GEDOC Clinical Database

https://www.neurodegenerationresearch.eu/survey/gedoc-clinical-database/

Title of the register

GEDOC Clinical Database

Name of Principal Investigator

Title	MD, PhD, Associate Professor
First name	Miia
Last name	Kivipelto

Address of institution where award is held

Institution	KI-Alzheimer Disease Research Center
Street Address	Stockholm
City	14186

Country

Sweden

Website

www.karolinska.se

Contact email

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