

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

Diabetes in Children and Adolescents under 18 Years in North Rhine-Westphalia

Abstract

Worldwide, there are substantial differences in the incidence of type 1 diabetes among 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. Type 2 diabetes is relatively rare in children and adolescents; however, its incidence has been rising in many countries over the past 20 years.

In North Rhine-Westphalia, the onset of type 1 diabetes in children under the age of 15 have been recorded by ESPED since 1996, enabling the estimation of long-term trends and regional differences in type 1 diabetes incidence. The data collection was expanded in 2002 to include new-onset type 1 diabetes and type 2 diabetes in the age group under 18 years. Continuous recording of new cases is essential to provide valid, 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 1996

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 incidence has increased worldwide by 3 % to 4 % per year, with considerable regional differences 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 incidence of type 2 diabetes in children and adolescents has also been rising in many countries for around 20 years, in parallel with the increase in overweight and obesity in this age group (Wu H, 2022, Diabetes Research and Clinical Practice, doi: 10.1016/j.diabres.2022.109785). By extending the age limit and including new-onset type 2 diabetes in the data collection from 2002 onwards, valid results of incidence trends over a period of 20 years and could already be shown for North Rhine-Westphalia (Stahl-Pehe, A et al. 2024, Diabetes & Metabolism, doi: 10.1016/j.diabet.2024.101567). 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 the future and to enable valid comparisons with international data, the continuous monitoring of all new-onset diabetes in youth in North Rhine-Westphalia is of great importance. The use of secondary data sources makes it possible to estimate the completeness of coverage of the study.

Research question

Estimation of incidence, temporal changes and spatial distribution patterns of type 1 and type 2 diabetes in children and adolescents under 18 years of age in North Rhine-Westphalia.

Case definition

Clinical diagnosis of new-onset type 1 or type 2 diabetes under 18 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 or type 2 diabetes in children and adolescents before their 18th birthday observed in the respective survey month. For each new case reported, the respective paediatric clinics receive an online questionnaire to enter some demographic, clinical and laboratory 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.