Rapid progressive Alzheimer’s disease (rpAD): clinical and molecular characterization of a distinct subtype of AD

https://neurodegenerationresearch.eu/survey/rapid-progressive-alzheimers-disease-rpad-clinical-and-molecular-characterization-of-a-distinct-subtype-of-ad/

Title of the register

Rapid progressive Alzheimer's disease (rpAD): clinical and molecular characterization of a distinct subtype of AD

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Inga

Name of Principal Investigator - Last name

Zerr

Address of institution -Institution

Department of Neurology, University of Göttingen

Address of institution - Street address

Robert-Koch-Str. 40

Address of institution - City

Göttingen

Address of institution - Postcode

37075

Country

Germany

Website

www.alzheimer.med.uni-goettingen.de

Contact email

ingazerr@med.uni-goettingen.de

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 factors for disease progression

Q2b. What distinguishes this register from other disease registers?
Q3a. i) Number of publications that involve use of your register to date

0

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

50

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

90

Q4b. Study criteria: what are the inclusion criteria?

Dementia, MRI, neuropsychological test profile

Q4c. Study criteria: what are the exclusion criteria?

Other dementia

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

Neuropsychological test, neurological exam, MRI, CSF, follow up tests

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

Yes

If YES, please describe

Progression rate

Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

01/01/2009

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|Data analysis ongoing

Q8. Funding of the register - How is the register funded?
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:
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)
% Available
Q12a. Please give information on the format and availability of data stored in a database (2)
% Available
Q12a. Please give information on the format and availability of data stored in a database (3)
% Available
Q12a. Please give information on the format and availability of data stored in a database (4)
% Available
Q12a. Please give information on the format and availability of data stored in a database (5)

% Available
Please specify language used
Q12b. Please give information on how data is held as individual records (1)
% Available
Q12b. Please give information on how data is held as individual records (2)
% Available
Q12b. Please give information on how data is held as individual records (3)
% Available
Q12b. Please give information on how data is held as individual records (4)
% 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?
Q14. What data sharing policy is specified as a condition of use?

Data to be made publicly available immediately

Q15a. Are tissues/samples/DNA available to other groups?
Q15b. i) If yes, please describe below:
Q15b. ii) In what form are tissues/samples/DNA supplied?
Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?
Q16a. Is information on biological characteristics available to other groups?

Yes, for all the cohort

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)?

Yes

Types:
Disease Registers

Member States:
Germany

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:

N/A

Database Tags:
N/A