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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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

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 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 recruted

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