

PREDICT-PD

<https://neurodegenerationresearch.eu/survey/predict-pd/>

Title of cohort

PREDICT-PD

Acronym for cohort

Name of Principal Investigator - Title

Dr

Name of Principal Investigator - First name

Alastair

Name of Principal Investigator - Last name

Noyce

Address of institution -Institution

UCL Institute of Neurology

Address of institution - Street address

1 Wakefield Street

Address of institution - City

London

Address of institution - Postcode

WC1N 1PJ

Country

United Kingdom

Website

www.predictpd.com

Contact email

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Funding source

Parkinson's UK

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Parkinson's disease and PD-related disorders

Q1b. When are studies on the above condition(s) expected to become possible?

2016-2020

Q2a. In a single sentence what is the stated aim of the cohort?

Identify subjects at increased risk of PD

Q2b. What distinguishes this cohort from other population cohorts?

Web-based assessment of multiple risk and early disease markers

Q3a. i) Number of publications that involve use of your cohort to date

2

Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)

Alastair Noyce, UCL, Follow up of intermediate markers and incident cases|Alastair Noyce, UCL, subtle parkinsonian signs in high and low risk|Alastair Noyce, UCL, DaTSCAN and TCS in PREDICT-PD

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

Noyce et al JNNP 2013;85:31-37, Noyce et al Movement Disord 2015;30:1002-1003

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 population

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

60

Q4a. Study criteria: what is the age range of participants at recruitment? To:

until death

Q4b. Study criteria: what are the inclusion criteria?

UK residents

Q4c. Study criteria: what are the exclusion criteria?

PD or neurodegenerative disease, drugs associated with parkinsonism

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

1,000-5,000 participants

Q6a. Please describe what measures are used to characterise participants

age, gender, BMI, lifestyle factors, constipation, sleep, smell, finger tapping, ED, genotype, cardiovascular risk

Q6b. Are there additional measures for participants with a clinical disorder?

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

Yes

If yes please specify

Incident PD

Q7. What is the study design (select all that apply)?

Prospective cohort|Longitudinal|Cross sectional survey

Q8. Are your cases matched by

Other health assessment

Q9a. Does your study include a specialised subset of control participants?

No

Q9b. If your study includes a specialised subset of control participants please describe

Q10a. i) Please enter the data collection start date

11/04/2011

Q10a. ii) Please enter the data collection end date

11/05/2021

Q10a. iii) Is data collection for this study

Data collection ongoing|Data analysis ongoing

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

Yes - funding applied for/funding awarded

Q11. Is data collected

Only through the study

Other please specify here

Q12. Is there a system in place to enable re-contact with patients to ask about participation in future studies?

Yes (participants given permission to be re-contacted via PIs)

Q13a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% available

Q13a. Please give information on the format and availability of data stored in a database (2)

Database is web-based

% available

Q13a. Please give information on the format and availability of data stored in a database (3)

Database on spreadsheet (e.g. excel)

% available

Q13a. Please give information on the format and availability of data stored in a database (4)

Database on paper

% available

Other (please specify)

% available

Q13b. Please give information on the format and availability of data held as individual records (1)

% available

Q13b. Please give information on the format and availability of data held as individual records (2)

% available

Q13b. Please give information on the format and availability of data held as individual records (3)

% available

Q13b. Please give information on the format and availability of data held as individual records (4)

Data held on cards

% available

20

Please specify language used

English

Q14a. Is data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource|Access committee mechanism

Q15. What data sharing policy is specified as a condition of use?

No policy exists

Q16a. Are tissues/samples/DNA available to other groups?

Yes

Q16b i) If yes, please describe below:

Living donors: blood|Living donors: peripheral nerve biopsy

Q16b. ii) In what form are tissues/samples/DNA supplied?

Secondary samples: plasma|Secondary samples: DNA

Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

Yes

Q17. Is information on biological characteristics available to other groups?

If available for a subset please specify number of patients and % of total cohort

Number of Patients

800

% of total cohort

Types:

Population Cohorts

Member States:

United Kingdom

Diseases:

Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

Database Tags:

N/A