Representativeness of the German National Register for Congenital Heart Defects. A clinically oriented analysis.

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Introduction:
The German National Register for Congenital Heart Defects (NRCHD) is a clinical register comprising data from approximately 48,000 members (largest patient database in Europe). Approximately 6,000 children are born with congenital heart disease (CHD) in Germany each year. They die from their chronic illness increasingly rarely. In the present data analysis, birth years recorded in the NRCHD are compared to results of the PAN study and a meta-analysis by van der Linde et al. with respect to prevalence rates and sex distribution.

Methods:
A descriptive data analysis was performed by using a minimal data set. The demographic data include sex and birth year; the medical data comprise the cardiovascular diagnosis according to the IPCCC Shortlist. Two birth years recorded in the NRCHD (2004/2005) and two birth years recorded in the PAN study (2007/2008), were compared with each other, as well as with the results of van der Linde et al., with respect to prevalence rates and sex distribution.

Results:
The two birth years of 2004/2005 as recorded in the NRCHD deviated from each other by an average 0.8% (minimum 0.0% to maximum 1.7%) regarding the diagnosis groups. In three of the nine diagnosis groups (ASD, TOF and Other), the prevalence difference between the two years was < 1.0%. The prevalence rates as recorded in the NRCHD can thus be assessed as very accurate. The birth years of 2007/2008 as recorded by the PAN study show an average deviation of 0.7% (min.: 0.0%, max.: 1.9%) with respect to the prevalence rates.

Being a clinical register, the NRCHD primarily includes clinical cases/cases relevant to health care. The prevalence values and sex ratios recorded therein are closer to the values given in the literature than those determined by the PAN study. Severe CHD are slightly overrepresented in the NRCHD as compared to van der Linde et al. Deviations with respect to prevalence values are within acceptable range.

Conclusions:
The patient population registered in the NRCHD can be considered as representative for CHD in Germany and Europe. Samples from the NRCHD can thus be expected to represent the gold standard for future studies.