

Workpackage progress update for ASDEU website – July 2017

Title: Update of prevalence estimation in Europe: Cross-sectional field study areas and Population-based registries

WP1: Prevalence and related social and economic costs

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The strategy followed within the ASDEU programme for estimating Autism Spectrum Disorder (ASD) prevalence in school-aged children at the European level is based on two methods in a total of 12 countries:

- 1) Cross-sectional field study: this is ongoing in eight European countries: **Austria, Bulgaria, Ireland, Italy, Poland, Portugal, Romania, Spain**, and will continue until the end of 2017.

After a preparatory phase, of school selection, authority's contacts and permissions, the field study is being carried out on a 3-stage strategy as follows:

Stage 1: Children are nominated in schools using the TNF (Teacher Nomination Form).

Stage 2: Screening TNF positive children with the SCQ (Social Communication Questionnaire).

Stage 3: Clinical evaluation of SCQ positive children using the ADI-R, ADOS and psychometric measures. (Evaluation Stage)

A target population of 80,000 children aged 7-9 years residing within the selected areas during the study period (2016-2018), is expected to be screened (8,000-10,000 per country). Each ASDEU partner chose to either study the whole country or particular regions.

In each geographical area, either all schools or schools selected after a sampling procedure were included. In larger regions, a stratified random sample procedure according to the number of children in each school was carried out. The approximate sample size in all regions was 10,000 children. All special education schools were selected (when existing).

- 2) Information from population-based registries or health data systems from the ASDEU partners: **Iceland, Finland, France and Denmark**. They will contribute harmonised data for prevalence estimation and comparison with results from the field study method.

Findings and outcomes to-date:

The school participation rate in the cross-sectional field studies has so far ranged from 12.6% to 100%, with a mean from 8 countries of 60.8%.

Ireland had completed a prevalence study for ASD in 2013 using a different protocol in some aspects, and is now conducting a second smaller study for validation and comparability purposes. Ireland, Romania, Bulgaria and Spain have completed the school

screening phase. The results collected up to March 2017, show good progress in terms of participation rates. The discrepancies in participation rates reflect differences between countries regarding ethical or administrative procedures. For instance, in Austria the schools cannot fill out the TNF, for ethical reasons, and will apply the SCQ to all children. In Portugal, groups of schools are administratively assigned to one main school, which had to authorise the project even after authorization by the Ministry of Education. The need to make this additional efforts suggests that more time is needed for the study, and not necessarily a diminished final participation rate.

Some regions or countries, like Italy and Gipuzkoa in Spain, do not have Special Education Centres (SPEC). Others, like Ireland and Portugal, have Autism Units in some regular schools. While in Romania there are 1,252 ASD diagnosed children in 95 SPECs. All SPEC and all schools with Autism Units have been included in the screening. Preliminary analysis of results in Portugal does not suggest a significant difference in participation rates between these different types of schools.

The TNF strategy, after translation and minor adaptation as necessary in each country, has been generally well received by teachers. A total of **39,324** school children have been screened so far in 7 countries. The TNF was piloted in schools known to have children with ASD and with other neurodevelopmental problems in Portugal. The accuracy of detection was 100%. These results indicated that the number and type of issues signalled by teachers for nominated children are different for ASD and other neurodevelopmental problems.

Ireland completed a prevalence study for ASD in 2013 using a protocol that did not include the TNF, but was based on parental response to the SCQ for all children. For their participation in the ASDEU programme, they are carrying out a validation study in 15 schools using the TNF, allowing a comparison of the SCQ detection rates, and an estimation of the usefulness of the TNF protocol.

Parental participation rate, responding to the SCQ, is so far very high, ranging from 40% to 100%. Italy is administering the SCQ to parents of all screened children, regardless of whether they were nominated or not. Together with Irish data, this procedure will allow the estimation of false negatives from the TNF-based protocol.

The main challenge in the implementation of the cross-sectional field study, would seem to be the schools' and parents' participation rate, but preliminary numbers are showing good progress.

Finally, countries using population-based registry strategies to estimate the ASD prevalence have their project approvals for this study and data collection is in hand or preparations for data collection are underway.

Key learning from activities:

What could be done differently

- It would be better when conducting school contacts and/or visits in the first trimester of the year, to make sure field studies could be finished before end of the school year.

- Differences in the educational systems in each country should be considered in advance.
- Each country had different ethical authorizations, and other permissions requirements (ranging in time from 4 months to 12 months).

What worked well

- Analysis of early results indicates the field study is feasible and challenges related to cultural and educational systems diversity can be overcome.
- ASDEU is the first study to estimate ASD prevalence across European countries using a common method.
- The final ASD prevalence estimated across Europe will be fundamental to establish an evidence-based, EU-wide response to the growing societal needs of individuals with autism.

Next steps:

- Full description of methods and results in a standardized template for each study area, including detailed descriptions in the following sections:
 - Study design
 - Geographical, social and educational setting;
 - Target population and sampling procedure when needed
 - Ethical permissions process
 - Preparatory study procedures
 - Case definition and exclusion criteria
 - Implementation of the Screening Protocol, describing the 3 stages procedures
 - Data management
 - Main numerical outcomes
 - Addition of the already diagnosed ASD cases procedures
- The population-based registries expect to perform analyses and prepare their site specific methods reports in the autumn of 2017, and the overall register-based prevalence study report will be prepared in late 2017 or early 2018.
- Final analysis of the main outcomes of each field-study country in late 2017
- Final prevalence report writing and presentation of main results in final conference in Madrid in early 2018.

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Autism Spectrum Disorders in the European Union

