Journal of Alzheimer's Disease 29 (2012) 891–902
DOI 10.3233/JAD-2012-111943
IOS Press

The 2008–2012 French Alzheimer Plan: Description of the National Alzheimer Information System

Franck Le Duff[a,*], Aude Emmanuelle Develay[b], Julien Quetel[a], Pierre Lafay[c], Stéphane Schück[d], Christian Pradier[a], Philippe Robert[e] and the participating centers[1]
[a]*CHU de Nice, Département de santé publique, Nice, France*
[b]*Institut de veille sanitaire, Département des maladies chroniques et des traumatismes, Saint-Maurice, France*
[c]*Ellipse, Ste Anastasie sur Issole, France*
[d]*Kappa Santé, Paris, France*
[e]*CMRR – EA CoBTeK-CHU – Université de Nice Sophia Antipolis, Nice, France*

Accepted 17 January 2012

Abstract. In France, one of the aims of the current national Alzheimer's disease plan is to collect data from all memory centers (memory units, memory resource and research centers, independent neurologists) throughout the country. Here we describe the French Alzheimer Information System and present a 'snapshot' of the data collected throughout the country during the first year of operation. We analyzed all data transmitted by memory centers between January 2010 and December 2010. Each participating center is required to transmit information on patients to the French National Alzheimer dataBank (BNA). This involves completing a computer file containing 31 variables corresponding to a limited data set on AD (CIMA: Corpus minimum d'information Alzheimer). In 2010, the BNA received data from 320 memory centers relating to 199,113 consultations involving 118,776 patients. An analysis of the data shows that the initial MMSE (Mini Mental State Examination) mean score for patients in France was 16.8 points for Alzheimer's disease, 25.7 points for mild cognitive impairment, and 18.8 points for 'related disorders related disorders. The BNA will provide longitudinal data that can be used to assess the needs of individual local health areas and size specialized care provision in each regional health scheme. By contributing to the BNA, the memory centers enhance their clinical activity and help to advance knowledge in epidemiology and medical research in the important field of Alzheimer's disease and related dementias.

Keywords: Alzheimer's disease, dementia, medical practice, public health

Alzheimer's disease (AD) and related disorders (vascular dementia and dementia of unknown etiology) are a major public health issue. In 2003, the estimated prevalence of these pathologies based on the PAQUID [1] and EURODEM [2] cohorts ranged from 5.7% for subjects aged 75–79 years to 38.4% for subjects aged over 85 years. In Western Europe, the estimated annual incidence in subjects aged 60 years and over is 9 per 1000 [3]. In 2004, an extrapolation based on the available prevalence data indicated that the number of people aged 65 years and older with dementia in France could be in excess of 850,000 [4], a figure that it is suggested to double by 2040 [3]. In view of the scale of these pathologies [5–7], a third Alzheimer Plan was launched in 2008 (French National Plan for "Alzheimer

*Correspondence to: Franck Le Duff, CHU de Nice, Département de santé publique, Hôpital de l'Archet 1. Route de St-Antoine de Ginestière, BP 3079 - 06202 Nice Cedex 3, France. E-mail: le-duff.f@chu-nice.fr.

ISSN 1387-2877/12/$27.50

and Related Disorders" 2008–2012) [8] to strengthen research on AD and related disorders, promote earlier diagnosis, and improve both patient management and support for carers.

The French National Plan for "Alzheimer and related disorders" 2008–2012 comprises 44 measures. Measure 34 is entitled "Setting up epidemiological surveillance and follow up". Its objective is to enable to through the ministry of health and regional health agency, a specialist memory care provision to be adapted through regional care organization schemes. Measure 34 aims to provide epidemiological data as well as activity indicators of the centers. To this end, it is important for each region to have activity data for specialized centers, data on patients' characteristics, and care quality indicators [9]. To achieve this objective, several steps were required: specification and definition of the data to be collected, computerization of memory units and volunteer independent neurologists, and finally the creation of a national database (known as the "BNA" the National Alzheimer data Bank) consolidating all the information obtained from specialized centers. The BNA comprises a centralized information system to collect data from participating centers and a data management system to ensure the reliability of the information collected. The information collected by the BNA consists of a limited data set, defined by national consensus.

This measure provides for the setting up of a nationwide system for collecting activity data and for epidemiological surveillance and follow-up within specialized centers (memory units and centers and independent specialists). This article presents the information system that was set up and describes the characteristics of the patients with AD or related disorders followed up in the various centers taking part in the collection of data between 1 January 2010 and 31 December 2010.

METHODS

Since the implementation of the first Alzheimer Plan in France in 2001, the organization of testing and follow up for AD has been based on a nationwide network comprising 400 'memory units' (CMs: Consultations mémoire) and 27 'memory resource and research centers' (CMRRs: Centres mémoire de ressources et de recherche). The CMRRs, located in teaching hospitals, also have teaching and research functions and are responsible for supervising the CMs. This public health service network is supplemented by independent specialists (neurologists, geriatricians, and psychiatrists), who also play a role in the diagnosis and follow up of AD patients.

CIMA, the Alzheimer limited data set (CIMA: Corpus Minimum d'Information Alzheimer)

The first step in implementing Measure 34 was to determine what data to collect on patients attending these centers. The data set on AD had to meet two very general constraints: it needed to contain the appropriate information to allow good quality statistical processing but had to be sufficiently short so as not to place too heavy a constraint on the centers taking part.

Development of the CIMA began in September 2007 with a working group comprised of representatives of the CMRRs and CMs. In 2008, the information set was completed and validated by the Directorate General of Care Provision (DGOS: Direction Générale de l'Offre de Soins), which is in charge of supervising Measure 34. The full list of items, with the possible choices for each one, and a glossary of definitions can be accessed on the CMRR-Nice website (http://www.cmrr-nice.fr/) or the website of the National Alzheimer Plan 2008–2012 (http://www.plan-alzheimer.gouv.fr/mesure-no34.html). The first part of the CIMA consists of background information on the patient. This includes information on the patient's identity and geographical location, some of these details subsequently being used to render the file anonymous. There are also data on the category of social care (i.e., "ALD" [long-term illness] and "APA" [personal autonomy allowance]) and the diagnosis. For the diagnosis, two levels are proposed; level 1, corresponding to a global diagnosis (presence or absence of dementia or other cognitive impairment), and level 2, corresponding to a specific diagnosis based on a classification drawn up by the National Federation of CMRRs in relation with the ICD 10. The second part provides details of the 'procedure' carried out during the patient's visit to the center, i.e., a consultation, a neuropsychological assessment, a day-hospital visit for a diagnostic work-up, or a group session. The only clinical characteristics required are the Mini Mental State Examination (MMSE) [10] and the Instrumental Activities of Daily Living (IADL) [11], which must be carried out for each patient at least once a year. Lastly, there are items on the type of social welfare. The CIMA currently has 31 variables to be completed (Table 1). For every procedure and every patient, a CIMA must be transmitted to the BNA. Once a year, each center is also required to submit information on its

