The European Joint Action on Dementia

alcove
ALzheimer COoperative Valuation in Europe

Synthesis Report

2013

Unremembering eyes
A smile that barely ages
Distant yet so close

Herman Van Rompuy
President of the European Council

This synthesis of knowledge on dementia, based in the exchange of information to promote health, quality of life, autonomy, and dignity among people living with dementia and their carers in European Member States arises from the ALCOVE Joint Action which has received funding from the European Union, in the framework of the Health Programme 2008-2013. Its represents the views of the contractors and sole responsibility lies with the authors. The European Commission and the Executive Agency for Health and Consumers are not responsible for any use that may be made of the information contained therein.

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FOREWORD

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Dementia is a growing priority for national and European decision-makers, given its burden on individuals living with dementia and their carers and the impact on social and health systems as Europe's population is ageing. This is why the European Commission promotes a range of actions to respond to this challenge.

In 2009, the Commission launched a European initiative on Alzheimer's disease and other dementias. A major instrument to implement this initiative was the establishment in 2010 of the Joint Action "Alzheimer COoperative Valuation in Europe (ALCOVE)", with co-funding from the EU-Health Programme. In parallel, a Joint Programming Initiative on Neurodegenerative Disorders was established, under which the participating countries coordinate their national strategies for research into neurodegenerative disorders. Already in 2008, the Commission brought forward the European Pact for Mental Health and Well-being as a framework for EU-level exchange and cooperation on mental health promotion and mental disorder prevention. Finally, in 2012 the European Innovation Partnership on Active and Healthy Ageing was launched.

The ALCOVE Joint Action brought together partners from 19 European Union Member States, under the lead of the French National Authority for Health. Over two years, these partners worked together to share knowledge and experiences to improve care and services for citizens living with dementia and their families.

The Joint Action focused on four crucial questions in the field of dementia: epidemiology and prevalence, diagnosis and systems for diagnosis, care for behavioural disorders with the goal of limiting antipsychotic use and institutionalisation, and the rights and dignity of people living with dementia.

I am pleased that ALCOVE developed responses in all these areas. It undertook a critical re-estimation of the number of people living with dementia. Practical recommendations for "timely" diagnoses were developed. The Joint Action generated proposals for the development of structures and care organisations to address the behavioural and psychological symptoms of dementia. It mapped out national regulations for advance declarations of will. Finally, it established a Toolbox for the limitation of the use of antipsychotics in the treatment of people living with dementia, in order to reduce the risk of overmedication.

The outcomes of the ALCOVE Joint Action underline the added value which structured exchange and cooperation between countries on important health policy issues creates. In particular, during times when health policies face budgetary constraints, there is a strong case for working together to share knowledge and to identify good practices and successful innovative models.

I am confident that this synthesis report, which presents the recommendations resulting from work under the ALCOVE Joint Action, will inform and inspire the further development of policies and programmes across the European Union.

Tonio BORG
Commissioner for Health and Consumer Policy
European Commission

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ALCOVE PARTNERS

France, Haute Autorité de Santé, Main Partner/Work Package 1 Leader: Armelle Leperre Desplanques, Nathalie Riolacci Dhoyen, Christine Barr, Maggie Galbraith; **Spain, Instituto de Salud Carlos III,** Dissemination/Work Package 2 Leader: Carlos Segovia, Tomás López-Peña Ordoñez, Gloria Villar Acevedo, Mercedes Garcia Garcia; **Slovakia, Slovenska Akademia Vied – Neuroimmunologicky Ustav,** Evaluation/Work Package 3 Leader: Michal Novak, Rostislav Skabrana, Martina Jezovicova; **Italy, Istituto Superiore di Sanità,** Epidemiological data/Work Package 4 Leader: Nicola Vanacore, Francesca Galeotti, Angela Giusti, Fiorentino Capozzoli, Roberto Raschetti, Paola Scardetta, Francesca Meduri; **United Kingdom, Department of Health,** Timely Diagnosis/ Work Package 5 Leader: Jerry Bird; Karim Saad; **The Association for Dementia Studies, University of Worcester**, Dawn Brooker, Simon Evans, Jenny La Fontaine, Jennifer Bray; **Finland, Institute of Health and Welfare,** Support Systems for BPSD/Work Package 6 Leader: Harriet Finne-Soveri, Matti Mäkelä, Kristina Saarkalle, Helka Hosia-Randell, Paivi Topo, Ulla Eloniemi-Sulkava; **Belgium, King Baudouin Foundation,** Autonomy, Rights & Dignity/Work Package 7 Leader: Gerrit Rauws, Bénédicte Gombault, Tom Goffin; **Cyprus**, Mental Health Services, Ministry of Health*: Irene K Georghiou ; **Czech Republic**: Ceska Alzheimerovska Spolecnost*, Martina Mátlová; **France**, Assistance Publique-Hôpitaux de Paris, Espace Ethique: Emmanuel Hirsch, Virginie Ponelle, Gregory Emery; Institut National de la Santé et de la Recherche Médicale: Catherine Helmer; **Greece**, Athens Association of Alzheimer's Disease and Related Disorders: Paraskevi Sakka, Areti Efthymiou, Eleni Margioti, Nikolaou Costas, Maria Panagiotou; **Hungary**, Szegedi Tudomanyegyetem*: Janos Kalman; **Italy**, Ministero dello Salute: Teresa di Fiandra, Giovanni Nicoletti, Fabrizio Oleari, Fiammetta Landoni, Cecilia Prezioso; Università degli Studi di Brescia: Alessandro Padovani, Barbara Borroni, Luca Rozzini, Enza Castronovo; **Latvia**, Rīgas Psihiatrijas un narkoloģijas centrs: Wladimir Kuznecovs; **Lithuania**, Vilniaus Universiteto Medicinos Fakulteto*: Valmantas Budrys; Lietuvos Respublikos Sveikatos Apsaugos Ministerija*: Genovaite Paulauskiene; Lietuvos Sveikatos Mokslų Universitetas: Daiva Rastenyte; **Luxembourg**, Ministère de la Famille et de l'Intégration*: Malou Kapgen; Ministère de la Santé*: Dorothee Knauf-Hübel; **Malta**, Ministeru tas-Sahha, l-Anzjani u l-Kura fil-Kommunitta*: Isabelle Avallone; **Netherlands**, Ministry of Health, Welfare and Sport*: Jacqueline Hoogendam; **Norway**, Ministry of Health and Care Services*: Kristin Løkke; **Portugal**, Coordenação Nacional de Saude Mental, Alto Comissariado para a Saude, Ministerio da Saude*: Miguel Xavier; **Slovakia**, Ministerstvo školstva Slovenskej Republiky*: Lubica Pitlova; **Spain**, Spanish Ministry of Health*: Isabel Saiz; Fundación Vasca de Innovación e Investigación Sanitarias & Agencia Vasca de Evaluación de Tecnologías Sanitarias: Gemma Villanueva, Marta Lopez-Argumendo, Iñaki Gutiérrez-Ibarluzea, Irune Vegas-Martínez; **Sweden**, Karolinska Institutet: Anders Wimo; **United Kingdom**, University of Stirling, Dementia Services Development Centre*: Louise McCabe.

**Collaborative partners, voluntary basis participation; others are associated partners with financial support from the European Commission*

ALCOVE BOARD MEMBERS

Armelle Leperre-Desplanques, ALCOVE Project Leader, Nathalie Riolacci-Dhoyen, *Haute Autorité de Santé*, Work Package 1 - Carlos Segovia, Tomas Lopez Peña-Ordoñez, *Instituto de Salud Carlos III,* Work Package 2; Michal Novak, Rostislav Skrabana, Work Package 3; Nicola Vanacore, Angela Giusti, *Istituto Superiore di Sanità,* Work Package 4; Dawn Brooker, Karim Saad, *The Association for Dementia Studies, University of Worcester,* Work Package 5; Harriet Finne-Soveri, Matti Mäkelä, *Institute of Health and Welfare,* Work Package 6; Gerrit Rauws, Bénédicte Gombault, *King Baudouin Foundation,* Work Package 7.

ALCOVE SYNTHESIS REPORT AUTHORS

Citation by alphabetic order: Linda Banaei-Bouchareb, Christine Barr, Jennifer Bray, Dawn Brooker, Luis Calvo Orra, Marie Erbault, Simon Evans, Harriet Finne-Soveri, Maggie Galbraith, Francesca Galeotti, Mercedes García García, Angela Giusti, Bénédicte Gombault, Martina Jezovicova, Pierre Krolak-Salmon, Jenny La Fontaine, Benoît Lavallart, Sandrine Lemery, Armelle Leperre Desplanques, Tomás López-Peña Ordoñez, Matti Mäkelä, José María de la Rúa, Francesca Meduri, Carole Micheneau, Gonzalo Nieto Arévalo, Michal Novak, Petr Novak, Herman Nys, Lyragen Peter, Roberto Raschetti, Gerrit Raws, Nathalie Riolacci Dhoyen, Caroline Roubaud, Karim Saad, Kristiina Saarikalle, Paola Scardetta, Carlos Segovia Pérez, Rostislav Skrabana, Nicola Vanacore, Gloria Villar Acevedo.

ALCOVE CONTRIBUTORS TO VARIOUS SECTIONS

Citation by alphabetic order: Peter J S Ashley, Mickaël Basson, Marikede Boer, Florence Bonte, Alison Bowes, Roger Bullock, Gily Coene, Bernie Coope, Jan Craenen, Jean-François Dartigues, Gregory Emmery, Sylvie Froucht-Hirsch, Chris Gastmans, Jean Georges, Jane Gilliard, Tom Goffin, Gabriel Gold, Dianne Gove, Fabrice Gzil, Karen Harrison Dening, Emmanuel Hirsch, Adrian Ivanoiu, Martine Joris, Josef Kuře, Marja-Liisa Laakkonen, Antonio Lobo, Anna Mäki-Petäjä-Leinonen, Paul Matthys, Alex Peltier, André Pereira, Emma Reynish, Andorno Roberto, Saïda Sakali, Michael Schuerch, Pablo Simon-Lorda, Isabelle Van der Brempt, Chandy Van De Venne, Patrick Verhaest, Heather Vickers, Anders Wimo, Régine Wilmotte.

ALCOVE SURVEY RESPONDENTS

Belgium: Yoeriska Antonissen, Jean Pierre Baeyens, Jean-Christophe Bier, Pierre-Yves Bolen; Daniel Crabbe, Catherine Dechevre, Bénédicte Gombault, Sabine Henry, Barbara Melard, Vinciane Quoidbach, Eric Salmon, Veerle Vanderlinden, Jurn Verschraegen; **Bulgaria**: Irina Ilieva, Galina Paeva; **Cyprus**: Irene Kyriacou Georghiou; **Czech Republic**: Iva Holmerová, Jakub Hort, Katerina Sheardova, Martin Valis, Martin Vyhnalek, **Denmark**: Peter Johannsen, Gunhild Waldemar; **Estonia**: Maarja Krais-Leosk, Ülla Linnamägi, Heli Paluste, Kai Saks, Irena Sirotkina; **Finland**: Mika Gissler, Malla Heino, Mikkola Hennamari, Helka Hosia-Randell, Nina Knape, Seppo Koskinen, Matti Makela, Jaana Martikainen, Anja Noro, Hanna Rautiainen, Veikko Salomaa, Matti Viitanen, **France**: Philippe Amouyel, Emilie Beaufils, Athastanase Benetos, Marie Berard, Laurence Bernard-Bourzeix, Françoise Bourgoin, Jean François Dartigues, Marie-Odile Desana, Olivier Dupont, Jean-Philippe Flouzat, Chantal Girtanner, Sandrine Harston, Catherine Helmer, Pierre Krolak-Salmon, Benoit Lavallart, Sandrine Lemery, Armelle Leperre Desplanques, Isabelle Merlet, Jean-Luc Novella, Julie Piano, Philippe Ricordeau, Thérèse Rivasseau Jeonveaux, Philippe Robert, Yves Rolland, Philippe Tuppin, Pierre Vandel, ALFA programme respondent, COGLIM Association respondent; **Germany**: Christian Berringer, Gabriele Doblhammer-Reiter , Lutz Froelich, C. Günster, Sabine Jansen, Sabine Nemitz, Steffi Riedel-Heller, H. Rothgang, Silvia Schelo; **Greece**: Eleni Margioti, Sakka Paraskevi, Magda Tsolaki; **Hungary**: Janos Kalman, Magdolna Pakaski; **Ireland**: Ann Coyle, Anne Mescal, Noel Mulvihill; **Italy**: Luisa Bartorelli, Susanna Conti, Teresa Di Fiandra, Claudia Gandin, Maria Masocco, Alessandro Padovani, Emanuele Scafato, Nicola Vanacore; **Latvia**: Zane Baltane, Valmantas Budrys, Aigars Kisuro, Liga Kozlovska, Vladimirs Kuznecovs, Ieva Paegle, Daina Zepa; **Lithuania**: Valmantas Budrys, Jurate Macijauskiene, Daiva Rastenyte; **Luxemburg**: Mariette Backes-Lies, Marcel Bruch, Malou Kapgen, Dorothee Knauf-Hübel, Guy Weber, Laurence Weber; **Malta**: Stephen Abela, Isabelle Avallone, Sandra Buttigieg, Roberto Debono, Joseph Dimech, Kathleen England, Ronald Fiorentino, Charles Scerri; **Netherlands**: Diana Abels, Jean-Pierre Gorissen, Jacqueline Hoogendam, Frans Verhey, **Norway**: Dag Abrahamsen, Knut Engedal, Bjorn Heine Strand, Kristin Mehre, Tor Molden, Elisabeth Vatten; **Poland**: Alicja Klich-Raczka; **Portugal**: Alvaro de Carvalho; **Romania**: Catalina Tudose; **Slovakia**: Maria Chmelova, Maria Cunderlikova, Dusan Dobrota, Stefan Krajcik, Jan Lehotsky, Denisa Mikusova, Marian Nagy, Edmund Skorvaga, Rostislav Skrabana, Peter Turcani, Alzbeta Vesela, Elena Zigova; **Slovenia**: Gorazd B. Stokin, Ales Kogoj; **Spain**: Jesús de Pedro-Cuesta, Iñaki Fernández-Manchola, Manolo Fernández-Martínez, Luis Galdos-Alcelay, Marian Gómez-Beldarrain, Pilar Hurtado, Begoña Indakoetxea, Tomás Lopez-Peña, Javier Angel Mediavilla-Serna, Pablo Martínez-Lage, Inés Olazábal, Alfredo Rodríguez-Antigüedad, Javier Ruiz-Ojeda, Juan M. Uterga-Valiente, Gemma Villanueva; **Sweden**: Yngve Gustavson, Susanne Holland, Mia Jönhagen, Mårten Lagergren, Andrejs Leimanis, Lennart Minthon, Katarina Nägga, Anders Norlund, Ingmar Skoog, Anders Wimo, Bengt Winblad; **Turkey**: Basar Bilgic; **United Kingdom**: David Berry, Jennifer Bray, Dawn Brooker, Alistair Burns, Anne Corbett, Simon Evans, Christine Jendoubi, Lindsay Kinnaird, Jenny La Fontaine, Esme D. Moniz-Cook, Karim Saad, Becky Sidwell, Sarah Watkins.

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A GENERAL PRESENTATION OF ALCOVE

A GENERAL PRESENTATION OF ALCOVE

Dr Leperre Desplanques, Armelle, ALCOVE Project Leader; Dr Riolacci Dhoyen, Nathalie; Barr, Christine; Galbraith, Maggie,
ALCOVE coordination team, Haute Autorité de Santé, France

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ALCOVE EXECUTIVE BOARD & ALL ALCOVE PARTNERS & CONTRIBUTORS: see chapter ALCOVE PARTNERS p.8

All ALCOVE reports & deliverables are available on the ALCOVE website– www.alcove-project.eu

ALCOVE'S GENERAL OBJECTIVES

- **Dementia, the most common form being Alzheimer's disease, concerns more than 7 million Europeans living with it as well as their estimated 20 million family carers**. Alzheimer's disease is characterised by progressive memory and cognitive problems as well as the occurrence of disturbing behaviour disorders. The current absence of curative treatment for Alzheimer's disease does not translate to an absence of care. Today in Europe, citizens, families, and health professionals are mobilised to provide better care and services all along the progression of dementia, from timely diagnosis to home or institutionalised care.

- **ALCOVE was born out of a need to share knowledge and experiences about Alzheimer's disease and related disorders in health policy between European Member States:** ALCOVE aims to capitalise on the European experience and knowledge on this disease and its consequences and to reflect together on the best means of preserving quality of life, autonomy and the rights of people living with dementia. Major cognitive disorders, with Alzheimer's disease and related disorders (AD) as a major cause, represent a challenge for our societies in terms of care organisation as well as in terms of social support and innovation to preserve quality of life, both for individuals living with the disorder as well as their family carers. The general objective of this Joint Action was to establish an independent and scientific European network to inform and advise decision-makers, health care professionals, carers, individuals living with dementia, and other European citizens through convergent operational recommendations from a health policy perspective.

ALCOVE PARTNERS & COOPERATION

- **Nineteen countries were committed to this 2-year Joint Action, and were represented by thirty organizations which were appointed by their respective governments:** Among these partners, 7 of the countries served as leaders of 7 Work Packages. Three transversal Work Packages were devoted to the **Coordination** of the Joint Action (WP1), led by the Main Partner, France's Haute Autorité de Santé, its **Dissemination** (WP2), led by Spain's Instituto de Salud Carlos III, and its **Evaluation** (WP3), led by Slovakia's Neuro Immunology Institute. Four Core Work Packages were led by Italy's Istituto Superiore di Sanità (**Epidemiological Data**, WP4), the UK's Department of Health in conjunction with the University of Worcester (**Timely Diagnosis**, WP5), Finland's National Institute for Health and Welfare (**Support systems for Behavioural and Psychological Symptoms of Dementia**, WP6), and Belgium's King Baudouin Foundation (**Rights, Autonomy and Dignity**, WP7). Besides these 4 core ALCOVE themes, the safety issue that is the overuse of antipsychotics in dementia, as well as solutions on how to limit it, was collaboratively examined by all the ALCOVE partners. In total, more than 100 people contributed to the ALCOVE work, and in addition about 170 respondents from 24 European countries participated in the different ALCOVE surveys. (see Chapter ALCOVE Partners p. 8).

- **ALCOVE and its collaboration with other European projects and networks in the field of dementia:** ALCOVE is a network which is made up of representatives from Member States within the framework of a public health mission. More than 10 previous or current European projects and networks related to dementia exist. ALCOVE acted in order to position and synergise its public health missions with respect to these other initiatives and research projects. Meetings and exchanges with other projects such as the Joint Programming on Neurodegenerative Disease or the European Alzheimer Disease Consortium were conducted. In particular, a formal, close, and fruitful cooperation was established with Alzheimer Europe, a patient and family umbrella association which includes all national Alzheimer associations. This collaboration permitted ALCOVE to avoid redundancy and allowed it to capitalise on Alzheimer Europe's expertise and previous work, such as its Eurocode project and its experience in analysing ethical issues.

ALCOVE METHOD

- **The aims of the ALCOVE Method were to identify good practices, gaps between real practices and evidence in the literature, and to propose public health options to support improvement in the ALCOVE targeted topics:** To generate an operational synthesis of these complex and evolving questions, with respect to already-existing European projects and the 10 new public health plans for dementia implemented since 2008, ALCOVE has chosen a method with 3 approaches. Besides literature reviews and the subsequent analyses of the texts identified therein and exchanges with European experts and networks, questionnaires were created and sent to holders of information in European Member States in order to access data and analyse effective practices and care. The collection, analysis and comparison of information collected both in the field and in the literature reviews led to the drafting of ALCOVE recommendations which address public health needs. (Figures 1 & 2).

- **To ensure that it would meet its objectives within the 2-year time frame, as well as to guarantee project management that was both collective and transparent, ALCOVE developed its own project management method and self evaluation process:**
  - A collaborative method based on consensual decisions made by the members of the ALCOVE Executive Board. All Executive Board members participate in regular meetings and conference calls and receive minutes of the decisions taken.
  - A global and coherent work plan including the specific work plan for each Work Package as well as systems for regular monitoring and assessment of progress.
  - A strong project management strategy with specialised leadership tools for both internal communication and evaluation (see Chapter ALCOVE Evaluation p. 96).

Figure 1. ALCOVE Method: Timeline

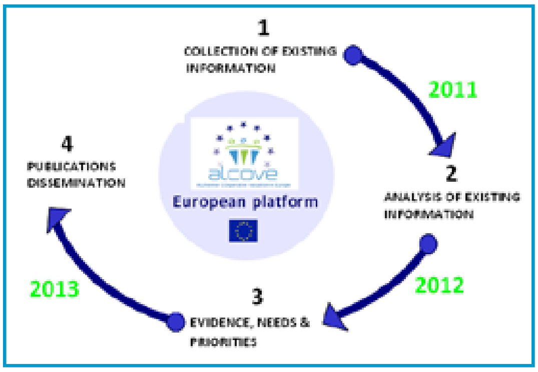
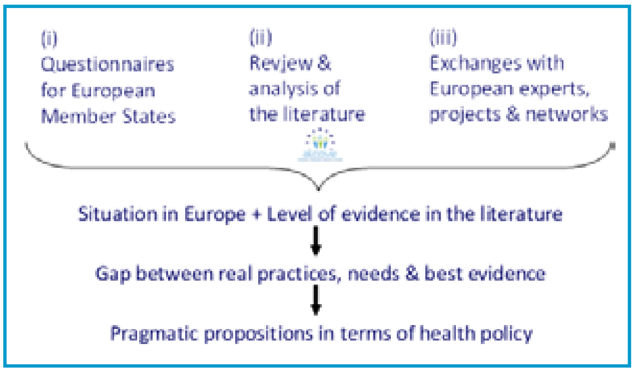


Figure 2. ALCOVE Method: 3 approaches



ALCOVE TOPICS

- **What do we know in scientific terms? What is the situation in Europe?** Each of the five topics - the four core questions and the shared question on antipsychotics - has been analysed while using these two questions to contextualise ALCOVE's work. In answering these questions, ALCOVE's aim is to make concrete recommendations which propose avenues for improvement.
  - **From an epidemiological perspective**, what data is available in Europe on Alzheimer's disease prevalence, the characteristics of persons living with dementia, and how they are taken care of medically and socially? What minimum body of knowledge and what good practices for data collection could be proposed to improve this knowledge? (see Chapter Epidemiological data p. 26).
  - **As concerns an Alzheimer's disease diagnosis**, what systems are in place to make such a diagnosis and how are they evaluated? What are the different options available for offering a timely Alzheimer's disease diagnosis and how can it best be paired with appropriate care for persons living with dementia and their family carers? (see Chapter Timely diagnosis p. 38).
  - **As concerns care for persons experiencing BPSD**, what are the options for the organisation of care and the subsequent evaluation of different options? How can we improve care for persons living with dementia and their carers? (see Chapter Support Systems for BPSD p. 54).
  - **As concerns both advance directives and competence assessment**, what are the current legislative and legal practices in Europe? How can we improve them so that the rights and autonomy of individuals living with dementia are better respected? (see Chapter Rights, Autonomy & Dignity p. 74).
  - **What is the risk of exposure to antipsychotics for persons living with dementia and how can it be limited**? What risk reduction programmes have been implemented to reduce this safety and ethical issue? During the course of the project, this issue was the common ground for the four thematic work packages. Together, along with WP1 and WP2, they constructed a Toolbox which contains information about outstanding projects which have supported the implementation of good practices in the field of antipsychotic risk prevention (see Chapter ALCOVE Toolbox p. 84).

ALCOVE RESULTS

- **ALCOVE's recommendations have been generated based on updated knowledge about scientific evidence and after having identified the needs and current situations in Europe:** ALCOVE's propositions target key decision-makers and seek to enlighten them about health policy as concerns Alzheimer's disease and related disorders., At the same time, these recommendations are designed to be useful for health and social professionals, researchers, and individuals living with dementia and their family.

  The knowledge on Alzheimer's disease has been undergoing a rapid and huge evolution, even as concerns the definition of dementia and major cognitive disorders themselves. At the same time, due to an ageing population, the urgent needs for persons living with dementia and their carers in Europe are dramatically increasing. ALCOVE proposes strategies with different levels of action which address the diverse current realities in European healthcare systems while proposing high level objectives for the near future for systems that may be ready to advance (see Chapter ALCOVE Recommendations p. 18).

- **ALCOVE's recommendations will be made public at the ALCOVE Final Symposium which is scheduled to take place in Paris on the 28th of March 2013 and will be further disseminated on the ALCOVE website (www.alcove-project.eu) which is to be sustained beyond the formal term of the project:** More than 23 countries will be represented by government officials and key actors in the field of dementia at the ALCOVE Symposium. This will include stakeholders, political figures, decision-makers and patients' and citizens' organisations. This ALCOVE Synthesis Report has been prepared and published so that it may be disseminated at the event (see Chapter ALCOVE Dissemination p. 90).

CONCLUSIONS

ALCOVE's partners' involvement and dynamism were key during the two years' of collaborative work between 2011 and 2013. As a result of this work, ALCOVE is able to present operational proposals in this Synthesis Report for several key aspects for improving, from a public health standpoint, care pathways and the quality of life for persons living with dementia as well as their carers: improve knowledge about dementia prevalence so as to be able to better anticipate needs; propose a diagnosis as early as possible, such a diagnosis should be accessible and accompanied by a long-term care cycle for persons living with dementia and their carers; design a public health strategy for the disturbing behaviours related to BPSD, and in doing so reducing burn-out among carers and allowing the person to stay in his or her home for the longest period possible; improve the respect of the rights and dignity of people living with dementia by encouraging good practices in advance directive and competency assessment use.

Due to its expected impact on health systems and society, dementia represents a serious threat to medical-social systems and intergenerational solidarity. At the same time, this collaborative approach which promotes benchmarking and sharing between European Member States is an opportunity to reform and to innovate. ALCOVE's proposals aim to improve care and quality of life for persons living with dementia and their family carers in Europe.

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ALCOVE RECOMMENDATIONS

ALCOVE RECOMMENDATIONS

** Behavioural & Psychological Symptoms of Dementia*

ALCOVE RECOMMENDATIONS FOR EPIDEMIOLOGICAL DATA ON DEMENTIA

Recommendations to improve data collection on estimates of dementia prevalence in Europe

[1] **Future studies on dementia prevalence should be performed using the highest quality epidemiological studies as defined in the 2009 ADI report** (Sample size: ≥3000 subjects; Design: One phase study or two phase study with appropriate sampling and weighting; Response proportion≥ 80%, Diagnostic assessment with Inclusion of multi-domain cognitive test battery, formal disability assessment, informant interview and clinical interview). *[WP4.1]*

[2] **Epidemiological studies on dementia using the DSM IV and NINCDS-ADRDA clinical criteria for dementia and Alzheimer's disease should be promoted. These clinical criteria are the only ones that have been validated with post-mortem data.** *[WP4.2]*

[3] **At the same time, dementia prevalence and incidence studies using the new clinical criteria of the National Institute on Aging and the Alzheimer's Association should be performed to promote new knowledge in this area.** *[WP4.3]*

[4] **Prevalence and incidence studies on people living with dementia aged ≤65 years should be promoted to define dementia frequency.** *[WP4.4]*

[5] **Studies in the same areas over different decades should be carried out to intercept any phenomenon of dementia decline as speculated by some evidence of literature.** *[WP4.5]*

Recommendations to improve data collection on antipsychotics in dementia

[1] **Prospective and systematic collection data on people living with dementia in specific settings (community, home care, memory clinic, nursing home) in all Member States is urgently necessary.** *[WP4.6]*

[2] **A list of antipsychotics used in each Member States should be compiled, underlining the off-label use for the specific drug contained therein.** *[WP4.7]*

[3] **The collection of data on the use of antipsychotics in people living with dementia should be characterised to allow for prescription analysis (notably, as appropriate or inappropriate).** *[WP4.8]*

[4] **Information on the use of antipsychotics in conjunction with other quality indicators (e.g., physical restraints used in nursing home residents with severe dementia) must be gathered.** *[WP4.9]*

[5] **A European database on the use of antipsychotics in people living with dementia should be implemented.** Such a database would be used to monitor antipsychotic prescriptions in Member States and to assess the efficacy of national programmes for antipsychotic use risk reduction. *[WP4.10]*

Recommendations to improve data collection on health and social care services for dementia

[1] **A minimum data set, shared among different Member States, should be adopted for administrative, clinical, epidemiological and other relevant data sources.** The dataset should include general data on chronic diseases and specific data on dementia. *[WP4.11]*

[2] **For data collection purposes, a predefined set of operational diagnosis criteria for dementia should be proposed.** *[WP4.12]*

[3] **Optimise existent data sources by providing an efficient system of record linkage.** *[WP4.13]*

[4] **A unique, depersonalised identifier should be made available for record linkage.** Privacy concerns needs to be addressed at the European level to assure the person's ownership of the data. *[WP4.14]*

ALCOVE RECOMMENDATIONS FOR DEMENTIA DIAGNOSIS

[1] **Fundamental principles: The diagnosis of dementia should be person-centred and actions associated with it should be based on the following principles** *[WP5.1]*

Timely diagnosis of dementia should be available to all citizens who require it **and accessible** to all sections of the community at a stage when people first notice changes in cognitive function; *[WP5.1.1]*

Decreasing fear and stigma about dementia are necessary pre-cursors for increasing the numbers of people coming forward for diagnosis; *[WP5.1.2]*

The **rights and wishes** of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis; *[WP5.1.3]*

Giving and receiving a **diagnosis of dementia is a key intervention** in the complex adjustment process to living with dementia. The needs of **the person and their family/significant others** are central to assessment, diagnosis and post-diagnostic interventions. *[WP5.1.4]*

[2] Case finding can be an effective process to identify people to Increase diagnosis in circumstances where there are services available that will benefit the person and their family *[WP5.2]*

Targeted or opportunistic case finding within primary care, acute hospitals or care homes should be undertaken and steps taken to ensure that services and support are available to bring benefit to the person and his or her family. *[WP5.2.1]*

General population screening is not recommended until there is better evidence of the reliability of screening alongside ways of preventing or delaying dementia. *[WP5.2.2]*

[3] The diagnostic process should support positive adjustment, provide an evidence based assessment and enable care planning to take place following diagnosis *[WP5.3]*

The diagnostic process is managed in a way that supports good adjustment to the news. This includes:
- The provision of pre-assessment counselling which should address:
    - Provision of information concerning the diagnostic assessment process;
    - Possible outcomes of the assessment process;
    - Promoting rights to choose and control whether to go forward for diagnosis.
- Who should be present for diagnostic feedback and where it should take place;
- What interventions can be offered following diagnosis;
- A sensitively delivered process of disclosure of the diagnosis;
- The provision of information and interventions post diagnosis. *[WP5.3.1]*

Timely diagnosis covers a sequence of four stages, each of which may be delivered by any properly trained professional but needs to be coordinated at the individual patient level:
- Initial detection of cognitive difficulties and other symptoms indicative of dementia;
- Assessment to decide whether symptoms are due to dementia or not;
- If dementia is present, to achieve diagnosis of the cause and relevant co-morbidities;
- Care planning to address current and future needs. *[WP5.3.2]*

Recent clinical criteria for diagnosis of dementia syndrome and its subtypes are used in clinical practice, recognising that this is a changing area and that further validation and revisions will occur. *[WP5.3.3]*

Systems need to be in place so that professionals stay up to date with the clinical criteria for diagnosis. *[WP5.3.4]*

Biomarkers (Cerebrospinal Fluid and functional neuro-imaging) are recommended only for use in research centres and not in general clinical practice. *[WP5.3.5]*

[4] Diagnosis of complex presentation of dementia is made in as timely a fashion as for simple cases *[WP5.4]*

Particular skills are required where people have a young age of onset, have pre-existing health difficulties or intellectual disability. *[WP5.4.1]*

In these situations case finding, **assessment processes and interventions** are utilised that are relevant to the particular needs of the population. *[WP5.4.2]*

[5] A consensus is required on how early cognitive changes at time point 2 (currently known as Mild Cognitive Impairment MCI) are to be responded to in clinical practice *[WP5.5]*

Proposed changes to diagnostic classifications, should clarify how early cognitive changes are defined and responded to in clinical practice. At the present time, the label MCI is, from the public health point of view, a research categories area. *[WP5.5.1]*

When people are informed that they have early cognitive changes, advice and support should be given alongside clear systems for monitoring and follow up. *[WP5.5.2]*

[6] Workforce development is required across all levels to facilitate timely detection, evidence based assessment and diagnosis and to facilitate good adjustment *[WP5.6]*

When planning national strategies for dementia, workforce and service development issues are taken into account. *[WP5.6.1]*

Family doctors and their colleagues working in Primary Care, Care Homes and Acute General Hospitals should receive education and learning, and evidence based decision support toolkits to assist them in their role in detection of dementia. *[WP5.6.2]*

Systems are developed to support detection at an early stage by family doctors including shared care with specialists, guidelines in detection, education and case management. *[WP5.6.3]*

Specialist services at the secondary level can improve timely diagnosis to good effect but there are challenges to implementing this model where there is a lack of specialist expertise and a dispersed rural population. *[WP5.6.4]*

Workforce development strategies are in place for the wide range of health, social care and community staff involved to enable these staff to facilitate good adjustment in those receiving a diagnosis and their families. *[WP5.6.5]*

ALCOVE RECOMMENDATIONS FOR A GLOBAL STRATEGY FOR BPSD* SUPPORT SYSTEMS

* Behavioural & Psychological Symptoms of Dementia

Recommendations on fundamental principles for a global strategy for BPSD

[1] **Because BPSD are sources of family carer burden and depression, as well as an increased rate of institutionalisation of persons living with dementia, all nations should develop a 3-dimensional holistic strategy**:
1st dimension: how to develop structures and care organisations - SCO - for BPSD,
2nd dimension: how to implement individualised patient & family carers interventions - IPCI - combining psychosocial interventions for carer and patient and non pharmacological and pharmacological therapies for patient,
3rd dimension: how to ensure a skilled workforce - WFS - with systematic education programmes for health & social professionals. *[WP6.1]*

[2] **These 3 dimensions of BPSD Support Systems should be adapted and implemented at each step of the patient pathway**: for the prevention and management of minor BPSD, for major BPSD crisis events and for the post crisis phase including secondary prevention. These implementations should be designed with close cooperation between decision makers, health and social services, and professionals and patient and family associations. *[WP6.2]*

[3] **Public information on BPSD prevention and management and about antipsychotics' risks should be part of general awareness campaigns for decreasing fear and stigma about dementia.** *[WP6.3]*

[4] **A multidisciplinary approach in all dimensions of Support Systems for BPSD should be promoted.** *[WP6.4]*

Recommendations on Structures and Care Organisations (SCO) for BPSD

[1] **Ambulatory SCO for persons experiencing BPSD should be developed, because it is crucial to prevent and manage BPSD at an early stage**. This will enhance the person's possibilities to live at home as long as possible. *[WP6.5]*

Mobile teams with specific skills for the caring of BPSD, both in the home and nursing home setting. For instance, specific mobile teams dedicated to BPSD in high population density areas and specific competencies within geriatric mobile teams in low population density areas. *[WP6.5.1]*

