Journal of Health Monitoring

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The health of children and adolescents – new data is needed!

Health monitoring of children and adolescents is of great importance for two main reasons: (1) continuous data collected without special occasions allow positive and negative trends to be identified and are available promptly for health policy decisions when acute changes occur in living environments; (2) the synopsis of socio-spatial characteristics, individual risk factors and health status offers opportunities to develop and implement a health-promoting Health in All Policies strategy and to measure the success of interventions.

For this purpose, federal health reporting requires continuous national data collections that are as representative as possible and contain both survey and examination data. For this purpose, the RKI Health Panel is currently being developed at the Robert Koch Institute (RKI). In the future, this panel will include about 100,000 recruited adults in Germany and through them it will be possible to survey their children as well.

For the first time and with great success, a large representative study on child health was conducted in 2003–2006, the German Health Interview and Examination Survey for Children and Adolescents (KiGGS). RKI staff interviewed and examined 17,641 children and adolescents. After the baseline study, a survey with 12,368 children and adolescents was conducted in 2009–2012, and another interview and examination survey with 15,023 participants in 2014–2017. The results are invaluable for all those working in the field of child and adolescent health, for health policy and science. Unfortunately, no further waves could be organised, which was particularly regretted in the context of the COVID-19 pandemic crisis. At the RKI and other institutions, new cross-sectional surveys were quickly set up during the pandemic, such as the study German Children’s Health Update (KIDA) presented in this issue by Loss et al. which, however, only began two years after the start of the pandemic.

Alternatively available health data such as school entrance examination data was used by Kühnelt et al. in their study on monitoring child health using obesity as an example. The selection and research of socio-economic and cultural characteristics of the social areas is impressive, as parameters such as care, nutrition and exercise were included. In the future, it would also be conceivable to consider aspects of environmental and climate justice and the experience of violence in the neighbourhood. It is remarkable that many state health offices participate in projects like this or others (cf. funding line ‘Strengthening the cooperation between public health services and public health research’ of the Federal Ministry of Health). The cooperation between the public health service as local public health and the Robert Koch Institute as National Public Health Institute is gaining momentum and is to be expanded not only in infection protection but also in health reporting.

In addition to these population-based data collections, more specific questions need to be answered by other approaches, for example by paying special attention to children and adolescents in surveillance systems, as shown in the article ‘Respiratory infections in children and adolescents in Germany during the COVID-19 pandemic’.
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The measures to contain the pandemic were justified by an anticipated overload of the health care system due to COVID-19 illnesses, such an overload did not occur in the area of outpatient and inpatient care of children suffering from COVID-19. However, there was a clear accumulation of infections with respiratory syncytial viruses (RSV) and influenza viruses in children, as well as a shift in typical seasonal courses. In autumn and winter 2022, this led to a very heated debate in the media about a feared collapse of children’s hospitals and life-threatening long transport routes, especially for the very youngest.

Another access point for health monitoring is offered by special diagnosis-specific registers. The concerns of children and adolescents with less common diseases cannot be reflected in general health surveys. For this purpose, this issue presents data from the German Childhood Cancer Registry, which is an exemplary and much-admired instrument for cancer reporting in children and adolescents worldwide. At the same time, it is used for therapy optimisation studies because of its very high acceptance in paediatric and adolescent oncology.

Over the next decade, questions will also need to be addressed about how changes in immunologic training during the COVID-19 pandemic will affect child and adolescent health. The same applies to children and adolescents with type 1 diabetes; here, too, detailed data are available from a clinical register, the Diabetes Patient Follow-up Documentation. The paper by Buchmann and Tuncer et al. in this issue also addresses the influence of socioeconomic factors on the quality of care and the possible impact of the COVID-19 pandemic.

By integrating information from population-based health monitoring, specific surveillance procedures and clinical epidemiological registers, comprehensive data can be made available in a timely and continuous manner for the promotion and protection of the health of children and adolescents in the country. This was the case even before the COVID-19 pandemic, the consequences of climate change, progressive social disadvantage and educational poverty among children and adolescents, but the experience of the last three years has shown us how difficult it is when crises encounter less resilient public health systems. This is about to change which is a good thing.

Conflicts of interest
The authors declared no conflicts of interest.

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School entrance examinations as a small-scale data source for health monitoring of children using obesity as an example

Abstract

Background: In the scope of the nationwide obligatory school entrance examinations (SEE), a standardised assessment of the preparedness for school of preschool children takes place in the federal states of Germany. For this purpose, height and weight of the children are determined. These data are available in aggregated form at county level, but are not yet being regularly compiled and processed at national level for use in policy and research.

Methods: In a pilot project, the indexing and merging of SEE data from 2015–2019 was tested in collaboration with six federal states. This was done using obesity prevalence at the time of the school entrance examination. In addition, prevalences were linked to small-scale indicators on settlement structure and sociodemographics from public databases, differences in obesity prevalence at county level were identified, and correlations to regional influencing factors were visualised.

Results: It was feasible to merge SEE data from the federal states with little effort. The majority of the selected indicators were freely available in public databases. In an interactive, easily comprehensible and user-friendly Tableau dashboard for visualising the SEE data, it can be seen that obesity prevalences differ significantly between counties that are similar in terms of settlement structure or sociodemographics.

Conclusions: Providing federal state SEE data and linking them to small-scale indicators enables region-based analyses and cross-state comparisons of similar counties and provides a data basis for continuous monitoring of the prevalence of obesity in early childhood.

1. Introduction

Small-scale data, e.g. at county or district level, are of central importance for the planning, implementation and evaluation of prevention and health promotion measures as well as for the provision of health care at federal, state and county levels. In terms of the ‘Public Health Action Cycle’ [1], aggregated data for small-scale analyses are an essential requirement for identifying existing needs in order to make health policy decisions based on actual evidence. However, few data sources are available that provide small-scale, meaningful data on the population health status or on health related risk and protective factors [2].

One such data source are the nationwide mandatory school entrance examinations (SEE), whose potential has not yet been fully used. The SEE are conducted nationwide...
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by the Child and Adolescent Health Services (KJGD) at county level or at district level in the city states. This involves a regular, standardised examination of body weight and height of children aged four to seven years, as well as of other parameters. It is the aim of the SEE to assess children’s preparedness for school and to identify deficits in their development. In addition to assessing social-emotional, cognitive and motor skills, the SEE also include a physical and medical examination, in which body height and weight are measured. The height and weight data and the classification of whether the child examined is overweight or obese are reported back to the respective parents and are thus mainly used for personal medical purposes. Some federal states regularly publish SEE data in the form of reports [3–6], dashboards [7, 8] or tables [9, 10]. In 2007, SEE data from the federal states on the prevalence of overweight and obesity in children starting school were researched nationwide and published for the first time [11]. A compilation and processing of the data for policy and (public health) research as well as for national health reporting has not yet taken place.

Overweight and, in particular, obesity in children and adolescents are associated with long-term adverse health outcomes such as type 2 diabetes and cardiovascular diseases [12]. In Germany, about 9% of children between the ages of three and six years are overweight, and about 2% are obese [13]. School enrolment age is considered to be a crucial time slot for the manifestation of obesity in children and adolescents [14]. The study ‘German Health Interview and Examination Survey for Children and Adolescents (KiGGS)’ was able to show that more than half of the children with overweight/obesity aged two to six years remain overweight or obese as adolescents. There are significant regional differences in the prevalence of obesity and its influencing factors [15]: According to a 2019 survey of federal states, between 8.1% and 13.0% of the children in SEE are overweight and between 2.8% and 6.0% of children are obese [16]. Within the framework of health monitoring, health risks, such as overweight and obesity, which are susceptible to appropriate action, are of central importance in the evaluation of the impact of interventions at population-level and the regular reassessment of the need for action.

The AdiRaum pilot project at the Robert Koch Institute (RKI) investigates the potential of SEE data for the description of obesity prevalences at small-scale level.

One project goal is to index the data from the SEE at county or district level and make it usable for nationwide health monitoring. The nationwide health monitoring’s task is to continuously monitor the development of disease incidences as well as the health and risk behaviour in Germany [17]. In addition, trends and changes in the health status are to be identified and analysed in relation to previous or future prevention measures.

Another aim of AdiRaum is to link the obesity prevalences available at small-scale level to additional geospatial information from publicly accessible sources and to present them visually. This is meant to enable the identification of similarities and differences in the prevalence of obesity at the time of the SEE at county level and to show possible correlations between the prevalence and regional influencing factors.

This paper describes the conceptual and practical procedure as well as the visualisation of the results using the prevalence of obesity at the time of the SEE for exemplary purposes.
2. Methods

AdiRaum was conducted from May to December 2022. Due to limited resources, the pilot project was tested with six federal states. This involved representatives from the health reporting departments of the states of Bavaria, Berlin, Brandenburg, Lower Saxony, North Rhine-Westphalia (NRW), and Saxony, as well as RKI staff. In the project, the merging of the small-scale SEE data as well as the linkage of this data to additional geospatial information was planned and implemented jointly with the federal states (see Figure 1).

2.1 Data from the school entrance examinations

The implementation of the SEE is regulated in federal state-specific manner. In order to be able to assess the extent to which the SEE data of the federal states are nevertheless comparable, similarities and differences in methodology and content of the SEE were identified in cooperation with the representatives of the federal states. This concerned, for example, the respective specifications for the recording of age, height and weight or examination periods and cut-off dates for school enrolment. The representatives of the health reporting departments of the participating federal states agreed to submit aggregated data on overweight and obesity to the RKI. The definition of overweight and obesity was based on the month-specific age- and sex-specific 90th and 97th percentiles according to Kromeyer-Hauschild [18]. For the pilot project, the years of enrolment 2015 to 2019 and, exclusively, data from initial examinations were selected. The reporting year corresponded to the year of enrolment. Counties merged during 2015 to 2019 due to regional reorganisation were adjusted to the most current county structure for the respective years. For uniform data transfer to the RKI, an Excel template was created in which the average age in months at the time of the SEE, the number of children examined and the number of children with overweight and obesity were to be entered for each county (rural county, independent city or district), year of age and sex.

2.2 Selection of contextual factors and indicators

Step 1: Selection of contextual factors

In AdiRaum, contextual factors were defined to be health-influencing factors that represent a person’s background [19]. On the one hand, contextual factors were taken into consideration that are relevant for the identification of counties that are similar in terms of settlement structure.
or sociodemographics. On the other hand, contextual factors that are relevant regarding the prevention of obesity at preschool age were considered. The selection was based on the topics that were identified in a systematic literature review in the AdiMon project (Population-wide monitoring of factors that influence childhood obesity) [20]. Additional factors relevant for the federal health reporting for the group of zero- to six-year-olds, such as from the context of child day care, were discussed and selected with the participating federal states.

Step 2: Selection of indicators
Indicators that are relevant for identifying counties with similar settlement structure or sociodemographics and for the prevention of obesity at preschool age were identified and selected through literature search. This was also based on the existing indicator system of AdiMon.

Step 3: Research and indexing of data sources
A review of databases providing the indicators free of charge and easily accessible was conducted in order to collect the data for the agreed indicators. If no information was available in the common, freely accessible databases, such as the Regionaldatenbank [21] or the INKAR database [22], the data were requested directly from data holders, such as regional sports confederations or Statistical Offices. If multiple similar indicators were available for a contextual factor or if several data sources were available for an indicator, the indicators were prioritised according to the Z.W.E.R.G. criteria (German abbreviation for importance, economic efficiency, simplicity, timeliness, accuracy) [23] and the characteristics periodicity, representativeness, regionalisability applied earlier in AdiMon. The corresponding data were then extracted from the available data sources or, occasionally, commissioned as special evaluations.

2.3 Visualisation of the results
For visualisation of the obesity prevalences, an interactive dashboard was created using TableauTM software, which enables the comparison of prevalences at county level (rural county, independent city or district) and differentiation by geospatial contextual factors. Dashboards can include various illustrations such as charts and maps and represent interactive, easily comprehensible, and user-friendly alternatives to tables. Besides free access and the ability to share the dashboard via a link, the requirement was that the data could be updated and expanded.

3. Results
3.1 Data from the school entrance examinations
Participating federal states submitted SEE data on overweight and obesity from 216 counties; no data were available from two counties only. One federal state was able to provide analysable data for 2015, one federal state for 2015 to 2018, and four federal states for 2015 to 2019. Four out of six federal states submitted data for children aged four to seven, two states for five- to six-year-olds. Data from the federal states were merged into one data set. Accordingly, a total of 1,627,949 children were examined. Considering the federal states’ confidentiality rules, 96.5% (1,570,568 children) with complete data were included in the analyses.
The confidentiality rules of the federal states aim to prevent re-identification of the examined children included and are applied when the number of examined children, the number of children with overweight or the number of children with obesity was below a state-specific defined threshold. In these cases, no data were reported to the RKI, but the number of children was reported in aggregated form: <3, <5, ≤5, or <10 depending on the federal state. If the number of examined children was below the respective threshold of the confidentiality rule, the children were excluded from the data set. If the confidentiality rule concerned the number of overweight or obese children, a value was imputed into the corresponding cell using the midpoint of the respective confidentiality rule, for example, if <5, a value of 2.5 was imputed.

The dashboard shows differences in the prevalence of obesity among children of school enrolment-age at county level. At county, independent city, and district levels, significant differences in prevalence were evident not only within but also between federal states. In the year of enrolment 2015 the average prevalence for all federal states was 4.0%, ranging from a lowest observed prevalence in one county of 0.5% to a highest prevalence of 8.4%.

3.2 Selected contextual factors and indicators

For AdiRaum, contextual factors were selected from the areas of settlement structure, sociodemographics or physical activity and food environment, and corresponding indicators were identified (see Table 1).

Data were not available for all context-related indicators for the five years of enrolment. For example, for the districts of Berlin the indicator ‘School leavers from general education schools: Proportion without secondary school certificate (in %)’ is only available for 2018 and 2019 in the Regionaldatenbank [21]. Moreover, the indicators that could be differentiated by age group differed in part with respect to their age limits (0–6 years, 3–5 years, or <6 years). For cost, time, and resource reasons within AdiRaum, the age reference of the corresponding indicator was retained and no uniform age limits were produced through special evaluations.

For visualisation of the results in the Tableau dashboard, the indicators had to be categorised. This was mostly done based on previously established stratifications of indicators of the Deutschlandatlas [24], AdiMon [20] and the Ländermonitor Frühkindliche Bildungssysteme of Bertelsmann Stiftung [25]. For five indicators, no corresponding reference was found in an internet search. In these cases, the median served as a threshold to form two categories (much/little). No geospatial indicators could be reflected for merged counties of Bavaria, as no corresponding data were available.

The selected indicators (Table 1) were linked to the SEE data set via the county or district name.
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### Table 1
Selection of context-related indicators of AdiRaum
Source: own table

<table>
<thead>
<tr>
<th>Subject area/Contextual factor</th>
<th>Indicator</th>
<th>Data source</th>
<th>Data access</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Settlement structure</strong></td>
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</tr>
<tr>
<td>Degree of urbanisation</td>
<td>Settlement-structural county types</td>
<td>Federal Institute for Building, Urban Affairs, and Spatial Development</td>
<td>Indicators and Maps of Spatial and Urban Development</td>
<td>Sparsely populated rural district</td>
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<td></td>
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<td></td>
<td>Rural district with initial densification</td>
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<td>Urban county</td>
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<td></td>
<td></td>
<td>Independent city</td>
</tr>
<tr>
<td>Regional deprivation</td>
<td>German Index of Socioeconomic Deprivation (GISD)</td>
<td>Robert Koch Institute</td>
<td>Robert Koch Institute</td>
<td>low</td>
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<tr>
<td></td>
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<td></td>
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<td>medium</td>
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<td>high</td>
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<tr>
<td><strong>Sociodemographics</strong></td>
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<tr>
<td>Poverty</td>
<td>Proportion of children in communities in need (SGB II) among children of the same age (in %) (^1)</td>
<td>Statistics of the Federal Employment Agency</td>
<td>Federal Employment Agency</td>
<td>≤5%</td>
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<td>5–&lt;10%</td>
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<td>10–&lt;15%</td>
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<td>≥20%</td>
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<tr>
<td>Education</td>
<td>School leavers from general education schools: Proportion without lower secondary school-leaving certificate (in %) (^1)</td>
<td>Statistics on the schools of general education</td>
<td>Regionaldatenbank</td>
<td>≤5.8%</td>
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<td>&gt;5.8%</td>
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<tr>
<td><strong>Physical activity and food environment</strong></td>
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<tr>
<td>Kindergarten</td>
<td>Proportion of children in all-day care (&gt;7h/day) among children of the same age (in %) (^1)</td>
<td>Statistics of child and youth welfare</td>
<td>Regionaldatenbank; Statistical Office Berlin-Brandenburg</td>
<td>≤20%</td>
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<td>20–&lt;40%</td>
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<td>40–&lt;60%</td>
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<td>60–&lt;80%</td>
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<td></td>
<td></td>
<td>≥80%</td>
</tr>
<tr>
<td>Kindergarten</td>
<td>Proportion of children receiving lunch among all children in care (in %) (^1)</td>
<td>Statistical Offices of the Federal States</td>
<td>German Federal Statistical Office</td>
<td>≤40%</td>
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<td>40–&lt;60%</td>
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<td></td>
<td>60–&lt;80%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>≥80%</td>
</tr>
</tbody>
</table>

\(^1\) refers to children between 0 and 5 years of age
\(^2\) Classification on the basis of the median as ‘much’ (value is above the median) or ‘little’ (value is below the median)
\(^3\) refers to children between 3 and 5 years of age
\(^4\) refers to children between 0 and 6 years of age
\(^5\) For Bavaria: refers to children between 0 and 5 years of age
SGB II = Second Book of the German Social Code

Continued on next page
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Table 1 Continued
Selection of context-related indicators of AdiRaum
Source: own table

<table>
<thead>
<tr>
<th>Subject area/Contextual factor</th>
<th>Indicator</th>
<th>Data source</th>
<th>Data access</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity and food environment</td>
<td>Number of playgrounds per 1,000 children(^2)(^4)</td>
<td>Open Street Map</td>
<td>Geo-Fabrik</td>
<td>≤16</td>
</tr>
<tr>
<td></td>
<td>Number of sports facilities per 1,000 children(^2)(^4)</td>
<td>Federal Agency for Cartography and Geodesy</td>
<td>Digital Basic-Landscape Model (Basic DLM)</td>
<td>&gt;16</td>
</tr>
<tr>
<td></td>
<td>Green spaces (ha) per 1,000 children(^2)(^4)</td>
<td>German Federal Statistical Office; Statistical Offices of the federal states</td>
<td>Regionaldatenbank</td>
<td>≤41</td>
</tr>
<tr>
<td>Sports activity</td>
<td>Number of memberships in sports clubs per 100 children(^4)(^5)</td>
<td>Regional sports confederations; Statistical Office Berlin-Brandenburg</td>
<td>Regional sports confederations; Statistical Office Berlin-Brandenburg</td>
<td>&lt;30</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>Number of paediatricians per 1,000 children(^2)(^4)</td>
<td>National Association of Statutory Health Insurance Physicians</td>
<td>Indicators and Maps of Spatial and Urban Development</td>
<td>≤0.4</td>
</tr>
</tbody>
</table>

\(^1\) refers to children between 0 and 5 years of age
\(^2\) Classification on the basis of the median as ‘much’ (value is above the median) or ‘little’ (value is below the median)
\(^3\) refers to children between 3 and 5 years of age
\(^4\) refers to children between 0 and 6 years of age
\(^5\) For Bavaria: refers to children between 0 and 5 years of age

SGB II = Second Book of the German Social Code

3.3 Visualisation in the Dashboard

For visualisation of the data, a dashboard was created with Tableau\(^\text{TM}\) software. In the dashboard the prevalence of obesity by rural county, independent city or district is shown on a map of Germany (Figure 2). The prevalence is shown colour-coded in five different categories (ranging from 0 to ≥8%). Individual counties can be selected manually. A pop-up window displays the name of the respective county, the number of children examined there, and the obesity prevalence. In addition to the map, column charts show the prevalence stratified by gender and year of enrolment, as well as by selected indicators. By setting filters, the prevalences shown in the map can be narrowed down by county according to these characteristics. Multiple filters can be selected. By selecting indicator categories, it is possible to display the prevalences of districts that are similar in terms of settlement structure, sociodemographics or physical activity and food environment on the map of Germany. In the current version of the dashboard, only one year can be stored for each indicator. It is possible to download selected prevalences.
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Linking the data to small-scale indicators enables regional analyses of obesity prevalence and cross-state comparisons of counties with similar settlement structure and sociodemographics.
Prevalences for different settlement-structural county types (sparsely populated rural county, rural county with initial densification, urban county, independent large city) or the degree of regional deprivation according to the German Index of Socioeconomic Deprivation (GISD) are displayed by selecting the appropriate filters. For example, the obesity prevalences of the 2015 school enrolment cohort ranged for sparsely populated rural counties from 2.1% to 8.4%, and from 1.5% to 6.7% for independent cities. The average obesity prevalence in 2015 was 3.3% in counties with488(539,473),(694,702)(694,488),(897,704)(897,478),(1100,701)(1100,488),(1293,701) low levels of deprivation, 4% in counties with medium levels of deprivation, and 5.2% in highly deprived counties. The release of the dashboard is currently being piloted and planned for mid-2023.

