

European Autism Information System EAIS-Project

60% Co-financed by DG SANCO
European Commission

Programme of Community Action in the Field of
Public Health (2003-2008)

Duration: 30 months

Total Cost: € 796,757.00

Started January 2006

Ending June 2008



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Four major issues on ASD in Europe

- ✓ Case Definition (autism Vs ASD), (ICD10 Vs DSM IV & French)
- ✓ Different methodologies have been used in measuring prevalence
- ✓ No system for trends follow-up
- ✓ No comparability



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Challenges

- ✓ Language
- ✓ Culture
- ✓ Institutional / Gov. Administration
- ✓ Methodological



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Main Components of EAIS Project

- Distance Learning Platform & Newsletters

Improvement of personnel expertise

- Validated Protocols; Prevalence and Financial Burden

Characteristics of ASD in Europe

Harmonised early detection tool

- Guidelines and Video tool for early detection

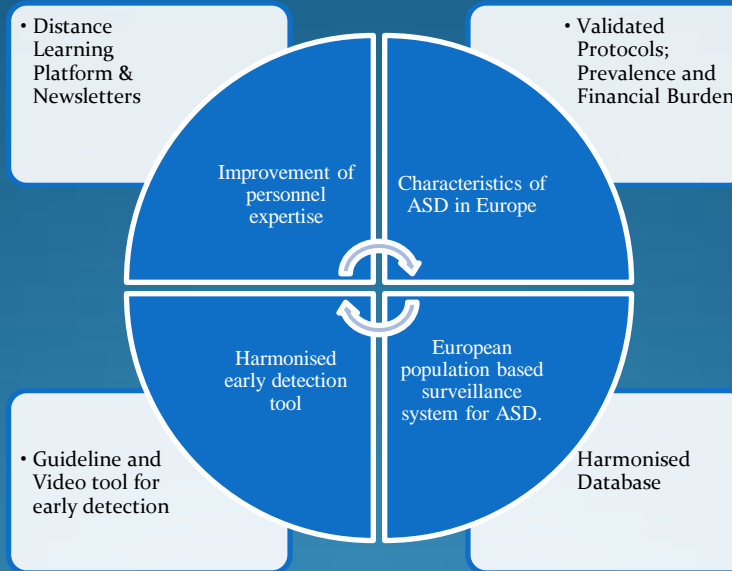
European population based surveillance system for ASD.

- Harmonised Database



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Main Components of EAIS Project



www.eais.eu

Dissemination

European Autism Alliance



What do we know in EU?

Characteristics
of ASD in
Europe



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COUNTRY	No. Prevalence Studies	Number of cases per 10,000 children
Albania		
Andorra		
Austria		
Belgium		
Bosnia and Herzegovina		
Bulgaria		
Byelarus		
Croatia		
Czech Republic		
Denmark	4	4.3 - 30
Estonia		
Faroe Islands		
Finland	1	5.6
France	4	4.7 - 5.4
Germany	1	5.8
Gibraltar		
Greece		
Guernsey		
Hungary		
Iceland	1	8.6
Ireland		
Italy		
Jan Mayen		
Jersey		
Latvia		
Liechtenstein		
Lithuania		
Luxembourg		
Macedonia		
Malta		
Man, Isle of		
Moldova		
Monaco		
Montenegro		
Netherlands		
Norway	2	3.8 - 5.5
Poland		
Portugal	1	9.2 - 15.6
Romania		
Russia		
San Marino		
Serbia		
Slovakia		
Slovenia		
Spain		
Svalbard		
Sweden	6	2.0 - 10.0
Switzerland		
Ukraine		
United Kingdom	14	4.1 - 57.0



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What are we suggesting in EU?

