

# Swiss National Cohort

<https://neurodegenerationresearch.eu/survey/swiss-national-cohort/>

## Title of the cohort

Swiss National Cohort

## Acronym for cohort

SNC

## Name of Principal Investigator

Title Prof. Dr. med.

First name Flex

Last name Gutzwiller

## Address of institution where award is held

Institution

Street Address Sumatrastrasse 30

City

Postcode 8006

## Country

Switzerland

## Website

<http://www.swissnationalcohort.ch/>

## Contact email

[snc\\_info@ispm.unibe.ch](mailto:snc_info@ispm.unibe.ch)

## Funding source

Swiss National Science Foundation

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

- Prion disease

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

### 2a. Stated aim of the cohort

The SNC is a long-term, 1990 census based, multipurpose cohort and research platform including currently mortality follow-up and other disease outcomes to be linked to this population in the future.

### 2b. Features distinguishing this cohort from other population cohorts

That it includes the whole Swiss resident population. Is purely based on record linkage procedures.

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

12

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

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

<http://www.swissnationalcohort.ch/index.php?id=2978>

**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: 0 to 100

To ('until death' if applicable): until death

**4b. Study criteria: inclusion criteria**

The whole Swiss resident population at census 1990 updated by census 2000

**4c. Study criteria: exclusion criteria**

None

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

More than 15,000

**6a. Measures used to characterise participants**

See the cohort profile:

Bopp M, Spoerri A, Zwahlen M, Gutzwiller F, Paccaud F, Braun-Fahrlaender C et al.

Cohort Profile: The Swiss National Cohort—a longitudinal study of 6.8 million people. *Int J Epidemiol* 2009;38:379-84.

**6b. Additional measures for participants with a clinical disorder**

None

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

death as recorded on death certificate

**7. Study design**

- Prospective cohort
- Longitudinal

**8. Cases matched by**

- Other health assessment (specify) / N/A

- none

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

No

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

**10a. i) Data collection start date**

05-12-1990

**10a. ii) Data collection end date**

31-12-2008

**10a. iii) Data collection for this study is**

Data collection ongoing

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

- Yes – funding applied for

**11. Data collected**

- Through links to other records or registers (such as dental records, police records etc). Please specify
- Bopp M, Spoerri A, Zwahlen M, Gutzwiller F, Paccaud F, Braun-Fahrlander C et al. Cohort Profile: The Swiss National Cohort—a longitudinal study of 6.8 million people. Int J Epidemiol 2009;38:379-84. PDF

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

No

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

Yes/No % available

Data summarised in database Yes

Database is web-based No

Database on spreadsheet No

Database is on paper No

Other (specify)

**Language used:**

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

Yes/No % available

Data held as individual records Yes

Data is web-based No

Data held on computer based records Yes

Data held on cards No

Other (specify)

**Language used:**

German, French, Italian, English

**14a. Are data available to other groups**

Yes

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

- Access Committee mechanism
- Applicant needs to provide separate external ethics approval
- Other criteria (please specify)
- Legal contracts with Swiss Federal Office of Statistics

**15. Data sharing policy specified as a condition of use**

No requirement to make data publicly available

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

No

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

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

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

No

**17. Is information on biological characteristics available to other groups**

- No