carers that can be used in the explanation of dealing with challenging behavior
- how the multidisciplinary cooperation in the DEC team is experienced
  - This collaboration has been experienced as very valuable by the team
  - However, the data showed that the visibility of the DEC team could be improved

Tailored implementation support

To support the evaluation of the Diagnostic Expertise Team in North Limburg, the WP5 dementia specialist provided in-depth content-related guidance and support. The implementation scientist provided guidance on developing intervention protocol and implementation plans.

- In January-March 2018, the dementia specialist and the specialist on difficult behavior at home assisted the development of an online semi-structured questionnaire. Further, they helped to code and analyzed the qualitative and quantitative data.
- The advisor from the national program on dementia had regular mail and phone contact with the care chain manager and five meetings with representatives from the DEC
- The WP5 dementia specialist met with case managers from three DEC teams.

### 7.2.5 Scotland

Focus on Dementia team, the national improvement program for Dementia in Scotland, based within the improvement hub of Healthcare Improvement Scotland, oversaw the Post-diagnostic Support (PDS) in Primary Care project in the East Edinburgh, Nithsdale, and Shetland GP clusters.

Scotland remains the only country to have a governmental guarantee that anyone with a new diagnosis of dementia in Scotland will have a minimum of one year's post diagnostic support. This support is delivered using the Alzheimer Scotland Five Pillars of Support.<sup>xxv</sup>

Whilst Scotland has made great strides with its dementia strategies and on the delivery of this target, there is still work to do to ensure timely access to post diagnostic support (PDS) and that this support is of consistently high quality across the country. Most PDS practitioners are based within community mental health teams and diagnosis of dementia largely continues to be made from psychiatry services rather than through primary care. People are not diagnosed early enough, often only receiving a formal diagnosis when their dementia is considerably progressed, which makes it difficult to maximize the potential of PDS being truly transformational.

The modernization of primary care agenda has the expectation that more focus is given within primary care to multi-disciplinary, comprehensive, person-centered and holistic condition management, especially for older people with frailty and co-morbidities. It is anticipated that, over time, relocating post diagnostic support into primary care will make it more accessible and "normalized" encouraging people to come forward sooner for a dementia diagnosis and receive early support to live well with dementia and plan for the future.

Intervention description: Post-diagnostic Support (PDS) in Primary Care

The Post-diagnostic Support (PDS) in Primary Care project aims to support improvements and redesign of community based post-diagnostic support services to improve experience and outcomes for people with dementia and their carers. Post diagnostic support helps build resilience in individuals and communities and helps people plan for the future, including anticipatory planning. The emphasis is on supporting people to stay well at home or in a homely setting for as long as possible. The project hypothesizes that improved diagnosis and post-diagnostic support services will in the longer term help prevent unnecessary hospital admissions by increasing individual resilience and community support.

Post-diagnostic Support (PDS) in Primary Care and Good Practice Recommendations

A case management approach to care is recommended for those with dementia and their families. In the *Overview of best practice recommendations* report, case management serves to coordinate care for those with dementia, plan care and care management strategies, assess the needs of the person with dementia and their family, provide support and encouragement, and refer those with dementia to needed services. Using a case management approach may reduce hospitalization, reduce carer burden, and reduce overall cost while increasing the use of services. Case management is person-centered and responsive to the needs of the person with dementia, their carers, and the healthcare system.

In line with the recommendations outlined in *Overview of best practice recommendations*, the Post-diagnostic Support (PDS) in Primary Care pilot project employs case management approach to dementia care through the Alzheimer Scotland Five Pillars of Support,<sup>xxvi</sup> through the use of a Dementia Support Facilitator, an Occupational Therapy (OT) assistant, or Health and Social Care practitioner to coordinate care, facilitate referrals and connections to other health centers, provide support to carers, and to work as members of multidisciplinary care teams. The case manager, whether a Dementia Support Facilitator, an Occupational Therapy (OT) assistant, or Health and Social Care practitioner, serves as connection points to care and support for those with dementia, their families, GPs in the area, and for other healthcare providers who treat people with dementia, as is recommended by *Overview of best practice recommendations*. The practitioner, regardless of their profession, are trained to the highest level of our education framework for dementia in Scotland (Promoting Excellence, NHS Education for Scotland) in order to ensure specialist support for people with dementia and their carers.