4. Discussion

In AdiRaum, it was possible for the first time to merge aggregated data from school entry examinations of several federal states using obesity prevalences on a small-scale level for exemplary purposes. In cooperation with representatives of health reporting departments of the states, the obesity prevalences in years of enrolment 2015 to 2019 of six federal states were merged at county or district level (if available), linked to context-related indicators, and interactively visualised in a dashboard.

AdiRaum piloted the merging of aggregated SEE data on county level from six federal states, thus went beyond mere data research on prevalences at the federal state level [11]. The feedback received from the representatives of the federal states showed that the data transfer was possible with little effort due to the agreements made beforehand and the provision of an Excel template. This made it possible to deliver the data to the RKI on time. Thus, data from complete age cohorts were available for these federal states.

Upon consolidation of the small-scale data on obesity from the SEE of various federal states, the indexing and linking of context-related indicators, and the presentation of the results in an interactive dashboard, findings are available that are discussed below in exemplary manner. On this basis requirements for a future continuation and expansion of the project are outlined before the selected method is discussed with regard to its limitations and strengths.

Indexing and use of context-related indicators

The majority of the context-related indicators were freely available in public data sources or could be obtained free of charge on request (sports club memberships) from the regional sports confederations and the Statistical Office Berlin-Brandenburg. Nevertheless, the effort required to index the indicators was not negligible. Indicators were available for different – albeit similar – age groups. For future use, special evaluations should be commissioned in order to align all indicators with regard to the parameter of age.

A major difficulty in the search for data sources was the selected regional depth (county level), at which data gaps were identified. For example, relevant indicators for obesity had to be excluded for Berlin districts due to a lack of availability at the small-scale level.

In order to better investigate the context of the living environment of children and adults, environmental indica-
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The SEE data are collected in a standardised manner, but inaccuracies in measurements and rounding by medical staff cannot be completely excluded. In the course of the project, it turned out that height and weight are measured in the SEE by the Child and Adolescent Health Services or through examinations for early detection of diseases (so called U9). This is done by paediatricians between 60th and 64th month of life [26]. This limits the comparability of the data and must be considered in the interpretation, as the implementation of the U9 is not standardised.

Interpreting the regional obesity prevalences and linking them to context-related indicators, it must also be kept in mind that the indicators at county level do not allow direct conclusions to be drawn, for example, about the actual residential environment or the socioeconomic background of the children, since the linked data are aggregated and not individual data. The regional diversity for the selected indicator within a county may be extensive. Based on the current availability of data for the indicators a differentiated consideration of the prevalences at municipality level cannot be realised by the RKI, but possibly by the counties and municipalities.

Although the period of the SEE data from 2015 to 2019 was jointly agreed with the federal states not all counties had data available for the entire period. This could be attributed, among other things, to the different timeliness of data compilation in the public health service of the respective federal states. Therefore, the planning of future projects must consider that the data of current years, in particular, may not be available in all states at the same time.
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Strengths
The SEE data aggregated on a small-scale level and the linkage to context-related indicators allowed analyses of the SEE at county level and the comparison of similar counties across state borders for the first time. The transfer of the data to the RKI and the indexing for public health research were successfully tested. In addition, the utilisation of the SEE data is a resource-saving option for a continuous, nationwide monitoring. The data represent a full survey of an, albeit limited, age group and are thus indispensable for assessing various aspects of child health. Among other aspects, the data can potentially be used for further research on the correlations between socioeconomic background and health of preschool children.

Outlook
Based on the visualisations in the dashboard and in addition to the brief presentation of results in this article, we plan to conduct further analyses and to publish the results together with the project partners. The focus is on the question of what role settlement structure and sociodemographic factors play in the differences in the prevalence of obesity among children of school enrolment-age at county level.

The participating federal states have expressed great interest in continuing the cooperation after completion of the project period and additional states have indicated interest in participating in a future project. An extension of the project to other federal states would bring the data base close to a nationwide full survey allowing living environment indicators to be mapped on a nationwide level. However, it can be assumed that in this case the diversity of the survey methods would increase, which would make the interpretation of the data more difficult. In the future the nationwide health monitoring could be extended to additional parameters of the SEE, provided that the data are collected in a uniform or comparable manner. In the pilot project, the analyses were focused on the prevalence of obesity. A future expansion to overweight – as a preliminary stage of obesity – or also underweight would be possible in this age group.

The SEE data are highly relevant for public health beyond the individual medical benefit. They are suitable to serve as a data basis for analysis of needs at county and district level and can be used in the future for targeted planning, implementation and evaluation of prevention measures and for detailed public health research on questions at population level. In this context, it should be examined whether uniform indicators for further parameters of the SEE can be developed in the future.

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Data protection and ethics
This study used aggregated data. The data owners are responsible for data protection and ethical issues.

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Conflicts of Interest
The authors declared no conflicts of interest.

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School entrance examinations as a small-scale data source for health monitoring of children using obesity as an example


School entrance examinations as a small-scale data source for health monitoring of children using obesity as an example
Respiratory infections in children and adolescents in Germany during the COVID-19 pandemic

Abstract

**Background:** Before the COVID-19 pandemic, acute respiratory infections (ARIs) in children were mainly characterised by three pathogens: respiratory syncytial viruses (RSV), influenza viruses and rhinoviruses. The impact of the COVID-19 pandemic and the measures taken in Germany (especially until the end of 2021) on the incidence of ARI in children and adolescents aged 0 to 14 years and the pathogens causing them has not yet been comprehensively analysed.

**Methods:** The evaluation is based on data from population-based, virological and hospital-based surveillance instruments up to the end of 2022.

**Results:** After the onset of the COVID-19 pandemic in early 2020, ARI rates remained almost consistently below pre-pandemic levels until autumn 2021, with only rhinoviruses continuously continuing to cause ARI. Only when the Omicron variant became predominant in 2022, there were measurable COVID-19 rates at population level in children, although COVID-19 hospitalisation rates remained comparatively low. RSV and influenza waves were initially absent and then occurred ‘out of season’, but were more severe than usual.

**Conclusions:** While the measures taken were effective in inhibiting the number of respiratory infections for almost 1.5 years, moderately frequent but rather mild COVID-19 cases occurred when measures were lifted. When Omicron emerged in 2022 COVID-19 became moderately frequent but led predominantly to mild illnesses. For RSV and influenza, the measures resulted in changes in their annual timing and intensity.

1. **Introduction**

Acute respiratory diseases are among the most common infectious diseases in childhood. They are mostly caused by viral pathogens with differences in the age group. Before the emergence of SARS-CoV-2 respiratory syncytial viruses (RSV) (Info box 1), influenza viruses (Info box 2) and rhinoviruses (Info box 3) dominated the epidemiology of acute respiratory diseases in children.

The activity of acute respiratory diseases in children had a distinct, typical annual course before the COVID-19 pandemic (faint grey curve in Figure 1). Only in the first three to four months of the year some variation in the activity of acute respiratory illnesses could be observed. Seasonal...
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Info box 1
Respiratory syncytial virus (RSV) infections
RSV infections occur seasonally, usually with a peak in incidence just before or after the turn of the year [1]. Although they can occur at any age, they clinically manifest as a typical illness in infancy and early childhood. By the second year of life, virtually all children have experienced a first infection with RSV, a large proportion even two of them [2]. The disease may be confined to the upper respiratory tract, but can also affect the lower respiratory tract (bronchiolitis, pneumonia or tracheobronchitis), especially in infants in their first months of life [3]. Febrile courses are frequent.

In December 2019, a cluster of pneumonia cases (including fatalities) with initially unknown causes occurred in Wuhan, China. The causative agent was identified as beta-coronavirus [12]. The virus and the disease it caused were later named SARS-CoV-2 and COVID-19, respectively [13]. Starting in January 2020 the first COVID-19 cases were diagnosed in Germany [14], and on 11 March 2020, the World Health Organization (WHO) declared the outbreak to be a pandemic [15].

Many countries around the world took – mostly – multiple complementary so-called non-pharmaceutical measures during the course of the pandemic, such as temporarily cancelling events with more than 1,000 participants [16]. In Germany, along with the first lockdown of the COVID-19 pandemic in week 12/2020 and the second lockdown in week 51/2020, daycare centres and schools were also closed. After six and eight weeks, respectively, the facilities were successively opened again [17], partly with restricted access and/or assigned fixed/divided groups.

Thus far, the impact of the COVID-19 pandemic on respiratory infections in children in Germany and the pathogens that triggered them have not been comprehensively analysed for the first three years of the pandemic, i.e. 2020–2022. There is a need to investigate to what extent the measures taken for COVID-19 and changes in everyday life may have changed the incidence of respiratory illnesses, or which pathogens have led to respiratory illnesses despite the measures taken. Furthermore, it is unclear how long possible changes in the incidence rates of pathogens lasted and whether or not there were any ‘catch-up effects’ later in the pandemic.

In this paper we assess and discuss the incidence of acute respiratory infections in children and adolescents aged 0 to 14 years during the COVID-19 pandemic, the pathogens that caused acute (and severe) respiratory infections in children, the pathogens that circulated concurrently, and the incidence of dual infections for the period of 2020–2022. We will focus on influenza viruses, RSV, rhinoviruses and, lastly, SARS-CoV-2.

2. Methods
2.1 Data basis
The data for the results shown here focus on children and adolescents (hereinafter ‘children’) between 0 to 14 years of age. For illustrative purposes, data from older age groups are occasionally included for comparison. We used data from the following surveillance instruments:

1. the population-based survey instrument GrippeWeb,
2. the Virological Surveillance of the German ‘Working Group for Influenza’ (Arbeitsgemeinschaft Influenza (AGI)),

Info box 2
Influenza
Influenza (common cold, flu) is caused by influenza viruses who are sub-divided into two types (influenza A and influenza B), with the influenza A viruses comprising two subtypes A(H1N1) and A(H3N2). Prior to the COVID-19 pandemic, influenza waves occurred seasonally, unless a novel influenza virus emerged in the population and led to pandemic spread, as was the case during the 2009 influenza pandemic caused by influenza virus A(H1N1)pdm09. Transmission of influenza virus from animals to humans occurs very rarely, but if so then through poultry or pigs. These cases are called zoonotic infections. Accordingly, a distinction is made between seasonal, pandemic and zoonotic influenza.

Continued on next page
Infobox 2 (Continued)
Influenza

Influenza affects all age groups. At the age of eight most children had at least one influenza A infection as can be shown through serological studies [4]. Between the child age groups either the 0- to 4-year-olds or the 5- to 14-year-olds have the highest incidence rate, depending on the season [5]. The incidence rate generally decreases with increasing age, but the probability of severe illness or illness requiring hospitalisation increases [5, 6].

(3) the ICD-10 code-based hospital surveillance of severe acute respiratory infections (ICOSARI).

The three systems have been described in detail by Goerlitz et al. [18]. GrippeWeb is an online portal of the Robert Koch Institute (RKI), where any person from the general population in Germany with a minimum age of 16 years can register. Parents with children younger than 16 years can report information on acute respiratory diseases for their children as well. Thus the entire age spectrum is covered. Participants report weekly whether or not they have had a new acute respiratory illness in the previous week. If this is the case further information on symptoms, among other items, is requested. For the analyses, acute respiratory illnesses (ARIs) are defined as acute illnesses of the respiratory tract with at least one of the three symptoms fever, sore throat or cough is reported. All ARIs with fever plus sore throat or cough are defined as ILI (influenza-like illness). Thus, ILI are a subgroup of ARIs. ‘Non-ILI’ are ARIs that do not meet the ILI definition, thus ILI + non-ILI = ARI.

To obtain population-based rates, data are adjusted for federal state, age group and sex. Current results from GrippeWeb are published weekly on the RKI website. In the analysis period 01. Jan 2020 – 31. Dec 2022 we received weekly reports from about 7,500–10,000 adults and children. The Virological Surveillance of the ‘Working Group for Influenza’ (Arbeitsgemeinschaft Influenza (AGI)) is a task of the National Reference Laboratory for Influenza (NRLI) at the RKI. For this purpose, a subgroup of physicians participating in the AGI take samples from the nose or throat of patients with acute respiratory illness. In addition, physicians collect and provide information about these patients’ respiratory symptoms. It is therefore possible to distinguish between patients with ILI and non-ILI. Samples and questionnaire are sent together to the NRLI, where they are tested for viral respiratory pathogens. These include SARS-CoV-2, influenza viruses, rhinoviruses and RSV.

In the hospital surveillance project ICOSARI the RKI works with approximately 70 sentinel hospitals throughout Germany within the framework of a scientific cooperation. Data on severe acute respiratory infections (SARI) are collected and sent to RKI via the network’s data centre. The system covers approximately 5 to 6% of all patients hospitalised in Germany. The data contain ICD-10 codes, with SARI being defined as inpatients with an ICD-10 code between J09 and J22 (influenza, pneumonia, other acute lower respiratory tract infections) in their main DRG diagnosis. Diagnosis-related groups (DRGs) refer to a classification system in which treatment cases are combined into case groups on the basis of certain criteria (ICD-10 codes). In addition, specific diseases such as COVID-19, influenza and RSV can be recorded via specific codes in the principal or secondary DRG diagnosis [19].

We analysed the different COVID-19 waves with dominance of certain SARS-CoV-2 variants (VOC – variants of concern) in the general population:

- Wild type from CW 10–20/2020 and CW 40/2020–08/2021,
- Alpha from CW 09–23/2021,
- Delta (a) from CW 31–39/2021,
- Delta (b) from CW 40–51/2021,
- Omicron BA.1 from CW 52/2021–08/2022,
- Omicron BA.2 from CW 09–21/2022,
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- Omicron BA.5 from CW 22/2022 until the end of the study period in CW 52/2022 [20, 21].

The influenza wave in the general population lasted in 2020 from CW 02–12 [22], in summer 2022 from CW 17–20 [23] and in autumn/winter 2022/2023 from CW 43/2022–CW 01/2023 [24]. The RSV wave in 2021 lasted from CW 35–50 [1], and in the 2022/2023 season it started in CW 41 and lasted until CW 03 [25].

2.2 Analyses and calculations

We used the ARI rate in the population collected via GripeWeb to calculate rates of ARI attributable to a particular pathogen (pathogen-specific ARI rates; Info box 4). This was done for the group of children (0 to 14 years) and partially also for adults (15 years and older), but also separately for the groups aged 0 to 4 years and 5 to 14 years. This allowed us to compare which pathogen-specific ARI rates were elevated in specific age groups.

We calculated the average number of ARI for consecutive six-month periods, starting with the autumn/winter half-year (CW 40/2017–CW 13/2018) and ending with the spring/summer half-year (CW 14–39/2022) in the age groups 0–4 years, 5–14 years and 15 years and older. For this purpose, we added up for each age group within the respective period the weekly number of SARIs for which the specific pathogen was detected: Influenza A(H3N2), influenza A(H1N1)pdm09, influenza B, RSV, rhinovirus, SARS-CoV-2, human coronavirus HKU1, human coronavirus NL-63, human coronavirus OC-43, human coronavirus 229E, parainfluenza virus type 1–4 (PIV) and human metapneumovirus (hMPV). We then compared the actual incidence to an expected incidence (Info box 5).

We assumed statistical significance if the calculated p-value was below 0.05 or if the (95%) confidence intervals did not overlap.

We thus calculated the cumulative number of illnesses hospitalised during a COVID-19 wave or a wave due to RSV or influenza by age groups (0–4, 5–14, 15–34, 35–59, 60–79 years and 80 years and older). For this purpose, we added up for each age group within the respective period the weekly number of SARIs for which the specific pathogen was coded via the ICD-10 code in the main or secondary diagnosis and extrapolated to the whole of Germany.

We used demographic data of the German population of the Federal Statistical Office with data status 31 Dec 2021 to calculate weekly rates, which are presented as a percentage of the population. A rate of e.g. 1% corresponds to an incidence of 1 per 100 residents or 1,000/100,000 residents.
3. Results

3.1 Respiratory infections in general and pathogen-specific ARI rates

Figure 1 shows the course of ARI or ILI rates in children up to 14 years of age (recorded by the GrippeWeb portal) in the period from CW 01/2020 to CW 52/2022 compared to pre-pandemic years. Figure 2 shows the proportion of the ARI rate that was caused by the respective pathogens.

At the start of the pandemic (around week 10/2020), ARI activity was roughly the same as expected from the respective weeks in the pre-pandemic years. After the first lockdown (CW 12/2020), both ARI and ILI rates dropped to very low levels. After the end of the first COVID-19 wave (CW 20/2020; [27]) and the gradual relaxation of many containment measures, rhinoviruses began to circulate again in May/June 2020 and the ARI rate in children rose to pre-pandemic levels (Figure 1). From around CW 37/2020 the ARI rate deviated again from the usual pre-pandemic course as it did not reach the usual early autumn peak, but gradually declined to very low levels by the end of the year. In the winter of 2020/2021, the usual wave of influenza in the first three to four months of the year was absent, as was the RSV wave. Rhinoviruses, in particular, continued...
to cause respiratory illnesses during this period and until the middle of 2021 (Figure 2).

In the early summer of 2021 as well as in the (early) summer of 2022, parainfluenza viruses circulated in children in addition to rhinoviruses, in the spring of 2022 human metapneumoviruses circulated also; the somewhat pronounced circulation of some endemic coronaviruses such as NL63 and OC43 in 2021 and 2022, on the other hand, does not seem to have had a major impact on ARI rates (Figure 2, PIV, hMPV and endemic coronaviruses are summarised under ‘other pathogens’).

The ARI rate in children increased rapidly after the usual low level in the summer (week 32/2021). This was accompanied by the start of a strong RSV wave in CW 35/2021 outside the usual season, to the extent that the early autumn peak of the ARI rate observed in pre-pandemic years was clearly exceeded in CW 36/37. Along with the onset of the fourth COVID-19 wave dominated by VOC Delta, illnesses with SARS-CoV-2 infections became detectable at population level for the first time in children, i.e. about 0.5% of children contracted COVID-19 on a weekly basis (light blue area in Figure 2).