Semi-urgent consultation for BPSD (delay < 1 week): at the hospital or via telemedicine, the aim being to respond quite rapidly to behavioural disorders so as to prevent emergency hospitalisation. Different specialists, such as neurologists, geriatricians or psychiatrists could perform such a medical consultation. A multidisciplinary approach involving specialised nurses and psychologists as well as providing telephone support to the person and/or his or her carers may be also useful. *[WP6.5.2]*

Respite care possibilities are necessary because it appears crucial to help informal carers by giving them a break from caring for the person when needed. This would serve to prevent psychological and physical carer exhaustion. Literature analysis shows that good carer health can prevent BPSD. Respite care possibilities include day care centres and temporary accommodations for the person living with dementia, and home professionals to support the carer. *[WP6.5.3]*

[2] **Dedicated units for BPSD in Nursing homes and Hospitals should be developed** because the development of this kind of nursing or hospitalisation unit has already shown to be of dramatic help for people experiencing major BPSD in several European countries. *[WP6.6]*

[3] **A shared medical and social patient file as an optimal tool, key to an indispensable multidisciplinary approach, should be promoted,** because for high care efficiency it appears important to rapidly share medico-social, clinical, diagnosis, psychological, behaviour data regarding the person and the main carer. A shared file would need to be kept up to date all throughout the patient care path. *[WP6.7]*

A multidisciplinary approach should be adopted at each structural level (nursing home, dedicated unit for BPSD, mobile team) and at the patient-centred pathway level (general practitioner, other physicians, case manager, therapist, social workers etc.). A specialised nurse-led multidisciplinary team including psychomotor therapists and occupational therapists has been shown to be beneficial in the prevention and care of minor BPSD in people with dementia living at home. As concerns more severe BPSD, the intervention of a medical doctor and a psychologist would be useful in preventing emergency hospitalisation. *[WP6.7.1]*

Consider specific skills key to caring for young people living with dementia in SCO, given their specific needs and those of their families. *[WP6.7.2]*

[4] **Quality and impact indicators for persons experiencing BPSD, family carers and professional carers should be collected** because it is crucial in daily practice to assure and monitor the quality of care within the different SCO. To set up new SCO for research purposes and in order to guarantee the usefulness of SCO in the real world, it is necessary to follow impact indicators which also target professional carers. *[WP6.8]*

Recommendations on Individualised Patient and Family Carer Interventions (IPCI) for BPSD

[1] **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.** This is because PSI are effective on behavioural disorders (agitation, aggression, disruption, shadowing, depression, and repetitive behaviours other than psychosis) and safer than antipsychotics. More precise evaluations of PSI combined with non pharmacological therapies for the patient should first be performed to identify which combination strategy is most effective and should also be evaluated in medical-economic terms. *[WP6.9]*

Psycho-educational programmes must be part of national programmes for dementia. This is because among PSI, Psycho-educational programmes are effective in preventing BPSD and they are easy to implement. Increased effectiveness has been shown with the use of a theoretical model and with the active participation of the carer. *[WP6.9.1]*

Multicomponent interventions could also be part of national programmes, because among PSI, multicomponent interventions (tailored to the needs of family carers and people living with dementia, with periodic follow-up and home-delivered) are the most effective option. They are effective for patient and carer outcomes and delay institutionalisation. However, they require coordination between community and specialised settings and are much more difficult to implement. *[WP6.9.2]*

[2] **All Psychosocial Interventions 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, because the dynamics in their relationship can be a source of BPSD, and therefore, key to BPSD management. Their needs must be assessed with the use of medical and social expertise. This includes researching contributing factors for the patient and assessing carer burden, stress, quality of life and self confidence. Because both pharmacological and non pharmacological treatments may have adverse effects, because the status of both the care recipients and their carers may change, and because carers often need emotional support, the continuity of care and of support must be ensured. *[WP6.10]*

[3] **A diagnosis approach & multiple therapies for BPSD should be applied at the patient level** - Evidence of managing BPSD in terms of individualised patient interventions should include 1) appropriate treatment of the disease index and in relevant cases: 2) research and treatment of the concomitant diseases and their symptoms (e.g. pain, balance, incontinence) combined with specific approaches for BPSD 3) non pharmacological and 4) pharmacological. *[WP6.11]*

Recommendations on Workforce & Skills (WFS) for BPSD

[1] **Access to education on BPSD has been shown to be necessary for carers, whether they are professionals or not.** Alarmingly, little information was available in the research literature on the impact of teaching BPSD at the basic level, e.g. in nursing schools or schools for other professionals. However, any teaching of care professionals seemed beneficial. *[WP6.12]*

[2] **Homogeneous guidelines on BPSD management and the side effects of antipsychotics should be disseminated.** Of the European Member States, 63% had national guidelines for dementia. However, only six guidelines addressed BPSD. However, it is important to keep in mind that not all BPSD affect the person living with dementia negatively and each person has different symptoms and needs. Therefore the guidelines should address the necessity of meeting both the care recipient's and the carer's needs with multicomponent and individually tailored programmes after having thoroughly and systematically assessed these needs. *[WP6.13]*

[3] **Quality and safety programmes focused on the limitation of antipsychotics are beneficial and complementary to the better management of BPSD in dementia.** The ALCOVE Toolbox provides tools and recommendations based on ALCOVE's European benchmarking. Quality improvements must address 4 key points: relevant references and systematic prescription reviews; public campaigns to raise awareness about antipsychotics risks and to inform about BPSD care; measurement and monitoring using relevant indicators at the national and local levels; collaborative approach with the involvement of all stakeholders. *[WP6.14]*

ALCOVE RECOMMENDATIONS FOR RIGHTS, AUTONOMY & DIGNITY OF PEOPLE WITH DEMENTIA

Recommendations on Competence Assessment for people living with dementia

[1] **A person diagnosed with dementia should not automatically be considered incompetent to exercise her/his right to self-determination.** Presumption of competence needs to be guaranteed for people living with dementia during the course of their disease. *[WP7.1]*

[2] **When the person living with dementia is not able to decide alone, the selected healthcare proxy should be involved.** Only when the person with dementia no longer has capacity for decision-making, the proxy and the treating healthcare professional should rely on the advance directive (if present) or the person's past values and critical interest. *[WP7.2]*

[3] **Competence needs to be assessed on the basis of a case-by-case approach and should be repeated for every important care or treatment decision.** *[WP7.3]*

[4] **When assessing the competence of a person, contextual factors need to be taken into account including medical, psychological and social factors.** *[WP7.4]*

[5] **Whether a person is competent to make a decision regarding care and treatment needs to be assessed by a qualified and skilled healthcare professional.** In many cases but not all, this will be the treating physician. However, this person should not decide alone in all cases and situations. If deemed appropriate, he or she needs to take into account the opinion of others (doctors, proxies or relatives, nurses, social workers, psychologists, etc.). *[WP7.5]*

[6] **Additional research on the development and validation of efficient and practical assessment tools are needed, especially for people with a progressive cognitive condition like dementia.** *[WP7.6]*

Recommendations on Advance Directives for people living with dementia

Contextual provisions of Advance Directives for people living with dementia:

[1] **Advance directives should be part of the broader context of advance care planning.** An advance directive is a means to provide high quality care in line with the wishes and will of the person living with dementia, and not a goal in itself or an end product of advance care planning. It is an opportunity for starting and maintaining a process of communication between the people living with dementia and her/his caregivers. *[WP7.7]*

[2] **National authorities are encouraged to provide a legal framework on advance directives adapted to the specific needs of people living with dementia.** *[WP7.8]*

[3] Proper models and good practices specifically oriented towards people living with dementia need to be implemented, further developed and disseminated, because all stakeholders – patients, relatives, informal and formal caregivers, healthcare policy organisations, etc… - have to be made aware of the specificities and complexity regarding advance care planning and advanced directives for people living with dementia. *[WP7.9]*

[4] The person's current attitude towards a certain treatment or a care intervention - ascertained feelings, desires and wishes - should always be taken into account, even if there is an advance directive or a designated proxy, since there can be major changes in values and preferences between the time when persons complete their advance directive and when it comes into effect. *[WP7.10]*

[5] Although the use of advance directives should be promoted, nobody can be forced to make up an advance directive. If a person does not want to address issues about future care and treatment or end-of-life her/himself, this needs to be respected. *[WP7.11]*

[6] Doctors and other healthcare professionals involved in the care of people living with dementia should be properly trained in advance care planning and the use of advance directives. *[WP7.12]*

[7] In order for advance directives to be sufficiently widely used and known, the costs for drafting up and registering these directives should be minimal for the people living with dementia. *[WP7.13]*

Content of Advance Directives for persons living with dementia:

[8] People should be encouraged to designate a healthcare proxy in their advance directives. This proxy represents the person living with dementia in making decisions on medical and care matters when the person is no longer competent to make these decisions. A healthcare proxy should be aware of the wishes, beliefs, values, preferences and decisions of the person he or she is representing, therefore communication and deliberation between this person and the proxy is indispensable. *[WP7.14]*

[9] Advance directives are preferably accompanied by a personal statement of values containing information about what is important and meaningful in the life of the person who has drawn up the directive. *[WP7.15]*

[10] The refusal of a specific treatment expressed in an advance directive is prima facie legally binding and should consequently be respected. *[WP7.16]*

[11] With regard to a request for a treatment in an advance directive, a healthcare professional should take this request into account, in so far as this treatment accords to professional standards. *[WP7.17]*

Validity and applicability of Advance Directives for people living with dementia:

[12] It is important to advise persons living with dementia on the possibilities of advance care planning and the use of advance directives whilst they still have the necessary competence and mental capacities to make use of them. Therefore, the importance of a timely and disclosed diagnosis needs to be underlined. Nevertheless, a sensitive approach is necessary, taking into consideration that not all persons are prepared to decide about their future. *[WP7.18]*

[13] In the context of high quality care, advance directives should be integrated in all relevant patient and care records with maximal respect of privacy and confidentiality. *[WP7.19]*

EPIDEMIOLOGICAL DATA ON DEMENTIA

EPIDEMIOLOGICAL DATA ON DEMENTIA

Dr Galeotti, Francesca; Dr Giusti, Angela; Dr Meduri, Francesca; Dr Raschetti, Roberto; Dr Scardetta, Paola; Professor Dr Vanacore, Nicola;
National Institute of Health, Italy

** Behavioural & Psychological Symptoms of Dementia*

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ALCOVE COLLABORATIVE PARTNERS: Armelle Leperre Desplanques; Nathalie Riolacci-Dhoyen; Maggie Galbraith; Christine Barr - Haute Autorite de Santé (HAS), France; Tomás López-Peña Ordoñez, Carlos Segovia, Mercedes Garcia Garcia - Institudo de Salud Carlos III (ISCIII), Spain; Michal Novak; Rostislav Skrabana; Martina Jezovicova, Slovenska Akademia Vied - Neuroimmunologicky Ustav (NIU SAV), Slovakia.

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Method, questionnaires and analysis are developed in the WP4 Report: Epidemiological data on dementia – www.alcove-project.eu

The aim of this chapter is to improve epidemiological data on Alzheimer's disease and other dementias with an overview of available data and the definition of best practices for data collection. In particular, the following topics will be addressed:

- **A systematic review of prevalence rates for dementia** in Europe using the same criteria adopted by the Eurocode systematic review as published on their website.
- **An evaluation of studies published in peer-reviewed journals on the exposure to antipsychotics in people living with dementia in Europe**; the development of a questionnaire for the identification of available data on psychotropic drug (antidepressants, antipsychotics, benzodiazepines) prescriptions in dementia in European countries.
- **A description of the possibility of identifying subjects with a clinical diagnosis of dementia exposed to psychotropic drugs in European countries**. In particular, a survey has been conducted using a current administrative database, with the general aim of describing psychotropic drug use in people living with dementia, with a particular emphasis on the use of antipsychotic and antidepressant drugs in people with Alzheimer's disease and related dementia (AD). These specific objectives are:
    - ➢ describing the characteristics of antipsychotic and antidepressant drug use in people living with AD;
    - ➢ comparing the characteristics of antipsychotic and antidepressant drug use in people with and without a diagnosis of AD;
    - ➢ describing the characteristics of antipsychotic and antidepressant drug use in people with dementia who are identified in different settings. A descriptive observational study conducted in 2011 on the population of the Umbria Region in Italy aged ≥65 has been included as a case study.
- **A questionnaire on National Programmes and the organisation of health and social services dedicated to dementia in Europe.** A further objective was to evaluate the possibility of obtaining data on health and social services dedicated to dementia in European countries.

PREVALENCE RATE FOR DEMENTIA

METHOD

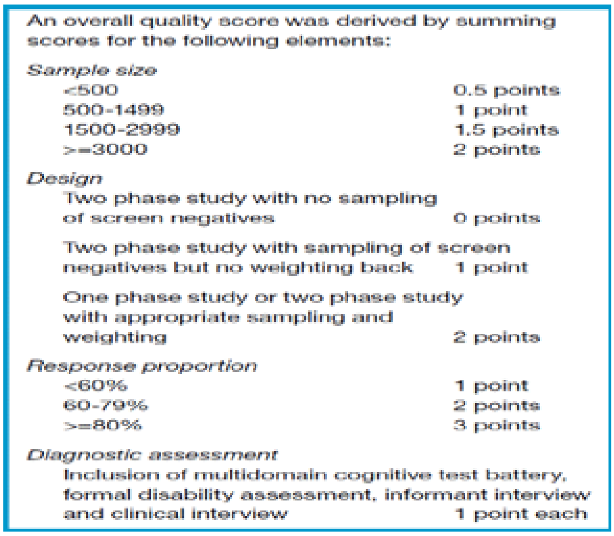
- **Literature review:** We performed a systematic review on prevalence rates for dementia in Europe using the same terms adopted by the Eurocode systematic review as reported on their website (http://www.alzheimer-europe.org/Alzheimer-Europe/Our-work/Completed-AE-projects/2006-2008-EuroCoDein). We covered reports published in the period spanning January 1st, 2008 to September 15th 2011, and used the terms both as MeSH terms and as free text in the title and abstract for the most recent articles.

  We identified 1,097 records. Subsequently, we acquired the full text of 14 articles [1-14]. These included data extraction tables with the following ten pieces of information: authors, country, period, procedures for identification of subjects (one or two phases), clinical criteria adopted, age-classes, number of subjects, number of patients, prevalence rate, participation rate. Moreover, we acquired the full text of 17 articles [15-31] included in Eurocode in order to identify the clinical criteria adopted for the diagnosis of dementia and to make a comparison with the same criteria reported in the 14 papers included in ALCOVE. To define the best practices for the collection of epidemiological data, we acquired three papers [32-34] as well as the Alzheimer's Disease International World Alzheimer Report so that we could summarise the scientific discussion on this issue [35].

  In this systematic review we identified the following principal characteristics that influence the quality and the variability of prevalence studies in dementia:
    - ➢ Sample size (a)
    - ➢ Design (b)
    - ➢ Response proportion (c)
    - ➢ Diagnostic assessment (d)
    - ➢ Clinical criteria adopted (e)

  The items from a. to d. were proposed by Alzheimer Disease International in 2009 [35] and an overall quality score was calculated (Table 1)(range 0-11), while item e. was proposed in the paper by Erkinjuntti et al 1997 [32].

Table 1. The quality score proposed by ADI, 2009 [35]



An overall quality score was derived by summing scores for the following elements:

Sample size	
<500	0.5 points
500-1499	1 point
1500-2999	1.5 points
>=3000	2 points
Design	
Two phase study with no sampling of screen negatives	0 points
Two phase study with sampling of screen negatives but no weighting back	1 point
One phase study or two phase study with appropriate sampling and weighting	2 points
Response proportion	
<60%	1 point
60-79%	2 points
>=80%	3 points
Diagnostic assessment	
Inclusion of multidomain cognitive test battery, formal disability assessment, informant interview and clinical interview	1 point each

This article shows a difference of about 10 times the estimated prevalence rates of dementia in the Canadian population aged 65 years or older, passing from the application of ICD 10 criteria (prevalence rate of 3.1 per 100 inhabitants) to those of DSM III (prevalence rate of 29.1 per 100 inhabitants)[32]. Out of the 14 studies identified by ALCOVE, two [5,8] have been excluded because the first was a review and the second focused on the epidemiology of young onset dementia (45-64 yrs).

RESULTS

- **Prevalence rate for dementia:** In the final assessment we included all Eurocode (n = 3)[21,27,29] and ALCOVE (n = 10)[2-4;6,7;9-11;13;-14] studies which adopted the clinical criteria of DSM IV (Figure 1). The mean quality score of all the studies (n= 13) that adopted DSM IV criteria was 6,85±1,93 (range 4,50-10,50, median 7). We included all Eurocode (n=3[21,27,29] and ALCOVE (n=4)[3,4,10,13] studies which adopted the DSM IV clinical criteria and had a quality score of ≥7 (median value of distribution) in the pooled analysis. In this phase we could not include the Lucca and Fish studies [3,13] because the raw data for age and sex were not supplied by the authors. **Estimates made using the highest quality studies included in Eurocode and the ALCOVE project that have adopted DSM IV clinical criteria showed a mean decrease of 22.1% in the total rate for dementia compared to Eurocode review estimates and a mean decrease of 12.2% in the total rate for dementia compared to ALCOVE review estimates (Table 2).** There was no statistically significant difference in quality score between the studies included in the ALCOVE and Eurocode projects. Therefore, most of the observed variability in epidemiological studies conducted on dementia in Europe is attributable primarily to the different clinical criteria adopted (DSM-IV versus DSM III and IIIR)[32].

Firure 1. Prevalence rate for dementia: Review estimates from a pooled analysis of the high quality studies from Eurocode & ALCOVE according to Eurostat population 2011

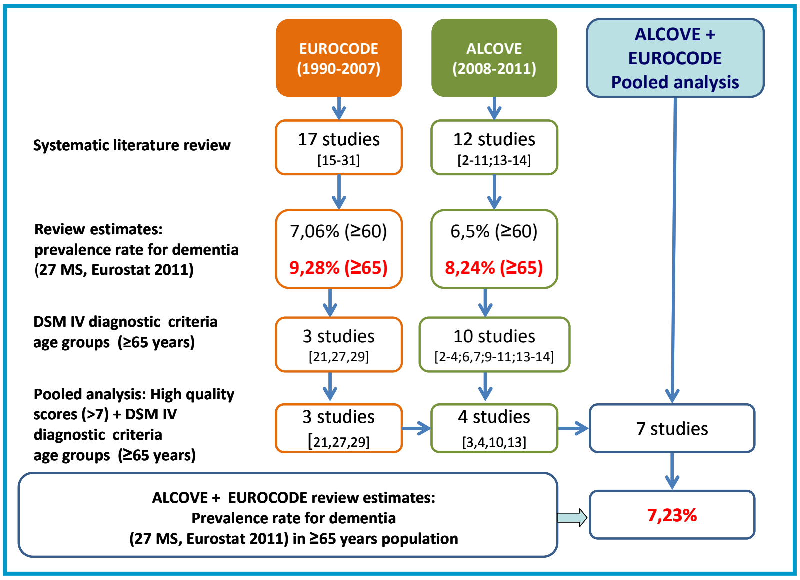


Table 2. The comparison between total prevalence rate and number of total estimated cases with dementia in relation to different projects (age > 65 yrs) (Eurostat 2011)(EU 27 countries)

	Total rate	CI 95 total rate	Pop. Eurostat 2011	Estimated total cases	CI 95% total cases
EUROCODE	9,28	8,95-9,61	88.074.340	8.175.204	7882653-8463944
ALCOVE	8,24	7,73-8,74	88.074.340	7.261.690	6808146-7697697
The high quality studies	7,23	6.74-7,72	88.074.340	6.367.526	5936210-6799339

RECOMMENDATIONS

- **Recommendations to improve data collection on estimates of dementia prevalence in Europe**

  [1] **Future studies on dementia prevalence should be performed using the highest quality epidemiological studies as defined in the 2009 ADI report** (Sample size: ≥3000 subjects; Design: One phase study or two phase study with appropriate sampling and weighting; Response proportion≥ 80%; Diagnostic assessment with Inclusion of multi-domain cognitive test battery, formal disability assessment, informant interview and clinical interview).

  [2] **Epidemiological studies on dementia using the DSM IV and NINCDS-ADRDA clinical criteria for dementia and Alzheimer's disease should be promoted. These clinical criteria are the only ones that have been validated with post-mortem data.**

  [3] **At the same time, dementia prevalence and incidence studies using the new clinical criteria of the National Institute on Aging and the Alzheimer's Association should be performed to promote new knowledge in this area [62].**

  [4] **Prevalence and incidence studies on people living with dementia aged ≤65 years should be promoted to define dementia frequency.**

  [5] **Studies in the same areas over different decades should be carried out to intercept any phenomenon of dementia decline as speculated by some evidence of literature.**

EXPOSURE TO ANTIPSYCHOTICS IN PEOPLE LIVING WITH DEMENTIA IN EUROPE

METHOD

- **Literature review for prevalence use of antipsychotics:** A survey of most of the studies on exposure to antipsychotics in people living with dementia in Europe published during the period of January 1994 to December 2010 in peer-reviewed journals was performed using the Pubmed site.

  Only studies that used large databases and assessed the proportion of drug use as one of their primary aims were considered. The literature search was divided into general population (community setting), specialist centres (memory units or hospitals), and residential care (nursing home). For this specific aim 26 articles were identified [36-61].

- **The Umbria survey study:** The study population and eligibility criteria for the identification of subjects with AD were defined.

  Two procedures were used to identify people with AD.

  - The first one (in the following AchE-I cohort) was based on the prescription of acetylcholinesterase inhibitors as a marker of the disease: all people who received at least one prescription of AchE-I during 2011 in the Umbria region were identified.
  - The second cohort included all people who were hospitalised during 2011 in the Umbria region and who were discharged with a diagnosis (either main or secondary diagnosis) of dementia. Discharge diagnoses were further characterised as AD and other dementia on the basis of the information recorded in the hospital discharge papers (SDO: scheda dimissione ospedaliera).

  As exclusion criteria, all patients aged <65 years and those residing outside the Umbria region were excluded. In order to compare the prescription of antipsychotics and antidepressants in people with and without AD (comparison cohort), each subject identified as a user of AchE-I was matched by age, sex and local health unit (LHU) with a resident of the Umbria region (in the following elderly cohort). Given the inclusion criteria in the AchE-I cohort, no subject in the elderly cohort received any prescription of AchE-I in 2011. The potential confounding effect of age and sex was taken into account by matching each subject with a diagnosis of dementia to a resident of the Umbria region.

The AchE-I cohort was described in terms of substance, age, and sex. The following age classes were used: 65-69; 70-74; 75-79; 80-84; 85-89; ≥ 90. The description of drug use was given in terms of prevalence of use and number of doses. The Defined Daily Doses (DDDs) were adopted, which indicate the average dose of drug prescribed to an adult for the main indication of the drug.

The indicators are defined as follows:

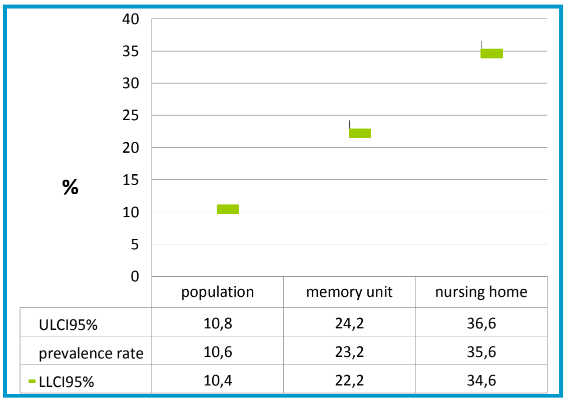
- Prevalence of use: proportion of inhabitants who received at least one drug prescription during the study period;
- DDD/1000 inhabitants die: number of DDDs per 1000 inhabitants per day;
- DDD per user: number of DDDs per user (inhabitants who received at least one drug prescription during the study period). This indicator shows the average duration of therapy by user.

- **The European questionnaire survey:** In addition to the literature review, a questionnaire was developed to identify available data on psychotropic drug (antidepressants, antipsychotics, benzodiazepines) prescriptions in people living with dementia in European countries. The questionnaire comprised seven questions which aimed to understand the use of antipsychotic medications by people living with dementia by using available information about medicine. It is necessary to consider that in this context cholinesterase inhibitors and memantine represent categories of disease-tracking drugs. However, only a fraction of people living with dementia takes drugs, especially in the early stages of the disease.

RESULTS

- **Prevalence use on antipsychotics:** A cumulative analysis estimate gave a 10.6% prevalence rate for antipsychotics use in the general elderly population with the range of values extending from 5.7% (France)[60] to 32.5% (Finland)[41]. The prevalence rate for antipsychotic use included 12.7% (Italy)[51] - detected in an Alzheimer's evaluation unit and 46.7% (UK)[42]- detected in a hospital setting with a cumulative estimate of 23.2%. Lastly, the cumulative analysis detected an estimated 35.6% prevalence rate for antipsychotic drug use in people living with dementia residing in nursing homes, with a range of values between 25.8% (Norway)[55] and 60% (Italy)[50]. A summary is reported in Figure 2.

Figure 2. The prevalence rate of antipsychotics use per setting in people living with dementia (Europe 1994-2010)



	population	memory unit	nursing home
ULCI95%	10,8	24,2	36,6
prevalence rate	10,6	23,2	35,6
🟩 LLCI95%	10,4	22,2	34,6

- **We can identify three current campaigns conducted in the UK, Sweden, and France for the reduction of exposure to antipsychotics in the population living with dementia.** Here is a brief summary of three actions: a) Pilot actions are being performed for antipsychotic risk reduction in people living with dementia in Sweden. Preliminary analysis shows a reduction of the mean NPI score & of the antipsychotic medication in favour of the use of analgesics and non-pharmacological interventions; b) The UK 2012 Audit. Antipsychotic prescriptions for people living with dementia have been reduced by 52% in three years, according to an audit carried out by the NHS Information Centre. The audit collected data from more than 3,800 GP practices in England and this provided information about nearly 197,000 people living with dementia. The 52% reduction took place between 2008 and 2011. It was also found that there were strong regional variations, with the rates for the prescribing of antipsychotic drugs up to six times higher in some areas than others; c) The French National Authority for Health created a national task force which sought to establish and monitor the rate of exposure to antipsychotics (AP) and other psychotropic drugs (PD) in people living with AD in France. The measurement of long-term AP and PD prescriptions was performed using the three national insurance databases from 2007 to 2010, for people over 65 (n= 9,984,693 in 2007; n= 10,609,439 in 2010) and for people over 65 with AD identified by coverage for specific treatments and chronic conditions (n= 385,070 in 2007; 437,583 in 2010). Three age categories were studied: 65-74; 75-84 and 85+. The lists of AP and PD were defined by the task force and updated each year. In 2007, persons with AD had an exposure rate to AP which was 5.8 times higher (16.9%) than that of the general elderly population (2.9%). Exposure in younger AD patients (aged 65-74) was even higher (19%). The rate of AP exposure in persons with AD decreased from 16.9% to 15.5% in 2010, with a similar trend observed in the three age categories and in the three different insurance databases. (see also p. 67)

- **The Umbria survey study:** In Italy, in 2011, the prescription of AchE-I was slightly greater than 2 DDD/1000 inhabitants die; the corresponding prescription of antipsychotics and antidepressant was 9 and 41 DDD/1000 inhabitants die respectively. For the three classes of drugs an increase in the level of use was observed between 2008 and 2011. In particular with regard to AchE-I, the increase was greater than 30% over the four year period, with a CAGR (Compounded Annual Growth Rate) of 8.9%.

  Through the Umbria region prescription monitoring system, 4,018 subjects who received at least one prescription of AchE-I during 2011 were identified. Out of these, 255 were excluded: 135 subjects were younger than 65 and 120 did not reside in Umbria (i.e. had an individual postal code not compatible with a resident of the Umbria region). The final analysis was conducted on 3,763 (93.6%) patients (AchE-I cohort).

  Within the elderly population (≥65 years) of the Umbria region, 1.8% received at least one prescription of AchE-I in 2011. The analysis by age and sex indicated that the prevalence of use increases with age, from around 0.3% in the age range 65-69 years to 3.5% between the 80-84 age group. The increase appears to be greater among older women: in the 80-84 age range the prevalence in the female population was almost 4%. The decrease in prevalence observed in subjects older than 90 is most likely attributable to a greater proportion of institutionalisation in people with AD in this age group (as indicated in the method section, no data is available on these people). Among users of AchE-I, 26% also received a prescription of antipsychotics and 56.5% a prescription of antidepressants. The corresponding figures among the elderly cohort were 3.7% and 20.6%. Thus, the use of antipsychotics was seven times greater in the AchE-I than in the elderly cohort and almost three times greater for antidepressants (Table 3).

Table 3. Use of antipsychotics and antidepressant drugs in the AchE-I and elderly cohorts (Umbria 2011)

Cohort	Antipsychotics		Antidepressants	
	N	%*	N	%*
AchE-I cohort	979	**26.0**	2,125	**56.5**
Elderly cohort	138	**3.7**	776	**20.6**

* Prevalence of users in each cohort (N=3,763)

- **The European questionnaire survey:** The principal findings of the questionnaire on psychotropic drugs (including AchE-I) showed that the medications prescribed are paid for in full by the National Health System in nine countries (Finland, France, Greece, Luxembourg, Malta, Norway, Slovakia, Spain, Sweden) and partially in nine other countries (Belgium, Cyprus, Czech Republic, Estonia, Italy, Latvia, Lithuania, Finland, Norway). Two countries (Finland and Norway) have provided mixed responses on payment system characteristics for these medications.

RECOMMENDATIONS

- **Recommendations for the improvement of data collection on antipsychotics in dementia**

  [1] **Prospective and systematic collection data on people living with dementia in specific settings (community, home care, memory clinic, nursing home) in all Member States is urgently necessary**

  [2] **A list of antipsychotics used in each Member States should be compiled, underlining the off-label use for the specific drug contained therein.**

  [3] **The collection of data on the use of antipsychotics in people living with dementia should be characterised to allow for prescription analysis (notably, as appropriate or inappropriate).**

[4] **Information on the use of antipsychotics in conjunction with other quality indicators (e.g., physical restraints used in nursing home residents with severe dementia) must be gathered.**

[5] **A European database on the use of antipsychotics in people living with dementia should be implemented.** Such a database would be used to monitor antipsychotic prescriptions in Member States and to assess the efficacy of national programmes for antipsychotic use risk reduction.

HEALTH & SOCIAL SERVICES & DATA SOURCES FOR DEMENTIA

METHOD

- **ALCOVE European surveys:** Between January and March 2012, the Work Packgage 4 team developed three other questionnaires. These were shared with the ALCOVE Associated Partners and modified subsequent to receiving their feedback. The first questionnaire "Q1 - Available data on health and social services dedicated to dementia, National Contact List" had the objective of obtaining a list of available data sources and the key holders of information in the different countries involved in the survey. The second questionnaire "Q2 - National programmes on organisation of health and social care services dedicated to dementia" was designed to describe and compare the National Programmes and services for people living with dementia. This questionnaire took variables described in key documents into consideration, including specific national plans and strategies for the care of people living with dementia as available in grey literature. The third questionnaire "Q3 - Available data on health and social services dedicated to dementia" was designed to describe different data sources, their possible use for dementia study purposes, their strengths and weaknesses and suggestions to improve the data collection system. All questionnaires were administered between March and September 2012. Although initially the study design included only Associated and Collaborative Partners, the investigation was subsequently extended to all European Member States willing to participate. The key holders of information were then contacted through the ALCOVE network relationships. All questionnaires were sent via email and self-administered. The team performed a quali-quantitative analysis for all variables, including free commentaries.

RESULTS

- **General analysis:** A total of 28 Countries participated in the survey, of which 11 ALCOVE Associated Partners, 8 ALCOVE Collaborative Partners and 9 other Member States, 8 Associated Partners and 9 Member States. We received 18 completed questionnaires for Q1 (National contacts), 24 for Q2 (National Programmes) and 23 for Q3 (Data sources). Note that the 11 ALCOVE Associated Partners completed 14 questionnaires in total as Belgium completed two, one each for the Flanders and Wallonia Regions, and the UK completed three, one each for England, Wales, and Northern Ireland.

  As pertains to the national programmes concerning the organisation of health and social care services dedicated to dementia the key question was “In your Country, is there a National Programmes (NP) or any written national policy on dementia health and social care services organisation?”. Table 4 shows the distribution by country. Out of 24 respondents, 11 have a NP, 5 will have one in the short term, while 8 do not have any specific plan dedicated to dementia. National Programmes have been delivered since 2007. In some cases, such as in Finland, their 2012-2020 national programme "Creating a memory-friendly Finland", provides for the implementation of a programme which will be coordinated with ongoing legislative initiatives and other national programmes despite not including all of the aspects analysed in the questionnaire

  Within the existing (11) and expected (5) NP, 5 are stand alone plans, 5 are included within the context of broader plans or policies (i.e. National Health Plan, national guidelines for chronic diseases care, mental health plans). In the Flanders Community in Belgium there are both a stand alone plan and a broader programme including policies for dementia. While the 11 respondents with an implemented NP answered all questions, respondents with NP that are in the works answered partially. For this reason, the variables described below will have different denominators.

  As for existing programmes or policies on dementia care service at the sub-national level, in 3/12 cases (Netherlands, Wales, Czech Republic) there are other programmes depending on the national level. In 3/12 cases (the Walloon Region of Belgium, Finland, Italy) there are independent programmes at the sub-national level while in 4/12 cases the sub-national programmes are partially dependent on the national level (the Flanders Region of Belgium, France, Norway, Sweden). England and Northern Ireland do not have additional programmes at the sub-national level, although individual regions are responsible for how they deliver health and social care locally.

