Young Onset Dementia

https://neurodegenerationresearch.eu/survey/young-onset-dementia/

Title of the register

Young Onset Dementia

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Florence

Name of Principal Investigator - Last name

Pasquier

Address of institution -Institution

CMRR, CHRU lille

Address of institution - Street address

2 Avenue Oscar Lambret

Address of institution - City

Lille

Address of institution - Postcode

59000

Country

France

Website

www.centre-alzheimer-jeunes.fr

Contact email

florence.pasquier@chru-lille.fr

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Alzheimer's disease and other dementias

Q2. In a single sentence, what is the stated aim of your register?

To determine the diagnostic and medical and social pathways followed by young patients suffering from early onset dementia

Q2b. What distinguishes this register from other disease registers?

Focus on early onset, inclusion of genetics, medical and social features and pathways (of patients and carers)

Q3a. i) Number of publications that involve use of your register to date

27

Q3a. ii) Please give up to three examples of studies to date (PI, Institution, Title of Study)
Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available?
Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the register
Q4a. Study criteria: what is the age range of participants? Age in years: from

18

Q4a. Study criteria: what is the age range of participants? Age in years: to

until death

Q4b. Study criteria: what are the inclusion criteria?

Volunteer patients referred to the CNR-MAJ (Lille-Rouen-Paris Salpêtrière) for a dementia syndrome begining before age 60. (AD, FTLD, DLB, VaD)

Q4c. Study criteria: what are the exclusion criteria?

onset after 60,

Q5. What is the size of the register (i.e. how many patients have been enrolled)?

0-500 clinical cases

Q6a. Please describe what measures are used to characterise participants

Standardized clinical assessment,neuropsychological tests, MRI, FDG-PET, CSF in most cases, plasma DNA, brain tissue when available

Q6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If YES, please describe
Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

01/06/2009

Q7a. iii) Please enter the data collection end date
Q7b. Could you provide some information about the data collection for this register?

Data collection ongoing

Q8. Funding of the register - How is the register funded?

Alzheimer Plan 2008-2012, PHRC G-MAJ 2009 and Exome 2010

Q8. Funding of the register - Is this funding expected to continue
Q8. Funding of the register - If so, for how long (months)?
Q9. Could you provide information about data sweeping? - How many data sweeps have taken place?
Q9. Could you provide information about data sweeping? - When was the most recent data sweep?
Q9. Could you provide information about data sweeping? - When is the next data sweep?
Q9. Could you provide information about data sweeping? - How many more data sweeps are planned on current funding? e.g 0,1,2…..
Q9. Could you provide information about data sweeping? -How many more data sweeps are planned in total (with funding and with funding yet to be secured) e.g. 0,1,2…
Q10. Is the clinical (phenotypic) information that is held in the register from patients and other participants such as family members:

Routinely collected as medical records

Q11. Is there a limit on the number of studies that can be based on this set of patients?

No

If YES, please give details
Q12a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% Available

100

Q12a. Please give information on the format and availability of data stored in a database (2)

No

% Available
Q12a. Please give information on the format and availability of data stored in a database (3)

No

% Available

100

Q12a. Please give information on the format and availability of data stored in a database (4)

Database on paper

% Available

100

Q12a. Please give information on the format and availability of data stored in a database (5)
% Available
Please specify language used

French

Q12b. Please give information on how data is held as individual records (1)

Data is held as individual records

% Available

100

Q12b. Please give information on how data is held as individual records (2)

No

% Available
Q12b. Please give information on how data is held as individual records (3)

Data held on computer based records

% Available

100

Q12b. Please give information on how data is held as individual records (4)

No

% Available
Please specify language used
Q13a. Is data available to other groups?

Yes

Q13b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource|Access through collaboration with PI only|Access Committee mechanism|Local/ regional access|National access|International access|Access to industry|Access for pilot studies permitted|Resource has own ethics approval so usually no need for separate external ethics approval

Q14. What data sharing policy is specified as a condition of use?

No policy exists

Q15a. Are tissues/samples/DNA available to other groups?

Yes

Q15b. i) If yes, please describe below:

Living donors:blood|Living donors: blood derivatives|Living donors: DNA|Living donors: cerebro-spinal fluid|Post-mortem donors: brain|saliva, urine, amniotic fluid,

Q15b. ii) In what form are tissues/samples/DNA supplied?

Primary Samples: Stabilised samples (frozen or fixed)|Secondary samples: plasma|Secondary samples: DNA

Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Yes

Q16a. Is information on biological characteristics available to other groups?

No

Number of patients
% of total cohort

Q16b. If yes, is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Types:
Disease Registers

Member States:
France

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:
N/A

Database Tags:
N/A