#### Project aims

- Implement and evaluate the delivery of dementia post-diagnostic support from the three GP cluster sites (27 practices in total), engaging the wider primary care team, social work, housing and the voluntary and independent sector
- Understand which groups of individuals benefit from post-diagnostic support in primary care, demonstrating those benefits and the scope for delivery of improved outcomes
- Understand the distribution of need and demand for post-diagnostic support within the primary care setting
- Assess cost and benefits of this approach to individuals and to health and social care systems.

#### Pilot project approach

The Post-diagnostic Support (PDS) in Primary Care project was conducted through a variety of means, which are described below. As described in the project's *Post-diagnostic Support in Primary Care: Progress Report* and the *Scottish Test Sites for WP5 EU Joint Action Post-diagnostic Support: Care Management Approach* document, the project worked through:

- supporting a practice champion. The project ensured each site had identified someone locally who had the skills and expertise, and who would be given dedicated time, to project manage the initiative and liaise with and report to the local project leadership on its implementation and progress.
- training primary care providers. The project provided training to primary care providers to allow for a greater range of learning from the various aspects of delivery that best suited local contexts; as well, the selected sites have been afforded the opportunity to innovate on how they approach the initiative. NHS Education for Scotland (NES) and Alzheimer Scotland are key partners in the program as members of the program's delivery group with NES also supporting the primary care site staff's dementia education requirements in relation to Scotland's Promoting Excellence framework.
- supporting monitoring. Healthcare Improvement Scotland's Data Measurement and Business Intelligence (DMBI) unit also support the measurement aspect of the program, supporting the development of a measurement framework and data collection tools in order to obtain and share data across sites.

- a toolkit. The project developed and disseminated the Dementia-friendly GP toolkit (DFGP) in collaboration with Alzheimer Scotland & Alzheimer's Society in order to support GP practices to become dementia friendly.
- a quality improvement framework. A Quality Improvement Framework (QIF) for Post Diagnostic Support has been developed with the support of people with dementia, carers, staff and partner organizations in order to set a vision for high quality post diagnostic support and to enable services to self-assess against this framework to identify service improvements. A companion document is being co-designed with and for people with dementia and carers so that people know what they can expect from a high quality post diagnostic support service. This will be dual branded with Healthcare Improvement Scotland and Alzheimer Scotland and will feature on the Alzheimer Scotland website and ensure accessibility to people with dementia and carers.

The approach included implementation support for each of the project sites. This implementation support included:

- Regular learning sessions, webinars and peer support sessions to share learning, challenges and progress
- Monthly reporting including improvement clinic telephone calls with the project team
- Implementation of a quality improvement methodology especially around measurement and project scope
- Providing the opportunity for a practitioner/project lead to be physically visible in the GP practices
- Robust project management to keep projects on track and within timescales
- Coordinating communication between sites including face to face learning sessions

#### Measures and metrics

Each of the Post-diagnostic Support (PDS) in Primary Care project sites have a customized Excel workbook to collect and share data with the support of the data measurement advisors at Healthcare Improvement Scotland. Data is also collected via the Information Services Division as part of Scotland's National Dementia Dataset. Data measurement advisors at Healthcare Improvement Scotland are assisting with data analysis. Data is being collected on a monthly basis as part of the monthly reporting process. Data will be used to form future improvements and will be shared with the innovation sites, the project delivery group and will be included in a final evaluation report, conducted and produced by an external evaluator, at the end of the project.

