

**Work package title:** *European Prevalence of ASD in 12 pilot areas*

**Presentation title:** *WP1 update from studies based on registries or other health information systems: Denmark*

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**Context:**

Four ASDEU sites (Denmark, Finland, Iceland, France) have population-based registries or health data systems that these sites will use to calculate ASD prevalence.

**Progress:**

The 4 sites are working together to harmonize: ICD codes, birth years, follow-up years and prevalence estimation.

Registry-based sites are targeting 7-9 year olds, like the non-registry sites, but in different birth cohorts due to differences in data availability

- The common cohort across all 4 sites is 8 year olds, born in 2007 and followed through 2015
- ICD codes for the registry case definition include: F84.0 childhood autism, F84.1 atypical autism, F84.5 Asperger syndrome, F84.8 other PDD, F84.9 PDD, NOS
- ASD prevalence estimates to be calculated:
  - all ASD, by sex, by birth year
  - Numerator: case children residing in catchment area at time of follow-up
  - Denominator: all children of same age as cases residing in catchment area at time of follow-up
    - DK, FI: children born in and still residing in country at time of follow-up (children who have emigrated or died are censored)
    - FR, IS: children of same age residing in catchment area at time of follow-up (birth place not considered)

Denmark Registry data requested - received notice that data will be available mid-September

**Initial findings**

- No analysis has been able to be performed as yet
- Previous validation of registry-reported childhood autism in Denmark:
  - Expert review of behavioral information in diagnostic medical records to determine if number and type of behaviors met childhood autism ICD10/DSM IV criteria (CDC ADDM-based approach)
  - 94% met criteria (499 reviewed cases)
    - Published reference: Lauritsen, M. B., Jørgensen, M., Madsen, K. M., Lemcke, S., Toft, S., Grove, J., et al. (2010). Validity of childhood autism in the Danish psychiatric central register—findings from a cohort sample born 1990–1999. *Journal of Autism and Developmental Disorders*, 40, 139–148.

**Key learning:**

- **What worked well?**
  - Group conference calls via telephone or skype meetings improved sites' understanding of WP tasks and ways to harmonize the different sites' approaches
- **What could be done differently?**
  - No suggestions

**Next steps:** Denmark site: generate prevalence estimates and write site-specific methods description in winter 2017.