

# EPIPAGE - Survival of very preterm infants

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## 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

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

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

Organisation status Public

## Additional contact

## Main features

## Type of database

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

Link to the document	<a href="http://www.hal.inserm.fr/EPIPAGE">http://www.hal.inserm.fr/EPIPAGE</a>
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Description	List of publications in HAL
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Link to the document	<a href="http://www.ncbi.nlm.nih.gov/pubmed/?term=epipage+OR+25541510[uid]+OR+19932945[uid]">http://www.ncbi.nlm.nih.gov/pubmed/?term=epipage+OR+25541510[uid]+OR+19932945[uid]</a>
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Description	List of publications in Pubmed
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## Access

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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