

AQUIPAGE - Physical and neurological becoming of highly premature children in the Aquitaine region

Head :Joly-Pedespan Laurence, Unité Inserm : CIC-EC 07

Leroy Valérieane, Unité INSERM U 897

Last update : 09/10/2014 | Version : 3 | ID : 3582

General

Identification

Detailed name Physical and neurological becoming of highly premature children in the Aquitaine region

Sign or acronym AQUIPAGE

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation

CNIL

General Aspects

Medical area Neurology
Psychology and psychiatry

Health determinants Genetic
Social and psychosocial factors

Keywords Prematurity, natural history, neurosensory troubles, physical development anomalies, speech and language disorders, concentration disorders, emotional development anomalies., development, prognostic factors, mobility

Scientific investigator(s) (Contact)

Name of the director Joly-Pedespan

Surname Laurence

Address 146 rue Léo Saignat 33076 Bordeaux cedex

Email laurence.joly@chu-bordeaux.fr

Unit Unité Inserm : CIC-EC 07

Organization ISPED- Institut de Santé Publique d'Epidémiologie et de développement

Name of the director	Leroy
Surname	Valériane
Address	146 rue Léo Saignat 33076 Bordeaux cedex
Email	valeriane.leroy@isped.u-bordeaux2.fr
Unit	Unité INSERM U 897
Organization	ISPED- Institut de Santé Publique d'Epidémiologie et de développement

Collaborations

Funding

Funding status	Public
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Details	PHRC REGIONAL 2001 ET 2004
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Governance of the database

Sponsor(s) or organisation(s) responsible	Centre Hospitalier Universitaire de Bordeaux
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Organisation status	Public
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Additional contact

Main features

Type of database

Type of database	Study databases
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Study databases (details)	Cohort study
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Database recruitment is carried out by an intermediary	A selection of health institutions and services
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Database recruitment is carried out as part of an interventional study	No
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Additional information regarding sample selection.	Exhaustive recruitment of the births at 24-33 weeks of amenorrhea in the centers participating to the study. A collect of information concerning the proceeding of pregnancy and birth is realized from data from the patient file.
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Database objective

Main objective	Study the neurologic and physical becoming of highly premature children (birth between 24 and 33 weeks of amenorrhea) at long term (seven years), in the framework of a multi-center study in the Aquitaine region. Natural history, prognostic factors, occurrence of long term neurological sequelae, in particular minor and moderate, the least known.
Inclusion criteria	Living births, stillborn births between 24-33 weeks of amenorrhea, in the centers participating to the study. Exclusion criteria : congenital abnormalities.
Population type	
Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Aquitaine Limousin Poitou-Charentes
Detail of the geography area	Aquitaine
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/2003
Date of last collection (YYYY or MM/YYYY)	01/2012
Size of the database	
Size of the database (number of individuals)	[500-1000[individuals
Details of the number of individuals	633
Data	

Database activity	Data collection completed
Type of data collected	Clinical data Declarative data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Clinical examination at inclusion and during the follow-up at 1, 4, 12, 18 and 24 months, then annually (neurologic check-up) Visual check-up (at 9 months and 2 years) Auditive check-up (at 1 and 3 years) Cognitive performance and psycho-emotional profile (at 1, 2, 4 and 7 years of adjusted age)
Declarative data (detail)	Face to face interview
Details of collected declarative data	Clinical examination at inclusion and during the follow-up at 1, 4, 12, 18 and 24 months, then annually (neurologic check-up) Visual check-up (at 9 months and 2 years) Auditive check-up (at 1 and 3 years) Cognitive performance and psycho-emotional profile (at 1, 2, 4 and 7 years of adjusted age)
Presence of a biobank	No
Health parameters studied	Health event/mortality
Procedures	
Data collection method	Standardized questionnaire of neonatal events and a neurologic check-up at 1, 4, 12, 18, 24 months; then annual neurologic examination until the age of 7. Neurosensory check-up at 9 months. Auditive check-up at 3 years. Cognitive performances and psycho-emotional profile at 12 months of adjusted age, 2, 4 and 7 years. An NRM imaging is scheduled at 18 months if severe or moderate sequelae are detected.
Quality procedure(s) used	Coherence request after computer data entry. Missing data checked with the original file. Doctors and subjects reminders for follow-up visits.
Participant monitoring	Yes
Details on monitoring of participants	7 years
Links to administrative sources	No

Promotion and access

Promotion

Link to the document

<http://www.ncbi.nlm.nih.gov/pubmed/?term=Aquipage>

Description

Liste des publications dans Pubmed

Access

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

Data utilization possible for academic teams.
Additional access condition : analysis before inside the cohort

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only