

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

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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)	
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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"> <li>- Parents (father, mother or tutors) of a child aged 6 to 18 years suffering from ADHD</li> <li>- Parents (father, mother, or tutors) accompanying their ADHD children for a routine consultation during the observation period,</li> <li>- Parent (father, mother or tutor) of an child whether or not treated for his/her ADHD.</li> </ul> <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	peadiatric 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