Using medical birth registry for birth defects surveillance: Russian experience

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ABSTRACT:

Introduction
An ongoing epidemiological surveillance is a core issue in a primary prevention of birth defects (BD). The aim of the study was to assess the prevalence of BD based on population-based birth registry data and to compare the completeness of registration with data of Federal BD monitoring system.

Materials and methods
The Arkhangelsk County Birth Registry (ACBR) and Federal BD monitoring system data were used in this retrospective cohort study. The ACBR includes information on all 57944 live- and stillbirths at gestational age 22 and more weeks registered in Arkhangelsk County, Northwestern Russia, in 2012-2015. Totally, 57449 newborns without missing information on BD were included in the study.

Results
In 2012-2015, 2841 various BD in 2274 newborns were registered in Arkhangelsk County according to the ACBR. The total prevalence of BD in the ACBR was 39.6 per 1000 newborns (95% CI: 39.6 – 41.2), the total prevalence in the Federal monitoring system was 16.2 per 1000 newborns (95% CI: 15.2 - 16.2) The completeness of registration varied across groups of BD and their severity: the accuracy and completeness of information on neural tube defects and chromosomal abnormalities were higher in Federal BD monitoring system, while registration of cardiovascular and genital-urinary malformation was more complete in the ACBR.

Conclusion
The total prevalence of BD in the ACBR was higher compared to that reported by the Federal BD monitoring system. Population-based registries can supplement the current system of BD surveillance to make an estimation of prevalence more precise.