Table 1
Limited data set on Alzheimer's disease (CIMA; Corpus minimum d'information Alzheimer)

Data on the patient
1. Surname
2. Last name
3. First name
4. Date of birth
5. Departement of birth
6. Code for commune of birth
7. Sex
8. New patient
9. Patient referred by
10. Present lifestyle
11. Geographical location with regard to the center
12. Educational level
13. A.P.A[a]
14. A.L.D[b]
15. Patient protection measures
16. Diagnosis: Level 1
17. Diagnosis: Level 2
Data on the procedure
18. Date of procedure
19. Type of procedure
20. The procedure is performed within the framework of a support mission (for CMRR only)
21. If yes: Type of research protocol
22. If yes: Type of visit protocol
23. The procedure is being carried out within the framework of a research protocol:
24. Mini-Mental Test Examination:
25. IADL[c]
26. Pharmacological treatment
27. Serious adverse event
28. Psycho social intervention and rehabilitation
29. Follow-up status
30. Date of entry into residential care (where applicable)
31. Date of death (where applicable)

[a]Personal autonomy allowance (Allocation personnalisée d'Autonomie).
[b]Long-term illness (Affection de longue durée).
[c]Instrumental Activities of Daily Living.

characteristics (type of center, number of ½ days open, number of full-time equivalent staff).

The BNA is thus the national database which collects all the limited data sets recorded by CMs, CMRRs, and volunteer independent specialists.

The computer application "Calliope" is made available to centers for data entry, though they can opt for any one of a number of alternatives (Rapid, Onyx, 4D Nord, Alpha, etc.). Every time a patient visits a center, the physician completes a patient file specifically designed for AD and related disorders, which can be filled out online using a fully web-based application (i.e., physicians can enter the data online via a web browser without needing to have the application installed on their computer). Once the data has been entered, the application extracts the required limited data set and transmits it to the BNA (see Fig. 1). The physician or user normally enters the data during the consultation, though this is sometimes done after. The system will indicate the items to be corrected if it detects any inconsistencies or gaps in the data.

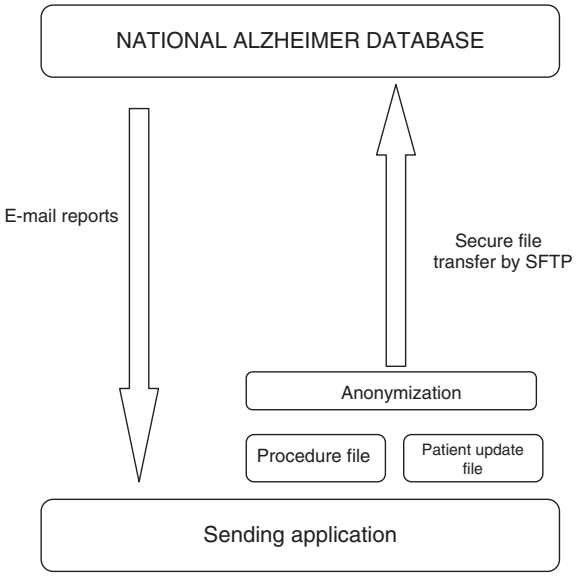

Fig. 1. Flow of data to the National Alzheimer Database (BNA).

The firm Ellipse was contracted to develop the database (the BNA), which had to be able to collect all the limited data sets, anonymize the data, and enable statistical analyses to be carried out. The server hosting the BNA is located on the premises of Nice University Hospital and is supervised by the Computer Systems Department, which is licensed to hold personal health data, thereby ensuring the necessary protection for this type of data. Data administration is carried out by the Public Health Department of Nice University Hospital, which ensures the consistency and operation of the database in cooperation with the French Institute for Public Health Surveillance (Institut de veille sanitaire) and DGOS. This institutional collaboration is governed by an agreement signed in December 2008, defining the duties of each partner and the expected targets for data collection during the subsequent months. The BNA team has a permanent staff consisting of a statistician in charge of data management and a computer systems manager. Other staff is composed of clinicians working in the Nice CMRR and the Public Health Department.

A key point in the development of the system is that, since 20 May 2010, all the participating centers have been provided with the necessary online tools. Each center now has its own access code enabling it to

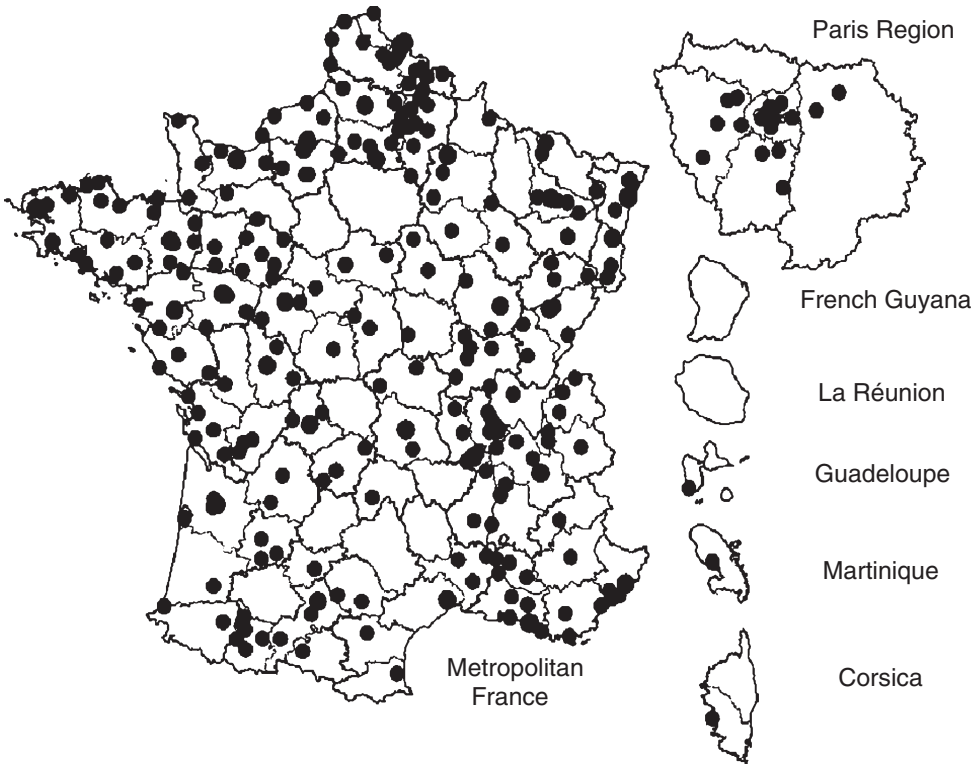

Fig. 2. Distribution of memory centers in France and overseas regions that submitted at least one limited data set (CIMA) during the period from 1 January to 31 December 2010.

query the national database at any time and also access its own consolidated and anonymized data.

