Research Group Epidemiology

Institute for Biometrics and Epidemiology, German Diabetes Center,
Leibniz Center for Diabetes Research at Heinrich Heine University Düsseldorf,
in cooperation with the
German Paediatric Surveillance Unit

Type 1 Diabetes in Children under 5 Years of Age

Abstract
Worldwide, there are significant differences in the incidence of type 1 diabetes in children and adolescents. In 2021, approximately 1.5 million children and adolescents under the age of 20 were living with a diagnosis of type 1 diabetes. On average, the global diabetes incidence has increased by 3% to 4% annually over the past decades, showing both regional and temporal variations.

In Germany, the onset of type 1 diabetes in children under 5 years of age have been recorded by ESPED since July 1992, enabling the estimation of long-term trends and regional differences in type 1 diabetes incidence within Germany. Continuous nationwide recording of new cases is essential to provide valid and up-to-date estimates of incidence trends. This enables the detection of short-term changes.

Head of Register
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Study period: Ongoing since 1992

Background
Type 1 diabetes is an autoimmune disease that is triggered by environmental factors in genetically predisposed individuals and is associated with destruction of the islet cells of the pancreas. In recent decades, the type 1 diabetes incidence has increased worldwide, however, considerable regional differences have been observed. In the years before the COVID-19 pandemic, there were indications of a slowing or even stagnating incidence trend in some high-income countries (International Diabetes Federation Atlas, 10th edition). The reasons for the changes in diabetes incidence and regional differences are still unknown. Temporal and regional differences in the incidence and prevalence of type 1 diabetes have also been observed within Germany. In order to provide a valid and up-to date picture of the temporal and spatial incidence patterns of diabetes in young age groups in Germany and to enable valid comparisons with international data, the continuous recording of all new-onset diabetes in Germany is of great importance. The temporal and seasonal fluctuations that have been observed in the COVID-19 pandemic in recent years impressively demonstrate the relevance of the continuous recording of new-onset of diabetes (e.g. for North Rhine-Westphalia: Stahl-Pehe, A et al. 2024, Diabetes & Metabolism, doi: 10.1016/j.diabet.2024.101567). The age restriction to children under 5 years ensures that children with new-onset diabetes are almost treated in paediatric departments that are included in the ESPED survey. This ensures a high level of completeness of data collection.

Research questions
Estimation of the incidence, temporal changes and spatial distribution patterns of type 1 diabetes in children under 5 years of age in Germany.

Case definition
Clinical diagnosis of new-onset type 1 diabetes under 5 years of age.

Logistics
The primary data collection takes place via the paediatric clinics in Germany. Every month, the clinics receive an online registration card from ESPED for reporting the number of all manifestations of type 1 diabetes in children before their 5th birthday observed in the respective survey month. For each new case reported, the respective paediatric clinics receive an online questionnaire to enter some demographic and clinical data from the patient's medical file. Surveys in internal medicine clinics and specialist diabetology practices, annual practice surveys and German Diabetes Prospective Follow-up Registry (DPV, University of Ulm) are used as supplementary secondary data sources to estimate the completeness of data collection.

Data protection
In accordance with data protection regulations, data are recorded in a de facto anonymised form.