

Behavioral Neurology and Movement Disorders Unit

<https://www.neurodegenerationresearch.eu/survey/behavioral-neurology-and-movement-disorders-unit/>

Title of the register

Behavioral Neurology and Movement Disorders Unit

Name of Principal Investigator

Title Prof Dr

First name Hakan

Last name Gurvit

Address of institution where award is held

Institution Istanbul Faculty of Medicine

Street Address Millet caddesi

City Istanbul

Postcode 34390 Capa

Country

Turkey

Website

Not available for the Unit

Contact email

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

Alzheimer's disease and other dementias

Parkinson's disease

Spinocerebellar ataxia (SCA)

2a. Stated aim of the cohort

To register all patients in a systematic way, who consult the Behavioral Neurology and Movement Disorders Unit

2b. Features distinguishing this register from other disease registers

Nothing special

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

2

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

Prof Jale Yazici; Prevalence of pain in Parkinson's disease
Assoc Prof Hasmet Hanagasi, LRRK2 mutation analysis in Turkish PD patients

1. Name of PI

Dr Ebba Lohmann; Genetic analysis of sporadic and familial PD in Turkish patients

3b. Publication list/link to where data or publications are accessible (if available)

Pain in PD is in publication, other papers are in preparation

4a. Study criteria: age range of participants

Age in years from: Any age except for young children

4b. Study criteria: inclusion criteria

This is a general registry, no strict inclusion criteria

4c. Study criteria: exclusion criteria

see above

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 demographic features

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

01-01-2001

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

Data collection ongoing

8. Funding of the register

How the register is funded No regular funds

Is funding ongoing n.a.

If so, for how long n.a.

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

12b. Data held as individual records

Yes/No % available

Yes

13a. Are data available to other groups

1

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: DNA

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

Primary samples: Supplied fresh

Primary Samples: Stabilised samples (frozen or fixed)

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