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New Results from Diabetes Surveillance in Germany

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Editorial: Diabetes surveillance in Germany – status and perspectives

Against the backdrop of the great public health importance of diabetes mellitus, receiving funds from the Federal Ministry of Health (BMG), the Robert Koch Institute (RKI) has begun a research project to establish diabetes surveillance in Germany. In the public health context, surveillance refers to a systematic long-term collection and analysis of health data to facilitate decisions regarding the planning, implementation and evaluation of public health measures [1]. Diabetes surveillance is thereby fundamentally concerned with transparently providing key information on diabetes in Germany for actors in health policy, health research and practice as well as the general public. This includes information on risk factors, disease rates, disease outcomes and the quality of medical care. Within the first four-year project phase (2015-2019), a scientific framework concept with four fields of action and 40 key indicators was developed, data sources to map these indicators were established, and formats for user-oriented reporting created. An interdisciplinary [scientific advisory board](#) has continuously guided the project [1].

Type 2 diabetes is the dominant form of diabetes at adult age and as one of the globally most common chronic diseases now stands in the focus of international action plans for the prevention of noncommunicable diseases [2]. Elevated blood sugar levels as a result of decreased insulin action (insulin resistance) are the hallmark of this type of diabetes. Besides genetic factors, the important risk factors for type 2 diabetes and other common noncommunicable diseases include in particular older age and health

risks such as obesity, physical inactivity and smoking, which have a high prevention potential. As behaviour-related risk factors are closely settings bound, i.e. tied to people's social, cultural and work environments or their physical environments, this translates into a responsibility for the whole of society to promote the prevention and containment of type 2 diabetes, other frequent noncommunicable diseases and contribute to reducing health inequalities [3, 4]. Next to type 2 diabetes, which is the most frequent form of diabetes at adult age, diabetes surveillance also covers the far rarer type 1 diabetes that usually develops at child and adolescent age as well as gestational diabetes. Both primary data from the RKI from national health surveys as well as disease registry data and disease management program (DMP) data for diabetes types 1 and 2 as well as routine billing data from the statutory health insurance system for secondary use (called secondary data) are continuously being used to fill indicators in the four fields of action: 1. Reducing diabetes risks, 2. Improving early detection and treatment of diabetes, 3. Limiting diabetes complications, 4. Reducing the disease burden and costs. To ensure the use of external data sources in the long term, develop potential uses, identify and reduce data use limits, annual tenders for [cooperation projects](#) have been published in the context of diabetes surveillance and selected based on standardised criteria. The articles in this issue of the Journal of Health Monitoring on [New Results from Diabetes Surveillance in Germany](#) provide an overview of the key results diabetes surveillance has provided towards

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the end of the first project phase set to conclude at the end of 2019.

In the first article, [Heidemann et al.](#) ask whether diabetes-related social inequalities have increased for adults in Germany over time. The findings are based on data from continuous health monitoring at the RKI with information that was collected in national population representative interview and examination surveys on adult health in Germany between 1997 and 1999 (German National Health Interview and Examination Survey, GNHIES98) and 2008 to 2011 (German Health Interview and Examination Survey for Adults, DEGS1). As the results convincingly show, levels of education have a clear impact on diabetes prevalence and estimated 5-year diabetes risks in Germany, however, not on quality of life and certain aspects of quality of care. During both survey points and for both genders, diabetes prevalence is considerably higher among adults with low education compared to those with high education. This finding applies for both medically diagnosed diabetes as well as to unknown diabetes. That the prevalence of unknown diabetes has dropped across all education groups, with a concomitant increase in medically diagnosed diabetes and relatively constant overall prevalence could indicate improved early detection. It is, however, problematic that over the same period the education gap in the estimated 5-year diabetes risk among adults in Germany has continued to widen. For both genders, a significant decline can only be seen in the high education group. This represents a major challenge for health promotion and primary care, the successes of which should be closely monitored at the population level. Regarding the developments of the impact of diverging levels of education on quality of

care, the results do not indicate pronounced levels of educational inequality at either survey point. Over time, clear improvements in particular in the low education group are visible. This applies to meeting guideline-based objectives for glycosylated haemoglobin (HbA1c or long-term blood sugar), blood pressure and blood lipids, self-measurement of blood sugar, and regularly attending medical examinations of the ocular fundus and the feet. At least between 1997 and 1999, taking statins was less common in both genders in the low education group in comparison to the medium or high education groups. However, these differences may not be statistically significant due to the very low number of statin users at the time. Yet, as even countries with universal access to their health care system report social differences in the quality of care [5-7], there is a need for further research here. In future, it will be important to include hard endpoints such as overall mortality and cardiovascular complications next to figures on care processes and target achievement criteria for the regulation of blood sugar, blood pressure and cholesterol values. In addition, the operationalisation of social inequality should be extended beyond merely education. Observations from Germany show that in children and adolescents with type 1 diabetes both lower individual social status and a higher regional deprivation index are associated with poorer quality of care [8-10].

The second article by [Rosenbauer et al.](#) shows how the data gaps on type 1 diabetes and type 2 diabetes in children and adolescents in Germany could be closed in the future. In contrast to the civilisation disease type 2 diabetes, type 1 diabetes, the second major form of diabetes mellitus, is much less common and has often already developed

in childhood or adolescence. Type 1 diabetes is caused by a not hitherto fully understood autoimmune reaction that destroys the pancreas' insulin-producing cells. The consequence is a lifelong insulin dependency that places high demands on the self-management of patients and the quality of medical care. Not least, this applies with regard to the important technological advances made in insulin pumps and measuring instruments for continuous glucose measurement in the subcutaneous tissue as well as on-demand insulin delivery by means of so-called 'closed loop systems' [11, 12]. Estimates on the prevalence of type 1 diabetes among children and adolescents in Germany have been based on (one national and three regional) incidence registries since the mid-1990s with a high degree of completeness [13, 14]. Still lacking in Germany are standardised comparable estimates over time on the prevalence and incidence of type 1 diabetes among adults and overall estimates across all age groups. An increase in type 2 diabetes in children and adolescents is generally suspected, yet so far no time series based on systematic and continuous data collection has been established. Both the regional registry in North Rhine-Westphalia (NRW) and the national DPV registry (Diabetes-Patienten-Verlaufsdokumentation) meanwhile include all newly diagnosed cases of type 1 diabetes in adults and type 2 diabetes in children and adolescents - however coverage is not complete. Based on statistical methods (capture-recapture), data from the registry in NRW was used to estimate coverage rates. Assuming varying degrees of completeness, capture-adjusted estimates of the prevalence and incidence of type 1 diabetes in adults aged over 18 were established based on German DPV registry data. For type 1 diabetes in adults aged over

18, current prevalence estimates (493 per 100,000 people or a total of 341,000 people for the year 2016) and incidence (6.1 per 100,000 person years or 4,150 new patients per year) are significantly higher than the earlier estimates based on analyses of statutory health insurance data. In the synopsis with the data on children and adolescents up to 18 years already available, the results for Germany indicate that there are currently 373,000 people with type 1 diabetes, implying an estimated absolute number of 7,265 new patients per year. For type 2 diabetes among children and adolescents, in addition to estimates based on the available NRW and DPV registry data, further surveys were conducted in diabetes registry clinics in Baden-Württemberg and Saxony. The results for the period 2014-2016 show that type 2 diabetes among children and adolescents in Germany remains a rare disease with a prevalence of an estimated 12 to 18 per 100,000 persons, a total of about 950 children and adolescents and an estimated 175 new cases per year. Based on the rare occurrence of type 1 diabetes and especially of type 2 diabetes in children and adolescents, population-based samples are poorly suited to record disease rates over time. Analyses of routine data, too, from statutory health insurances have their limits because of often unclear or incomplete coding and changing case definitions. An expansion of the available registry data with improved completeness detection is therefore essential for reliable, comparable trend estimates over time on the disease burden and need for care in the context of diabetes surveillance.

The third article by [Schmidt et al.](#) discusses the question of secondary data. Secondary data refers to data that has been primarily collected for a different purpose [15].

This can be data which has been collected for a study and is then analysed to answer a new research question. Often, secondary data is data that is primarily collected for routine or billing purposes, for example the data of social security institutions such as health or pension insurances, medical record data or disease management program data. It has clear disadvantages compared to primary data such as the survey data referred to above. For example, it does not usually contain any patient-reported variables (such as quality of life). The validity of this data for the research question needs to be carefully evaluated. However, such data also has a number of relevant advantages. Large populations can be observed. There is no selection due to non-participation. Regional stratifications are possible. Some events, which are of key importance as outcome indicators, are well and fully described, for example amputations or strokes. Furthermore, process variables can be collected that cannot be validated easily in interviews, such as the number of doctors' appointments or certain examinations, that patients either do not reliably remember or are not aware of. In addition, longer periods of time can be surveyed in a tight temporal sequence [15]. Many key findings on diabetes in Germany are based on secondary data, such as diabetes prevalence, stroke and amputation incidence [16, 17], referrals to doctors [18], and cost of medical care [19]. However, little data has routinely been available so far and separate studies are required. In addition, methodological aspects need to be critically reflected, such as differences between different health insurance organisations regarding the composition of the insured population or the suitability of routine data to assess health events [20]. Using routine data in diabetes surveillance therefore depends on

the one hand on establishing the validity of data sources and possibly reviewing the methodology. On the other hand, it is important to determine the availability and potential of continuity in terms of a regular provision of data for surveillance. Such an approach is highly important because 14 of the 40 indicators of diabetes surveillance exclusively use secondary data and a further eleven indicators, which are mainly based on RKI health monitoring data, in addition require secondary data. The article describes the two 'work packages' diabetes surveillance has devoted to secondary data. First, [cooperation projects](#) were conducted in which external partners examined data sources regarding their validity, availability and usability for surveillance. Secondly, based on the DaTraV dataset (according to the Data Transparency Regulations), criteria for the operationalisation of diabetes prevalence were defined and the data evaluated.

The following [projects](#) were realised:

1. On the basis of data from the diagnosis related groups statistics (DRG statistics), trends in outpatient-sensitive hospital cases in diabetes mellitus were analysed: There was a marked decrease in age-adjusted amputation rates, which - at least partially - could be related to improvements in care [21].
2. The usability of DMP data for diabetes surveillance was tested: It turned out that DMP data, despite some limitations (selection, questionable validity of the documentation), can provide important results, such as the achievement of quality objectives and the implementation of care in accordance with guidelines.
3. The presentation of relevant quality of care indicators based on AOK data was analysed: The project highlighted

that adequately prepared secondary data has the potential to close data gaps in diabetes surveillance. Based on the project results, four further indicators were included in the diabetes surveillance indicator set.

4. DaTraV data was used to project future scenarios of diabetes development in Germany: Assuming that demographic developments continue and diabetes prevalence remains constant, the absolute number of persons with diagnosed type 2 diabetes would increase by 21% between 2015 and 2040 [22].
5. The potential value of geocoding services data to make statements on the obesogenicity of an environment, which means an environment that potentially increases obesity, was analysed: The project developed a method that allows areas with obesogenic and/or protective environmental factors to be identified. Potentially, this could be used in diabetes surveillance.
6. Healthy life years and life years lost were calculated as indicators for diabetes burden: The majority of models indicated an increase in healthy life years between 2015 and 2040 as well as a relative decline in lost life years by up to 64%.
7. The incidence trends for renal replacement therapy were analysed based on medical records and a concept was established for analysis based on the data of statutory health insurances. Furthermore, the usability of DaTraV data for monitoring the trends in terminal renal insufficiency was analysed: Unlike for other complications, no decline in the incidence of renal replacement therapy was observed during the 2000s. Currently, the trend between 2002 and 2016 is being analysed. An analysis of DaTraV data showed that validation by comparing

data on renal replacement therapy with data on the diagnosis of terminal renal replacement therapy can provide insights as to whether information on a terminal renal replacement therapy is continuously available for diabetes surveillance based on DaTraV data and can therefore provide a valid measure.

The second work package, in cooperation with experts from epidemiology and health services research, developed a reference definition for the future presentation of the documented prevalence of diabetes in the context of diabetes surveillance, which is based on DaTraV data. Overall, the article clearly shows that secondary data is a key element to map indicators of diabetes surveillance that substantially complements RKI health monitoring. This data can provide time series for the development of numerous indicators.

