Cohort – Diagnosis and treatment of dementia patients

https://www.neurodegenerationresearch.eu/survey/cohort-diagnosis-and-treatment-of-dementia-patients/

Title of the cohort

Cohort – Diagnosis and treatment of dementia patients

Acronym for cohort

Name of Principal Investigator

Title	Prof.
First name	Maria
Last name	Barcikowska

Address of institution where award is held

Institution	Medical Research Center Polish Academy of Sciences
Street Address	5 Pawinski Str.
City	Warsaw
Postcode	02-106

Country

- Poland

Website

www.cmdik.pan.pl

Contact email

Funding source

Governmental grants

1. The cohort includes, or expects to include, incidence of the following conditions

- Alzheimer’s disease and other dementias
- Parkinson’s disease
- Neurodegenerative disease in general

When studies on the above condition(s) are expected to become possible

- Already possible

2a. Stated aim of the cohort

Research on clinical, genetic and proteomic markers of neurodegenerative disorders in early stage of

the disease

2b. Features distinguishing this cohort from other population cohorts

In the clinical part the multidisciplinary team: neurologist, psychiatrists, neuropsychologists and logopedics take care of about 1000 patients with neurodegenerative disorders per year, who are assured a full differential (including genetic) according to international standards

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

68

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

1/ prof. C. Zekanowski, Medical Research Center Polish Academy of Sciences, "Analysis of genetic variation in late-onset Alzheimer’s disease"
2/ prof.Maria Barcikowska, Medical Research Center Polish Academy of Sciences, "Medical, psychological, sociological aspects of aging in Polish population"
3/ Maria Barcikowska, Medical Research Center Polish Academy of Sciences, "Analysis of the role of PARK2, TFAM and mitochondrial control region varaibility in pathogenesis of early onset Parkinson’s disease and the study of the influence of mutated parkin and mitochondrial physiology"

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

PubMed, Barcikowska M.

3c. Information (i.e. research findings) expected to be gained from the population cohort

4a. Study criteria: age range of participants at recruitment

Age in years from: 38

To (‘until death’ if applicable): until death

4b. Study criteria: inclusion criteria

Dementia, MCI only ambulatory

4c. Study criteria: exclusion criteria

Severe agitations, non ambulatory, beridden

5. Size of the cohort (i.e. number of participants enrolled)

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

MMSE, CDR, GDS, NPI, CT, MRS (some), SPECT (some), APO E, genetic examination (APP, Presenilins1, 2 MAPT, progranuline), CSF Amyloid beta and tau from 2009; 14-3-3 from 2000

6b. Additional measures for participants with a clinical disorder

Somatic, ECG, EEG (some)

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

- No

7. Study design

- Prospective cohort
- Retrospective cohort
- Longitudinal

8. Cases matched by

- Age
- Sex
- Co-morbidities
- Cognitive function
- Physical ability

9a. Does the study include a specialised subset of control participants

- Yes

9b. If yes, description of specialised subset of control participants

Not more than 150 cases over 55 years old, free of dementia, examined clinically (MMSE, psychrometric eveluation) and CT

10a. i) Data collection start date

01-12-1998

10a. ii) Data collection end date
10a iii) Data collection for this study is

- Data collection ongoing
- Data analysis ongoing

10b. Plans to continue the cohort study beyond the current projected end date

- Yes – funding applied for

11. Data collected

- Only through the study

12. System in place to enable re-contact with patients for future studies

- Yes (participants have given permission to be re-contacted via the PIs to ask if they would participate in further studies)

13a. Format and availability of data stored in a database

	Yes/No	% available
Data summarised in database	Yes	50
Database is web-based	No	
Database on spreadsheet	Yes	50
Database is on paper	No	
Other (specify)	No	

Language used:

Polish

13b. Format and availability of data held as individual records

	Yes/No	% available
Data held as individual records	Yes	100
Data is web-based	No	
Data held on computer based records	Yes	50
Data held on cards	Yo	50
Other (specify)		

Language used:

Polish

14a. Are data available to other groups

Yes

14b. Access policy/mechanisms for access if data are available to other groups

- Apply to PI or co-ordinator at resource
- Access restricted to peer-reviewed work
- Applicant needs to provide separate external ethics approval

15. Data sharing policy specified as a condition of use

- No policy exists

16a. Are tissues/samples/DNA available to other groups

Yes

16b. i) Description of available tissues/samples/DNA

- Living donors:blood
- Living donors: blood derivatives
- Living donors: DNA
- Living donors: cerebro-spinal fluid
- Post-mortem donors: brain
- Post-mortem donors: spinal cord

16b. ii) Form available tissues/samples/DNA are supplied in

- Primary Samples: Stabilised samples (frozen or fixed)
- Secondary samples: derivatives of primary samples
- Secondary samples: plasma

16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

Yes

17. Is information on biological characteristics available to other groups