- Gironde register of primitive tumors of the central nervous system (qualified register 2012-2015)

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General

Identification

Detailed name	Gironde register of primitive tumors of the central nervous system (qualified register 2012-2015)
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	900044

General Aspects

Medical area	Cancer research Neurology
Health determinants	Geography Social and psychosocial factors
Keywords	Health surveillance, primitive tumors, distribution, histologic type, epidemiological research, etiology, risk factors, evaluation, care, incidence

Scientific investigator(s) (Contact)

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Organization	Institut de Santé Publique, d'Epidémiologie et de

Développement

Funding status	Public
Details	- Institut national de veille sanitaire (InVS)- Institut national du cancer (INCA)

Governance of the database

Sponsor(s) or organisation(s) responsible	l'Institut de Santé Publique, d'Epidémiologie et de Développement (ISPED)
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects presenting requested inclusion criteria. Several sources have been employed to identify cases: - Neuropathology services - Neurosurgery services - Pediatric neurosurgery - Neurology services - Private neurologists - Otorhinolaryngology services - Geriatric services - Cancer specialist radiotherapist - DIM Gironde - Gironde malignant hemopathy register - National registry of children solid tumors - Long-term duration-Farmer's social mutual fund (MSA) - Independent professionals - General Social Security regime - Occupational medicine service

Database objective

Main objective	1) Health surveillance: the main objective is to evaluate the incidence of CNS primitive tumors from exhaustive and continuous cases recording, to study cases distribution by age and sex, for different histologic types in order to compare this

incidence to national data, and study geographic and temporal variations of this incidence.
2) Epidemiological research: other objectives are to further research in the CNS primitive tumors etiology domain through risk factors research, case-control epidemiological studies on general population about the role of intrinsic and extrinsic factors, which are environmental and professional factors such as pesticides, electromagnetic fields, solvents, nitrosamines or petroleum products. Moreover, we will have the possibility to cross epidemiological and biological data allowing to research biological factors of vulnerability to environmental agents exposition.
3) Participate to the evaluation of therapeutic care: knowledge of the health care networks and caring periods, as well as health care activities indicators surveillance (biopsy rates, anatomo-pathologies practices, diagnosis circumstances) are other long-term objectives of Gironde CNS tumor register. A first approach has begun by a systematic follow-up of the vital status and death causes of patients suffering by these pathologies.

Inclusion criteria	1) Every subject suffering from a primitive CNS tumor, cerebral or medullary, benign or malignant. 2) All ages (children and adults) 3) Residents in the Gironde department at the moment of the diagnosis 4) Clinical and radiological diagnosis, confirmed or not by an anatomico-pathological samples 5) Diagnosis realized from 1st Mai 1999

Population type

Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	Departmental

French regions covered by the database	Aquitaine Limousin Poitou-Charentes
Detail of the geography area	Gironde

Dates

Date of first collection (YYYY or MM/YYYY)	05/1999

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2000-2008: 2289 tumeurs cérébrales

Data

Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data Administrative data
Clinical data (detail)	Direct physical measures
Paraclinical data (detail)	Anatomical pathology
Administrative data (detail)	Identification data
Presence of a biobank	Yes
Contents of biobank	Tissues
Details of biobank content	Tumor bank associated: CEREPEG program at the CHU of Bordeaux (Pr. Loiseau)
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Active for most of the sources
Participant monitoring	Yes
Details on monitoring of participants	Vital status for all recorder people. Clinical follow-up on samples

Links to administrative sources	Yes
Linked administrative sources (detail)	Hospital diagnosis-related group database (PMSI), Assurance Maladie data (CRAM, MSA, RSI), CEPIDC

Promotion and access

Promotion

Link to the document	http://www.isped.u-bordeaux2.fr/FR_HTM_equipe_activites_details.aspx?CLE_EQU
Link to the document	http://tinyurl.com/PUBMED-TSNCGironde
Description	Liste des publications dans Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay)	Register open to collaboration, please contact the scientific investigator
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only