TEDIS, Pervasive Developmental Disorder’ Patients Information System, Preliminary results

Mohamed BEN SAID a, b, Laurence ROBEL c, Marie PELLEGRIN-TOUATI c, Berangere ROUSSELOT-PAILLY c, Bernard GOLSE c, Jean Philippe JAIS a, b, Paul LANDAIS a, b

a) Paris Descartes University, Faculty of Medicine, Department of Biostatistics and Medical Informatics, APHP - Necker Enfants Malades Hospital, Paris, France
b) Paris Descartes University, UPRES EA 4067- Paris, France
c) Department of Child Psychiatry APHP - Necker Enfants Malades Hospital, Paris, France

Corresponding author : mohamed.ben-said@ext.parisdescartes.fr
Pervasive Developmental Disorder (PDD) is an extension of the concept of Autism (Aut).

Association of disorders:

- difficulties to communicate
- difficulties to communicate
- restricted, repetitive and stereotypes of behavioral patterns
Introduction (2)

- Affects young children 3 years and older.
- Frequent association with neurological and organic disorders suggests a multifactorial aetiology.
- Diagnosis: behavior & communication.
- Life treatment compliance may significantly improve relational capabilities, social interactions, and communication.
Introduction (3)

• Estimated prevalence à 0.6% in France

• Therapy costs 2-3 * (Diabetes | Asthma)

• Issues in public health, education and social issues

• Involves actors and institutions: health care providers, patient families’ associations, educators, social assistants, researchers, decision makers, public health authorities,
Autism Resource Centers Organization:

- High Health Authority (HAS)
- National Autism Resources Center

Association (ANCRA) is very active:
- 29 regional autism resource centers - CRA
- CRA of Ile- de-France has conventions with 7 child psychiatry expertise’ departments to
- Establish PDD’ patients diagnosis,
• Provides PDD’s patient assessment to about 50 patients / year
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  Follow-up assessments for each patient are planned every 18 months until the end of adolescence.

Need to manage PDD’ patient information

Long term partnership with the department of Biostatistics and Medical Informatics
TEDIS Objectives (1)

1. Provide support for a better knowledge of the psychopathological mechanisms as well as etiologies in the context of PDDs’ patients.

Proposed to realize:

• Systematic and Continuous and Controlled PDD’s patient data collection

• Incident patients
TEDIS Objectives (2)

2. Improving epidemiological data quality and providing consolidated data to support public health decision making.

Proposed to:
- Focus on data quality control
- Progressively extend data collection
- Progressively extend data collection to be exhaustive at the level of administrative regions:
TEDIS: Data Processing Model

1. Patient data production
   - Physicians
   - Clinicians

2. Data quality control
   - Clinical Research Assistant

3. Datawarehouse
   - Database designers / managers

4. Support of Epidemiology
   - Public Health Decisions
   - Epidemiologists / Biostatisticians
   - Public health decision makers

Consolidation
TEDIS patient data model

- Focus on referring to common ontology to share terms for describing PDD’s disorders,
- Use of standard nomenclatures and validated assessment scales.
- Inclusion of incident patients who had their PDD diagnosis at the child psychiatry dept. at Necker hospital.
- Longitudinal study of a cohort of PDD’s incident patients
TEDIS: n-tiers architecture

End user

Middleware

Information tiers

Serveur Web Dynamique
Logique métiers

Consolidation
Réponse
Requête
Transactions

Data warehouse
Production database
ID database

TEDIS >> BEN SAID M >> Pervasive Developmental Disorder' Patients Information System, Preliminary Results
TEDIS Results

- Patient record model
- Tested paper forms
- Prototype application
- Use and test by physicians on simulated patient data
- Patient data collection / gaps / behavioral changes to improve systematic data collection
TEDIS: PDD’s patient record summary

TEDIS—BEN SAID M—Pervasive Developmental Disorder’ Patients Information System, Preliminary Results
TEDIS Results (2)

- Support research work and theses for graduate students and medical interns,
- Communication about the system
- Planned presentation to the regional and national Autism Resources Center
- Local online-deployment (submitted authorization demand to the national ethics commission (CNIL))
TEDIS Discussion / conclusion

- It federates physicians, clinicians and decision makers,
- Physicians adherence to the project is crucial
- Physicians awareness of improving data quality (original medical observation, necessity of hiring a clinical research assistant);
- It is a long process. It is a long term partnership commitment between Medical informaticists, clinicians and public health decision makers.
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mohamed.ben-said@ext.parisdescartes.fr