From around week 46/2021 onwards, the ARI rate began to decline steadily again and was below pre-pandemic levels – similar to 2020, but less marked. After the onset of the Omicron wave (subvariants BA.1 and then BA.2 between January and April 2022), COVID-19 affected children to a clearly detectable degree. At least 1 to 2% of children contracted COVID-19 every week (Figure 2) during these four months. Nevertheless, respiratory illnesses caused by rhinoviruses also occurred at least as frequently as those caused by SARS-CoV-2 during this period (light grey area, Figure 2). During that time, the ARI rate did not exceed the values observed in pre-pandemic RSV or influenza waves in the months of January to March.

In May (CW 17–20/2022), there was a mild and short influenza wave, and from May/June 2022 (from about CW 21/2022), the BA.5 subvariant of Omicron also caused weekly illnesses again in children at a level of up to 1.3%. Even at the time of the lowest level of the year (while summer vacations of most federal states were ongoing), ARI activity was somewhat higher than usual (Figure 1). In late summer, rhinoviruses were the first to cause a steep rise...
In the winter of 2020/2021, the usual influenza wave normally occurring in the first three to four months of the year was absent, as was the RSV wave.

3.2 Seasonal individual ARI frequency and multiple infections in ARI in different age groups

The mean number of ARI decreased with increasing age in all half-years from 2017–2022, and was – before the pandemic – about 1.5–2 times higher in the autumn/winter season (CW 40–CW 13) than in the spring/summer half-year (CW 14–CW 39; Figure 4) in all age groups. Children aged 0–4 years had an average of about 3–4 ARI in the autumn/winter half-year, while 5- to 14-year-olds had just under 2 ARI and adults approximately 1.3 ARI. Upon the start of the pandemic, the average number of respiratory infections decreased sharply in all age groups, but then rose again and almost reached the pre-pandemic level again in the autumn/winter half-year 2021/2022 (CW 40/2021−CW 13/2022).

Table 1
Proportion of all ARI due to different respiratory pathogens in 0- to 1-year-olds; sorted in descending order (period 2020–2022; proportion adjusted for ILI and non-ILI)

<table>
<thead>
<tr>
<th>Pathogen</th>
<th>0–14 years of age</th>
<th>Pathogen</th>
<th>0–14 years of age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhinovirus</td>
<td>25.3%</td>
<td>RSV</td>
<td>10.5%</td>
</tr>
<tr>
<td>Influenza (all)</td>
<td>11.5%</td>
<td>Parainfluenza virus</td>
<td>8.1%</td>
</tr>
<tr>
<td>RSV</td>
<td>10.5%</td>
<td>hMPV</td>
<td>4.4%</td>
</tr>
<tr>
<td>Influenza A(H3N2)</td>
<td>8.9%</td>
<td>SARS-CoV-2</td>
<td>4.4%</td>
</tr>
<tr>
<td>Parainfluenza virus</td>
<td>8.1%</td>
<td>Coronavirus OC43</td>
<td>2.7%</td>
</tr>
<tr>
<td>hMPV</td>
<td>4.4%</td>
<td>Coronavirus NL63</td>
<td>2.2%</td>
</tr>
<tr>
<td>SARS-CoV-2</td>
<td>4.4%</td>
<td>Influenza A(H1N1)</td>
<td>1.5%</td>
</tr>
<tr>
<td>Coronavirus OC43</td>
<td>2.7%</td>
<td>Influenza B</td>
<td>1.1%</td>
</tr>
<tr>
<td>Coronavirus NL63</td>
<td>2.2%</td>
<td>Coronavirus HKU1</td>
<td>0.9%</td>
</tr>
<tr>
<td>Influenza A(H1N1)</td>
<td>1.5%</td>
<td>Coronavirus 229E</td>
<td>0.4%</td>
</tr>
<tr>
<td>Influenza B</td>
<td>1.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coronavirus HKU1</td>
<td>0.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coronavirus 229E</td>
<td>0.4%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Dual infections with the viruses examined in the NRLI occurred between 2020 and 2022 mainly in 0- to 4-year-old children, at about 12% (Figure 5). However, infections by more than two of the pathogens examined in the pathogen panel were rare even in this age group. In children aged five years and older, the proportion of co-infections was about 5%.

RSV and rhinoviruses both circulated concurrently at the end of 2021; the incidence of rhinovirus-RSV co-infections among 0- to 4-year-olds during this period was roughly in line with the expected incidence (Figure 6), while the actually observed incidence of influenza-RSV co-infections at the end of 2022 among 0- to 4-year-olds was below the expected incidence by a factor of 5 (Figure 7). Likewise, rhinovirus-SARS-CoV-2 co-infections did not occur as frequently as expected from theory for 0- to 4-year-olds between CW 01 and CW 16/2022 (not shown).
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Towards the end of 2021 – the COVID-ARI rate increased for the first time to about 0.5% (Figure 8). In the first four months of 2022, the predominant subvariants were Omicron BA.1 and BA.2. During this time the COVID-ARI rate in children increased to more than 2.0% and was clearly higher than the COVID-ARI rate in adults. This scenario reversed when Omicron subvariant BA.5 became predominant in two waves with one peak in CW 26/2022 and one in CW 37 (children) or CW 39 (adults). According to this estimate, approximately 6% of 0- to 14-year-old children were affected by COVID-ARI cumulatively from the beginning of the pandemic until the end of 2021, approximately 38% by the end of June 2022 and 53% by the end of 2022 (squares in Figure 8).

3.3 COVID-19

COVID-19 rate in children with symptoms of acute respiratory infection

The rate of COVID-19 plus ARI (COVID-ARI rate) among children aged 0 to 14 calculated via GrippeWeb and from the data of the virological surveillance remained at a low level, i.e. well below 0.5%, until the fourth wave with the predominant Delta variant. During the Delta (b) wave – towards the end of 2021 – the COVID-ARI rate increased for the first time to about 0.5% (Figure 8). In the first four months of 2022, the predominant subvariants were Omicron BA.1 and BA.2. During this time the COVID-ARI rate in children increased to more than 2.0% and was clearly higher than the COVID-ARI rate in adults. This scenario reversed when Omicron subvariant BA.5 became predominant in two waves with one peak in CW 26/2022 and one in CW 37 (children) or CW 39 (adults). According to this estimate, approximately 6% of 0- to 14-year-old children were affected by COVID-ARI cumulatively from the beginning of the pandemic until the end of 2021, approximately 38% by the end of June 2022 and 53% by the end of 2022 (squares in Figure 8).
Severe courses of disease

The cumulative incidence of severe acute respiratory infections (SARI) diagnosed with COVID-19 was lowest among 5–14 year old children in all phases of the pandemic (Figure 9). Among children between 0 and 4 years of age, the cumulative COVID-SARI incidence was higher than in 5- to 14-year-old children, but clearly lower than among adults aged 60 to 79 years or even older. Among 0- to 4-year-olds and 5- to 14-year-olds, the cumulative incidence was highest during the predominance of Omicron subvariants BA.1 and BA.2 at the start of 2022, at 0.4% (corresponding to 40 COVID-SARI cases per 100,000 residents) and 0.1% (corresponding to 10 COVID-SARI cases per 100,000 residents), respectively.

Figure 10 shows how often children were affected by severe respiratory illness with a COVID-19 diagnosis (i.e. hospitalisation). This is compared to the burden of disease of severe acute respiratory illnesses caused by other pathogens that circulated in 2020–2022 and frequently resulted in SARI. For this purpose, we compared the cumulative rate (incidence per 100 residents) during the Omicron-BA.1/BA.2 waves to the cumulative SARI rate of the (abbreviated) influenza wave in 2020, the RSV waves in 2021 and 2022, and the influenza wave in 2022 (Figure 10). It was evident that the RSV waves led to the highest cumulative rates in 0- to 4-year-olds (dark blue bars in Figure 10), whereas the influenza waves led to the highest cumulative rates in 5- to 14-year-olds (blue bars in Figure 10). The cumulative rates of the 5- to 14-year-olds are lower than those of 0- to 4-year-olds for all pathogens and in all waves. Whereas an average of 0.5% of 0- to 4-year-old children was hospitalised for RSV in winter between 2014/2015 and 2019/2020 before...
In the period studied (2020–2022) a quarter of the children experienced a respiratory illness due to rhinovirus followed by influenza viruses and RSV.

After the start of the pandemic, this increased significantly by a factor of 2.2 to 1.1% in the 2021 RSV wave. Likewise, in 2022 (CW 41–CW 52/2022), the proportion of 0.9% was 1.8-fold higher as compared to an average pre-pandemic RSV wave (the difference is also significant; not shown). Similarly, the influenza wave at the end of 2022 resulted in higher rates of SARI due to influenza in children between 0 and 4 years of age and between 5 and 14 years of age than in the six pre-pandemic seasons (not shown).

4. Discussion

The present analysis compiles data not only for SARS-CoV-2 but also for the other major respiratory pathogens to investigate how the epidemiology of respiratory illnesses in children has changed in the three pandemic years from 2020–2022. Children’s ARI rates remained almost consistently below the ARI rates that would have been expected based on previous years over a period of approximately 1.5 years after the start of the pandemic. While rhinoviruses continued to lead to ARI after a short break, the usual wave of influenza occurring in the first three to four months of the year was absent in winter 2020/2021, as was the RSV wave.

In autumn 2022, there was an almost simultaneous, premature RSV and influenza wave leading to very high ARI rates. COVID-19 did not lead to measurable morbidity in children at population level until the emergence of the Omicron variant (from 2022), but even then the hospitalisation rate remained comparatively low.

Since the beginning of the pandemic the course of the ARI rate in children differed substantially in almost all phases from the course known from pre-pandemic years. The greatest similarities in terms of trend and incidence were observed for just a few weeks during the usual low-incidence phases in summer 2020 and 2021. The at times extensive contact reduction measures (during the first lockdown including school closures, or, during the second lockdown including school closures, split and alternating class
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COVID-19 did not lead to measurable morbidity in children at population level until the emergence of the Omicron variant (from 2022), but even then the hospitalisation rate remained comparatively low.

attendance, systematic testing in schools (and day-care centres), wearing of masks and the spatial or temporal separation of groups) and the responsible behaviour in the population effectively reduced ARI rates and thus the transmission of any respiratory pathogens over an extended period of time.

Initially (from around May/June 2020), rhinoviruses were the only pathogens that still seemed to cause respiratory illness. This was analysed and described early on in a more detailed review [8]. Possible explanations that were discussed included that rhinoviruses are transmitted more than other viruses via fomite and contact infection or also that masks prevent the transmission of rhinoviruses via droplets or aerosol less effectively than other viruses [8]. The almost complete ‘suppression’ of RSV and influenza virus transmission in the winter of 2020/2021 resulted in an increasing proportion of susceptible, immune naive young children over time. In the two RSV waves in 2021 and 2022, the proportion of children between 0 and 4 years of age admitted as inpatients with an RSV diagnosis (2021: 1.1%; 2022: 0.9%) was about twice the average of the pre-pandemic waves in the years between 2014/2015 and 2019/2020 (average 0.5%). The extent to which the increased incidence of RSV illnesses had an impact on the number of very severe courses, especially cases of bronchiolitis in infants, needs to be explored by further analyses. In France, the RSV wave shifted as well, but started already in spring 2021 and the peak of the disease was not as high as usual [28, 29]. An increased unusually timed circulation of influenza virus in May 2022 failed to build up to an influenza wave to a degree as commonly observed. Likewise, the next RSV wave starting in October 2022 in Germany began unusually early. This was also consistent with the results from several European countries [30]. An aggravating factor – consistent with the scenario in Germany – was the parallel and very early co-circulation of (RSV and) influenza viruses [30]. In Germany, the influenza wave at the end of 2022 led to a higher influenza-related SARI rate in both age groups of children than in the entire six pre-pandemic seasons. In summary, it can be concluded that, especially after the absence of RSV waves and influenza waves, stronger and earlier waves occurred compared to pre-pandemic years. As these waves also occurred – at least at the end of 2022 – simultaneously, this led to hardly manageable challenges for the health care system [31].

It is evident from our analyses that the incidence of respiratory illnesses depends above all on age and season. On average, young children experience approximately 3–4 ARI on average, systematic testing in schools (and day-care centres), wearing of masks and the spatial or temporal separation of groups) and the responsible behaviour in the population effectively reduced ARI rates and thus the transmission of any respiratory pathogens over an extended period of time. At the beginning of each COVID-19 wave, the highest incidence of COVID-19 cases reported to the RKI (via the mandatory reporting system) was consistently observed in adolescents or young adults first and only in the weeks thereafter in the neighbouring age groups, i.e. older adults and (young) children [32–35]. Thus, after the third year after its appearance COVID-19 has not (yet) developed into a disease that – unlike many other infectious respiratory diseases – receives its impulse and momentum from child age groups.
The incidence of viral co-infections was particularly high in infants in the analysed period and decreased clearly after the age of 5 years (Figure 5). Similar findings were also observed prior to the COVID-19 pandemic, e.g. by Mandellia et al. [36] detecting an even more pronounced difference between under-18-year-olds and adults (factor of 7 [36] vs. factor of 3 in our results) in an analysis of data from 2013–2018. However, this might be related to the different time periods (with different pathogen incidences) and boundary conditions. It is interesting to note that the actual co-infection incidence in this age group does not always correspond to the expected incidence, i.e. extensive co-circulation of two pathogens does not mean that dual infections by these two pathogens occur as frequently as expected. There could be many reasons for the fact that the combination of rhinovirus + RSV in 0- to 4-year-olds during the last quarter of 2021 roughly corresponds to the expected incidence (Figure 6), but the combination of influenza + RSV, for example, falls clearly short (Figure 7). It is possible that rhinovirus or RSV infections are generally not severe enough that the affected child is excluded from the social network for an extended period of time and is thus almost continuously exposed to the infection pressure of the second pathogen as well. Conversely, it is possible that the regional distribution is inhomogeneous, and finally, blocking mechanisms at the cellular level might also play a role [37, 38]. Greer [26] had indicated that RSV and rhinovirus infections are significantly less frequent than expected, however, he also found that the negative correlation was much weaker when the analysis was restricted to certain age groups, e.g. infants. Therefore, we limited our analyses to 0- to 4-year-old children from the very beginning. A relevant question is whether or not children with co-infections also have more severe courses of disease. In that regard a systematic review in 2020 of publications up to 2019 investigating co-infections with RSV found no evidence for more severe courses of disease, although co-infections by RSV and hMPV may be an exception [39].

Since the onset of the COVID-19 pandemic, there has been evidence that the severity of the COVID-19 disease was clearly lower in children than in (older) adults [40]. Scientific studies suggest that this is related to innate immunity, which responds immediately to the virus at the local (anatomical) level, for example through cells of the nasal mucosa [41, 42]. Cross-protection by infection with other human coronaviruses that have been circulating seasonally for a long time, e.g. NL63, HKU1 or OC-43, which frequently affect children under five years of age, has also been suggested [43, 44]. Although the susceptibility of children to SARS-CoV-2 infection (measured, for example, via the household attack rates) increased from the Alpha variant onwards [45, 46], it was not until the phases of the Delta (b) wave (in the second half of 2021) and during the Omicron BA.1 and BA.2 waves (in the first four months of 2022) that there was a significant increase at population-level reaching a low percentage level of SARS-CoV-2 infections in children with ARI symptoms. Nevertheless, the comprehensive testing of children in daycare and school settings conducted in the second half of 2021 and first half of 2022 may have resulted in children with COVID-19 visiting a doctor’s office less frequently. This, in turn, may have caused the proportion of children with COVID-19 in the virological surveillance sample to be underrepresented and consequently it is possible that we underestimated the...
COVID-ARI rate. In addition, especially in children, the symptoms were sometimes so mild that the ARI definition used in GrippeWeb (experience of cough, sore throat or fever) was not met. As a result, the COVID-ARI rate did not include asymptomatic children, but also children with very mild COVID-19 symptoms were not taken into consideration. Asymptomatic SARS-CoV-2 infections were particularly common in children: according to one review article, the proportion of asymptomatic infections was highest in school-age children (at 36%) and steadily decreased with older ages [47]. Indeed, estimates from a Bavarian seroprevalence study [48] in children and adolescents aged 1–17 years at the end of 2021 and after the first half of 2022 were 20% and 74%, respectively, which is clearly higher than our calculated cumulative COVID-ARI rates in children of 6% and 38%, respectively, at the same points in time. In adults, on the other hand, a seroprevalence of anti-spike antibodies of at least 90% was already detectable towards the end of 2021 [49]. Antibodies against the spike protein are produced by the immune system either after an infection or after a vaccination. It was interesting to note that as early as during the two Omicron BA.5 waves (that followed the BA.1 and BA.2 waves) the COVID-ARI rate was again higher in adults than in children. This suggests that (possibly multiple) exposures of the immune system to the virus or its components (antigens) had led to a stronger or longer lasting immune reaction in children than in adults.

Limitations
A limitation of our analyses is that the participants in GrippeWeb can generally be considered to be rather health-savy. Nevertheless, it has been shown that comparable data from GrippeWeb were – also quantitatively – quite consistent with those from the sentinel surveillance system using data from primary care physicians (Working Group for Influenza (Arbeitsgemeinschaft Influenza)) and can therefore be considered trustworthy [50]. Another possible limitation is the calculation of pathogen-specific ARI rates is based on the pathogens detected in virological surveillance. Thus, data from two systems (firstly, ARI consultations in the outpatient setting, and secondly, the GrippeWeb population reporting data independent of a doctor’s visit) are combined. However, we took into account the differences that may arise from different consultation behaviour of individuals affected by ILI and non-ILI by adjusting for ILI and non-ILI rates. This allowed us to calculate population-based estimates of pathogen-specific ARI rates. A third limitation is that the calculation of the expected incidences of co-infections assumes that infections with the individual pathogens occur independently of each other and are evenly distributed throughout Germany. As a fourth limitation, it could be mentioned that the cumulative SARI rates due to certain pathogens do not include information on vaccinations. However, this was not intended as the rates shown here are meant to reflect exactly what occurs in the population regardless of vaccination.

Conclusion
Respiratory infections occurred much less frequently than usual in children during the COVID-19 pandemic as a result of contact-reducing and transmission-inhibiting measures over a period of approximately 1.5 years. Whereas rhinoviruses spread continuously again, COVID-ARI rate. In addition, especially in children, the symptoms were sometimes so mild that the ARI definition used in GrippeWeb (experience of cough, sore throat or fever) was not met. As a result, the COVID-ARI rate did not include asymptomatic children, but also children with very mild COVID-19 symptoms were not taken into consideration. Asymptomatic SARS-CoV-2 infections were particularly common in children: according to one review article, the proportion of asymptomatic infections was highest in school-age children (at 36%) and steadily decreased with older ages [47]. Indeed, estimates from a Bavarian seroprevalence study [48] in children and adolescents aged 1–17 years at the end of 2021 and after the first half of 2022 were 20% and 74%, respectively, which is clearly higher than our calculated cumulative COVID-ARI rates in children of 6% and 38%, respectively, at the same points in time. In adults, on the other hand, a seroprevalence of anti-spike antibodies of at least 90% was already detectable towards the end of 2021 [49]. Antibodies against the spike protein are produced by the immune system either after an infection or after a vaccination. It was interesting to note that as early as during the two Omicron BA.5 waves (that followed the BA.1 and BA.2 waves) the COVID-ARI rate was again higher in adults than in children. This suggests that (possibly multiple) exposures of the immune system to the virus or its components (antigens) had led to a stronger or longer lasting immune reaction in children than in adults.

