

# ASD Prevalence Study across Europe

## Strategy Design based on two different methodologies



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## Background and objectives

Over the past 30 years the number of reported cases of ASD has increased. Consequently, ASD organizations are requesting more services and pressuring governments to respond. The few mechanisms to obtain reliable information on ASD trends are an obstacle to generate political decisions. One of the difficulties in comparing ASD prevalence rates across Europe lies in the fact that standardized methods have not been used to collect data. The main objective of this study, is to present the strategy of the Autism Spectrum Disorder in the Euopean Union (ASDEU) project (linked with the **European Comission-EC-**) **to estimate the ASD prevalence in school-aged children at the European level.**

## Study Design

**Phase 1. Case Ascertainment**

- **Authorities contacts and permissions.**
- **Ordinary schools, special needs schools and ASD organizations visits.**
- **Teacher Nomination** and SCQ
- **Validity study**

**Phase 2. Diagnosis evaluation**

- Medical History
- Cognitive evaluation (WISC IV or WPPSI-IV)
- **Adaptive Behaviour Evaluation** (Vineland)
- Autism Diagnostic Interview Revised (ADI-R)
- Autism Diagnostic Observation Schedule Generic (ADOS-G).
- Diagnosis classification based on DSM-5 and DSM-IV-TR

**Phase 3. Medical assessment and parent diagnosis information**

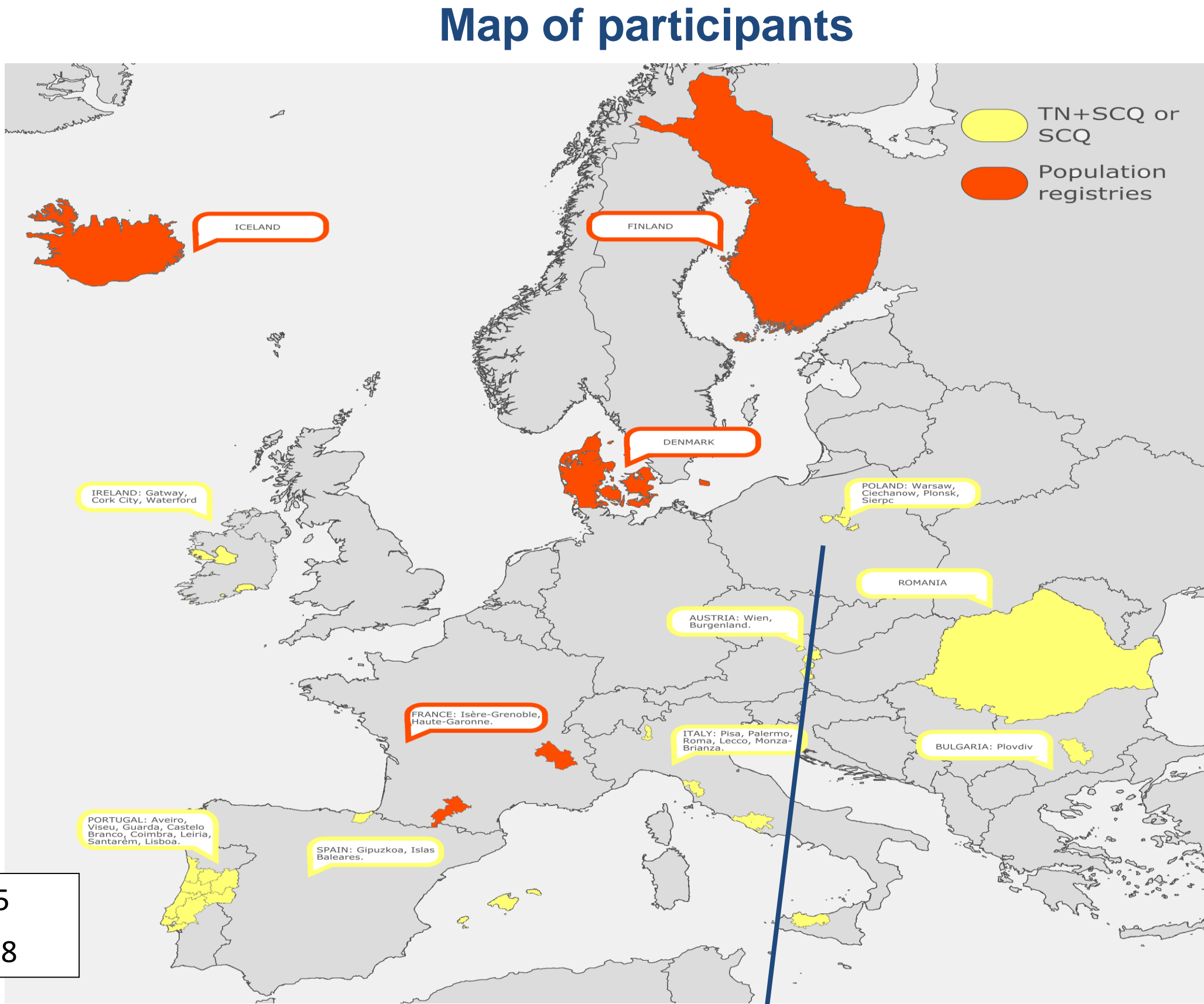
- Diagnosis information to parents by coordination with Health and Educational services (also with ASD Parent’s organization if appropriated)
- Support and intervention guidelines
- Burden and costs of disease survey
- Medical co-morbidity should be checked in those ASD cases finally confirmed

