20,000 Volunteers for Medical Research

https://www.neurodegenerationresearch.eu/survey/20000-volunteers-for-medical-research/

Title of cohort

20,000 Volunteers for Medical Research

Acronym for cohort

GAZEL

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Marcel

Name of Principal Investigator - Last name

Goldberg

Address of institution -Institution

INSERM UMS 11

Address of institution - Street address

16 avenue Paul Vaillant-Couturier

Address of institution - City

Villejuif

Address of institution - Postcode

94800

Country

France

Website

http://www.gazel.inserm.fr/fr/

Contact email

Funding source

CCAS, IReSP, various grants

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

Neurodegenerative disease in general

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

Already possible

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

It was designed as an “open epidemiologic laboratory” characterized by a broad coverage of health problems and determinants and accessible to the community of researchers

Q2b. What distinguishes this cohort from other population cohorts?

Gazel originality is the diversity of the collected health problems, the high number of data collection waves and the multiplicity of the data collected from various sources in a permanent way

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

more than 250

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

Occupational exposure and cognitive functioning-Claudine Berr, Inserm| Socioeconomic consequences of alcohol consumption-Marie Zins, Inserm| Depression and CV diseases-Cédric Leogne, HEGP

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
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:

35

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

50

Q4b. Study criteria: what are the inclusion criteria?

EDF-GDF workers aged 35-50 at inclusion

Q4c. Study criteria: what are the exclusion criteria?

none

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

More than 15,000 participants

Q6a. Please describe what measures are used to characterise participants

Socioprofessionnal, lifestyle, environment, morbidity

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

Collection of medicla records for a subset

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

No

If yes please specify
Q7. What is the study design (select all that apply)?

Prospective cohort|Longitudinal

Q8. Are your cases matched by

Other health assessment

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

Yes

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

The whole cohort

Q10a. i) Please enter the data collection start date

01/01/1989

Q10a. ii) Please enter the data collection end date

Follow-up still active; no end planned

Q10a. iii) Is data collection for this study

Data collection ongoing| Data analysis ongoing| Closed to new patients

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

Through links to other records or registers (e.g dental records, police records etc)

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

100

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

No

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

No

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

No

% available
Other (please specify)
% available
Q13b. Please give information on the format and availability of data held as individual records (1)

No

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

No

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

Data held on computer based records

% available

100

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

No

% available
Please specify language used

French and 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| National access| International access| Access to industry| Resource has own ethics approval so usually no need for separate external ethics approval

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

No requirement to make data publicly available

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

Yes

Q16b i) If yes, please describe below:

Living donors blood| Living donors: blood derivatives| Living donors: DNA| Bucal cells

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

Primary Samples: Stabilised samples (frozen or fixed)

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

about 5000

% of total cohort

25

Types:
Population Cohorts

Member States:
France

Diseases:
Neurodegenerative disease in general

Years:
2016

Database Categories:
N/A

Database Tags:
N/A