

## ALCOVE RECOMMENDATIONS



<b>ALCOVE RECOMMENDATIONS FOR EPIDEMIOLOGICAL DATA ON DEMENTIA</b>	<b>19</b>
Recommendations to improve data collection on estimates of dementia prevalence in Europe	19
Recommendations to improve data collection on antipsychotics in dementia	19
Recommendations to improve data collection on health and social care services for dementia	19
<b>ALCOVE RECOMMENDATIONS FOR DEMENTIA DIAGNOSIS</b>	<b>19</b>
Recommendations on fundamental principles for dementia diagnosis	19
Recommendations on case finding & screening for dementia diagnosis	20
Recommendations on the diagnostic process for dementia diagnosis	20
Recommendations on complex diagnosis of dementia	20
Recommendations on early cognitive changes diagnosis (currently mild cognitive impairment)	20
Recommendations on workforce for dementia diagnosis	21
<b>ALCOVE RECOMMENDATIONS FOR BPSD* SUPPORT SYSTEMS</b>	<b>21</b>
Recommendations on fundamental principles for a global strategy for BPSD	21
Recommendations on Structures and Care Organisations for BPSD	21
Recommendations on Individualised Patient and Family Carer Interventions for BPSD	22
Recommendations on Workforce and Skills for BPSD	23
<b>ALCOVE RECOMMENDATIONS FOR RIGHTS AUTONOMY &amp; DIGNITY OF PEOPLE WITH DEMENTIA</b>	<b>23</b>
Competence Assessment for people living with dementia	23
Advance Directives for people living with dementia	23

\* 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:  $\geq 3000$  subjects; Design: One phase study or two phase study with appropriate sampling and weighting; Response proportion  $\geq 80\%$ , 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  $\leq 65$  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:**

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

2<sup>nd</sup> 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,

3<sup>rd</sup> 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.** Alarming, 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]