Characteristics
of ASD in
Europe



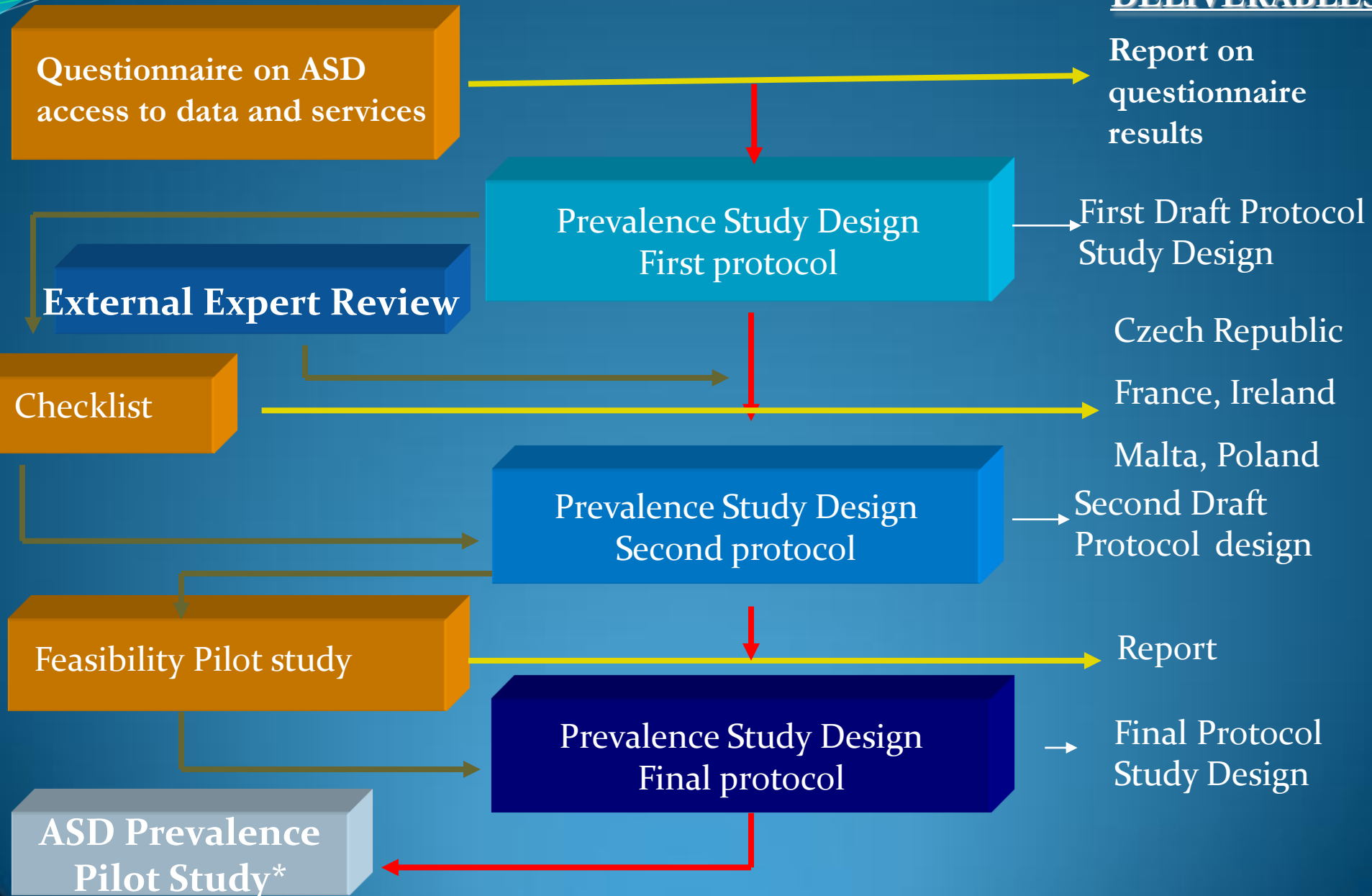
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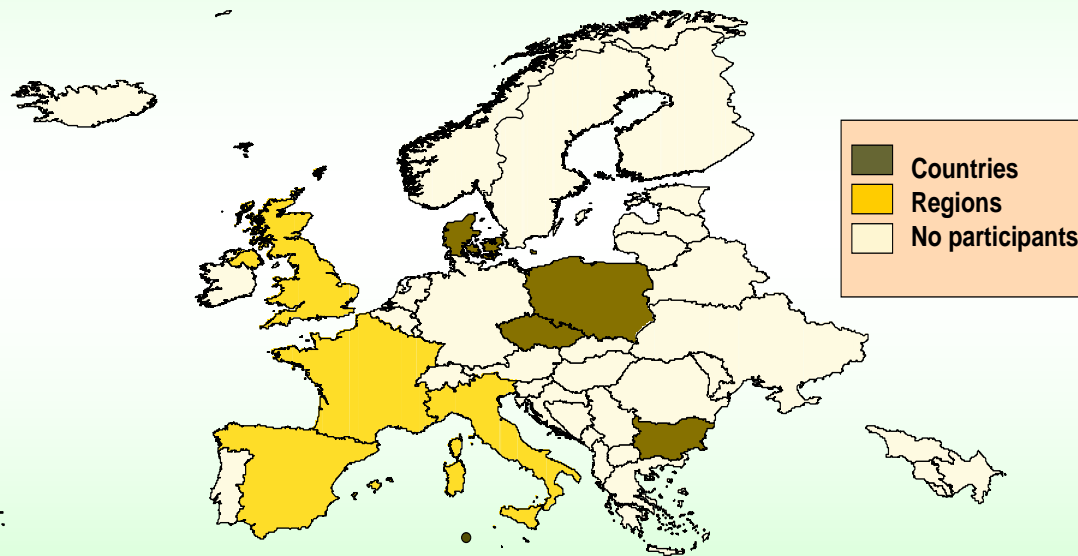
Autistic Spectrum Disorders Prevalence Study