To understand how and to what extent the Post-diagnostic Support (PDS) in Primary Care project impacted care delivery and care outcomes, the project was evaluated. The evaluation measured the:

- Increase in % of population with diagnosis
- Increase in % of those diagnosed who receive Post Diagnostic Support in line with current LDP standard
- Staff demonstrate increased knowledge and understanding of use of tools to support improvements in the quality of PDS
- People with dementia and carers report a positive experience of post diagnostic support
- Number of expressions of interest to become an innovation site and part of a wider network to learn from testing post diagnostic support within a primary care context
- Levels of engagement and staff groups involved in PDS Network sharing practice
- Eq5d quality of life for carers and QoLAD for people with dementia within Dumfries and Galloway (Nithsdale practice only) as part of ICHOM dataset
- Increase in % of PDS uptake
- Person/carer experience of PDS from Primary Care setting
- Primary Care staff experience increase in dementia skills and knowledge
- Reduced time between diagnosis and receipt of PDS.
- Number of GP practices who have implemented the dementia-friendly toolkit

## Results

The pilot sites have conducted a variety of activities. As of November 2018:

- The East Edinburgh site appointed a full-time Dementia Support Facilitator who is attached to the cluster and primary care staff refer cases to her. She is providing one to one support for post-diagnostic support (PDS) and is also helping to run PDS group work sessions. Three courses have taken place and have evaluated well. She also receives referrals for people with mild cognitive impairment (MCI) where it is having an impact on daily living. Referrals to her are coming from GPs in all eight practices within the cluster and she currently has a caseload of approximately 60 people including 12 for MCI support.
- The Nithsdale project site's main focus has always been about changing their systems and making that sustainable after this initiative ends with a key aim of getting GPs diagnosing dementia for non-complex cases and/or referring on more efficiently for diagnosis with a clearer route from primary care into accessing PDS, Occupational Therapy support and specifically Home Based Memory Rehabilitation. They have implemented a Friday morning clinic in Gillbrae, one of the GP Practices. This clinic has half-hourly appointments which GPs can refer people to for cognitive screening or for support if they are either worried about their memory, need PDS or general advice about dementia. They have a dementia information stand outside the clinic room and the Occupational Therapy (OT) assistant who runs the clinic can see people right away. The OT assistant has had 17 referrals from GPs so far and two from other practice staff. Some of the Nithsdale work was delayed as the original Project Manager left. However a new manager took up post on 1 October 2018. She has worked with senior OT colleagues, psychiatry and primary care staff to design a new diagnostic pathway. From January to March, the OT department will be seconding a Band 6 OT a half day a week in Gillbrae to support the diagnostic process and referral onto appropriate support following diagnosis in the hope that they can demonstrate that this

- works and then spread this model to other practices. They are testing the feasibility of collecting quality of life data for people with dementia and carers who are receiving post diagnostic support, within routine practice.
- The Shetland site has used this initiative to transform the whole post diagnostic support (PDS) service in Shetland. They have seconded a senior Occupational Therapist to their program two days a week and have also seconded one of the existing Health and Social Care Workers to work with the senior OT solely as a PDS worker 35 hours per week. Between them, they are forging stronger links with the large health centers, Lerwick and Scalloway, and are now attending multi-disciplinary team meetings to promote the service and receive referrals. The senior OT has developed a new referral system for GPs to refer for PDS through the OT referral gateway. People who have previously declined PDS are taking up the service. The Health and Social Care Worker now has 29 on her caseload, 5 requiring intensive support. They've set some target timescales, 5 days from diagnosis to referral and 21 days from referral to first contact with the Health and Social Care Worker. The Shetland site has been meeting these target timescales.

Through the activities conducted in the Post-diagnostic Support (PDS) in Primary Care project in the East Edinburgh, Nithsdale, and Shetland GP clusters, people with dementia have access to post diagnostic support from a primary care setting. In particular, one of the sites have demonstrated a 46% increase in uptake of post diagnostic support.

Other project outcomes include:

- reduced waiting times for post diagnostic support. Wait time was reduced by 9 months in some cases.
- people with dementia and carers reported experiencing high quality post diagnostic support from a primary care setting. Positive quotes and feedback from people with dementia has reported positive experiences.
- staff have improved knowledge, understanding, and confidence in supporting people with dementia and carers. In one area, there has been 58% increase in staff confidence following dementia training and an 86% increase in diagnosis rates in one area.
- Improved anticipatory care planning and key information summary completion has resulted in a 100% ACP completion rate in one area.