RESULTS

Of the 427 memory centers in France, 320 centers (75%) submitted at least one limited data set (CIMA) to the BNA (27/27 CMRRs and 263/399 CMs) in 2010. Thirty-three independent neurologists participated in data collection. Figure 2 shows the distribution of participating CMRRs and CMs in France, including French overseas départements (administrative districts).

Between 1 January 2010 and 31 December 2010, 118,776 patients (women: 63.2%; men: 36.8%) consulted a center participating in the collection of data for the BNA. A total of 199,113 CIMA were submitted (Fig. 3). Patients had a mean age of 77.4 years (women: 78.5 years; men: 75.6 years). The mean age for AD patients is 82.2, 79.5 for patients with related disorders, and 76 for patients with mild cognitive impairment (MCI). Of the patients who consulted at a CMRR, 19.4% lived over 50 km from the center; this compares

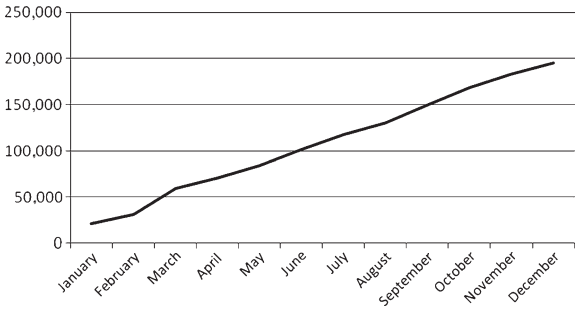

Fig. 3. Increasein the number of limited data sets (CIMA) transmitted to the National Alzheimer Database (BNA) between 1 January and 31 December 2010.

to only 5.3% in the case of patients who consulted at a CM.

Table 2 shows the distribution of diagnoses in decreasing order of frequency. Out of a total of 118,776 patients, AD accounted for 27.3% of diagnoses, related disorders for 20.1%, and diagnoses pending for 25.8%. MCI accounted for 8.4%. There were marked differences in the distribution of diagnoses by type of center. The proportion of patients diagnosed with AD was higher for patients consulting independent neurologists

Table 2
Diagnoses of patients recorded in the National Alzheimer Database (BNA), by diagnostic category

Diagnosis	%	No.
Alzheimer disease	27.3	32,426
Related disorders	20.1	23,861
Mild cognitive impairment	8.4	9,958
Depression and other psychiatric disorders	7.5	8,950
Subjective memory complaint	6.5	7,751
Other neurological disorders	4.2	4,970
Other	0.2	212
Diagnoses pending	25.8	30,684

Distribution of diagnoses/categories

Category	Diagnosis
Alzheimer's disease	Alzheimer's disease
Related disorders	Mixed dementia + Other vascular dementia + Vascular dementia + Fronto – temporal dementia + Creutzfeldt – Jakob disease + Huntington's disease + Parkinson's disease dementia + Dementia with Lewy bodies + HIV dementia + Limbic encephalitis + Progressive supranuclear palsy + Cortico basal degeneration + Primary progressive aphasia + Semantic dementia + Posterior cortical atrophy + Normal – pressure hydrocephalus + Dementia not classified elsewhere
Diagnosis pending	Diagnosis pending
Mild cognitive impairment	Amnesic MCI + Other MCI
Depression and other psychiatric disorders	Organic brain disorder directly related to the use of alcohol or other toxic substances + Psychotic disturbances + Isolated depressive symptoms + Recurrent depressive symptoms + Depressive/anxiety disorders + Anxiety disorders (including anxiety disorders such as OCD) + Post traumatic stress disorder + Other psychiatric disturbances (amnesia, psychogenic, simulation, etc.)
Subjective memory complaint	Memory complaint
Other neurological disorders	Organic brain disorder directly related to a disease (e.g., metabolic, endocrine, hepatic, respiratory, SAS, renal, inflammatory, cancer) + Other neurological disorders (tumors, post-surgical, aneurysms) + Parkinson's + Multiple sclerosis + Epilepsy+Head injury
Other	Iatrogenic

(39.9%) than for those seen in CM (31.2%) or CMRR (24.3%). Figure 4 shows the mean scores obtained at the initial MMSE for patients in each of the three types of center. The initial MMSE mean score for patients in France was 16.8 points for AD, 25.7 points for MCI, and 18.8 points for related disorders.

In terms of referrals reported by centers participating in the BNA, 86.9% of the patients seen by independent neurologists were referred by their general practitioner; the comparable percentage for CMs was 66.7% and for CMRRs 50.4%.

Most of the patients with a diagnosis of AD and related disorders had a MMSE from 10 to 26 and the proportion of AD patients with a MMSE lower than 10 is equal to 12.6% (Table 3). The proportion of patients with subjective memory complaint diagnosis with a MMSE less than 27 is equal to 31.0%, and 95.7% of the patients with MCI account for a score above 20.

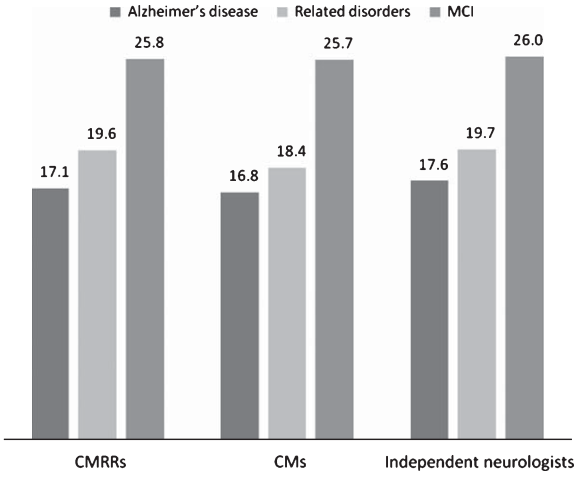

Fig. 4. Mini-Mental State Examination: mean score by type of center (CMRRs, CMs, independent neurologists) for the three main diagnostic categories: Alzheimer's disease, related disorders, mild cognitive impairment (MCI).

Finally, Table 4 shows the repartition of the patients according to their way of living.

DISCUSSION

The BNA set up under the National Plan for "Alzheimer's Disease and Related disorders" 2008–2012, provides a 'life-size' view, for an entire country, of persons consulting specialized memory centers and independent neurologists for memory disorders.

The initial data derived from the BNA indicate that the centers receive a wide variety of patients, as shown by the different types of diagnoses. Indeed, about 30% of diagnoses were for AD and 20% for related disorders, these two categories thus accounting for just over half of all diagnoses. The remaining patients comprised MCI, diagnoses pending, and other diagnoses.