In the final article, [Reitzle et al.](#) consider the central question of data processing and dissemination of the results of surveillance to actors in politics, research and practice. Taking diabetes as a concrete example, between April and September 2018, the models and experiences in 46 countries, among them 28 EU member states, five further European nations and 13 non-European OECD member states, were taken stock of. Structured online interviews with public health and health policy experts in 27 countries as well as structured internet searches (key word searches on the websites of public health institutes, health ministries, statistical offices and keyword-based searches on Google) provided the basis. There were 19 countries in which no interviews could take place. Information from web searches that were not available either in English,

French or German were translated into English and included where appropriate. The results highlight the great importance awarded to health reporting on diabetes in 80% of the 46 countries (n=37), which is underwritten in more than three quarters of these countries by a national diabetes strategy or a national diabetes action plan. Reporting is mainly based on indicators (n=29) and in many countries (n=21) not diabetes specific but set within the context of an indicator-based reporting on a number of noncommunicable diseases. As in Germany, many countries use a diverse set of data sources in reporting, in many cases primary data from health surveys, but they also use secondary data from available routine data. The results of this analysis are already being considered in the development of formats for continuous diabetes reporting in Germany. The first report (print and online) will be published at the end of the first project phase of diabetes surveillance at the end of 2019. During the second project phase (2020-2021), expanding cooperation with actors in politics, public health research and practice in Germany, as well as with international public health institutes, will play a fundamental role.

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Social inequality and diabetes mellitus – developments over time among the adult population in Germany

Abstract

The connection between social disadvantage and the presence of known diabetes and specific risk factors is well documented. This article summarises the results from the Robert Koch Institute examination surveys that were conducted between 1997 and 1999 as well as 2008 and 2011 to address social inequality – operationalised by level of education – with regard to prevalences of known and unknown diabetes, risk of diabetes and care of diabetes as well as their development over time. Both survey periods showed that the low education group has higher prevalences of known and unknown diabetes as well as a higher risk of developing diabetes within the next five years compared to the medium and high education group. Over time, prevalence tended to increase for known diabetes and to decrease for unknown diabetes for all education groups. For the 5-year diabetes risk, only the high education group showed a clear decrease over time. The chosen indicators of diabetes care indicated no clear differences between education groups and an improvement of diabetes care over time. For some indicators of care (foot examination, statins), improvements were only seen in the low education group. In conclusion, social inequalities in the prevalence of known and unknown diabetes as well as in diabetes risk remain in Germany; for the indicators of care, however, no clear education gradient is evident. Over time, inequality regarding the prevalence of diabetes has not increased further. However, with regard to diabetes risk, inequality has become slightly more evident. For individual care indicators, improvements are limited to specific education groups.

DIABETES MELLITUS · EDUCATION · PREVALENCE · DIABETES RISK · DIABETES CARE

1. Introduction

Diabetes mellitus is a metabolic disease with a disturbed regulation of blood glucose (blood sugar) [1]. The main risk factors of the disease's most common form, type 2 diabetes, include unfavourable health-relevant behaviours such as lack of exercise, an unhealthy diet, and smoking, along with being overweight as a frequent consequence [2]. Unknown or inadequately treated diabetes leads to

chronically elevated blood glucose concentrations. Blood vessels and the nervous system can be subsequently damaged, resulting in diabetes-specific complications (such as renal dysfunction, eye disease, diabetic foot syndrome, and amputations of the lower limb) as well as cardiovascular diseases (such as heart attack and stroke). These severe diabetes-related diseases lead to a loss of health-related quality of life and life expectancy for affected individuals and place a high financial burden on the health system [3].

Info box 1:**Nationally representative interview and examination surveys for adults conducted by the Robert Koch Institute (cross-sectional surveys)**

- ▶ German National Health Interview and Examination Survey 1998 (GNHIES98, 1997-1999)
- ▶ German Health Interview and Examination Survey for Adults (DEGS1, 2008-2011)

Objectives: Providing information on health status, health behaviour and health care of the population in Germany and analysis of trends over time

Survey methods: Self-administered written questionnaire, physical examinations and tests, computer-assisted medical interview, assessment of currently used medications, laboratory analyses of blood and urine samples

Target population: Adults aged 18 to 79 years with permanent residence in Germany

Sampling method: GNHIES98: Registry office sample; randomly selected individuals from 120 municipalities in Germany were invited to participate
DEGS1: Registry office sample; randomly selected individuals from 180 municipalities in Germany were invited to participate (120 original sample points of the GNHIES98 and 60 new sample points).

Participants: GNHIES98: 7,124 adults
DEGS1: 7,987 adults (3,795 GNHIES98 revisiting participants, 4,192 first time participants)

Response rate: GNHIES98: 61%
DEGS1: 64% for GNHIES98 revisiting participants, 42% for first time participants

More information can be found at Thefeld et al. 1999 [8], Kamtsiuris et al. 2013 [9] and Scheidt-Nave et al. 2012 [10] as well as at www.degs-studie.de/en

Due to these health impacts and the rising prevalence of diabetes – particularly of type 2 diabetes, which tends to become more frequent with increasing age – diabetes presents a major public health challenge in Germany and most other countries [2, 4].

Analyses of the temporal development of the presence of diabetes and its risk factors as well as the diabetes care situation are a decisive prerequisite to adapt or monitor prevention and care measures and to estimate the development of diabetes-related health system expenditure. As socioeconomic factors are often related to health-relevant behaviour and its associated diseases, comparing population groups and, where appropriate, developing target group- or setting-specific measures are important [5].

Such an analysis and provision of results on risks, presence and care of diabetes in Germany is the purpose of the national diabetes surveillance currently being developed at the Robert Koch Institute (RKI) [6]. The aim is to regularly provide information on 40 defined indicators or indicator groups [7]. This article considers the development over time of some key indicators of diabetes surveillance from the fields of diabetes risk, diabetes prevalence (frequency of diabetes) and diabetes treatment for the overall German adult population as well as stratified by level of education and gender. It is based on the data of the population-representative health interview and examination surveys of the RKI.

2. Methodology**2.1 Study population**

This article is based on data collected by two nationwide interview and examination surveys, the German National Health Interview and Examination Survey 1998 (GNHIES98, 1997-1999) and the German Health Interview and Examination Survey for Adults (DEGS1, 2008-2011) conducted as part of the continuous health monitoring at the RKI (Info box 1). Figure 1 shows the study populations as they were defined for both survey periods and used for the estimation of indicators of diabetes prevalence, diabetes risk and diabetes care.

2.2 Indicators

The definitions can be found for the indicators known diabetes and unknown diabetes in info box 2, for the indicator 5-year risk of developing type 2 diabetes in info box 3, for indicators related to the quality of care for type 2 diabetes in the areas of achieving treatment goals and self-management or medical care in info box 4 and info box 5, and for subjectively assessed health-related quality of life of type 2 diabetes in info box 6.

The data used to calculate indicators stem from GNHIES98 and DEGS1 and were collected in the form of self-administered written questionnaires (including questions on smoking habits, physical activity, diet, health-related quality of life), physical examinations (including measurements of body height, waist circumference, systolic and diastolic blood pressure), a computer-assisted medical interview (including questions on physician-diagnosed

Info box 2:

Indicator known diabetes:

- ▶ Physician-diagnosed diabetes mellitus or
- ▶ Taking anti-diabetic drugs (ATC-Code A10)

Indicator unknown diabetes:

- ▶ No known diabetes and
- ▶ Glycated haemoglobin (HbA1c) value $\geq 6.5\%$

Both indicators are given as a prevalence, i.e. a proportion (in %) of people with known or unknown diabetes mellitus (without differentiating between types of diabetes) in the population.

Source: Nationale Diabetes-Surveillance am Robert Koch-Institut 2018 [7], Heidemann et al. 2016 [12]

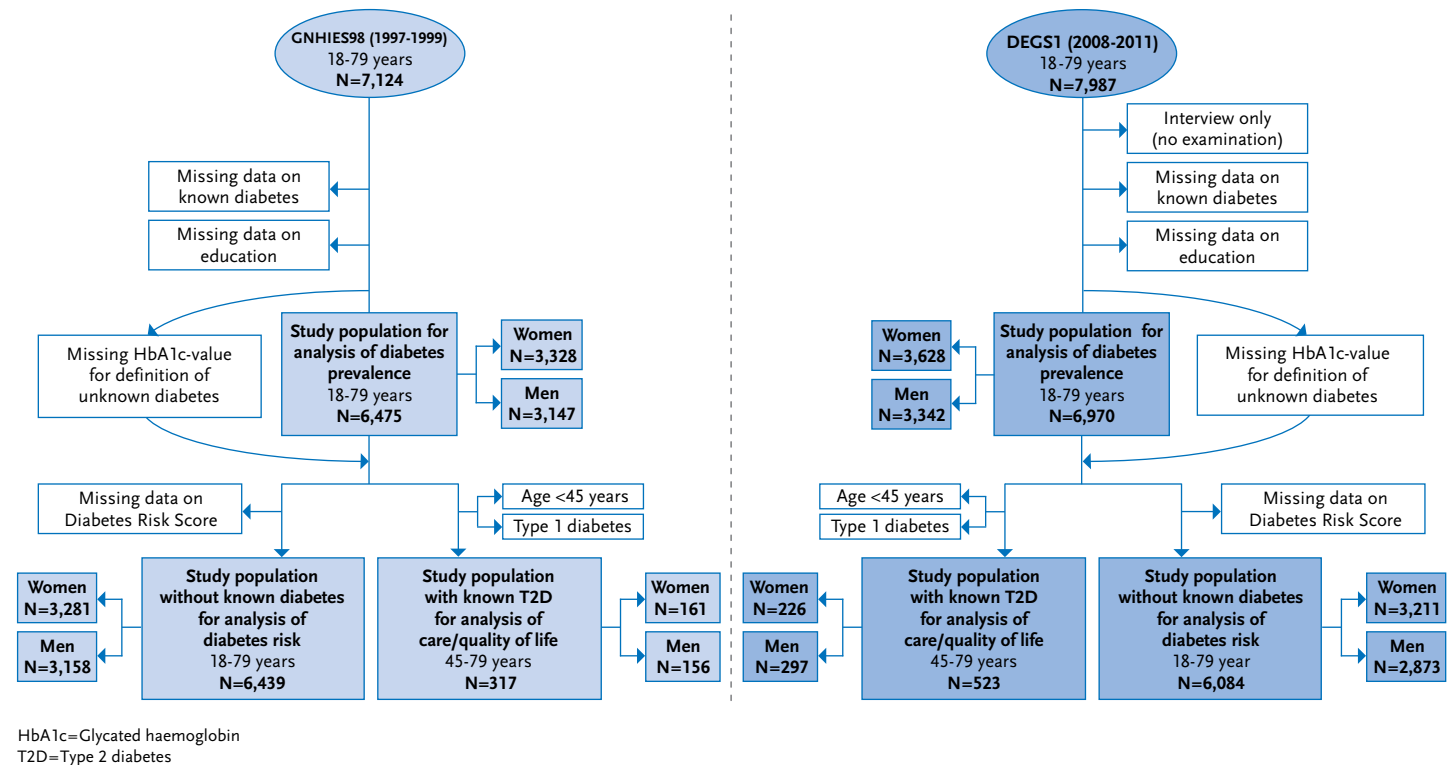
ATC=Anatomical Therapeutic Chemical Classification System

diseases, family history of diabetes, self-monitoring of blood glucose, medical examinations of the eyes and feet), an assessment of currently used medications (including documentation of medications to treat diabetes (anti-diabetic drugs) and certain medications to treat lipid metabolism disorders (statins)) as well as laboratory analyses of blood samples (including determination of glycated haemoglobin (HbA1c, a long-term blood sugar value), total and high-density lipoprotein cholesterol (HDL cholesterol)). In both surveys, indicators were obtained by similar methods. Only the health-related quality of life was assessed by different versions of the Short Form-36 Health Survey

(SF-36). However, a recommended standardisation procedure was used to ensure comparability between the two versions [11]. The family history of diabetes was assessed exclusively in DEGS1. Detailed descriptions of the data collection process have been published elsewhere [11-14].

