

Work package title: WP1: Prevalence and related social and economic costs

Presentation title: Overview of ASDEU Prevalence study fields in Europe

Presenter: Manuel Posada de la Paz, ISCIII. WP1 Coordinator.

Update on activities:

Study design

Cross-sectional study design (n=23 areas – 8 countries)

- Spain (2) Italy (4) Poland (4), Portugal (7), Austria (2), Bulgaria (1)
- Romania (whole country)
- Ireland (validation study 2 areas + previous prevalence study-3 areas)

Population-based approach (n=5 areas – 4 countries)

- France (2 registries)
- Denmark & Finland (1 full and global country registry)
- Iceland (global surveillance country system)

Screening: SCQ only (some areas) vs Teacher Nomination + SCQ (most areas)

Diagnosis: ADOS-G & ADI-R vs clinical record review

Progress

- Geographical areas have been selected based on population estimations and geographical mappings for school population sampling have been performed.
- Several materials development for the study: letters for authorities and participant teachers, informed consents, leaflet with study info in many languages.
- “Teacher Nomination” and “SCQ” tools translated to 8 languages.

Initial findings

Over 13,000 already children screened and 2,035 nominated – Preliminary results from Bulgaria, Romania and Italy.

Key learning:

What worked well

- The biggest effort for a prevalence study in Europe
- High level of collaboration among ASD registries in Europe for the prevalence study.
- New ASD diagnosis expert team(s) have been created in Bulgaria, Poland and Austria.
- Great support from Ministry of Health/Education in some countries also for local educational and health authorities

What could be done differently

- Avoid as much as possible the delays on ethical Committees for final approvals
 - School calendar year should be considered because it differs from the research calendar
 - Asses and look for the best way of collaboration with parent´s organizations as much as possible.
 - Check the viability of study designs and screening methods for maximum harmonization previous of selection of areas
- Validity study planning for diagnosis reliability across countries

Next steps:

Outline Schedule: Site Visits (1st and 2nd round accomplished) and SEN Units Records to be reviewed in all countries (by middle 2017); Validity study and last positive cases evaluation.

*Possible new outcome: Definition of surveillance prevalence European units across MS and their methods.