

EMPATHIE - Enfants - Parents - Trouble déficit de l'attention avec Hyperactivité : Impact et Evaluation

Head :Ponthieux Anne

Last update : 12/01/2018 | Version : 1 | ID : 174

General

Identification

Detailed name Enfants - Parents - Trouble déficit de l'attention avec Hyperactivité : Impact et Evaluation

Sign or acronym EMPATHIE

General Aspects

Medical area Neurology
Psychology and psychiatry

Health determinants Social and psychosocial factors

Others (details) Attention-deficit hyperactivity disorder (ADHD)

Keywords Proximology siblings Parents

Scientific investigator(s) (Contact)

Name of the director Ponthieux

Surname Anne

Phone +33 (0)1 55 47 64 14

Email anne.ponthieux@novartis.com

Organization Novartis Pharma

Collaborations

Funding

Funding status Private

Details Novartis Pharma S.A.S.

Governance of the database

Sponsor(s) or organisation(s) responsible Novartis Pharma S.A.S.

Organisation status	Private
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Not-repeated cross-sectional studies (except case control studies)
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.	<p>Each investigator proposed the study and collected informed consent to all eligible parents and siblings viewed in consecutive routine consultation for the ADHD.</p> <p>A short questionnaire was completed by the investigator at inclusion. The patient and his/her family were blind of investigator assessment. Parents/tutors and sibling filled in each a self-questionnaires, send back by mail (pre-paid envelope).</p>
Database objective	
Main objective	<p>Study of the impact of the Attention-Deficit Hyperactivity Disorder (ADHD) on the parents/tutors of afflicted school children.</p> <p>The study also strives to evaluate the impact of the ADHD on the siblings of the children afflicted and likewise of the impact of the disease on the school environment, thanks to the evidence provided by parents/tutors.</p>
Inclusion criteria	<p>Inclusion criteria for parents/tutors:</p> <ul style="list-style-type: none"> - Parents (father, mother or tutors) of a child aged 6 to 18 years suffering from ADHD - Parents (father, mother, or tutors) accompanying their ADHD children for a routine consultation during the observation period, - Parent (father, mother or tutor) of an child whether or not treated for his/her ADHD. <p>Inclusion criteria for siblings:</p>

- Brother or sister without ADHD of a child corresponding to the aforementioned criteria,
- Brother or sister at least 9 years old and living with the ADHD child.

Non-inclusion criteria :

- ADHD child with important co-morbidity that could influence assessment of ADHD impact on psycho-socio-economic value,
- Patients sibling / parents with important co-morbidity that could influence the evaluation of their experience (i.e. at the level of the socio-psycho-economic impact),
- Parents unable to complete a self-questionnaire,
- Parents who participated to the feasibility study (interviews)

Population type

Age Childhood (6 to 13 years)
Adolescence (13 to 18 years)

Population covered General population

Gender Male
Woman

Geography area Local

French regions covered by the database Nord - Pas-de-Calais Picardie

Detail of the geography area paediatric psychopathology department, Robert Debré Hospital (Paris) and pediatric neurology department, University Hospital of Amiens

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 09/2007

Date of last collection (YYYY or MM/YYYY) 12/2008

Size of the database

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

Details of the number of individuals 129

Data

Database activity Data collection completed

Type of data collected Clinical data
Declarative data

Clinical data (detail) Direct physical measures

Declarative data (detail) Paper self-questionnaire

Presence of a biobank No

Health parameters studied Quality of life/health perception

Procedures

Data collection method self-questionnaires filled in by parents and siblings
at home and returned by mail

Participant monitoring No

Links to administrative sources No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay) methods for accessing the database are currently being defined

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only