PROCESS

DELIVERABLES



Participants in the First Q-EAIS



10 countries

**Collaborators
partners: 4 of 31 (12%)**
(France / Rhone-alpes /
Iserre, Malta, Bulgaria and
Poland)

**Associated partners: 6
of 6 (100%)**
(Czech Republic, Italy,
Scotland -Highland
Region, England, Spain
and Denmark)



EAIS

Advances in Financial Burden Pilot Study

Prof. Martin Knapp & Renée Romeo

King's College, London
Personal Social Services Research Unit, London School
of Economics & Political Science

2ND PANEL MEETING, LUXEMBOURG 24-25 SEPTEMBER 2007



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EAIS Financial Burden

Modular approach

Five elements can be considered:

- ✓ Prevalence
- ✓ Age group
- ✓ Place of residence
- ✓ Average annual cost per individual
- ✓ Aggregate cost for each pilot site



What are we suggesting in EU?

European
population based
surveillance
system for ASD.



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Database for ASD Surveillance



- Instruction Manual
- Online Database

Poul Thorsen, MD, PhD,
NANEA, University of Aarhus, Denmark



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European Population Based Surveillance

➤ Validation study

➤ Where are the pilot areas?

- ❖ Spain
- ❖ Italy
- ❖ Portugal
- ❖ Poland
- ❖ Malta
- ❖ Czech Republic
- ❖ Luxembourg
- ❖ Ireland



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What are we suggesting in EU?

Harmonised
early
detection
tool



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Harmonised early detection tool

Dr. Maurizio Brighenti

Analysis of Existing Tools for:

- Warning Signs
- Warning Symptoms
- Diagnosis



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Harmonised early detection tool



Video & Guidelines for early diagnosis
(In progress...)



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What are we suggesting in EU?

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ЕВРОПЕЙСКИ ПАРЛАМЕНТ PARLAMENTO EUROPEO EVROPSKÝ PARLAMENT EUROPA-PARLAMENTET
 EUROPAÏSCHES PARLAMENT EUROOPA PARLAMENT ΕΥΡΩΠΑΪΚΟ ΚΟΙΝΟΒΟΥΛΙΟ EUROPEAN PARLIAMENT
 PARLEMENT EUROPÉEN PARLAIMINT NA HEORPA PARLAMENTO EUROPEO EIROPAS PARLIAMENTS
 EUROPOS PARLAMENTAS EUROPAI PARLAMENT IL-PARLAMENT EWROPEW EUROPEES PARLEMENT
 PARLAMENT EUROPEJSKI PARLAMENTO EUROPEU PARLAMENTUL EUROPEAN
 EUROPSKY PARLAMENT EVROPSKI PARLAMENT EUROOPAN PARLAMENTTI EUROOPAPARLAMENTET

EUROPEAN AUTISM ALLIANCE



**RARE DISEASE
OR**



MAJOR AND CHRONIC DISEASE

Dr. Diana Schendel - *Center for Disease Control, CDC Atlanta*

Dr. Alvaro Ramirez - *European Autism Information System*

Antoni Montserrat - *Head of Information Unit - DG Sanco*

17th October 2007

European Parliament

Spinelli Building - ASP 1E2

Registration 8 to 9 am

Official Launch of the European Autism Alliance

Part of the European Autism Information System (EAIS)

Project. Co-founded by European Commission DG-SANCO

Launch by / **Commissioner Kyprianou**



Hosted by **Kathy Sinnott (Ind/Dem)** 

Maria Carlshamre (ALDE) 

Den Dover (EPP) 



477/EN

Logo and printing
GROUP HANDELT



European Autism Information System

The EAA is to be a sustainable association committed to providing information on:

- ✓ early detection and diagnosis of autism for professionals
- ✓ management of data systems (surveillance)
- ✓ prevalence and financial burden of autism spectrum disorders in the EU
- ✓ issues surrounding public awareness of ASD.

The role of the EAA will include:

- ✓ training (including an on-line distance learning platform)
- ✓ distribution of software and information systems
- ✓ providing a forum for health information professionals and managers, policy makers, ministries of health, academic and research organisations.



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Main Activities to date

1. **Scientific Group Meeting:** Case definition established, based on DSMIV. Early detection video tool agreed upon, now being developed.
2. **International Autism Epidemiology Network Planning Meeting:** Strengthened relationship with CDC, Autism Speaks and other institutions.

Contacts for International collaboration

Participation in the global strategy for ASD.

3. **Panel of Experts on Autism, Luxembourg, September, 2006 & 2007.**

Definition of Pilot Areas (Poland, Czech Republic, Denmark Luxembourg, France, Spain and Ireland) these areas will be known as European Autism Information Centres (EAIC).



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Outputs and other developments

1 Website www.eais.eu

2 We are working on promoting Autism as a health priority during Czech Republic Presidency Jan-July 2009

3 ENSACP

4 Autism is included in the MCD report DG-SANCO

5 ASD is a Rare Disease as well as a Major and Chronic Disease in EU



Thank You



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