Table 3
Distribution of the diagnosis by MMSE categories

	MMSE			
	0–9 (%)	10–19 (%)	20–26 (%)	27+ (%)
Alzheimer's disease	12.6	49.1	34.5	3.7
Related disorders	8.5	41.5	39.5	10.5
Mild cognitive impairment	0.2	4.1	47.0	48.7
Depression and other psychiatric disorders	1.1	10.0	37.7	51.1
Subjective memory complaint	0.8	3.8	26.4	68.9
Other neurological disorders	1.8	12.3	39.7	46.2
Other	2.9	13.9	48.0	35.3
Diagnoses pending	2.5	24.5	45.2	27.7

Table 4
Distribution of the places to live by diagnosis

	Home alone (%)	Home with help (%)	Hospital (%)	Nursing home (%)	Other (%)
Alzheimer disease	32.3	48.7	1.0	16.1	2.0
Related disorders	28.4	51.2	2.4	16.4	1.6
Mild cognitive impairment	34.1	60.0	0.6	3.7	1.6
Depression and other psychiatric disorders	34.9	52.7	2.9	7.0	2.6
Subjective memory complaint	33.6	60.6	0.9	2.5	2.5
Other neurological disorders	25.3	64.7	2.9	4.2	2.9
Other	29.7	50.0	6.6	9.4	4.2
Diagnoses pending	34.9	51.1	3.1	7.8	3.1

Distribution of the places to live

Category	
Home alone	At home alone, at home alone with family geographically close
Home with help	At home with spouse/husband, In family home
Hospital	General hospital, Psychiatric hospital
Nursing home	Medical Nursing home, home for elderly people
Other	Host family, Housing Home

This finding also raises questions about the commonly accepted figure for the prevalence of this pathology among all forms of dementia, since AD is generally the principal cause of dementia, at least in 70% of cases [15].

This first analysis of the BNA also shows that, in 2010, among the 118,776 persons who consulted specialist memory centers (hospital-based or otherwise) participating in the BNA, 56,287 had AD or related disorders (66,245 with MCI). This number is far smaller than the estimated figure for the prevalence of AD and related disorders provided by the PAQUID study, namely 850,000 persons in France [12, 13]. Several factors could account for this result. The first is directly related to the way the BNA operates. As the BNA only started to function in October 2009, not all memory centers were actively participating in 2010 and, in addition, independent specialists were under-represented. Furthermore, it is likely that the participating centers were still not entering a complete record of their activity in the BNA. A quality control procedure to check the exhaustiveness of data entry at source is currently in progress and should provide a clearer assessment of the extent of this problem. The second factor concerns the number of AD cases that remain undiagnosed. Indeed, studies by Dartigues et al. suggest that 50% of AD cases go undiagnosed. It would appear that only a third of cases are detected at an early stage of the disease. These authors also estimate that nearly 27% of advanced cases remains undetected [12, 14, 15]. The third factor is that a part of the studied population consists of residents in nursing homes (EHPAD: Etablissements d'Hébergement pour Personnes Agées Dépendantes). Little information is currently available within the BNA on this subject. In fact the BNA reveals that very few patients are referred by these nursing homes. It should be expected that older age alone is also an important factor for not referring to a CM. Lastly, according to the report of an evaluation mission on CMs and CMRRs by the Directorate for Hospitalization and Healthcare Management (DHOS: Direction de l'Hospitalisation et de l'Organisation des Soins) [16], there are considerable variations in the way memory centers are organized. Even though they are also responsible for follow-up activities, it may well be that some centers are currently prioritizing their diagnostic activities to the detriment of follow-up activities. Since our study was confined to the year 2010, we were unable to estimate the number of persons returning each year for a follow-up consultation in the context of AD or related disorders. However, since the BNA is designed to allow for the longitudinal, prospective study of patients in France, we should soon have a clearer view of the frequency with which patients visit the various categories of memory centers, and also refine the analysis of types of care, by category of memory center.

Another important finding concerns the degree of severity of the disease in patients presenting with AD. In terms of the mean score on the first MMSE performed at the time of diagnosis, Ramaroson [17] reported a mean score of 19 points at diagnosis in the PAQUID cohort, whereas the mean score is 17.1 across all the centers currently participating in the BNA. This confirms that patients in France are still consulting at too advanced a stage of the disease.

The results we have presented must be interpreted with caution. Indeed, since the BNA system came into operation gradually, some centers transmitted nearly 12 months of data to the BNA during the year 2010, whereas others submitted only three or four months of usable data. Discrepancies of this type also existed between the different categories of center. The CMRRs were the first centers to participate. As a result, the volume of their activity is most likely over-represented, at least with regard to the data for 2010, the first year in which the BNA was in operation. The CMs are both more numerous and more disparate in their activities and consequently may not be properly represented in the current database. Furthermore, this overview across all BNA centers throughout France fails to reflect the gradual phasing in of the system and the increasingly active participation of independent neurologists throughout the year. It is most likely that, as more and more CIMA from independent neurologists are included during the coming months, the BNA will increasingly reflect the particular characteristics of the service they provide. All these points explain that the sample presented here are only a limited subset of the overall population.

The BNA was devised and designed as a huge matrix where the CIMA variables interact with the various types of procedure performed within the centers. The requirement of confidentiality, achieved through data anonymization [18], and the impossibility of going backward in time, means that any data entry errors will remain embedded until the next consultation. Nevertheless, errors that become incorporated into the database may well remain and only the constant improvement of the database management and quality control will gradually be able to correct the first data entry errors.

In terms of quality control, the BNA coordinating team endeavors to trace the source of the data to

ensure that the information entered in the BNA does indeed correspond to that observed in the field and accurately reflects the consultation. The comprehensiveness and quality of the information supplied are the two key areas targeted by this continuing process of quality improvement carried out by the BNA team. For instance, we can notice that 0.2% ($n = 19$) of patients with MCI have a MMSE score lower than 10. Centers need to be informed in order to control this type of incongruence. The quality control is a major and necessary step for a scientific epidemiological use of the BNA.

AD and related disorders databases already exist in several countries. Although the BNA provides a minimum dataset in comparison with others containing biological [19], histological [20, 21], or clinical data [22, 23], its advantage is of course its size and statistical power. With the example of the French Hospital Database on HIV [24], the BNA is one of the rare national databases allowing the ongoing collection of socio-demographic, epidemiological, and clinical data on AD and related disorders. Participating centers benefit both from enhancing their national visibility and from being able to access information in each of the fields covered by data collection. The database explores three fields (medical, psychological, and social) and seeks to cover all aspects of care for patients with AD and related disorders. Analyses of the data can be used to prepare activity reports but can also lead to research hypotheses and improvements in patient care. The medical field is principally covered by clinical data (diagnosis, investigations, and treatments), the clinical psychology field is covered by the type of intervention and the neuropsychological scores (especially the MMSE), and the social field covers the patient's environment (entourage, housing, and resources).