All indicators are stratified by level of education and, additionally, gender. Level of education as an indicator of social inequality was defined via the CASMIN Index (Comparative Analysis of Social Mobility in Industrial Nations). This is based on the data provided by self-administered written questionnaires in GNHIES98 and DEGS1, which take both general and vocational training into account and

Figure 1
Study populations of the German National Health Interview and Examination Survey 1998 and the German Health Interview and Examination Survey for Adults
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011)



Info box 3:**Indicator 5-year risk of developing type 2 diabetes**

The German Diabetes Risk Score (DRS) developed by the German Institute of Human Nutrition Potsdam-Rehbrücke calculates the absolute 5-year risk of developing type 2 diabetes (in %) for people who have so far not been diagnosed with diabetes. For example, a 5-year risk of 8% means that eight out of 100 people with the same DRS points will be diagnosed with type 2 diabetes over the course of the next five years.

Diabetes Risk Score (DRS) points =

- +5,1 x age (years)
- +7.6 x waist circumference (cm)
- 2.7 x body height (cm)
- +47 x physician-diagnosed hypertension
- 2 x physical activity (hours/week)
- +15 x former smoker <20 cigarettes/day
- +45 x former smoker ≥20 cigarettes/day
- +23 x smoker <20 cigarettes/day
- +77 x smoker ≥20 cigarettes/day
- 7 x whole grain consumption
(per 50g portion/day)
- 5 x coffee consumption (per 150ml cup/day)
- +55 x red meat consumption
(per 150g portion/day)
- +56 x 1 parent with diabetes
- +106 x both parents with diabetes
- +48 x brother or sister with diabetes

5-year risk of developing type 2 diabetes =

$$1 - 0.99061 \exp [(DRS \text{ points} - 474.17096591)/100]$$

This article indicates the average 5-year risk of developing diabetes for the population without known diabetes.

Source: Nationale Diabetes-Surveillance am Robert Koch-Institut 2018 [7], Paprott et al. 2017 [13]

allow a categorisation into low, medium and high education groups [15]. To depict indicators of care among persons with type 2 diabetes, the medium and high education group were combined to avoid that the number of cases in the subgroups become too small.

2.3 Statistical analysis

All prevalence estimates and mean values as well as corresponding 95% confidence intervals have been calculated using weighting factors. Weighting factors correct for deviations within the sample from the population structure as of 31 December 1997 for GNHIES98 and 31 December 2010 for DEGS1 (regarding sex, age, region, German citizenship, size of municipality and education) and also consider the deviations in probability of participation in DEGS1 between participants who previously took part in GNHIES98 and DEGS1 first time participants [8-10]. For a comparison over time of the total samples of GNHIES98 and DEGS1 that was independent of the changes in the age pyramid, GNHIES98 data were age-standardised based on the population as of 31 December 2010. To take into account both weighting and the correlation of participants within one municipality, results were calculated using SAS 9.4 survey procedures. Differences with p-values <0.05 were considered as statistically significant.

3. Results**3.1 Prevalence of known and unknown diabetes**

To reflect the total diabetes burden in the population, the diabetes surveillance provides data for both indicators the

prevalence of known diabetes as well as the prevalence of unknown diabetes (Info box 2). For the survey periods 1997 to 1999 and 2008 to 2011, the prevalence of known diabetes was 5.6% and 7.2%, the prevalence of unknown diabetes was 3.8% and 2.0%, and the prevalence of total diabetes was 9.3% and 9.2%, respectively. Once differentiated by level of education, higher prevalence estimates of known and unknown diabetes, and therefore also of total diabetes, were found in the low compared to the medium and high education group in both survey periods. For the period between the two surveys, tendencies towards an increase in the prevalence of known diabetes and a decrease in the prevalence of unknown diabetes were evident in all education groups. For overall diabetes, no significant changes in prevalence over time were observed [12] (Figure 2).

The sex-stratified analysis showed no significant differences in the prevalence of known diabetes between women (1997-1999: 5.7%, 2008-2011: 7.4%) and men (5.5%, 7.0%) [12]. Men, however, had a higher prevalence of unknown diabetes (1997-1999: 4.3%, 2008-2011: 2.9%) compared to women (3.2%, 1.2%) [12]. During the first survey period, this difference was particularly clear for the high education group, and during the second period, it was apparent for all education groups. Overall, however, for both survey periods, the pattern of higher prevalence estimates of known and unknown diabetes in the low education group compared to the medium and high education groups has been observed for both genders. Over time, the prevalence of known diabetes increased and the prevalence of unknown diabetes decreased for both genders [12], whereby a further differentiation by education group was not always permitting robust findings due to the low number of diabetes

Info box 4:**Indicators of quality of care for type 2 diabetes – achieving treatment goals****Treatment goal for HbA1c:**

- ▶ In the presence of diabetes-specific complications (diabetic renal dysfunction, diabetic eye disease, diabetic neuropathy, diabetic foot, diabetes-related amputation) or cardiovascular comorbidity (physician-diagnosed stroke, heart insufficiency, heart attack or other coronary heart diseases) and an age ≥ 45 years: HbA1c value $< 8.0\%$
- ▶ In the absence of diabetes-specific complications and cardiovascular comorbidity:
 - ▶ For an age ≥ 65 years: HbA1c value $< 7.5\%$
 - ▶ For an age 45 to 64 years: HbA1c value $< 7.0\%$

Treatment goal for non-HDL cholesterol:

- ▶ Total cholesterol serum value minus HDL cholesterol serum value < 130 mg/dl

Treatment goal for blood pressure:

- ▶ Systolic blood pressure < 140 mmHg and
- ▶ Diastolic blood pressure < 80 mmHg

Each indicator is given as proportion (in %) of persons with type 2 diabetes who achieve the respective treatment goal in relation to all persons with type 2 diabetes.

Source: Nationale Diabetes-Surveillance am Robert Koch-Institut 2018 [7], Du et al. 2015 [14]

HbA1c = glycated haemoglobin (long-term blood sugar value)
non-HDL = non-high-density lipoprotein

cases for certain subgroups – this applies in particular to women with high education in the survey period 1997 to 1999 (Figure 2).

3.2 5-year risk of developing type 2 diabetes

The indicator for the 5-year diabetes risk combines a set of established diabetes risk factors and helps to estimate how likely it is that a person will be diagnosed with type 2 diabetes within the next five years (Info box 3). For the survey periods 1997 to 1999 and 2008 to 2011, the average 5-year diabetes risk for the population was 1.5% and 1.1%, respectively. For both survey periods, the risk of getting diagnosed with diabetes was significantly higher for the low education group compared to the medium and high education groups. Over time, a significant decrease in the 5-year diabetes risk was only observed in the high education group [13] (Figure 3).

Stratified by gender, the analysis of both survey periods indicated a higher 5-year diabetes risk for men (1997-1999: 2.2%, 2008-2011: 1.5%) relative to women (1.1%, 0.8%). This difference between genders was observed across all education groups. In both genders, the pattern of a higher 5-year diabetes risk for the low education group compared to the medium and high education groups was evident. While for women, only the high education group showed a decrease in the 5-year diabetes risk over time, this tendency was visible across all education groups for men. However, it was also most pronounced in the high education group among men (Figure 3).

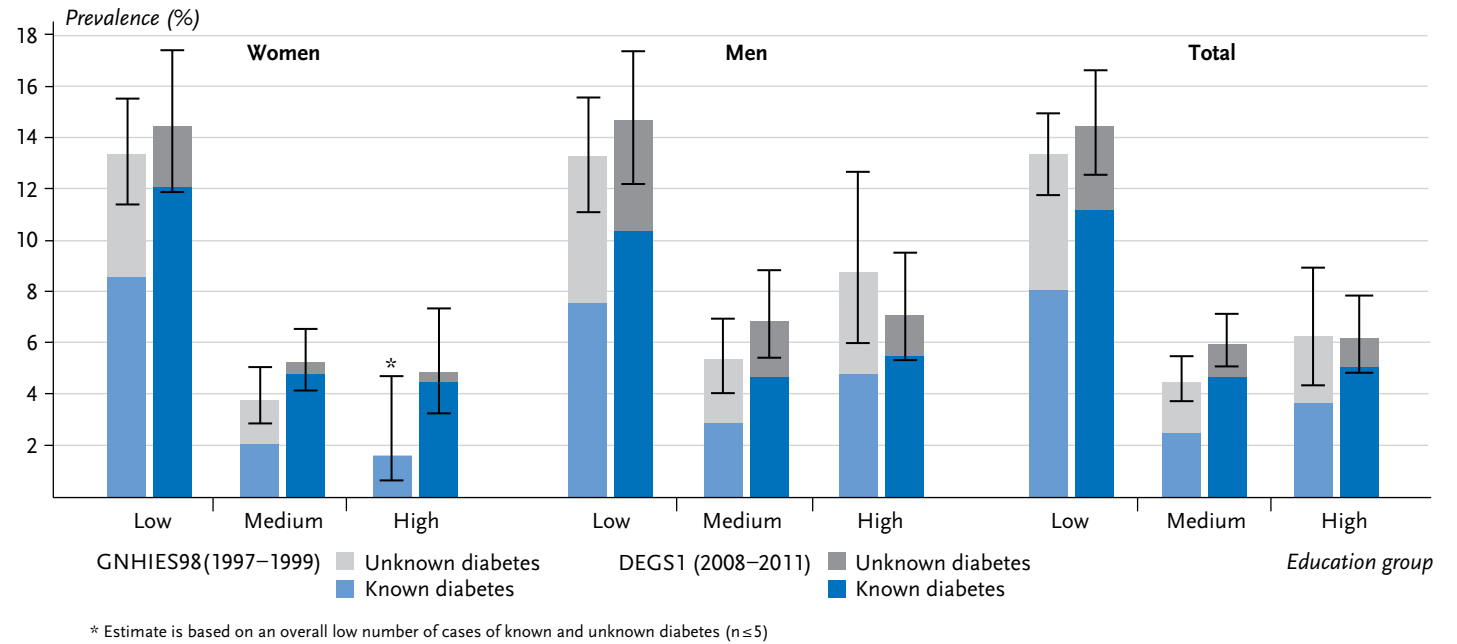
3.3 Type 2 diabetes care**Achieving treatment goals**

The indicators for treatment goals of HbA1c-, non-HDL cholesterol and blood pressure were defined in the context of the diabetes surveillance based on treatment targets set out in the national guideline for the therapy of type 2 diabetes [16] or in the international recommendations on the treatment of high blood glucose levels [17, 18] and lipid metabolism disorders in people with type 2 diabetes [19, 20] (Info box 4). By outlining the proportion of persons with type 2 diabetes who achieve the respective treatment goal, they provide intermediate outcome measures on the quality of care for type 2 diabetes.

