

EpiTED - Developmental trajectory study from childhood to adulthood in a cohort of EpiTED patients: Research prognostic, clinical and biological factors

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General

Identification

Detailed name Developmental trajectory study from childhood to adulthood in a cohort of EpiTED patients: Research prognostic, clinical and biological factors

Sign or acronym EpiTED

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL : 1585321 v 0; CPP : n°12 04 02 autorisé le 5/06/2012; ANSM : ref B120572-70 autorisé le 11/05/2012

General Aspects

Medical area Psychology and psychiatry

Health determinants Genetic
Social and psychosocial factors

Keywords developmental trajectories, autism, Cohort, quality of life

Scientific investigator(s) (Contact)

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Organization Centre de Ressources Autisme

Collaborations

Funding	
Funding status	Mixed
Details	PHRC National 1996; PHRC National 2006; Fondation Orange; ANR blanc 2011
Governance of the database	
Sponsor(s) or organisation(s) responsible	CHRU Montpellier
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
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.	Prospective
Database objective	
Main objective	<p>Main objective: Study on the developmental trajectories in a cohort of young adults with autism prospectively monitored since childhood (followed over a total period of 10 years) and to research clinical and biological developmental risk factors.</p> <p>Secondary objective: To describe the characteristics of this young adult population with autism from a clinical, medical, developmental, social and family environment perspective as well as study the relationship between genetic score (developed by IntegraGen) and developmental trajectories highlighted during the 10 year follow-up, as identified among SNPs (panel developed by Intragen) that accurately predict the given trajectory</p>

Inclusion criteria	Inclusion criteria - Patients previously included in the cohort formed in 1997/1999 within the PHRC 96/97 network and having been followed for 10 years. - Adult patients (aged 18 years old and over)
Population type	
Age	Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years)
Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	Patients are enrolled from 46 centres located throughout the national territory.
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	10/1997
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	152
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Face to face interview
Biological data (detail)	Saliva samples taken at third time of collection in

order to identify genetic markers.

Presence of a biobank

No

Health parameters studied

Health event/morbidity
Quality of life/health perception

Procedures

Data collection method

Self-administered questionnaire: manual input from a paper questionnaire. Interviews: manual input from a paper questionnaire. Clinical Examinations: handwritten

Participant monitoring

Yes

Details on monitoring of participants

Time 1: 280 children aged 4.9 years enrolled between 1997 and 1999, Time 2: 219 children aged 8.1 years enrolled between 2001 and 2002, Time 3: 152 adolescents aged 15 years enrolled between 2007 and 2009, Time 4: start of 10/2012 enrolment

Links to administrative sources

No

Promotion and access

Promotion

Link to the document

<http://www.autisme-ressources-lr.fr/epited>

Link to the document

<http://tinyurl.com/Pubmed-EPITED>

Description

List of publications in Pubmed

Access

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

Access to data base is subject to approval of scientist in charge and sponsor of the study

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only