

The Swedish BioFINDER study

<https://neurodegenerationresearch.eu/survey/the-swedish-biofinder-study/>

Title of study

The Swedish BioFINDER study

Acronym for cohort

BioFINDER

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Oskar

Name of Principal Investigator - Last name

Hansson

Address of institution -Institution

Lund University

Address of institution - Street address

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Country

Sweden

Website

www.biofinder.se

Contact email

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Funding source

ECR, SRC, Wallenberg etc

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

Alzheimer's disease and other dementias| Parkinson's disease

Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)

To development of new biomarkers and brain imaging techniques for Dementia and Parkinsonian disorders with the aim to better understand the disease mechanisms, to improve early diagnosis and to advance drug development.

Q2b. What distinguishes this case-control study from other studies?

The BioFINDER study is a prospective and longitudinal study where the study participants are very well characterised using assessments of cognitive, neurologic and psychiatric status, advanced MR imaging, CSF and blood collection, and PET imaging for amyloid and tau. Few such studies are available in the world, why the pharma industry has a high interest in the study.

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

40

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

Oskar Hansson, Lund University, Increased amyloidogenic APP processing in APOE ϵ 4-negative individuals with cerebral β -amyloidosis| Oskar Hansson, Lund University, 18F-AV-1451 tau PET imaging correlates strongly with tau neuropathology in MAPT mutation carriers| Oskar Hansson, Lund University, Comparison of Amyloid PET and CSF Biomarkers for Identifying Early Alzheimer's Disease.

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

<http://biofinder.se/publications/>

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 case-control study

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

65

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

until death

Q4b. Study criteria: what are the inclusion criteria?

see www.biofinder.se for details

Q4c. Study criteria: what are the exclusion criteria?

see www.biofinder.se for details

Q5a. What is the size of the cohort (i.e. how many participants have enrolled)?

1,000-5,000

Q5b. What is the expected number of control participants?

1,001-5,000

Q6a. Please describe what measures are used to characterise participants

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

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

If YES please specify

Q7. What is the study design?

Prospective cohort

Q8. Are your cases matched by

Age| Sex

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

Yes

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

350 healthy elderly cases with cognitive testing, MRI, CSF biomarkers, blood biomarkers, Amyloid PET and some also Tau PET

Q10a. 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 - intend to apply for funding

Q11. Are data collected

Only through study

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

Q13a. Please give information on data stored in a database (1)

Data summarised in database

% Available

100

Q13a. Please give information on data stored in a database (2)

No

% Available

Q13a. Please give information on data stored in a database (3)

Database on spreadsheet (e.g. excel)

% Available

100

Q13a. Please give information on data stored in a database (4)

No

% Available

Q13a. Please give information on data stored in a database (5)

No

% Available

Please specify language used

100% of baseline data, but longitudinal data is still collected

% Available

Q13b. Please give information on how data is held as individual records

No

% Available

Q14a. Are data available to other groups?

Yes

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

Access through collaboration with PI only| Local/ regional access| National access| International access| Access to industry| Access for pilot studies permitted

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: DNA| Living donors: cerebro-spinal fluid

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?

Yes, for all the cohort

Types:

Case Control Studies

Member States:

Sweden

Diseases:

Alzheimer's disease & other dementias, Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

Database Tags:

N/A