Based on a computerized medical file focusing on the patient, the BNA, like the aforementioned database on HIV, should eventually provide to policy makers and to the others measures of the French Alzheimer Plan, longitudinal data for periodic or thematic analysis (estimate of active file population, follow-up studies, etc.). In so doing, it is possible to inform the discussion on what resources are required to best meet the needs of the population in each area and especially to scale the supply and delivery of specialized "memory" healthcare through each regional health organization scheme. As well as helping to inform policy decisions, these anonymized data should ultimately serve as a basis for reflection and the starting point to develop more specific studies involving independent cohorts. By the end of 2012, in order to be more exhaustive, use of the BNA will be mandatory for keeping the label Memory consultation. A descriptive analysis will be carried out periodically to review the progress of the National Alzheimer Database and further develop this nationwide data collection system.

ACKNOWLEDGMENTS

Measure 34 is subsidized by DGOS (Direction Générale de l'Offre de Soins, France), under the 2008–2012 National Alzheimer Plan, and by ARMEP (Association Recherche Méthodologie Evaluation Psychiatrie, France). We would like to thank Cécile Balandier (project officer, DGOS), Philippe Mayer (CHU director), André Garrel (computer scientist), Amandine Gastaldi (Coordinator, Calliope), and Rolland Chevrier (CHU) for their tireless support and Prof. Joel Menard for redrafting the manuscript.

Authors' disclosures available online (http://www.j-alz.com/disclosures/view.php?id=1139).

PARTICIPATING CENTRES

[1]Centers actively participating in the BNA, 1 August 2011: Adn Saumur (Devy Richard); Adna (Galmiche Jean); Adna Bretagne (Hamon Jean Baptiste); Adnaals (Catherine Stephan); Adnalor (Jager Alain); Ahfc Ch Saint Remy (Talon Jean Marc); Berck (Nicolas Fanjaud); Bethune (Lavenu); Boulogne (Philippe Devos); C.A.M.T Agen (Vogt Luc); Cabinet De Neurologie Bergerac (Delabrousse Mayoux Jean Philippe); Cabinet De Neurologie Du Dr Marion (Marion Jean Luc); Cabinet De Neurologie_ Cmp Bordeaux (Fleuri Laurence); Cabinet Dr Catherine Stephan (Stephan Catherine); Cabinet Dr Chambaud (Chambaud Loïc); Cabinet Dr Follin (Follin Erika); Cabinet Dr Kubler Christophe (Kubler Christophe); Cabinet Dr Thilbaultstoll (Thibaultstoll Anne); Cabinet Dr Bazinpetiau Aurélie (Bazinpetiau Aurélie); Cabinet Dr Cottinmear Corine (Cottinmear Corine); Cabinet Du Dr Decombe (René Decombe); Cabinet Du Dr Dib (Dib Joseph); Cabinet Du Dr Galmiche (Galmiche Jean); Cabinet Du Dr Jb Hamon (Hamon Jean Baptiste); Cabinet Du Dr Kopf Audrey (Kopf Audrey); Cabinet Du Dr Meinnel (Nelly Meinnel); Cabinet Du Dr Muh Philippe (Muh Philippe); Cabinet Du Dr North Pierre (North Pierre); Cabinet Du Dr Pouyet Alain (Pouyet Alain); Cabinet Du Dr Schatz Pierre Marie (Schatz Pierre Marie); Cabinet Du Dr Schoenfelder (Schoenfelder Françis); Cabinet Du Dr Sergeant (Sergeant Thierry);