Reflections and potential areas of improvement

#### *Setting up the project*

- Effective contracting with sites around expectations, roles, responsibilities and contingency arrangements and escalation processes is crucial at the start of the project.
- Robust project management and reporting framework is necessary to monitor the project progress and enable clarity of next steps.
- Any improvements in primary care should be multiagency and therefore involving key stakeholders from the start of the project is critical to ensure active engagement

#### *Skills*

- Local quality improvement knowledge and skills are essential in taking forward an improvement project. We learned that by frontloading education of participating staff at the early stages of the project to be beneficial
- Local data and administration support is beneficial in ensuring timeous data collection and analysis.

#### *Implementing the project*

- Ensure there are mechanisms in place to understand the experiences of people with dementia and staff feedback built into the process.
- Peer support between sites is beneficial in sharing learning, challenges and problem solving.
- Allowing innovation in the local context gives staff ownership of the project but can make overall evaluation of project more difficult.

#### *Evaluating the project*

- Formative evaluation as well as summative allows project to be modified to suit local sites, for example we used “pause point” surveys to capture real time feedback during the process and enable us to adapt our practices to ensure we were able to achieve our outcomes.
- Post diagnostic support needs to be and should be person centered and therefore flexible, as it should reflect the needs and desires of the person with dementia.
- Local contexts differ and, as a result, will have different improvement priorities.
- Dementia and quality improvement education have been beneficial in raising awareness and supporting implementation
- Even greater frontloading of quality improvement methodology education with local staff would be used to support the change process in practice
- More facilitated stakeholder events locally could increase interest/ownership of work amongst primary care staff
- An increased presence of the national team at the local level, for example attendance at GP cluster meetings, could be an area of improvement

#### *Next Steps*

This work will continue until September 2021 in order to embed in practice and achieve longer term outcomes. This continued work will include sharing of the learning via PDS Leads and PDS Practitioner Networks, the continued spread of Quality Improvement Framework and Companion document across Scotland, the promotion of the Dementia Friendly Primary Care Toolkit, following testing this in practice, and the development of a Dementia Friendly Primary Care Model incorporating the learning from the pilot work.

This work is informing commitment 2 of Scotland's Dementia Strategy through the testing and independent evaluation of the relocation of post-diagnostic dementia services in primary care hubs as part of modernisation of primary care.<sup>xxvii</sup> This work will also inform work to improve care co-ordination in Scotland through a two year Focus on Dementia commission to implement integrated whole system care co-ordination in one health and social care partnership in Scotland.

#### Ethical considerations

Individuals diagnosed with dementia in the test site areas during the piloting period who did not receive their post diagnostic support as part of the project had the opportunity to receive their post diagnostic support via the traditional pathways in their area e.g. via community mental health teams or Alzheimer Scotland link worker, so that no one would be disadvantaged.

The project took a human rights PANEL approach ensuring that people living with dementia and their carers were involved in the evaluation process.

### Tailored implementation support

The implementation scientist and the dementia specialist from the Trimbos Institute supported the implementation of the Post-diagnostic Support (PDS) in Primary Care project. This support included meetings, suggestions based on the *Overview of best practice recommendations* report, reviews of the project protocol, assistance completing the implementation reporting template, and sending needed and requested academic materials to the project leader. The implementation scientist took the lead on supporting implementation, while the dementia specialist provided content-related assistance, especially as related to case management and evaluation measures.

Details about the support provided are listed below:

- In May 2018, the WP5 team met with the Post-diagnostic Support (PDS) in Primary Care project in the Netherlands. They discussed the protocol and plans for the pilot project as well as plans for how the WP5 team could provide support, especially with regard to providing support on how the Overview of best practice recommendations report could be used to inform project plans.
- In June 2018, the WP5 team reviewed the first description of Scottish test sites and provided support on maintaining motivation in practice sites. As well, the WP5 team helped the Post-diagnostic Support (PDS) in Primary Care project tell the story of their project's "improvement journey" through sharing examples and tips on how to frame the summary of their project.
- In July-August 2018, the dementia specialist and the implementation scientist on the WP5 team reviewed and made suggestions on the project plan, especially as related to adding concrete details and steps to the programs and their evaluation.
- In January 2019, the WP5 team, using the project proposal and resources found online, completed the implementation reporting template. The completed template was shared with the Post-diagnostic Support (PDS) in Primary Care project team for their review, edits, and additional information.
- In February 2019, the WP5 implementation scientist met with the Post-diagnostic Support (PDS) in Primary Care project team. Together they reviewed the pilot projects and discussed next steps.
- In March 2019, the WP5 implementation scientist provided requested articles and tools on sustainability with the project leader.
- In May 2019 Trimbos Institute gave a new presentation on implementation strategies (appendix 14).

