

Turkuaz Alzheimer's Working Group Register

<https://neurodegenerationresearch.eu/survey/turkuaz-alzheimers-working-group-register/>

Title of the register

Turkuaz Alzheimer's Working Group Register

Name of Principal Investigator

Title MD, PhD

First name

Last name Yener

Address of institution where award is held

Institution

Street Address Mithatpasa Cad.

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Turkey

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

Alzheimer's disease and other dementias

Parkinson's disease

Neurodegenerative disease in general

2a. Stated aim of the cohort

To pool the patients' data across Turkey when needed for a clinical dementia study

2b. Features distinguishing this register from other disease registers

It is the first and the only web-based dementia registry in Turkey, as far as we know.

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

3

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: 40+

4b. Study criteria: inclusion criteria

applying to memory clinics nationwide

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

To apply or to be referred to dementia outpatient clinics

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

No

7a. i) Is the register of fixed duration

2

7a. ii) Data collection start date

01-09-2006

7a. iii) Data collection end date

01-04-2011

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

Data collection ongoing

8. Funding of the register

How the register is funded Between 01-06-2006 and 01-04-2011 a drug company Sanovel funded this registry

Is funding ongoing We are applying to Turkish Neurological Society

If so, for how long 36 months

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 100

yes 100

yes when needed

yes 50

12b. Data held as individual records

Yes/No % available

yes 100

yes 100
yes 50
0 0

13a. Are data available to other groups

2

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

Resource has own ethics approval so usually no need for separate external ethics approval

14. Data sharing policy specified as a condition of use

No requirement to make data publicly available

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

15b. ii) Form available tissues/samples/DNA are supplied in

Primary samples: Supplied fresh

Primary Samples: Stabilised samples (frozen or fixed)

Secondary samples: derivatives of primary samples

Secondary samples: plasma

Secondary samples: DNA

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

No

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

2