Cabinet Du Dr Steinmetz Gisèle (Steinmetz Gisèle); Cabinet Du Dr Stephan Michel (Stephan Michel); Cabinet Du Dr Zaenker Christophe (Zaenker Christophe); Cabinet Neurologie Du Village Santé Angersloire (Bossu Vannieu Wenhuyse Catherine); Calais (Olivier Dereeper); Cambrai (Marie Trocmet); Cambrai St Roch (Joel Cliche); Carvin (Bertrand Junique); Cdprv Valence (Ferry Grand Monique); Centre Ambulatoire Nantais Gérontologie Clinique (Berrut Gilles); Centre De Soins Tilleroyes (1250000759) (Martine Iehl Robert); Centre Hospitalier De Chaumont (Dumontier François); Centre Hospitalier De Sedan (Ponceletgochard Marie Paule); Centre Hospitalier De Trévoux (Gitenet René); Centre Hospitalier Départemental De Bischwiller (Ismer Helene); Centre Hospitalier Geneviève De Gaulle Anthonioz (Anne Aubertin); Centre Hospitalier Mulhouse (Stoffel Michèle); Centre Hospitalier Vitre (Ibazizen Abrous Fazia); Centre Mémoire De Ressource Et Recherche De Caen (De La Sayette Vincent); Centre Mémoire De Saint Nicolas De Port (Perreinflorence); Centre Mémoire Du Piémont (Blancplatier Anne); Centre Mémoire Saint Michel (Sandrine Gallandmorice); Ch Belfortmontbéliard (Bataillard Marc); Ch Cholet (Marie D'avigneau); Ch Dignelesbains (Gilardi Marie Josee); Ch Ham (Guigra Joseph); Ch L Pasteur Dole (1390000222) (Apffel Jeandaniel); Ch Lons Le Saunier (Berthier Eric); Ch Montluçon (Almeida Eva); Ch Pontarlier (1250000700) (Degois Marc); Ch Saumur (Herve Causeret); Ch Vesoul (Jary Annabelle); Ch De Fréjus Saint Raphaël (Cornée Bertaud Sophie); Ch Eureseine (Large Patrice); Chru De Strasbourg Hôpital De Jour (Martin Hunyadi Catherine); Chs Novillars (Fierobe Martine); Chu De Reims (Novella Jean Luc Puph); Chu Jean Minjoz (Vandel Pierre); Cm Ch Chinon (Lagier Marc); Cm Abbeville (Bastea Licuti); Cm Aix En Provence (Viallet François); Cm Aix Les Bains (Favremonnet Dominique); Cm Ajaccio (Tafani Bastien); Cm Alberville moutiers Et Bourg Saint Maurice (Mertuk Dominique); Cm Alençon (Thenint Jean Philippe); Cm Alès (Peju Liliane); Cm Alois Avicenne (Belin Catherine); Cm Alpes Nord (Assemat Eric); Cm Angoulême (Devoize Jeanlouis); Cm Annecy (Debray Matthieu); Cm Annemasse (Dartiguepeyrou André); Cm Annonay (Essertelroncari Annie); Cm Antibes (Le Nechet Anne); Cm Apt (Queneau Christine); Cm Arcachon (Le Roux Véronique); Cm Arpajon 91 (Barboux Philippe); Cm Aubenas (Grosclaude Bernard); Cm Aurillac (Vert Catherine); Cm Autun (Chausse Stéphane); Cm Auxerre (Jouanne Monique); Cm Avignon (Tourniaire Patricia); Cm Bagnères De Bigorre (Carpuat Christian); Cm Bain De Bretagne (Bordes Didier); Cm Ballainvilliers (Rigoulet Yoanna); Cm Bayeux (Mialon Michel); Cm Bayonne_Neuro (Ballan Guillaume); Cm Beaune (Sixt Marc); Cm Bernay (Daluzeau Nathalie); Cm Bohain (Gallopin Véronique); Cm Bois Guillaume (Levasseur Caroline); Cm Bourg En Bresse (Boge Thierry); Cm Bourges (Rajaonarivo Josiane); Cm Brignoles (Codron Pierre); Cm Brive (Gourdeau Nauche Florence); Cm Bry (Haddad Victor); Cm Caluire (Merrot Severine); Cm Cannes (Dyckmans Lydian); Cm Carcassonne (Attane Françoise); Cm Carpentras (Perrouty Bruno); Cm Ch Avranchesgranville (Verger Patrick); Cm Ch Bagnolssurcèze (Bouttier Florence); Cm Ch Château Du Loir (Franques Patrice); Cm Ch Du Val DAriège (Bories Lawrence); Cm Ch Haut Anjou (Collet Nadine); Cm Ch Les Sables D'olonne (Redureau Nicolas); Cm Ch Sainte Marie Nice (Maurin Henri); Cm Ch Saintjunien (Thomas Delphine); Cm Ch Soissons (Petitnicolas Gil); Cm Challans (Taddei Franck); Cm Châlon S/Saône (Minier Dominique); Cm Chambery (Desmonceaux Martine); Cm Champcueil (Baptiste Nathalie); Cm Chantepie (Mayaudon Charles); Cm Châteaubriant (Salim Samar); Cm Châteauneuf/Charente (Dubourg Masse Jean Philippe); Cm Chateauroux (Hallak Habib); Cm Chatellerault (Desforges Eric); Cm Chauny (Jullin Martine); Cm Chd Multi Site La Roche/Yon (Lejeune Pascal); Cm Cherbourg (Dupuy Benoît); Cm Chg La Fère (Seneschal Françoise); Cm Chic Amboise Châteaurenault (Naceur Tarik); Cm Clermont (Samad Zouheir); Cm Clinique Les Sources (Barres Philippe); Cm Compiègne (Polroux Sabine); Cm Cpa Bourg En Bresse (Caschera Virginie); Cm Creil (Woerth Florence); Cm Crest (Pelletier Henri); Cm Croixrouge 69 (Bodier Nadège); Cm De Saint Gaudens (Parneix Caroline); Cm De Saint Girons (Del Mazo Frédéric); Cm De Saintes (Lemaitre Mariehélène); Cm Dieppe (Pesqué Thierry); Cm Dieppe Neufchatelenbray (Jasnot Karine); Cm Dinan (Lotton Barbotin Sylvie); Cm Du Ch De LAgglomération Montargoise (Filippi Marie); Cm Du Ch De Noyon (Ledoux Valerie); Cm Du Ch Nordmayenne (Rollini Jean Jacques); Cm Du Léman (Creisson Eric); Cm Elbeuf/Louviers (Simon Thibault); Cm Ferté Bernard (Bouchart Christian); Cm Feurs (Jurine Jean Paul); Cm Firminy (Auguste Nicolas); Cm Flers (Quillard Anne); Cm Fontenay Le Comte (Bounaceur Nora); Cm Fougères (Toujas Catherine); Cm Francheville (Gaujard Sylvain); Cm Grasse (Ribiere Jacques); Cm Guingamp (Brilleaud Michel); Cm Guise (Soyez Sophie); Cm Haut Vaucluse (Celles Laurent); Cm Hennebont (Barbot Anneclaire); Cm Hôpital Bretonneau