## 8. Recommendations from pilot sites.

The WP5 pilot project on “Crisis and Care Coordination” for people with dementia share some important results. Almost all the experiences reported by the pilot test sites are consistently support the strengthening the assistance at primary care level, in order to improve the care coordination of people with dementia and to reduce the crisis potentially harming the wellbeing of subjects and their families living with dementia at home. Therefore, the WP5 teams share the following recommendation:

***Primary care support is the first-line approach concerning the crisis and care coordination of people with dementia.***

The experiences reported by Scottish government and Netherland are the models of care coordination at executive level. The Scottish government aimed at improving the relocation of post-diagnostic dementia services; in addition a comprehensive support to the community of three selected primary care hubs (namely East Edimburg, Nithsdal, and Shetland) was reported. The Netherland strengthen the cooperation between the regional manager, the case managers (e.g. coordinator) and the multidisciplinary DEC; in particular, Netherland improve and promote a more suitable activity of the DEC in management of people with dementia.

Otherwise, the experiences reported by France, Italy and Bulgaria resulted in a more operative approach, aimed at enhancing the cooperation between GPs and specialists for management of people living with dementia. France adopted the mobile team for management of BPSD aimed at implement the last ALCOVE recommendations. Italy proposed a telephone consultation between GPs and specialists. Bulgaria offered an intensive training course for GPs and relatives of people living with dementia, aimed at enhancing the early identification and management episodes of BPSD.

Moreover, the results from France, Italy and Bulgaria highlight the following important recommendation:

***The enhancement of cooperation between GPs and specialist at home, with a multidisciplinary approach, improve the appropriate management of subject experienced BPSD.***

The experience from France and Italy shared common results with a reduction of avoidable hospitalization (France) or referral to Emergency Department (Italy). The results coming from Bulgaria showed also a good satisfaction reported by relatives and caregivers of people with dementia.

Generally, the three experiences showed how the multidisciplinary approach lead to a reduction of pharmacological treatment for subjects presented with BPSD. In particular: France implements the mobile team improving the cooperation between nurse and GPs; Italy strengthen the cooperation between GPs and specialists through a phone consultation; Bulgaria improve the cooperation between GPs and psychologists by implementing the psycho-social interventions as valid option.

Finally, the experience from Italy and Bulgaria showed an important effect from tailored education program for GPs. Italy proposed a distance learning course aimed at improving the skill for a correct identification of people with dementia. Bulgaria offered a tailored training course aimed at implementing the correct and appropriate use of psycho-social interventions for people with dementia. This results lead to the following recommendation:

***Tailored educational program improve the skill in management and early identification of people with dementia by GPs.***

Overall, the results coming from the WP5 pilot sites highlight the need of a patients-centered model for the care coordination for people with dementia. All the interventions proposed by the pilot sites used this approach leading to an important support to patients and caregivers at primary care level. Therefore, the WP5 team share the following general recommendation:

***Patient-centered model is a good implementation method to enhance the patients and caregivers supports at primary care level.***

## 9. Reflections on the five pilot projects

The focus of *Act on Dementia Joint Action: Crisis and Care Coordination Work Package 5* was to improve crisis response services and care coordination for those with dementia. To this end, evidence-informed recommendations were developed and shared with each of the five pilot projects. These recommendations informed the development and implementation of the implementation of pilot dementia care projects in Bulgaria, France, Scotland, Italy, and the Netherlands. While each of the pilot projects had a unique aim and worked to improve different aspects of crisis response services and care coordination for those with dementia, there were common themes across the projects.