For the indicator HbA1c treatment goal, no substantial differences between the low education group and the medium and high education group were evident for both survey periods. Over time, the proportion of people with type 2 diabetes that achieve the HbA1c goal increased almost equally in all education groups. The patterns and temporal developments were similar for both genders (Figure 4). The same applies for the indicators non-HDL cholesterol goal and blood pressure goal. However, only a small proportion of persons with type 2 diabetes reached the non-HDL cholesterol goal; only men from the medium or high education group achieved a more moderate result (nearly 50%) in the more recent survey period. For the proportion of people with type 2 diabetes who reach the blood pressure goal, the overall increase over time was less pronounced compared to the proportion of those who reached the HbA1c or non-HDL cholesterol goal. As a tendency, a slightly higher proportion of men in the medium and high

Figure 2

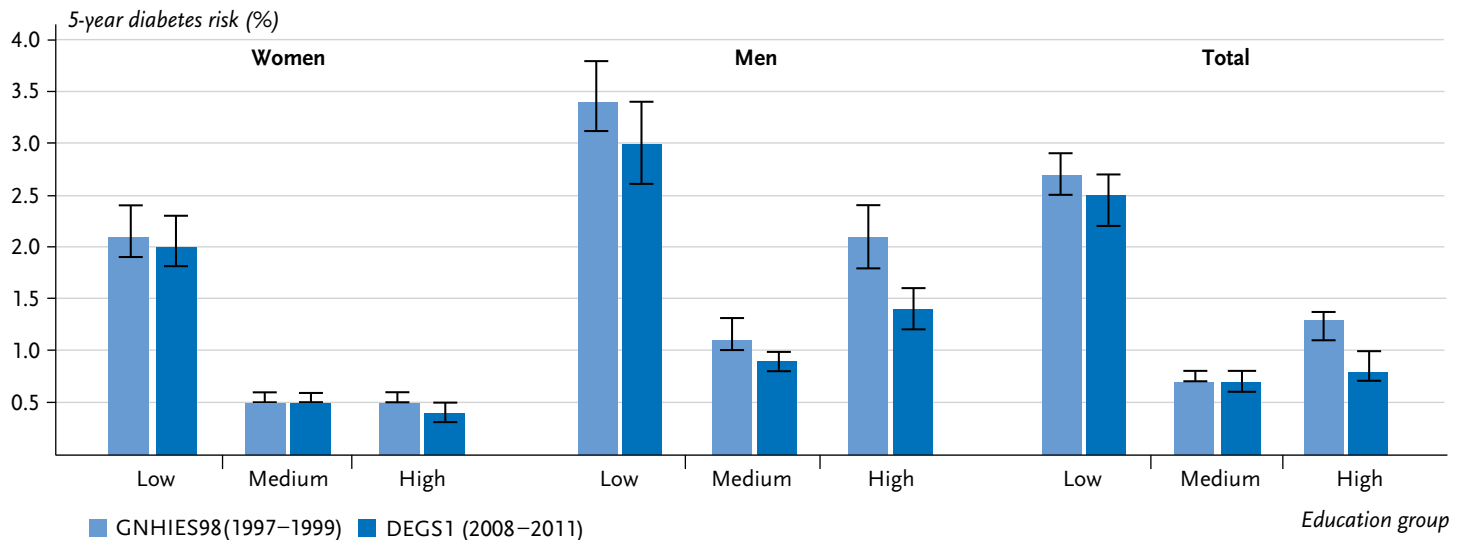
Prevalence of known and unknown diabetes over time for the 18- to 79-year-old population according to gender and education level (GNHIES98 n=3,328 women, n=3,147 men; DEGS1 n=3,628 women, n=3,342 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Heidemann et al. 2016 [12]



* Estimate is based on an overall low number of cases of known and unknown diabetes (n ≤ 5)

Figure 3

5-year risk of developing type 2 diabetes over time for the 18- to 79-year-old population without known diabetes according to gender and education level (GNHIES98 n=3,281 women, n=3,158 men; DEGS1 n=3,211 women, n=2,873 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Paprott et al. 2017 [13]



education group reached the blood pressure goal compared to those in the low education group.

Self-management and medical care

The diabetes surveillance system also considers further indicators such as self-monitoring of blood glucose, medical eye and foot examinations as well as taking lipid-lowering statins based on national guidelines for the therapy of type 2 diabetes [16] and the prevention and treatment of retinal and foot complications [22, 23] as well as European

recommendations for the prevention of cardiovascular diseases in the presence of diabetes [20] (Info box 5). These indicators reflect results on the quality of diabetes care processes through the respective proportion of type 2 diabetes patients with self-management or medical care.

For both survey periods, the indicator self-monitoring of blood glucose showed no significant differences between the low education group and the medium and high education group. Over time, the proportion of type 2 diabetes patients who self-monitor their blood glucose level

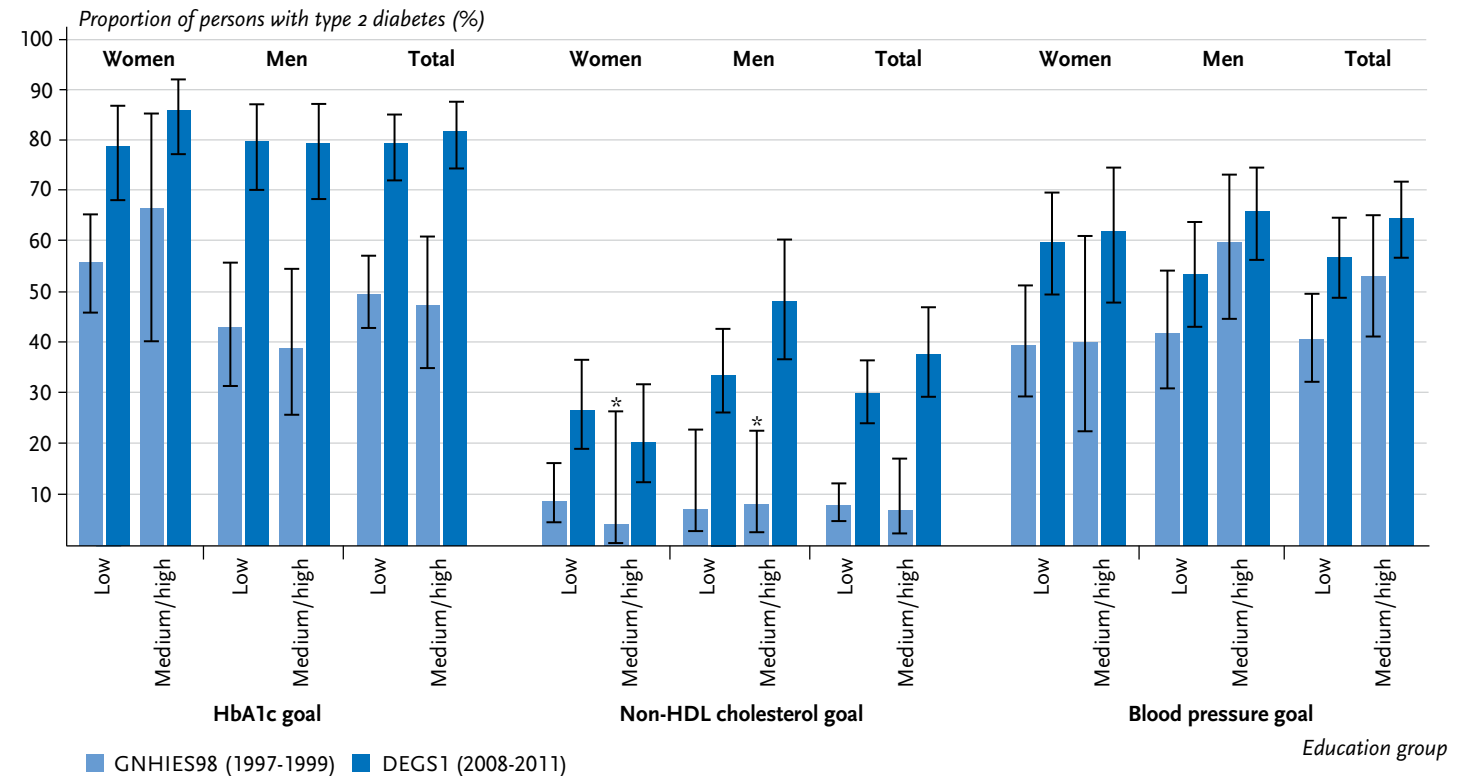


Figure 4
Comparison over time of the proportion of 45- to 79-year-old persons with type 2 diabetes who reach the treatment goal for HbA1c, non-HDL cholesterol or blood pressure according to gender and education level (GNHIES98 n=161 women, n=156 men; DEGS1 n=226 women, n=297 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Du et al. [14, 21]

* Estimate is based on a low number of cases of known type 2 diabetes with achieved treatment goal (n≤5)
 Missing values for GNHIES98/DEGS1: HbA1c goal n=28/n=61, non-HDL cholesterol goal n=24/n=5, blood pressure goal n=1/n=2

Info box 5:

Indicators of quality of care for type 2 diabetes – self-management and medical care

Self-monitoring of blood glucose:

- ▶ Self-monitoring of blood sugar levels

Eye examination:

- ▶ Ophthalmologic examination of the ocular fundus during the last twelve months

Foot examination:

- ▶ Medical examination of the feet during the last twelve months

Statin use:

- ▶ Taking the prescribed statin group medications (cholesterol synthesis-enzyme inhibitors; ATC codes C10AA, C10BA)

Each indicator is given as proportion (in %) of persons with type 2 diabetes who achieve the respective care target in relation to all persons with type 2 diabetes.

Source: Nationale Diabetes-Surveillance am Robert Koch-Institut 20188 [7], Du et al. 2015 [14]

ATC=Anatomical Therapeutic Chemical Classification System

increased considerably, and this increase was similar across the education groups. These findings apply in principle to both genders, whereby the proportion of men in the two upper education groups who self-monitor their blood glucose level is slightly higher in both survey periods compared to the low education group (Figure 5). These observations cannot be fully transferred to the indicators for eye and foot examination. For eye examination in both survey waves, the proportion of women with higher levels of education who have had this examination during the last

twelve months tended to be lower compared to those with low education. And the proportion of men with higher levels of education who have had this examination increased to a smaller extent over time than for men with low education. The proportion of persons with type 2 diabetes who have had their feet examined by a doctor during the last twelve months was lower in the higher education groups compared to the low education group for the period 2008 to 2011, and this is related to the increase observed over time in the low education group only.

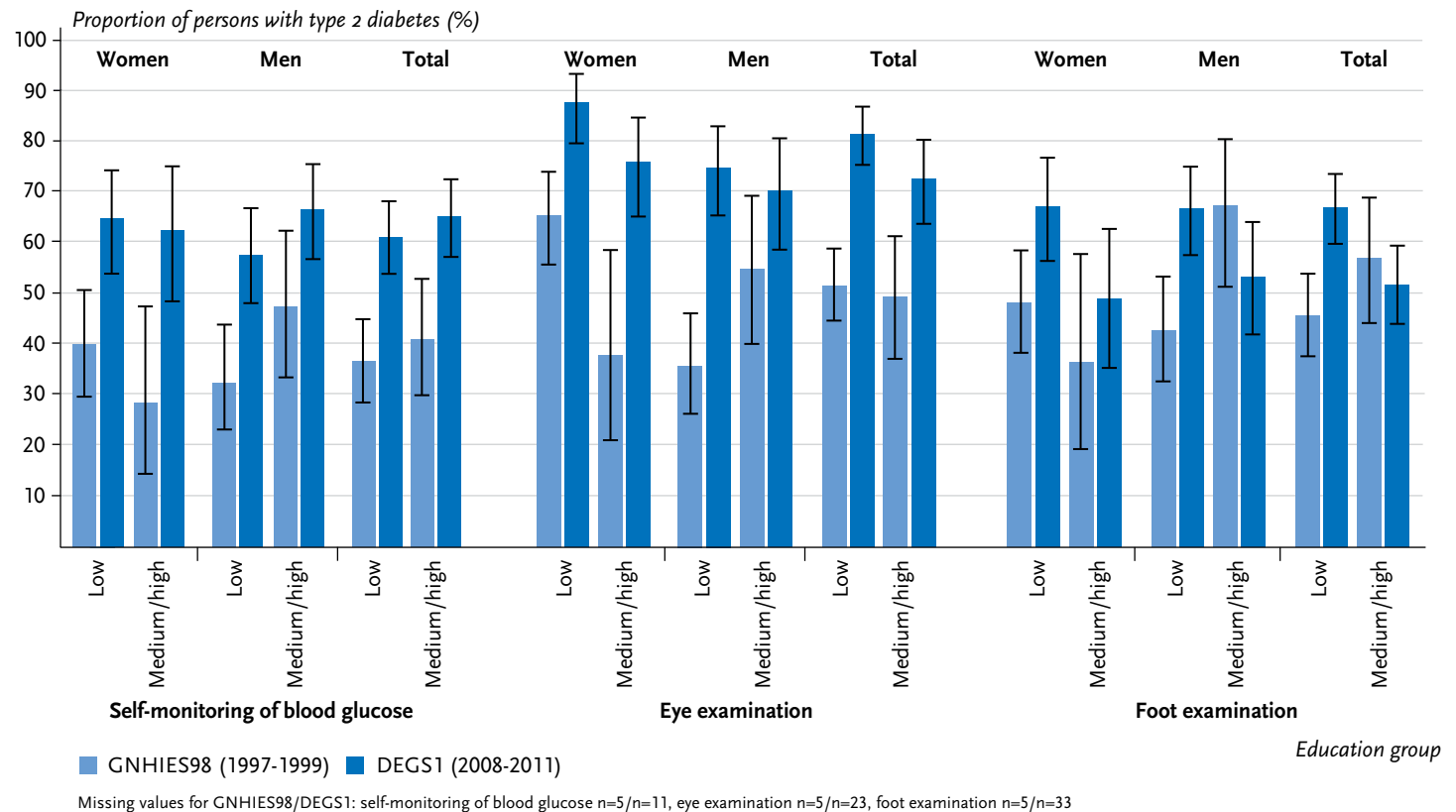


Figure 5
Comparison over time of the proportion of 45- to 79-year-old type 2 diabetes patients with self-monitoring of blood glucose, eye examination and foot examinations according to gender and education level (GNHIES98 n=161 women, n=156 men; DEGS1 n=226 women, n=297 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Du et al. [14, 21]

Info box 6:**Health-related quality of life of people with type 2 diabetes**

Based on 36 questions (Short Form-36 Health Survey questionnaire, SF-36) and the scales developed from these on eight dimensions of health, two sum scales are calculated:

Physical dimension:

► Physical sum scale as the sum of the eight scales, whereby the highest weighting is given to the scales for physical functioning, physical role functioning, bodily pain and general health perception.