Paris (Drunat Olivier); Cm Hôpital De Muret (Liger Salvy Marlène); Cm Hyères (Alonso Violaine); Cm Invalides (Marchal Dominique); Cm Issoire (Denozi Philippe); Cm Jonzac (Moras Jean Baptiste); Cm La Ciotat (Ruggieri Irène); Cm La Jonchèrele Colombier (Schadler Denis); Cm La Rochelle (Nedelecciceri Claudine); Cm Lagny Sur Marne (Poulain Valerie); Cm Landerneau (Rampelberg Anne); Cm Lannemezan (Bordes Serge); Cm Lannion (Brahambeaumont Leila); Cm Laon (Szczurdordain Mariehelene); Cm Laval (Touzard Claude); Cm Lavaur (Desclaux Françoise); Cm Le Bailleul (Stephane Pierre); Cm Le Bouscat (Clementy Anne); Cm Le Creusot (Petit Veronique); Cm Le Grand Luce (Rondeau Mariehelene); Cm Le Havre (Pinel Valerie); Cm Le Mans (Lejoyeux Annie); Cm Les Fontaines De Monjous (Ah Soune Marie Françoise); Cm Libérale Lambersart (Douay Xavier); Cm Libourne (Louis Frederique); Cm Lisieux (Daluzeau Nathalie); Cm Lourdes (Barrere Michel); Cm Lyon Fourviere (Gonzalez Louis); Cm Lyon Pierre Garraud (Coste Mariehélène); Cm Lyon Saint Jean De Dieu (Gallice Isabelle); Cm Macon (Menecier Pascal); Cm Malestroit (Lembelembe Jean Paul); Cm Marseille Départemental (Gayraud Dominique); Cm Martigues (Straton Ferrato Isabelle); Cm Meaux (Nodzenski Nadine); Cm Montauban _ Clinique Du Pont De Chaume (Angibaud Gilles); Cm Montceau Les Mines (Gerard Dominique); Cm Montélimar (Kayser Jeanlous); Cm Montmorillon (Cafardy Sylvie); Cm Morlaix (Le Meur Nicole); Cm Moulins (Valvin Valérie); Cm Nerac (Salleles Louis); Cm Nevers (Renaudin Francois); Cm Nîmes (Strubel Denise); Cm Niort (Leger Dominique); Cm Nord Isère (Ducarre Françoise); Cm Oisselchu De Rouen (Moynot Yves); Cm Orléans (Lemonnier Jean Yves); Cm Paray Le Monial (Faucher Bruno); Cm Paris St Joseph (Volpegillot Lisette); Cm Péronne (Gallopin Veronique); Cm Perpignan (Barnier Genevieve); Cm Petit Quevilly (Landrin Isabelle); Cm Plaisir (Tager Beatrice); Cm Poissy (Bodenan Laure); Cm Pôle Sanitaire Du Vexin _ Ch Gisors (Foison Olivier); Cm Pontivyloudéac (Rey Barbara); Cm Pyrénées (Dyan Alain); Cm Quimper (Diraison Philippe); Cm Quimperlé (Buronfosse Dominique); Cm Rambouillet (Allard Isabelle); Cm Roanne (Salzmann Martin); Cm Rochefort (Luizy Joelle); Cm Romans Sur Isère (Remy Claude); Cm Royan (Negrier Guillaume); Cm Saint Brieuc (Golfier Véronique); Cm Saint Chamond (Barrellon Marieodile); Cm Saint Nazaire (Hily Sylvie); Cm Saint Sébastien De Morsent (Chauvin Didier); Cm Saint Sever (Vanhoenackere Marie Christine); Cm Sainte Marie Clermontfd (Becamel Gilles); Cm Saintlô/Coutances (Dress Dominique); Cm Salon De Provence (Toupet Dominique); Cm Senlis (Woerth Florence); Cm Sens (Rossignol Sylvie); Cm Sillé Le Guillaume (Bera Michel); Cm St Germain (De La Forest Divonne François); Cm St Quentin (Gallopin Veronique); Cm St Yrieixlaperche (Burguet Myriam); Cm Sud Charente (Chaumier Jeanalbert); Cm Talence (Trophy Francoise); Cm Tarbes (Skolil Pierre); Cm Tarnsud (Castan Dominique); Cm Tonneins (Anxolabehere Tassoula); Cm Treguier (Nicodéme Jeanluc); Cm Tulle (Graval Hugedee Valérie); Cm Ussel (Laporte Philippe); Cm Valence Geriatrie (Mischis Christelle); Cm Valence Neurologie (Grosclaude Max); Cm Vannes Auray La Roche Bernard (Le Provost Christian); Cm Versailles (Samson Michel); Cm Vicenbigorre (Gasnier Yannick); Cm Vienne (Diot Eric); Cm Villejuif (Feteanu Dorin); Cm Villiers St Denis (Schneider Guy); Cm Voiron (Cezard Odile); Cmp Beauvais (Cnockaert Xavier); Cmp Blois (Friocourt Patrick); Cmp Draveil (Rabus Maite); Cmp Haute Côte D'or (Plassard Claude); Cmp Verger Des Balans (Demoures Geneviève); Cmp Vierzon (Hovasseprely Elisabeth); Cmrr Amiens (Godefroy Olivier); Cmrr Angers (Beauchet Olivier); Cmrr Auvergne Equipe Psychiatrique (Jalenques Isabelle); Cmrr Bordeaux_Arnozan (Harston Sandrine); Cmrr Bordeaux_Pellegrin (Dartigues Jeanfrançois); Cmrr Brest (Tilly Gentric Armelle); Cmrr Clermont Ferrand (Deffond Didier); Cmrr De La Région Centre (Hommet Caroline); Cmrr De Toulouse (Vellas Bruno); Cmrr Délocalisé Adna (Pierre Vandel); Cmrr Dijon (Rouaud Olivier); Cmrr Grenoble (Moreaud Olivier); Cmrr Limoges (Clement Jean Pierre); Cmrr Limoges_Rebeyrol (Dantoine Thierry); Cmrr Lorrain (Benetos Athanase); Cmrr Lyon Charpennes (Krolaksalmon Pierre); Cmrr Lyon Neurologie D Ghe (Vighetto Alain); Cmrr Lyon Neuropsycho (Croisile Bernard); Cmrr Lyon Pierre Benite (Bonnefoy Marc); Cmrr Marseille (Ceccaldi Mathieu); Cmrr Marseille _ Site Nord (Rochefort Nicolas); Cmrr Montpellier (Touchon Jacques); Cmrr Nantes Partie Neurologique (Vercelletto Martine); Cmrr Nice (Robert Philippe); Cmrr Paris 13 Broca (Rigaud Annesophie); Cmrr Paris Nord Idf Hop Widal (Hugon Jacques); Cmrr Paris Pitié Salpêtrière (Dubois Bruno); Cmrr Poitiers (Gil Roger); Cmrr Rennes (Michel Olivier); Cmrr Rennes _ Service De Neurologie (Belliard Serge); Cmrr Rouen (Hannequin Didier); Cmrr Saint Etienne Gériatrie (Girtanner Chantal); Cmrr Saint tienne Neurologie (Thomas Anterion Catherine); Consultation Mémoire De Saint diédes Vosges (Russo Luciano); Consultation Mémoire D'epernay (Annie Parent); Consultation

Mémoire D'epinal (Huttin Bernardph); Consultation Mémoire Saint Charles (Dautreppe Jean Noel); Consultation Mémoire St Luc Niderviller (Mechkour Abdellatif); Denain (Pascale Leurs); Dr Delassaux Sébastien (Delassaux Sébastien); Dr Hourmant Patrick (Hourmant Patrick); Dr Planque Evelyne (Planque Evelyne); Gham Site De Sezanne (Fleitz Sylvie); Ghicl (Gauthier Calais); Hôpital De Altkirch (Anfossi Agnès); Hôpital De Fécamp (Villers Valérie); Hôpital De Jour Gériatrique De Luneville (Dautreppe Jean Noël); Hôpital Medicogeriatrique Le Kem (Serge De Nadai); Hôpital Vaugirardgabriel Pallez (Okra Nicole); Hôpitaux Civils De Colmar (Sellal François); Hôpitaux Civils De Colmar Pôle De Gérontologie (Michel Jean Marc); Hôpitaux Universitaires De Strasbourg (Blanc Frédéric); Jager Alain (Jager Alain); Labo De Neuropsychologie Hôpital Neurologique (Bernard Croisile); Le Cateau (R. Abied); Le Quesnoy (Denis Lefebvre); Lens (Olivier Senechal); Les Bateliers (Jean Roche); Lille Bailleul (Pasquier); Maubeuge (Rosolacci Thierry); Mutuelle Le Chateau (Dct Battaglia); Reseau Albigny (Val De Saône) (Hamy Isabelle); Réseau Coglim (Cartz Piver Leslie); Réseau Mémoire Alois (Defontaines Bénédicte); Reseau Villefranche (Val De Saône) (Nove Josserand Anne); Reseda Dijon Cabinet Buffon (Manceau Eric); Reseda Dijon Cabinet Debrosses (Gras Pierre); Reseda Dijon Cabinet Point Médical (Madinier Guillaume); Roubaix (Pierre Forzy); Rsi Cmrr Nice (Robert Philippe); Seclin (Véronique Berriot); Service De Gériatrie Hôpital Des Charpennes (Pierre Krolaksalmon); Service De Gériatriech Pierre Garraud (Mariehélène Coste); Service De Gériatriehôpital Antoine Charial (Gilles Albrand); Service De Gériatriehôpital Frédéric Dugoujon (Elisabeth Andrefouet); Service De Médecine Gériatriquech Lyon Sud (Marc Bonnefoy); Service De Neurologie Hôpital Neurologique (Alain Vighetto); St Omer (Garcon Karine); Tourcoing (Karim Gallouj); Valenciennes (Isabelle Girardbuttaz); Wasquehal (Houria Idiri); Zuydcoote (Rémi Messin).

