EPICE - Effective Perinatal Intensive Care in Europe

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General

Identification

Detailed name	Effective Perinatal Intensive Care in Europe
Sign or acronym	EPICE
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL n°1585577

General Aspects

Medical area	Gynecology/ obstetrics Pediatrics
Health determinants	Genetic Healthcare system and access to health care services Social and psychosocial factors
Keywords	very preterm infants, evidence based médicine, neonatal intensive care. neurodevelopmental outcomes. follow-up at 2-5 years of age. european consortium.

Scientific investigator(s) (Contact)

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Organization	Institut National de la Santé et de la Recherche Médicale

Collaborations

Participation in projects, networks and consortia	Yes
Details	SHIPS (Screening to Improve Health in Very Preterm Infants in Europe). RECAP Preterm (Research on European Children and Adults born Preterm).

Funding

Funding status	Public
Details	Epice is a Collaborative Project funded under the European Commission's 7th Framework Programme (259882)

Governance of the database

Sponsor(s) or organisation(s) responsible	Institut National de la Santé et de la Recherche Médicale - 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 institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Very preterm infants born before 32 weeks of gestation. Followed-up at 2 and 5 years of age.

Database objective

Main objective	To improve the survival and long-term health of very preterm infants by ensuring that medical knowledge is translated into effective perinatal care. To assess care provided in the first five years of life and neurodevelopmental outcomes at 2 and 5 years of age.
Inclusion criteria	very preterm infants born before 32 week of gestation

Population type

Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years)
Population covered	General population
Pathology	
Gender	Male Woman
Geography area	International
Detail of the geography area	19 regions in 11 European countries (Belgium, Denmark, Estonia, France, Germany, Italy, Netherlands, Poland, Portugal, UK, Sweden)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2011
Date of last collection (YYYY or MM/YYYY)	2017

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	10000 pregnancy. 6800 survival to discharge. 5000 follow-up at 2 or 5 years of age.

Data

Database activity	Current data collection
Type of data collected	Clinical data

	Declarative data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Characteristics of pregnancy, Birth and infant's health status. Neurodevelopmental status at 5 years of age.
Declarative data (detail)	Paper self-questionnaire
Details of collected declarative data	Characteristics of pregnancy, infant and child's health status and development.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Quality of life/perceived health (detail)	Neurodevelopment, health and wellbeing.

Procedures

Data collection method	Quantitative and qualitative methods to collect information on the use of evidence-based practices at the patient, unit and regional levels. Parent report questionnaires. Medical assessment.
Participant monitoring	Yes
Monitoring procedures	Monitoring by contact with the participant (mail, e-mail, telephone etc.)
Details on monitoring of participants	Follow-up at 2 and 5 years of age.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=epice+AND+cohort+AND+%28Zeitlin+J+[Author]+OR+Bonet+M+[Author]%29

Description	EPICE publications.
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the website
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only