### Central role of primary care providers

Each of the pilot projects worked to improve crisis response services and care coordination for those with dementia at the primary care level. By improving care at the primary care level, the pilot projects worked to reduce unnecessary use of the emergency room and hospitalization, improve quality of life for people with dementia, reduce stress in carers, and establish systems so that people with dementia could stay at home longer.

In the projects in Bulgaria, Italy, and Scotland, educational and training programs were developed to improve GP knowledge of dementia, dementia care option, and the management of dementia symptoms. These educational and training programs ranged from both online and in-person courses, as well as ongoing educational support and peer support sessions. The pilot project in France focused on strengthening the knowledge and confidence of GPs by connecting them to multidisciplinary mobile dementia care teams and/or to a nurse specialist, who provided support and assessment. The pilot projects in France and Italy worked to connect GPs to dementia care specialists to increase and improve dementia care at the primary care level. The dementia care specialists provided support, answered questions, and/or conducted assessments. In Scotland, primary care practices were supported through dementia care coordinators at the practices, as well as through learning sessions, webinars, and peer support sessions. The pilot project in the Netherlands sought to understand the needs of primary care providers, especially with regard to the support provided by dementia care specialists at an external dementia care center.

### Supporting carers

As each of the projects sought to improve dementia care for those living at home, most of the pilot projects worked to support informal carers, such as family members. In the pilot project in Bulgaria, this support came through the development and implementation of carer education and support groups, which aimed at improving carer knowledge of dementia and of techniques to cope with challenging behavior. The pilot project in France worked to reduce carer stress through home visits, which included information, support, and tools for carers to equip them to better respond to crisis episodes. The pilot project in the Netherlands sought to learn how care and support for people with BPSD is viewed by carers and family members of those with dementia. This information will be used to develop and implement improvement strategies in dementia care coordination. In the pilot project in Scotland, the project team worked to reduce carer stress and burden through practice champions, who were contact points for carers seeking additional information and support.

## Pilot project overview

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

- connect primary care providers with external support from dementia care specialists
- train primary care providers in the tools and techniques needed to provide care for those with dementia
- coordinate care between primary care providers and dementia care specialists
- develop dementia care pathways in the primary care setting, such as care coordination by nurses or other care providers
- reduce carer burden and stress, especially with regard to care for people with dementia and BPSD
- provide support for people with dementia so that they can live at home longer
- tailor dementia care approaches and improvement strategies to each pilot site context
- conduct ongoing evaluation of care in order to improve care coordination and crisis response services for those with dementia

## 10. Limitations

The WP5 team worked to provide evidence-informed recommendations and support for implementing programs to all five pilot practices. However, there were challenges that should be addressed in order to implement more successful work packages and dementia care in the future.

The WP5 team and the project leaders were limited by time. Many, if not all, of the project leaders had limited time in which to meet with the WP5 team to develop implementation plans. This time limitation was also reflected in the sharing of project plans. For projects that had already had a well-developed project plan in English, sharing it with the WP5 team was relatively simple, as was completing the implementation planning template. For projects that did not already have such a protocol in English, sharing protocols and completing the template was an additional time investment.

Many of the project leaders had experience leading similar projects or studies in the past. However, for project leaders for whom this sort of work was new, there was a learning curve with regards to protocol development, information sharing, and project implementation. While the WP5 team supported this process, it did result in a greater time investment, (somewhat) delayed projects, and different needs from the more experienced project leaders.

It is possible that the project leaders were unsure of the support offered by the WP5 team and were unclear as to whether their project needed it. The support offered by the WP5 team was clarified through calls and materials; however, more could have been done earlier in the project to support better uptake of the offerings of the WP5 team.

For some of the project leaders, there may have been a language barrier between the WP5 team and the project team. This may have resulted in less use of the support offered by the WP5 team. In these cases, effort was made to offer support by email or through materials, which could be translated as needed.

