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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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 il 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

	semaines d'âge gestationel
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 cgnitive 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 andasks 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	http://www.hal.inserm.fr/EPIPAGE
Description	List of publications in HAL
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=epipage+OR+25541510[uid]+OR+19932945[uid]
Description	List of publications in Pubmed

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