

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

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| 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

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|---------------------|---|
| 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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|----------------------|-----------------------------------|
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| Unit | Laboratoire Epsilon EA 4556 |
| 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: 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. 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

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| 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) |
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Population type

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| Age | Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) |
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|--------------------|-----------------|
| Population covered | Sick population |
|--------------------|-----------------|

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|--------|---------------|
| Gender | Male Woman |
|--------|---------------|

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| Geography area | National |
|----------------|----------|

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| Detail of the geography area | Patients are enrolled from 46 centres located throughout the national territory. |
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Data collection

Dates

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|--|---------|
| Date of first collection (YYYY or MM/YYYY) | 10/1997 |
|--|---------|

Size of the database

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|--|-------------------|
| Size of the database (number of individuals) | < 500 individuals |
|--|-------------------|

| | |
|--------------------------------------|-----|
| Details of the number of individuals | 152 |
|--------------------------------------|-----|

Data

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|-------------------|-------------------------|
| Database activity | Current data collection |
|-------------------|-------------------------|

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|------------------------|--|
| Type of data collected | Clinical data Declarative data Biological data |
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| Clinical data (detail) | Direct physical measures Medical registration |
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|---------------------------|--|
| Declarative data (detail) | Paper self-questionnaire Face to face interview |
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|--------------------------|---|
| 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