While the pilot projects focused on care coordination and crisis response services for those with dementia, each project had its own aims, methods, and desired outcomes. While it was hoped that the projects would be able to share resources, such as educational materials and metrics, between themselves, this was not feasible for most of the projects as the project aims and timelines were different. When it was possible, sharing was facilitated by the WP5 team.

The pilot projects had limited funds to purchase, translate, or modify materials from existing external projects, such as educational videos, brochures, or metrics. While the WP5 team was able to share free relevant external project resources with the project leaders, the project leaders were limited in what they could use due to funding.

The WP5 team supported each project leader as they completed the implementation planning template. In some cases, the WP5 team was able to complete aspects of the template from available materials (such as earlier project plans or materials found online) and then share the partially completed template with the pilot project leader. However, this was not possible for all of the projects, as the information available online or shared earlier was limited.

## 11. References

- 
- <sup>i</sup> World Health Organisation. (2017). Dementia. Fact sheet.
- <sup>ii</sup> Georges, J., & Miller, O. (2018, November 5). Dementia in Europe: a public health priority? Retrieved from <https://www.health.europa.eu/dementia-in-europe/88813/>
- <sup>iii</sup> Joint Action on Dementia: ALCOVE. Implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias. 2014.
- <sup>iv</sup> Welcome to Act on Dementia | Act on dementia. (n.d.). Retrieved May 6, 2019, from <https://www.actondementia.eu/>
- <sup>v</sup> Deliverable 1 from EU Joint Action On Dementia 2 – Act On Dementia, Work Package 5 “Crisis and care coordination – Evidence and recommendation” – Deliverable 1.1. Grant Agreement No 678481, funding from the European Union's Health Programme (2014-2020).
- <sup>vi</sup> Deliverable 1 from EU Joint Action On Dementia 2 – Act On Dementia, Work Package 5 “Crisis and care coordination – Evidence and recommendation” – Deliverable 1.1. Grant Agreement No 678481, funding from the European Union's Health Programme (2014-2020).
- <sup>vii</sup> MacNeil Vroomen, J., Bosmans, J. E., van Hout, H. P., & de Rooij, S. E. (2013). Reviewing the definition of crisis in dementia care. *BMC geriatrics*, 13, 10. doi:10.1186/1471-2318-13-10.
- <sup>viii</sup> *5.1 Evidence and recommendations* - Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>ix</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>x</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xi</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xii</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xiii</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xiv</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xv</sup> *5.1 Evidence and recommendations*- Mapping report and identification of Recommendations, deliverable 1.1. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xvi</sup> *Overview of best practice recommendations* report, deliverable 1.2. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).
- <sup>xvii</sup> *Overview of best practice recommendations* report, deliverable 1.2. report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).

---

<sup>xviii</sup> EU Compass for Action on Mental Health and Well-being: Good practices in Mental Health and Well-being booklet. 2016

<sup>xix</sup> DG Santé. Criteria to select best practices in health promotion and chronic disease prevention and management in Europe. 2017.

<sup>xx</sup> Ng E, De Colombani P. Framework for Selecting Best Practices in Public Health: A Systematic Literature Review. *Journal of Public Health Research*. 2015;4(3):577. doi:10.4081/jphr.2015.577.

<sup>xxi</sup> Trimbos International [coordinating institution of the EU Compass Consortium for Action on Mental Health and Well-being]. (2018). Good Practices in Mental Health and Well-being survey. Funded by the European Union in the frame of the 3rd EU Health Programme (2014-2020).

<sup>xxii</sup> Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science*, 4(1), 50.

<sup>xxiii</sup> *Deliverable 5.2 Overview of best practice recommendations* report. Report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).

<sup>xxiv</sup> *Deliverable 5.2 Overview of best practice recommendations* report. Report from the EU Joint Action On Dementia - Act On Dementia, Work Package 5. Funded by the European Union's Health Programme (2014-2020).

<sup>xxv</sup> [https://www.alzscot.org/campaigning/five\\_pillars](https://www.alzscot.org/campaigning/five_pillars)

<sup>xxvi</sup> [https://www.alzscot.org/campaigning/five\\_pillars](https://www.alzscot.org/campaigning/five_pillars)

<sup>xxvii</sup> (Scottish Government)