Limitations
A limitation of our analyses is that the participants in GrippeWeb can generally be considered to be rather health-
time, the RSV and influenza waves did not occur in the autumn-winter season of 2020/2021. The (almost simultaneous) RSV and influenza wave in the last quarter of 2022 started earlier and were stronger than was common before the pandemic. Whether this ‘catch-up effect’ reduced the incidence of particularly severe manifestations, especially of bronchiolitis in infants, must be investigated by further, more in-depth analyses and, if necessary, through the inclusion of other systems. Only after the emergence of the Omicron variant did SARS-CoV-2 lead to infection in about half of the children and this occurred over a short period of time, but even then illnesses requiring hospitalisation remained rare compared to RSV or influenza waves. Future developments will show whether COVID-19 will become a ‘children’s disease’ or if the highest incidences and more severe illnesses will occur primarily in adults.

Data protection and ethics
The surveillance instruments were coordinated with the data protection officers of the Robert Koch Institute with regard to collection and management. The data protection regulations of the EU Data Protection Regulation (DSGVO) and the Federal Data Protection Act (BDSG) were met. The Ethics Committee of the Charité agreed with procedures used for virological surveillance; the patients declare their written consent to sample collection.

Availability of data
The publication of aggregated data is in preparation.

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Conflicts of interest
The authors declared no conflicts of interest.

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Respiratory infections in children and adolescents in Germany during the COVID-19 pandemic

What is the health status of girls and boys in the COVID-19 pandemic? Selected results of the KIDA study

Abstract

Background: It is well known that there are gender differences in the health behaviour and physical and mental health of children. The COVID-19 pandemic influenced the health and lifestyles of children and adolescents by changing their living conditions. The present work investigates whether gender differences in selected health indicators are evident more than two years after the onset of the pandemic.

Methods: In the study Kindergesundheit in Deutschland aktuell (KIDA) (German Children’s Health Update), cross-sectional telephone surveys were conducted with parents of 3- to 15-year-olds (n=3,478). Parental information on the general and mental health of the child, on increased need for health care and mental health services, as well as on physical activity and utilisation of sports activities were queried in standardised manner. Gender differences were assessed using Chi² tests.

Results: A total of 91% of the girls and 92% of the boys had their general health assessed as being (very) good by their parents (difference not significant, n.s.). An increased need for care and support was indicated for 10.6% of the 3- to 15-year-olds (girls: 9%, boys: 12%, n.s.). Boys met the physical activity recommendations of the WHO significantly more often (60%) than girls (54%). Good to excellent mental health was reported for 93% of both boys and girls. When changes during the pandemic were reported, no differences were found in the responses for girls compared to boys.

Conclusions: Gender differences were found for individual parameters and age groups. These differences must be assessed in the context of other social determinants of health, and need to be considered when planning preventive measures.

Child and Adolescent Health · Gender · COVID-19 Pandemic · Physical Activity · Mental Health

1. Introduction

In late 2019, the novel coronavirus (SARS-CoV-2) was identified, resulting in a multi-year pandemic. To reduce the risk of disease by contracting SARS-CoV-2, governments around the world implemented varying containment measures, ranging from recommendations to wear a face mask, social distancing measures, to broader lockdowns as well as school and daycare closures, depending on the phase of the pandemic [1]. In the course of the COVID-19 pandemic, these measures repeatedly led to a variety of changes in the living conditions of children and adolescents, such
What is the health status of girls and boys in the COVID-19 pandemic? Selected results of the KIDA study

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as short-term closures of schools and day-care centres, restrictions on contact with classmates or friends, as well as on leisure activities and social activities. As such, these mitigation measures also influenced the physical and mental health and health behaviour of children and adolescents [2–9]. Delivery of medical care was also repeatedly limited, for the purpose of infection control or due to capacity bottlenecks caused by the pandemic. Further negative factors influencing health could have been caused by family distress, such as when jobs were lost in context of the COVID-19 pandemic, with low-income parents more likely to be affected [10–12]. Long-term effects on children’s health may also result if children or family members experience severe SARS-CoV-2 infection of and if symptoms persist for a long time (so-called post-COVID syndrome) [13, 14].

We know from studies conducted before the COVID-19 pandemic that there are gender-related differences in the health behaviour and physical and mental health of children and adolescents. For example, the KiGGS study showed that girls are generally healthier in childhood – both in terms of parent-reported general health and disease frequencies – and exhibit healthier behaviour than boys. In adolescence, on the other hand, the physical and mental health status of female adolescents tends to be worse than that of their male counterparts, as they experience stress more often and engage less in sports activities. However, they have a healthier diet than male adolescents [15–18]. These gender differences are due not so much to biological factors, but rather to different living conditions of boys and girls, whereby gender-related socialisation, gender roles and images and thus associated expectations of femininity and masculinity are also of crucial importance [17].

Gender-related differences are also evident in leisure activities and social interactions [19, 20]. As some of these areas were significantly affected by the COVID-19 pandemic, differences in the effects on girls and boys can be expected. Previous studies also point to age- and gender-related differences in the response to stressors [21]. Against this backdrop, it is important to investigate whether gender differences exist with regard to various health outcomes in the current pandemic scenario. For example, results of a study from Germany on mental health show that a greater proportion of girls had a reduced health-related quality of life during the COVID-19 pandemic as compared to boys [3, 4]. Several studies on physical activity of children have shown that boys reduced their physical activity more than girls during the pandemic [22, 23]. This may be due, for example, to the fact that boys are more likely to participate in organised team sports, which were temporarily suspended during the pandemic.

The fact that everyday life is largely shaped by the infection scenario and, at times, by containment measures was considered a temporary exceptional situation at the onset of the pandemic. However, as the COVID-19 pandemic continued over several years, this situation has become the ‘new normal’. Many children have now spent a large part of their lives in the pandemic. Some effects caused by containment measures may be receding; for example, it is conceivable that children’s physical activity behaviour may return to normal as daycare centres, sports fields and sports clubs reopen. Other health changes, such as an increase in anxiety symptoms or an increased need for medical care, may have become more permanent. It therefore seems sensible to survey the health status of children

KIDA
Survey on children’s health in Germany (German Children’s Health Update)

Data holder: Robert Koch Institute

Objectives: provision of reliable information on the physical and mental health status and health behaviors of children and adolescents aged 3 to 17 years.

Study design: nationwide cross-sectional telephone survey and follow-up in-depth online survey

Population: parents of children aged 3–15 years and adolescents aged 16–17 years who are integrated in the ongoing GEDA study.

Sampling: random sample of landline and mobile phone numbers (dual frame method) from the sampling system of the ADM (Arbeitskreis Deutscher Markt- und Sozialforschungsinstitute e.V.)

Sample size: approx. 7,000 participants

Study period: February 2022 – June 2023

Further information in German is available at www.rki.de/kida
and adolescents as a status quo after approximately three years of the pandemic and to continue monitoring it in the future, including in a post-pandemic phase.

The investigation of age- and gender-related differences in health status during the COVID-19 pandemic is important in order to be able to develop effective interventions for now and also in the future that are adapted to the special circumstances of boys and girls in various age groups in epidemiologically significant social scenarios or crises [24–26]. Health promotion and prevention should not be ‘gender-blind’ in childhood and adolescence, but rather should take into account the possibility of boys and girls having special needs. This can be implemented in various ways, for example by approaching adolescent boys and girls differently in educational campaigns [27], or through gender-homogeneous offers in areas such as sports or healthy nutrition [28]. In environmental and structural approaches, e.g. in school settings, attention should also be paid to whether or not both genders benefit equally [29]. If, for example, new sports and play areas in the school’s playground are mainly used by (athletic) boys, and girls are not given the opportunity to be active there, gender differences are increased rather than diminished [29]. Health promotion measures should therefore be targeted to reduce gender-related health inequalities. For this purpose, it is important to recognise existing inequalities.

Therefore, data from the Kindergesundheit in Deutschland aktuell (KIDA) (German Children’s Health Update) study, which was collected from February – October 2022 from parents of children and adolescents between 3 and 15 years of age, were analysed with regard to gender-related differences. The following questions are in focus of this article:

Are there differences between boys and girls in terms of:

- general health and subjective mental health?
- need for care and support?
- physical activity and utilisation of physical activity programmes?

In part, we will also consider whether those gender-related differences that were already described for children and adolescents in pre-pandemic times continue to exist, and whether changes observed during the COVID-19 pandemic concern girls and boys to the same extent.

2. Methods
2.1 Study design and study procedure

Within the framework of the Kindergesundheit in Deutschland aktuell (KIDA) (German Children’s Health Update) study, continuous (cross-sectional) telephone surveys were conducted from February to October 2022. The part of the populace living in private households with children and adolescents between 3 and 15 years of age who stated Germany as their current usual place of residence served as the base population of the study. In each case, one parent was interviewed about the health of the children, i.e. all information about the health situation of the children and adolescents was collected on a parent-reported basis. KIDA was embedded in the Gesundheit in Deutschland aktuell (GEDA 2022) study [30]. GEDA is a telephone survey of the adult populace living in Germany that is representative of the population and has been conducted regularly since 2008. For the sampling, the telephone sampling system of
What is the health status of girls and boys in the COVID-19 pandemic? Selected results of the KIDA study

The Arbeitskreis Deutscher Markt- und Sozialforschungsinstitute e.V. (ADM) is used based on two selected populations: a mobile phone population and a fixed network population. Based on this access, all persons with children between 3 and 15 years of age living in the household as well as adolescents aged 16 years and older are included for participation in the telephone survey of the KIDA study. The survey was conducted using a standardised questionnaire. The responses of the participants were recorded in computer-aided manner by trained interviewers using the ‘VOXCO Interviewsuite’ software. Data for up to two children or adolescents living in the household were obtained for KIDA. For households with more than two children, the selection of the children to report on was random. Information on two children or adolescents from the same family was taken into account in the design and adjustment weighting via a household variable.

2.2 Indicators

For recording of the internationally established indicator of general health, parents were asked in accordance with a recommendation of the World Health Organisation (WHO) [31]: ‘How would you describe your child’s state of health in general?’ [32] The parents responded using a five-point scale, which was combined into the categories of ‘very good/good’ and ‘average/bad/very bad’ for the present evaluations.

Parent-reported subjective mental health was measured by an established single item [33]: ‘How would you rate your child’s mental health in general?’ The response options were: ‘excellent’, ‘very good’, ‘good’, ‘fair’, ‘poor’. Analogous to the surveillance systems in Canada [34] and Australia [35], the two categories ‘excellent’ and ‘very good’ were combined. In addition, a differentiation was made between ‘good’ and ‘fair’ or ‘poor’ mental health. Furthermore, parents were queried about the change in their children’s mental health compared to the time before the onset of the COVID-19 pandemic in Germany: ‘Compared to the time before the Corona pandemic (i.e. before March 2020), how would you describe your child’s current mental health?’ The response options were: ‘much better’, ‘somewhat better’, ‘about the same’, ‘somewhat worse’, ‘much worse’. The response categories ‘much better’ and ‘somewhat better’ as well as ‘somewhat worse’ and ‘much worse’ were combined, whereas the response category ‘about the same’ was kept as ‘unchanged’ (‘improved’, ‘unchanged’, ‘worsened’).

An item from the validated German translation of the Children with Special Health Care Needs (CSHCN) screener [36, 37] was used to record an increased need for care or support. The question was: ‘Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?’ If this question was answered in the affirmative, it was followed by the questions ‘Is this because of any medical, behavioral or other health condition?’ and ‘Is this a condition that has lasted or is expected to last for at least 12 months?’. If all three questions were answered in the affirmative, an increased need for care or support was seen to be evident.

Physical activity was recorded through the question: ‘How much lively exercise has your child had in the last week?’ With response categories being ‘less than 1 hour’, ‘1–2 hours’, ‘3–4 hours’, ‘5–6 hours’ and ‘at least 7 hours’. The question is based on the WHO recommendation...
according to which children and adolescents from 5 to 17 years of age should be active with moderate to vigorous intensity for an average of at least 60 minutes a day [38]. In addition, it was asked whether the child had participated (a) in voluntary physical activity or sport courses at school, and (b) in sports courses at sport clubs, fitness studios, ballet or swimming schools in the previous four weeks. If the response to the question was negative, it was asked in each case why the child/adolescent did not participate in such activities with the response categories being ‘Because the sports activity programmes at school (or sports courses in sports clubs/gyms) do not take place due to the pandemic’, ‘Because the child does not participate/is not registered due to the pandemic’, and ‘Because he/she does not participate/is not registered for other reasons’. In the case of an affirmative response, it was asked whether the pandemic had changed how often the child participates in the corresponding physical activity programmes (‘less frequently’/’more frequently’/’no change’).

The gender of the children and adolescents was recorded through the question: ‘Which gender was entered on your child’s birth certificate?’ The possible responses were ‘male’, ‘female’, ‘The gender entry was not completed’ or ‘diverse’. Due to missing or low numbers of cases in the categories ‘The gender entry was not completed’ and ‘diverse’, these children and adolescents are excluded when considering the genders separately. The parents’ information on the age of their children was combined into the age groups of 3–6 years, 7–10 years, and 11–15 years.

In order to be able to generate meaningful results for Germany, a weighting factor was created for the present analyses. The weighting consists of a design weight and an adjustment weight. The design weight is determined by the selection probability of the participating person. The adjustment weighting counteracts the fact that persons from certain population groups with a lower willingness to participate are under-represented compared to the base population of the study. The weighting adjusts the sample as a whole to the population distribution of variables such as region, age, gender, and education level (CASMIN classification) [39]. For example, participants from the low education group are weighted up, giving more weight to responses from these individuals and compensating for the aspect of lower participation rates from this group.

Stratified, weighted prevalences and 95% confidence intervals are reported below for the total group and by age group. Pearson’s Chi-square tests (Chi² test) were used to assess statistical health differences between boys and girls. A p-value of <0.05 was considered statistically significant. However, the p-values were not adjusted for multiple testing, so that statistically significant group differences determined herein are to be seen as statistical anomalies of an explorative and descriptive testing rather than as confirmation of tests of hypotheses.

3. Results

During the survey period from February – October 2022, parent-reported data were recorded from a total of 3,478 children and adolescents between 3 and 15 years of age (girls: n=1,639, boys: n=1,838, no information provided: n=1; Table 1). For the age group of 3–6 years, responses were available for 917 children. For the age groups of 7–10
years and 11–15 years, parents provided information for 1,027 children and 1,534 children, respectively.

### 3.1 General health

A total of 92.0% of the participating parents rated the general health of their child (aged 3–15 years) as very good or good; 8.0% of the parents rated the general health of their child as moderate or poor. There was no statistically significant difference between girls and boys (p=0.63). The age-specific analysis also showed no statistically significant gender differences in the general health for the three age groups of 3–6 years (p=0.51), 7–10 years (p=0.14), and 11–15 years (p=0.98). However, it was striking that among the 7-to 10-year-olds, just less than 13% of the girls were in mediocre to poor general health, but only just less than 7% of the boys (Figure 1).

### 3.2 Subjective mental health

Subjective mental health was rated positively by parents for a majority of children and adolescents between 3 and 15 years of age: 63.2% of parents rated their child’s mental health as ‘excellent’ or ‘very good’, and another third (29.6%) rated the mental health as ‘good’. For 7.2% of the children and adolescents, their parents rated their mental health as ‘fair’ or ‘poor’. The evaluation stratified by gender (Figure 2) showed no statistically significant differences between girls and boys (p=0.48).

When examining age-specific gender differences in subjective mental health, there were no statistically significant differences between the children and adolescents in the

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**Table 1**

Sample description with unweighted data

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
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<th>Gender of the child</th>
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<tr>
<td>Gender of the child</td>
<td>n=1,639</td>
<td>52.9</td>
<td>1,838 (52.9)</td>
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</table>

| Gender of the child | n=1,838 | 52.9 | 1,838 (52.9) |
|          |        |       | Male                |
|          |        |       | 1,639 (47.1) |
|          |        |       | Diverse             |
|          |        |       | 0 (0.0) |
|          |        |       | No information provided |
|          |        |       | 1 (0.0) |

| Age of the child (age group) | n=917 | 26.4 |
|                             |       |     |
| 3–6 years | 431 | 61.6 |
| 7–10 years | 493 | 65.1 |
| 11–15 years | 715 | 77.7 |

| Age of the child (age group) | n=1,027 | 26.4 |
|                             |       |     |
| 3–6 years | 485 | 47.4 |
| 7–10 years | 534 | 52.2 |
| 11–15 years | 819 | 79.9 |

| Age of the child (age group) | n=1,534 | 26.4 |
|                             |       |     |
| 3–6 years | 917 | 59.6 |
| 7–10 years | 1,027 | 66.5 |
| 11–15 years | 1,534 | 79.9 |

| Age of the child (age group) | n=3,478 | 26.4 |
|                             |       |     |
| 3–6 years | 1,838 | 52.9 |
| 7–10 years | 1,027 | 29.5 |
| 11–15 years | 1,534 | 44.1 |

| Highest education group of persons in the household (CASMIN) | n=1,017 | 2.6 |
|                                                             |       |     |
| Low education group | 42 | 5.1 |
| Medium education group | 539 | 6.2 |
| High education group | 1,057 | 12.6 |

| Highest education group of persons in the household (CASMIN) | n=1,017 | 2.6 |
|                                                             |       |     |
| Low education group | 59 | 7.0 |
| Medium education group | 556 | 6.5 |
| High education group | 1,223 | 14.8 |

| Highest education group of persons in the household (CASMIN) | n=1,017 | 2.6 |
|                                                             |       |     |
| Low education group | 101 | 12.9 |
| Medium education group | 1,095 | 13.4 |
| High education group | 2,281 | 27.4 |

| Missing values | n=1 | 0.0 |
|               |       |     |
| Low education group | 1 | 0.1 |
| Medium education group | 0 | 0.0 |
| High education group | 0 | 0.0 |

| Missing values | n=1 | 0.0 |
|               |       |     |
| Low education group | 0 | 0.0 |
| Medium education group | 0 | 0.0 |
| High education group | 1 | 0.0 |

---

**Figure 1**

Frequency of parent-reported very good or good general health of 3- to 15-year-olds by gender and age group (total: N=3,478; girls: n=1,639; boys: n=1,838; 3–6 years: n=916; 7–10 years: n=1,027; 11–15 years: n=1,534). Proportions in percent and 95% confidence intervals

Source: KIDA study (survey period 02/2022–10/2022)
analysed age groups. This was true for the age group of 3- to 6-year-olds (excellent or very good: girls 79.7%, boys 74.3%, $p=0.77$) as well as for the age group of 7- to 10-year-olds (girls 61.5%, boys 55.9%, $p=0.52$) and the 11- to 15-year-olds (girls 56.0%, boys 54.4%, $p=0.30$).

According to parents’ assessment, the mental health of 72.0% of children and adolescents between 3 and 15 years of age remained steady during the COVID-19 pandemic as compared to the pre-pandemic period (Figure 3). Parents reported an improvement in mental health for 7.8% of children and adolescents and a deterioration for 20.2%. An evaluation stratified by girls and boys showed no statistically significant gender differences ($p=0.86$). Likewise, an analysis of age-stratified gender differences also showed no statistically significant differences: diminished mental health was reported for 9.9% of girls and 10.1% of boys in the age group of 3- to 6-year-olds ($p=0.79$), for 20.3% of girls and 20.9% of boys in the age group of 7- to 10-year-olds ($p=0.96$), and for 30.5% of girls and 26.3% of boys in the age group between 11 and 15 years of age ($p=0.60$).

