REAL.FR - Longitudinal Study on Patients in Alzheimer's Disease Network

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General

Identification

Detailed name	Longitudinal Study on Patients in Alzheimer's Disease Network
Sign or acronym	REAL.FR
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL approval.

General Aspects

Medical area	Geriatrics Neurology
Health determinants	Genetic
Keywords	healthcare sector, institutionalisation, network

Scientific investigator(s) (Contact)

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Unit	Inserm U 1027
Organization	CHU de

Collaborations

Funding

Funding status	Public
Details	Ministry of Health.
Governance of the database	
Sponsor(s) or organisation(s) responsible	CHU de Toulouse
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	The study population consists of patients with Alzheimer's-type dementia.
Database objective	
Main objective	To ensure regular monitoring of the patient and those close to them in order to assess the cognitive and non-cognitive aspects of the disease. To analyse treatment methods, as well as drug- and non-drug-related therapy for elderly people with AD across a national sample with diverse socio-cultural contexts. To identify potential treatment issues, such as repeated hospitalisation or emergency institutionalisation.
Inclusion criteria	- Male and female; - Patient with Alzheimer's-type dementia.
Population type	
Age	Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population

Gender	Male Woman
Geography area	National
Detail of the geography area	16 university hospital centres for geriatrics, neurology and psychiatry.

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2000
Date of last collection (YYYY or MM/YYYY)	2002

Size of the database

Size of the database (number of individuals)	[500-1000[individuals
Details of the number of individuals	700

Data

Database activity	Data collection completed
Type of data collected	Declarative data Paraclinical data
Declarative data (detail)	Face to face interview
Details of collected declarative data	Case report form: sociodemographic data, medical and surgical history, date of initial symptoms and disease diagnosis age, current list of medication taken, list of different psychotropic or specific disease treatments, ADL and IADL autonomy assessment, overall assessment of cognitive function by MMS and ADAS-Cog, assessment of dementia stage by Reisberg GDS and CDR, assessment of patient's behavioural problems by NPI, nutritional status assessment using MNA, balance disorder assessment (one-leg balance, living arrangement, use of home care service, such housekeeping, home nursing care, private nurse, use of private paid help such a domestic worker, overnight care, cleaning lady, home meal deliveries, allowances received for dependent elderly people (Prestation Spécifique Dépendance [Specific

	Dependency Benefit], Allocation Personnalisée d'Autonomie [Personal Autonomy Allowance]), sources of income (retirement, family or caregiver support, various allowances, pensions), level of education (level of education, the highest qualification obtained), former occupation(s).
Paraclinical data (detail)	- Brain scan - thyroid assessment.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Quality of life/health perception

Procedures

Data collection method	Data is collected during visits carried out over 6 months in university hospital centres participating in the study. Data are gathered through a case report form by a medical team trained to administer different tests.
Participant monitoring	Yes
Details on monitoring of participants	Follow-up over 4 years.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://tinyurl.com/Hal-REAL-FR
Description	List of publications in HAL
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=Vellas+B[author]+AND+%28REAL.FR+OR+REAL-FR%29
Description	List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only