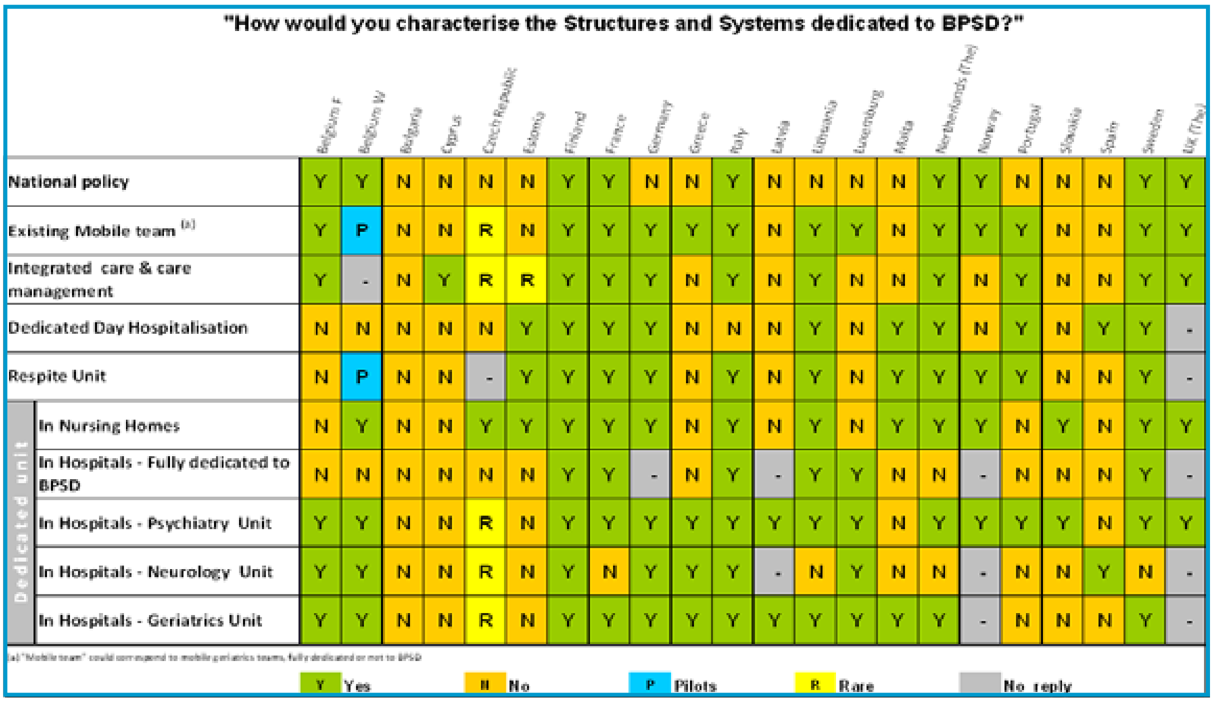
Most of the NP (10/13) were established based on the available national data. In 2/13 cases they were only partially based on national data and in 1/13 cases, the NP were not based on national data.

Table 4. Countries with a National Programme on Dementia

	Belgium Fl	Belgium Wa	Bulgaria	Cyprus	Czech Republic	Estonia	Finland	France	Germany	Greece	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Portugal	Slovakia	Spain	Sweden	UK England	UK North Ireland	UK Wales
Yes	■	■					■	■			■					■	■				■	■	■	■
No			■			■				■		■	■					■	■	■				

- **Structures and Systems dedicated to BPSD**[*]**:** The last section of the questionnaire is dedicated to the characterisation of the structures and systems dedicated to BPSD. The analysed variables are the presence (Y/N) and the estimated general population coverage of mobile teams (mental health, geriatrics, multi disciplinary, etc), integrated care and case management, day hospitalization dedicated to BPSD, respite units, dedicated units in Nursing Homes, dedicated units in hospitals (fully dedicated to BPSD-AD, psychiatry unit, neurology unit, geriatrics unit). Table 5 shows the distribution of the different services. Given the internal heterogeneity of every country and the difficulty in obtaining comparable data, it has not been possible to make a quantitative analysis.

Table 5. Structures and Systems dedicated to BPSD



"How would you characterise the Structures and Systems dedicated to BPSD?"

		Belgium F	Belgium W	Bulgaria	Cyprus	Czech Republic	Estonia	Finland	France	Germany	Greece	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands (The)	Norway	Portugal	Slovakia	Spain	Sweden	UK (The)
National policy		Y	Y	N	N	N	N	Y	Y	N	N	Y	N	N	N	N	Y	Y	N	N	N	Y	Y
Existing Mobile team [a]		Y	P	N	N	R	N	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	N	N	Y	Y
Integrated care & care management		Y	-	N	Y	R	R	Y	Y	Y	N	Y	N	Y	N	N	Y	N	Y	N	N	Y	Y
Dedicated Day Hospitalisation		N	N	N	N	N	Y	Y	Y	Y	N	N	N	Y	N	Y	Y	N	Y	N	Y	Y	-
Respite Unit		N	P	N	N	-	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	Y	Y	N	N	Y	-
Dedicated unit	**In Nursing Homes**	N	Y	N	N	Y	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	Y	N	Y	N	Y	Y
	In Hospitals - Fully dedicated to BPSD	N	N	N	N	N	N	Y	Y	-	N	Y	-	Y	Y	N	N	-	N	N	N	Y	-
	In Hospitals - Psychiatry Unit	Y	Y	N	N	R	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y
	In Hospitals - Neurology Unit	Y	Y	N	N	R	N	Y	N	Y	Y	Y	-	N	Y	N	N	-	N	N	Y	N	-
	In Hospitals - Geriatrics Unit	Y	Y	N	N	R	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	-	N	N	N	Y	-

(a) "Mobile team" could correspond to mobile geriatrics teams, fully dedicated or not to BPSD

Y Yes N No P Pilots R Rare ▨ No reply

- **Sources of data available for dementia in Europe:** As part of the survey we collected information on available data on health and social services for dementia. Two questionnaires were created in order to describe some of the sources of data available and currently in use in different countries, analysing their strengths and weaknesses and seeking opinions and suggestions to improve the data collection systems. The questionnaire, "Q1 - Overview of all available data sources for the purpose of the dementia study", provided a list of main data sources and the reference person for each country. In turn, this person was contacted to gather more information on available data.

A total of 82 current data sources have been cited for this study of dementia and the systems dedicated to it. The data sources described for each country's respondent were coded as either administrative or clinical/epidemiological data. Administrative data count for 37,8% of total data sources, and includes personal computerised files, medications files,

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[*] Behaviourial & Psychological Symptoms of dementia

reimbursement databases, and hospital administrative databases. Data coded as being for clinical and epidemiological purposes count for 57,4% and included computerised medical files, nursing home and mental services information, national death registries, cohorts, registries, and surveys. Coding was not possible for 4,8% of the data sources. All key contact persons for the data sources were sent a more detailed questionnaire. Out of 82 initial sources, 34 questionnaires were returned.

Lastly, it is possible to define the strengths of Administrative data as : a) providing a comprehensive description of all characteristics of persons living with dementia; b) often being mandatory; c) covering all health care institutions (public and private) and most social welfare institutions; c) providing important coverage of the general population. **The strengths of the Clinical/Epidemiological data are**: a) providing population-based cohort data on all cases of dementia occurring in the general population (versus the underestimation by health care system and administrative data collection by up to 50%); b) they are representative of the general population, provide information on temporal trends, estimate risk of death associated with dementia, incidence and prevalence, socio-demographic data.

In contrast, the weaknesses of Administrative data are: a) great potential but some degrees of imprecision; b) absence of a standardised coding system on diagnosis; c) dementia is not always recognised nor reported on medical records; d) data may lack broad population coverage, socio-economic and clinical data (quantity and quality) and information on people living in institutions; e) the underestimation is higher at the onset of the disease. **The weaknesses of Clinical/Epidemiological data are**: a) lack of a unique patient identifier (no record-linkage with other data sources); b) dementia diagnosis is a process made over a period of time; c) collecting good quality data is time consuming; d) legislation concerning the use of personal data; e) need to discuss and receive patient/carer informed consent; f) in some countries legislation on patients' decisional capacity is lacking; g) specific population groups might be lacking in certain epidemiological data sources.

All respondents were asked to say how they would improve data sources for the purpose of dementia study. The results of a textual analysis of their commentaries is shown in Figure 3. In order to improve administrative and non-specific data sources for the purpose of dementia study, providing record-linkage and a unique patient identifier are the main suggestions. With the exception of Finland, Sweden and Norway, the other respondents do not seem to have a structured system of record-linkage among health, social and administrative data sources. Within the health sector, record-linkage should produce a minimum dataset including hospital discharge records, death certificates, drug prescriptions archives and high quality clinical data. Record-linkage presupposes the availability of performing Information and Communications Technologies (ICT) systems, accessibility to all relevant stakeholders, especially the persons living with dementia and/or their carers. Integration of health and social care data sources is essential for the drawing of a comprehensive picture, and a wide and shared coding reference system should be an integral part of this. As an additional comment, it seems difficult to deeply improve an administrative system rooted in economic function and not designed for epidemiological information purposes. Some items e.g., disability items, should be converted into International Classification of Functioning, Disability, and Health (ICF) values. However, even with the mentioned weakness, national dementia registries should be created and supported.

The suggestions proposed for administrative data systems also apply to specific clinical and epidemiological data sources: a unique patient identifier, a computerised system for data collection, comprehensive record-linkage including health, social, administrative and social security system data. Because of their clinical and epidemiological specificity, special attention must be paid to extensive clinical and neuropsychological evaluations carried out by specialists. Self-reported data such as observations and comments elicited from patients or their carers should be promoted as they are useful for a better understanding of risk factors, co-morbidities, medications used and other relevant information. Having a shared minimal individual dataset available will be critical at both the National and European levels. This minimal dataset should then be updated on a regular basis. It has also been suggested that incentives should be provided for data collection. And, of course, all information systems need to be kept thoroughly up-to-date. The ALCOVE partners' experiences could be proposed to other Member States.

Figure 3. Word cloud of the main category « Suggestions to improve the data source » (all sources, n=34)

RECOMMENDATIONS

Recommendations for the improvement of data collection on health and social care services for dementia.

European societies' needs in terms of health and social care are in rapid evolution. The burden of chronic diseases and different forms of dementia is changing the public demand. In this complex scenario, good quality data is essential to support planning, governance and to respond to individual's expectations.

Combining different data sources which have been created for different purposes might be challenging. Nevertheless, it seems to be the most efficient way to combine clinical, epidemiological, administrative and economic assessments, as on their own they have missing elements. Administrative data sources lack specific and good quality clinical data starting from diagnosis. Clinical and epidemiological data sources lack extensive socio-economic and demographic information. Record linkage might be the solution, provided a legal framework to safeguard citizens' privacy is in place.

[1] **A minimum data set, shared among different Member States, should be adopted for administrative, clinical, epidemiological and other relevant data sources.** The dataset should include general data on chronic diseases and specific data on dementia.

[2] **For data collection purposes, a predefined set of operational diagnosis criteria for dementia should be proposed.**

[3] **Optimise existent data sources by providing an efficient system of record linkage**.

[4] **A unique, depersonalised identifier should be made available for record linkage.** Privacy concerns needs to be addressed at the European level to assure the person's ownership of the data.

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TIMELY DIAGNOSIS OF DEMENTIA

TIMELY DIAGNOSIS OF DEMENTIA

Professor Brooker, Dawn; La Fontaine, Jenny; Dr Evans, Simon; Bray, Jennifer - Association for Dementia Studies, University of Worcester;
Dr Saad, Karim - Department of Health, England

"Dementia is not something that suddenly happens to you; that you are suddenly a different person in need of help. It is a complicated and slow process of internal recognition and acknowledgement, external acknowledgement within families and relationships and finally a slow journey through health services" [1].

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AUTHORS OF SECTION 5 OF PROGRESS ON THE FRENCH NATIONAL PLAN: Benoit Lavallart, MD, Project Manager, Steering Committee National Alzheimer Plan - Geriatrician & Public Health physician, France; Sandrine Lemery, Project Manager, Steering Committee National Alzheimer Plan - Actuary & General engineer of "corps des mines" France; Florence Bonte – MD, Geriatrician, France; Armelle Leperre-Desplanques, MD, PhD, Head of department Pilot Programmes & Clinical Impact - The French National Authority of Health, France; Nathalie Riolacci-Dhoyen, MD, Adjoint, Pilot Programmes & Clinical Impact - The French National Authority of Health, France.

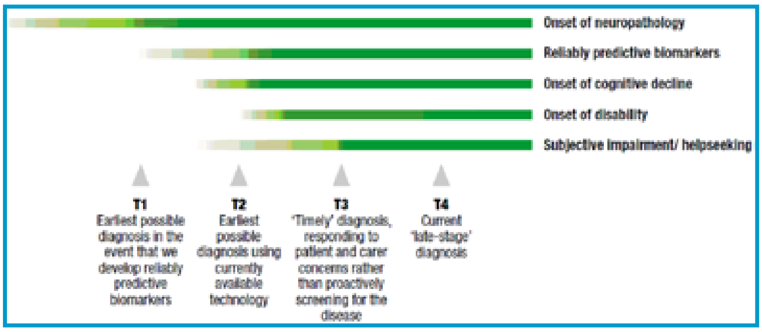
ALL SURVEY RESPONDENTS: Alfredo Antiguedad; Jennifer Bray; Dawn Brooker; Maria Chmelova; Ann Coyle; Maria Cunderlikova; Teresa Di Fiandra; Simon Evans; Inaki Fernandez Manchola; Manuel Fernandez Martinez; Lutz Froelich; Luis Galdos; Jakub Hort; Peter Johannsen; Janos Kalman; Alicja Klich-Raczka; Dorothee Knauf-Hubel; Ales Kogoj; Liga Kozlovska; Pierre Krolak-Salmon; Vladimirs Kuznecovs; Jenny La Fontaine; Benoit Lavallart; Jan Lehotsky; Ülla Linnamägi; Pablo Martinez-Lage; Denisa Mikusova; Noel Mulvihill; Marian Nagy; Ruiz Ojeda Javier; Alessandro Padovani;Ieva Paegle; Galina Paeva; Magdolna Pakaski; Sakka Paraskevi; Vinciane Quoidbach; Daiva Rastenyte; Philippe Robert; Karim Saad; Charles Scerri; Katerina Sheardova; Gorazd B. Stokin; Catalina Tudose; Peter Turcani; Juan M. Uterga; Martin Valis; Nicola Vanacore; Frans Verhey; Matti Viitanen; Martin Vyhnalek; Gunhild Waldemar; Anders Wimo; Daina Zepa.

ASSOCIATED PARTNERS: Department of Health, UK; Athens - Association of AD and Related Disorders (AAADRD), Greece; Riga Centre of Psychiatry and Addiction Disorders (RPNC), Latvia; Lithuanian University of Health Sciences (LUHS), Lithuania; Institute of Neuroimmunology of Slovak Academy of Sciences (NIU SAV), Slovakia; Fundación Vasca de Innovación e Investigación Sanitarias & Agencia Vasca de Evaluación de Tecnologías Sanitarias (BIOEF-OSTEBA), Spain; Karolinska Institute (KI), Sweden.

Method, questionnaires and analysis are developed in the WP5 Report: Timely diagnosis of dementia – www.alcove-project.eu

Research highlights that many people never receive a diagnosis of dementia and furthermore, where a diagnosis does occur, it is frequently much later in the experience of dementia, when clinical signs have progressed and activities of daily living, cognition, relationships, behaviour and quality of life are already significantly challenged [2, 3]. Up to 28 of 36 million people living with dementia world-wide have not received a diagnosis, limiting their access to treatment, information and care [3]. Some countries have set targets within their dementia strategies to improve early diagnosis rates. However, it is necessary to define clearly what is meant by early as opposed to later diagnosis particularly given such issues as the current debate concerning diagnosis and interventions in the prodromal (pre-clinical) phase of Alzheimer's disease. Prince *et al.* [3] usefully propose a four stage timeline of disease progression (Figure. 1) which is how the evidence is structured.

Figure 1. The four-stage timeline of disease progression (Prince et al. [3])



However, for the purposes of public health, it should also be recognised that:

- T1 is an area of long term research,
- T2 is an area of short term research for possible diagnosis of Early Cognitive Changes/Mild Cognitive Impairment (MCI),
- **T3, as timely diagnosis, is the priority area to be achieved for dementia diagnosis,**
- **T4 is a late stage diagnosis area to be decreased in favour of T3.**

The aim of this chapter is to present a brief overview of the in-depth evidence from two pieces of work:

1. A critical literature review of the diagnosis of dementia including screening
2. A questionnaire survey of existing diagnostic systems in EU Member States

This evidence was synthesised to formulate recommendations for improving early diagnosis, both in ambulatory and in nursing home settings, which could be utilised by policy makers and influencers across the EU. These recommendations are presented as classical text as well as strategies for ealth policy in the form of pyramids.

METHOD

LITERATURE REVIEW

An initial literature search on definitions of dementia diagnosis; covering screening, practice guidelines, economic costs, and primary and health care utilising Medline and PubMed provided 1,855 abstracts plus 20 government policy documents from the EU and beyond. In order to provide evidence-based recommendations on the process of diagnosis, searches were also undertaken in Psychinfo, Psycharticles and Cinahl along with hand searches of relevant journals which generated a further 1,943 abstracts. Evidence concerning technical issues of diagnosis (e.g. classifications and testing procedures) and the care and support processes associated with diagnosis were assessed. The literature review was structured in consultation with ALCOVE partners and utilising the expertise of an external reference group.

Over 200 references were included in the critical literature review. The review consisted of sections focusing on issues of diagnosis at T1, T2, T3 and T4 [3] under the following headings:

- Differential diagnosis
- Diagnostic Classifications
- Criteria for diagnosis in each of the diagnostic subtypes
- Who presents at each stage and what they present with?
- Who do they present to?
- How long before presenting?
- What process should be delivered and by whom
- What are the key challenges?
- What are the benefits/drawbacks of diagnosis at this stage?

The progress of both dementia strategies for France and England on early diagnosis was also considered. Detailed recommendations were made at the end of each section within the literature review and a shorter recommendation list was developed through five phases of iteration with people living with dementia, family carers and wide range of health and social care professionals.

ALCOVE QUESTIONNAIRE SURVEY

The questionnaire survey was sent to all 27 EU countries via five regional coordinators. It covered data about the age profile of the country and the numbers of health care professionals; who makes the diagnosis and how; what happens in practice as compared to official guidelines; legislation; access to specialist services and relationships between family doctors and specialists. The questionnaire was produced as a Word document and subsequently made available as an on-line survey. Following significant follow-up, responses were received from 24 countries (a response rate of 89%), although many questionnaires had incomplete sections. The questionnaire results were considered separately for each of its six sections. The analysis methods used varied depending on the individual question and the nature of the responses.

RESULTS

LITERATURE REVIEW

Undertaking a conclusive review of the literature in early diagnosis and dementia required that both the technical aspects of diagnosis and the processes associated with it were addressed, as both are necessary to facilitate a depth of understanding. The complexity of bringing together these bodies of evidence became apparent, not least because evidence concerning technical aspects of diagnosis has a significant focus on developing our understanding of the causation, prevention and treatment of dementia and is thus largely addressing diagnosis at T1 and T2. However, evidence concerning the care and support of people already living with dementia and their families has a greater focus on those who have already developed clinical signs, so will primarily be at T3 and T4. Consequently, it was necessary to consider evidence concerning advances in diagnosis; even though it might not impact practice now; in addition to a review of current evidence concerning early diagnosis and intervention.

- **Research categories at T1 and T2:** Recent advances in the technical aspects of diagnosis include the adoption of a life course perspective for the risk of developing dementia (Figure 1). These advances have prompted considerable expansion in research exploring enhanced methods of detecting and intervening at T1, specifically in the pre-clinical phase of Alzheimer's Disease (AD) and vascular dementia (VaD) [3], to prevent or delay onset [4]. This challenges what is meant by an early diagnosis. In recent years such research has advanced early detection in developing biomarker tests which, for example, measure tau protein and amyloid-beta levels in cerebrospinal fluid [5]. Currently biomarker usage is restricted to research and is not recommended for clinical practice. Further research is required to establish their ability to predict progression to dementia [3, 6, 7]. The Dubois research criteria [8] for AD recommends the use of biomarkers as part of the assessment, but has not yet been evaluated for use in clinical practice [9].

  These advances have generated debate concerning at what point diagnosis should occur, and whether population screening is therefore desirable. This wider debate will continue as new evidence emerges. However population screening is not currently recommended for a number of reasons:

  1. The efficacy of biomarkers and other tests at this early stage is not clear;
  2. Although clinical trials are currently ongoing to deliver interventions which may delay or prevent the onset of AD or VaD [10, 11, 12], results determining the efficacy of these interventions will not be available for some time;
  3. While screening for dementia might be acceptable in the future if clear benefits were identified, there are significant concerns about the potential harms arising from such screening now. These harms include concerns about extended feelings of hopelessness arising from an early diagnosis, the impact of stigma associated with dementia, and the legal ramifications including the impact upon insurance premiums and mortgages [13, 14].

  Mild Cognitive Impairment (MCI) is a construct which represents detection at T2 [3] when the earliest clinical signs of dementia may be emerging. Whilst MCI as a construct has been increasingly used in the past decade across both research and clinic settings, there have not, until recently been any established consensus guidelines for diagnosing MCI [15], [16]. Evidence indicates methods to diagnose MCI require further development [16, 17, 18], especially as not all those with MCI will go on to develop dementia [19]. Limited evidence exists concerning the factors which are predictive of this transition [15].

  A number of studies identify that individuals feel very uncertain after being given a diagnosis of MCI, that they do not always receive appropriate support following a diagnosis and that they feel that they have nowhere then to turn [20, 21]. While concerns continue to exist around the utility of the category of MCI, and its application in clinical practice, revisions to the

2013 DSM- V major diagnostic classifications propose a category which will replace the label of MCI with Minor Neuro-cognitive Disorder [22]. This is an area that is in a state of change and there is a need for all involved in policy development and clinical practice to be actively aware of changes as new evidence emerges.

- **Dementia Diagnosis at T3 and T4**

  - Many people currently do not receive a diagnosis at all, and if they do, it is at a later point in their experience of dementia [3]. Many factors are thought to influence this delay including:
    - The significant stigma associated with dementia held by the general public and professionals;
    - The availability and accessibility of diagnostic services;
    - The availability of interventions and support following diagnosis.

  These factors have a profound impact both on the number of people seeking help and the point at which help is sought. Thus Prince et al. [3] identify that currently it is more appropriate to bring forward the point of diagnosis to the earliest stage possible – T3.

  There are a number of compelling reasons for supporting people to come forwards for investigation of cognitive changes:

  - There are many treatable reasons why people experience confusion. The investigations completed as part of the diagnostic process will ensure these are identified and dealt with promptly;
  - There are some benefits from pharmacological treatments for some individuals following diagnosis. These do not provide a cure, but may help with symptom control;
  - New treatments are likely to have more benefit in these early stages.

  National strategies agree that one of the main reasons for providing people with an early diagnosis is to provide the foundations for living well with dementia, including having information, opportunity to adapt and maintain valued life experiences and making plans for the future [23]. Living well with dementia importantly involves a process of psychological and emotional adjustment, in which the person and their family are able to make choices and have control over the process of assessment, disclosure and receipt of post-diagnostic support, information and interventions [24, 25, 26]. There are significant challenges facing the person and their family in undergoing assessment: the stigma associated with dementia, fears for the future and support following diagnosis. Thus in order to facilitate a process of adjustment and adaptation, it is proposed that early diagnosis should also be timely diagnosis, occurring at a point when the person and their family are ready to undergo assessment [25].

  Thus early and timely diagnosis requires:

  - A sensitive and staged approach to assessment – which begins by a societal response to challenging the stigma associated with dementia through public and professional education, which informs and educates people about the advantages of seeking a diagnosis;
  - Assessment of difficulties, a comprehensive assessment, and a sensitive process of diagnostic disclosure;
  - Early intervention and care planning for the future [25, 3, 26, 27].

ALCOVE QUESTIONNAIRE SURVEY

Questionnaires were completed by a variety of sources – the majority being returned by lead clinicians. Analysis of responses from the 24 countries has highlighted a range of similarities and differences in terms of self-reported current practices across the EU.

- **Most countries report missing 40-60% of theoretical dementia diagnoses:** Some countries reported missing above 60% and some reported missing only 30%. When a diagnosis is made it tends to be when the dementia is already at a moderate or late stage. An ageing population is a common issue across the EU with around 10-20% of the population within each country being 65+ (6-10% are 75+ and 1.5-3% are 85+).

- **Overall, four main professions were identified as being responsible for the majority of the key tasks involved in the diagnosis of dementia:** These were General Practitioners, Neurologists, Geriatricians, Psychiatrists. Other professionals were involved in assessment, case management, follow-up and monitoring including Nursing, Psychologists, Neuro-psychologists and Occupational Therapists.

  The prevalence of the different professionals is country specific and varies widely. The EU median of the different key professionals per 1,000 citizens aged 65+ is GP's = 3.47 GPs; Psychiatrists = 0.61; Neurologists = 0.35; Geriatricians = 0.09 and Old Age Psychiatrists = 0.02. The more specialist professions in the diagnosis of dementia are less widespread. Typically, GPs make the diagnosis in the majority of simple cases whereas it is specialists who are involved in the diagnosis of complex dementias. The average waiting time from referral to see a specialist for assessment was reported as eight weeks or less by 81% of countries responding, with nearly a third of countries reporting four weeks or less.

- **Most EU countries report having screening services for dementia and MCI:** These appear to be mainly undertaken by hospital based staff. However, it is unclear whether this term is used consistently across the EU. It may be that this is case detection for "at risk" groups (such as hospital patients over the age of 75) rather than population screening per se.

  The vast majority of countries report the presence of memory clinics although geographical and population coverage is not considered to be widespread. There is also variation between countries in terms of memory clinic coverage, with the EU median being approximately 50% coverage by memory clinics. Around 50-60% of countries felt they had good coverage by dementia specialists and specialist memory centres. Overall, the opinion in most countries is that memory assessment is accessible to all people but a sizeable proportion (41%) reported that it was not.

  Magnetic Resonance Imaging scans were generally the most commonly used type of medical imaging, except for people in late stage dementia, when Computed Tomography scans were more common. For late stage dementia imaging was much less commonly used. The actual imaging used across all people with dementia was reported as being generally similar to that proposed by the official guidelines, although in some cases availability of equipment or resources meant that it was not always possible to follow the guidelines. Cerebrospinal fluid biomarkers were not routinely measured in any country, and where they were measured it was generally for specific patients or for research.

  In terms of assessing cognitive function the Mini-Mental State Examination and Clock Drawing Test were by far the most commonly reported.

- **The information on post diagnostic support and interventions was sparse:** Only 61% of those countries responded saying that they always or often provided information about dementia and only 39% reporting that they provided education and social support. More specifically, therapeutic interventions such as cognitive stimulation therapy were much less frequently reported.

- **Legislation in general for people with dementia was varied:** Approximately one-third of respondents reported that they did not have legislation to protect people with dementia, and nearly 50% do not have legislation for advance statements and directives. Even where legislation exists, it was reported that it was often not consistently implemented, supported or promoted. For example, many questionnaire respondents reported that greater clarity is required regarding who is responsible for promoting advance directives, and there needs to be more awareness of them and what they relate to (on this topic see also p. 78).

- **Almost all countries report having dementia awareness campaigns for both professionals and the general public:** Only 43% of countries reported having specific policies in place to improve the quality of diagnosis. In the countries that had policies they tended to report diagnosis being made at an earlier stage. Only four countries responded by saying they had integrated dementia pathways. Without these elements it is difficult for people with symptoms and professionals to understand clearly the process of diagnosis. Developing such information would therefore be important to help different groups and services fit together and potentially improve the timeliness of dementia diagnoses.
- **The guidelines and policies would help to support GPs in their role,** especially as it is reported by 70% of the countries that GPs have inadequate training in diagnosing dementia and in recognising symptoms of early dementia. This lack of training, combined with a lack of understanding or clarity regarding their role, could have an impact on the relationship between GPs and specialists. There is some disparity concerning information sharing between these two parties, with information not necessarily being shared as and when required. The transmission of information appears to be better from specialists to GPs than from GPs to specialists, although it should be noted that the questionnaires were more likely to be completed by people in roles that would count as specialist rather than by GPs.

If it is recommended that people are diagnosed at an earlier stage, the complexity of the diagnostic process increases. In terms of workforce planning therefore the non specialists either need ways of dealing with this complexity or more specialists will be required.

RECOMMENDATIONS FOR DEMENTIA DIAGNOSIS

Taken together, the recommendations from the literature and the current reported situation across the European Union have been synthesised into a series of final recommendations that can be utilised across different countries. Recommendation 1 is concerned with the fundamental principles on which underpin all further recommendations in this area.

[1] The diagnosis of dementia should be person-centred and actions associated with it should be based on the following principles:

Timely diagnosis of dementia should be available to all citizens who require it **and accessible** to all sections of the community at a stage when people first notice changes in cognitive function;

Decreasing fear and stigma about dementia are necessary pre-cursors for increasing the numbers of people coming forward for diagnosis;

The **rights and wishes** of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis

Giving and receiving a **diagnosis of dementia is a key intervention** in the complex adjustment process to living with dementia. The needs of **the person and their family/significant others** are central to assessment, diagnosis and post-diagnostic interventions.

[2] Case finding can be an effective process to identify people to Increase diagnosis in circumstances where there are services available that will benefit the person and their family

Targeted or opportunistic case finding within primary care, acute hospitals or care homes should be undertaken and steps taken to ensure that services and support are available to bring benefit to the person and his or her family.

General population screening is not recommended until there is better evidence of the reliability of screening alongside ways of preventing or delaying dementia.

[3] The diagnostic process should support positive adjustment, provide an evidence based assessment and enable care planning to take place following diagnosis

The diagnostic process is managed in a way that supports good adjustment to the news. This includes:
. The provision of pre-assessment counselling which should address:
  - Provision of information concerning the diagnostic assessment process;
  - Possible outcomes of the assessment process;
  - Promoting rights to choice and control over whether to go forward for diagnosis.

. Where and who should be present for diagnostic feedback;
. What interventions can be offered following diagnosis;
. A sensitively delivered process of disclosure of the diagnosis;
. The provision of information and interventions post diagnosis.

Timely diagnosis covers a sequence of four stages, each of which may be delivered by any properly trained professional but needs to be coordinated at the individual patient level:
. Initial detection of cognitive difficulties and other symptoms indicative of dementia;
. Assessment to decide whether symptoms are due to dementia or not;
. If dementia is present, to achieve diagnosis of the cause and relevant co-morbidities;
. Care planning to address current and future needs.

Recent clinical criteria for diagnosis of dementia syndrome and its subtypes are used in clinical practice, recognising that this is a changing area and that further validation and revisions will occur [28, 29, 30, 31, 32, 33, 34].

Systems need to be in place so that professionals stay up to date with the clinical criteria for diagnosis.

Biomarkers (Cerebrospinal Fluid and functional neuro-imaging) are recommended only for use in research centres and not in general clinical practice.

[4] Diagnosis of complex presentation of dementia is made in as timely a fashion as for simple cases

Particular skills are required where people have a young age of onset, have pre-existing health difficulties or an intellectual disability.

In these situations case finding, **assessment processes and interventions** are utilised that are relevant to the particular needs of the population.

[5] A consensus is required on how early cognitive changes at time point 2 (currently known as Mild Cognitive Impairment MCI) are to be responded to in clinical practice

Proposed changes to diagnostic classifications, should clarify how early cognitive changes are defined and responded to in clinical practice. At the present time, the label MCI is, from the public health point of view, a research categories area.

When people are informed that they have early cognitive changes, advice and support should be given alongside clear systems for monitoring and follow up.

[6] Workforce development is required across all levels to facilitate timely detection, evidence based assessment and diagnosis and to facilitate good adjustment

When planning national strategies for dementia, workforce and service development issues are taken into account

Family doctors and their colleagues working in Primary Care, Care Homes and Acute General Hospitals should receive education and learning, and evidence based decision support toolkits to assist them in their dementia detection role.

Systems are developed to support detection at an early stage by family doctors including shared care with specialists, guidelines in detection, education and case management.

Specialist services at the secondary level can improve timely diagnosis to good effect but there are challenges to implementing this model where there is a lack of specialist expertise and a dispersed rural population.

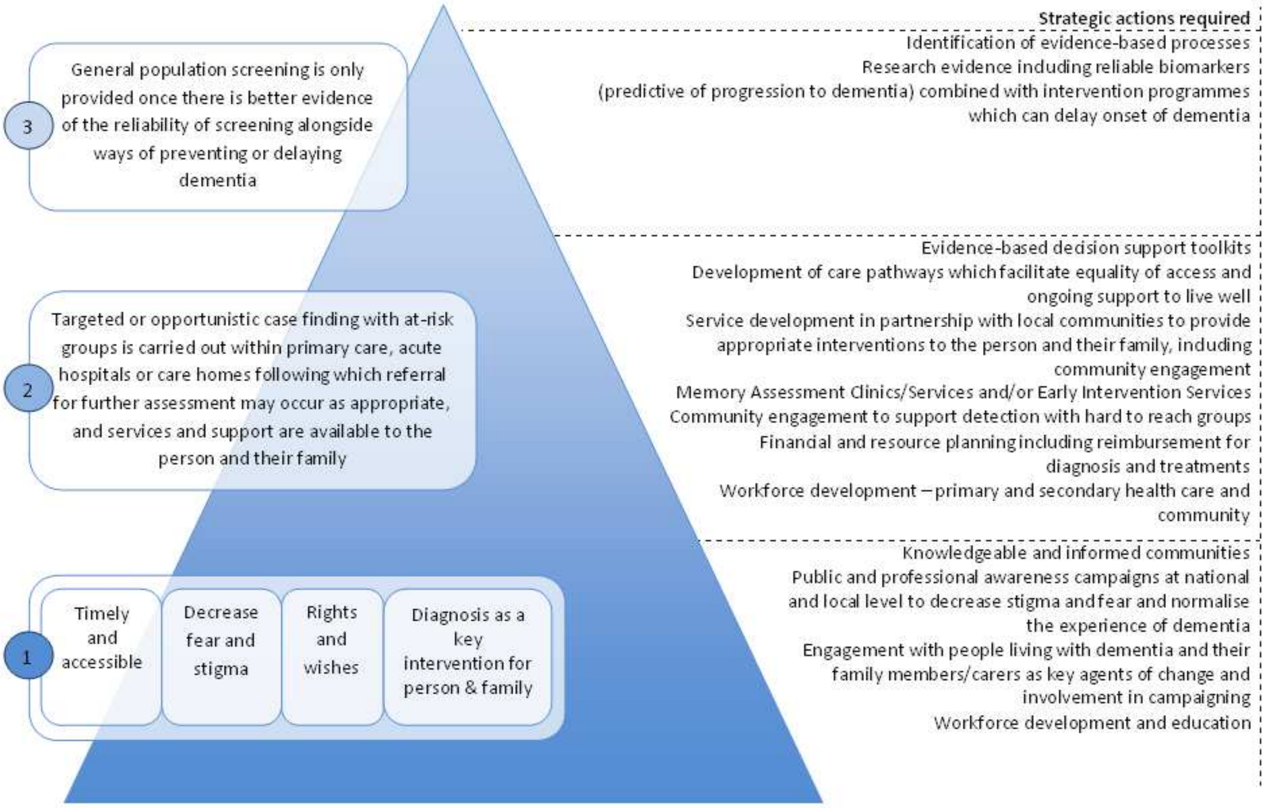
Workforce development strategies are in place for the wide range of health, social care and community staff involved to enable these staff to facilitate good adjustment in those receiving a diagnosis and their families.

STRATEGIES FOR HEALTH POLICY FOR DEMENTIA DIAGNOSIS

The recommendations relate to the key areas identified by the work and are presented as strategies for health policy in the form of pyramids. These pyramid diagrams could be utilised at a national or local level to benchmark and plan service provision.