3.3 Increased care or support needs

Participating parents reported increased medical, mental health or educational care or support needs for 10.6% of the children in the age group of 3 to 15 years of age (Figure 4). Across all age groups, the more frequent need for care or support reported for boys (12.1%) as compared to girls (9.1%) was not statistically significant ($p=0.12$). When examining age-specific gender differences, a statistically significant difference was only found for children between 3 and 6 years of age ($p=0.01$), but there was no difference in the age groups of 7-10 years ($p=0.41$) and 11-15 years ($p=0.73$).
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3.4 Physical activity

According to the responses by the parents, between January and October 2022, a total of 57% of the children and adolescents engaged in at least seven hours of moderate to vigorous physical activity per week; they thus met the WHO’s physical activity recommendation of an average of at least 60 minutes of moderate to vigorous physical activity per day (Figure 5). The proportion was statistically significantly higher for boys than for girls (60.0% versus 53.8%, p=0.02).

The gender difference in the extent of physical activity was more pronounced for younger children than for older children and adolescents. In the age group of 3–10 years, 70.2% of the boys but only 61.6% of the girls met the physical activity recommendations (p=0.01). These proportions balanced out at an older age (boys: 43.3%, girls 40.9%, no significant difference). Overall, the proportion of children and adolescents who were sufficiently active decreased with age: the WHO physical activity recommendation was met by 66.1% of the 3- to 10-year-olds and 42.2% of the 11- to 15-year-olds.

Half of the children and adolescents (54.8%, n=1,897) were active in club or commercial sports programmes in the four weeks prior to the survey; the proportion was higher for boys than for girls (57.7% versus 51.6%, p=0.04). A similar picture emerged with regard to participation in sports activity programmes (AGs) at school: a total of 52.7% of the pupils (n=1,134/2,151) took part in sports activity programmes in the four weeks before the survey: 56.5% of the boys and 48.7% of the girls (p=0.04). A total of 22.3% of the pupils did not take part in any organized sport offer, either in a sports activity programme at school or in sports clubs or studios; this was more frequent for female pupils (27.6%) than male pupils (17.2%; p<0.01).

Looking at the group of children and adolescents who (according to their parents) had been active in sports clubs and/or sports or dance studio in the previous four weeks (n=1,866), 22.4% of them stated that they had used the corresponding course less often due to the pandemic. There were no statistically significant gender differences in these proportions (boys 20.1% versus girls 25.1%, p>0.05). For the group of children and adolescents who had not used this kind of offer in the previous four weeks (n=1,179), 14.6% of the parents reported that this was due...
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4. Discussion
4.1 Summary of the most important results

The KIDA study provides parents’ responses on the subjective general health and mental health, on the care and support needs, and on the physical activity behaviour of almost 3,500 children and adolescents between 3 and 15 years of age. Statistically significant gender differences were found especially with regard to physical activity: boys met the WHO physical activity recommendations slightly more often than girls, and they also used sports activities in school sports activity programmes and sports clubs or studios more often than girls.

In contrast, no statistically significant gender-related differences were found in general health and subjective mental health, which were predominantly rated as good, very good or excellent for both genders. Boys more frequently experienced an increased need for care and support, though this was seen in the youngest age group between 3 and 6 years of age only. Age-related gender differences were also found in the overall physical activity, especially at younger age: Boys between 3 and 10 years of age were more likely to engage in moderate to vigorous physical activity; in the group of older children and adolescents (11–15 years), the difference between boys and girls was no longer statistically significant.

With regard to the questions that explicitly referred to changes during or due to the COVID-19 pandemic, no differences between girls and boys were found in the parent-reported responses. This was true, for example, for deteriorations (or improvements) in subjective mental health during the COVID-19 pandemic. Also, girls and boys were equally affected by cancellations or reduced use of sports activities attributable to the COVID-19 pandemic.

4.2 Classification of the results and derivation of recommendations for action

The results of the present study give no indication that the general health of girls and boys between 3 and 15 years of age is assessed differently by the parents. Likewise, in KiGGS Wave 2 (2014–2017), no differences were found regarding the parent-reported general health of girls and boys between 3 and 17 years of age [32]. Gender differences in general health, on the other hand, are more likely to be found in studies on older children and adolescents to the disadvantage of female adolescents [32]. However, a comparison of the results is limited by the different age groupings, since the age group of 16- and 17-year-old adolescents was not included in this evaluation of the KIDA study. The fact that a larger proportion of the male adolescents rate their general health as good to excellent as compared to their female counterparts was also observed, in particular, in studies based on self-reporting by adolescents [40]. Therefore, the absence of a gender difference in the present study may well be due to the fact that the assessments were made exclusively by the parents. For example, [41] showed with regard to health issues that no gender differences were found in the parents’ assessment, while the adolescents themselves – female adolescents in particular – reported...
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Gender needs to be studied in the context with other social determinants over an extended period of time to assess the impact of the COVID-19 pandemic in more detail.

significantly more internalising anomalies, such as anxiety or dejection. Both the extent and the existing gender differences were underestimated by the parents [41]. With regard to younger children, though, it is necessary to rely on the parents’ assessment as a proxy. Moreover, the assessment of general health is a valid global indicator that combines physical, mental, and social dimensions of health and well-being into a single item [42, 43]. However, this multidimensionality may mask specific differences in health between girls and boys which thus may not be detectable [44, 45]. In further analyses, more specific indicators for measuring different aspects of health should therefore be used in addition to global overview measures in order to be able to report differences in health by gender in a more differentiated manner.

For subjective mental health, a clear majority of girls and boys are reported by their parents to be in excellent to good mental health. However, according to the parents’ assessment, the mental health of about 20% of the children and adolescents deteriorated during the COVID-19 pandemic as compared to their previous status. Analogous to the findings on general health, no statistically significant differences by gender were found in the KIDA study either in the subjective mental health or in its change. Only a tendency towards ‘fair’ or ‘poor’ mental health was found more frequently for girls between 11 and 15 years of age than for boys of the same age. These gender differences in subjective mental health were also found in a survey from Canada conducted before the pandemic. Here, girls between 12 and 14 years of age were more likely to rate their mental health as ‘fair’ or ‘poor’ than boys of the same age [46]. This is consistent with the fact that upon the onset of adolescence, mental health problems are reported more frequently in girls in the context of increasing internalising problems such as anxiety and depression [44]. During pre-adolescence, though, mental health problems predominate in boys rather than girls of the same age due to a higher prevalence of externalising problems (ibid.). Looking at a deterioration of mental health, further results from Germany showed that during the pandemic, the proportion of girls with a reduced health-related quality of life was higher than of boys [3]. The inconsistent findings so far indicate that further research is needed on gender-related risks for mental health, but also on gender-related resources and coping strategies [47].

Finding that boys between 3 and 6 years of age were more likely than their counterpart girls to have special care and support needs confirms results from the KiGGS study (Basiserhebung (baseline survey), 2003–2006), which found higher prevalences of increased care needs for boys than for girls, with the strongest differences among children between 3 and 10 years of age [37]. Just under 11% of all children and adolescents have longer-term increased care and support needs according to their parents’ responses in KIDA. More research is needed to find out whether the health or social system is able to meet these increased needs, or whether they are unmet (healthcare) needs for which new structures or services need to be established [48]. For this purpose, the existing care and support needs would have to be differentiated in more detail. Initial indications of this come from an interim evaluation of a more in-depth online survey of the KIDA sample from the period of April to August 2022 [49]. It was apparent that this concerned primarily educational and/or mental health services.
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needs rather than medical care needs. It is therefore important to establish gender-sensitive structures through which children and adolescents with poorer general and mental health can be identified at an early stage and referred for help and support, e.g. in educational institutions or in outpatient medical care [4]. Possible gender differences in support needs should be taken into account in facilities for counselling (e.g. family and social counselling centres or school counselling) or support (e.g. family education centres, youth work, outpatient services, preparation for school or maternity centres). Day care centres should also be sensitised to gender-related differences in educational support needs, as differences between boys and girls in KIDA at preschool age were statistically significant. However, some experts also express concerns that ‘typical boy behaviour’ may not infrequently be interpreted as being pathological. If, for example, boys stand out through restlessness and risk-seeking behaviour, this can be part of their normal development, in which they try out behaviour that is perceived as masculine. It does not necessarily have to be considered a disorder on a pathological level that requires increased support [50].

Specific and gender-related support needs are also evident for behavioural risk factors. The analyses with the KIDA data confirm results from earlier national as well as international studies that show that girls are not as physically active as boys [51–53]. This was evident in the KIDA results, in particular in children of nursery or primary school age. A systematic review of the activity of 5- to 17-year-olds in the COVID-19 pandemic confirms that the discrepancies in the physical activity behaviour of boys and girls that were widespread before the pandemic were also observed during the pandemic in the majority of international studies [54]. Various reasons for these gender differences have been described in the literature. During socialisation, for example, different gender-related role models can lead to sports often being seen in a positive context with male identity, and boys place more value on sporting competitions and successes than girls [55, 56]. Negative experiences in physical education are reported more often for girls, which may also have an unfavourable effect on their extracurricular physical activity behaviour [55]. Organised sports, in which a considerable proportion of young people’s physical leisure time activity takes place, also play an important role. The KIDA results show a gender-related difference in their participation in organised sports, which is statistically significant for sports club or commercial offers as well as for participation in voluntary sports activity programmes at school. It is possible that the structure and/or culture of organised sports, especially of the sports clubs, favours boys. This may be a consequence of gender bias in the structure of the offers made by clubs and sports clubs, which, for example, offer more competitive team sports such as football, handball or basketball, which appeal more to boys than girls [55]. Especially in order to compensate for limitations in physical activity such as those brought about by the COVID-19 pandemic, it is important to create offers that are attractive to girls and boys alike. Public health measures should focus specifically on increasing the physical activity of girls. This requires studies that identify specific barriers and promoting factors for the physical activity of girls in everyday life as well as for their participation in organised sports [54]. When organising community sports programmes – whether in clubs or through
physical activity programmes at school – care must be taken to respond to the perspectives and interests of girls and boys and to offer a diverse range of sports and courses in order to reduce gender inequalities [55].

4.3 Limitations

Due to the sample size, the subgroups were sometimes relatively small in the simultaneous stratification by both gender and age. This led to the results, to some extent, being associated with a relatively large statistical uncertainty, and gender differences may have remained undetected.

The results originate from the telephone survey of the KIDA study. Telephone surveys can be associated with methodological limitations such as selection bias or socially desirable response behaviour [57]. People in the low education group were often less willing to participate in the study, particularly in telephone surveys. Respondents from the low education group are clearly under-represented in the KIDA sample as well. Deviations between the surveyed sample and the population distribution in Germany with regard to age, gender, and region of residence are also possible. In order to address these circumstances and to be able to determine meaningful results, a corresponding design and adjustment weighting was carried out that takes the aforementioned aspects into account [57]. For example, respondents from the low education group were given a high weighting, thus attaching more weight to the answers and doing justice to the lower response rate this group of persons. Furthermore, all interviews in the scope of the KIDA study were conducted in German. Parents with little or no knowledge of German could not, or only to a limited extent, take part in the study.

Another limiting factor concerns the interpretation of comparisons between the current situation and the situation before the onset of the COVID-19 pandemic: The underlying data for the analyses were collected more than two years after the onset of the pandemic. The results therefore only allow limited conclusions to be drawn about whether the health of girls and boys has deteriorated as a result of the pandemic or whether gender differences have changed over time. Over a period of two years, many changes take place in the development of children and adolescents, regardless of external influences such as a pandemic. For this reason, pandemic-related and development-related changes cannot be differentiated unambiguously.

The indicator of subjective mental health was surveyed for the first time for children and adolescents in Germany in the KIDA study, as was the question on total physical activity, which takes into account the new WHO minimum recommendations (an average of one hour of moderate to vigorous exercise per day instead of exactly one hour every day). Therefore, no German reference data are available thus far, which is why a comparison with pre-pandemic time points cannot be made. The same applies to the assessment of mental health in a comparison of during versus before the COVID-19 pandemic, and to the pandemic-related changes in the utilisation of available sports activities.

Various items of physical and mental health were addressed in the telephone survey in KIDA. In order to allow for this broad range of aspects addressed, many aspects could only be queried in abbreviated manner. This also applies to the CSHCN screener, as only one of its 5
items was included in the telephone survey. This allows for an exploratory assessment of the proportion of children with increased care or support needs, but may underestimate the actually existing need. The comparison with previous population-based surveys is therefore also possible to a limited extent only. The survey with the full screening instrument is conducted in a more in-depth online survey of the same respondents, the results of which have not yet been reported here.

4.4 Conclusion and outlook

The results of the KIDA survey show that the health of children and adolescents between 3 and 15 years of age is predominantly assessed positively by their parents after approximately three years of the pandemic, whereby statistically significant differences between girls and boys were seen above all in certain age groups and in physical activity. However, gender should not be considered isolated, but always embedded in people’s social environment.

Further analyses should therefore, in the sense of the intersectional approach [58], also take into account other social determinants in addition to gender, such as the socioeconomic situation or migration history. An earlier interim evaluation from the KIDA study [49] shows that girls and boys growing up in families with low educational status and low income suffered the most under the restrictions during the pandemic and were more likely to have developed dysfunctional coping strategies than their age-peers growing up in socially better-off circumstances [59, 60]. Experiences of the loss of a parent’s job or severe family conflicts might also accumulate in different ways with the stresses on girls and boys during the pandemic and thus contribute – possibly only in the longer term – to an increase in differences in the health of socially disadvantaged girls and boys.

Furthermore, it would make sense to survey and analyse the health status of girls and boys using differentiated health indicators, since there are often gender differences in specific health issues [17]. Global health indicators were utilised in the present evaluation.

There is a need for further research with regard to questions like whether the health and health behaviour of girls and boys has changed as a result of the pandemic and, if so, whether gender differences in health have increased or decreased (trend analyses). In order to be able to depict differences in the health of girls and boys over the course of time, long-term surveillance of the health of children and adolescents is required. In addition, the sample must be sufficiently large to be able to carry out differentiated analyses and simultaneously include different age groups, different social determinants, and gender, also in the sense of the intersectional approach. Building on a comprehensive gender-sensitive data collection, corresponding aspects should be integrated into the training and further education of educational, medical, and psychotherapeutic professionals in order to enable boys and girls to grow up in a manner that is fair to both genders.

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Data protection and ethics
The KIDA study is subject to strict compliance with the data protection provisions set out in the EU General Data Protection Regulation (GDPR) and the Federal Data Protection Act (BDSG). The Ethics Committee of the Charité – Universitätsmedizin Berlin assessed the ethics of the study and approved the implementation of the study (application number EA2/201/21). Participation in the study was voluntary. The participants were informed about the aims and contents of the study and about data protection. Informed consent was obtained verbally.

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Abstract

Background: Trends over time and possible socio-spatial inequalities in the incidence and care of type 1 diabetes mellitus (T1D) in children and adolescents are important parameters for the planning of target-specific treatment structures.

Methodology: The incidence and prevalence of type 1 diabetes, diabetic ketoacidosis and severe hypoglycaemia as well as the HbA1c value are presented for under 18-year-olds based on data from the nationwide Diabetes Prospective Follow-up Registry (DPV) and the diabetes registry of North Rhine-Westphalia. Indicators were mapped by sex over time between 2014 and 2020, and stratified by sex, age and regional socioeconomic deprivation for 2020.

Results: In 2020, the incidence was 29.2 per 100,000 person-years and the prevalence was 235.5 per 100,000 persons, with the figures being higher in boys than in girls in either case. The median HbA1c value was 7.5%. Ketoacidosis manifested in 3.4% of treated children and adolescents, significantly more often in regions with very high (4.5%) deprivation than in regions with very low deprivation (2.4%). The proportion of severe hypoglycaemia cases was 3.0%. Between 2014 and 2020, the incidence, prevalence and HbA1c levels changed little, while the proportions of ketoacidosis and severe hypoglycaemia decreased.

Conclusions: The decrease in acute complications indicates that type 1 diabetes care has improved. Similar to previous studies, the results suggest an inequality in care by regional socioeconomic situation.

1. Introduction

Type 1 diabetes mellitus (T1D) is understood to be an autoimmune disease: an immune system-induced destruction of the insulin-producing cells in the pancreas leading to absolute insulin deficiency [1]. The development of the disease is assumed to be determined by an interplay of genetic and environmental factors [2, 3]. T1D develops more commonly in childhood and adolescence than in adulthood, unlike type 2 diabetes (T2D), which is associated with a relative insulin deficiency [4]. The disease can cause damage to small and large blood vessels and, in due course, to vital organs as well. Long-term complications during the course of disease include cardiovascular disease [5–7], eye and kidney disease [8] and amputations [9]. Given the serious health consequences, T1D can reduce both quality of life [10] and
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life expectancy [11]. High-quality T1D care, especially during childhood and adolescence, is crucial for achieving optimal metabolic control and health in the later stages of life of the afflicted and is highly relevant in public health.

Approximately 1.5 million people under the age of 20 being afflicted by T1D in 2021 throughout the world [12] make this one of the most common chronic metabolic diseases in childhood and adolescence, and a global increase in the rate of new diagnoses (incidence rate) by 3 to 4% per year has been observed in recent decades, with strong regional differences [13]. Against the background of changing living and environmental conditions, which are discussed as reasons for the increase, the development of the incidence must be monitored reliably and promptly. To be able to make an optimal offer of prevention and care services of the health care system, it is just as important to reliably map the proportion of T1D patients at a certain time (prevalence) as well as the development of the quality of T1D care provided (e.g. long-term blood glucose level, acute complications) and long-term complications (e.g. kidney disease, nerve damage) [14]. One of the aims of the National Diabetes Surveillance established at the Robert Koch Institute (RKI) is to provide, and regularly update, central results on these public health-relevant indicators in childhood and adolescence based on regional and supraregional registry data [15].

The long-term blood glucose value HbA1c (proportion of haemoglobin bound to glucose in total haemoglobin) reflects the average blood glucose level of the previous two to three months and is used to assess the quality of diabetes care. In children and adolescents, the current German guidelines for T1D therapy recommend a value <7.5%, whereas international guidelines recommend <7.0% [16, 17]. In therapy, a balance must be attained between the increased risk of hypoglycaemia upon intensive reduction of glucose levels and the increased risk of secondary diseases in the presence of long-term high blood glucose levels [16, 18].

Diabetic ketoacidosis is one of the common acute complications during the course of this disease. It is a severe metabolic derailment due to insulin deficiency, e.g. during an interruption of therapy or febrile infections. It involves a major increase in the blood sugar level and formation of so-called ketone bodies [18]. This complication can lead to brain oedema (swelling of the brain) in the short term [19] and can be fatal in rare cases. In the long term, it is associated with an unfavourable further course of the diabetes disease [20, 21], kidney damage [22] and cognitive impairment [23]. Age-appropriate diabetes training can have a preventive effect, as can good educational and psychological support for children and adolescents [24].

Hypoglycaemia is an acute complication that is associated with overly low blood glucose levels (low blood sugar) and can become manifest mainly in the context of intensive insulin therapy. The complication manifests when insulin intake is too high relative to the amount of sugar supplied by food or when glucose consumption is increased due to physical activity [18]. Depending on its severity, it can lead to unconsciousness, seizures and, in extreme cases, death; often hospitalisation is required [21, 25]. Hypoglycaemia can be prevented to a large degree by the currently common forms of insulin therapy (conventional and intensive injection therapy, insulin pump therapy), if necessary combined with the use of continuous glucose monitoring (CGM) devices or systems for automated insulin delivery (AID),
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and training of the patients [26–29]. When hypoglycaemia becomes manifest, hospital admission can be avoided through rapid intake of sugar-containing foods or drinks or through glucagon intake (an antagonist of insulin, e.g. as a nasal spray) [30].