Mental dimension:

► Mental sum scale as the sum of the eight scales, whereby the highest weighting is given to the scales for vitality, social functioning, emotional role functioning and mental health.

Both dimensions of health-related quality of life can potentially achieve values between 0 and 100 and have been transformed for a comparison between GNHIES98 (SF-36V1) and DEGS1 (SF-36V2) into a sample mean of 50 and a standard deviation of 10. This article compares the mean values for different groups of people with type 2 diabetes, whereby a higher mean value represents a higher health-related quality of life.

Source: Nationale Diabetes-Surveillance am Robert Koch-Institut 2018 [7], Ellert et al. 2013 [11]

For the period 1997 to 1999, a higher proportion of type 2 diabetes patients with higher levels of education took statins compared to those with low levels of education, whereas for the period 2008 to 2011, the proportion of those taking statins tended to be higher in the low education group. This result is due to a greater increase in the use of statins in the low education group compared to the higher education groups. These observations apply to both genders (Figure 6).

Health-related quality of life

In the diabetes surveillance, subjective assessments are also considered as relevant care indicators. These include self-perceived health-related quality of life, which is obtained by summing up the scales for the physical and mental dimensions of quality of life (Info box 6). In addition to objectively measurable care indicators (such as the treatment goals mentioned above), self-perceived quality of life plays an important role for health and well-being and is therefore anchored as a general therapy objective in the national guideline for the therapy of type 2 diabetes ('maintaining or regaining quality of life') [16].

Regarding the physical dimension of health-related quality of life for type 2 diabetes patients, the period 1997 to 1999 showed a similar – and the period 2008 to 2011 a slightly more positive – self-assessment in the higher education groups compared to the low education group. This can be traced back to a marginally improved self-assessment over time in the higher education groups. Regarding the self-assessed mental dimension of health-related quality of life, no differences between education groups were present in either survey period and a slight decline over

time is apparent. This pattern applies to both genders (Figure 7).

4. Conclusion

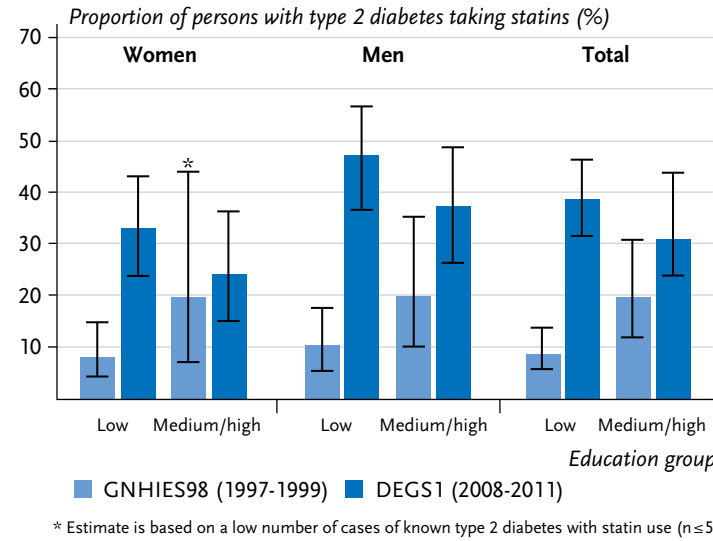
For public health research and health policy, analyses of trends in health inequality over time are a key factor to develop necessary target group focused prevention measures and evaluate existing prevention programmes.

As the results of this and other studies indicate, higher prevalence of diabetes in the low education group appears to be a persistent issue [12, 25-28]. The prevalence of both known and unknown diabetes remains twice as high in the low education group compared to the medium or high education group [12]. The observed decline of unknown diabetes between the two survey periods, 1997 to 1999 and 2008 to 2011, across all education groups and the simultaneous and roughly equivalent increase of known diabetes could indicate general improvements in the early detection of diabetes (secondary prevention). However, additional measures that aim at reducing the risk of developing diabetes (primary prevention) and focus primarily on the low education group seem necessary.

This fact is highlighted by the results for the 5-year risk of developing type 2 diabetes, which is twice as high for the low education group compared to the medium and high group and has clearly decreased only in the high education group [13]. Studies of the individual behaviour-related risk factors of smoking and physical inactivity indicate a similar widening of inequality due to improvements exclusively in the groups with high education or high professional status [29, 30]. In addition to prevention strategies

Figure 6

Comparison over time of the proportion of 45- to 79-year-old persons with type 2 diabetes who take statins according to gender and education level (GNHIES98 n=161 women, n=156 men; DEGS1 n=226 women, n=297 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Du et al. [14, 21]

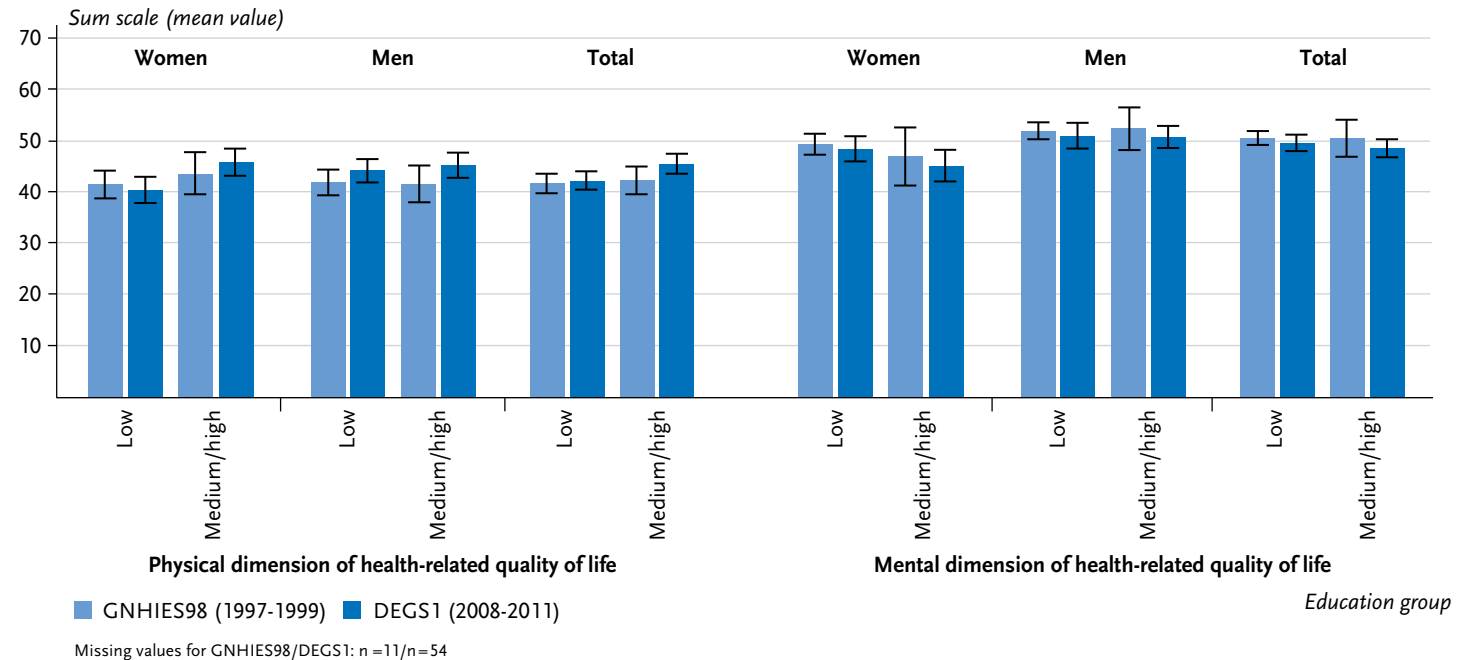


that aim to promote healthy lifestyles (behavioural prevention), such as those already anchored in the national health target for type 2 diabetes [31], more emphasis needs to be put on the development of living environments and frameworks that promote healthy living (structural prevention) and reach all education groups.

With regard to the diabetes care situation, a positive development has been that improvements over time have been achieved in several areas with no clearly visible differences between education groups. Improvements are not only reflected for several indicators (HbA_{1c}, non-HDL cholesterol and blood pressure treatment goals, blood glucose self-monitoring and eye examination) across different education groups in this study on the basis of RKI survey

Figure 7

Comparison over time of mean values of sum scales for the physical and mental dimensions of health-related quality of life in 45- to 79-year-old persons with type 2 diabetes according to gender and education level (GNHIES98 n=161 women, n=156 men; DEGS1 n=226 women, n=297 men)
 Source: GNHIES98 (1997-1999), DEGS1 (2008-2011), Schmidt et al. [24]



The prevalences of known and unknown diabetes and the 5-year risk of diabetes are considerably higher in the low education group than in the medium or high education group.

data [14]. Moreover, further sources providing additional data also indicate improvements in a row of aspects of care. Regional KORA (Cooperative Health Research in the Region of Augsburg) study data, for example, show an increase in the proportion of persons with type 2 diabetes who achieve their treatment goal for HbA_{1c}, blood pressure and LDL cholesterol as well as a decline in the 10-year risk for coronary heart diseases [32]. Current data from studies by the DIAB-CORE (Diabetes-Collaborative Research of Epidemiologic Studies) consortium indicate an increase in awareness, treatment and control of hypertension of people both with and without type 2 diabetes [33]. An earlier analysis of DIAB-CORE data showed that educational level had no influence on the presence of a high blood pressure or lipid metabolism disorders in persons with type 2 diabetes [34]. Furthermore, data from the Disease Management Program (DMP) from the North Rhine region reflect an increase in type 2 diabetes patients who achieve their blood pressure quality targets and have taken part in the recommended diabetes course as well as a stably high proportion of patients with an HbA_{1c} value <8.5%. In 2017, ten out of 14 quantitatively assessable and contractually defined DMP quality targets were achieved [35]. Moreover, data from a regional stroke registry show that while the stroke rate has remained nearly constant for people without diabetes, it has decreased for people with diabetes [36]. National data from hospital statistics (DRG statistic) show a decrease in lower limb amputations (major amputations) in hospitalised diabetes patients [37]. Jointly, these positive trends could indicate improved outpatient care or better self-monitoring of diabetes. These positive developments may also stem from the introduction of modules to the national

guideline for the therapy of type 2 diabetes on specific diabetes complications, which encourage diabetes patients to play an active role in their treatment [38] as well as the DMP implementation for type 2 and type 1 diabetes [39]. Analysis of DMP data shows that a continuous DMP participation increases the chance for patients to achieve defined targets for diabetes quality of care [40].