STRATEGY FOR TIMELY DETECTION

- **ALCOVE pyramid for timely detection (Figure 2)**



Strategic actions required

3 General population screening is only provided once there is better evidence of the reliability of screening alongside ways of preventing or delaying dementia

Identification of evidence-based processes
Research evidence including reliable biomarkers (predictive of progression to dementia) combined with intervention programmes which can delay onset of dementia

2 Targeted or opportunistic case finding with at-risk groups is carried out within primary care, acute hospitals or care homes following which referral for further assessment may occur as appropriate, and services and support are available to the person and their family

Evidence-based decision support toolkits
Development of care pathways which facilitate equality of access and ongoing support to live well
Service development in partnership with local communities to provide appropriate interventions to the person and their family, including community engagement
Memory Assessment Clinics/Services and/or Early Intervention Services
Community engagement to support detection with hard to reach groups
Financial and resource planning including reimbursement for diagnosis and treatments
Workforce development – primary and secondary health care and community

1 Timely and accessible | Decrease fear and stigma | Rights and wishes | Diagnosis as a key intervention for person & family

Knowledgeable and informed communities
Public and professional awareness campaigns at national and local level to decrease stigma and fear and normalise the experience of dementia
Engagement with people living with dementia and their family members/carers as key agents of change and involvement in campaigning
Workforce development and education

Figure 2. ALCOVE pyramid for timely detection. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- **Questionnaire findings relating to timely detection:** Most countries currently diagnose dementia when it has already reached a moderate or mild-moderate stage, with only a few countries diagnosing people when the dementia is at a mild stage. The majority of countries have opportunistic screening in place in hospital settings.

  It is not clear whether different countries use the term 'screening services' to mean the same thing. A clear and common definition of what these services are and what they entail needs to be established, together with their place within the dementia pathway. This will support consistency in the development of services that, integrated with the wider dementia pathway – including workforce training, interventions and support – take into account the broader impact of an earlier diagnosis.

Examples from England and France:

Professionals recognise that family doctors have difficulty in identifying early signs of dementia. Actions are underway **in England** to address these challenges and support family doctors and their colleagues in earlier and timely detection. The Prime Minister's Challenge also addresses timely detection in its efforts to increase the diagnosis rate in England. To bring both the professional and public sides together, initiatives such as the NHS Health Check aim to raise awareness of dementia and the memory services available. Supporting this are national public awareness campaigns which focused on raising awareness of the early signs of dementia, and encouraging people to have potentially difficult conversations with family members who they suspect may have early signs of dementia.

STRATEGY FOR PROCESS OF DIAGNOSIS

- **ALCOVE pyramid for process of diagnosis (Figure 3)**

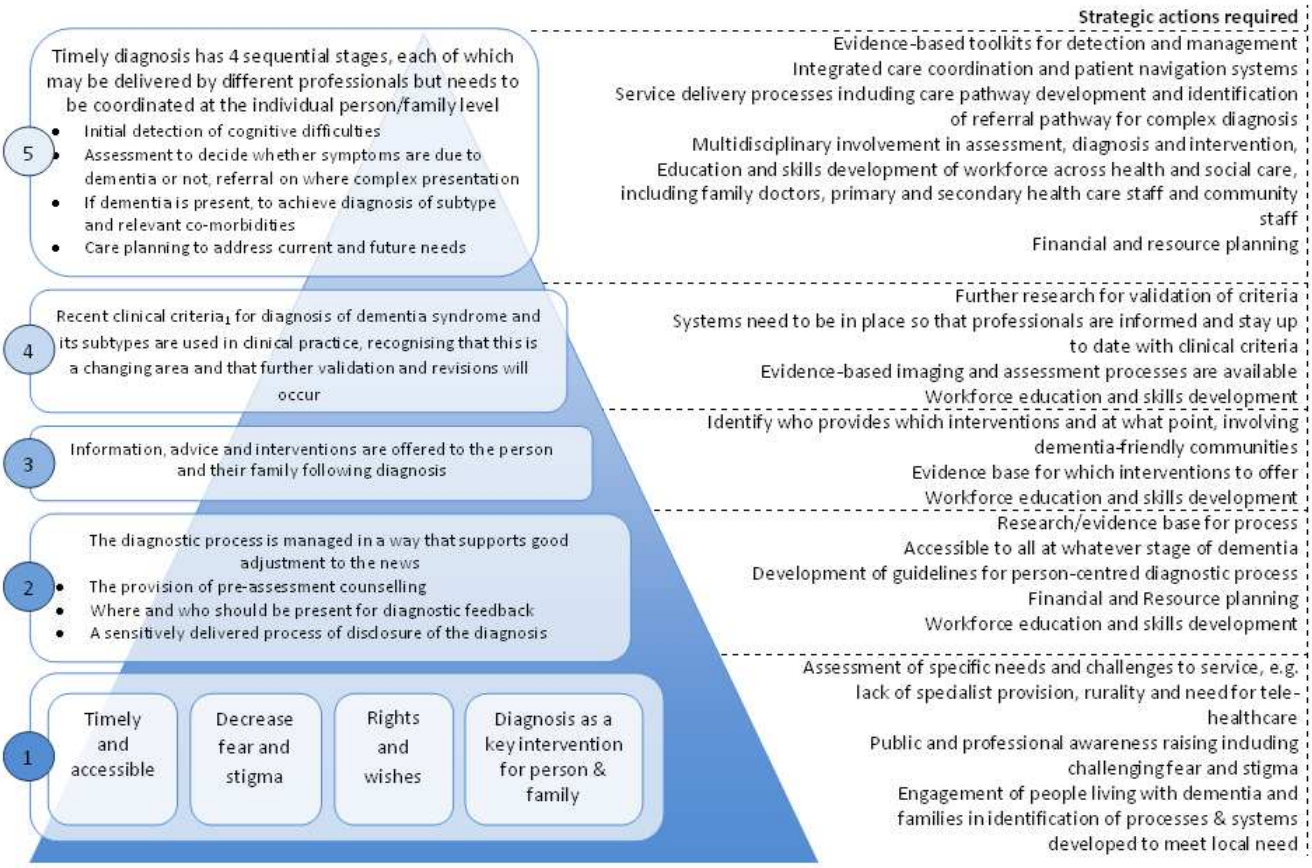


Figure 3. ALCOVE pyramid for process of diagnosis [28-34]. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- **Questionnaire findings relating to process of diagnosis:** Across the EU, most countries have raised awareness of dementia through communication campaigns, with the majority being aimed at both the general public and professionals. These campaigns will hopefully encourage people to seek help sooner if they are concerned about their memory. They therefore need to be backed up by a robust diagnosis process. Approximately two thirds of countries have national official guidelines in place to support diagnosis, and these tend to be the countries that are more likely to diagnose dementia earlier.

Examples from England and France:

- In England, the Prime Minister's Challenge has encouraged the development of dementia friendly communities, where there is increased awareness, understanding and support for people living with dementia and their carers. The wide reach of these communities include dementia friends, businesses, schools and public sector services such as the fire brigade. In England there has been an increase in the provision of memory services, with 98% of respondents to a national audit saying that they commission memory services or intend to in the future. The quality of memory services is also being addressed through a national programme of accreditation. Local memory services are being encouraged to sign up to this process.To help people with dementia following diagnosis, services such as the Dementia Advisors have been piloted in a number of areas, with some continuing beyond their initial pilot phase. Although an evaluation of these services has yet to report, local evaluations indicate that such services are beneficial for people with dementia and their carers.
- France has seen similar progress in relation to improving the process of diagnosis. The French National Health Authority has helped by publishing good practice information on giving the diagnosis, providing counselling, and defining the role of each person involved in the process. The process itself has two stages, initially giving the diagnosis, followed by confirming and explaining the diagnosis and providing support. This process is supported by the creation of home visits carried out by family doctors, which allow the person with dementia and their family to be part of decisions around their therapeutic, medical and social care needs. France has also increased the number of memory units, especially in areas not covered previously, and created a national network of such units. These units offer specialised medical consultations and have minimum staffing requirements. In addition to these units, they have also created a number of specialist memory resource and research centres which provide a range of services including research, specialist consultation and education and diagnosis in the most complex cases.

STRATEGY FOR COMPLEX DIAGNOSIS

- **ALCOVE pyramid for complex diagnosis (Figure 4)**

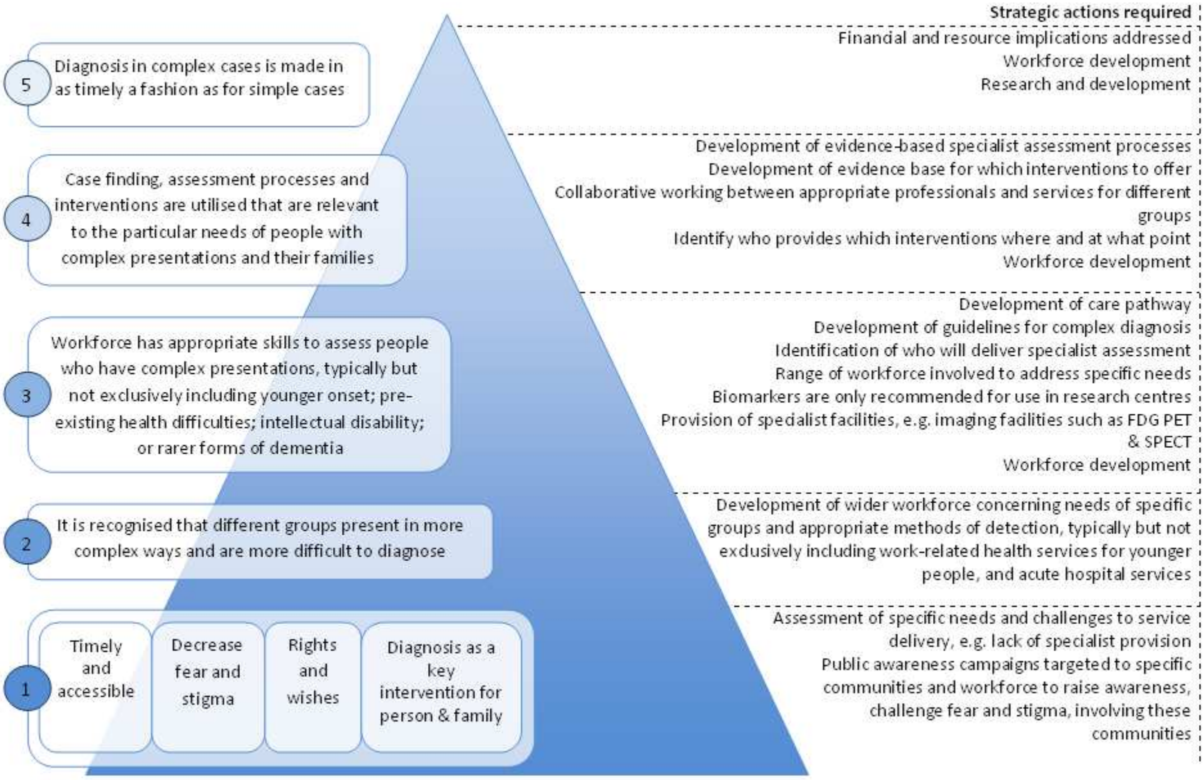


Figure 4. ALCOVE pyramid for complex diagnosis. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- **Questionnaire findings relating to complex diagnosis:** The majority of countries said that they do not have specific centres for younger people of working age with dementia, suggesting that the workforce in more general services will need to be trained appropriately to ensure that the needs of younger people are met. In terms of making a diagnosis in complex cases, there is recognition that it requires more specialist knowledge, with family doctors generally not being involved – although they are in simple cases. Complex diagnoses are usually carried out by Neurologists, Geriatricians and Psychiatrists.

Examples from England and France:

- In England, there is recognition that there is a need in relation to the availability and provision of information for specific groups whose diagnosis may be particularly difficult or who may not easily access services. This is being addressed by an equalities action plan and covers people who have co-existing disabilities or health difficulties, people from migrant communities and younger people with dementia.
- France has also made progress with complex diagnosis through increasing the number, and consequently coverage, of CMRR (Centres Mémoire de Ressources et de Recherche). These specialist centres provide diagnosis in the most complex cases and for the earliest forms of dementia. In addition, help for younger people with dementia has been provided by establishing a reference centre to develop research and evidence for medical and psycho-social care and standards of practice with younger people with dementia.

STRATEGY FOR PEOPLE REPORTING EARLY COGNITIVE CHANGES (CURRENTLY MILD COGNITIVE IMPAIRMENT MCI)

- **ALCOVE pyramid for people reporting early cognitive changes (Figure 5)**

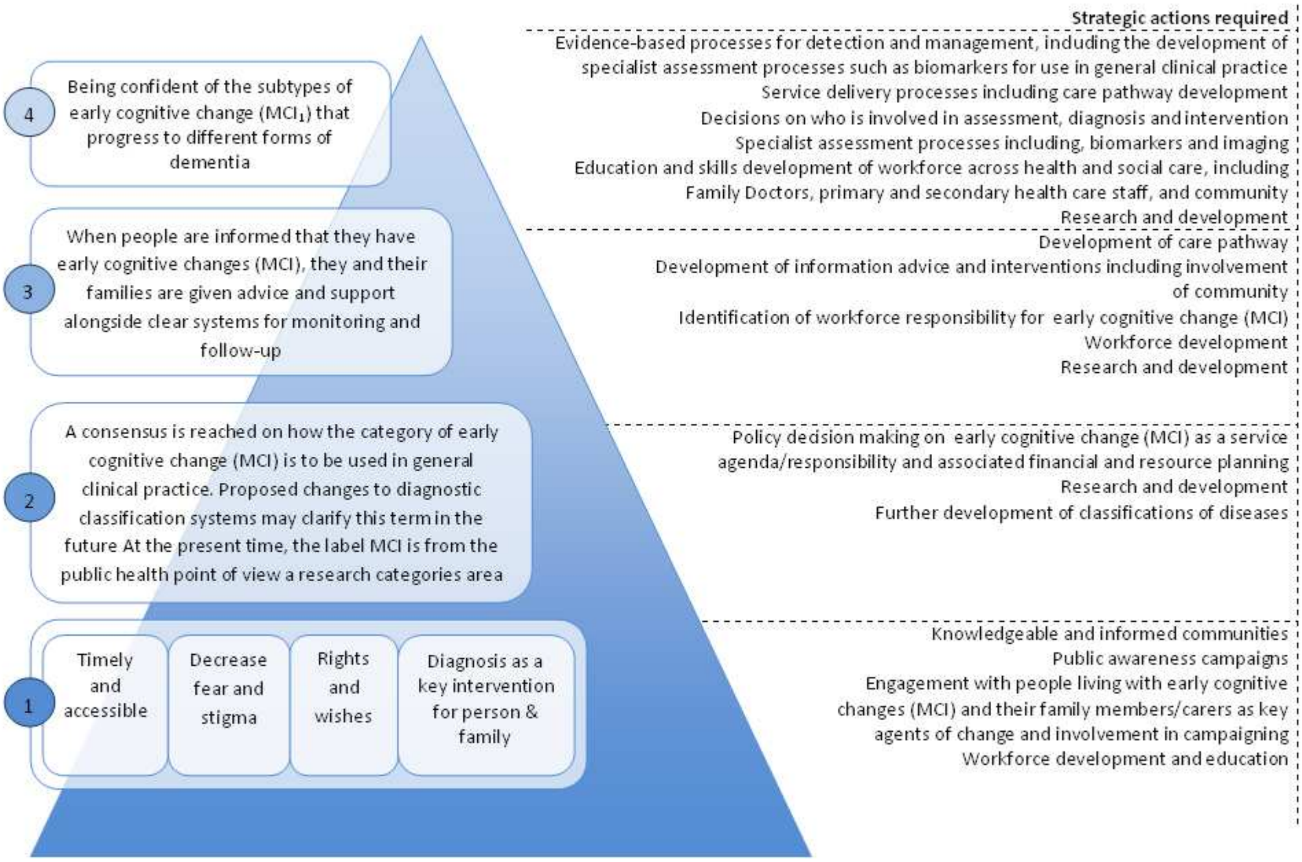


Figure 5. ALCOVE pyramid for people reporting early cognitive changes. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- **Questionnaire findings relating to early cognitive changes:** As with complex diagnosis, many of the previous comments around the process of diagnosis are also relevant to MCI. There were only a few areas in the questionnaire focusing specifically on MCI, so additional comments are limited.

  It is possible that at least some of the activities known to be taking place across the EU will include MCI and that in the two thirds of countries with national guidelines for diagnosis, those guidelines will cover MCI. Also, although few countries have dementia pathways at present, when such pathways are developed they will need to include MCI as well as dementia.

  As the level of missed dementia diagnosis across the EU is currently 40-60%, diagnosis as a whole needs to improve significantly before detection of MCI can be properly addressed.

STRATEGY FOR WORKFORCE

- **ALCOVE pyramid for Workforce (Figure 6)**

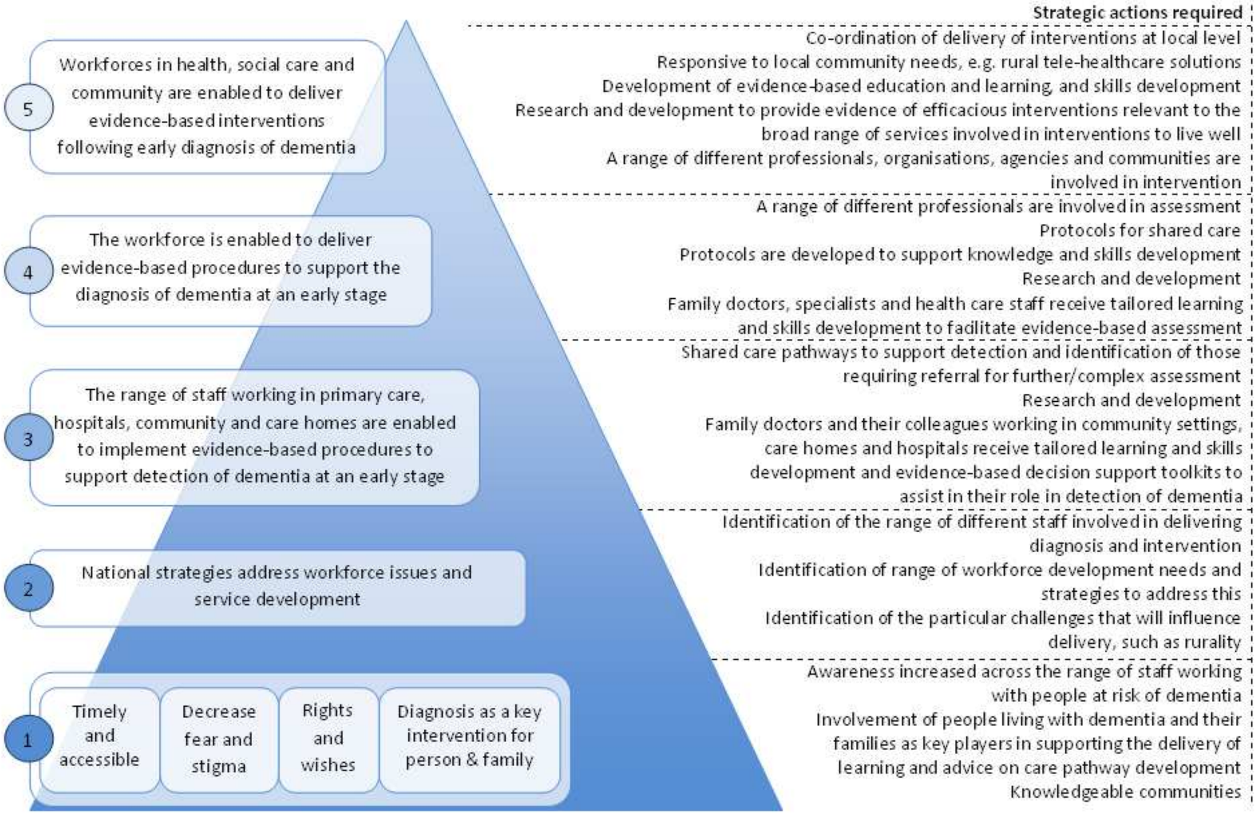


Figure 6. ALCOVE pyramid for Workforce. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- **Questionnaire findings relating to workforce:** Although two thirds of countries have national guidelines for diagnosis, professionals need to know where they fit and what their role is with respect to those guidelines. The same is true for overall dementia pathways, although only a few countries have these in place at present.

  Four main professions – Family Doctors, Neurologists, Geriatricians and Psychiatrists – are involved at every step of the diagnosis process, so they need to know what is expected of them at each stage. Other professionals also need to know how they are expected to work with and support these four main groups, indicating that communication and joint working is key to making the diagnosis process work for the person with dementia and their family.

  The workforce in general, and particularly family doctors and specialists, need to have a wide range of information regarding dementia, or at least have sufficient awareness of different areas, such as legislation on advance statements and advance directives. One area that was highlighted as needing improvement in every country was training for family doctors. Most countries do not have training and/or accreditation to enable them to diagnose dementia or to recognise the symptoms of early dementia, and consequently less than half of family doctors are trained in these areas.

Examples from England and France:

- In England, the recognition that the range of professionals who come into contact with people with dementia need better education and training has resulted in a number of on-going initiatives to embed dementia skills and knowledge and competencies within the workforce, including medical and nurse education, core common principles in practice, an e-learning package for health and social care staff, and a website for sharing good practice.
- Improving the workforce has also been an aim in France, and has focussed on clarity of individual staff roles within. For example, the professional team in all memory units will include a doctor and is highly likely to have a geriatrician and either a psychologist or a neurophysiologist. The French National Health Authority has published good practice information on giving the diagnosis, providing counselling, and defining the role of each person involved in the process. This helps professionals to have a clearer understanding of where they fit in the wider care pathway. In addition, guidelines for practitioners have been updated according to clinical guidelines on diagnosis and describe ideal clinical pathways.

CONCLUSIONS

Achieving a timely diagnosis of dementia is something that is supported by the research literature. It is something that many European countries see as important and an area that they would like to improve upon. Timely diagnosis needs to be based within a context that decreases fear and stigma about dementia; respects the centrality of the rights and wishes of the person with suspected dementia; recognises that the diagnosis of dementia is a key intervention and that the needs of the person and their family/significant others are central to assessment, diagnosis and post-diagnostic interventions. Using the recommendations set out in this chapter it is possible to benchmark the progress at a local, national and European level in the key areas of timely detection, the diagnostic process, complex diagnoses, response to early cognitive changes and work-force. This is an area where new evidence is emerging and it is important that clinicians, policy makers and citizens have up-to-date information in order to make informed decisions.

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SUPPORT SYSTEMS
FOR THE BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

A "3D VIEW" ALL ALONG THE PATIENT PATHWAY

SUPPORT SYSTEMS FOR THE BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

A «3D view» all along the Patient Patway

Dr Leperre Desplanques, Armelle[a] ; Professor Finne-Soveri, Harriet[b]; Dr Roubaud, Caroline[a,e]; Dr Mäkelä, Matti[b]; Saarikalle, Kristiina[b];
Dr Riolacci-Dhoyen, Nathalie[a], Micheneau, Carole[a]; Dr Banaei-Bouchareb, Linda[a]; Barr, Christine[a]; Lemery, Sandrine[c]; Dr Lavallart, Benoît[c];
Dr Vanacore, Nicola[d]; Dr Giusti, Angela[d]; Dr Scardetta, Paola[d]; Professor Krolak-Salmon, Pierre[a,e].
[a]Haute Autorité de Santé (HAS), France; [b]The National Institute for Health and Welfare (THL), Finland; [c]Alzheimer Plan, France;
[d]Istitute Superiore de Sanita (ISS), Italy; [e]Hospices Civils de Lyon, France

The first dimension of Support Systems for BPSD

The second dimension of Support Systems for BPSD

The third dimension of Support Systems for BPSD

** Behavioural & Psychological Symptoms of Dementia*

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Method, questionnaires and analysis are developed in the WP6 Report: Support Systems for BPSD– www.alcove-project.eu

The behavioural and psychological symptoms of dementia (BPSD) originate from multiple sources, with the main source being degenerative processes caused by brain disease. Other sources include concomitant psychological or psychiatric conditions, like depression or psychoses, and environmental influences which may be strongly associated to an underlying diagnosis of a disease causing dementia. Since dementia is more prevalent in older persons than in younger ones, somatic illnesses that do not directly relate to dementia are also common. For example, such diseases include cardiovascular diseases, asthma and chronic obstructive pulmonary disease, diabetes mellitus or osteoarthritis. Additionally, common conditions which might be a factor in BPSD are pain, immobility, malnutrition, and incontinence. BPSD may also originate from a person's erroneous interpretation of his or her surroundings which can occur either with or without the loss of senses such as eyesight or hearing, or even balance. In addition, human emotions such as frustration, worry, sorrow or need of company or love, may play a role.

In addition to the cognitive and functional declines caused by Alzheimer's disease and Related Disorders, BPSD represent the main causes of a dramatic impairment of quality of life among people living with dementia and their carers, as well as the principal cause of subsequent institutionalisation. Different manifestations of BPSD may present at different stages of Alzheimer's disease. Specifically, anxiety, depression and apathy are often observed at mild stages of the disease, whereas aberrant motor behaviour and resisting care and help tend to occur at moderate to severe stages. Still other manifestations may occur at all stages of the disease, and this category includes agitation and aggressiveness, hallucinations, delusions, sleep and appetite disorders. Since pharmacological interventions are still far from efficient and are not well-tolerated, a non pharmacological strategy for treating BPSD appears to be crucial for both the prevention of such symptoms and their care.

The aim of this work has been to summarise the existing knowledge on support systems for BPSD. This included conducting a literature search on articles covering all non pharmacological and pharmacological strategies for BPSD, and identifying outstanding projects in Europe in order to promote best practices and to propose recommendations.

With the objective of proposing operational recommendations, ALCOVE has classified support systems for BPSD into three types or dimensions which are described in this chapter: **structures and care organisations** (first dimension) which are fully or partially dedicated to treating BPSD. These include ambulatory, hospital or nursing home settings, which provide a physical environment where pharmacological, psychosocial and other non pharmacological interventions may be applied. The second dimension involves thse **Individualised patient and family carer interventions** and the third dimension involves **workforce & skills** which includes educational programmes designed for professional or informal carers.

STRUCTURES & CARE ORGANISATIONS* FOR BPSD

The first dimension of Support Systems for BPSD in dementia

*SCO

METHOD

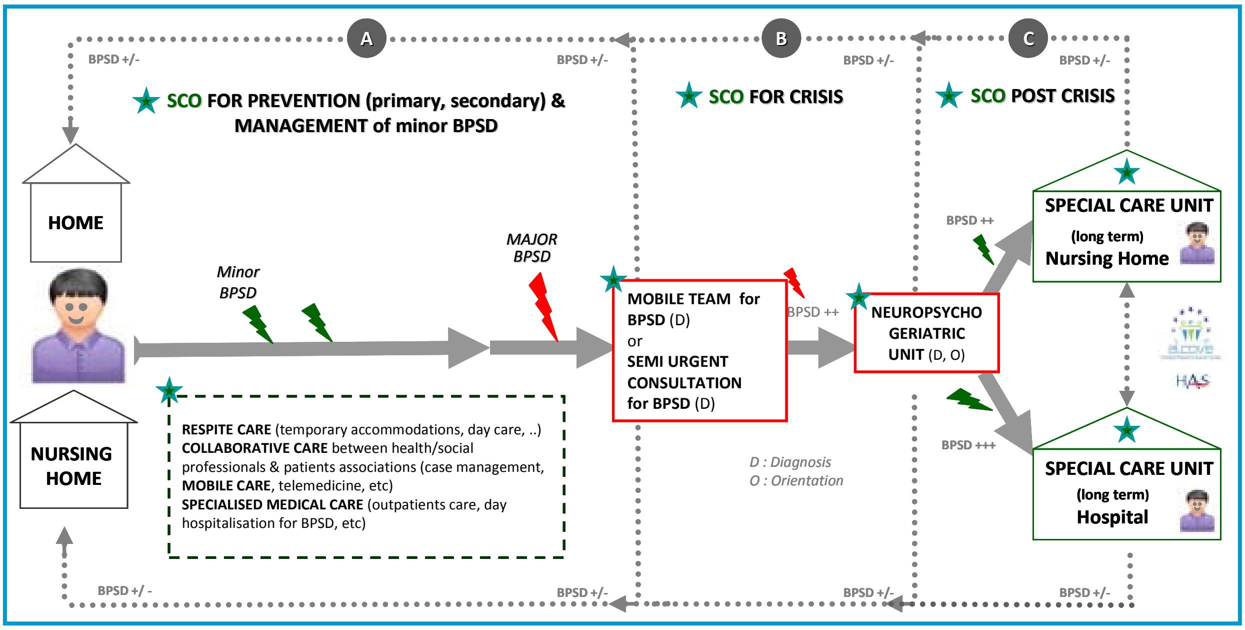
- **Literature review:** A literature review was performed on original articles referenced in Pubmed from January 2000 to March 2012: 660 references were identified, 30 were relevant to the specific topic of SCO for BPSD.
- **Surveys:** A quantitative self-administered questionnaire was developed on National Programmes for Alzheimer disease, including 9 dedicated questions related to SCO for BPSD, with or without national dementia strategy. The questionnaire was sent via email to 28 European countries between March and September 2012. A qualitative and quantitative data analysis was performed, using both EpiInfo 3.5.4 and NVivo 10 software. Another qualitative self-administered questionnaire was developed to collect information about Support Systems, and, in particular, outstanding innovative SCO projects across Europe. The questionnaire was sent via email to ALCOVE Member States between July and Sept 2012. This non exhaustive survey aimed to better describe some specific SCO, running the spectrum from major research projects to minor care organisations, illustrating some innovative dynamics for managing BPSD. A qualitative analysis of the data was performed using a grid with shared criteria.

RESULTS

- **Description of SCO for BPSD all along the patient pathway (Figure 1):** The SCOs were considered at all steps of the care pathway for the patient and the carer. These support systems bring some contributions to preventing BPSD and caring for persons experiencing BPSD. These SCO can be involved even before the first BPSD episode (primary prevention, step A), at the moment of occurrence of minor or major BPSD (crisis, step B), or after the BPSD episode (secondary prevention, step C).

The SCO which are principally involved at the prevention stage (step A) include "**respite care**", such as temporary nursing home accommodations or day care, **collaborative care**, such as multidisciplinary interventions at home or in a nursing home, and special medical care involving the GP or specialised medical follow-ups performed in outpatient setting or in day care units, for example. Before considering hospitalisation in **specific neuropsychiatric units** for major BPSD or crises (step B), some structures propose innovative **outpatient consultation services or mobile teams dedicated** to BPSD. After the crisis (step C), patients presenting with persistent minor BPSD may be followed up with within **dedicated day care structures** and all SCO involved at the primary prevention stage, or may be admitted into **specialised units within nursing homes or hospitals** (Figure 1).

Figure 1. Structures and Care Organisations for BPSD all along the Patient Pathway
Step A: minor BPSD prevention & management - Step B: major BPSD crisis management - Step C: BPSD management & prevention



- **Assessment of SCO for BPSD care in the literature people with dementia:** Very few studies evaluated SCO. When SCO were evaluated, it was done by using behavioural scales assessing and not exclusively the family carers. Nevertheless, collaborative care provided to the family carer and integrated within primary care involving multidisciplinary teams led by an advanced practice nurse may be more efficient in preventing BPSD than current care practices (1). Most of the studies which disclosed significant behavioural benefits have combined multiple approaches. Corbett et al. performed a systematic review of services providing information and/or advice to people with dementia and/or their carers (2). They found 13 randomised controlled trials in which 2 out of 3 measured quality of life and indicated benefits regarding neuropsychiatric symptoms. However, they did not address carer burden. Most interventions included key elements such as skills training, telephone support and direct help in navigating the medical and care system. There seems to be some support for the value of information services, however, more information is needed to determine the specific elements that are effective. Moreover, combined support for people with dementia and carers provided in Meeting Centres may be more efficient in improving behaviour and mood than regular day care support (3). In their 2009 review, Lai et al.'s (4) evidence for special care units pointed out that no randomised controlled trials meeting the selection criteria had been identified. France's new type of neuropsychiatric units dedicated to BPSD "Cognitive and Behavioural Units" has been recently evaluated in observational studies (5, 6). The NeuroPsychiatric Inventory score may thus decrease at the two week after discharge mark from a Cognitive and Behavioural Unit, in particular, the sub-scores assessing delusion, agitation, depression, anxiety, disinhibition and aberrant motor activity symptoms (6).

- **Structures & Care Organisations for BPSD in Europe**

  - **Quantitative analysis of the European Survey on SCO for BPSD**. Twenty-four questionnaires from 21 countries (there were more questionnaires than countries because of autonomous divisions within some countries) were collected for the quantitative survey (response rate: 87%). Survey results show that countries with a national Dementia strategy (national plan) have developed more SCO for BPSD than countries without strategies (see Table 5 p.33 Structures and Systems dedicated to BPSD).

These SCO are developed for the prevention and management of minor BPSD both in ambulatory settings (step A) and when individuals are at home, as well as for major BPSD (crisis, step B & post crisis, step C). The observed difference between countries with and without a national plan is statistically significant except for day hospitalisation (Figure 2a: SCO, step A) and hospitalisation units in neurology and in geriatrics dedicated to Alzheimer disease (Figure 2b: SCO, step B & C).

