

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
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Details	2008-2012 Alzheimer Plan
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Funding

Funding status	Public
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Details	French Institute for Health Promotion and Health Education (INPES)
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Governance of the database

Sponsor(s) or organisation(s) responsible	French Institute for Health Promotion and Health Education (INPES)
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Organisation status	Public
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Presence of scientific or steering committees	Yes
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Additional contact

Main features

Type of database

Type of database	Study databases
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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
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Base or register (detail)	population, Partner networks (ANLLF, memory appointments, CMRR, MAIA, associations), FINES file
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Database recruitment is carried out as part of an interventional study	No
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Additional information regarding sample selection.	Further information on the survey methodology of different studies and surveys: http://alzheimer.inpes.fr
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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
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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)
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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