Health inequalities in relation to diabetes have been reported in many studies. For adults in Germany, there continues to be a clear correlation between socioeconomic status (according to educational status) and prevalence of known and undiagnosed diabetes. In contrast, at least for some selected type 2 diabetes care indicators (e.g. HbA1c therapy target), no marked differences between educational groups are evident [31]. Dependence on socioeconomic status has been reported for children and adolescents, internationally as well as in Germany, with regard to the utilisation of medical-technical aids in T1D care and with regard to the HbA1c value [32]. In addition to the fear of incurring costs (despite reimbursement by health insurance funds), lower health literacy and lower self-efficacy of parents are assumed to be some of the possible reasons for socioeconomic differences in treatment, since the utilisation of medical care by children and adolescents is strongly dependent on the parents [33]. For this reason, there is a need to consider regional socioeconomic differences in the incidence, metabolic state and care of diabetes.

The aim of this paper is to present the incidence and prevalence of type 1 diabetes as well as selected indicators of the quality of care (in the following: care indicators; long-term blood glucose value HbA1c, proportion of ketoacidosis and hypoglycaemia) in children and adolescents in Germany for the year 2020, differentiated by sex, age and regional socioeconomic deprivation. In addition, an overview of the development of these indicators over time between 2014 and 2020 is provided.

2. Methods
2.1 Data sources

The nationwide Diabetes Prospective Follow-up Registry (DPV) was used to estimate nationwide incidences and prevalences of type 1 diabetes in children and adolescents as well as the care indicators. The documentation began in 1995 and is a computer-supported longitudinal recording of treatment-relevant data of diabetes patients that has been continuously developed at Ulm University, Germany. The aim of the DPV initiative, which has more than 400 treatment facilities in Germany, Austria, Luxembourg and Switzerland participating, is to improve the treatment outcomes of people afflicted by diabetes [34, 35].

The analyses of incidence and prevalence over time from 2014 to 2020 are based on the DPV data status of 16 March 2022. The stratified incidence and prevalence analyses for the year 2020 are based on the data status of 03 October 2022. For estimation of the completeness of coverage of the DPV, data from the diabetes registry of the German Diabetes Center (DDZ; North Rhine-Westphalia 0–34 years) were used and, on this basis, coverage-corrected nationwide incidence and prevalence values for under 18-year-olds were calculated [34, 36]. The care indicator results for the trend over time and the stratified analysis for the year 2020 are based on the data status of 28 November 2022 with the data from the DPV software made anonymous.

In the incidence and prevalence estimates, registered persons were included if they were under 18 years of age...
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at the time of diagnosis of the disease or at the end of the calendar year. For the calculations on the care indicators for 2020, 24,978 children and adolescents with T1D from the DPV Registry ranging in age from half a year to under 18 years, who had been diagnosed for at least three months and had at least one documented examination in the treatment year 2020, were included in the analysis.

Variables
Registry-based estimated incidences and prevalences served as indicators for the descriptive analysis.

The care indicator HbA1c value was presented as median with interquartile range (IQR). In each case, all HbA1c readings of the respective year were used and aggregated into the median for each person. The values were standardised according to the reference range of the Diabetes Control and Complications Trial [37]. Further care indicators considered herein were hospital-treated diabetic ketoacidosis in the course of the disease, severe hypoglycaemia (self-reported hypoglycaemia with the person dependent on outside help), severe hypoglycaemia associated with unconsciousness and severe hypoglycaemia associated with subsequent hospitalisation, as percentages relative to the group of children and adolescents with type 1 diabetes.

The German Index of Socioeconomic Deprivation (GISD) was used to examine the selected indicators from the perspective of health inequality. The GISD maps socioeconomic differences on a spatial level [38]. Based on the 'Indicators and Maps of Spatial and Urban Development' (INKAR) database of the Federal Institute for Research on Building, Urban Affairs and Spatial Development, an index of the socioeconomic deprivation was formed from nine indica-
Completeness of coverage was estimated according to a log-linear model. For this purpose, log-linear models were fitted to the data taking into account overdispersion, and the model that best described the registry data was selected according to the AICC criterion [40–42]. Assuming the cases to fit a Poisson distribution, incidences and prevalences were estimated with 95% confidence intervals using the person-year method and were directly sex- and/or age-standardised, and trends over time of incidence and prevalence were calculated using Poisson regression analyses [43]. Due to the values being low, the prevalence is not given as a percentage, as is common practice, but as diabetes cases per 100,000 persons.

For the year 2020, the indicators were analysed differentiated by sex, age and regional socio-economic deprivation. Five age groups were taken into consideration: under 3 years, 3 to 6 years, 7 to 10 years, 11 to 13 years and 14 to 17 years of age. As the number of cases for the care indicators in the lowest two age groups was too small, these were combined into an under-7-years age group for severe hypoglycaemia, diabetic ketoacidosis and HbA1c value. For the estimated T1D incidence and prevalence values by GISD quintiles, direct age and sex standardisation was performed based on the age groups listed and with equal weighting of the sexes. In addition, the association between incidence, prevalence and regional socioeconomic deprivation was investigated in a Poisson model, adjusted for geographical location (North/Central/South), age and sex.

For the time trends from 2014 to 2020, the estimators for incidence, prevalence and care indicators are presented overall and differentiated by sex.
Incidence, prevalence and care of type 1 diabetes in children and adolescents in Germany

Statistically significant differences were assumed to exist if either the 95% confidence intervals do not overlap or if the corresponding p-values from Chi-square test of independence or Wilcoxon tests were ≤0.05. Statistical analyses were performed using the SAS statistical package, version 9.4 (SAS Institute, Cary, NC, USA); maps were produced using the free open source software QGIS 3.26.2 [44].

3. Results
3.1 Incidence and prevalence of type 1 diabetes in children and adolescents in Germany

Table 1 shows the coverage-corrected nationwide incidence and prevalence estimates for the year 2020 overall, by sex and age, and age- and sex-standardised by regional socioeconomic deprivation. The overall estimated incidence of T1D is 29.2 per 100,000 person-years, which corresponds to an estimated number of 4,044 new diagnoses in 2020 (girls: 1,784; boys: 2,260). The overall T1D incidence is higher for boys than for girls (31.9 vs. 26.5 per 100,000 person-years, respectively), with statistically significant differences in incidence by sex being evident in the age groups of 11 to 13 years and 14 to 17 years. The incidence is highest in girls in the age groups of 7 to 10 and 11 to 13 years (37.1 and 35.9 per 100,000 person-years, respectively), and in boys in the age group of 11 to 13 years (48.8 per 100,000 person-years). Differentiating by regional socioeconomic deprivation, a higher incidence is seen in districts with very high deprivation (31.9 per 100,000 person-years) than in districts with very low deprivation (27.3 per 100,000 person-years).

Approximately 4,000 children and adolescents had a new type 1 diabetes diagnosis in 2020, with the prevalence being approximately 235.5 per 100,000 persons.

Table 1

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Incidence (per 100,000 person-years)</th>
<th>Prevalence (per 100,000 persons)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=1,784 girls, n=2,260 boys)</td>
<td>(n=15,239 girls, n=16,991 boys)</td>
</tr>
<tr>
<td></td>
<td>(95% CI)</td>
<td>(95% CI)</td>
</tr>
<tr>
<td>&lt;3</td>
<td>15.0 (12.9–17.4)</td>
<td>17.0 (14.8–19.5)</td>
</tr>
<tr>
<td>3–6</td>
<td>27.0 (24.5–29.7)</td>
<td>26.6 (24.2–29.3)</td>
</tr>
<tr>
<td>7–10</td>
<td>37.1 (34.1–40.4)</td>
<td>39.1 (36.0–42.3)</td>
</tr>
<tr>
<td>11–13</td>
<td>35.9 (32.4–39.6)</td>
<td>48.8 (44.9–53.0)</td>
</tr>
<tr>
<td>14–17</td>
<td>17.1 (15.1–19.4)</td>
<td>28.3 (25.7–31.1)</td>
</tr>
<tr>
<td>Regional socioeconomic deprivation:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very low</td>
<td>24.2 (21.9–26.6)</td>
<td>30.3 (27.7–32.9)</td>
</tr>
<tr>
<td>Low</td>
<td>28.0 (25.2–30.7)</td>
<td>29.5 (26.8–32.3)</td>
</tr>
<tr>
<td>Medium</td>
<td>27.6 (25.0–30.3)</td>
<td>33.9 (31.1–36.8)</td>
</tr>
<tr>
<td>High</td>
<td>25.9 (23.0–28.9)</td>
<td>30.6 (27.4–33.7)</td>
</tr>
<tr>
<td>Very high</td>
<td>27.4 (24.1–30.7)</td>
<td>36.5 (32.8–40.2)</td>
</tr>
<tr>
<td>Total</td>
<td>26.5 (25.3–27.8)</td>
<td>31.9 (30.6–33.2)</td>
</tr>
</tbody>
</table>

1 coverage-corrected
2 coverage-corrected and standardised for age and sex

Source: DPV Registry; data status: 03 October 2022
In 2020, the estimated nationwide prevalence of T1D in children and adolescents was 235.5 per 100,000 persons (Table 1). This corresponds to an estimated number of 32,230 persons (girls: 15,239; boys: 16,991). The T1D prevalence is higher in boys than in girls (241.4 vs. 229.5 per 100,000 persons, respectively), with differences by sex being statistically significant in the age groups of under-3-year-olds and 14 to 17-year-olds. As expected, there is a dependence of T1D prevalence on age, with higher prevalences being observed in older age groups. With regard to regional deprivation, regions with very low and low socioeconomic deprivation show statistically significantly lower
prevalences of T1D than regions with medium to very high deprivation (Table 1).

Looking at the geographical situation, no consistent pattern emerges in the distribution of T1D incidence and prevalence in 2020 at the district level (Figure 2). Clusters of low-incidence districts tend to be seen in Saxony-Anhalt and Brandenburg, whereas a clustering of high-incidence districts tends to be seen in the Northwest. Similarly, there is marked clustering of high prevalences in the Northwest. When viewed in conjunction with Figure 1, it is evident that the distribution patterns of incidence, prevalence and regional socioeconomic deprivation at district level are not congruent. The association between incidence and socio-spatial deprivation that is evident from Table 1 on the basis of the stratified analysis is no longer seen in a Poisson model after adjustment for geographical location (North/Central/South) (Annex Table 1).

Between 2014 and 2020, there is no clear overall trend with regard to the incidences (Figure 3). For 2020, there is a statistically significant increase in the incidence, both overall and in boys, compared to 2019 (overall 2019: 27.0, 95% CI: 26.1–27.9, 2020: 29.3, 95% CI: 28.4–30.2; boys 2019: 28.8, 95% CI: 27.6–30.1, 2020: 32.0, 95% CI: 30.7–33.4). In the observation period from 2014 to 2020, new diagnoses are estimated to a total of 26,080 (girls: 11,819, boys: 14,261; average 3,725 per year) and the average incidence, standardised for age and sex, is 27.7 cases of diabetes per 100,000 person-years (girls: 26.0; boys: 29.5). In each of the years considered except 2015, the incidence is significantly higher in boys than in girls. The incidence per 100,000 person-years for girls is lowest in 2017 (24.8) and highest in 2015 (26.8); for boys, it is lowest in 2015 (28.5) and highest in 2020 (32.0).

Over time, the nationwide T1D prevalence in individuals under 18 years of age shows some fluctuation from 231.8 in 2014 to 232.2 per 100,000 persons in 2020 (Figure 4; annual change, girls: 0.2% (-0.2–0.7, p=0.325); boys: 0.4% (-0.2–1.1, p=0.221)). On average, the prevalence is 231.5 per 100,000 persons. Starting from 2018, significantly higher prevalences are observed for boys than for girls.
3.2 Quality of care

In 2020, statistically significantly higher HbA1c values were measured in girls than in boys (7.6%; IQR: 6.9–8.4 versus 7.5%; IQR: 6.8–8.3, p<0.001). In increasingly older age groups, the median increased slightly from 7.3% in the under-7-years age group to 7.8% in the 14 to 17-years age group.

The median measured HbA1c value in regions with very low socioeconomic deprivation was 7.4% (IQR: 6.8–8.1) and was statistically significantly higher in regions with very high socioeconomic deprivation, where it was 7.7% (IQR: 7.0–8.6, p<0.001). Overall, there was a gradient in median HbA1c values from regions with low socioeconomic deprivation to regions with high deprivation (Table 2).

The median HbA1c values did not change between 2014 (Girls: 7.5% (IQR: 6.8–8.4); Boys: 7.5% (IQR: 6.8–8.3)) and 2020 (Girls: 7.6% (IQR: 6.9–8.4); Boys: 7.5% (IQR: 6.8–8.3)), apart from minor fluctuations between 2016 and 2018.

A total of 3.4% of the children and adolescents with T1D were hospitalised for diabetic ketoacidosis at least once in 2020. Overall, the proportion of girls experiencing diabetic ketoacidosis at least once was statistically significantly higher (3.8%; 95% CI: 3.4–4.1) as compared to boys (3.2%; 95% CI: 2.9–3.5, p=0.03). In children and adolescents from the age of 11, the proportions of diabetic ketoacidosis were significantly higher (in 11 to 13-year-olds: 3.6%; 95% CI: 3.2–4.0; in 14 to 17-year-olds: 4.0%; 95% CI: 3.7–4.4) than in children and adolescents under 11 years of age (under 7 years of age: 2.6%; 95% CI: 2.1–3.1; in 7 to 10-year-olds: 2.3%; 95% CI: 2.0–2.7) (Table 3).

The proportion of all children and adolescents with T1D who had diabetic ketoacidosis in 2020 was statistically significantly lower in regions with the lowest deprivation quintile (2.4%; 95% CI: 2.1–2.7) than in the other deprivation quintiles.

Looking at the trend over time, the proportion of children and adolescents experiencing diabetic ketoacidosis has decreased between 2014 and 2020 (Figure 5). It decreased from 4.5% in 2014 to 3.4% in 2020. The proportions decreased more strongly in girls than in boys (girls: 2014: 5.1%, 2020: 3.8%; boys: 2014: 4.0%, 2020: 3.2%).

Severe hypoglycaemia manifested in 3.0% of children and adolescents with T1D in 2020, with no statistically significant differences by sex and age (Table 3). In 2020, 0.7% of children and adolescents with T1D experienced severe hypoglycaemia with unconsciousness at least once and 0.5% had severe hypoglycaemia with hospitalisation at least

### Table 2

Median long-term blood glucose level HbA1c in children and adolescents with type 1 diabetes in 2020 by sex, age group and regional socioeconomic deprivation

<table>
<thead>
<tr>
<th>Regional socioeconomic deprivation</th>
<th>Girls (%)</th>
<th>IQR</th>
<th>Boys (%)</th>
<th>IQR</th>
<th>Total (%)</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
<td>7.4</td>
<td>(6.8–8.1)</td>
<td>7.4</td>
<td>(6.8–8.1)</td>
<td>7.4</td>
<td>(6.8–8.1)</td>
</tr>
<tr>
<td>Low</td>
<td>7.5</td>
<td>(6.9–8.2)</td>
<td>7.5</td>
<td>(6.8–8.2)</td>
<td>7.5</td>
<td>(6.8–8.2)</td>
</tr>
<tr>
<td>Medium</td>
<td>7.7</td>
<td>(7.0–8.5)</td>
<td>7.6</td>
<td>(6.9–8.4)</td>
<td>7.6</td>
<td>(6.9–8.4)</td>
</tr>
<tr>
<td>High</td>
<td>7.6</td>
<td>(7.0–8.4)</td>
<td>7.5</td>
<td>(6.9–8.4)</td>
<td>7.6</td>
<td>(6.9–8.4)</td>
</tr>
<tr>
<td>Very high</td>
<td>7.8</td>
<td>(7.1–8.6)</td>
<td>7.7</td>
<td>(6.9–8.6)</td>
<td>7.7</td>
<td>(7.0–8.6)</td>
</tr>
<tr>
<td>Total</td>
<td>7.6</td>
<td>(6.9–8.4)</td>
<td>7.5</td>
<td>(6.8–8.3)</td>
<td>7.5</td>
<td>(6.9–8.3)</td>
</tr>
</tbody>
</table>

M = Median
IQR = Interquartile Range

The median long-term blood glucose level HbA1c in children and adolescents with type 1 diabetes in 2020 was 7.5%, while the German guidelines recommend a value <7.5%.

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At least one incident of ketoacidosis requiring hospitalisation occurred in 3.4% of treated children and adolescents with type 1 diabetes, more common in regions of very high socioeconomic deprivation.

The proportion of children and adolescents experiencing severe hypoglycaemia at least once in a year shows a strong decrease over the observation period from 2014 to 2020 (Figure 6). In 2014, the proportion was 5.3% (95% CI: 5.0–5.6); in 2020 it had dropped to 3.0% (95% CI: 2.8–3.2). A strong decrease is noted both in boys (2014: 5.0%; 2020: 3.0%) and girls (2014: 5.6%; 2020: 3.0%).

Both the proportions of severe hypoglycaemia with unconsciousness and severe hypoglycaemia with hospitalisation showed a steady annual decrease between 2014 and 2020 (Annex, Figure 1). In 2014 and 2020, the proportion of treated children and adolescents with type 1 diabetes experiencing severe hypoglycaemia with loss of consciousness was 1.7% (95% CI: 1.6–1.9) and 0.7% (95% CI: 0.6–0.8), respectively.
Incidence, prevalence and care of type 1 diabetes in children and adolescents in Germany

FOCUS

The proportion of severe hypoglycaemia in 0–17 year-olds with type 1 diabetes was 3.0%.

respectively. In 2014, 1.2% (95% CI: 1.0–1.3) experienced severe hypoglycaemia and were admitted to hospital; in 2020, this proportion was 0.5% (95% CI: 0.4–0.6).

4. Discussion
4.1 Incidence and prevalence of T1D in children and adolescents

Interpretation of the results and comparison to other studies

Globally, the incidence of type 1 diabetes in children and adolescents is estimated to have increased by 3 to 4% each year on average over the past decades [13, 45]. This estimate is consistent with the annual 3.4% increase in incidence in children and adolescents up to 14 years of age in Germany, which was calculated on the basis of registry data from the period of 1999 to 2008 [36]. In contrast, as described here, no significant change in the incidence of type 1 diabetes in under-18-year-olds in Germany is detectable between 2014 and 2020. A levelling off of the increase or a decrease in incidence in recent years has also been noted in other countries, for example in Sweden [46] and Finland [47].

In a global comparison, the country-specific incidence rates and trends over time vary strongly [48–50]. Indeed, for the 0–14 years age group, they range from less than 5 per 100,000 person-years (e.g. Japan: 2.2) to more than 30 per 100,000 person-years (e.g. Finland: 52.2) [49, 50]. Regional differences in the development of the incidence over time are evident within Germany as well [14].

The overall T1D prevalence in children and adolescents is almost unchanged between 2014 and 2020. Prevalence estimates based on data for children and adolescents aged 0–19 years for the period from 2002 to 2020 in North Rhine-Westphalia are indicative of a similar prevalence of 247.1 per 100,000 persons (95% CI: 240.3–253.9), with an annual increase of 2.9% (95% CI: 2.7–3.1) [51]. Data that is also based on the nationwide DPV Registry show that the previous significant increase in T1D prevalence levelled off between 2002 and 2020 (increase between 2002 and 2008: 6.3%; 2008–2014: 3.1%; 2014–2020: 0.5%), and that the prevalence increased only in the age group of 15 to 19 years of age since 2014 [52]. For 2020, it was observed that prevalence increased by age group, as expected. This is consistent with findings from North Rhine-Westphalia from 2010 [14].