Nonetheless, the currently available study results on care of people with type 2 diabetes all highlight the considerable potential for improvement in the prevention of secondary and concomitant diseases (tertiary prevention). In the present study, for example, the proportions of persons with type 2 diabetes who achieved the non-HDL cholesterol treatment goal or took statins were below 50% across all education groups in the period 2008 to 2011, and less than 70% had their feet examined by a doctor. In spite of the mentioned improvements, KORA and DIAB-CORE data also indicate a suboptimal management of blood sugar levels and of the cardiovascular risk factors of high blood pressure and high LDL cholesterol levels in persons with type 2 diabetes [32, 33]. Moreover, DMP data from the North Rhine region show that only 51% of type 2 diabetes patients with severe foot ulcers also receive treatment from an institution specialized in treating the feet of diabetics, although the agreed target value is at least 75% [40]. In addition, for certain aspects the development over time has stagnated or begun to reverse. In this study, an increase in the proportion of persons with type 2 diabetes who had their feet examined by a doctor and took statins was limited to the low education group. With regard to the physical dimension of quality of life, however, improvements were only seen in the high education group. Irrespective of the edu-

There is no evident shift of the education gradient in the prevalence of known and unknown diabetes over time.

For the 5-year risk of diabetes, there are indications of a further divergence in the educational gap, which can be attributed to a clear reduction of this risk in the high education group.

cation level, persons with type 2 diabetes generally saw a slight deterioration in the mental dimensions of quality of life. Interestingly, an education gradient for the physical dimension of quality of life, with better values achieved by the high education group, was also observed for the 30- to 49-year-old general population based on socioeconomic panel (SOEP) data. This was not, however, observed for the mental dimension [41]. For first-time renal replacement therapy, no decline was observed either in the diabetic or non-diabetic population based on data of a regional dialysis centre [42]. Further, North Rhine DMP data indicate a decline in the proportion of type 2 diabetes patients who have had their kidney function tested during the last twelve months [35]. According to epidemiological studies, the incidence rates of complications such as heart attack, stroke, lower limb amputations, loss of sight and renal insufficiency remains two to eight times higher for people with diabetes than for those without diabetes, despite improvements observed in some of these complications [43].

Moreover, our results and further studies highlight that in addition to educational differences, gender differences also persist with regard to prevalence, risk and care of diabetes. Men, for example, show a higher prevalence of unknown diabetes compared to women [12, 44] as well as a higher risk of type 2 diabetes [45-47]. Regarding treatment, the results of this study show that for women with known diabetes the proportions of those who achieve the non-HDL cholesterol treatment goal or take statins are lower than that of men. Extended analyses based on RKI survey data reflect that gender differences in statin use are no longer significant once a cardiovascular disease is diagnosed in addition to diabetes [21, 48]. This observation

points to a less strict tertiary preventive medication therapy of female compared to male diabetes patients. A possible explanation currently under discussion is the higher frequency of the unintended side-effects statins have on women than on men [49]. A further possibility is that diabetes is underrated as a cardiovascular risk factor in women. It has been shown that the cardio-protective effect in women compared to men is significantly reduced by the presence of a diabetes, in particular with regard to lipid metabolism disorders, central obesity and the risk for a heart attack [50-53]. Because cardiovascular diseases in men develop on average around ten years earlier compared to women [50, 51], it is plausible that the proportion of people with cardiovascular comorbidities, including among diabetes patients, is overall considerably higher for men than for women, as is shown, for example, in regional registry and DMP data for the North Rhine region [36, 54, 55].

This article presents selected indicators related to diabetes risk, prevalence and quality of care, which will be continuously presented in the context of the national diabetes surveillance based on RKI survey data. The strengths of this data resource lie in the possibilities to combine interview data with measurement and laboratory data as well as with subjective perceptions, and thereby compare population groups stratified by gender, age or education. For the interpretation of stratified results in this article, it is important to remember that this is a descriptive analysis. Extended complex analyses would be useful to analyse the effects of explanatory factors, such as potential age differences between education groups and possible cohort effects [56], on the observed results. Furthermore, the assessment of social inequality in this article is based exclu-

There are no pronounced differences regarding quality of diabetes care between groups with different levels of education.

Overall, the quality of diabetes care has improved over time.

sively on the operationalisation of individual school education and professional training. Other established operationalisations to describe social inequality of people or households are based on professional status, income or multi-dimensional indices composed of the three dimensions of education, occupational status and income [56, 57]. Moreover, to operationalise social inequality, regional level measures such as the unemployment rate, poverty risk rate or again multi-dimensional indices are often applied, for example, when individual level data are not available [58, 59].

The limitations connected to the applied RKI survey data are that certain groups of people – in particular seriously ill persons, nursing home residents, persons with a migration background, and (in examination surveys) persons aged 80 years and over – have so far not been representatively included and that the limited number of feasible survey participants usually does not allow multi-layered stratifications. For this study, for example, the number of cases following stratification by education group and, additionally, gender were sometimes too small to evidence statistical significance, despite the potential existence of differences between groups.

Looking to the future, a stable data synthesis of key diabetes indicators by merging of RKI survey data with available secondary data, which are discussed in the article [Secondary data in diabetes surveillance – co-operation projects and definition of references on the documented prevalence of diabetes](#) in this issue [60], should be ensured in the context of the national diabetes surveillance system [6]. The planned next steps include a regular review of the set of indicators [7] for required adaptations (for example, regard-

ing new available data sources or updating of guideline recommendations) as well as a regular and structured provision of results [61] to promote the planning and evaluation of measures aiming at reducing diabetes risk and supporting early detection and optimal treatment of diabetes. It will thereby remain relevant to consider socioeconomic factors to assess the need, orientation and prevention potential of target group- or settings-focused measures.

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Data protection and ethics

The studies GNHIESg8 and DEGS1 are subject to strict compliance with the data protection regulations of the Federal Data Protection Act and have been approved by the Federal Commissioner for Data Protection and Freedom of Information in Germany. Charité – Universitätsmedizin Berlin's ethics committee assessed the ethics of the study

and provided its approval (No.EA2/047/08). Participation in the studies GHNIES98 and DEGS1 was voluntary. The participants were informed about the aims and contents of the studies and about data protection. Informed consent was obtained in writing.

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Conflicts of interest

The authors declared no conflicts of interest.

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Types of diabetes are not limited to age groups: type 1 diabetes in adults and type 2 diabetes in children and adolescents

Abstract

Based on data from the national diabetes registry DPV (Diabetes patient documentation), the diabetes registry of North Rhine-Westphalia and surveys conducted at hospitals and practices in Baden-Württemberg and Saxony, this study estimates the incidence and prevalence of type 1 diabetes in over-18-year-old adults and type 2 diabetes in 11- to 18-year-old children and adolescents.

The national incidence of type 1 diabetes in adults was 6.1 per 100,000 person-years from 2014 to 2016, with slightly lower figures for women compared to men. Annually, around 4,150 adults develop type 1 diabetes. In 2016, the prevalence of type 1 diabetes was estimated at 493 per 100,000 persons and was lower in women at 445 per 100,000 people than in men at 544 per 100,000. Based on this data, there were around 341,000 adults with type 1 diabetes in 2016.

For 11- to 18-year-old children and adolescents, the national incidence of type 2 diabetes was 2.8 per 100,000 person-years between 2014 and 2016 and higher for girls than for boys. Annually, around 175 adolescents in this age group develop type 2 diabetes. The incidence estimates for Saxony were higher (4.3 per 100,000 person-years). The prevalence of type 2 diabetes between 2014 and 2016 for 11- to 18-year-old children and adolescents was estimated between 12 and 18 cases per 100,000 persons. During this period, there were about 950 children and adolescents of this age group with type 2 diabetes in Germany.

📌 TYPE 1 DIABETES · TYPE 2 DIABETES · INCIDENCE · PREVALENCE · DIABETES SURVEILLANCE

1. Introduction

Diabetes mellitus means a chronic increase of glucose levels in the body. From a health policy perspective, two forms of diabetes in particular play an important role: immune-mediated type 1 diabetes, which generally leads to absolute insulin deficiency, and type 2 diabetes, in which both insulin resistance as well as reduced insulin secretion play a role. The disease reduces both life expectancy and quality

of life, mainly due to chronic damage to small and large blood vessels. Data on the incidence and prevalence of diabetes, therefore, provide important information to build and further develop a diabetes care infrastructure.

Three regularly updated regional paediatric diabetes incidence registries from Baden-Württemberg, North Rhine-Westphalia (NRW) and Saxony, as well as the national DPV registry, provide sound data on the incidence of type 1 diabetes in under-15-year-old children and adolescents.

These data sources also indicate the long-term trends for the incidence of type 1 diabetes in this age group [1-3]. In addition, the data from these three regional incidence registries feed into the European surveillance of type 1 diabetes within the framework of the EURODIAB (Epidemiology and Prevention of Diabetes) study group [4-6]. The project described here aims to make this data available for national level diabetes surveillance too.

However, only limited information is available on the incidence of type 1 diabetes among adults. Based on the data from statutory health insurances, national prevalences across all age groups in 2009 and 2010 were estimated at 300 cases per 100,000 persons [7]. Accordingly, there were around 256,000 persons with type 1 diabetes in Germany in 2009 and 252,000 in 2010. Germany-wide claims data between 2009 and 2015 estimate similar prevalences, as well as a downward trend from 330 to 280 cases per 100,000 persons [8]. Projected for the German population, around 230,000 persons, accordingly, had type 1 diabetes in 2015. Reports from the disease management programs (DMP) of statutory health insurances estimated a significantly higher figure of around 311,000 persons with type 1 diabetes across all age groups for 2014 [9]. According to the DMP quality report for type 1 diabetes in Westfalen-Lippe, there were 22,807 DMP registered patients across all age groups in 2015 [10]. This corresponds to a prevalence of 314 per 100,000 persons among those covered by statutory health insurance. Taking into account the estimated completeness of DMP in Westfalen-Lippe (78.4% to 89.4%), this would result in a prevalence of 351 to 400 per 100,000 persons [10].

Based on 2009 and 2010 statutory health insurance data, national age-specific incidences of type 1 diabetes

were estimated for the first time for the age group up to 55 years of age [11]. The incidence for 15- to 55-year olds was 7.1 and 6.1, respectively, per 100,000 person-years.

A better data situation is given for type 2 diabetes in adulthood. A number of national and representative regional studies have analysed the prevalence and incidence of known and unknown diabetes. Various publications present the results of these studies [3, 12, 13]. In particular, there are estimates based on the data from statutory health insurances and claims data from statutory health insurance-authorized physicians [7, 8].

For type 2 diabetes in adolescents, however, there is only insufficient data available. A study conducted in Baden-Württemberg between the years 2004 and 2005 reported the prevalence of known type 2 diabetes in 0- to 20-year-old children and adolescents as 2.3 per 100,000 persons [14]. For North Rhine-Westphalia, the prevalence among 5- to 19-year-old children and adolescents in 2010 was estimated at 5.8 per 100,000 persons. According to the study, 600 to 800 5- to 19-year-old children and adolescents had a known type 2 diabetes in 2010 [15]. According to data from the nationwide DPV register, in the last 10 years about 5% to 6% of children and adolescents aged 11 to 18 years newly diagnosed with diabetes have type 2 diabetes [16]. Based on 2009 and 2010 statutory health insurance data, the national prevalence for under-20-year-old girls and boys was estimated to be much higher at 30 and 40 cases, respectively, per 100,000 persons [7]. On the basis of claims data from all over Germany, the prevalence in 2009 and 2015 for 0- to 19-year olds was estimated as 66 and 41 cases per 100,000 persons, respectively [3]. However, it is a well-known fact that claims data leads to an

overestimation of the prevalence, also because other forms of diabetes, when no insulin therapy is prescribed, are erroneously categorised as type 2 diabetes.

The diabetes registry of North Rhine-Westphalia provides estimates for the incidence of type 2 diabetes in children and adolescents. Recently, an average incidence of 1.3 per 100,000 person-years was estimated for the period 2002 to 2014 for children and adolescents aged 5 to 19 years, whereby the incidence between 2011 and 2014 was 1.6 per 100,000 person-years. Accordingly, 130 to 160 persons in the 5- to 19-year-old age group developed type 2 diabetes annually. Again, based on Germany-wide claims data for the 2012 to 2014 period, a 15-fold higher incidence of 20 and 30 cases per 100,000 person-years was estimated for girls and boys under the age of 20, respectively. [8].

