

EPIPAGE - Survival of very preterm infants

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Last update : 01/01/2018 | Version : 2 | ID : 3438

General

Identification

Detailed name Survival of very preterm infants

Sign or acronym EPIPAGE

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL n° 911009 / CCTIRS 10.626

General Aspects

Medical area Neurology

Keywords morbidity, death rate, behaviour, cognitive capacities, school education

Scientific investigator(s) (Contact)

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Organization INSTITUT NATIONAL DE LA SANTE ET DE LA
RECHERCHE MEDICALE -

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| Organization | INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE - |

Collaborations

Funding

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| Funding status | Mixed |
| Details | PHRC National 2001, DGS, PHRC 8 ans, contrat MERCK DOLME/INSERM, Fondation de la recherche médicale, Fondation Wyeth |

Governance of the database

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| Sponsor(s) or organisation(s) responsible | INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE - INSERM |
| Organisation status | Public |

Additional contact

Main features

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| Type of database | Study databases |
| Study databases (details) | Cohort study |
| Database recruitment is carried out by an intermediary | A selection of health care professionals A selection of health institutions and services |
| Database recruitment is carried out as part of an interventional study | No |

Additional information regarding sample selection. Maternity files and GP

Database objective

Main objective Study the evolution of severely preterm children born between 22 and 32 weeks of gestational age in 9 regions of France in 1997, and 2 comparison groups at 33-34 and 39-40 weeks.

Inclusion criteria Severely preterm children (birth or interruption 22-32 weeks of amenorrhea (SA) or weight between 0,5 and 1,499 Kg.
Control group: Group 1: 39-40 SA ; Groupe 2 : 33-34 SA in centers participating to the study.

Population type

Age Newborns (birth to 28 days)
Infant (28 days to 2 years)
Early childhood (2 to 5 years)

Population covered Sick population

Gender Male
Woman

Geography area National

Detail of the geography area 9 régions of France: Alsace, Franche-Comté, Languedoc - Roussillon, Lorraine, Midi-Pyrénées, Nord Pas-de-Calais, Haute Normandie, Pays de Loire and Paris and Petite couronne

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 01/1997

Date of last collection (YYYY or MM/YYYY) 01/2008

Size of the database

Size of the database (number of individuals) [1000-10 000] individuals

Details of the number of individuals 3219 sujets avec suivi accepté à la période néonatale: 2276 grands prématurés, 382 nés à 33-34 semaines d'âge gestationnel, 555 nés à 39-40

semaines d'âge gestationnel

Data

Database activity Data collection completed

Type of data collected Clinical data
Declarative data

Clinical data (detail) Direct physical measures

Declarative data (detail) Paper self-questionnaire
Face to face interview

Presence of a biobank No

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Data collection method On inclusion: data from maternity files (pregnancy surveillance, identified pathologies, medical care used, childbirth, child health on birth...) or neonatology (pathology appearing while in the hospital, complications, medical care used, health of child when going out). sociodemographic data is gathered during an interview. Aftercare: At 2 years old, a medical exam (motricity-oriented) of the child is done by the GP. Parents are also interviewed. At 5 years old: weight, size, skull perimeter are measured and a neurologic exam and cognitive tests are performed by a psychologist. An autoquestionnaire is sent to the parents at 9 months old, 1, 2, 3, 4, 5 and 8 years old. This questionnaire is adapted to the child's age and asks about his/her health and development, and gathers sociodemographic data.

Participant monitoring Yes

Details on monitoring of participants Aftercare of children until 8 years old

Links to administrative sources Yes

Linked administrative sources (detail) CédiDCA study in Departmental Homes for Disabled Persons (MDPH) was conducted for children with sequelae or if the parents did not answer.

Promotion and access

Promotion

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| Link to the document | http://www.hal.inserm.fr/EPIPAGE |
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| Description | List of publications in HAL |
|-------------|-----------------------------|

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| Link to the document | http://www.ncbi.nlm.nih.gov/pubmed/?term=epipage+OR+25541510[uid]+OR+19932945[uid] |
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| Description | List of publications in Pubmed |
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Access

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| Terms of data access (charter for data provision, format of data, availability delay) | Contact scientific investigator |
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| Access to aggregated data | Access on specific project only |
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| Access to individual data | Access on specific project only |
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