For 2020, higher T1D incidence values are evident in districts with very high deprivation as compared to districts with very low deprivation. However, after adjustment for
Overall, international ecological analyses of the incidence of type 1 diabetes yielded inconsistent results, so that there is no clear evidence yet on the influence of spatial socioeconomic or climatic factors on the incidence [48]. The regional differences in the incidence of type 1 diabetes and the changes over time indicate that the disease process is multifactorial [48]. The extent to which genetic and/or environmental factors affect the risk of disease is still the subject of research. Environmental factors that are closely related to the degree of urbanisation and the socioeconomic status are discussed as being relevant for the disease, though the evidence is inconsistent [48]. There is evidence that early childhood exposure to pathogens, more common in high population density settings, may be protective against the development of type 1 diabetes in those with a genetic predisposition. Accordingly, in some countries, low incidence rates were linked to high population density, whereas in other countries high incidence rates were detected in urban areas. Different definitions of rural and urban areas and differences in socioeconomic deprivation are being discussed as possible causes of these contradictory observations [48]. Furthermore, there are indications for an association to exist between the incidence of type 1 diabetes and climatic conditions [56].

The increase in incidence in 2020 compared to the previous year, both overall and in boys, should also be evaluated against the background of the COVID-19 pandemic. An analysis from 2022 showed an unexpected increase in the incidence of T1D in the first 1.5 years of the pandemic [57]. For example, between 1 January 2020 and 30 June 2021, the incidence was 24.4 per 100,000 person-years (95% CI: 23.6–25.2) exceeding the expected incidence of geographical location (North/Central/South), there is no longer any evidence of an association to exist between regional socioeconomic deprivation according to the GISD at the district level and the T1D incidence in children and adolescents in Germany. Data on new diagnoses in persons under 20 year of age for the period between 2007 and 2014 in North Rhine-Westphalia show a higher incidence (relative to environmental factors and employment rate) in less deprived communities as well as in more remote regions. The association between incidence and degree of urbanisation is stronger than the association between incidence and socioeconomic deprivation [53]. This is consistent with data on the incidence of type 1 diabetes in children and adolescents between 0 and 14 years of age in North Rhine-Westphalia for the period from 1996 to 2000 [54].

The underlying data demonstrated a higher T1D prevalence in districts with higher socioeconomic deprivation. Data from England and Wales show only insignificant differences in T1D prevalence by socioeconomic deprivation, at best being somewhat indicative of a higher proportion of children with T1D in regions of highest deprivation [55]. While there may be explanations for an increased T2D prevalence in more deprived regions (e.g. limited access to exercise opportunities, higher proportion of obesity) [55], the association with regard to T1D is unclear and not unambiguous.

Interpreting the regional socioeconomic contextual differences in incidence and prevalence, a possible influence of other factors such as environmental factors exhibiting geographical differences should be taken into consideration. By the eye test, there is no significant association between incidences or prevalences and GISD (Figure 2).
21.2 (95% CI: 20.5–21.9), and resulted in an ‘incidence rate ratio’ (IRR) of 1.15 (95% CI: 1.10–1.20), meaning that the incidence was about 15% higher than expected based on the long-term trend. There were no differences between boys and girls. Stratified by age groups, there was an increased IRR for children under 6 years of age (1.23; 95% CI: 1.13–1.33) and between 6 and 11 years of age (1.18; 95% CI: 1.11–1.26), but not in children and adolescents older than these ages [57]. A meta-analysis of 24 international studies provided evidence of a statistically significant association to exist between the COVID-19 pandemic and a worldwide increase in T1D incidence in children and adolescents [58]. Overall, the state of research on the development of T1D incidence is heterogeneous [59]. Further studies are needed to investigate the causes of the increase in T1D incidence. On the one hand, SARS-CoV-2 infection might possibly promote the development of T1D directly. On the other hand, the measures taken to contain the COVID-19 pandemic and the associated stress might have had an indirect influence on the development of the disease [60].

Conclusions related to Public Health
The prevalence of T1D is a crucial measure for planning the care to be provided. According to the results, at least an unchanged need for care of children and adolescents with type 1 diabetes must be expected in the upcoming years [14]. The increase in incidence during the COVID-19 pandemic should be kept in mind and should be investigated further [60]. According to the Diabetes Atlas of the International Diabetes Federation, Germany is among the ten countries with the highest incidence of cases and the highest estimated prevalence of type 1 diabetes [50, 61].

4.2 Quality of care indicators in children and adolescents with T1D
Interpretation of the results and comparison to other studies
The HbA1c values are constant over time. Since the median HbA1c value of 7.5% is just above the recommended value of the German guidelines of <7.5% [16] and above the recommended value of the international guidelines of <7.0% [17], it can be assumed that there is a need for improvement. Consistent with our study, other studies noted significant differences by sex in indicators such as metabolic control and diabetic ketoacidosis over time, and report higher HbA1c values for girls than for boys [62]. For the care indicators considered herein, a positive development is seen over the observation period from 2014 to 2020. The incidence of acute complications in children and adolescents with T1D have decreased during this period, both in girls and in boys. The evident decrease of diabetic ketoacidoses is mainly due to a strong decrease in girls. Nevertheless, girls were more frequently afflicted by diabetic ketoacidosis than boys in 2020. The higher risk of diabetic ketoacidosis in the older age groups reported in the literature [63] was also observed for the year 2020 in this study. Diabetic ketoacidosis manifested more frequently in children and adolescents with T1D in regions of higher socioeconomic deprivation than in regions of lower socioeconomic deprivation. This observation is consistent with results from other studies [64, 65].

The observed decrease in the proportions of severe hypoglycaemia over the years is consistent with the literature [66], and is quite pronounced in both boys and girls.
With regard to the regional socioeconomic context, no clear associations were detected. Only in boys with T1D do the descriptive analyses show significantly more severe hypoglycaemia cases in regions with the lowest socioeconomic deprivation as compared to the other regions. A study using data from 2015 and 2016 [64] reported the incidence of severe hypoglycaemia to gradually decrease from regions with the lowest deprivation to regions with the highest deprivation.

Similarly, between 2014 and 2020, there was a decrease in the proportion of children and adolescents with T1D who experienced hypoglycaemia with unconsciousness or hypoglycaemia with hospitalisation in the respective year of treatment.

Conclusions related to Public Health
Looking at the trend over time from 2014 to 2020, it was evident that, for acute complications, the proportions of girls and boys have become equal and significant differences between girls and boys exist only for diabetic ketoacidosis in 2020. Although treatment choices were not a subject of the analysis, one possible explanation for the convergence of the difference by sex is that the use of insulin pumps has become more widespread in girls than in boys, so that insulin pump therapy is now used more commonly in girls than in boys [33, 62].

The prevention of severe hypoglycaemic episodes in particular can be seen as a quality indicator of good glycaemic control and may point to increasing recipient-appropriate training [26]. Hypoglycaemia can have secondary complications such as cardiovascular events and dementia or accidents and fall-related fractures and even death [67]. In recent years, medical-technical aids such as continuous glucose monitoring and insulin pumps, which facilitate the dosing adjustments in type 1 diabetes therapy, have become widespread among children and adolescents in Germany [68]. The risk of hypoglycaemia while on insulin pump therapy is lower than on injection therapy, and on average a better metabolic control is achieved [69, 70]. A total of 93% of all children with T1D under five years of age in 2020 used an insulin pump [69]. Furthermore, an improvement in blood glucose control and a lower average HbA1c value are evident to result from the use of continuous glucose monitoring [71]. In addition, the risk of hypoglycaemia can be reduced even more through a more widespread use of AID systems, which allow for automated cut-off of insulin delivery if hypoglycaemia manifests or before impending hypoglycaemia [30, 72]. In this context, the effects of the spread of medical-technical aids and the correlation with the regional socioeconomic context in children and adolescents should be further investigated in the future.

Looking at the trend over time from 2014 to 2020, it was evident that, for acute complications, the proportions of girls and boys have become equal and significant differences between girls and boys exist only for diabetic ketoacidosis in 2020. Although treatment choices were not a subject of the analysis, one possible explanation for the convergence of the difference by sex is that the use of insulin pumps has become more widespread in girls than in boys, so that insulin pump therapy is now used more commonly in girls than in boys [33, 62].

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Exhibit a high degree of coverage (completeness), which was estimated using capture-recapture methods based on the data for North Rhine-Westphalia from the DDZ Diabetes Register. Data collection in North Rhine-Westphalia has been conducted for more than 20 years, mainly using the same methodology [36]. The estimates of incidence and prevalence were corrected for the low degree of undercoverage. Nevertheless, it should be noted that the data quality depends on the documentation of the clinics and practices, which voluntarily participate in the registries. The estimates of the incidence and prevalence of T1D and the corresponding trends are based on model analyses and should therefore be seen as approximations. With the multidimensional index of regional socioeconomic deprivation used, an ecological correlation of the indicators considered was conducted at the small-scale regional level. The index can therefore not replace a measurement of socioeconomic status at the individual level.

4.4 Conclusion

The incidence and prevalence of type 1 diabetes in children and adolescents have changed only marginally in the period from 2014 to 2020. There are some differences evident upon differentiation by regional socioeconomic deprivation. The association between the regional socioeconomic deprivation and the incidence is not clear and should be the subject of further research, as should the influence of genetic and environmental factors and of the COVID-19 pandemic. In this context, it would be of interest to look at the age distribution of incidence and prevalence values with respect to regional socioeconomic deprivation.
With regard to the long-term blood glucose value HbA1c, no change over time was observed. It should be analysed which measures and interventions might contribute to a long-term reduction of the HbA1c values and thus to improved diabetes care for children and adolescents.

Regarding the acute complications considered, there is an improvement in the trend over time as well as a decrease of the differences between boys and girls. This indicates that the widespread use of medical-technical aids in the care provided to children and adolescents with type 1 diabetes has contributed to a reduction of the complications. Furthermore, a higher proportion of children and adolescents with type 1 diabetes experiencing diabetic ketoacidosis at least once is detected in regions with higher socioeconomic deprivation. It can safely be assumed that, especially in these socioeconomically deprived areas, the care provided for this disease and the education about risk factors and causes of diabetic ketoacidosis can be improved.

The data on the T1D incidence and care in children and adolescents in Germany demonstrate the importance of the registries and of the integration of the registry data into the diabetes surveillance system at the RKI. The aim of diabetes surveillance is a regular indicator-based diabetes reporting to provide timely and action-oriented information in the realms of health policy, health research, health care and public health practice.

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Data protection and ethics
All data sources used herein were assessed by the ethics committees in charge, and the use thereof was approved. The compilation and analysis for the National Diabetes Surveillance and for this article was based exclusively on data rendered completely anonymous.

Data availability
DPV data can be utilised both in the context of scientific collaborations and for remote data processing. The DPV committee and the group of authors are the contact persons in this regard.

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Data protection and ethics
All data sources used herein were assessed by the ethics committees in charge, and the use thereof was approved. The compilation and analysis for the National Diabetes Surveillance and for this article was based exclusively on data rendered completely anonymous.

Data availability
DPV data can be utilised both in the context of scientific collaborations and for remote data processing. The DPV committee and the group of authors are the contact persons in this regard.

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Incidence, prevalence and care of type 1 diabetes in children and adolescents in Germany


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Incidence, prevalence and care of type 1 diabetes in children and adolescents in Germany

Incident cases
Regional socioeconomic deprivation

<table>
<thead>
<tr>
<th>Regional socioeconomic deprivation</th>
<th>T1D incidence (95% CI)</th>
<th>Relative risk (95% CI)</th>
<th>p-value</th>
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<tr>
<td>Very low</td>
<td>929 (27.3 (25.5–29.0))</td>
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<tr>
<td>Low</td>
<td>854 (28.8 (26.8–30.7))</td>
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<td>Very high</td>
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Prevalent cases
Regional socioeconomic deprivation

<table>
<thead>
<tr>
<th>Regional socioeconomic deprivation</th>
<th>T1D prevalence (95% CI)</th>
<th>Relative risk (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low</td>
<td>7,444 (223.4 (218.3–228.5))</td>
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<td>Low</td>
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<td>7,460 (240.4 (234.9–245.8))</td>
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<td>1.058 (1.017–1.101)</td>
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<tr>
<td>Very high</td>
<td>5,018 (256.2 (249.1–263.3))</td>
<td>1.092 (1.048–1.138)</td>
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Proportion of children and adolescents experiencing severe hypoglycaemia with unconsciousness at least once

<table>
<thead>
<tr>
<th>Treatment year</th>
<th>With unconsciousness</th>
<th>With hospitalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>0.7 (0.4–0.9)</td>
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<tr>
<td>2015</td>
<td>0.6 (0.4–0.8)</td>
<td>0.0 (0.0–0.0)</td>
</tr>
<tr>
<td>2016</td>
<td>0.5 (0.3–0.7)</td>
<td>0.0 (0.0–0.0)</td>
</tr>
<tr>
<td>2017</td>
<td>0.4 (0.2–0.6)</td>
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<tr>
<td>2018</td>
<td>0.3 (0.1–0.5)</td>
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<tr>
<td>2019</td>
<td>0.2 (0.0–0.3)</td>
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</tr>
<tr>
<td>2020</td>
<td>0.1 (0.0–0.2)</td>
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Proportion of children and adolescents experiencing severe hypoglycaemia with hospitalisation at least once

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Girls (95% CI)</th>
<th>Boys (95% CI)</th>
<th>Total (95% CI)</th>
<th>Girls (95% CI)</th>
<th>Boys (95% CI)</th>
<th>Total (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;7</td>
<td>0.7 (0.3–1.1)</td>
<td>0.5 (0.2–0.8)</td>
<td>0.6 (0.3–0.8)</td>
<td>0.5 (0.2–0.9)</td>
<td>0.4 (0.1–0.6)</td>
<td>0.4 (0.2–0.6)</td>
</tr>
<tr>
<td>7–10</td>
<td>0.6 (0.4–0.9)</td>
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<td>0.6 (0.4–0.8)</td>
<td>0.5 (0.3–0.7)</td>
<td>0.5 (0.3–0.7)</td>
<td>0.5 (0.3–0.6)</td>
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<tr>
<td>11–13</td>
<td>0.6 (0.4–0.8)</td>
<td>0.9 (0.6–1.1)</td>
<td>0.7 (0.5–0.9)</td>
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<td>0.6 (0.4–0.8)</td>
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<td>14–17</td>
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<td>0.8 (0.7–0.9)</td>
<td>0.6 (0.4–0.8)</td>
<td>0.5 (0.4–0.7)</td>
<td>0.6 (0.4–0.7)</td>
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Proportion of children and adolescents with type 1 diabetes experiencing severe hypoglycaemia with unconsciousness or hospitalisation at least once in 2020 by sex, age group and regional socioeconomic deprivation

<table>
<thead>
<tr>
<th>Regional socioeconomic deprivation</th>
<th>Girls (95% CI)</th>
<th>Boys (95% CI)</th>
<th>Total (95% CI)</th>
<th>Girls (95% CI)</th>
<th>Boys (95% CI)</th>
<th>Total (95% CI)</th>
</tr>
</thead>
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<td>0.5 (0.3–0.8)</td>
<td>0.7 (0.5–1.0)</td>
<td>0.6 (0.5–0.8)</td>
<td>0.5 (0.2–0.7)</td>
<td>0.5 (0.3–0.7)</td>
<td>0.5 (0.3–0.7)</td>
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<tr>
<td>Low</td>
<td>0.9 (0.6–1.2)</td>
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<td>0.6 (0.4–0.7)</td>
</tr>
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<td>0.8 (0.5–1.1)</td>
<td>0.7 (0.5–1.0)</td>
<td>0.8 (0.6–1.0)</td>
<td>0.5 (0.3–0.7)</td>
<td>0.6 (0.4–0.9)</td>
<td>0.6 (0.4–0.7)</td>
</tr>
<tr>
<td>High</td>
<td>0.6 (0.3–0.8)</td>
<td>0.8 (0.5–1.1)</td>
<td>0.7 (0.5–0.9)</td>
<td>0.4 (0.2–0.6)</td>
<td>0.7 (0.4–0.9)</td>
<td>0.5 (0.4–0.7)</td>
</tr>
<tr>
<td>Very high</td>
<td>0.7 (0.4–1.1)</td>
<td>0.9 (0.5–1.2)</td>
<td>0.8 (0.6–1.0)</td>
<td>0.6 (0.3–0.9)</td>
<td>0.5 (0.2–0.7)</td>
<td>0.5 (0.3–0.7)</td>
</tr>
<tr>
<td>Total</td>
<td>0.7 (0.6–0.9)</td>
<td>0.7 (0.6–0.9)</td>
<td>0.7 (0.6–0.8)</td>
<td>0.5 (0.4–0.7)</td>
<td>0.5 (0.4–0.7)</td>
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T1D = type 1 diabetes
Childhood and adolescent cancer in Germany – an overview

Abstract

Background: Childhood and adolescent cancer constitutes only a very small fraction of the cancer cases in Germany and throughout the world, but it is the most frequent cause of disease-related death in children. The diagnostic spectrum differs markedly from that of adults. More than 90% of all cases of childhood and adolescent cancer in Germany are treated according to centralised protocols or in therapy studies.

Methods: The main epidemiological data for this group are collected by the German Childhood Cancer Registry (GCCR) since 1980. Based on this data, three typical diagnoses and their incidence and prognosis are described in exemplary manner: Lymphoid leukaemia (LL), astrocytoma and neuroblastoma.

Results: Approximately 2,250 new cancers are diagnosed in children and adolescents under the age of 18 in Germany every year. In this age group, leukaemia and lymphoma account for almost 50% of all new cancer cases, predominately acute forms. Overall, the prognosis is considerably better than in adults.

Conclusions: There is relatively little consistent evidence available on external factors as risk factors for childhood cancer, despite decades of research. For LL, the immune system and infections are assumed to play a role, as early training of the immune system appears to be protective. To an increasing degree, research is identifying genetic risk factors for many types of childhood and adolescent cancer. The therapy is sometimes very intensive and leads to a variety of late effects for at least 75% of the survivors, which may occur soon after the primary diagnosis, but also decades later.

CANCER · CHILDREN · ADOLESCENTS · GERMANY · EPIDEMIOLOGY · PROGNOSIS · LONG-TERM FOLLOW-UP

1. Introduction

Childhood and adolescent cancer constitutes only a very small proportion of cancer cases in Germany and throughout the world: The approximately 2,250 newly diagnosed cases in children and adolescents in Germany each year account for less than half a percent of the total number of cancer cases [1, 2]. From a different point of view, however, cancer is the most frequent cause of disease-related death in children aged 1 year and older. Since pediatric cancer survivors’ life expectancy is long and late-effects can last for or manifest during their entire lifetime, the relevance of the topic is larger than it initially seems based on the number of patients.

One in 370 girls and one in 310 boys are diagnosed with cancer before their 18th birthday, about half of them before school age. The spectrum of diagnoses and the proportional distribution of the diagnoses differ considerably from what is seen in adults: Some diagnoses which are relatively common in childhood and adolescence are not or rather
rarely seen in adulthood (the most frequent diagnosis at an adult age which also occurs in children, i.e. lymphoma, accounts for about 4% of adult cancer cases [2]); conversely, none of the diagnoses that are particularly frequently observed in adults (carcinomas of breast, prostate, bowel and lung) play a major role in children and adolescents [1]. The risk factors discussed for a large proportion of cases in adulthood generally do not apply.

The German Childhood Cancer Registry (GCCR) began to record the essential epidemiological data in 1980; here we briefly introduce the registry. Based on registry-data, three typical forms of childhood cancer along with their incidence and prognosis are herein presented in exemplary manner: Lymphoid leukaemia, astrocytoma and neuroblastoma. Furthermore, we will present a brief outline of what is known on causes and risk factors.

