

DEOMA - General public perceptions, knowledge and attitudes towards Alzheimer's disease

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General	
Identification	
Detailed name	General public perceptions, knowledge and attitudes towards Alzheimer's disease
Sign or acronym	DEOMA
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL
General Aspects	
Medical area	Disability/handicap Geriatrics Neurology
Pathology (details)	Alzheimer's disease
Health determinants	Healthcare system and access to health care services Lifestyle and behavior
Keywords	Social representations, Surveys, Health-care professionals, General population, Caregivers, Patients, Alzheimer's disease, Opinions
Scientific investigator(s) (Contact)	
Name of the director	LEON
Surname	Christophe
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Organization	French Institute for Health Promotion and Health Education (INPES)
Collaborations	

Participation in projects, networks and consortia	Yes
Details	2008-2012 Alzheimer Plan
Funding	
Funding status	Public
Details	French Institute for Health Promotion and Health Education (INPES)
Governance of the database	
Sponsor(s) or organisation(s) responsible	French Institute for Health Promotion and Health Education (INPES)
Organisation status	Public
Presence of scientific or steering committees	Yes
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Database recruitment is carried out by an intermediary	A selection of health care professionals A selection of health institutions and services A population file An administrative base or a register
Base or register (detail)	population, Partner networks (ANLLF, memory appointments, CMRR, MAIA, associations), FINES file
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Further information on the survey methodology of different studies and surveys: http://alzheimer.inpes.fr
Database objective	
Main objective	Included in the third strategic main line of the 2008-2012 Alzheimer Plan entitled "mobilising for a societal challenge", all DEOMA studies and surveys

aim to improve the "knowledge of how the disease is perceived". DEOMA offers a cross-examination of Alzheimer's disease through the general public, formal and informal caregivers, general practitioners and sick people.

Inclusion criteria	The system combines qualitative approaches, which are designed to go into perceptions in depth, expectations and needs of the target audiences, as well as quantitative methodologies that provide quantified indicators and track them over time. It includes eight surveys and studies conducted between 2008 and 2013. Further information on the inclusion criteria on the dedicated website: http://alzheimer.inpes.fr
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	General population
Pathology	
Gender	Male Woman
Geography area	National
Detail of the geography area	France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2008
Date of last collection (YYYY or MM/YYYY)	2013
Size of the database	
Size of the database (number of individuals)	[10 000-20 000[individuals
Details of the number of individuals	4,500 from the general population, 161 sick people, 305 caregivers, 1,500 health-care professionals

Data	
Database activity	Data collection completed
Type of data collected	Declarative data
Declarative data (detail)	Paper self-questionnaire Face to face interview Phone interview
Details of collected declarative data	Social representation, knowledge, attitudes and behaviours in relation to the disease, quality of life, proximity to the disease, perceived help, perception of the health-care system, sociodemographic criteria of Alzheimer's disease.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services Quality of life/health perception
Care consumption (detail)	Medical/paramedical consultation
Procedures	
Data collection method	By telephone, face to face, semi-directive group interviews, individual semi-directive interviews
Quality procedure(s) used	Using polling institutes with their own quality labels (BVA, Ifop, Ipsos, GFK-SLI)
Participant monitoring	No
Followed pathology	
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://alzheimer.inpes.fr
Description	Questionnaire, report and summary
Access	
Presence of document that lists variables and coding procedures	Yes
Terms of data access (charter	The databases are made available upon request and

for data provision, format of data, availability delay)	after signature of an agreement with INPES (Stata and Spss)
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only