

# 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	
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	
Medical area	Neurology Pediatrics Psychology and psychiatry
Health determinants	Genetic Social and psychosocial factors
Keywords	trajectories of change, clinical epidemiology, childhood, adolescence, autism spectrum disorders, cohort
Scientific investigator(s) (Contact)	
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Organization

Centre de Ressources Autisme

Collaborations

Funding

Funding status

Public

Details

Appel d'offre interne cohorte 2011 - CNSA 2012 - PHRCN2013

Governance of the database

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

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 made on the basis of:

Another treatment or procedure

Database recruitment is carried out as part of an interventional study

No

Database objective

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

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

## Population type

Age  
Early childhood (2 to 5 years)  
Childhood (6 to 13 years)  
Adolescence (13 to 18 years)

Population covered  
Sick population

Pathology  
F84 - Pervasive developmental disorders

Gender  
Male  
Woman

Geography area  
National

Detail of the geography area  
13 centers

## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY)  
01/2012

Date of last collection (YYYY or MM/YYYY)  
in progress

### Size of the database

Size of the database (number of individuals)  
[500-1000[ individuals

Details of the number of individuals  
550 patients recruited

## 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  
ADI, ADOS, Vineland 2, IQ, motricity

Declarative data (detail)  
Paper self-questionnaire  
Internet self-questionnaire

Face to face interview  
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  
Health event/mortality  
Health care consumption and services  
Quality of life/health perception

Care consumption (detail)

Hospitalization  
Medical/paramedical consultation  
Medicines consumption

## Procedures

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

