EPIDEMIOLOGICAL DATA ON DEMENTIA

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ALzheimer COoperative Valuation in Europe

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 ASSOCIATED PARTNERS: Francesca Galeotti; Angela Giusti; Francesca Meduri; Roberto Raschetti; Paola Scardetta; Nicola Vanacore - ISS, Italy; Saarikalle Kristiina; Harriet Finne-Soveri - National Institute of Health and welfare (THL), Finland; Catherine Helmer - Institut National de Santé et Recherche Médicale (INSERM), France; Anders Wimo - Karolinska Institute (KI), Sweden; Paraskevi Sakka, Athens - Association of AD and Related Disorders (AAADRD), Greece; Teresa di Fiandra - Ministero della Salute (MINSAL), Italy.

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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ALL SURVEY RESPONDENTS: Stephen Abela; Dag Abrahamsen; Philippe Amouyel; Yoeriska Antonissen; Isabelle Avallone; Mariette Backes-Lies; Zane Baltane; Christian Berringer; Christian Berringer; David Berry; Pierre-Yves Bolen; Françoise Bourgoin; Dawn Brooker; Marcel Bruch; Valmantas Budrys; Alistair Burns; Sandra Buttigieg; Susanna Conti; Daniel Crabbe; Maria Cunderlikova; Jean François Dartigues; Alvaro de Carvalho; Roberto Debono; Catherine Dechevre; Joseph Dimech; G. Doblhammer-Reiter; Dusan Dobrota; Knut Engedal; Ronald Fiorentino; Jean-Philippe Flouzat; Claudia Gandin; Mika Gissler; Bénédicte Gombault; Jean-Pierre Gorissen; C. Günster; Yngve Gustavson; Bjorn Heine Strand; Catherine Helmer; Susanne Holland; Iva Holmerová; Jacqueline Hoogendam; Helka Hosia-Randell; Irina Ilieva; Christine Jendoubi; Mia Jönhagen; Aigars Kisuro; Nina Knape; Dorothee Knauf-Hübel; Seppo Koskinen; Maarja Krais-Leosk; Stefan Krajcik; Vladimirs Kuznecovs; Irene Kyriacou Georghiou; Mårten Lagergren; Benoit Lavallart; Andrejs Leimanis; Armelle Leperre-Desplanques; Tomás López-Peña Ordoñez; Matti Makela; Eleni Margioti; Jaana Martikainen; Maria Masocco; Kristin Mehre; Barbara Melard; Hennamari Mikkola; Lennart Minthon; Tor Molden; Katarina Nägga; Sabine Nemitz; Anders Norlund; Anja Noro; Jean Luc Novella; Alessandro Padovani; Heli Paluste; Sakka Paraskevi; Jesus de Pedro-Cuesta; Hanna Rautiainen; Philippe Ricordeau; Steffi Riedel-Heller; Philippe Robert; Yves Rolland; H. Rothgang; Kai Saks; Veikko Salomaa; Emanuele Scafato; Charles Scerri; Silvia Schelo; Irina Sirotkina; Ingmar Skoog; Edmund Skorvaga; Rostislav Skrabana; Phillipe Tuppin; Peter Turcani; Nicola Vanacore; Veerle Vanderlinden; Elisabeth Vatten; Jurn Verschraegen; Päivi Voutilainen; Bengt Winblad; Sarah Watkins; Guy Weber; Anders Wimo; Bengt Winblad; Antonissen Yoeriska; Elena Zigova.

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

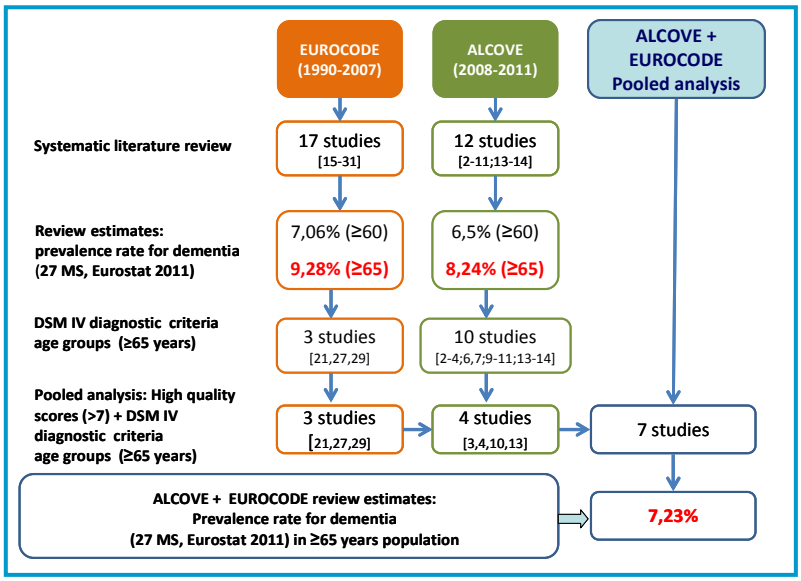


Table 2. The comparison between total prevalence rate and number of total estimated cases with dementia in relation to different projects (age > 65 yrs) (Eurostat 2011)(EU 27 countries)

	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:

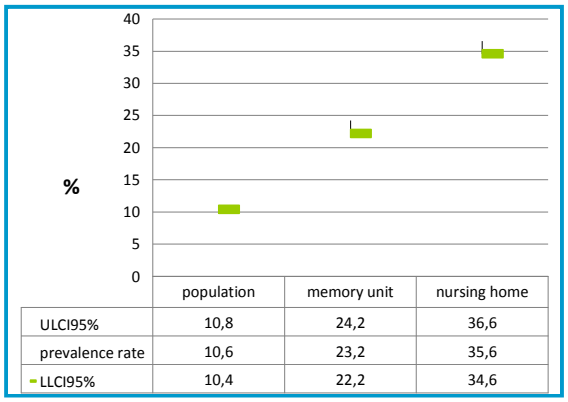
- Prevalence of use: proportion of inhabitants who received at least one drug prescription during the study period;
- DDD/1000 inhabitants die: number of DDDs per 1000 inhabitants per day;
- DDD per user: number of DDDs per user (inhabitants who received at least one drug prescription during the study 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)



- **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.

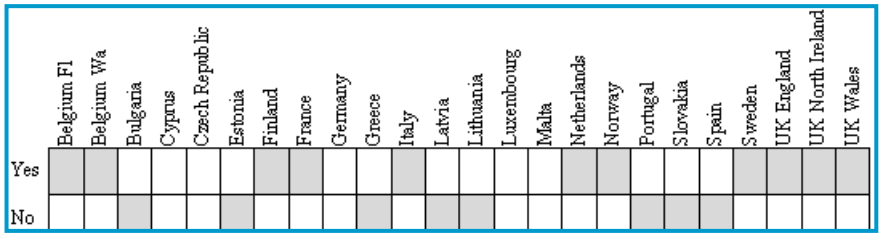
  As pertains to the national programmes concerning the organisation of health and social care services dedicated to dementia the key question was "In your Country, is there a National Programmes (NP) or any written national policy on dementia health and social care services organisation?". Table 4 shows 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



- **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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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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