### 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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<thead>
<tr>
<th>Name of the director</th>
<th>Ancel</th>
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<tbody>
<tr>
<td>Surname</td>
<td>Pierre-Yves</td>
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<tr>
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<td>Email</td>
<td><a href="mailto:pierre-yves.ancel@inserm.fr">pierre-yves.ancel@inserm.fr</a></td>
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**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
  - 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 gestationel, 555 nés à 39-40
### Data

<table>
<thead>
<tr>
<th>Database activity</th>
<th>Data collection completed</th>
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| 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**
<table>
<thead>
<tr>
<th>Link to the document</th>
<th><a href="http://www.hal.inserm.fr/EPIPAGE">http://www.hal.inserm.fr/EPIPAGE</a></th>
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<tbody>
<tr>
<td>Description</td>
<td>List of publications in HAL</td>
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<td>Description</td>
<td>List of publications in Pubmed</td>
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### Access

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<tr>
<th>Terms of data access (charter for data provision, format of data, availability delay)</th>
<th>Contact scientific investigator</th>
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<tbody>
<tr>
<td>Access to aggregated data</td>
<td>Access on specific project only</td>
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<tr>
<td>Access to individual data</td>
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