The therapy protocols (guidelines for diagnosis and treatment) in paediatric and adolescent oncology are centrally organised per diagnostic group throughout Germany, and often even across countries within Europe, and they are monitored closely. This has a tradition in German paediatric oncology, and is also necessary due to the small number of cases. This structure aims to achieve continuous improvement of the treatment and thus of the survival probability [3]. As meanwhile the prognosis has become very good for a considerable proportion of affected children and adolescents, many survivors have a life-long risk of late effects which can be attributed to the disease and/or the intensive therapy. The therapeutic improvements lead to an increase in the number of survivors with health care needs, ensuing specific and new challenges for the health care system. The most important aspects of research on late effects and long-term follow-up care are presented herein.

2. Data basis

The German Childhood Cancer Registry (GCCR) was founded in 1980 at the University Medical Centre of the Johannes Gutenberg University Mainz, with support of the predecessor societies of the Society for Paediatric Oncology and Haematology (GPOH). At the time the GCCR was founded, nationwide cancer registration was not yet established in Germany. The GCCR is one of the largest and oldest childhood cancer registries in the world. The GCCR contributed the largest single data set to the current worldwide overview ‘International Incidence of Childhood Cancer, Volume 3 (IICC3)’ of the IARC (International Agency for Research on Cancer of the WHO) [4]. The reports in Germany are almost exclusively provided by centres for paediatric and adolescent oncology. The guideline on paediatric oncology (KiOn-RL) of the Federal Joint Committee (G-BA) recommends that paediatric and adolescent oncology centres inform the affected families of the option to be reported to the GCCR [5]. Currently, there are still approximately 60 specialised centres in Germany, although there is an ongoing trend towards further centralisation [1, 6]. With the exception of a few types of cancer in older adolescents, which are not predominantly treated in paediatric and adolescent oncology centres, registration was mostly complete since about 1987, which is also reflected in internationally comparable rates of new cases (incidence rates).

Currently most paediatric and adolescent oncology centres treating these patients report a newly diagnosed child
to the GCCR on a paper form. This system is being transitioned to a digital reporting procedure compatible with that of the clinical-epidemiological state cancer registries. These electronic notifications are transferred by the digital tumour documentation systems of the centres, which also handle the mandatory reporting to the state cancer registries this task for all oncology departments of a clinic. A written informed consent from the custodians (parents) and/or patients is required so the German Childhood Cancer Registry can receive and process the data. By law, the state cancer registries are in charge of documenting all adult cancer patients from age of 18. The cooperation between the state cancer registries acting on a legal basis and the GCCR is a challenge which is currently being addressed. The joint goal is avoiding gaps in registration and enabling long-term follow-up across all ages.

The GCCR provides important functions for the German health system. In addition to regular annual reports [1] these include contributions to ‘Cancer in Germany’ of the RKI [2], contributions to governmental health reporting (e.g. [7]) and the implementation of research projects for various institutions (e.g. Federal Office for Radiation Protection). Investigations of suspected local clusters are conducted on request. The German Childhood Cancer Registry represents Germany in the international reporting of childhood and adolescent oncology, such as the IICC or EUROCARE [8].

Advances in therapy have led to long-term survival for more than 80% of all childhood and adolescent cancer patients. As a consequence, long-term follow-up has become as important in the tasks of the GCCR as the registration of new patients. With regard to long-term follow-up, the focus of the registry is on vital status and the recording of subsequent cancer cases, which occur considerably more frequently after a first cancer diagnosis in childhood and adolescence compared to cancer in the general population at the same age [9].

In addition to basic registration (recording new cases, recording subsequent cases, and deaths), the GCCR contributes to a variety of research projects – on its own, in cooperation, and by contributing logistics and/or data. More information is available in the annual reports and at www.kinderkrebsregister.de [1].

The data presented in the following are based on publicly accessible sources. Specifically these include the annual report of the German Childhood Cancer Registry (GCCR) [1], the regular publication ‘Cancer in Germany’ of the Robert Koch Institute (RKI) [2], the publications of the EUROCARE group [8], as well ‘International Incidence of Childhood Cancer (IICC)’ [10].

In addition, there are a number of reviews and synoptic publications, mainly from the Society for Paediatric Oncology and Haematology (GPOH) or in collaboration with researchers and physicians of the GPOH, such as [3].

3. Childhood and adolescent cancer
3.1 Overview

The German Childhood Cancer Registry began registration in 1980, and registration has been complete for most diagnoses since about 1987 judging by international standards. In 1991, registration was extended to include former East Germany. From 2009, registration was extended from age 0–14 to 0–17. A total of 74,258 new cancer cases were
registered from 1980 to 2021. Given the current total population, this is equivalent to approximately 2,250 newly diagnosed cases (incident cases) in children and adolescents under 18 years of age in Germany every year [1].

Incident cases in children are grouped and reported according to the International Classification of Childhood Cancer (ICCC), a fundamentally different classification than that used for adults; the ICCC3 version based on the ICD-O-3 is currently in use [11, 12]. Systemic malignant neoplasms, i.e. leukaemia and lymphoma and related diseases, account for almost 50% of all new cases in children and adolescents under the age of 18 (Figure 1). Acute forms predominate. Chronic forms, such as chronic lymphoid leukaemia, which is the most common form of leukaemia in adulthood, are diagnosed very rarely in children (approx. 10 cases per year in Germany).

With regard to solid tumours, sarcomas, blastomas, and some other forms of neoplasms predominate. Carcinomas, which predominate in adulthood, occur very rarely and when they do, mainly in older adolescents. Subsequent cancer represents a known late effect and some of the further cancers, so-called ‘subsequent primary neoplasms (SPN)’ may already occur in childhood and adolescence, for example thyroid carcinomas and skin tumours [9]. A SPN is a new subsequent cancer that is different from the initial diagnosis and also is not a relapse of the initial diagnosis. It can be an independent event, but can also be a consequence of an underlying genetic variant and/or a consequence of the therapy of the initial disease.

Figure 1
Percentages of the most frequent cancer diagnoses in children and adolescents under 18 years of age in Germany by sex (2010–2019)
Source: German Childhood Cancer Registry, [1]
Childhood and adolescent cancer in Germany – an overview

3.2 Incidence rates, age distribution and survival probability of three exemplary cancer diagnoses

Despite the current survival probabilities being generally high (see below), cancer in childhood and adolescence remains the most frequent disease-related cause of death in this age group.

In this paper we present three selected diagnoses: lymphoid leukaemia is the single most frequent diagnosis, astrocytoma is the most common tumour of the central nervous system (CNS) and neuroblastoma is a typical malignant disease in early childhood (aside from CNS tumours this is the most frequent solid tumour in children).

Lymphoid leukaemia

Lymphoid leukaemias (LL, ICCC3 group I(a)) account for 75% of all leukaemias, myeloid and myeloproliferative diseases (ICCC3 class I) in childhood and adolescence. Other important diagnoses in this class include acute myeloid leukaemia (I(b)) and the myelodysplastic syndrome (I(d)). A total of 98% of all LL are B-precursor cell leukaemias (I(a)1) and thus acute lymphoid leukaemias. One in 1,700 girls (approx. 210 new diagnoses/year) and one in 1,350 boys (approx. 280 new diagnoses/year) are diagnosed before their 18th birthday. The average age at diagnosis is between the 5th and 6th birthday, with children between their 1st and 6th birthday being affected particularly frequently. However, the disease also manifests in infants (‘infant leukaemia’) and older adolescents. Boys are affected more often than girls in almost all age groups except for the first year of life (Figure 2) [1].

The incidence rate in Germany, and also in Europe, has increased slightly but steadily since the 1980s, with a plateau being reached since about 2005 [1, 13]. The incidence rate in the former GDR was about 20% lower than in the West of Germany, but the incidence rates have converged since about 1997. The different living conditions in the former GDR, such as the higher vaccination rate, higher
The 15-year survival probability is now 90% (Figure 3). The 5-year survival of 92% in Germany is slightly above the European average of 90% [1, 8]. Survival has improved significantly since the 1980s, when the 15-year survival probability was 64%, to today's 90% 15-year survival probability, with most of the progress having been achieved before 2000. The incidence of SPN after LL is average compared to the incidence after all childhood cancers; LL in turn are not particularly frequent as SPN. In contrast, acute myeloid leukemias (ICCC3 I(b)) are rather common SPNs, and in the first 5 years after an initial cancer diagnosis they are the single most frequent subsequent cancer diagnosis [1, 9].

Astrocytoma
Astrocytoma (ICCC3 III(b)) accounts for 45% of all reported CNS tumours (ICCC3 III). About half of the reported astrocytoma diagnoses were reported as malignant or as ‘uncertain’ respectively. Of all reported CNS tumours, 56% are malignant and astrocytomas account for 38% of these.

The diagnostic range in childhood and adolescence differs considerably from that in adults.

Figure 3
Survival probability after lymphoid leukaemia in children and adolescents under 18 years of age in Germany by decade of diagnosis
Source: German Childhood Cancer Registry

Figure 4
Astrocytoma incidence rates in children and adolescents in Germany by sex and age (2010–2019)
Source: German Childhood Cancer Registry, [1]
Childhood and adolescent cancer in Germany – an overview

One in 3,180 girls (approximately 110 new diagnoses/year) and one in 3,150 boys (approximately 120 new diagnoses/year) are diagnosed with the disease before their 18th birthday. Girls and boys are affected more or less equally, and there is no marked age dependence (Figure 4). In Germany, an increase in incidence was observed until about 2005: We assume that the non-malignant brain tumours were not completely reported earlier and that the increase in incidence reflects the efforts to improve completeness. By now, the incidence rates in Germany are comparable to those in the Nordic countries, whose registries are considered to have practically complete coverage [4].

The current long-term prognosis of 81% for astrocytomas is rather good compared to other CNS tumours (Figure 5). The 5-year survival in Germany is 84%, which is slightly above the European average of 80% [16]. In the most recent 1–2 decades, further improvements in survival probability have been achieved. The risk of SPN after astrocytoma is below average compared to the incidence after all childhood cancers. CNS tumours account for almost a quarter of SPNs observed in the first 30 years after the primary diagnosis, more than half of those are meningiomas (ICCC3 III(e)5), astrocytomas are the second most frequent ones [1, 9].

Neuroblastoma

Neuroblastoma (ICCC3 IV(a)) is part of the group of embryonal tumours, which are mostly diagnosed very early in life, in rare cases even prenatally. Other embryonal tumours in childhood include nephroblastomas (ICCC3 VI(a)), hepatoblastomas (ICCC3 VII(a)), retinoblastomas (ICCC3 V(a)) and medulloblastomas (ICCC3 III(c)1) [17]. One in 6,850 girls (approximately 50 new diagnoses/year) and one in 5,300 boys (approximately 70 new diagnoses/year) are diagnosed with neuroblastoma by their 18th birthday [1]. Neuroblastoma occurs almost exclusively before school age, most frequently in the first year of life, and most frequently in the first months of life. Overall, boys are affected 40% more often (Figure 6).

A large-scale study was conducted in Germany from 1995 to 2001 to investigate whether the prognosis can be improved through screening, by diagnosing neuroblastoma before it becomes metastatic. It turned out that the number of children with metastases could, unfortunately, not be reduced, while a relatively large number of tumours, which otherwise would have regressed spontaneously without diagnosis and treatment, were additionally diagnosed by screening. Accordingly, some children were thus possibly overtreated [18, 19]. The German study focused on children after their first birthday, a similar project with younger children in Canada produced the same results. The contribution of the German Childhood Cancer Registry was crucial for this project [20, 21].
The prognosis is considerably better than for adult cancer, making late effects an important issue.

There was considerable progress made in therapy in the 1980s and early 1990s, but no major further improvements have been achieved since. The 15-year survival is now at 77% (Figure 7). The 5-year survival of 80% in Germany is clearly above the European average of 75% [1, 8]. The prognosis depends very much on age and cancer stage at diagnosis: While almost all children under 18 months of age with a localised tumour survive, and chemotherapy and radiotherapy can sometimes be omitted from the treatment, the prognosis for children 18 months of age and older, relatively many of whom are already diagnosed at a metastatic stage, is unfortunately still slightly below 50%, despite decades of research and improvements in therapy [22]. The risk of SPN is below average compared to the incidence after all childhood cancer diseases; neuroblastomas almost never manifest as SPN [1].

3.3 Causes and risk factors

Despite many years of major international research initiatives, there are relatively few consistent insights into the causes and risk factors of childhood cancer as far as it concerns external factors; in particular, study results on environmental factors are very inconsistent. As far as currently known, external risk factors, i.e. potentially alterable risk factors, are responsible for at most a small fraction of the cases in children.
In leukaemias and CNS tumours, radiation exposure and exposure to pesticides play a role in a small number of cases [23, 24]. For leukaemias, an increased risk by birth weight (20% increase in risk per kg of extra weight or increased risk for children above 4000g) has been reported in several studies [25]. From many different perspectives, a role of the immune system and infections has been reported, at least for LL, especially for the most common subtype B-precursor cell leukaemia. Early training of the immune system (in the first years of life) lowers the risk somewhat. Immune system training is associated with breastfeeding, vaccination, many social contacts with humans and animals (which in turn is associated with social status (higher or lower social status depending on the social background), large families or living with older siblings, institutional child care and cramped living conditions) and infections experienced in early life [26–29]. In some cases, an untrained (‘naïve’) immune system seems to respond with leukaemia to an infection, a phenomenon demonstrated for influenza epidemics [30–32].

Little is known about risk factors for astrocytomas. With regard to astrocytomas and meningiomas, cases occur more often after prior therapeutic cranial irradiation [9, 33]. Many embryonal tumours, especially nephroblastomas, have been reported to be associated with congenital malformations [34]. Hardly anything is known about risk factors specifically for neuroblastoma. The emergence of neuroblastoma cells is an ongoing research issue [35, 36].

Strong associations of cancer risk in childhood and adolescence have been identified with a growing number of rare genetic syndromes, some of which are very specific for certain combinations of rare syndromes and cancer types [37–44]. For example, patients with RASopathies (a specific group of rare genetic syndromes such as Noonan syndrome), have ten times the cancer risk than expected, an approximately 30-fold risk was observed for Beckwith-Wiedemann syndrome and about 40-fold for Fanconi anaemia. In recent years, research focussed on the search for other previously unknown genetic risk factors, which seem to play a greater role in childhood cancer than previously assumed [37, 44]. These genetic syndromes also seem to be partly responsible for patients experiencing multiple subsequent cancers in their lifetime. According to the most recent findings, the increased risks of SPN after childhood and adolescent cancer due to chemotherapy or radiotherapy of the initial disease may also be modified by predisposing genetic factors [45].

3.4 Therapy

More than 90% of all patients with childhood and adolescent cancer in Germany are treated according to the nationally standardised protocols or in therapy studies centrally organised by the GPOH. Mostly initiated in the 1970ies, this system involves the GPOH appointing experts to diagnostic groups, who then develop and further improve the therapy protocols and monitor compliance with the protocols in the paediatric oncology centres [3, 46]. Due to the rarity of each single diagnosis, it is of considerable importance for the centres to have knowledgeable consulting specialists for each patient during the treatment within the framework of this system. A wide range of therapy elements are used for childhood and adolescent cancer, including surgery, cytostatic chemotherapy, radiotherapy, stem cell.
therapy and antibody therapies [46–48]. The therapy regimens have become increasingly differentiated over the past decades, so that today the therapy is largely tailored to the individual patient. For this reason, further therapy research now requires international cooperation for almost all diagnostic groups. The GPOH cooperates with the working groups of the SIOP (International Society of Pediatric Oncology) and the SIOPE (SIOP Europe). Especially in the case of diagnoses where further improvements in prognosis are difficult to achieve, the focus of clinical research is increasingly shifting towards reducing the short- and long-term physical consequences of the therapy on healthy tissue (toxicity), while still maintaining the same level of survival.

3.5 Long-term survival and late effects

Since the prognosis is good and the life expectancy of the affected children and adolescents is long, the long-term follow-up after cancer in childhood and adolescence plays a major role [49]. The sometimes very intensive therapy leads to considerable late effects on the body, including increased mortality, sometimes soon after the primary diagnosis, sometimes decades later [50–52]. The international literature assumes that at least 75% of all survivors are affected by late effects [53]. Some late effects are known from adult oncology, but in many cases the fact that a body was exposed to chemotherapy or radiotherapy during growth plays a special role. Late effects can affect all aspects of health beyond the notable SPN risk, as exemplified by relatively early onset of heart failure (cardiomyopathy), hearing impairment, fertility and other endocrine (hormonal) disorders. Irradiation of the brain can also lead to cognitive impairment [54–56].

The world wide data on late effects for former patients up to a current age of about 50 years is relatively good, but unfortunately relatively few data are available for patients beyond this age [57, 58]. This is due to the fact that before about 1970 the prognosis of childhood cancer was still very poor, but also because hardly any systematically collected data and major long-term cohorts are available from before this: the German Childhood Cancer Registry was founded in 1980; with some exceptions, the earliest registries, cohorts and data collections in Europe and the USA did not start much before the 1970s [59–61].

In Germany, as in many other countries, the transition of long-term survivors from paediatric and adolescent oncology to community-based care as they reach adulthood is a major problem for the survivors. Ongoing projects on healthcare address many different aspects, such as the Verskik project [62], which examines the extent of survivors’ current usage of the healthcare system and whether the care meets the standards recommended in the guidelines. A wide range of GPOH initiatives aim to provide survivors with care better tailored to their needs and to improve the pertinent guidelines [63]. At the European level, there are established structures in some countries [64, 65] and initiatives to improve it under the umbrella of PanCare [66].

4. Conclusion

Childhood and adolescent cancer is rare and rather special in terms of diagnoses and research topics. Still there are some overlaps with the registration of and research efforts
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on the much more frequent cancer cases in adulthood. Germany has special established structures for the care and registration of childhood and adolescent cancer: the Society for Paediatric Oncology and Haematology (GPOH) and the German Childhood Cancer Registry (GCCR).

The close cooperation with the specialised centres for paediatric and adolescent oncology ensures complete reporting up to the age of 15, but not necessarily beyond this age, which leads to less than complete reporting of cases in older adolescents from the age of 15 and certain diagnoses, as some of these older patients are being treated in general oncology centres. The reporting channels to the GCCR have not yet generally been extended to this group. The implementation of electronic reporting out of the tumour documentation systems of the hospitals, analogous to the procedure adopted by the state cancer registries, is expected to solve this problem.

The 10-year survival probability of 85% is much better than the cancer survival for older age groups (less than 50%) [1, 2]. The 10-year prognosis improved from overall 66% and 74% in the 1980s and 1990s, respectively, to 85% in the most recent decade [1]. For many types of childhood and adolescent cancer, a plateau has by now been reached, where further improvement seems unlikely for now. In contrast to adults, individual lifestyle-related risk factors play only a minor role. A steadily increasing number of genetic risk factors for childhood and adolescent cancer have been identified through research in recent years, which opens up new paths for diagnostics and therapy, perhaps even for screening.

The focus on long-term follow-up of the many long-term survivors and their broad range of symptoms and late effects is a challenge for paediatric and adolescent oncology to get involved in healthcare research beyond the traditional inpatient clinical care to improving long-term care.

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Data protection and ethics
The data of the German Childhood Cancer Registry are collected with the informed consent from patients and/or caretakers in compliance with the General Data Protection Regulation (GDPR). A separate consent or an ethics vote were not required for this report. Data of the German Childhood Cancer Registry are not publicly available beyond the aggregated figures published in annual reports or publications. Cooperation for scientific projects is generally possible upon request.
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