# ELENA-E0 - Study of outcome trajectories and risk factors in a cohort of children and adolescents with Autism Spectrum Disorders (ASD)

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## General

### Identification

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|---|---|
| Detailed name | Study of outcome trajectories and risk factors in a cohort of children and adolescents with Autism Spectrum Disorders (ASD) |
| Sign or acronym | ELENA-E0 |
| CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation | 1601742 v 0 |

### General Aspects

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|---|---|
| Medical area | Neurology<br>Pediatrics<br>Psychology and psychiatry |
| Health determinants | Genetic<br>Social and psychosocial factors |
| Keywords | trajectories of change, clinical epidemiology, childhood, adolescence, autism spectrum disorders, cohort |

### Scientific investigator(s) (Contact)

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|---|---|
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| Unit | CESP INSERM U 1178 |

| | |
|---|---|
| Organization | Centre de Ressources Autisme |

## Collaborations

## Funding

| | |
|---|---|
| Funding status | Public |
| Details | Appel d'offre interne cohorte 2011 - CNSA 2012 - PHRCN2013 |

## Governance of the database

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|---|---|
| Sponsor(s) or organisation(s) responsible | CHU MONTPELLIER |
| Organisation status | Public |
| Presence of scientific or steering committees | Yes |

## Additional contact

# Main features

## Type of database

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|---|---|
| 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 is made on the basis of: | Another treatment or procedure |
| Database recruitment is carried out as part of an interventional study | No |

## Database objective

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| Main objective | 1) To describe the characteristics of a large sample of individuals with a diagnosis of ASD aged between 2 and 16 years, in the clinical, biological, developmental and psychosocial domains 2) To identify outcome trajectories over years and their determinants. |
| Inclusion criteria | Children and adolescents under age 20, with a diagnosis of ASD formally established by a |

| | |
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| | multidisciplinary team according to international criteria. Parents must have given their oral consent. |

## Population type

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| Age | Early childhood (2 to 5 years)<br>Childhood (6 to 13 years)<br>Adolescence (13 to 18 years) |
| Population covered | Sick population |
| Pathology | F84 - Pervasive developmental disorders |
| Gender | Male<br>Woman |
| Geography area | National |
| Detail of the geography area | 13 centers |

## Data collection

### Dates

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| Date of first collection (YYYY or MM/YYYY) | 01/2012 |
| Date of last collection (YYYY or MM/YYYY) | in progress |

### Size of the database

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|---|---|
| Size of the database (number of individuals) | [500-1000[ individuals |
| Details of the number of individuals | 550 patients recruted |

### Data

| | |
|---|---|
| Database activity | Current data collection |
| Type of data collected | Clinical data<br>Declarative data |
| Clinical data (detail) | Direct physical measures<br>Medical registration |
| Details of collected clinical data | ADI, ADOS, Vineland 2, IQ, motricity |
| Declarative data (detail) | Paper self-questionnaire<br>Internet self-questionnaire |

| | |
|---|---|
| | Face to face interview<br>Phone interview |
| Details of collected declarative data | medical history, Quality of lie, aberrant behavior checklist, comorbidities, |
| Presence of a biobank | No |
| Health parameters studied | Health event/morbidity<br>Health event/mortality<br>Health care consumption and services<br>Quality of life/health perception |
| Care consumption (detail) | Hospitalization<br>Medical/paramedical consultation<br>Medicines consumption |

## Procedures

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| Participant monitoring | Yes |
| Monitoring procedures | Monitoring by contact with the referring doctor |
| Details on monitoring of participants | The follow-up consists of multidisciplinary assessments spaced out of 30 months and a yearly collection of life and medical events, adaptive behaviors and intervention. |
| Links to administrative sources | No |

## Promotion and access

## Promotion

| | |
|---|---|
| Link to the document | http://www.ncbi.nlm.nih.gov/pubmed/25444837 |
| Description | Mise en place d'une cohorte française d'enfants et adolescents présentant des troubles du spectre autistique : cohorte ELENA. A. Baghdadli, J. Loubersac, M. Soussana, C. Rattaz, C. Michelon. RESP 2014 Oct;62(5):297-303. doi: 10.1016/j.respe.2014.07.002 |

## Access

| | |
|---|---|
| Terms of data access (charter for data provision, format of data, availability delay) | access to the data base is subject to the approval of the scientific leader and the sponsor of the study |
| Access to aggregated data | Access on specific project only |
| Access to individual data | Access on specific project only |