Figure 2a. Structures and Care Organisations for the Prevention & Management of minor BPSD (SCO step A)

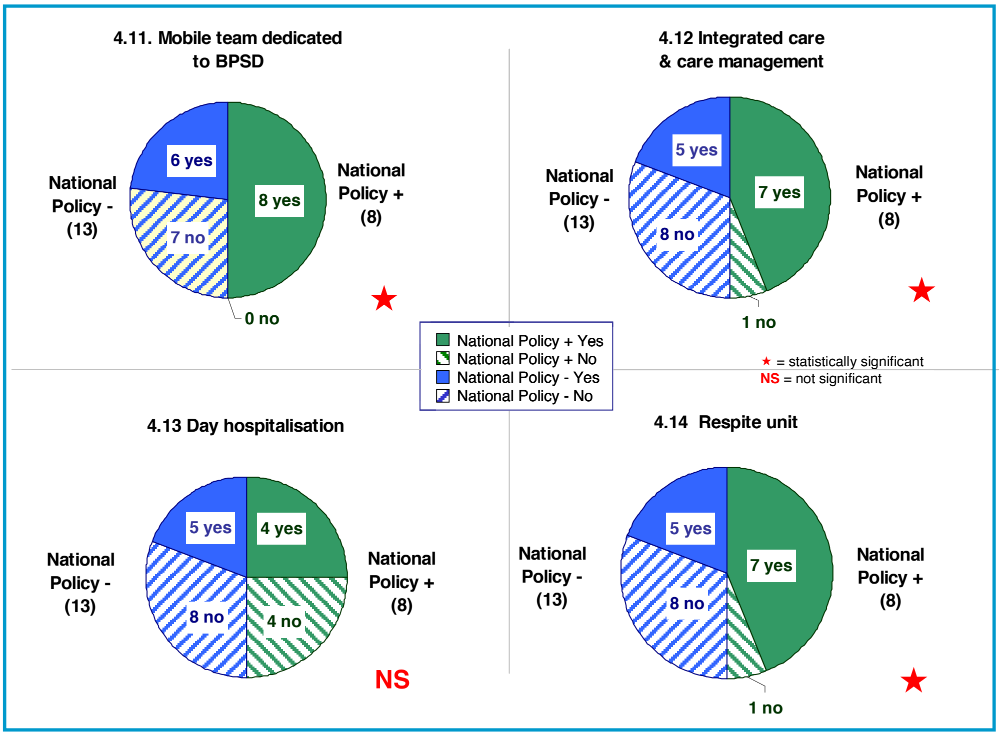
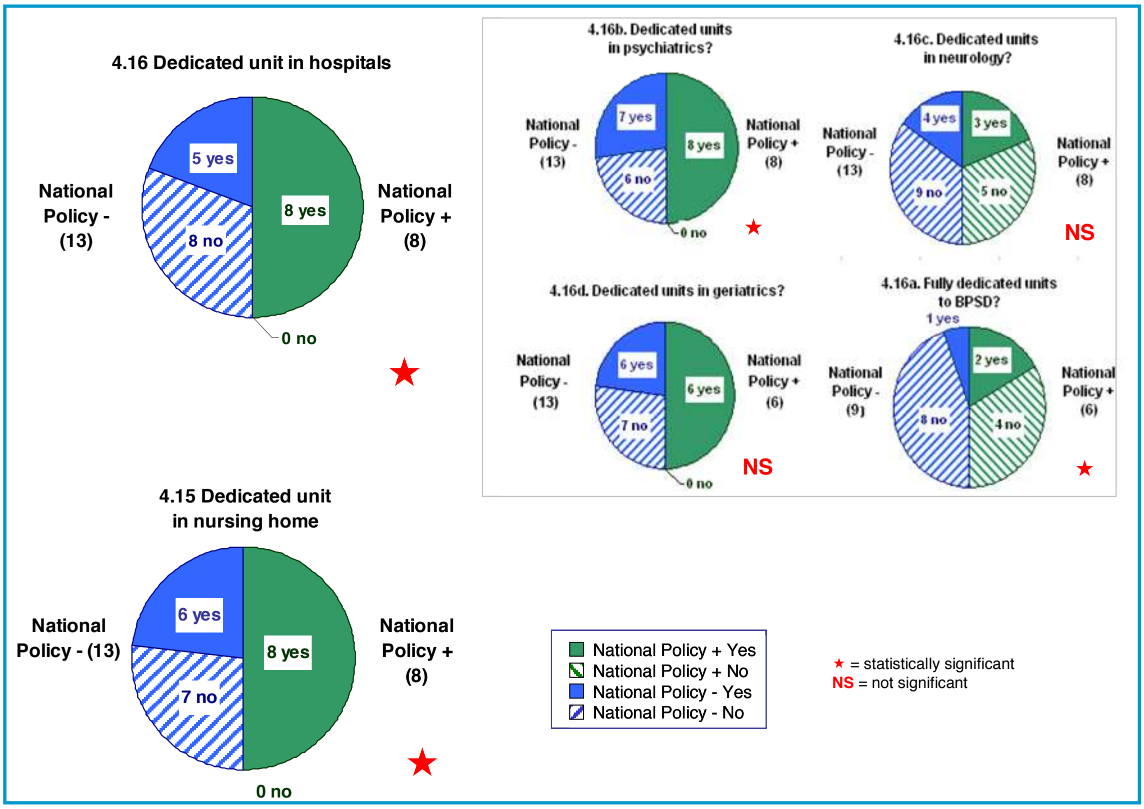


Figure 2b. Structures and Care Organisations for the Prevention & Management of major BPSD: Crisis (SCO step B) and Post-Crisis (SCO step C)



- **European Qualitative Survey on outstanding SCO projects for BPSD.** Fifteen responses from 5 countries were collected. Collected projects could be classified into 3 types: Home interventions/case management (e.g. Home support in France, see below); Hospital and Nursing Home dedicated units; Registries collecting data from various SCO about people experiencing BPSD (e.g. The national Swedish BPSD Registre, see below). All referenced projects or programmes are included in the ALCOVE Toolbox

Home support provided by multidisciplinary specialised teams to prevent BPSD in France

International scientific literature and clinical studies show that multidisciplinary home interventions involving specialised nurses and other carers such as psychomotor therapists and occupational therapists bring significant benefits to the prevention and care of behavioural disorders (8, 9). Therefore, the French Alzheimer Plan has set up specialised teams within the framework of home nursing services. These are spread out equitably across France. Based on the medical prescription, teams combining the intervention of gerontological assistants, occupational therapists and psychomotor therapists visit the home. As soon as a diagnosis of dementia is made, these teams educate the person living with dementia, and assess the need for housing adjustments, rehabilitation and cognitive stimulation and help with behavioural problems.

The National BPSD Registry in Sweden

This national quality registry initiated in November 2010, aims to improve and guarantee the quality of the treatment and care for persons experiencing BPSD (7). All included persons are assigned a score using the NeuroPsychiatric Inventory, and basic information such as diagnosis, age, gender, all medications used and different non pharmacological care interventions applied are registered. BPSD profiles are created and the different interventions applied are followed up with and evaluated continuously, with automatic feedback given to the teams for making quality improvements. To date, 216 municipalities and 1,505 units, nursing homes and BPSD-teams in specialised clinics are participating in the registry which monitors 5,350 patients. The registry is being expanded rapidly throughout the country. This information is used to gather knowledge on BPSD prevalence, BPSD prevention and management and quality improvement. Preliminary results will be available by the end of 2013. This national, person-centred support system is an example of sharing medical & social information concerning persons experiencing BPSD, whatever their SCO may be.

RECOMMENDATIONS ON STRUCTURES & CARE ORGANISATION FOR BPSD

The first dimension of Support Systems for BPSD

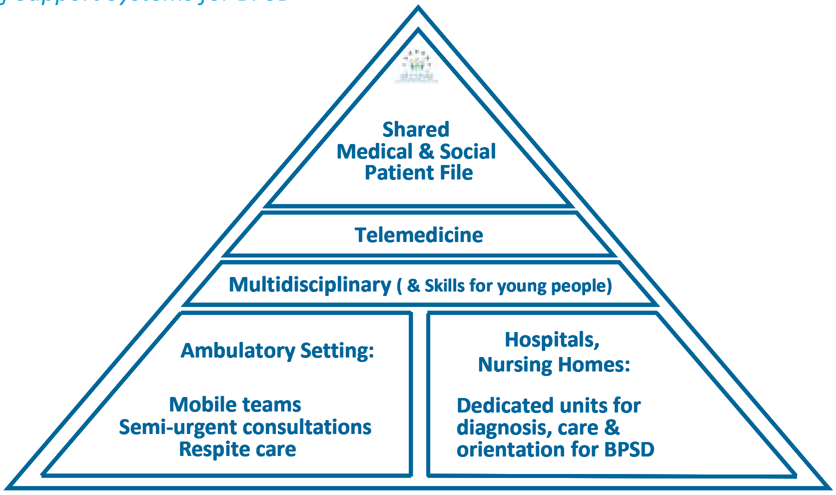


Figure 3. Structures and Care Organisations (SCO): Pyramid of Recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Recommendations on Structures & Care Organisations for persons experiencing BPSD are the following (Figure 3):

[1] **Ambulatory SCO for persons experiencing BPSD should be developed**, because it is crucial to prevent and manage BPSD at an early stage. This will enhance the person's possibilities to live at home as long as possible.

Mobile teams with specific skills for the caring of BPSD, both in the home and nursing home setting. For instance, specific mobile teams dedicated to BPSD in high population density areas and specific competencies within geriatric mobile teams in low population density areas.
Semi-urgent consultation for BPSD (delay < 1 week): at the hospital or via telemedicine, the aim being to respond quite rapidly to behavioural disorders so as to prevent emergency hospitalisation. Different specialists, such as neurologists, geriatricians or psychiatrists could perform such a medical consultation. A multidisciplinary approach involving specialised nurses and psychologists as well as providing telephone support to the person and/or his or her carers may be also useful.
Respite care possibilities are necessary because it appears crucial to help informal carers by giving them a break from caring for the person when needed. This would serve to prevent psychological and physical carer exhaustion. Literature analysis shows that good carer health can prevent BPSD. Respite care possibilities include day care centres and temporary accommodations for the person living with dementia, and home professionals to support the carer.

[2] **Dedicated units for BPSD in Nursing homes and Hospitals should be developed** because the development of this kind of nursing or hospitalisation unit has already shown to be of dramatic help for patients presenting with major BPSD in several European countries.

[3] **A shared medical and social patient file as an optimal tool, key to an indispensable multidisciplinary approach, should be promoted**, because for high care efficiency it appears important to rapidly share medico-social, clinical, diagnosis, psychological and behavioural data regarding the patient and the main carer. A shared file would need to be kept up to date all during the patient care path.

A multidisciplinary approach should be adopted at each structural level (nursing home, dedicated unit for BPSD, mobile team) and at the patient-centred pathway level (general practitioner, other physicians, case manager, therapist, social workers etc.) A specialised nurse-led multidisciplinary team including psychomotor therapists and occupational therapists has been shown to be beneficial in the prevention and care of minor BPSD in people living with dementia at home. As concerns more severe BPSD, the intervention of a medical doctor and a psychologist would be useful in preventing emergency hospitalisation.

Consider specific skills key to young patients' care among all SCO, because of the specific needs of these people and their families.

[4] **Quality and impact indicators for persons experiencing BPSD, family carers and professional carers should be collected** because it is crucial in daily practice to assure and monitor the quality of care within the different SCO. To set up new SCO for research purposes and in order to guarantee the usefulness of SCO in the real world, it is necessary to follow impact indicators which also target professional carers (see ALCOVE Toolbox for criteria).

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NON PHARMACOLOGICAL & PHARMACOLOGICAL THERAPIES FOR PEOPLE EXPERIENCING BPSD

METHOD

- **Literature review:** The objective of this chapter is to investigate BPSD management. A literature review covering two databases, Cochrane and PUBMED, was performed. First, we searched for available studies on BPSD management by using the following key words: BPSD, behaviour, dementia, management and therapies. Limitations were: RCT, five years, and text or abstract available, randomised control trial or review. Study protocols were excluded, 17/125 abstracts were extracted from the Cochrane database for further review, as well as 148 abstracts from PUBMED.

RESULTS

- **BPSD management at the individual patient level (pharmacological & non pharmacological):** The primary management strategies for a person experiencing BPSD, include:

  1) always treating the underlying disease when possible, AND adopting non pharmacological approaches to relieve the symptoms causing distress by assessing the underlying needs of the person

  2) treating concomitant diseases and symptoms when appropriate.

  Furthermore, marking a division between pharmacological and non pharmacological treatments may not serve our purposes. Rather, person-centred approaches centred in the person's and carer's needs should be adopted. The non pharmacological and homeopathic therapies used to treat BPSD as listed in the literature are listed in Table 1, and BPSD pharmacological therapies are listed in Table 2.

  The literature review unveiled the thinness of evidence in existing studies as to the efficacy of non pharmacological approaches in BPSD management. Most of the benefits shown were either achieved when pooling data from several studies and approaches, or from multicomponent studies which included the possibility of tailoring the interventions individually. Thorough cost benefit analyses of non pharmacological therapies, including those that individually tailored support to meet personal needs, are few but promising.

  In addition, it is important to keep in mind that several effective pharmacological treatments may have serious adverse effects e.g. antipsychotic medications, mood stabilisers such as carbamazepine, or valproate. Because of their negative benefit/risk balance in BPSD treatment and because of their high rate of prescription, long term antipsychotic limitation is a crucial safety topic (see Chapter ALCOVE Toolbox p. 84).

Table 1. Non pharmacological and homeopathic therapies according to their impact on BPSD

Therapy	Evidence	Therapy	Evidence
Acupuncture for vascular dementia	I	Massage and touch	W/I
Antioxidants	I	Multisensory stimulation	I
Aroma Therapy	I/NE	Music therapy	I/W/C
Behavioral interventions:Agitation	S	Transcranial magnetic stimulation	I
Behavioral interventions:Depression in PWD	S	Transcutaneous electrical stimulation (TENS)	W/I
Behavioral interventions: Need driven in PWD	S	Physical activity	I
Bright light therapy#	NE/W	Reminiscence	W/I
Cognitive stimulation#	W/I	Robot	W
Cognitive training	I	Snoezelen	I
Dog assisted therapy	I (W)	Support and psychotherapy	S
Environment	W/I	Validation	I
Exercise	W/I	Yokukansan	W/I
Homeopathic methods	I	Non pharmaclogical studies in BPSD	S
Horticulture	I	S=strong evidence, W=some evidence, weak, C=controversial evidence, I=insufficient data, NE=No evidence# Multicomponent interventions (see Method for specifications)	

Table 2. Pharmacological therapies as to the disease index and some concomitant diseases according to their impact on BPSD

Therapy	Evidence	Therapy	Evidence
Antidepressants in Dementia#	NE	Melatonine	W/C
Antipsychotic (atypical)	S*	Memantine	S
Cannabinoids	NE/I	Modanifil	NE
Cholinesterase inhibitors for BPSD	S/I	Mood stabilizers#	W
Cyproterone	W/I	Oxytocin	W/I
Donepezil	W	Prazosin	W
Gingseng	I	THERAPY FOR CONCOMITANT DISEASES SYMPTOMS	
Hirudin + Donepezil	W	Malnutrition	I
Cerebrolysin + Donepezil	NE/W	Pain	W

CAUTION: Because of their negative benefit/risk balance in BPSD treatment & because of their high rate of prescription, long term antipsychotic limitation is a crucial safety issue
S=strong evidence, W=some evidence, weak, C=controversial evidence, I=insufficient data, NE=No evidence # heterogeneous group, results may vary

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OVERVIEW OF INTERVENTIONS FOR FAMILY CARERS

A general review of educational and social supports for family carers was performed as well as a separate review focused on psychosocial interventions (PSI) and BPSD outcomes.

METHOD

- **Literature review**: The literature review was performed for educational and social supports for informal carers. An Internet-based search of 10 previous EU projects and 3 dementia networks and their results concerning dementia and BPSD was conducted. 9 publications were extracted from Cochrane and 47 from PUBMED.

RESULTS

- **Main findings:** The main findings were the following:
  - Multicomponent information services are beneficial, particularly if they include psychosocial interventions (PSI). Therefore the PSI were also evaluated separately (see next review): Focus on PSI & BPSD
  - Carer support, including information and education, showed:
    - strong evidence of reducing depression; may have impact on the informal carer's care burden
    - underutilised potential for reducing care costs
    - some evidence of reducing BPSD
  - Gerontechnology is promising and
    - shows evidence as a source of information and social support
    - has a conditional effect which depends on the type of technology, its purpose, the design and individual tailoring of the programme, the target person of the programme e.g. care recipient vs carer
    - however, available human contact may be needed to increase feasibility

  - may be useful in solving some safety issues
- Respite care
  - Definitions for respite care varied depending on whether programmes for the person with dementia and BPSD were available or not
  - Day care programmes designed for respite care are effective. However, attention should be paid to the availability of any multicomponent, individually-tailored programme targeted to BPSD.
- A care coordinator was useful in organising collaboration among persons with BPSD and their carers and included a cost benefit. Such coordination may delay institutionalisation.
- Special care units were superior in managing depression and avoiding physical restraints than in ordinary nursing homes, however their use of antipsychotic drugs was higher.
- Assessing and meeting the needs of both the care recipient AND the informal carers is necessary

FOCUS ON PSYCHOSOCIAL INTERVENTIONS & BPSD

One of the most demanding and difficult aspects of care for family carers is the management of BPSD. Non pharmacological interventions are recommended as the first step of BPSD prevention and management, but there is a lack of precise recommendations concerning family carer interventions. The objective of this work was to assess the effectiveness of informal carer interventions and, in particular, PsychoSocial Interventions (PSI) for BPSD prevention and management, as well as proposing a classification system for these interventions and assessing their implementation and further needs across Europe.

METHOD

- **Literature review:** A systematic review was conducted through the use of different databases (PUBMED, COCHRANE, WOS, PsycINFO, Psycarticles, Alzforum) of all interventions involving informal carers, either alone or with the patient, and having an outcome related to BPSD. The search was limited to the past twelve years. Guidelines, reports, meta-analyses, systematic reviews, randomised controlled trials, and clinical trials were included. The quality assessment for each article was assessed based upon the SIGN criteria and each article was analysed with the same criteria grid. The selected outcomes included the ability of the carer to prevent and manage BPSD and/or a decrease in BPSD using the NeuroPsychiatric Inventory and/or a decrease in antipsychotics prescriptions and/or a delay in institutionalisation and/or a decrease in the use of emergency services.

- **Surveys:** A self-administered quantitative questionnaire was developed to collect information about outstanding care-giver interventions across Europe. The questionnaire was sent via email to 41 national or regional Alzheimer associations thanks to and via Alzheimer Europe, to 24 national level health authorities who were asked to redirect it to the appropriate memory clinics, and to the French memory centres. Recipients responded during the period of July -Sept 2012. A qualitative data analysis was then performed. Another qualitative self-administered questionnaire was developed on National Programmes for Alzheimer disease (see p. 32) and included a dedicated question related to explicit actions for structured training for family carers. The questionnaire was sent via email to 28 European countries between March and September 2012. A quali-quantitative data analysis was performed, combining the use of both EpiInfo 3.5.4 and NVivo 10 software.

RESULTS

- **Data collected:** Included in the literature review were the following: 1 guideline, 2 reports, 12 meta-analyses or systematic reviews, 45 randomised controlled or clinical trials. The qualitative survey included 15 questionnaires completed by 15 different countries (response rates: Alzheimer associations: 34 %, European memory clinics: 24 %, French memory centres: 33%; please note that response was not mandatory if there was no outstanding project to describe). The quantitative survey included 24 questionnaires completed by 21 countries (there were more questionnaires than countries because of autonomous divisions within some countries, response rate: 87%).

- **Classification**:** There is a great heterogeneity of terms used in literature to describe Psychosocial Interventions (PSI).

  Based on the most recent literature, ALCOVE proposes to establish a terminology consensus and in doing so proposes classifying PSI for Carers & Patients, tailored to their respective needs, into 9 categories (Figure 4). PSI Carers and Patients are part of the IPCI (Individualised Patient and family Carer Interventions), with non pharmacological and pharmacological therapies for Patient. The IPCI is one of the 3 main dimensions of support systems for BPSD (Figure 9 p. 70).

- **Effectiveness in the literature**:** The quality of intervention studies has improved over the last few years. There is strong evidence (level 1) that PSI are effective in decreasing BPSD and carers' negative reactions to these symptoms. PSI have comparable effectiveness or are more effective than antipsychotics and are safer, having no side effects (level 1). All interventions are not equally effective on BPSD. Comments on Figure 4 and the following:

  - ➢ Multi-component interventions (1), tailored to the needs of both the family care giver and the patient, delivered at the patient's home with regular follow-ups are the best option (level 1) but it is not possible to precisely determine which strategy or specific components is most effective on specific symptoms. Multicomponent interventions [e.g. psycho-educational programmes (2) and home visits (4)] demonstrated efficiency in decreasing BPSD, improving carer outcomes and delaying institutionalisation.
  - ➢ Psycho-educational programmes (2), rather than educational programmes (3), are effective in decreasing BPSD and improving carer outcomes (level 1). Use of theoretical models increases effectiveness and promotes transposition of these programmes.
  - ➢ Home-visits (4) are effective for crisis management, and may be part of a more comprehensive BPSD prevention programme.
  - ➢ No significant effects on BPSD outcomes have been shown for programmes that are (6) technology-based, (7) promote self-care techniques, (8) peer-support, or (9) conference/meeting/counselling, but these interventions are interesting when they are combined with other interventions. The type of BPSD and carer characteristics can influence the efficiency of the intervention.
  - ➢ There is still a need for an evaluation of the cost effectiveness of the different interventions, both on their own and combined with pharmacological treatments.

Figure 4. ALCOVE Classification of Psychosocial Interventions for Carers & Patients, tailored to their respective needs

1. Multicomponent (e.g. Psycho-Educational + home visit)*
2. Psycho-educational programmes*
3. Skills training & Educational programmes focused on the disease, therapies, environment,… *
4. Home-visit/Mobile team*
5. Activity planning, environmental redesign, Socio-cultural programmes
6. Technology-support for family carers (web or telephone support)
7. Self-care techniques for family carers (Cognitive Behavioural Therapy, stress management, coping with change as a result of caregiving)
8. Peer-support group
9. Conference/Meeting

* Interventions demonstrated as effective on BPSD in the literature

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- **Implementation across Europe**

  - **The quantitative survey** found that only 7 European countries have made an explicit decision concerning structured training for familycarers: 6 of these 7 countries are among the 8 countries with a national dementia policy in place, the 1 remaining country does not have a national policy, which is statistically significant. We do not have sufficient data to determine implementation of specific interventions at the European level (Figure 5).

Figure 5. Quantitative analysis of national strategies in Europe

  - However, in the **qualitative survey**, the PSI programmes collected from 15 countries were consistent with literature findings. Multicomponent and psycho-educational interventions provide a comprehensive approach to BPSD (management skills, prevention, emotional management, treatment, structural factors). More than 2/3 of described PSI performed a self-assessment, with tools that are mostly evidence-based. Only the home-visit programmes provide a follow-up evaluation. All of these projects are available in the online ALCOVE Toolbox and in the WP6 ALCOVE report. Two examples are described below.

Psychological Interventions for Family Carers in Greece

A regional programme delivered at Memory clinics/hospitals/day centres in Thessaloniki, with a combination of multiple PSI:

- Psycho-educational: with active participation of the carers; provide information on an ongoing basis , and information for more effective care, coping strategies, shared experiences, psychological support
- Support groups aim to help the carers to be effective in their role and build up the necessary psychological skills to deal with difficult aspects of the disease and feelings of loneliness, loss and helplessness. Techniques from CBT
- Family therapy helps family members express their feelings, manage the challenge of care giving, deal with the changes in roles and develop communication skills, while supporting family adaptation.
- Relaxation programmes aim to reduce anxiety levels and manage psychosomatic symptoms using the therapeutic techniques of Progressive Muscle Relaxation and Autogenic Relaxation which lead to deep relaxation of the body and mind. Relaxation training sessions help carers to develop well-being and decrease stress levels
- Web-based services provide the opportunity to carers who cannot attend a traditional face-to-face support group due to geographic and time constraints to participate in an online support group. Group meetings are performed by online video conferencing through the use of a standard platform.

Community Service Programmes for people living with dementia inCyprus

Mobile team interventions for persons living with dementia and their carers delivered at home by mental health service.

The psychiatrist first evaluates the patient who is usually accompanied by his or her carer. After this evaluation, the patient is referred to the community nurse trained in dementia and to the occupational therapist that has also been trained in dementia.

- The psychiatrist follows up regularly with the patient at the clinic and prescribes the needed medication. The psychiatrist has regular meetings with the other professionals who are also treating the patient. The therapeutic team evaluates and supports the family and the carers.
- The therapeutic team also provides programmes for persons living with dementia and supports the carers at Day Centres.

RECOMMENDATIONS ON INDIVIDUALISED PATIENT & CARER INTERVENTIONS FOR BPSD

The second dimension of Support Systems for BPSD

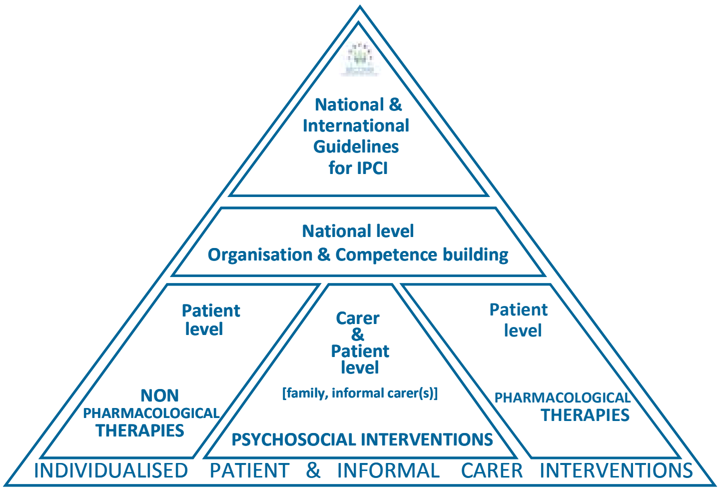
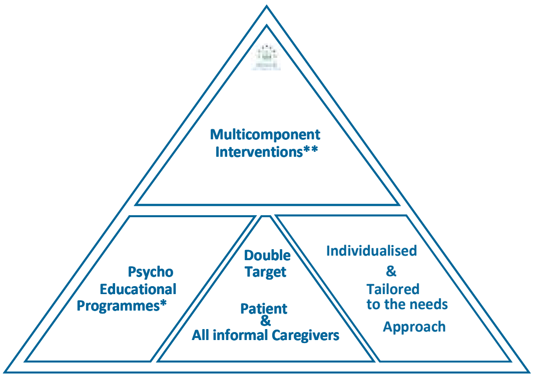


Figure 6a. ICPI Pyramid of recommendations
for all Individualised Patient & Family Carers Interventions



* Multidisciplinary, in link with Patient & Family Associations, with information on BPSD
** Factors of efficacy on BPSD : Psychoeducational programmes, home site interventions, periodic follow up; coordination between community & specialized settings are required

Figure 6b. PSI Pyramid of recommendations
For Psycho Social Interventions for Family Carers and Patients

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Reminder: To clarify its recommendations ALCOVE proposes to distinguish among ICPI - Individualised Patient and family Carer Interventions - (1) the non pharmacological and (2) pharmacological therapies for the patient and (3) the psychosocial interventions for both carer and patient (also found in the literature as non pharmacological interventions).

Recommendations on Individualised Patient and Carer Interventions for BPSD are the following (Figures 6a & 6b):

[1] 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. This is because PSI are effective on behavioural disorders (agitation, aggression, disruption, shadowing, depression, and repetitive behaviours other than psychosis) and safer than antipsychotics. More precise evaluations of PSI combined with non pharmacological therapies for the patient should first be performed to identify which combination strategy is most effective and should be evaluated in medical-economic terms.

Psycho-educational programmes must be part of national programmes also for dementia. This is because among PSI, Psycho-educational programmes (category 2, see PSI classification Figure 4) are effective in preventing BPSD and they are easy to implement. Increased effectiveness has been shown with the use of a theoretical model and with the active participation of the carer.

Multicomponent interventions could also be part of national programmes, because among PSI, multicomponent interventions (category 1, see PSI classification Figure 4 tailored to the needs of carer and patient, with periodic follow-up and home-delivered) are the most effective option. They are effective for patient and carer outcomes and delay institutionalisation. However, they require coordination between community and specialised settings and are much more difficult to implement

[2] All Psychosocial Interventions 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 because the dynamics in their relationship can be a source of BPSD, and therefore, key to BPSD management. Their needs must be assessed with the use of medical and social expertise. This includes researching contributing factors for the patient and assessing carer burden, stress, quality of life and self confidence. Because both pharmacological and non pharmacological treatments may have adverse effects, because the status of both the care recipients and their carers may change, and because carers often need emotional support, the continuity of care and of support must be ensured.

[3] A diagnosis approach & multiple therapies for BPSD should be applied at the patient level - Evidence of managing BPSD in terms of individualised patient interventions should include 1) appropriate treatment of the disease index and in relevant cases: 2) research and treatment of the concomitant diseases and their symptoms (e.g. pain, balance, incontinence) combined with specific approaches for BPSD 3) non pharmacological and 4) pharmacological.

WORKFORCE & SKILLS

The third dimension of support systems for BPSD in dementia

TRAINING & EDUCATION FOR PROFESSIONALS

METHOD

- **Literature review:** A literature review for staff educational systems was performed. The literature was explored to find trials and systematic reviews that concerned the effectiveness of staff education for BPSD management. The databases used included Cochrane Reviews and the EBSCO Discovery Service, and these covered the following databases: Academic Search Elite, AgeLine, Business Source Index, CINAHL, ERIC, GreenFILE, Library, Information Science & Technology Abstracts, MEDLINE, PsycINFO, and SocINDEX with Full Text. Six systematic reviews and six controlled trials of appropriate quality were identified.

- **Survey:** A survey was sent to the ALCOVE partner countries concerning the educational frameworks in place ensuring the competence of care professionals in managing BPSD. The survey also sought to find how the competence of different care professionals encountering BPSD is ensured by basic and systematic post-basic education.

RESULTS

- **Main findings in the literature:** Systematic staff training can be recommended to facilitate a unified, systematic way of handling persons experiencing BPSD in a care organisation.

  It can also be stated, on the basis of general knowledge, although without specific evidence, that training usually does provide the trainees with improved resources to deal with BPSD. Policy recommendations need to be based in general knowledge of best practices (such as competence-based adult education principles) – not only direct evidence of training specifically addressing BPSD.

  The learning process of how to deliver staff training seems to be ongoing with the creation of new evidence. Most staff members received their basic education on BPSD at least ten years prior, and many have received little or no education dealing specifically with BPSD management. Therefore, continuous or repeated education is necessary. It also needs to be kept in mind that “the absence of evidence is not evidence of absence”.

- **Situation in Europe:** Thirteen responses were received. This low response rate may reflect a basic difficulty in the approach, since the educational frameworks differ greatly from country to country, and the respondents may not have had enough information about all the different kinds of professional care education programs available in their countries.

  It appears that these 13 ALCOVE Partners Member States, some kind of education, training or course focusing on memory diseases (including BPSD) is provided to care professionals. The programmes vary greatly in length, depth and the professions to which they are targeted, and especially in the emphasis that they place on BPSD. Also, the organisations responsible for the content of the education vary. The content may come from governmental organisations or patient organisations.

  On-the-job training and staff education courses are seen by many, but not all, the respondents as an important component of competence development for BPSD management.

CLINICAL GUIDELINES IN EUROPE

METHOD

- **Survey:** Support for care professionals’ competence in dealing with persons experiencing with BPSD as provided by national clinical guidelines was evaluated by a questionnaire presented to the ALCOVE partners. A survey concerning the existence and contents of national dementia guidelines was sent to all Member States. The questionnaire provided information on 17 of the 19 participating countries, which represents 63% of the EU Member States.

RESULTS

- **Situation in Europe:** In many countries, no national or widely accepted clinical guidelines exist that address care for BPSD. Most countries have guidelines on the management of Alzheimer's disease - all the guidelines stress the importance of using appropriate disease-specific medications, e.g. AChEI as the primary treatment - dementia or memory disorders, and these also cover BPSD. In France, the UK and the Netherlands, specific guidelines have been adopted for the management of BPSD.

  All guidelines emphasise non pharmacological interventions for BPSD as primary. If non pharmacological treatment proves to be inadequate, pharmacological interventions could be applied. The guidelines vary as to the place of antipsychotics in the pharmacological approach and the information about their risk. Many guidelines emphasise the need to carefully evaluate and analyse any concomitant problems that may cause or exacerbate BPSD before deciding on any treatment.

IMPROVEMENT PROGRAMMES FOR ANTIPSYCHOTICS LIMITATION IN EUROPE

The overprescribing of antipsychotics for behavioural disorders in dementia represents a major safety & ethical issue [1]. It is well known today that chronic exposure to antipsychotics is non-effective and deleterious for these people as it can lead to falls, excessive sedation, stroke and an increased risk of mortality, with an overall profoundly negative impact on the individual's health, ability to communicate and quality of life. The shared objective is to revise and modify prescription practices. Also, alongside general policies for dementia, including BPSD prevention and management (BPSD being the main cause of the prescribing of antipsychotics), ALCOVE aims to identify specific policy measures and/or national improvement programmes designed to inform about the risk of long term antipsychotic use in dementia and to limit their overuse in individuals living with dementia.

METHOD

Three approaches were combined: a European quantitative survey, the consulting of websites, and directly contacting teams and experts throughout the ALCOVE network. This research strategy is not exhaustive and aims to share improvement programmes and tools. A self-administered questionnaire was developed on National Programmes for Alzheimer's disease, including 1 dedicated question related to an explicit general statement and/or recommendation for the « Reduction in the use of antipsychotic medication in people with dementia ». The questionnaire was sent via email to 28 European countries between March and September 2012. A quali-quantitative data analysis was performed, combining the use of EpiInfo 3.5.4 and NVivo 10 software.

RESULTS

Among the 8 European countries having national Alzheimer plans, 5 responded that they have a dedicated general statement and/or recommendation regarding the reduction in the use of antipsychotics (see also ALCOVE survey on Clinical guidelines in Europe). ALCOVE has only received information about dedicated actions/programmes in national strategies for the limitation of antipsychotics in dementia with implementation and specific objectives from France and the UK. Of note, Italy has a specific legal framework for antipsychotic prescriptions and Sweden has developed a national BPSD registry. These programmes are described, along with all their tools, in the online ALCOVE Toolbox.

The AMI Alzheimer programme in France [2] [4]

In conjunction with a national task force composed of health professionals and the other institutions, the French National Authority for Health has developed, within the framework of the French Alzheimer Plan, the programme: Alert and Mastering of Iatrogeny (AMI) of antipsychotics in Alzheimer's disease. The objective of the programme AMI-Alzheimer is to reduce the inappropriate use of antipsychotics and to improve care for behavioural disturbances in dementia, while having recourse to other alternative treatments (for example: new care techniques) without deferring to other sedatives or physical restraints.

Dissemination of the AMI Alzheimer programme to all of the healthcare actors should provide for a common alert measurement at the national level (macro), regional level (meso) and even the local level. Only local alert/mastering actions led by teams and prescribers will allow for the reduction of the national alert. Furthermore, this national indicator has been implemented by various institutions.

The measurement of long-term antipsychotics and psychotropics prescriptions was performed using the 3 national insurance databases from 2007 to 2010. The French study showed that Alzheimer's patients and, in particular younger Alzheimer's patients, are overexposed to psychotropics and particularly to antipsychotics (AP). The rate of antipsychotics exposure in persons living with dementia decreased from 16.9% in 2007 to 15.5% in 2010.

The Right Prescription in the United Kingdom [3]

The NHS Institute for Innovation and Improvement together with the Dementia Action Alliance, have launched a Call For Action to work together in a way that will unite them in their common cause to improve the quality of life of people with dementia and their carers by reducing the inappropriate use of antipsychotics for these people.

General practitioners, nurses, leaders in care homes, people with dementia and their families, pharmacists, psychiatrists and many others have organised themselves into eight groups who are committed to leading and taking action to ensure that every person with dementia on antipsychotic medication receives a clinical review and has an evidence-based, personalised care plan developed in partnership with them, their family and the multidisciplinary clinical team. The aim is that all people with dementia who are receiving antipsychotic drugs will have undergone a clinical review to ensure that their care is compliant with current best practices and guidelines, that alternatives to their prescription have been considered and a shared decision has been agreed to regarding their future care by 31st March 2012.

The National Dementia and Antipsychotic Prescribing Audit National Summary Report available online, shows over the last 5 years a decrease of 10.25 percentage points in the prescription of antipsychotic medication from 17.05 per cent in 2006 to 6.80 per cent in 2011. However, these results should be considered with caution due to the absence of information on potential deferral to other psychotropics' drugs; furthermore no data is available on the other 400,000 dementia people living with dementia in the UK, not included in this audit (ALCOVE Executive Board meeting 9-11 January 2013, [5]).

A specific legal framework for antipsychotic prescription in Italy

In 2005, the Italian Medicine Agency (Agenzia Italiana del Farmaco), defined a programme of active pharmacovigilance for antipsychotics prescriptions and their role in the treatment of psychotic and behavioural disorders in persons living with dementia. The prescribing of antipsychotics for persons living with dementia should be made by authorised Specialist Centres as identified by their Region and in accordance with the Italian National Health System's reimbursement procedures.