So far, a continuous provision of estimates based on a standardised methodology to account for the incidence and prevalence of type 1 diabetes across the entire adult age spectrum, as well as of type 2 diabetes in adolescents, has not been established in Germany, although such data would be relevant to diabetes surveillance and the further development of the infrastructure of health care provision. Precisely, because many diabetes prevention approaches target the group of young, at risk people, surveillance would need to reliably and promptly show changes in the incidence in this age group. The objectives of this project in the context of diabetes surveillance at the Robert Koch Institute (RKI) were therefore to network with existing structures and develop supplementary structures for the continuous monitoring of the regional and the national incidence and prevalence in this group of patients.

2. Methodology

2.1. Definition of type 1 and type 2 diabetes

Our analysis uses the term type 1 diabetes only in the sense of 'classical' clinically diagnosed type 1 diabetes. The practice guidelines of the German Diabetes Association also classify patients with latent autoimmune diabetes in adults (LADA) as type 1 diabetes, i.e. a form of immune-mediated diabetes, which in most cases leads to complete insulin insufficiency in patients shortly after the onset of diabetes [17]. Diagnosing this form of diabetes requires complex laboratory examinations. However, an examination of all newly diagnosed adult diabetes patients for beta-cell antibodies (indicating the immune reaction against insulin-producing cells in the pancreas) and for C-peptide (reflecting the remaining insulin secretion by islet cells), is currently not diagnostic standard. This lack of standardisation means that results are only comparable to a limited extent, we therefore have not categorised LADA as type 1 diabetes. The diagnosis of type 2 diabetes is based on the German Diabetes Association's current guidelines [18].

2.2 Data sources

Table 1 provides an overview of the data sources used. To estimate the incidence and prevalence of type 1 diabetes in adults (≥ 18 years) in North Rhine-Westphalia and nationwide, the population-based diabetes registry of North Rhine-Westphalia [1] and the national DPV registry [19] were used as data sources.

The North Rhine-Westphalian registry has collected data for 0- to 14-year-old children and adolescents since 1996.

Table 1
Indicators and data sources
Own table

Indicators	Data sources
Incidence and prevalence of type 1 diabetes in adults	<ul style="list-style-type: none"> ▶ Diabetes registry of North Rhine-Westphalia ▶ DPV registry
Incidence and prevalence of type 2 diabetes in children and adolescents	<ul style="list-style-type: none"> ▶ Diabetes registry of North Rhine-Westphalia ▶ DPV registry ▶ Interview survey Saxony (only incidence) ▶ Interview survey Baden-Württemberg (only prevalence)

DPV = Diabetes patient documentation

It has recorded newly diagnosed cases of type 1 and type 2 diabetes in the 0- to 34-year-old age group since 2002 based on three data sources: the clinic-based German Paediatric Surveillance Unit (ESPED), annual surveys of medical specialists working in private practices, paediatricians, general practitioners, as well as the national DPV registry.

The DPV initiative was started throughout Germany in 1995 and is a computer-aided longitudinal collection of data on treatment of diabetes patients and outcomes. For the diabetes surveillance at the RKI, only the data from German centres (420 institutions: 181 internal medicine and 239 paediatric centres) was used. Data for older age groups is presumably far less complete, because DPV data collection only began in the mid 1990s and patients aged over 35 years in 2016 would have developed the disease well before 1990.

The incidence and prevalence of type 2 diabetes in 11- to 18-year-old children and adolescents in North Rhine-Westphalia and at the national level was estimated by using the population-based diabetes registry of North Rhine-Westphalia and the nationwide DPV registry. In addition, data on incidence was collected in Saxony (11- to 18-year-olds)

and data on prevalence in Baden-Württemberg (under 20-year-olds).

The data source in Saxony was a survey (by post, telephone or e-mail) on the number of new cases of type 2 diabetes in children and adolescents (11 to 18 years) in 2016 among the clinics participating in Saxony's diabetes registry (all 31 paediatric clinics) and specialised diabetological practices [20, 21].

The data source in Baden-Württemberg was a survey (by telephone, e-mail or fax) on the number of children and adolescents with type 2 diabetes (under 20 years of age) treated in 2016 among the participating clinics of the DIARY registry (Diabetes Incidence Registry in Baden-Württemberg, 31 paediatric clinics and one diabetes centre) [22, 23], the 242 members of the German association of diabetologists (BVND) in Baden-Württemberg as well as the 266 members of the working group diabetes in Baden-Württemberg (ADBW). An initial written request was made in July 2017, a second request in September 2017. According to an earlier analysis of the prevalence of type 2 diabetes and the available care in Baden-Württemberg, around 50% of type 2 diabetes patients aged under 20 years of age are treated in paediatric clinics, 39% by office-based diabetologists, 7% by diabetologists in clinics, 2% in clinics and 2% in practices without diabetologists. The current survey of paediatric clinics and office-based diabetologists therefore covers around 90% of all cases.

The population data necessary to estimate incidence and prevalence was obtained from the Federal Statistical Office. Unless otherwise stated, the population data result from an update of the population level for 2015 on the basis of the 2011 census [24], since the population data for North

Currently, around 4,150 adults and 3,100 children and adolescents (aged 0 to 17) develop type 1 diabetes annually.

Rhine-Westphalia (and Baden-Württemberg) were not yet available for 2016 at the time of the analysis. This also applies to the calculations for person years 2014 to 2016, which are based on 2014 and two times on 2015.

2.3 Statistical methods

The recording of new cases of diabetes by the registry of North Rhine-Westphalia, which is based on three data sources, allows estimating the completeness of the data collected by applying capture-recapture methods. Thereby, the proportion of patients who appear in more than one data source allows an estimate of the number of patients who were not recorded. Subsequently, the figures can then be adjusted. To estimate the completeness of the data collected, a suitable statistical model was adapted to the data (log-linear model that accounts for overdispersion) [25, 26]. After applying a standard statistical criterion (AICC [27]), the model was chosen that best describes the available registry data. Both the completeness of the registry in general and, in addition, of the DPV database was estimated.

Estimates regarding the completeness of the North Rhine-Westphalia registry were used to calculate estimates corrected for underreporting for the incidence and prevalence in North Rhine-Westphalia from the data observed in the North Rhine-Westphalia registry. Estimates for the completeness of the DPV data basis for North Rhine-Westphalia were used to calculate ascertainment corrected estimates of incidence and prevalence for Germany in national DPV data. Based on the North Rhine-Westphalia and DPV registries, completeness of ascertainment could only be estimated for the 18- to 34-year-old age group; it was

therefore necessary to make a plausible assumption for the completeness of the DPV registry for older age groups. The presumed completeness of ascertainment for older age groups was varied in terms of a sensitivity analysis. Incidence and prevalence with 95% confidence intervals (95%-CI, range in which the true value lies with 95% certainty) were estimated applying a Poisson distribution [28, 29]. A detailed description of the methodology can be found in [25-29].

3. Results

3.1 Incidence of type 1 diabetes

Incidence of type 1 diabetes in 18- to 34-year-olds in North Rhine-Westphalia between 2014 and 2016

Between 2014 and 2016, the Rhine-Westphalian diabetes registry recorded 391 newly diagnosed type 1 diabetes patients in the 18- to 34-year-old age group. This is an incidence of 3.6 per 100,000 person-years. The registry captured an estimated 29.5% of the population; adjusted for underreporting, the incidence was therefore estimated at 12.0 per 100,000 person-years (Table 2). Correspondingly, the absolute figure for new cases between 2014 and 2016 was 1,326, i.e. an average of 442 new cases per year. Adjusted for underreporting, the incidence for women was only about half that for men (7.9 vs. 16.1 per 100,000 person-years) and the incidence was slightly higher for 18- to 24-year-olds than for 25- to 34-year-olds (12.9 vs. 11.7 per 100,000 person-years). Table 2 also shows the incidence for registered cases by age and gender.

Incidence of type 1 diabetes in adults over 18 years of age in Germany between 2014 and 2016

Between 2014 and 2016, 2,144 patients at least 18 years of age were registered in the DPV diabetes registry with newly diagnosed type 1 diabetes. Against 205,986,915 person-years [31], this is an incidence of 1.0 per 100,000 person-years

(Table 2). The ascertainment rate of DPV for the 18- to 34-year-old age group was estimated at 17.2% based on the North Rhine-Westphalia registry. Assuming that DPV has the same capture rate in older age groups too, the incidence in the age group 18 years and older adjusted for underreporting was estimated as 6.1 per 100,000 person-years.

Study population			2014-2016		
	Registered	CR ²	Incident cases Adjusted ^{3,4}	Incidence (95% CI) ¹	
				Registered ⁵	Adjusted ³
North Rhine-Westphalia 18-34 years					
Total	391	29.5%	1,326	3.6 (3.2-3.9)	12.0 (11.4-12.7)
Women	138	32.6%	423	2.6 (2.2-3.1)	7.9 (7.2-8.7)
Men	253	27.8%	911	4.5 (3.9-5.1)	16.1 (15.1-17.2)
18-24 years	184	32.3%	569	4.2 (3.6-4.8)	12.9 (11.9-14.0)
25-34 years	207	26.8%	772	3.2 (2.7-3.6)	11.7 (10.9-12.5)
Germany ≥18 years					
Total	2,144	17.2% ⁶	12,495	1.0 (1.0-1.1)	6.1 (6.0-6.2)
Women	895	15.7% ⁶	5,685	0.9 (0.8-0.9)	5.4 (5.3-5.5)
Men	1,249	21.3% ⁶	5,857	1.2 (1.2-1.3)	5.8 (5.7-6.0)
18-24 years	436	17.2%	2,541	2.3 (2.1-2.5)	13.5 (12.9-14.0)
25-34 years	546	17.2%	3,182	1.7 (1.6-1.9)	10.1 (9.8-10.5)
35-44 years	367	17.2% ⁷	2,139	1.2 (1.1-1.4)	7.2 (6.9-7.5)
45-54 years	384	17.2% ⁷	2,238	1.0 (0.9-1.1)	5.6 (5.3-5.8)
55-64 years	226	17.2% ⁷	1,317	0.7 (0.6-0.8)	3.9 (3.7-4.1)
65-74 years	122	17.2% ⁷	711	0.5 (0.4-0.6)	2.9 (2.6-3.1)
≥75 years	63	17.2% ⁷	367	0.2 (0.2-0.3)	1.4 (1.2-1.5)

CR=coverage rate, ESPED=German Paediatric Surveillance Unit, DPV=diabetes patient documentation, AICC=Akaike information criterion, adjusted version for small samples, CI=Confidence interval
¹ per 100,000 person-years

² Estimated coverage rate based on capture-recapture analysis using three sources of data (ESPED, practices, DPV) according to best log linear model based on AICC criterion with main effects ESPED, practices and DPV for models of incidence and prevalence, and interactions ESPED*practices and ESPED*DPV for prevalence models for the data from the diabetes registry North Rhine-Westphalia (type 1 diabetes 18- to 34-years-old, type 2 diabetes 11- to 18-years-old)

³ Adjusted according to the estimated underreporting

⁴ The sum of adjusted case numbers for both genders and/or age groups may not correspond to the adjusted case number for the total group because the number of cases is estimated based on different log linear models

⁵ Estimated based on registered number of cases

⁶ Estimated as sum of all captured cases across all age groups divided by the sum of all cases adjusted by under-coverage for all age groups

⁷ Assumed DPV coverage rate according to the 18- to 34-year-old age group

Table 2

Incidence and prevalence of type 1 diabetes in Germany

Source: Diabetes registry of North Rhine-Westphalia, Diabetes patient documentation (DPV registry) [1, 19]

Continued on next page

Table 2 Continued
Incidence and prevalence
of type 1 diabetes in Germany

Source: Diabetes registry of North Rhine-Westphalia, Diabetes patient documentation (DPV registry) [1, 19]