Cross-sectional study and population based approach, using two methods of ascertaining ASD cases in a total of 12 countries\* :

**1) Study- field methods** based on screening in primary schools described in the “ASDEU Prevalence Protocol” based on the EPAP (EAIS Project funded by DG-SANCO). Target population: children aged 7-9 years residing within the selected areas during 2016 (**Austria, Bulgaria, Ireland, Italy, Poland, Portugal, Romania & Spain** : 8,000-10,000 children per country).

**2) population-based registries** approach (**Denmark, Finland, France and Iceland**) Prevalence rates and their 95% confidence intervals. Comparisons between countries will be also made.

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None conflict of interest*

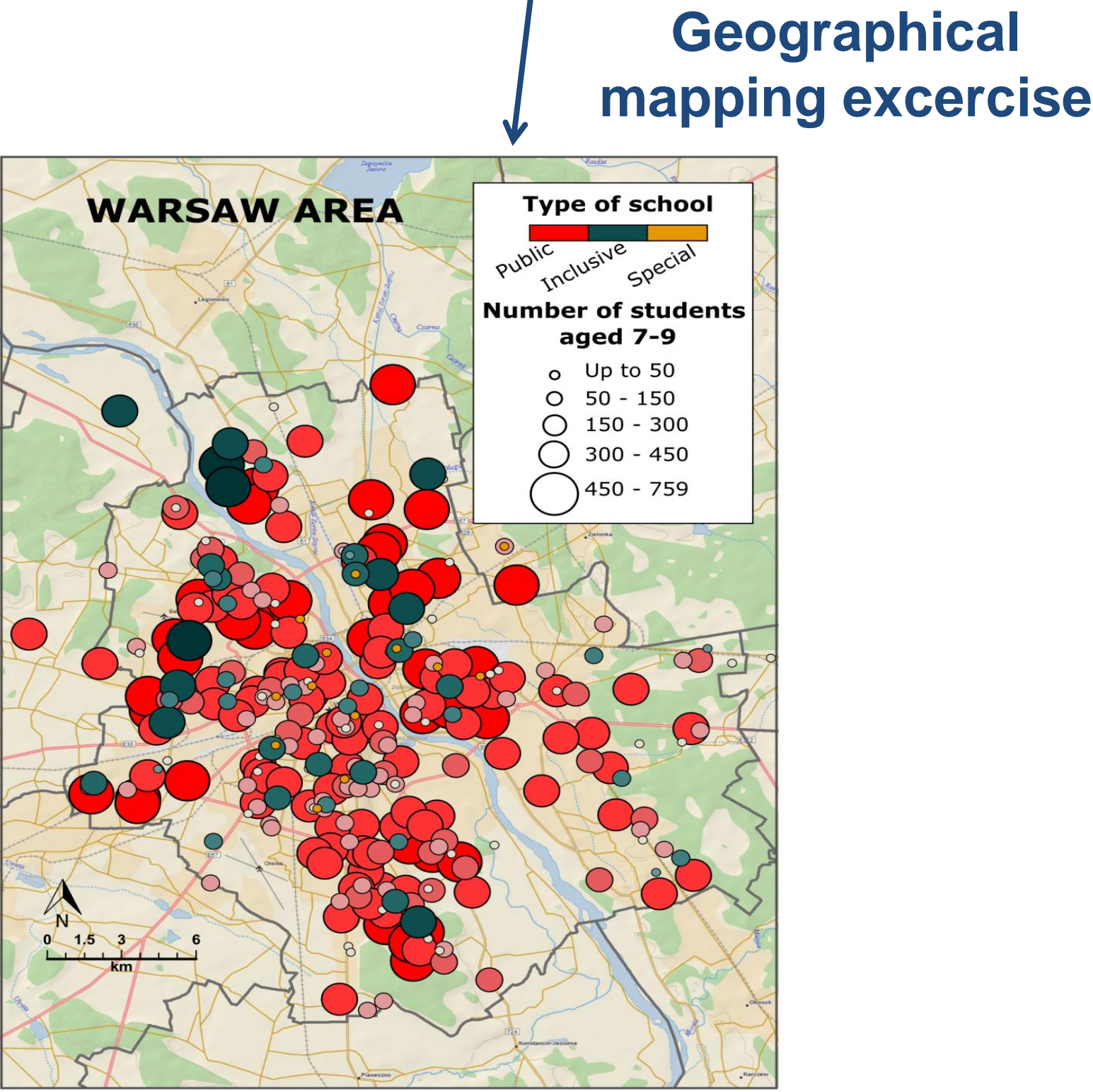


Starting date: 01/02/2015  
Finishing date: 01/02/2018

## Results

- Geographical areas have been selected based on population estimations and geographical mappings for school population sampling have been performed.
- Inventory of schools (mainstream and Special Education Needs-SEN-), and health and social entities.
- Study materials: letters for authorities and participant teachers, informed consents, leaflet with study info in many languages. “Teacher Nomination” and “SCQ” tools translated to **8 languages.**

- Common database, including a selection of common variables of National Database for Autism Research (NDAR) and EU-AIMS network is being developed in coordination.
- All study areas achieved approval from their Ethical Committee and other required entities.
- New ASD diagnostic expert team(s) have been established in some countries, such in Bulgaria, Poland and Austria, after an ADOS training course.



### STUDY FIELD – SCREENING APPROACH

Geographical area*		Screening Tools	Target Population (7-9 years)	Study Progress**
	Baleares Islands (SPAIN)	TN + SCQ (when TN positive)	13000	Pilot study with TN in 11 schools. Period: 26th may- 14th June. 56 nominated children.
	Gipuzkoa county (SPAIN)		14600	Starts in Sept 2016, special collaboration provided by the Dept. of Education, Basque Government"
	ROMANIA (Whole country)		10000	Already screened the great majority of SEN: 1252 with ASD from 6151children. 9000 screened with TN in regular schools (1295 nominated)
	Coimbra (PORTUGAL)		45000	Screening phase to start in Sept, and first data end of 2016