In December 2006, it was decided that this prescribing of antipsychotics for persons living with dementia should be considered on a case-by-case basis, in accordance with each patient's clinical conditions and upon receiving informed consent from the person or his or her legal representative. A clinical pathway has been developed for the prescribing of antipsychotics in dementia for physicians operating within the Specialist Centres. Information on the impact of this policy in Italy has not yet been made available to ALCOVE.

BPSD Registry & Quality improvement programmes in Sweden

This national quality registry initiated in November 2010, financed by the Swedish Association of Local Authorities and Regions (SALAR), is supported by a special Ministry of Health & Social Affairs programme directed at improving the situation for the most ill elderly. A web-based educational programme is mandatory before joining the registry.

The aim is to improve and to ensure the quality of treatment and care for persons experiencing BPSD. The settings are nursing homes, sheltered accommodations for persons living with dementia, and BPSD-teams at specialist clinics. To date, 216 municipalities, 1,505 units, nursing homes and BPSD-teams in specialised clinics and 5,350 patients are participating in the registry. The registry is being expanded rapidly throughout the rest of the country.

The development of BPSD profiles & different interventions are followed up with & evaluated continuously, with automatic feed back for quality improvement and follow up care. This registry is used as a foundation for quality improvement programmes.

CONCLUSIONS

- **Key points for quality improvement:** Facing a risk situation, quality improvements must address 4 key points to ensure changes to current practice:
    - **Relevant references** must be made available (clinical guidelines, accurate information/knowledge, …) and systematic reviews of prescriptions must be established (with the involvement of the prescribers, the pharmacists and all involved carers, ie. dedicated visits, multidisciplinary consultations, …)
    - **Public campaigns** for health professionals, patients, families, carers, etc. These public education campaigns should be launched to raise awareness about antipsychotics risks and to inform about BPSD care, including non pharmacological alternatives to antipsychotics.
    - **Monitoring relevant indicators** (at the national/macrolevel, and at the local/micro level) is necessary, specifically in terms of impact and results. This would include collecting warning indicators on the exposure of individuals living with dementia

to antipsychotics, while taking into account the possible deferring to other sedatives or physical restraints (i.e. by audit, survey, registry, other databases).

- **A collaborative approach** must be applied with the Involvement of all stakeholders: health and social professionals, patients, carers, etc.

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RECOMMENDATIONS ON WORKFORCE & SKILLS FOR BPSD

The third dimension of support systems for BPSD in dementia

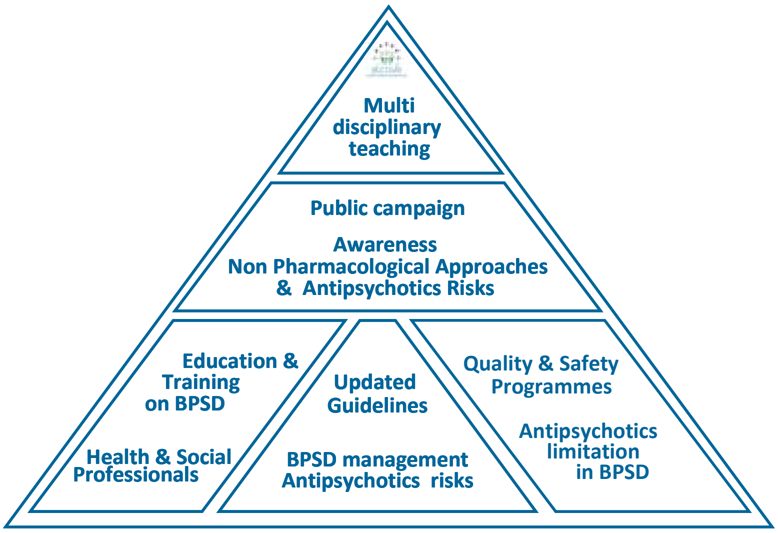


Figure7: Workforce and Skillsfor BPSD - ALCOVE Pyramid of recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

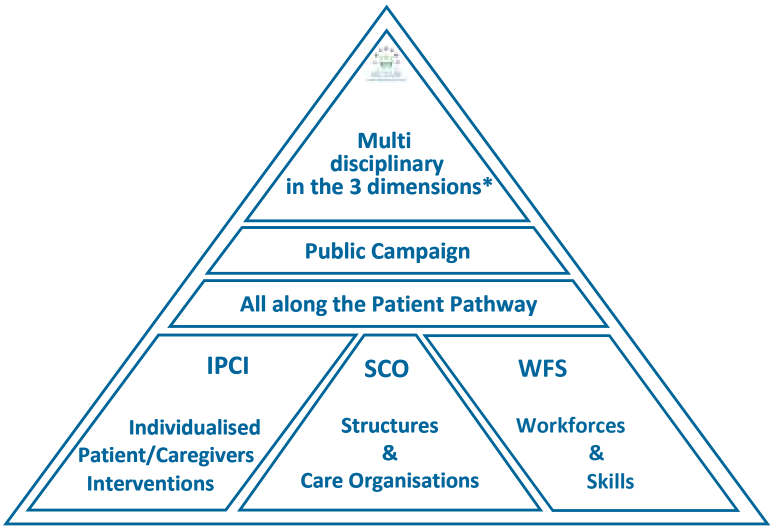
Recommendations on Workforce & Skills for BPSD are the following (Figure7):

[1] **Access to education on BPSD has been shown to be necessary for carers, whether they are professionals or not.** Alarmingly, little information was available in the research literature on the impact of teaching BPSD at the basic level, e.g. in nursing schools or schools for other professionals. However, any teaching of care professionals seemed beneficial.

[2] **Homogeneous guidelines on BPSD management and the side effects of antipsychotics should be disseminated.** Of the European ember States, 63% had national guidelines for dementia. However, only six guidelines addressed BPSD. However, it is important to keep in mind that not all BPSD affect the person living with dementia negatively and each person has different symptoms and needs. Therefore the guidelines should address the necessity of meeting both the care recipient's and the carer's needs with multicomponent and individually tailored programmes after having thoroughly and systematically assessed these needs.

[3] **Quality and safety programmes focused on the limitation of antipsychotics are beneficial and complementary to the better management of BPSD in dementia.** The ALCOVE Toolbox provides tools and recommendations based on the ALCOVE European benchmarking. Quality improvements must address 4 key points: relevant references and systematic prescription reviews; public campaigns to raise awareness about antipsychotics risks and to inform about BPSD care; measurement and monitoring using relevant indicators at the national and local levels; collaborative approach with the involvement of all stakeholders.

RECOMMENDATIONS FOR A GLOBAL STRATEGY FOR BPSD SUPPORT SYSTEMS



* IPCI: Multicomponents interventions; SCO: Shared medical & social patient file; WFS: Multidisciplinary teaching

Figure 8. Global Strategy for BPSD: ALCOVE Pyramid of Recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Recommendations for a global strategy for BPSD support systems are the following (Figure 8):

[1] Because BPSD are sources of family carer burden and depression, as well as an increased rate of institutionalisation of persons living with dementia, all nations should develop a 3-dimensional holistic strategy (Figure 9):

1st dimension: how to develop structures and care organisations - SCO - for BPSD,

2nd dimension: how to implement individualised patient & family carers interventions - IPCI - combining psychosocial interventions for carer and patient and non pharmacological and pharmacological therapies for patient,

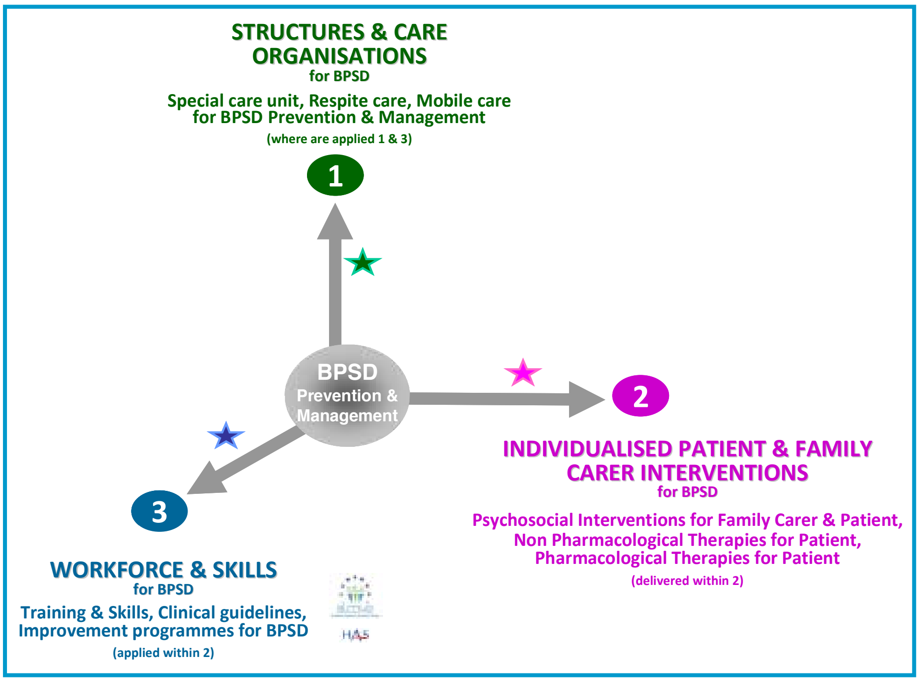
3rd dimension: how to ensure a skilled workforce - WFS - with systematic education programmes for health & social professionals.

[2] These 3 dimensions of BPSD Support Systems should be adapted and implemented at each step of the patient pathway (Figure 10): for the prevention and management of minor BPSD (step A), for major BPSD crisis events (step B) and for the post crisis phase (step C) including secondary prevention. These implementations should be designed with close cooperation between decision makers, health and social services, and professionals and patient and family associations.

[3] Public information on BPSD prevention and management and about antipsychotics' risks should be part of general awareness campaigns for decreasing fear and stigma about dementia.

[4] A multidisciplinary approach in all dimensions of Support Systems for BPSD should be promoted.

Figure 9. ALCOVE “3D view” on Support Systems for BPSD ★★★



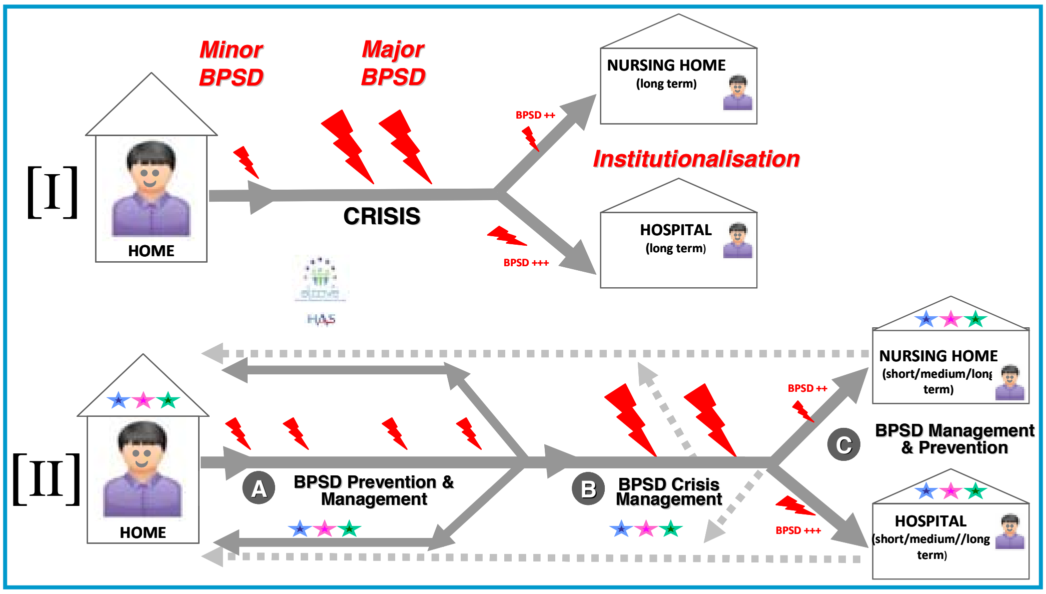
Comments Figure 9:

The 3 dimensions of BPSD support systems, i.e. structures and care organisations (1, SCO), Individualised patient and family carer interventions (2, IPCI) and workforce & skills (3, WFS), are independent and represent 3 “orthogonal” axes resumed as a “3D view”. All combinations involving some particular SCO, applying diverse IPCI (i.e. non pharmacological interventions) and some WFS (i.e. trainings and skills) may be thus considered.

The “3D view” is not fully taken into consideration in literature since numerous interventions combine the evaluation of SCO, such as day care centres, IPCI, such as psychosocial interventions, and WFS, such as specific professional education programmes. Furthermore, most of the studies mix functional, cognitive and behavioural evaluations, both in the patient and the carer. Disentangling these multiple interventions and approaches helps to better evaluate them, and more importantly, to consider the best combination.

Figure 10. Patient Pathway without [I] and with [II] dedicated 3D Supports Systems for BPSD

The 3 dimensions of BPSD Support Systems ★★★ (see Figure 9) are applied all along the Patient Pathway



Comments Figure 10:

[I]: Without 3D support systems for BPSD

[II]: With 3D support systems, there are less BPSD crises and they occur in later phases of the disease. The quality of life of persons experiencing BPSD and their carers is preserved. Out- or in-hospital care and services taking care of persons experiencing BPSD vary. With these support systems for minor and major BPSD, persons could stay at home longer.

Step A: minor BPSD prevention and management

Step B: major BPSD crisis management

Step C: BPSD prevention & management

RIGHTS, AUTONOMY & DIGNITY OF PEOPLE WITH DEMENTIA

ALzheimer COoperative Valuation in Europe

RIGHTS, AUTONOMY & DIGNITY OF PEOPLE LIVING WITH DEMENTIA

Professor Dr Nys, Herman, University of Leuven; Raeymaekers, Peter, Lyragen; Gombault, Bénédicte; Rauws, Gerrit,
King Baudouin Foundation, Belgium

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PARTICIPANTS TO WORKSHOPS: Roberto Andorno, University of Zurich; MickäelBasson, CHU Saint-Louis; Alison Bowes, University of Stirling; Gily Coene, Universiteit Gent; Jan Craenen, KULeuven; Marikede Boer, VU University Medical Center; EMGO Institute for Health and Care Research; Sylvie Froucht-Hirsch, Fondation Rothschild de Paris; Chris Gastmans, University of Leuven; Tom Goffin, University of Leuven; Gabriel Gold, EUGMS and Geneva University Hospitals; Dianne Gove, Alzheimer Europe; Fabrice Gzil, Fondation Médéric Alzheimer; Karen Harrison Dening, Dementia UK; Emmanuel Hirsch, Université Paris-Sud 11 - Assistance publique/Hôpitaux de Paris; Adrian Ivanoiu, Université catholique de Louvain - Cliniques universitaire Saint-Luc; Martine Joris, De Wingerd; Josef Kuře, Masarik University - Faculty of Medecine; Marja-Liisa Laakkonen, Helsinki City Hospital Laakso, Memory Clinic and University of Helsinki; Antonio Lobo, Hospital Clínico Universitario and University of Zaragoza; Anna Mäki-Petäjä-Leinonen, University of Helsinki; PaulMatthys, Belgian Federal Public Service for Health; Alex Peltier, Mutualités chrétiennes; André Pereira, University of Coimbra, Faculty of Law; Saïda Sakali, King Baudouin Foundation; Pablo Simon-Lorda, Andalusian School of Public Health; Chandy Van de Venne, Belgian Federal Public Service for Health; Isabelle Van der Brempt, Belgian Federal Public Service for Health; Régine Wilmotte, Belgian Federal Public Service for Health; Michael Schuerch, Clinique Le Péri; Patrick Verhaest, Expertisecentrum Dementie Vlaanderen vzw.

ASSOCIATED PARTNERS: Assistance Publique-Hôpitaux de Paris, Espace Ethique, France ; King Baudouin Foundation, Belgique ; Institute of Health and Welfare, Finland.

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CONTEXT, OBJECTIVES & METHOD

CONTEXT & OBJECTIVES

The dignity and identity of all human beings need to be protected, regardless of their medical condition. In the case of dementia, we are forced to explore the dignity, decision-making competence and civic rights of the individual in new terms.

Autonomy is an essential value in medical ethics. The respect given to a person's rights, choices and preferences is crucial. Dementia raises difficult ethical issues because the person's competence (and by extension competence to consent) is changing and evolving continuously.

From an ethical perspective it is crucial to strike the right balance between the autonomy of the person living with dementia and the protection of this person and his or her environment. The availability of high quality care and legal provisions is a prerequisite for the respect of a person's dignity. But striking the right balance is not only a question of care models or laws, but also, and more importantly, one of listening and understanding. In order to take into account the diversity of personal wishes, social values, and cultural backgrounds; as well as the fluctuating cognitive and functional competences resulting from the disease, a permanent dialogue between the person living with dementia and his or her formal and informal caregivers is needed.
Competence assessment tools and advance directives have been suggested as tools to foster and support dialogue between persons living with dementia and their environment.

- **Specific Objective :** We have explored how on one hand the assessment of competence and on the other hand the drawing up and use of advance directives by persons living with dementia can help these persons to strengthen their rights and have their autonomy respected while protecting them and their environment at the same time.

METHOD

Three specific tasks were undertaken:

- **A critical review** of the medico-legal (KU Leuven, Belgium) and bioethical (Espace Ethique, Assistance Public-Hôpitaux de Paris, France) literature regarding the concept and assessment of competence and the international and national regulation of advance directives.
- **A questionnaire survey** regarding the legal regulation of advance directives in EU Member States.
- **3 workshops:**
  - International workshop 1: Finding the right balance between autonomy and protection of the person with dementia. Advance directives and competence assessment
  - Workshop 2: Antipsychotics and Alzheimer-like diseases
  - International workshop 3: Finding the right balance between autonomy and protection of the person with dementia. Advance directives and competence assessment: discussion of the draft-of recommendations

COMPETENCE ASSESSMENT

RESULTS [1]

- **Key messages:**

Competence & Dementia

- Presumption of competence.
- Distinction between decision-making capacity (in a care and treatment context) and functional competence. Functional competence relates to the ability to perform activities of daily life, live alone, drive a car, etc.
- Respect of the person's remaining capacities.
- Differentiating between competence and incompetence remains difficult.
- Repeated assessment on a case by case approach is necessary.

- **The presumption of competence:** The term competence cannot easily be defined. It is a multidimensional construct with important clinical, legal, ethical, social, and policy aspects. Competence in a care and treatment setting refers to 'decision making capacity' or 'capacity for autonomy'. This decision-making capacity in a care and treatment setting is not linked to performing acts with legal consequences – as competence does in a juridical framework - but refers to a more personal context. It is linked to making choices regarding the integrity of the individual him/herself, restricted to a specific (medical) care intervention, and this competence is usually assessed by a medical professional and not a judge.
  One must also make the distinction between decision-making capacity (in a care and treatment context) and functional competence or functional capacity. Functional competence relates to the ability to perform activities of daily life, live alone, drive a car, etc.

  For a person to be competent, (s)he should be able to understand a task or a situation, appreciate the relevance, the emotional impact, the rational requirements or the future consequences of a decision. (S)he should be able to reason on the risks and benefits and weigh the arguments, and finally (s)he should be able to express a choice. This implies that competence varies with regard to the purpose under consideration. It also depends on various aspects of personality, affective regulation, and intellectual or cognitive functioning of the person. In addition, somatic factors play a role: visual and hearing functioning, as well as the influence of substances or drugs might influence competence and its assessment.

  Because of the important impact of the disease on daily life, a person living with dementia is almost always confronted with a presumption of incompetence. Before the person has even spoken, his or her words are marked by a systematic devaluation [2] of his or her capacities. The opposite approach should be promoted. The person living with dementia should be "presumed capable": "still capable of" rather than "now incapable of" [3]. Incapacity is not to be deduced automatically from a diagnosis of dementia.

  A protective attitude, inspired by the "precautionary principle" is too often privileged when coping with the alteration and the progressive loss of decision-making capacities of a person with dementia. But this attitude can threaten a person's capacity of taking initiatives and his or her feeling of control over his or her own life, whether (s)he is staying at home or living in an institution. Under certain circumstances, giving up specific activities (when the disease is at an advanced stage) can be justified by the best interest of the person and his or her surroundings (driving a vehicle, manipulating dangerous objects), but it is doubtful whether systematic decisions of this kind are respectful of the person's autonomy and take into account his or her remaining capacities. The specific context in which these decisions are taken should always be examined thoroughly and re-evaluated regularly. Numerous tools to assess competence have been developed [4], but many have not been validated or are not task-specific. Assessment of competence should be used to enhance the welfare of people with dementia. It should serve to provide help and shelter to those whose competence is reduced and autonomy to those whose competence is maintained [5].

- **Competence assessment & advance directives:** An important question is whether patients who have been diagnosed with dementia can at that stage still make up an advance directive. The fact that capacity is frequently impaired in persons living with dementia provides reasonable grounds for doubt and prudence.
  Given the possibility of fluctuating capacity in dementia, the capacity should be carefully assessed at the time an advance directive is prepared and also before it is implemented; assessments should be performed during lucid intervals so as to promote the patient's autonomous decision-making ability. Written records should be kept of who carried out the assessment of capacity, and of the criteria and methods used; if any doubts remain, another expert should be consulted [6].

- **Competence assessment & driving:** Contrary to competence assessment within the context of advance directives, competence assessment as regards driving is a rather strictly regulated domain in European jurisdictions. This is not a surprise as dementia and driving safety is of particular concern to society. The question arises whether the diagnosis of dementia has legal consequences regarding the license [7] to drive of the person concerned. We have looked for an answer to this question in different European jurisdictions [8].
  A preliminary condition for the competent authorities to take a measure is that they have in one or another way access to the health information of the person concerned. Also in this respect different possibilities can be distinguished.

  - **A first possibility** is the competent authorities being notified of the dementia diagnosis by the treating physician or the person him-or herself (or a relative). This notification can be either on an obligatory or a voluntary basis. If the treating physician notifies of the diagnosis (s)he can do so either with the consent of the patient or without his or her consent or even his or her knowledge. Still another distinction is notification to a health inspectorate that in turn can notify the road safety authorities of the diagnosis or the latter may be informed directly.

- **A second possibility** for informing the competent authorities of a dementia diagnosis is by submitting persons who request a driving license or to renew existing one to a health examination, be it obligatory or voluntary. With regard to the competent authorities' access to a dementia diagnosis, in all European jurisdictions a diagnosis of dementia is protected by the obligation of the treating physician to respect medical secrecy and confidentiality. Article 8 of the European Convention of Human Rights obliges the Member States to take positive measures to legally protect medical secrecy. A legal requirement for physicians to notify a health inspectorate or road safety inspectorate of each diagnosis of dementia is too disproportional to be in accordance with article 8 of the Convention. If such an obligation would be limited to a diagnosis of dementia and not exist for other diseases which might create risks for driving safety also, article 14 (prohibition of discrimination) would be breached. To our knowledge, no such blunt obligation to notify the competent authorities of a dementia diagnosis exists in European jurisdictions.
- **A third approach** which is more acceptable from the point of view of protecting medical secrecy and privacy consists of granting physicians the possibility of notifying the competent authorities of a diagnosis of dementia or any other medical condition that may create a risk for safe driving. This possibility of notifying authorities while respecting medical secrecy concerning a diagnosis of dementia may create a danger for the person himself or herself, or even third persons, because the patient may continue to drive despite there being evidence that he or she is not capable to do so in a safe way. Most of the times this possibility to notify is not based on statutory law but is 'judge made law'. The advantage of such an approach is its flexibility. A danger is that it lacks objective criteria and may lead to arbitrary decisions by physicians when notifying (or not) of a diagnosis of dementia.
- **A fourth approach** consists in legally obliging the treating physician to inform and warn the person living with dementia of the risk that a cognitive impairment may affect his ability to drive. It is then that person's responsibility to inform the relevant authorities because the obligation to respect medical secrecy prevents the physician to inform the competent authorities. This solution lays the responsibility to inform the competent authorities entirely upon the person living with dementia or his relatives and may create a false feeling of reassurance because the treating physician has no means to control whether notification by the person has been made or not.

Next to notification in one or another way, access to health information may also be guaranteed by making the initial request for a license to drive or its renewal dependent upon a health examination. An important legal problem here is how to prevent discriminatory measures based on medical condition and/or age. The most straightforward solution is to make any request for a driving license (initial request and request for renewal) dependent upon a health examination. In this way no one is discriminated against. A disadvantage may be that this is probably a very costly procedure. Another option is to limit the validity of a driving license until a certain age and make its renewal dependent upon a medical examination.

Once they are informed in one or another way that a diagnosis of dementia has been made, authorities responsible for safe driving such as the police can react in different ways. To our knowledge the diagnosis of dementia does not automatically lead to the withdrawal of the driving license of the person concerned in European countries. The right to autonomy and privacy (article 8 European Convention on Human Rights) would oppose such an automatic measure. Nonetheless, there are countries where measures exist that may have this result. Another possibility is to oblige the treating physician to recommend the person living with dementia to stop driving. If the person does not want to stop driving and the physician, the relatives or the police find him unable to drive they can refer him to a consultative driving test. In other countries a diagnosis of dementia may be followed by a medical examination in order to control the ability of the person to drive.

CONCLUSIONS & MAIN RECOMMENDATIONS

Competence Assessment for people living with dementia: Competence assessment has the goal, on the one hand, to protect the person's rights but on the other hand to, in the best way, respect their autonomy. Therefore, deciding on the competence of a person is a question of **striking the right balance between the autonomy of the person living with dementia and the protection of this person**.

[1] **A person diagnosed with dementia should not automatically be considered incompetent to exercise her/his right to self-determination.** Presumption of competence needs to be guaranteed for people living with dementia during the course of their disease.

[2] **When the person living with dementia is not able to decide alone, the selected healthcare proxy should be involved.** Only when the person living with dementia no longer has capacity for decision-making, the proxy and the treating healthcare professional should rely on the advance directive (if present) or the person's past values and critical interest.

[3] Competence needs to be assessed on the basis of a case-by-case approach and should be repeated for every important care or treatment decision.

[4] When assessing the competence of a person, contextual factors need to be taken into account including medical, psychological and social factors.

[5] Whether a person is competent to make a decision regarding care and treatment needs to be assessed by a qualified and skilled healthcare professional. In many cases but not all, this will be the treating physician. However, this person should not decide alone in all cases and situations. If deemed appropriate, he or she needs to take into account the opinion of others (colleagues, proxies or relatives, nurses, social workers, psychologists, etc.)

[6] Additional research on the development and validation of efficient and practical assessment tools are needed, especially for people with a progressive cognitive condition like dementia.

ADVANCE DIRECTIVES

RESULTS [9]

- **Introduction:** Advance directives are written or oral statements that are intended to govern healthcare and related decision-making for their authors, for both positive (consent) and negative (refusal) decisions, should they lose decisional capacity in the future. The basis for the moral (and legal) validity of advance directives is the person's right to autonomy or to self-determination, regardless of his/her current cognitive capacity and capacity to express wishes. The aim of advance directives in the context of advance care planning for a person living with dementia is to clarify this person's wishes and will concerning his/her future in the light of an anticipated decline of the capacity to make decisions and/or of the ability to express these towards others. Advance directives may or may not include end-of-life decisions.

- **Key messages:**

Advance directives & Dementia

Advance directives

- can be a major improvement in respecting the person with dementia as it gives the opportunity to express wishes on matters considered as being important for the person,
- are ideally part of an ongoing process and dialogue with relatives, doctors, and other caregivers,
- and advance care plans become intertwined tools to support the autonomy of people with dementia,
- need to be reviewed regularly.

The legal validity of advance directives is recognised in 22 Member States of the European Union.

There is no obligation to make an advance directive.

- **Mapping of national regulations on advance directives:** The legal status of advance directives is a complex issue as many elements have to be considered. One of these is the Biomedicine Convention of the Council of Europe (Oviedo, 1997). The ratification of this Convention has important legal consequences and mitigates the distinction between states that have enacted specific legislation on advance directives and states that have not enacted specific legislation but that have ratified the Convention.

  - **Countries with specific legislation regarding advance directives (Table 1)**
    Some interesting conclusions can be drawn from Table 1. Regulating advance directives is a (very) recent phenomenon in Europe. Ten of the 15 laws were approved after 2005. Only two are dated before 2000. Nine countries have ratified the Biomedicine Convention while six did not ratify. In only one country the refusal of a treatment is not binding. In the other countries an advance directive that contains a refusal is prima facie binding but there are important differences between the countries. In different countries only refusals of treatment by terminally ill patients are binding while in all other cases refusals are not binding. In other countries a refusal is binding but may be overruled by physicians when there are good reasons to do so. And still other countries have limited the validity in time of an advance directive. Such a limit may vary between 2 to 5 years. The question arises as to what the exact legal consequences are when a person living with dementia who has drawn up a valid advance directive subsequently becomes incompetent, and therefore unable, to confirm its validity when this period of validity has expired. One possible consequence is that this person may no longer have a valid advance directive. In practice, this would mean that most persons living with dementia could only have a

valid advance directive for a period where they are still competent to make decisions, in other words, when they do not need an advance directive. A more useful interpretation of the consequence of the limitation in time is that the advance directive has to be confirmed when this period of time has expired in order to stay valid when the author still has the competence to do so. However, if the author has become incompetent in the meantime, the advance directive remains valid and this time for an undetermined period. It goes without saying that the older such an advance directive is, the less likely it will be considered as prima facie binding.

Table 1. Countries with specific legislation regarding advance directives

COUNTRY	YEAR OF LAW	REFUSAL OF TREATMENT BINDING OR NOT	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Austria	2006	Yes (limited to 5 y)	No
2. Belgium	2002	Yes (No time limit)	No
3. Denmark	1998	Yes, terminally ill - No in other cases	Yes (1999)
4. Estonia	2001	Text law not clear	Yes (2002)
5. Finland	2005	Yes, emergency treatment - No in other cases	Yes (2010)
6. France	2005	No (limited to 3y)	Yes (2012)
7. Germany	2009	Yes (no time limit)	No
8. Hungary	2009	Yes (limited to 2y)	Yes (2002)
9. Latvia	2009	Yes (no time limit)	Yes (2010)
10. Luxembourg	2009	In principle; unless good reasons	No
11. Netherlands	1994	In principle; not if good reasons	No
12. Portugal	2012	Yes (limited to 5 y)	Yes (2001)
13. Slovenia	2007	Yes, terminally ill - No in other cases	Yes (1999)
14. Spain	2002	In principle; not if against good medical practice	Yes (2000)
15. United Kingdom	2005	Yes	No

- **Advance directives & the Biomedicine Convention**

Article 9 of the Convention relates to previously expressed wishes and provides the following: 'The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account. It is not clear what is to be understood by 'taken into account' – i.e. what authority is to be accorded to an advance directive and what an advance directive may legitimately cover: it remains open whether the advance directive merely provides an indication of presumed wishes or whether it has a binding authority. In this respect it is relevant to refer to article 27 of this Convention that provides that: 'None of the provisions of this Convention shall be interpreted as limiting or otherwise affecting the possibility for a Party to grant a wider measure of protection with regard to the application of biology and medicine than is stipulated in this Convention'. If article 9 has to be understood in a way that an advance directive is not binding but only indicative, article 27 authorises Member States to give patients wider protection by providing that an advance directive has to be respected under certain conditions.

Ratification of an international treaty such as the Biomedicine Convention has important legal consequences. Article 1 § 2 of the Biomedicine Convention clearly imposes the responsibility for the development and effective implementation of the Convention's norms upon the States that have ratified it. In other words: the internal law of the States that have ratified the Convention has to conform to the Convention. In this respect it is helpful to cite the Explanatory Report to the Convention: "Conformity between the Convention and domestic law may be achieved by either applying directly the Convention's provisions in domestic law or by enacting the necessary legislation to give effect to them. With regard to each provision (of the Convention), the means will have to be determined by each Party in accordance with its constitutional law and taking into account the nature of the provision in question. In this respect, it should be noted that the Convention contains a number of provisions which may under the domestic law of many States qualify as directly applicable ('self-executing provisions')". In other words, conformity of internal law with the provisions of the Convention does not necessarily imply that existing national legislation has to be adapted or new national legislation should be enacted. There is a general agreement that article 9 of the Biomedicine Convention is directly applicable. This means in practice that an advance directive becomes legally valid in a country that has ratified the Biomedicine Convention although there is no specific regulation of advance directives in that country. This conclusion mitigates of course the importance of the distinction between countries that dispose of specific legislation of advance directives and those that haven't but have ratified the Biomedicine Convention. Table 2 gives an overview of the status of the Biomedicine Convention in the countries without specific legislation on advance directives.

Table 2. Countries without specific legislation regarding advance directives

COUNTRY	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Bulgaria	Yes (2003)
2. Cyprus	Yes (2001)
3. Czech Republic	Yes (2001)
4. Greece	Yes (1999)
5. Ireland	No
6. Italy	No
7. Lithuania	Yes (2003)
8. Malta	No
9. Poland	No
10. Romania	Yes (2001)
11. Slovakia	Yes (1999)
12. Sweden	No

Seven of these countries have ratified the Biomedicine Convention. Given the direct applicability of article 9 of this Convention, the legal validity of advance directives in these countries is beyond any discussion. If we also take into consideration the countries where specific legislation of advance directives already exists (Table 1) this means that the legal validity of advance directives is recognised in 22 Member States of the EU. Moreover, 2 of the 5 countries without specific legislation and which have not yet ratified the Biomedicine Convention are in the process of approving specific legislation: Ireland and Italy.

- **Advance directives & persons living with dementia:** The ethical and legal questions raised by advance directives have a general character, regardless of the specific type of disease. However we will focus here on some specific issues relating to dementia.
  - **Ethical issues: continuity and foreseeability**

    In ethical and legal terms, so called continuity of the person is a necessary condition for the validity of an advance directive. In other words, the instructions contained in an advance directive may only be carried out if the person living with dementia by implementation is the same person as the author of the directive. This requirement may appear to be trivial. However, with regard to dementia, doubts have been expressed as to whether such continuity is in fact present. Much philosophical discussion exists about the relationship between the ‘then’ self that existed prior to the onset of dementia and the ‘now’ self that lives almost entirely in the present without any connection to the past. Proponents of the ‘precedent autonomy or critical interest’ approach underline the stewardship responsibility of the ‘then’ self for the journey into forgetfulness. As a consequence, post-dementia decisions should be based on historical lifetime values and beliefs. Proponents of the ‘experiential interest approach’ argue that there can be major changes in values between the time when persons complete their advance directive and when it comes into effect.

    This led them to propose that the person with predementia and the person living with dementia are two different people. Even if persons living with dementia might be incompetent, they still have the capacity to experience their life and the context wherein it is embedded. Hence, according to the experiential interest approach, contemporary preferences, needs, and desires, coupled with the present well-being of the person living with dementia should be the main area for substituted decision-making. It could thus be concluded that an advance directive has no claim to be strictly binding in cases of dementia.

