

# Turkuaz Alzheimer's Working Group Register

<https://www.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.

City Izmir

Postcode 35340

## Country

Turkey

## Website

[www.epikriz.com](http://www.epikriz.com)

## Contact email

[email protected]

## 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