REFERENCES

[1] Ramaroson H, Helmer C, Barberger-Gateau P, Letenneur L, Dartigues JF (2003) Prévalence de la démence et de la maladie d'Alzheimer chez les personnes de 75 ans et plus: Données réactualisées de la cohorte Paquid. *Rev Neurol (Paris)* **159**, 405-411.

[2] Lobo A, Launer LJ, Fratiglioni L, Andersen K, Di Carlo A, Breteler MM, Copeland JR, Dartigues JF, Jagger C, Martinez-Lage J, Soininen H, Hofman A (2000) Prevalence of dementia and major subtypes in Europe: A collaborative study of population based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology* **54**(Suppl 5), S4-S9.

[3] Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Scazufca M, Alzheimer's Disease International (2005) Global prevalence of dementia: A Delphi consensus study. *Lancet* **366**, 2112-2117.

[4] Institut national de la santé et de la recherché médicale (Inserm). Maladie d'Alzheimer–enjeux scientifiques, médicaux et sociétaux (2008) Éditions Inserm. Collection Expertise collective, http://www.inserm.fr/mediatheque/infr-grand-public/fichiers/thematiques/sante-publique/expertises-collectives/alzheimer-enjeux-2007. Posted 2008, Accessed on 15 November 2011.

[5] Benoit M, Robert PH, Staccini P, Brocker P, Guerin O, Lechowski L, Vellas B (2005) One-year longitudinal evaluation of neuropsychiatric symptoms in Alzheimer's disease. The REAL.FR Study. REAL.FR Group. *J Nutr Health Aging* **9**, 95-99.

[6] Nourhashémi F, Ousset PJ, Gillette-Guyonnet S, Cantet C, Andrieu S, Vellas B (2008) A 2-year follow-up of 233 very mild (CDR 0.5) Alzheimer's disease patients (REAL.FR cohort). *Int J Geriatr Psychiatry* **23**, 460-465.

[7] Perez F, Helmer C, Dartigues JF, Auriacombe S, Tison F (2010) A 15-year population-based cohort study of the incidence of Parkinson's disease and dementia with Lewy bodies in an elderly French cohort. *J Neurol Neurosurg Psychiatry* **81**, 742-746.

[8] Plan Alzheimer 2008–2012 (2008) http://www.plan-alzheimer.gouv.fr/

[9] Aouba A, Péquignot F, Le Toullec A, Jougla E (2007) Les causes médicales de décès en France en 2004 et leur évolution 1980–2004. *Bull Epidemiol Hebd* **35-36**, 308-314.

[10] Folstein MF, Folstein SE, McHugh PR (1975) Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* **12**, 189-198.

[11] Lawton MP, Brody EM (1969) Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist* **9**, 179-186.

[12] Amieva H, Andrieu S, Berr C, Buée L, Checler F, Clément S, Dartigues JF, Desgranges B, Dubois B, Duyckaerts C, Joel ME, Lambert JC, Nourhashemi F, Pasquier F, Robert P, Blanchard F, Bloch MA, Ganem-Chabenet D, Lacomblez L, Saint-Jean O (2007) Maladie d'Alzheimer: Enjeux scientifiques, médicaux et sociétaux Institut national de la santé et de la recherche médicale (INSERM) – Rapport, http://hdl.handle.net/2332-1336.

[13] Tyas Sl, Tate RB, Wooldrage K, Manfreda J, Strain LA (2006) Estimating the incidence of dementia: The impact of adjusting for subject attrition using health care utilization data. *Ann Epidemiol* **16**, 477-484.

[14] Commenges D, Joly P, Letenneur L, Dartigues JF (2004) Incidence and mortality of Alzheimer's disease or dementia using an illness-death model. *Stat Med* **23**, 199-210.

[15] Dartigues JF, Helmer C, Berr C (2009) La maladie d'Alzheimer: Syndromes apparentés et épidémiologie. Paris: Phase 5.

[16] Nizri D, Verrier B (2009) Mission d'évaluation des consultations mémoire et des centres mémoire de ressources et de recherche de la Direction de l'Hospitalisation et de l'Organisation des Soins, 16-21.

[17] Ramaroson H, Helmer C, Barberger-Gateau P, Letenneur L, Dartigues JF PAQUID (2003) Prevalence of dementia and Alzheimer's disease among subjects aged 75 years or over: Updated results of the PAQUID cohort. *Rev Neurol (Paris)* **159**, 405-411.

[18] Quantin C, Binquet C, Bourquard K, Pattisina R, Gouyon-Cornet B, Ferdynus C, Gouyon JB, François-André A (2004) Which are the best identifiers for record linkage? *MedInform Internet Med* **29**, 221-227.

[19] Johannsen P, Jørgensen K, Kørner A, Elmo EG, Lauesen LB, Utzon J (2011) Development of a dementia assessment quality database. *Aging Ment Health* **15**, 40-46.

[20] Beekly DL, Ramos EM, van Belle G, Deitrich W, Clark AD, Jacka ME, Kukull WA (2004) The National Alzheimer's Coordinating Center (NACC) Database: An Alzheimer disease database. NIA-Alzheimer's Disease Centers. *Alzheimer Dis Assoc Disord* **18**, 270-277.

[21] Gatz M, Fratiglioni L, Johansson B, Berg S, Mortimer JA, Reynolds CA, Fiske A, Pedersen NL (2005) Complete ascertainment of dementia in the Swedish Twin Registry: The HARMONY study. *Neurobiol Aging* **26**, 439-447.

[22] The 3C Study Group (2003) Vascular factors and risk of dementia. Design of the Three-City Study and baseline characteristics of the study population. *Neuroepidemiology* **22**, 316-325.

[23] Auriacombe S, Helmer C, Amieva H, Berr C, Dubois B, Dartigues JF (2010) Validity of the free and cued selective reminding test in predicting dementia: The 3C study. *Neurology* **74**, 1760-1767.

[24] Epidémiologie, stratégies thérapeutiques et virologie cliniques dans l'infection à VIH, http://ccde.fr. Posted, 2006, Accessed on 15 November 2011.