    A different view can be taken from a practical and legal point of view. In every jurisdiction the law always assumes continuity of the person, irrespective of illness or change of personality. Without wishing to settle these controversies, the facts of bodily identity, and, in particular, social connections, provide important grounds for considering the person as the same person throughout the full course of the illness [10].

    Another point of controversy is whether it is possible to imagine the life of a person with dementia. Some people therefore deny that a person living with dementia can draw up an advance directive. In response to these doubts, it may be objected that there is always a discrepancy between reality as it is imagined and experienced, and that decisions are never made with full knowledge of the facts. In addition, advance directives are generally prepared by older people. Their experiences with their own illnesses and those of others will have shaped their ideas of a good life and a good death, and the advance directive will be an authentic expression of these values. Moreover a person confronted with early-stage dementia retains mental capacity. His initial experience of the disease and his knowledge regarding its likely course allow him to draw up a well-grounded advance directive [11].

Against this background, the rights of people with dementia to play their part in medical decision-making with the aid of an advance directive should be supported.

- **Advance directives and advance care planning**
  In Europe few people with dementia have made advance directives [12]. They are usually associated with life-threatening diseases such as cancer or heart disease, cover emergency situations where patients have lost consciousness or refer to prolonged states of unconsciousness. The situation is different in the case of dementia. Depending on the stage at which a person is diagnosed, she/he may live for another 5 to 20 years. During this time, the mental capacity of the person concerned will gradually and progressively deteriorate and this will affect his or her ability to make decisions. At various times during the illness, situations will arise when care and treatment decisions must be made.

It is obvious that no pressure should be exerted on any individual to draw up an advance directive. Advance directives are there to support people who feel strongly to make their preferences effective. In the case of dementia, advance directives:

- contribute to the peace of mind and to maintain a feeling of some kind of control over one’s future care and treatment;
- offer the opportunity to express wishes about care and treatment one would like to have;
- offer the opportunity to protect oneself against inappropriate care and unwanted treatment;
- help to realise that even with a diagnosis of dementia, it is possible to make decisions about one’s own life;
- offer an opportunity to discuss various options with the doctor;
- offer the opportunity to understand what certain treatments involve and perhaps allay fears.

Advance directives are also important for formal and informal carers. They:

- contribute to the peace of mind that the person is receiving the care and treatment (s)he would have liked and not what s(he) would have objected to;
- help professional carers to comply with the obligation to take into consideration the wishes of the person with dementia;
- help informal carers to deal with decision-making dilemmas;
- help to avoid conflicts between informal and formal carers about what the person living with dementia would have wanted [13].

Ideally advance directives are part of an ongoing process and dialogue with relatives, doctors and other caregivers. This is best achieved within the broader context of advance care planning [14]. Advance care planning is a structured way to initiate and maintain a dialogue about future care. It is a process of communication, consultation and decision-making between a person, his or her carers and other relevant persons (relatives, proxy, etc.) concerning future (health) care options. Aspects of advance care planning include opening the conversation, exploring options, identifying wishes and preferences, deciding about specific treatment, asking someone to speak for you or appointing someone to make decisions (proxy) on your behalf, and letting people know your views, preferences and wishes. In some countries guidelines for the implementation of advance care plans have been published [15]. According to the NHS Guide on this topic, aspects of advance care planning include: opening the conversation, exploring options, identifying wishes and preferences, deciding about specific treatment, asking someone to speak for you or appointing someone to make decisions (proxy) on your behalf, and letting people know your views, preferences and wishes. The wish to make an advance care plan as well as including general wishes concerning care can be part of an advance directive [16]. In that sense advance directives and advance care plans become intertwined tools to support the autonomy of people with dementia.

CONCLUSIONS & MAIN RECOMMENDATIONS

Contextual provisions of Advance Directives for persons living with dementia

[1] **Advance directives should be part of the broader context of advance care planning.** An advance directive is a means to provide high quality care in line with the wishes and will of the person living with dementia, and not a goal in itself or an end product of advance care planning. It is an opportunity for starting and maintaining a process of communication between the person living with dementia and his or her carers.

[2] **National authorities are encouraged to provide a legal framework on advance directives adapted to the specific needs of people living with dementia.**

[3] P**roper models and good practices specifically oriented towards people living with dementia need to be implemented, further developed and disseminated,** because all stakeholders – patients, relatives, informal and formal carers, healthcare

policy organisations, … – have to be made aware of the specificities and complexities regarding advance care planning and advanced directives for people living with dementia.

[4] **The person's current attitude towards a certain treatment or a care intervention - ascertained feelings, desires and wishes - should always be taken into account,** even if there is an advance directive or a designated proxy, since there can be major changes in values and preferences between the time when persons complete their advance directive and when it comes into effect.

[5] **Although the use of advance directives should be promoted, nobody can be forced to make up an advance directive.** If a person does not want to address issues about future care and treatment or end-of-life for his- or herself, this needs to be respected.

[6] **Doctors and other healthcare professionals involved in the care of people living with dementia should be properly trained in advance care planning and the use of advance directives.**

[7] **In order to increase peoples' knowledge about advance directives and to encourage their use, the costs for drafting and registering these directives should be minimal for the person living with dementia.**

Content of Advance Directives for people living with dementia

[8] **People should be encouraged to designate a healthcare proxy in their advance directives.** This person represents the person living **with** dementia in making decisions on medical and care matters when the person is no longer competent to make these decisions. A healthcare proxy should be aware of the wishes, beliefs, values, preferences and decisions of the person s(he) is representing, therefore communication and deliberation between this person and the proxy is indispensable.

[9] **Advance directives are preferably accompanied by a personal statement of values containing information about what is important and meaningful in the life of the person who has drawn up the directive.**

[10] **The refusal of a specific treatment expressed in an advance directive is prima facie legally binding and should consequently be respected**

[11] **With regard to a request for a treatment in an advance directive, a healthcare professional should take this request into account, in so far as this treatment accords to professional standards.**

Validity and applicability of Advance Directives for people living with dementia

[12] **It is important to advise persons living with dementia of the possibilities of advance care planning and the use of advance directives whilst they still have the necessary competence and mental capacities to make use of them**. Therefore, the importance of a timely and disclosed diagnosis needs to be underlined. Nevertheless, a sensitive approach is necessary, taking into consideration that not all persons are prepared to decide about their future.

[13] **In the context of high quality care, advance directives should be integrated in all relevant patient and care records with maximal respect of privacy and confidentiality.**

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THE ALCOVE TOOLBOX FOR ANTIPSYCHOTICS LIMITATION IN DEMENTIA

A WORLDWIDE SHARED SAFETY ISSUE

THE ALCOVE TOOLBOX FOR ANTIPSYCHOTICS LIMITATION IN DEMENTIA
A wordwide shared safety issue

Dr Banaei-Bouchareb, Linda[a]; Professor López-Peña Ordoñe, Tomás[b]; Micheneau, Carole[a]; Dr Villar Acevedo, Gloria[b]; Arévalo Nieto, Gonzalo[b]; Dr García García, Mercedes[b]; Calvo Orra, Luis[b]; María de la Rúa, José[b]; Professor Segovia Pérez, Carlos[b]; Dr Leperre Desplanques, Armelle[a]
[a]Haute Autorité de Santé, France; [b]Instituto de Salud Carlos III, Spain

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THANKS TO THE ENTIRE ALCOVE EXECUTIVE BOARD FOR THEIR CONTRIBUTION TO THE ALCOVE TOOLBOX: Armelle Leperre-Desplanques, ALCOVE Project Leader, Nathalie Riolacci-Dhoyen, Haute Autorité de Santé, Work Package 1 - Carlos Segovia, Tomas Lopez Peña-Ordoñez, Instituto de Salud Carlos III, Work Package 2; Michal Novak, Rostislav Skrabana, Institute of Neuroimmunology, Work Package 3; Nicola Vanacore, Angela Giusti, Istituto Superiore di Sanità, Work Package 4; Dawn Brooker, Karim Saad, The Association for Dementia Studies, University of Worcester, Work Package 5; Harriet Finne-Soveri, Matti Mäkelä, Institute of Health and Welfare, Work Package 6; Gerrit Rauws, Bénédicte Gombault, King Baudouin Foundation, Work Package 7.

WE ALSO WISH TO THANK: Christine Barr, Nadia Chambers, Alistair Burns and Philippe Robert

ALL SURVEY RESPONDENTS: Stephen Abela, Anasthanase Bénétos, Jean-Christophe Bier, Jean-François Dartigues, Chantal Girtanner, Catherine Helmer, Thérèse Jonveaux, Esme D. Moniz-Cook, Katarina Nägga, Sakka Paraskevi, Eric Salmon

All the contents of the ALCOVE Toolbox are available on line: www.alcove-project.eu

WHY SUCH A TOOLBOX?

Overprescribing of antipsychotics for the behavioural disorders in dementia represents a major worldwide safety & ethical issue that has been underlined by the World Health Organisation [1]. It is well known today that chronic exposure to antipsychotics (AP) is non-effective and deleterious for people living with dementia as it can lead to falls, excessive sedation, stroke and an increased risk of mortality, with an overall profoundly negative impact on the individual's health, ability to communicate and quality of life.

The ALCOVE sustainable network has provided the opportunity to make a statement in Europe on the crucial issue of iatrogenicity and overuse of antipsychotics in dementia, underlined by the WHO and identified by the European Medicine Agency [2] as a priority research for 2013. In Europe, methods, references, tools and expertise are available in the field of safety & antipsychotics risk reduction. These successful experiences might be useful for those European countries wishing to promote risk reduction programmes.

To avoid deferring to other sedative drugs or physical restraints & to achieve improvements in outcome for people living with dementia, antipsychotics reduction in behavioural and psychological symptoms of dementia (BPSD) should be developed along with BPSD prevention and management improvement, using non pharmacological alternatives to antipsychotics and individualised patient and carer interventions, including psychosocial interventions.

ALCOVE European Member States have chosen to build a shared Toolbox to tackle the safety issue of limiting antipsychotics in dementia (Figure 1). This Toolbox provides concrete tools, key messages and experiences for all actors and in all dimensions of care: dedicated risk measurement (Figure 2) & risk reduction programmes (Figure 3), timely diagnosis, prevention & management of BPSD, and ethics in practice (Figure 4), all related to the use of antipsychotics.

WORLD HEALTH ORGANISATION POINT OF VIEW

Issues in the use of antipsychotic medication for people living with dementia, WHO, 2012 (1)

"There has been increasing concern about the use of antipsychotic drugs for the management of behavioural and psychological symptoms in dementia. These drugs appear to be used too often and, at their likely level of use, potential benefits risks may be more than the benefits. This is a problem across the world.

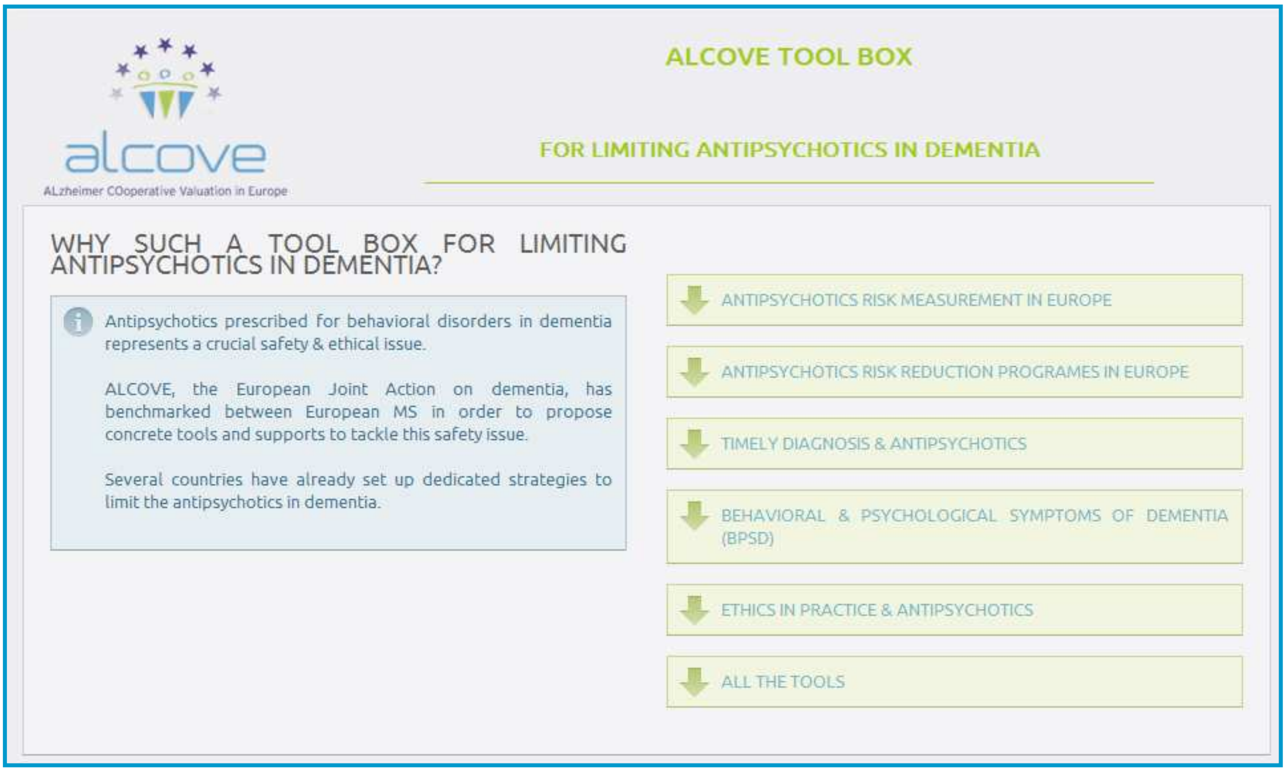
Although the first-line treatment for behavioural and psychological symptoms of dementia is non pharmacological, the prescription of psychotropic medication remains high and it appears that current systems deliver a largely antipsychotic-based response. These drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia. The risks include cerebrovascular adverse events and mortality. Clearly, some people benefit from these medications (e.g. where there is severe and complex risk). However, the current level of use of antipsychotics for people with dementia presents a significant issue in terms of quality of care, with negative impacts in patient safety, clinical effectiveness and the patient experience.

The mounting body of evidence documenting these risks has led North American and European regulatory authorities to issue warnings against the use of atypical antipsychotics to treat patients with dementia, and the US Food and Drug Administration now requires both atypical and typical antipsychotic drugs to carry a "black box" warning label highlighting the increased risk of mortality. Despite these warnings, antipsychotic drug use still seems to be widespread, particularly in care settings. Studies indicate that prescribing rates for antipsychotic medication use in dementia varies from 20% to 33% and most cases are residing in nursing homes. Less is known of the use of these medicines in the community and in acute hospital settings.

Evidence exists that, in many cases, difficult behaviour can be safely managed by use of psychosocial interventions or a person-centred care approach. Staff should receive training and guidance in delivering psychosocial interventions. Antipsychotics should be considered as an option only in cases of imminent risk of harm to self and other. If these drugs must be used, they should be prescribed in low doses over short periods and maintained only if benefits are apparent. Discontinuation should be attempted regularly."

ILLUSTRATIONS

Figure 1. The online ALCOVE TOOLBOX for antipsychotics limitation in Dementia: the Home page.



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ALCOVE TOOL BOX

FOR LIMITING ANTIPSYCHOTICS IN DEMENTIA

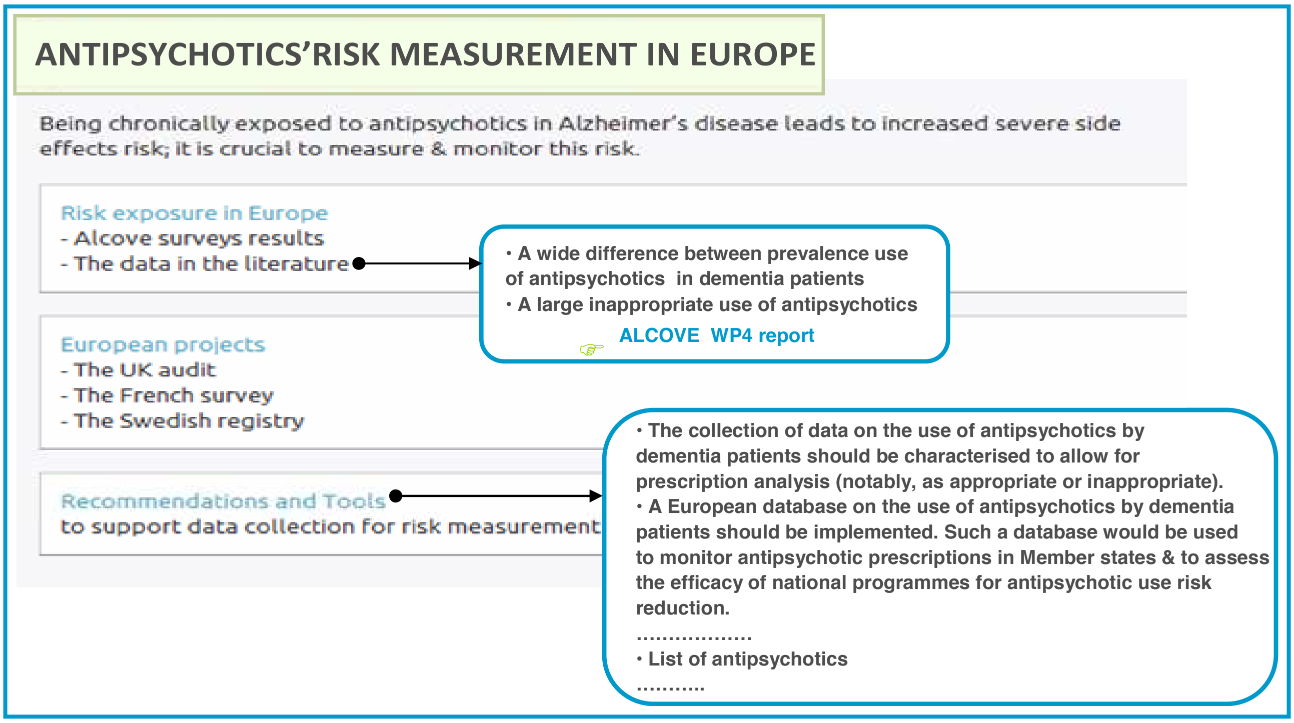
WHY SUCH A TOOL BOX FOR LIMITING ANTIPSYCHOTICS IN DEMENTIA?

Antipsychotics prescribed for behavioral disorders in dementia represents a crucial safety & ethical issue.

ALCOVE, the European Joint Action on dementia, has benchmarked between European MS in order to propose concrete tools and supports to tackle this safety issue.

Several countries have already set up dedicated strategies to limit the antipsychotics in dementia.

Figure 2. The online ALCOVE TOOLBOX for antipsychotics limitation in Dementia: Antipsychotics' Risk Measurement



ANTIPSYCHOTICS'RISK MEASUREMENT IN EUROPE

Being chronically exposed to antipsychotics in Alzheimer's disease leads to increased severe side effects risk; it is crucial to measure & monitor this risk.

Risk exposure in Europe
- Alcove surveys results
- The data in the literature

European projects
- The UK audit
- The French survey
- The Swedish registry

Recommendations and Tools
to support data collection for risk measurement

- A wide difference between prevalence use of antipsychotics in dementia patients
- A large inappropriate use of antipsychotics

☞ ALCOVE WP4 report

- The collection of data on the use of antipsychotics by dementia patients should be characterised to allow for prescription analysis (notably, as appropriate or inappropriate).
- A European database on the use of antipsychotics by dementia patients should be implemented. Such a database would be used to monitor antipsychotic prescriptions in Member states & to assess the efficacy of national programmes for antipsychotic use risk reduction.

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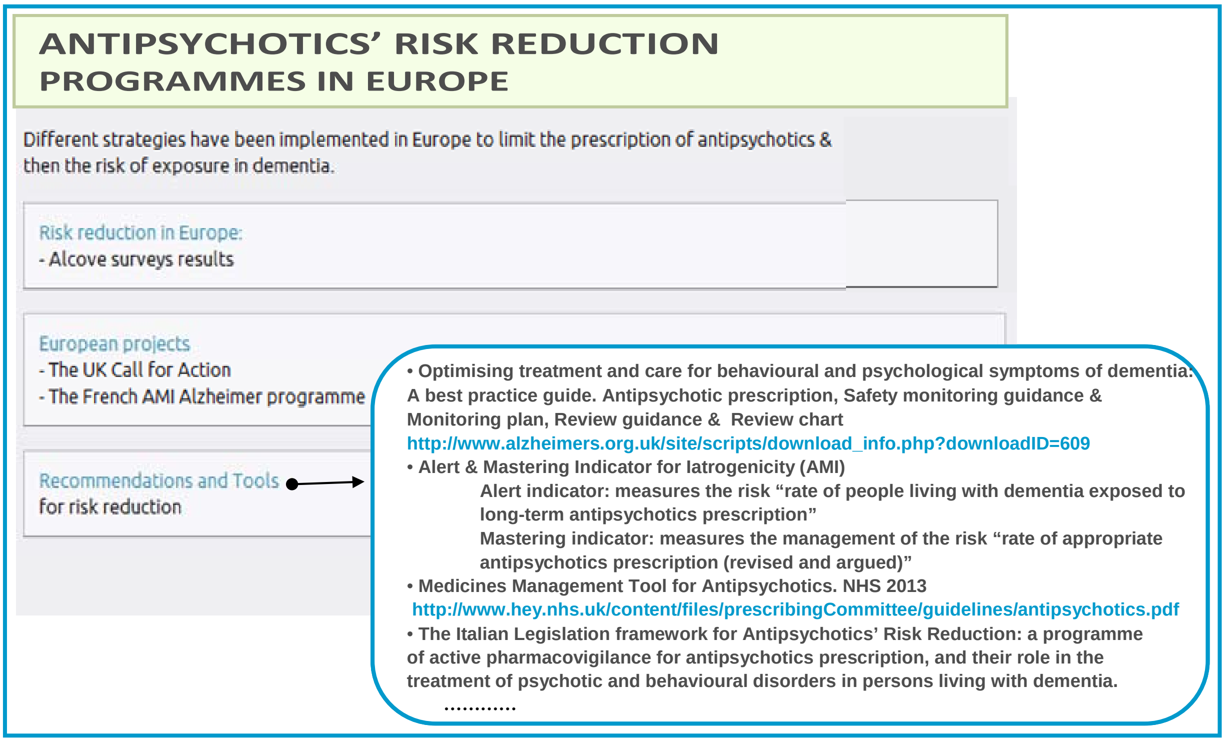
- List of antipsychotics

………..

Figure 3. The online ALCOVE TOOLBOX for antipsychotics limitation in Dementia: Antipsychotics' Risk Reduction Programmes



ANTIPSYCHOTICS' RISK REDUCTION PROGRAMMES IN EUROPE

Different strategies have been implemented in Europe to limit the prescription of antipsychotics & then the risk of exposure in dementia.

Risk reduction in Europe:
- Alcove surveys results

European projects
- The UK Call for Action
- The French AMI Alzheimer programme

Recommendations and Tools for risk reduction

- Optimising treatment and care for behavioural and psychological symptoms of dementia: A best practice guide. Antipsychotic prescription, Safety monitoring guidance & Monitoring plan, Review guidance & Review chart http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=609
- Alert & Mastering Indicator for Iatrogenicity (AMI)
  - Alert indicator: measures the risk "rate of people living with dementia exposed to long-term antipsychotics prescription"
  - Mastering indicator: measures the management of the risk "rate of appropriate antipsychotics prescription (revised and argued)"
- Medicines Management Tool for Antipsychotics. NHS 2013 http://www.hey.nhs.uk/content/files/prescribingCommittee/guidelines/antipsychotics.pdf
- The Italian Legislation framework for Antipsychotics' Risk Reduction: a programme of active pharmacovigilance for antipsychotics prescription, and their role in the treatment of psychotic and behavioural disorders in persons living with dementia.

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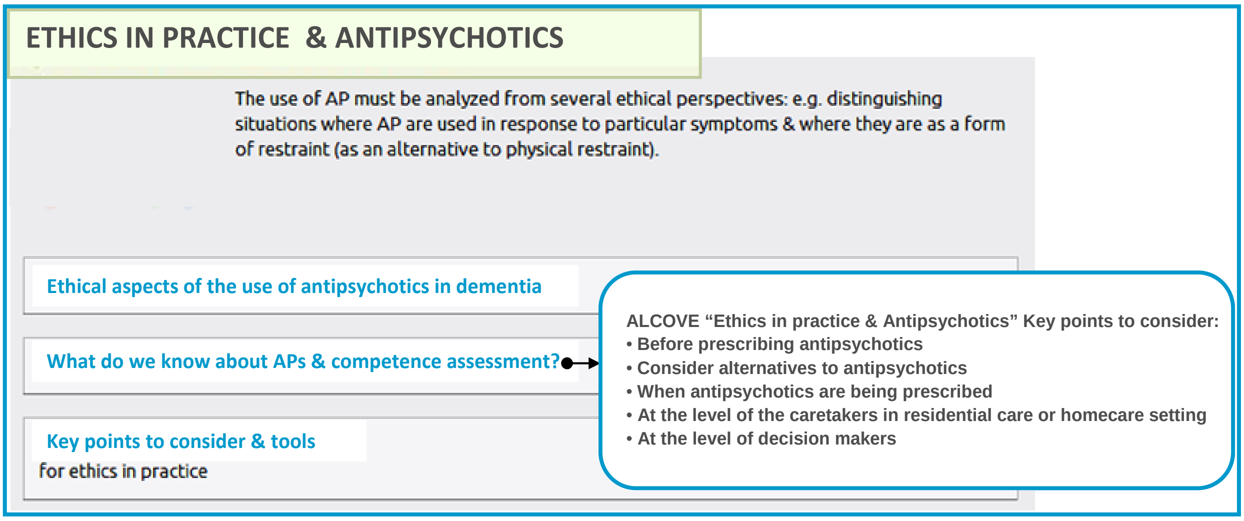
Figure 4. The online ALCOVE TOOLBOX for antipsychotics limitation in Dementia: Ethics in practice & Antipsychotics



ETHICS IN PRACTICE & ANTIPSYCHOTICS

The use of AP must be analyzed from several ethical perspectives: e.g. distinguishing situations where AP are used in response to particular symptoms & where they are as a form of restraint (as an alternative to physical restraint).

Ethical aspects of the use of antipsychotics in dementia

What do we know about APs & competence assessment?

Key points to consider & tools for ethics in practice

ALCOVE "Ethics in practice & Antipsychotics" Key points to consider:
- Before prescribing antipsychotics
- Consider alternatives to antipsychotics
- When antipsychotics are being prescribed
- At the level of the caretakers in residential care or homecare setting
- At the level of decision makers

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ALCOVE DISSEMINATION

ALCOVE DISSEMINATION

Professor López-Peña Ordoñez, Tomás[a]; Professor Segovia Pérez, Carlos[b]; Dr Villar Acevedo, Gloria[b]; Arévalo Nieto, Gonzalo[b]; Dr García García, Mercedes[b]; Calvo Orra, Luis[b];María de la Rúa, José[b]; Barr, Christine[a]; Dr Banaei-Bouchareb, Linda[a]; Dr Riolacci Dhoyen, Nathalie[a]; Erbault, Marie[a]; Dr Leperre-Desplanques, Armelle[a]; [a]Haute Autorité de Santé, France; [b]Instituto de Salud Carlos III, Spain ;

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WE ALSO WISH TO THANK: Renaud David, Nice University, for representing ALCOVE at the ALCOVE Focus Group Session at the Symposium on Psychotropic Use in Dementia in Greece.

Method, tools and analysis are developed in the WP2 Report: ALCOVE Dissemination - www.alcove-project.eu

BACKGROUND & OBJECTIVES

ALCOVE’s dissemination objectives aim to answer the following questions:

- How to generate an effective flow of information and publicity about the objectives and results of the Joint Action?
- How to ensure the most appropriate and effective methods of dissemination and communication to target each stakeholder group?
- How to facilitate internal communication among the participants in the ALCOVE work packages?

METHOD

The method for disseminating the ALCOVE Joint Action is based on:

- The collaborative work of the ALCOVE Executive Board
- The use of targeted dissemination tools: During the project, the following dissemination tools were created and used: ALCOVE’s logo, website, project flyer, poster, newsletter, and towards the end of the project, the ALCOVE Synthesis Report and the ALCOVE TOOLBOX. The website consists of an external site and Intranet. Both are updated regularly with pertinent information and the Intranet has been used to share working documents and reports among the Partners of the ALCOVE Joint Action.
- Three main levels of dissemination have been identified (Table 1): (1) Awareness and identification of the project’s main messages; (2) Gathering further information to Understand what steps needs to be taken; (3) Action/ Participation then takes place whereby the dissemination strategies are implemented with concrete actions.

Table 1. Target groups and corresponding dissemination levels

	AWARENESS	UNDERSTANDING	ACTION
Policy Makers	▨	▨	▨
Health Research Organisations	▨	▨	▨
Care Givers and General Public	▨	▨	
Project partners main stakeholders	▨	▨	▨
International and National NGOs	▨	▨	
EU legislative and research bodies	▨		
Relevant related Projects	▨		
Public Media	▨		

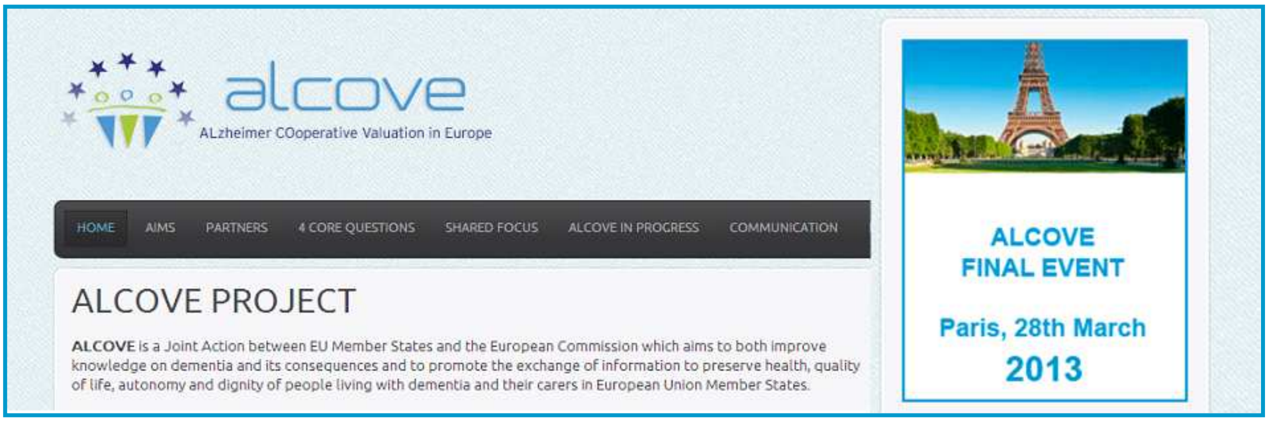
RESULTS

THE DISSEMINATION TOOLS

Prior to beginning dissemination, the ALCOVE partners worked together to establish an extensive mailing list of relevant target groups in Europe: 588 policy makers, 2, 084 health researchers, 383 carers, 566 others; for a total of 3,621 targeted individuals.

- **The ALCOVE Website (Figure1):** An interactive and accessible project website has been developed and was made available at the beginning of the project. The website includes both a public and a private restricted area along with links to the Associated Partners’ Institutional websites and to international networks dedicated to dementia, such as Alzheimer Europe.

Figure 1. The ALCOVE Web site: www.alcove-project.eu



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ALCOVE PROJECT

ALCOVE is a Joint Action between EU Member States and the European Commission which aims to both improve knowledge on dementia and its consequences and to promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers in European Union Member States.

ALCOVE FINAL EVENT

Paris, 28th March 2013

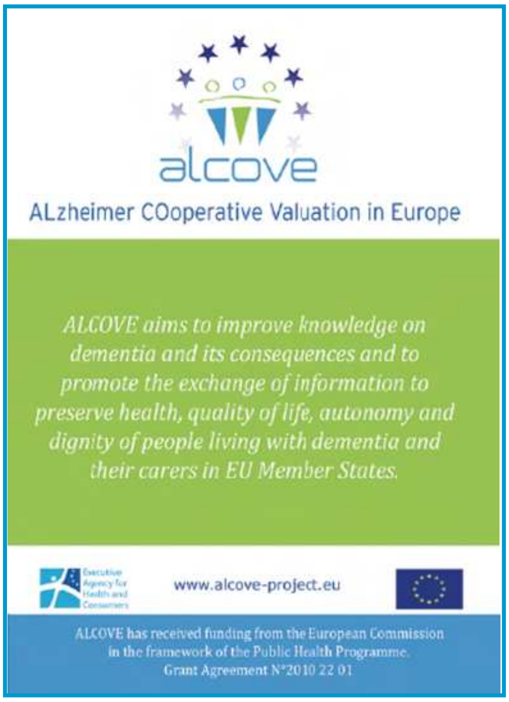
- **The ALCOVE Flyer (Figure 2) and the ALCOVE Poster:** Used as communication tools to support presentations made by all the project partners in those events where the project could be communicated. 100 posters were printed and sent out to the project's Partners.

  Poster title: Sharing knowledge to advance healthcare policies in Europe for People Living with Dementia and their Carers.

  The poster focuses on four topics: ALCOVE's objectives and background information about the project, the ALCOVE Method and Timeline, ALCOVE's future steps, and presenting the members of the ALCOVE group;

  The ALCOVE poster and flyer were valuable instruments which allowed ALCOVE Partners to communicate a clear and unified vision of the project at different events.

Figure 2. The ALCOVE flyer: www.alcove-project.eu



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ALzheimer COoperative Valuation in Europe

ALCOVE aims to improve knowledge on dementia and its consequences and to promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers in EU Member States.

Executive Agency for Health and Consumers

www.alcove-project.eu

ALCOVE has received funding from the European Commission in the framework of the Public Health Programme.
Grant Agreement N°2010 22 01

- **ALCOVE Newsletter:** Two electronic newsletters were published during the life of the project. They were distributed via e-mail to those on the ALCOVE mailing list as well as to additional selected stakeholders. The newsletters were also made available on the ALCOVE website. Each Newsletter included the following: An editorial written by the coordinator or a work package leader; Main milestones achieved at each stage of the project; Main outcomes from project meetings and workshops; Announcements of future events organised by ALCOVE and also of external events relevant to the scope of the project. More than 3,600 policy makers, health professionals and carers received them.

  A third and final newsletter is planned for dissemination around the time for the ALCOVE Final Event.

- **The online ALCOVE Toolbox for Antipsychotics limitation in dementia:** Lastly, ALCOVE has designed a Toolbox which is an information-exchange platform which includes tools and feedback to facilitate benchmarking and the implementation of public health actions including antipsychotic risk reduction.

  The Toolbox is structured in such a way that allows web-visitors to click through the box and access the different dimensions of this safety issue: risk measurement, risk reduction, timely diagnosis, ethic, support systems (see Chapter ALCOVE Toolbox p. 84).

