# National Data Bank for Alzheimer's Disease

**Title of the register**

National Data Bank for Alzheimer's Disease

**Name of Principal Investigator - Title**

Prof

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

Neurodegenerative disease in general

**Q2. In a single sentence, what is the stated aim of your register?**

French National Alzheimer Database (BNA) aim to provide epidemiological data as well as activity indicators within the network of the french memory center and private specialist

**Q2b. What distinguishes this register from other disease registers?**

The register is totally integrated in the clinical activity of the center

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

11

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

Evolution of the Antidepressant Prescribing in Alzheimer's Disease and Related Disorders Between 2010 and 2014 : Results from the French National Database on Alzheimer's Disease (BNA). Journal of Alzheimer's

**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 register Q4a. Study criteria: what is the age range of participants? Age in years: from**

45

**Q4a. Study criteria: what is the age range of participants? Age in years: to**

until death

**Q4b. Study criteria: what are the inclusion criteria?**

Patients from French memory centres and voluntary independent physicians.

**Q4c. Study criteria: what are the exclusion criteria?**

nothing

**Q5. What is the size of the register (i.e. how many patients have been enrolled)?**

More than 10,000 clinical cases

**Q6a. Please describe what measures are used to characterise participants**

Diagnosis according to the clinician point of view (ICD10)

**Q6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)?**

No

**If YES, please describe**
**Q7a. i) Is the register of fixed duration?**

No

**Q7a. ii) Please enter the data collection start date**

01/10/2009

**Q7a. iii) Please enter the data collection end date**
**Q7b. Could you provide some information about the data collection for this register?**

Data collection ongoing|Data analysis ongoing

**Q8. Funding of the register - How is the register funded?**

Direction générale de l'offre de soins

**Q8. Funding of the register - Is this funding expected to continue**

yes

**Q8. Funding of the register - If so, for how long (months)?**

at least till the end of the national plan

**Q9. Could you provide information about data sweeping? - How many data sweeps have taken place?**
**Q9. Could you provide information about data sweeping? - When was the most recent data sweep?**
**Q9. Could you provide information about data sweeping? - When is the next data sweep?**
**Q9. Could you provide information about data sweeping? - How many more data sweeps are planned on current funding? e.g 0,1,2…..**
**Q9. Could you provide information about data sweeping? -How many more data sweeps are planned in total (with funding and with funding yet to be secured) e.g. 0,1,2…**
**Q10. Is the clinical (phenotypic) information that is held in the register from patients and other participants such as family members:**

Routinely collected as medical records

**Q11. Is there a limit on the number of studies that can be based on this set of patients?**

No

**If YES, please give details**
**Q12a. Please give information on the format and availability of data stored in a database (1)**

Data summarised in database

**% Available**
**Q12a. Please give information on the format and availability of data stored in a database (2)**

Database is web-based

**% Available**
**Q12a. Please give information on the format and availability of data stored in a database (3)**

Database is web-based

**% Available**
**Q12a. Please give information on the format and availability of data stored in a database (4)**

No

**% Available**
**Q12a. Please give information on the format and availability of data stored in a database (5)**

No

**% Available**
**Please specify language used**

French

**Q12b. Please give information on how data is held as individual records (1)**

Data is held as individual records

**% Available**
**Q12b. Please give information on how data is held as individual records (2)**

No

**% Available**
**Q12b. Please give information on how data is held as individual records (3)**

Data held on computer based records

**% Available**
**Q12b. Please give information on how data is held as individual records (4)**

No

**% Available**
**Please specify language used**

French

**Q13a. Is data available to other groups?**

Yes

**Q13b. 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|Other access mechanism|Local/ regional access|National access|International access|Access for pilot studies permitted|Access restricted to peer-reviewed work

**Q14. What data sharing policy is specified as a condition of use?**

No requirement to make data publicly available

**Q15a. Are tissues/samples/DNA available to other groups?**

No

**Q15b. i) If yes, please describe below:**
**Q15b. ii) In what form are tissues/samples/DNA supplied?**
**Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?**

No

**Q16a. Is information on biological characteristics available to other groups?**

No

**Number of patients**
**% of total cohort**
**Q16b. If yes, is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?**

**Types:**
Disease Registers

**Member States:**
France

**Diseases:**
Neurodegenerative disease in general

**Years:**

2016

**Database Categories:**
N/A

**Database Tags:**
N/A