

GEDOC Clinical Database

<https://neurodegenerationresearch.eu/survey/gedoc-clinical-database/>

Title of the register

GEDOC Clinical Database

Name of Principal Investigator

Title MD, PhD, Associate Professor

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1. Conditions included, or expected to be included, in the disease register

Alzheimer's disease and other dementias

2a. Stated aim of the cohort

To collect data about patients at the Memory Clinic, Karolinska University Hospital, Huddinge that can be used for quality control and studying etiology and diagnoses of AD

2b. Features distinguishing this register from other disease registers

Includes most of the patients coming to the Memory Clinic. Detailed investigations including CSF, neuroimaging, neuropsychological tests etc

3a. i) Number of publications that involve use of register to date

20

3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)

1. Name of PI

4a. Study criteria: age range of participants

Age in years from: no limit

To ('until death' is applicable): no limit

4b. Study criteria: inclusion criteria

Patient investigated at the Memory Clinic and signed informed consent

4c. Study criteria: exclusion criteria

none

5. Size of the register (i.e. number of patients enrolled)

1,001 – 5,000 clinical cases

6a. Measures used to characterise participants

Clinical and neuropsychological examination, depression scale, blood tests, neuroimaging, EEG, CSF

6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)

No

7a. i) Is the register of fixed duration

1

7a. ii) Data collection start date

01-01-1998

7b. Stage of data collection/analysis for the register

Data collection ongoing

8. Funding of the register

How the register is funded FoUU

Is funding ongoing yes

10. The clinical (phenotypic) information held in the register from patients and other participants such as family members is

Routinely collected as medical records

11. Limit on the number of studies that can be based on this set of patients

No

12a. Data stored in a database

Yes/No % available

yes 50

13a. Are data available to other groups

2

13b. Access policy/mechanisms for access if data are available to other groups

Access Committee mechanism

14. Data sharing policy specified as a condition of use

No policy exists

15a. Are tissues/samples/DNA available to other groups

2

15b. i) Description of available tissues/samples/DNA

Living donors: blood

Living donors: blood derivatives

Living donors: DNA

Living donors: cerebro-spinal fluid

15b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

2

16a. Is information on biological characteristics available to other group

16b. Is the access policy/mechanism for obtaining details of the characteristics the same as that for obtaining other data

2