ALCOVE SCIENTIFIC PRESENTATIONS & PUBLICATIONS

- **ALCOVE scientific presentations:** Face to face communication activities were regarded as a dissemination priority. After mapping congresses and events dedicated to dementia during the period covered by the ALCOVE JA, the ALCOVE Executive Board proposed to present ALCOVE at several international conferences. ALCOVE was presented at 26 international conferences including those organised by: the World Health Organisation, Alzheimer Europe, Alzheimer Disease International, International Forum and International Society for Quality and Safety in Health Care, International, Psychogeriatric Association, Interdem, European Alzheimers Disease Consortium, EU Joint Programming on Neurodegenerative Diseases, etc. ALCOVE was also presented at several national conferences by the Main Partner HAS and by the work package leaders WP 4,5,6 & 7.

- **A specific leaflet regarding the possible ALCOVE contributions to EIP-AHA** (the European Innovation Partnership on Active and Healthy Ageing) was elaborated by the Main Partner HAS and then edited and disseminated (Table 1).

Table 1. ALCOVE's possible future implementations in the European Innovative Partnership on Active and Healthy ageing framework

Pillar EIP AHA	Priority Action Area EIP AHA	Specific Action EIP AHA	ALCOVE's contribution Examples of actions
Prevention screening and early diagnosis	Health literacy, patient empowerment, ethics and adherence programmes, using innovative tools and services	Prescription and adherence action at regional level	**Carers:** information about Alzheimer's disease and disruptive behavioural disorders, educational programmes for the limitation of antipsychotics Use of the Internet, simulation programmes
	Personalised health management	Personalised health management, starting with a Falls Prevention Initiative	**People living with Alzheimer's disease**: advanced declaration of will, competences assessment and rehabilitation programmes
	Prevention and early diagnosis of functional decline, both physical and cognitive, in older people	Action for prevention of functional decline and frailty	**People living with Alzheimer's disease:** timely diagnosis memory centers, telediagnosis **Carers** : support system to prevent depression, burnout and breakdown
Care and Cure	Protocols, education and training programmes for health workforce and carers (e.g.comprehensive case management, multimorbidity, polypharmacy, frailty and remote monitoring	Expected to be defined further	**Health professionals:** educational programmes (including quality criteria) for Alzheimer's disease diagnosis and care and particularly about disruptive behavioural disorders and limitation of antipsychotics overuse and iatrogenicity **People living with Alzheimer's disease:** telehealth with multidisciplinary medical and social consultation
	Multimorbidity and R&D	Expected to be defined further	**Evaluation of fragile patients'pathways:** quality indicators for innovative dedicated structures or supports such as mobile units
	Capacity building and replicability of successful integrated care systems based on innovative tools and services	Replicating and tutoring integrated care for chronic diseases, including remote monitoring at regional level	**People living with Alzheimer's disease:** implementation of integrated care for people living with Alzheimer's disease with limitation of avoidable hospitalisation and improvement of quality of life (assessed performant models which could be transferred to other settings, capacity building)
Active Ageing and Independent Living	Assisted daily living for older people with cognitive impairment	Expected to be defined further	**People living with Alzheimer's disease:** robots, rehabilitation, alarms etc. **Carers:** blog, social innovation Café alzheimer, social network Respite home for individuakls and their family carers Peer carers : experienced and experts carers for younger future carers (university of carers)
	Extending active and independent living through Open and Personalised solutions	Development of interoperable independent living solutions including guidelines for business models	**People living with Alzheimer's disease:** programmes to maintain skills, competences , physicval activities with movies, videogames and other mediaprogrammes on the Internet or on TV
	Innovation improving Social Inclusion of older people	Expected to be defined further	

- **ALCOVE publications:** Although ALCOVE publications are expected after the completion of the project's work, 2 scientific articles about ALCOVE were already published in 2012 [2] [3].
  Additionally, the ALCOVE Executive Board decided to publish this ALCOVE Scientific Synthesis Report for the Final Symposium.

THE ALCOVE FINAL SYMPOSIUM

After two years of collaborative work, ALCOVE is planning to share its conclusions during its Final Symposium which has been organised at the Palais d'Iéna in Paris on the 28th of March 2013. Each partner contributed to targeting European stakeholders involved in the development of quality in dementia care and these persons were sent invitations. This event will provide them the opportunity to learn about the evidence from the in-depth reviews and surveys that ALCOVE has carried out across Europe. The resulting recommendations for policymakers and lead clinicians will be disseminated at this event, including the distribution of this ALCOVE Synthesis Report.

At the time that this Synthesis Report was being finalised, one month prior to the Symposium, 230 participants from 23 countries had confirmed their participation, including : 15 countries with representatives from their Ministries of Health, European and national health, social, patient and family associations, scientific, innovative and research projects and initiatives, health and social professionals, experts, and researchers. The ALCOVE Final Symposium will be opened by the French Ministry of the Elderly and Autonomy and will include the active participation of a discussion panel comprised of representatives from the Organisation for Economic Cooperation and Development, the World Health Organisation, Alzheimer Europe, the European Working Group of People living with Dementia, the French Alzheimer Foundation and the US Mayo Clinic. The panel will question ALCOVE's work and give their perspectives.

Organised by the French National Authority for Health in close cooperation with the Instituto de Salud Carlos III and the entire ALCOVE Executive Board, the ALCOVE Final Symposium promises to be a great opportunity to share knowledge and solutions between European Member States and well as with participating representatives from Japan, Chili and the USA, as a first step for further appropriation and implementation.

CONCLUSIONS

The dissemination activities carried out during the project period were key to the project's success. Many communication and dissemination activities have been carried out by all ALCOVE partners. To know ALCOVE's full impact in terms of awareness level achieved will require additional time following the culmination of the project with the ALCOVE Final Symposium

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ALCOVE EVALUATION

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ALzheimer COoperative Valuation in Europe

ALCOVE EVALUATION

Professor Novak, Michal[a]; Dr Skrabana, Rostislav[a]; Jezovicova, Martina[a]; Dr Novak, Petr[a]; Dr Riolacci Dhoyen, Nathalie[b]; Barr, Christine[b]; Galbraith, Maggi[b]; Dr Leperre Desplanques, Armelle[b]; [a]Institute of Neuroimmunology of Slovak Academy of Sciences, Slovakia; [b]Haute Autorité de Santé, France

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Method, tools and analysis are developed in the WP3 Report: ALCOVE Evaluation –www.alcove-project.eu

BACKGROUND & OBJECTIVES

The evaluation of the ALCOVE Joint Action consists of an in-house systematic internal appraisal of the quality of ALCOVE's outputs and effects. The entire evaluation process is based on a regular and continuous use of evaluation tools. The evalution focuses on supporting each Work Package's activities – providing a prospective audit function and overall assessment as well as verification and thorough feedback processes. So that the evaluation can meet its specific objectives, it strives to answer the following questions:

- Was the implementation of the ALCOVE Joint Action (JA) complete and timely, and according to the approved Work Plan?
- Has ALCOVE achieved its proposed objectives?
- What were the emerging problems; were they solved appropriately?
- What are ALCOVE's outcomes and impact; have the dissemination objectives been achieved?
- Have good practices for the reduction of inappropriate antipsychotics use in dementia been sufficiently promoted?

METHOD

The entire evaluation process starts with a self-evaluation as performed by each Work Package Leader. On a periodic basis, each Work Package Leader monitor whether its milestones have been met and they maintain vigilance over emerging difficulties. Then, a synthesis of work progress and emerging issues for the entire project is generated by the Evaluation Work Package. This synthesis is then discussed within the ALCOVE Executive Board and any comments are taken into consideration.

INDICATORS

Indicators are expressed in percentage form based on each Work Package's milestones to be achieved. Each milestone has been broken down into several main tasks. Timing indicators (i.e. indicators for the timely achievement of milestones or completion of deliverables) are constructed in accordance with the work plans of the work packages. These serve to map out the Project's progress towards the achievement of objectives, milestones and deliverables. They are quantified as percentages of work finished at specific points in time throughout the JA period. Timing indicators are agreed upon by the Executive Board. In the quantification of indicator progress it has proven important to take into account that several activities are "on-going" tasks in nature. For these activities to be defined as having been fulfilled, it was deemed necessary that they be sustained up until the point where the task's objective was met.

DIRECT COMMUNICATION TOOLS

Personal communication among Executive Board members has been crucial for assuring progress on the Project milestones, tasks and deliverables. The communication of results and feedback on project progress has been accomplished through continuous open e-mail exchange. Executive Board conference calls have been conducted on a regular basis (at least once per month). Their informal structure has facilitated communication between the Work Package Leaders on on-going work and making common decisions on 'hot' issues. Each conference call was monitored in detail and subsequent to each call the minutes were distributed to all Executive Board members. These minutes represent an important tool for evaluating the JA. Dedicated conference calls on specific topics between involved Work Package Leaders have been organised according to emerging needs.

ALCOVE STEERING COMMITTEES & EXECUTIVE BOARD MEETINGS

On average, face-to-face ALCOVE Executive Board meetings have been organised every six months and a Steering Committee with all ALCOVE associated and collaborative partners every year. They have represented an opportunity to extensively report on each Work Package's achieved progress. During these ALCOVE meetings, awareness of ALCOVE's activities has been increased through presentations of its work to representatives from the European Commission and other important dementia networks at the national and European levels in attendance.

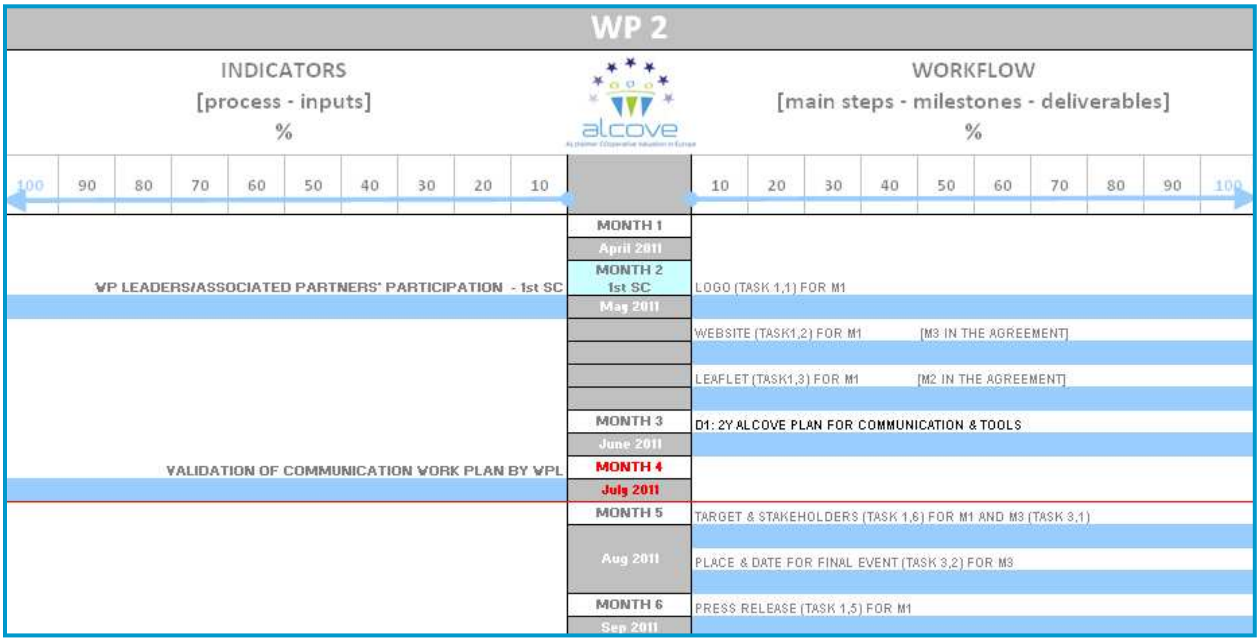
COORDINATION REPORTS

Every two months, each Work Package Leader has filled in a coordination report. The section headings of the report include actions achieved, actions in progress, actions planned; activities completed for other work package, warnings, significant events for dissemination, and key persons contacted. In the coordination report, Work Package Leaders describe activities completed during the particular reporting period, comment on their expectations for future progress and how they have handled any issues which might have arisen while performing their activities. The project's progress is measured by milestones, tasks and achieved objectives.

ALCOVE PROGRESS MONITORING SHEETS

The monitoring sheet includes the indicators for each Work Package arranged in the form of a monitoring table which provides a visual aid that illustrates quantification of project process (see examples in Figures 1, 2). Process indicators and inputs are included along with the components of the workflow, as measured by the milestones and deliverables, and make up the activities which are quantified on a regular basis. The Evaluation Work Package takes this data and calculates the percentage of achieved progress for individual activities based on the information gleaned from the bi-monthly coordination reports and direct communication tools as described above. The progress monitoring sheets are then shared with the Work Package Leader along with a detailed explanation of the quantification procedure.

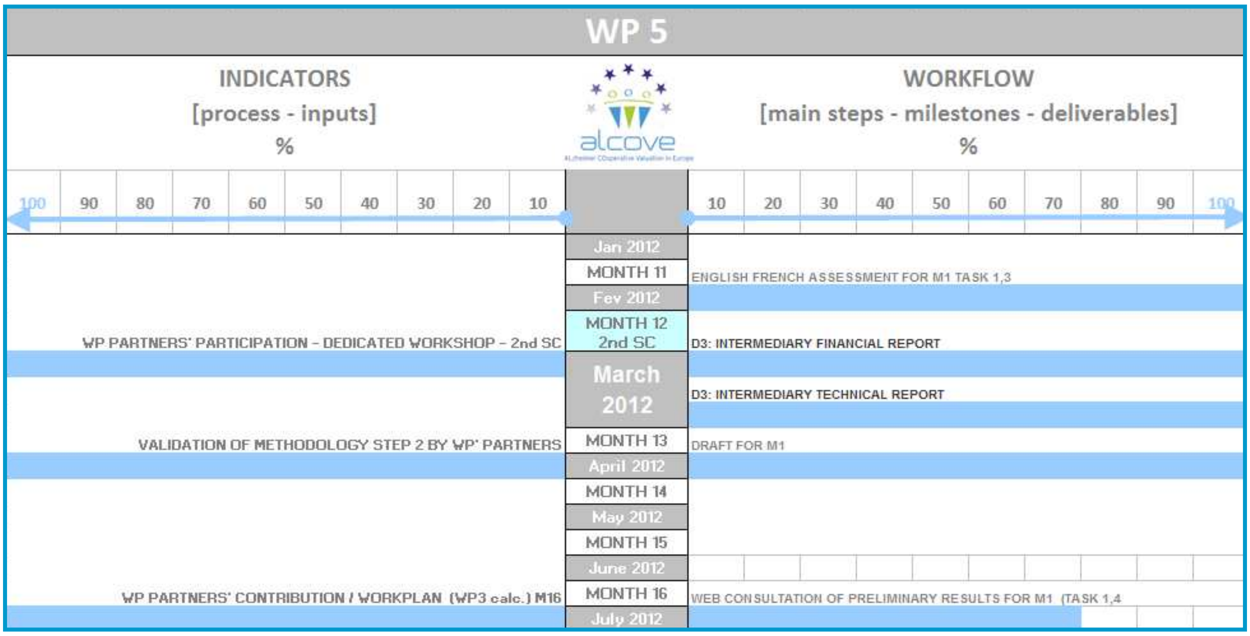
Figure 1. Example 1: Work Package 2 (WP2) monitoring sheet *Months 1 - 6*



WP 2

INDICATORS [process - inputs] %		WORKFLOW [main steps - milestones - deliverables] %
100 90 80 70 60 50 40 30 20 10		10 20 30 40 50 60 70 80 90 100
	MONTH 1	
	April 2011	
WP LEADERS/ASSOCIATED PARTNERS' PARTICIPATION - 1st SC	MONTH 2 1st SC	LOGO (TASK 1,1) FOR M1
	May 2011	
		WEBSITE (TASK1,2) FOR M1 [M3 IN THE AGREEMENT]
		LEAFLET (TASK1,3) FOR M1 [M2 IN THE AGREEMENT]
	MONTH 3	D1: 2Y ALCOVE PLAN FOR COMMUNICATION & TOOLS
	June 2011	
VALIDATION OF COMMUNICATION WORK PLAN BY WPL	MONTH 4	
	July 2011	
	MONTH 5	TARGET & STAKEHOLDERS (TASK 1,6) FOR M1 AND M3 (TASK 3,1)
	Aug 2011	PLACE & DATE FOR FINAL EVENT (TASK 3,2) FOR M3
	MONTH 6	PRESS RELEASE (TASK 1,5) FOR M1
	Sep 2011	

Figure 2. Example 2: Work Package 5 (WP5) monitoring sheet between *Months 11 - 16*



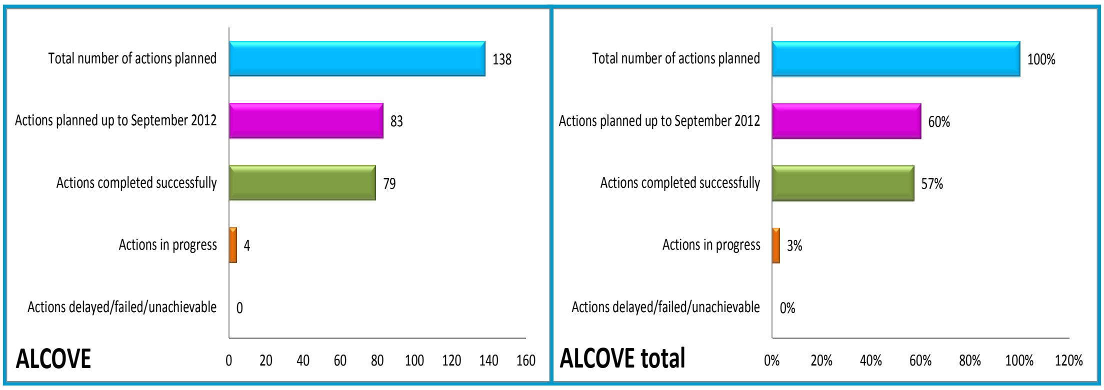
WP 5

INDICATORS [process - inputs] %		WORKFLOW [main steps - milestones - deliverables] %
100 90 80 70 60 50 40 30 20 10		10 20 30 40 50 60 70 80 90 100
	Jan 2012	
	MONTH 11	ENGLISH FRENCH ASSESSMENT FOR M1 TASK 1,3
	Fev 2012	
WP PARTNERS' PARTICIPATION – DEDICATED WORKSHOP – 2nd SC	MONTH 12 2nd SC	D3: INTERMEDIARY FINANCIAL REPORT
	March 2012	D3: INTERMEDIARY TECHNICAL REPORT
VALIDATION OF METHODOLOGY STEP 2 BY WP' PARTNERS	MONTH 13	DRAFT FOR M1
	April 2012	
	MONTH 14	
	May 2012	
	MONTH 15	
	June 2012	
WP PARTNERS' CONTRIBUTION / WORKPLAN (WP3 calc.) M16	MONTH 16	WEB CONSULTATION OF PRELIMINARY RESULTS FOR M1 (TASK 1,4
	July 2012	

ALCOVE IN PROGRESS GRAPHING TOOLS

- **The quantification of each ALCOVE Work Package's activities is summarised in a graph** and includes the categories of planned activities, finished activities and activities in progress (Figure 3). This graphing tool was designed to help Work Package Leaders visualise the progression of their work. Once the synthesis is finalised by the Executive Board, it is released as a report to all Partners on the website.

Figure 3. Example of the graphing tool for the monitoring of ALCOVE progress



- **Description of feedback processes for monitoring and evaluation:** As established in the ALCOVE Collaborative method, bi-monthly coordination reports are a regular tool for assessing individual Work Packages' progress towards work plan completion. These are filled out by the Work Packages and the information contained therein is used to prepare progress monitoring sheets with a quantisation of the reported work. Planned activities are compared against activities which have actually been completed. Each Work Package Leader then has the opportunity to communicate any explanations, comments, or questions that it might have. This feedback procedure serves to approve the quantification of work completed before final release of the data in the ALCOVE progress report.

KEY POINTS OF THE ALCOVE EVALUATION METHOD

The key components of the ALCOVE evaluation method and procedures

Continuous information flow between Executive Board members:

- e-mail exchanges
- conference calls: regularly scheduled with Executive Board participation to discuss project progress / dedicated conference calls on specific topics
- face-to-face Executive Board meetings (every 6 months), Steering Committee meetings every year

Written reporting tools

- coordination reports
- ALCOVE in progress graphings

Feedback tools

- ALCOVE progress monitoring sheets for each Work Package
- comments on the monitoring sheets issued for each Work Package
- collaborative approach with the involvement of all stakeholders

RESULTS

In answering the questions proposed for the ALCOVE Evaluation Work Package, we can conclude that regular quantitation of project progress has confirmed that ALCOVE has been proceeding in accordance with the proposed time schedule. However, the most important question that the Evaluation Work Package faces concerns the ALCOVE Joint Action's outcomes and impact. Specifically, will ALCOVE be successful in disseminating the project's achievements, in particular the promotion of recommendations for good practices for the reduction of inappropriate antipsychotics use in dementia?

OUTCOME & IMPACT

Because of the nature of the ALCOVE Project and its recommendations being shared at the end of the two-year period, it will not be possible for the Evaluation Work Package to assess the project's final impact. This being said, the project was disseminated all thoughout its duration and this will serve to support continuous dissemination after the termination of the project. Several important tools were designed to achieve this preliminary dissemination objective:

- Communication on the project and progress made: newsletters were sent out to more than 4,000 key people in the field; a scientific article was published in a peer-reviewed journal; an ALCOVE poster was disseminated at several scientific events and ALCOVE presentations were made at key dementia events (see Chapter ALCOVE Dissemination p. 90).
- A Final Event with key actors in the field of dementia from over 20 EU Member States; including stakeholders, political figures, decision-makers, people living with dementia and family organisations, and citizens (see Chapter ALCOVE Dissemination p. 90).
- Contact was made with the stakeholders of the main European networks dedicated to dementia and principles for inter-network collaboration were established.
- Creation of the ALCOVE Toolbox, which includes recommendations and methodologies which target the reduction of antipsychotic use that have been identified and implemented in other projects. This Toolbox is geared towards patients, their carers, health professionals and managers, as well as decision-makers (see Chapter ALCOVE Toolbox p.84).
- The ALCOVE Toolbox is to be presented at the Final Event and is discussed in greater detail in this ALCOVE Synthesis Report which will be distributed to the main stakeholders. The Toolbox will be posted on the ALCOVE website and will remain there for dissemination purposes after the official closing of the project.
- ALCOVE is participating in the European Innovation Partnership for Active and Healthy Ageing initiative and will disseminate its conclusions via this forum (see Chapter ALCOVE Dissemination p.90).

ALCOVE IN EXTERNAL DIALOGUE & COLLABORATION

ALCOVE established contacts with the major European networks on dementia, namely Alzheimer Europe, EU Joint Programme - Neurodegenerative Disease Research, European Alzheimer Disease Consortium and European Innovation Partnership for Active and Healthy Ageing. Further contacts were made for the dissemination of ALCOVE with the World Health Organization, the European Commission and with national stakeholders working in the fields addressed by ALCOVE's core questions regarding prevalence, diagnosis, care models, legal aspects of dementia and antipsychotics' limitation.

CONCLUSIONS

The ALCOVE Joint Action has entered its final phase as it moves toward accomplishing the milestones and objectives as articulated in the initial project proposal and contract. Over the course of the collaborative work carried out by the Partners from 19 different European countries which make up ALCOVE, important tools and procedures for the evaluation and dissemination of ALCOVE's work were created. These have supported ALCOVE's goal of having a large impact in sharing its achievements for improving health policy in dementia. Additionally, the ALCOVE Toolbox is an information-exchange platform which includes tools and feedback which will facilitate benchmarking and the implementation of dementia health policy actions, including antipsychotic risk prevention.

REFERENCES

[1] ALCOVE Evaluation Plan & Tools (2011). Institute of Neuroimmunology, Slovak Academy of Sciences, French National Authority for Health and ALCOVE group, www.alcove-project.eu

[2] Bennett and Rockwell model of targeting outcomes- http://citnews.unl.edu/TOP/downloads/TOP.pdf

[3] ALCOVE Newsletter No. 2, November – December 2012. http://www.alcove-project.eu

GLOSSARY

Alzheimer’s disease: Alzheimer’s (or Alzheimer’s Disease & Related Disorders) is frequently used interchangeably to cover all dementias, possibly because it is thought to be less stigmatising than the word dementia. Alzheimer’s Societies and Associations, Alzheimer Europe and the Alzheimer’s Disease International movement (the main charities associated with Dementia) represent all the dementias not just Alzheimer’s Disease. Alzheimer’s Disease, the most common form of dementia, occurs when protein 'plaques' and 'tangles' develop in the structure of the brain, leading to the death of brain cells. Other types of dementia include notably Vascular Dementia, Dementia with Lewy Bodies and Fronto-temporal Dementia. Each has its own causes and different characteristics. See also: Dementia.

Advance care planning: A process of communication, discussion, consultation and decision-making between an individual, his/her care providers (informal and formal) and other possible relevant persons (relatives, proxy, etc.) concerning future care and treatment options for that individual. Aspects of advance care planning include opening the conversation, exploring options, identifying wishes and preferences, making decisions about specific treatment options, asking someone to speak on your behalf or appointing someone to make decisions (proxy), expressing your views, preferences and wishes to other people (NHS Guide – Planning for your future care).

Advance directives: Written or oral statements that are intended to govern healthcare and related decision-making for their authors, for both positive (consent) and negative (refusal) decisions, should they lose decisional capacity in the future. The basis for the moral (and legal) validity of advance directives is the person’s right to autonomy or to self-determination regardless of his/her current cognitive capacity and capacity to express wishes. Advance directives may or may not include end-of-life decisions. Advance directives can be divided into two groups: instruction directives and proxy-directives.

AMI: Alert & Mastering Indicators: Alert indicator: measures the risk, e.g. the rate of people living with dementia exposed to long-term antipsychotics prescription. Mastering indicator: measures the management of the risk, e.g. the rate of appropriate antipsychotics prescription (revised & argued).

Behavioural and Psychological Symptoms of Dementia (BPSD): Heterogeneous range of psychological reactions, psychiatric symptoms, and behaviours occurring in people living with dementia of any aetiology, such as delirious ideas, hallucinations, agitation, aggression, disinhibition, shouting, apathy. Disruptive BPSD are the main sources of caregiver burden and antipsychotics prescription.

Care coordinator: A professional involved in coordinating the care provided to a person living with dementia, especially when the care involves several care providers within a multi-disciplinary context.

Care Pathway: See Pathway.

Clinical guidelines: A document providing recommendations of good practices for health professionals based on available evidence and experts’ consensus.

Community Service: Refers to the broad range of services that people living with dementia and their families may come into contact with. These typically, but not exclusively, include statutory social care, non-governmental organisations, third sector organisations or community-led services.

Competence in people living with dementia/Decision-making capacity: Competence is a multidimensional construct with important clinical, legal, ethical, social and policy aspects. In a care and treatment setting, it refers to ‘decision-making capacity’ or ‘capacity for autonomy’ in the personal context of the person living with dementia. It is linked to making choices regarding the integrity of the individual, restricted to a specific (medical) care intervention. The competence is usually assessed by a medical professional and not a judge. Decision-making capacity (in a care and treatment context) is different from the functional competence/capacity, which relates to the ability to perform activities of daily life, live alone, drive a car, etc.

Decision-making capacity: See Competence in people living with dementia.

Dementia: Dementia is an umbrella term for a set of symptoms where there is a significant and often progressive decline in cognitive function (thinking abilities). Changes can include problems with memory, language, perceptual problems, carrying out practical tasks, mood changes or making considered judgements. The underlying causes of dementia are a number of disease processes that affect the health of the person’s brain, the most common form being Alzheimer’s Disease. See also: Alzheimer’s disease.

Detection: Refers to the initial processes involved in identifying that cognitive changes are present which might indicate the need to assess further for dementia. This may involve the use of screening tools such as the Mini Mental State Examination (MMSE), the General Practitioner Assessment of Cognition (GPCOG) and the 6 Item Cognitive Impairment Test (6CIT).

Early Cognitive Changes: Subjective and objective difficulties with cognition that represent a change in the person's normal level of functioning. These may be accompanied by mild changes in independent activities of normal living. These cognitive changes are beyond those that would be expected in relation to the person's age and educational background, but are not severe enough to warrant a diagnosis of dementia.

Family Carer (synonym: Informal Caregiver): Family member or other person caring for a person living with dementia, with or without a formal recognition of such a relationship.

Financial and Resource Planning: Refers to the planning at governmental and policy levels that needs to take place in order to commission services and implement timely diagnosis.

Gerontechnology: Assistive technology, inclusive design ("Design for All") and other solutions matching technological environments to health, housing, mobility, communication, leisure and work of older people.

Individualised patient and family caregivers interventions (IPCI) for BPSD: Support systems for BPSD prevention and management are classified by ALCOVE in 3 dimensions:

1. Structures and care organisations (SCO) for BPSD such as special care units, respite care, and mobile care;
2. Individualised patient and family caregivers interventions (IPCI) for BPSD including psychosocial interventions for family carers and people living with dementia, non-pharmacological therapies and pharmacological therapies for people living with dementia;
3. Workforce and skills for BPSD such as training & skills, clinical guidelines, improvement programmes.

Instruction directives for people living with dementia: Advance directives can be divided into two groups: instruction directives and proxy-directives. Instruction directives are written documents designed to allow people to express their preferences regarding the provision (positive instruction directives) or not (negative instruction directives or advanced refusals) of specific treatments in the event that they become unable to make decisions in the future.

MCI (Mild Cognitive Impairment): Cognitive difficulties that individuals experience which are beyond what would be expected in normal ageing, but are not severe enough to warrant a diagnosis of dementia. As of February 2013, more research is required in order to establish the relationship between different categories of Early Cognitive Change/MCI and different forms of dementia. See also: Early Cognitive Changes.

Memory Clinic or Centre/Memory Assessment Services/Early Intervention Services: Assessment, diagnosis and intervention services for people with suspected dementia and their families, provided by a multi-disciplinary team of specialists specialising in memory troubles.

Multi-disciplinary: Refers to the range of disciplines that may be involved e.g. in timely diagnosis. For instance, this typically but not exclusively involves specialist and generalist doctors, clinical psychologists, nurses, occupational therapists and social workers.

National Plan or National Policy or National Dementia Strategy: Stated principles which guide the actions of government. A public policy is a purposive and consistent course of action produced as a response to a perceived problem of a constituency, formulated by a specific political process, and adopted, implemented, and enforced by a public agency. A National Programme usually, but not always, follows and translates a National Policy into action.

Opportunistic Screening: Using specific assessment processes to identify the presence of a condition when people present for other reasons, for example, screening for Alzheimer's Disease when a person consults a family doctor about non-memory-related complaints. The person may not have raised concerns about the specific difficulties being screened for, but a discussion will have taken place to ensure that the person is in agreement with screening before this is undertaken.

Pathway: Care pathway: An anticipated process of care within a specific time frame which is written and agreed by the health care practitioners involved in delivering care. It includes standards based on evidence about what is most effective in providing appropriate care for the person and their family. Patient pathway: Patient pathway describes the patient/family/circle journey throughout care structures and organisations.

Patient Pathway: See Pathway.

Population Screening: The process through which people that are showing no clinical signs of a condition are assessed to identify if they are at risk of developing the condition. A discussion will have taken place and consent achieved before such screening takes place.

Primary Care: The first point of contact for a person and his/her family for his/her health care needs provided by a range of professionals. These typically but not exclusively include family doctors, practice nurses and health visitors.

Proxy directives for people living with dementia: Advance directives can be divided into two groups: instruction directives and proxy-directives. Proxy-directives allow individuals to appoint someone as a 'healthcare proxy', 'representative' or a 'medical power of attorney' to make healthcare decisions on their behalf once they lose the ability to do so. Healthcare proxies differ from legal guardians. The latter are appointed as the legal authority to make financial or general decisions on behalf of a person. In some countries, it is possible for a person to appoint a welfare attorney or guardian, who can also make healthcare decisions among others, or it may be possible to have a court-appointed healthcare guardian.

Psychosocial intervention for BPSD: Individualised patient and family caregiver interventions for BPSD, considered as a non-pharmacological therapy for caregivers and people living with dementia, like multi-compoment (e.g. psycho-educational and home visit, …), psycho-educational, skills training & educational programmes, home visit, technology support, self-care techniques (cognitive behavioural therapy, stress management, coping with change as a result of caregiving), peer support group.

Respite care for BPSD: Structure and care organisation, like temporary nursing home or day care home for example to provide care to the person living with dementia and relief to the regular caregiver.

Screening: See Population screening & Targeted screening.

Secondary Care: Refers to health care services provided by specialist health care practitioners in hospital, outpatient or community settings. These services can generally be accessed following a consultation with a primary health care practitioner who provides a referral.

Structures and care organisation (SCO) for BPSD: Support systems for BPSD prevention and management are classified by ALCOVE in 3 dimensions:

1. Structures and care organisations (SCO) for BPSD such as special care units, respite care, and mobile care;
2. Individualised patient and family caregivers interventions (IPCI) for BPSD including psychosocial interventions for family carers and people living with dementia, non-pharmacological therapies and pharmacological therapies for people living with dementia;
3. Workforce and skills for BPSD such as training & skills, clinical guidelines, improvement programmes.

Support systems for BPSD: Support systems for BPSD prevention and management are classified by ALCOVE in 3 dimensions:

1. Structures and care organisations (SCO) for BPSD such as special care units, respite care, and mobile care;
2. Individualised patient and family caregivers interventions (IPCI) for BPSD including psychosocial interventions for family carers and people living with dementia, non-pharmacological therapies and pharmacological therapies for people living with dementia;
3. Workforce and skills for BPSD such as training & skills, clinical guidelines, improvement programmes.

Targeted Screening: Occurs where specific populations, known to be at greater risk of developing a condition, are assessed to see if the condition is present. For example those with current health difficulties related to cardio-vascular problems such as stroke or heart disease, or where vascular risk factors such as high blood pressure are present. Consent is achieved with the individual prior to screening.

Timely Diagnosis of dementia: Timely diagnosis is the priority area to be achieved for dementia diagnosis. Onset of cognitive decline and disability, subjective impairment and/or help seeking, focus on timely diagnosis, responding to people living with dementia and carer concerns rather than proactively screening for the disease, according to time point 3 of Prince et al. 2011 definition.

Workforce & Skills for BPSD: Support systems for BPSD prevention and management are classified by ALCOVE in 3 dimensions:

1. Structures and care organisations (SCO) for BPSD such as special care units, respite care, and mobile care;
2. Individualised patient and family caregivers interventions (IPCI) for BPSD including psychosocial interventions for family carers and people living with dementia, non-pharmacological therapies and pharmacological therapies for people living with dementia;
3. Workforce and skills for BPSD such as training & skills, clinical guidelines, improvement programmes.

alcove

ALzheimer COoperative Valuation in Europe

ALCOVE HAS Coordination Team
Armelle Leperre Desplanques, MD, PhD, ALCOVE project leader, Nathalie Riolacci-Dhoyen, MD, scientific coordination,
Christine Barr, project manager, Maggie Galbraith, project manager, Haute Autorité de Santé
alcove@has-sante.fr - www.alcove-project.eu