# EPIPAGE - Survival of very preterm infants

Head: Larroque Béatrice, U953 - Unité de recherche épidémiologique en santé périnatale et santé des femmes et des enfants  
Ancel Pierre-Yves, U953 - Unité de recherche épidémiologique en santé périnatale et santé des femmes et des enfants

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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

## 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

### Scientific investigator(s) (Contact)
<table>
<thead>
<tr>
<th><strong>Main features</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of database</strong></td>
<td>Study databases</td>
</tr>
<tr>
<td><strong>Study databases (details)</strong></td>
<td>Cohort study</td>
</tr>
<tr>
<td><strong>Database recruitment is carried out by an intermediary</strong></td>
<td>A selection of health care professionals</td>
</tr>
<tr>
<td><strong>Database recruitment is carried out as part of an interventional study</strong></td>
<td>A selection of health institutions and services</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
</tr>
<tr>
<td>Additional information regarding sample selection.</td>
<td>Maternity files and GP</td>
</tr>
<tr>
<td>Database objective</td>
<td>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.</td>
</tr>
<tr>
<td>Main objective</td>
<td>Severe 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.</td>
</tr>
<tr>
<td>Inclusion criteria</td>
<td>Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years)</td>
</tr>
<tr>
<td>Population type</td>
<td>Sick population</td>
</tr>
<tr>
<td>Age</td>
<td>Male Woman</td>
</tr>
<tr>
<td>Population covered</td>
<td>National</td>
</tr>
<tr>
<td>Geography area</td>
<td>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</td>
</tr>
<tr>
<td>Data collection</td>
<td>Size of the database (number of individuals)</td>
</tr>
<tr>
<td>Dates</td>
<td>Date of first collection (YYYY or MM/YYYY) 01/1997</td>
</tr>
<tr>
<td></td>
<td>Date of last collection (YYYY or MM/YYYY) 01/2008</td>
</tr>
<tr>
<td>Size of the database</td>
<td>[1000-10 000] individuals</td>
</tr>
<tr>
<td>Details of the number of individuals</td>
<td>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 semaines d'âge</td>
</tr>
</tbody>
</table>
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

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

Yes

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.
<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>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>List of publications in HAL</td>
</tr>
<tr>
<td>Description</td>
<td>List of publications in Pubmed</td>
</tr>
</tbody>
</table>

**Access**

**Terms of data access (charter for data provision, format of data, availability delay)**

Contact scientific investigator

**Access to aggregated data**

Access on specific project only

**Access to individual data**

Access on specific project only