YOD - Youg Onset Dementia

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General

Identification

Detailed name	Youg Onset Dementia
Sign or acronym	YOD

General Aspects

Medical area	Psychology and psychiatry
Health determinants	Social and psychosocial factors
Keywords	Dementia, Alzheimer's disease, Frontotemporal dementia, Vascular dementia, Dementia with Lewy bodies, Early Onset, Pronostic factors, Social impact, Medical pathway, genetics

Scientific investigator(s) (Contact)

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Unit	UMR INSERM 744
Organization	Université Lille Nord de France, Lille2 et Institut National de Santé et Recherche

Collaborations

Funding

Funding status	Public
Details	Plan Alzheimer 2008-2012- Mesure 19 (CNR-MAJ: Centre national Alzheimer malades jeunes) Le programme hospitalier de recherche clinique PHRC G-MAJ 2009 et Exome 2010 (D. Hannequin Rouen)

Governance of the database

Sponsor(s) or organisation(s) responsible	CHRU Lille
Organisation status	Public
Sponsor(s) or organisation(s) responsible	Université Lille Nord de France, Lille2
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Morbidity registers
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.	all consecutive volunteer patients referred to CNR-MAJ (Lille, Rouen, Paris la Salpêtrière) for early onset dementia

Database objective

Main objective	Collect of medical, medicosocial, economic,

	neuropsychological,biological and imaging information in young patients consulting at CNR-MAJ, with follow-up every 6 months until death. If specific consent has been granted, an autopsy for neuropathological confirmation of the diagnosis will be performed. Primary objective - To determine the diagnostic and medicosocial pathways followed by young patients suffering from early onset dementia Secondary objectives - To evaluate factors associated with diagnostic delay - To constitute clinical, imaging and biological resources for this dementia occuring in young subjects.
Inclusion criteria	volunteer patients referred to the CNR-MAJ (Lille-Rouen-Paris Salpêtrière) for a dementia syndrome begining before age 60.
Population type	
Age	Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years)
Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	Lille, Rouen, Paris Salpêtrière
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2009
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	338 (dont/with 220 Alzheimer)
Data	

Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Face to face interview
Paraclinical data (detail)	MRI, FDG-PET (for Alzheimer's disease and frontotemparal dementia patients), neuropsychological and functional evaluations
Biological data (detail)	Genetic data for Alzheimer's disease and fontotemporal dementia patients
Administrative data (detail)	age, gender, educational level, medico social assistance
Presence of a biobank	Yes
Contents of biobank	Serum Plasma Fluids (saliva, urine, amniotic fluid, ?) DNA Others
Details of biobank content	CSF, Brain, serum, plasma, DNA
Health parameters studied	Health event/morbidity Health event/mortality Others
Other (detail)	neuropsychological evaluation, evaluation of social impact, imaging, biological and neuropathological collections
Procedures	
Data collection method	Standardized medical, social, neuropsychological data and family and personal history will be recorded at inclusion and at each follow-up. These data will be collected in a paper based questionnaire and be validated and informatised with a e-crf in each center by a clinical research assistant.
Participant monitoring	Yes

Details on monitoring of participants	Clinical and medicosocial follow-up every 6 months until death or withdraw . Alzheimer's disease patients will have another MRI and PET at 1 year interval
Links to administrative sources	No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay)	Not defined
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only