	Warsaw & 3 provinces (POLAND)		11200	After 1003 screened, 57 (5.6%)nominated, 64% filled SCQ. 3 schools refused participation
	Waterford & Galway (IRELAND)		2300	TN validation study, since DCU team had recently carried out a Prevalence study (Boilson 2016)
	Municip. Of Plovdiv (BULGARIA)		10000	Visited all 53 schools individually. 276 nominated children.111 SCQs ( 30 scoring above 15)+ 6 from a local Autism centre
	Viena & Burgenland (AUSTRIA)	SCQ directly to all parents	8000	Screening phase to start in Sept. Many undiagnosed cases. 30-40% Immigrant population in some schools (bias?).
	Pisa (ITALY)	TN + SCQ to all teachers	10100	4086 screened with SCQ (41% ). 167 (49%) above 9 cut-off.From Sept,to try again with parents who refused SCQ
	Palermo,Rome & Lecco-Monza-Brianza (ITALY)	TN + SCQ (Some areas only TN )	36000	SCQ will have its official validation in italian language thanks to this study.
			160200	= TOTAL (children population expected to be screened in this study)

### POPULATION BASED APPROACH

Geographical area		Data sources for the Prevalence Study	Population size (7-9 years: YEAR 2015)	ASD Diagnosis Tools used
	France (2 registries)	Haute-Garonne department (RHE31)	31600 (generations 2006 and 2007)	ADOS+ ADI-R (not always)
		Isere, Savoy & Upper-Savoy dep. (RHEOP)	62000 (generations 2006 and 2007)	
	Iceland	Several population based information systems+	13551	ADOS > 90% ; ADI-R < 50%
	Denmark	Danish Psychiatric Central Research Register (DPCRR)	194,377 (2006-2008 livebirths)	ADOS+ ADI-R (not always)
	Finland	Finnish Hospital Discharge Register and the Register for Disability Benefits for ASD diagnoses	178,917 (2007-2009 livebirths)	

## Conclusions

This is **the first study aimed to estimate ASD prevalence throughout Europe** using different methodological approaches. This work is in its early stages, and screenings in all participating countries are expected to be finished soon in the middle of 2017 year. We have faced, as expected, many challenges when performing this ambitious study but also many gains have already been achieved. The final results will be fundamental to compare data across standardized methodologies and different geographical areas. Lastly the results will contribute to better services policy planning across countries within the European Union.