Study population	2016 (2015, 2014)				
	Prevalent cases			Prevalence (95% CI) ¹	
	Registered	CR ²	Adjusted ^{3,4}	Registered ⁵	Adjusted ³
North Rhine-Westphalia 18-34 years					
Total	11,284	72.5%	15,554	303.8 (298.3-309.5)	418.8 (412.3-425.4)
	10,803	70.4%	15,352	290.9 (285.4-296.4)	413.4 (406.9-420.0) (2015)
	10,291	67.2%	15,313	286.6 (281.1-292.2)	426.4 (419.7-433.2) (2014)
Women	5,123	72.9%	7,030	285.7 (277.9-293.6)	392.1 (382.9-401.3)
Men	6,161	72.5%	8,499	320.8 (312.8-328.9)	442.5 (433.1-452.0)
18-24 years	5,099	88.6%	5,754	344.1 (334.7-353.7)	388.3 (378.4-398.5)
25-34 years	6,185	59.6%	10,379	277.1 (270.2-284.1)	465.0 (456.1-474.0)
Germany ≥18 years					
Total	83,215	24.4% ⁶	340,664	120.5 (119.7-121.3)	493.3 (491.7-495.0)
	79,812	24.1% ⁶	331,203	115.9 (115.1-116.7)	481.1 (479.4-482.7) (2015)
	76,450	23.6% ⁶	324,393	112.3 (111.5-113.1)	476.4 (474.8-478.1) (2014)
Women	38,733	24.7% ⁶	157,063	109.7 (108.6-110.8)	445.0 (442.8-447.2)
Men	44,582	24.2% ⁶	183,446	131.8 (130.6-133.0)	543.5 (541.0-546.0)
18-24 years	21,259	79.1%	26,879	336.1 (331.6-340.6)	425.0 (419.9-430.0)
25-34 years	22,978	42.6%	53,932	217.0 (214.2-218.4)	509.4 (505.1-513.7)
35-44 years	10,131	15.0% ⁷	67,540	102.5 (100.5-104.5)	683.6 (678.4-688.8)
45-54 years	9,702	15.0% ⁷	64,680	73.3 (71.8-74.7)	488.4 (484.6-492.1)
55-64 years	8,072	15.0% ⁷	53,813	70.2 (68.6-71.7)	467.8 (463.8-471.7)
65-74 years	5,229	15.0% ⁷	34,860	63.6 (61.9-65.4)	424.2 (419.7-428.6)
≥75 years	5,844	15.0% ⁷	38,960	62.9 (61.3-64.5)	419.3 (415.3-423.5)

CR=coverage rate, ESPED=German Paediatric Surveillance Unit, DPV=diabetes patient documentation, AICC=Akaike information criterion, adjusted version for small samples, CI=Confidence interval

¹ per 100,000 persons

² Estimated coverage rate based on capture-recapture analysis using three sources of data (ESPED, practices, DPV) according to best log linear model based on AICC criterion with main effects ESPED, practices and DPV for models of incidence and prevalence, and interactions ESPED*practices and ESPED*DPV for prevalence models for the data from the diabetes registry North Rhine-Westphalia (type 1 diabetes 18- to 34-years-old, type 2 diabetes 11- to 18-years-old)

³ Adjusted according to the estimated underreporting

⁴ The sum of adjusted case numbers for both genders and/or age groups may not correspond to the adjusted case number for the total group because the number of cases is estimated based on different log linear models

⁵ Estimated based on registered number of cases

⁶ Estimated as sum of all captured cases across all age groups divided by the sum of all cases adjusted by under-coverage for all age groups

⁷ Assumed DPV coverage rate according to the 18- to 34-year-old age group

Around 341,000 adults and 32,000 children and adolescents have type 1 diabetes.

Accordingly, there was an absolute number of 12,495 new cases between 2014 and 2016, i.e. an average of 4,165 new cases per year. Assuming a completeness of DPV in the age group over 35 years of 22.2% or 12.2% ($17.2 \pm 5\%$), this gives an adjusted incidence estimate of 5.3 (95% CI 5.2-5.4) or 7.4 (95% CI 7.3-7.5) per 100,000 person-years. The absolute number of new cases was then estimated as 3,653 and 5,082.

The incidence adjusted for underreporting of type 1 diabetes was slightly lower for women compared to men (5.4 vs. 5.8 per 100,000 person-years) and decreased continuously with age, from 13.5 per 100,000 person-years in 18- to 24-year-olds to 1.4 per 100,000 person-years in the group aged at least 75. Table 2 moreover shows the incidence for registered cases by age and gender as well as corresponding estimates of ascertainemnet rates and incidences.

Incidence and number of new cases of type 1 diabetes among children and adolescents aged 0 to 17 years in Germany

To provide a fuller picture, we include previously published figures on paediatric type 1 diabetes patients. According to current estimates from North Rhine-Westphalia, the incidence for type 1 diabetes in the 0- to 17-year-old age group is 23.6 per 100,000 person-years, so that for Germany we can assume a figure of 3,100 new cases of type 1 diabetes annually [30].

Total number of new cases of type 1 diabetes for Germany (all age groups)

Based on these estimates, annually, around 7,265 persons newly develop type 1 diabetes in Germany.

3.2 Prevalence of type 1 diabetes

Prevalence of type 1 diabetes in 18- to 34-year-olds in North Rhine-Westphalia between 2014 and 2016

In 2016, 11,285 patients with type 1 diabetes aged 18 to 34 years were registered in the North Rhine-Westphalian diabetes registry. Against a total population of 3,713,823 [31], the prevalence was 303.8 per 100,000 persons (Table 2). The estimated coverage rate was 72.5%, and the underreporting-adjusted prevalence was therefore estimated at 418.8 per 100,000 persons. Accordingly, in 2016, around 15,554 adults in the 18- to 34-year-old age group had type 1 diabetes in North Rhine-Westphalia. Adjusted for underreporting, the prevalence was 426.4 per 100,000 persons in 2014 and 413.4 per 100,000 persons in 2015. In 2016, the underreporting-adjusted prevalence for women was around 12% to 13% lower than for men (392.1 vs. 442.5 per 100,000 persons, Figure 1) and the adjusted prevalence was significantly higher for 25- to 34-year-olds compared to 18- to 24-year-olds (465.0 vs. 388.3 per

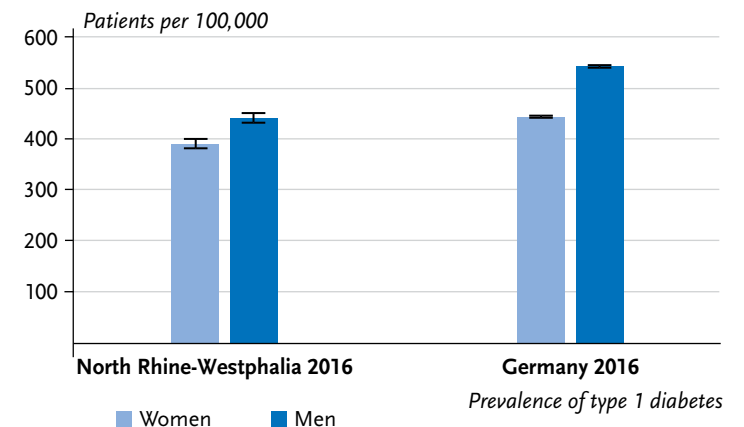


Figure 1

Underreporting-adjusted prevalence of type 1 diabetes according to gender in the age groups 18 to 34 years (North Rhine-Westphalia) and 18 years and older (projected for Germany)

Source: Diabetes registry of North Rhine-Westphalia, Diabetes patient documentation (DPV registry) [1, 19]

Currently, about 175 children and adolescents aged 11 to 18 years develop type 2 diabetes annually.

100,000 persons). Furthermore, [Table 2](#) shows the prevalence for registered cases by age and gender as well as the corresponding coverage rates and prevalence estimates.

Prevalence of type 1 diabetes in adults over 18 years of age in Germany between 2014 and 2016

In 2016, 83,215 patients with type 1 diabetes aged 18 years or older were registered in the DPV diabetes registry. Against a population of 69,051,391 (as at 31.12.2016) [31], the prevalence was 120.5 per 100,000 persons ([Table 2](#)). The coverage rate of DPV in the 18- to 24 and 25- to 34-year-old age group was estimated as 79.1% and 42.6%, respectively. Assuming a DPV coverage rate of 15% in the higher age groups, a prevalence of 493.3 per 100,000 persons was estimated for the age group of 18 years or older in 2016. For 2015 and 2014, the underreporting-adjusted prevalence was 481.1 and 476.4 per 100,000 persons, respectively. Correspondingly, in 2016, 340,664 adults had type 1 diabetes in Germany. Assuming a DPV coverage rate of the age group over 35 years of 20% and 10%, respectively, an adjusted prevalence estimate of 399.3 (95% CI 397.8-400.8) and 681.5 (95% CI 679.6-683.5) per 100,000 persons resulted for 2016. The absolute number of adults with type 1 diabetes was then estimated to be 275,701 and 470,591, respectively, in 2016.

The underreporting-adjusted prevalence in 2016 was around 18% lower for women than for men (445.0 vs. 543.5 per 100,000 persons, [Figure 1](#)). Moreover, in 2016, the underreporting-adjusted prevalence rose from 425.0 per 100,000 persons in the 18- to 24-year-old age group to 683.6 per 100,000 persons in the 35- to 44-year-old age group and then decreased with age continuously to 419.3 per 100,000 persons aged 75 and over ([Table 2](#)).

Prevalence and number of children and adolescents aged 0 to 17 years with type 1 diabetes in Germany

According to current estimates from North Rhine-Westphalia, the prevalence of type 1 diabetes in the 0- to 17-year-old age group was 240 per 100,000 persons, which means that around 32,000 children and adolescents in Germany had type 1 diabetes [32].

Total number of persons with type 1 diabetes in Germany

Based on these estimates, the total number of type 1 diabetes patients across all age groups in Germany is currently almost 373,000.

3.3 Incidence of type 2 diabetes in children and adolescents

Incidence of type 2 diabetes in children and adolescents aged 11 to 18 years in North Rhine-Westphalia between 2014 and 2016

Between 2014 and 2016, 105 patients with newly diagnosed type 2 diabetes aged 11 to 18 years were registered in the North Rhine-Westphalian diabetes registry. Against a total of 4,308,426 person-years, the incidence was 2.4 per 100,000 person-years ([Table 3](#)). The registry coverage rate was 71.9%, and the estimated underreporting-adjusted incidence, correspondingly, 3.4 per 100,000 person-years. Accordingly, there were an absolute number of 146 new cases between 2014 and 2016, which is an average annual incidence of 49 cases. For girls, the underreporting-adjusted incidence rate was over 60% higher than for boys (4.2 vs. 2.6 per 100,000 person-years). No significant difference was found between the 11- to 14-year-old and the 15- to 18

year-old age group (3.5 vs. 3.3 per 100,000 person-years). Table 3 also shows the incidence for registered cases by age and gender, as well as the corresponding estimates of coverage rates and incidences.

Incidence of type 2 diabetes in children and adolescents aged 11 to 18 years in Saxony in 2016

The 2017 interview surveys in Saxony achieved response rates of 100% among paediatric hospitals (n=31) and 88.1% among diabetological practices (n=119). In 2016, ten new cases of type 2 diabetes were registered, three cases in paediatric clinics and seven in diabetological practices.

Study population				2014-2016	
	Registered	Incident cases		Incidence (95% CI) ¹	
		CR ²	Adjusted ^{3,4}	Registered ⁵	Adjusted ³
North Rhine-Westphalia 11-18 years					
Total	105	71.9%	146	2.4 (2.0-3.0)	3.4 (2.9-4.0)
Girls	63	72.4%	87	3.0 (2.3-3.9)	4.2 (3.4-5.2)
Boys	42	72.4%	58	1.9 (1.4-2.6)	2.6 (2.0-3.4)
18-24 years	53	74.6%	71	2.6 (2.0-3.4)	3.5 (2.7-4.4)
25-34 years	52	69.2%	75	2.3 (1.7-3.0)	3.3 (2.6-4.1)
Saxony 11-18 years					
	10	90.9% ⁶	11	4.0 (1.5-6.4)	4.3 (1.8-6.9) (2016)
	21	84.0% ⁶	25	4.2 (2.4-6.1)	5.1 (3.1-7.1) (2014/2015) ⁷
Germany 11-18 years					
Total	273	51.6%	529	1.5 (1.3-1.6)	2.8 (2.6-3.1)
Girls	172	55.1%	312	1.9 (1.6-2.2)	3.4 (3.1-3.9)
Boys	101	45.7%	221	1.1 (0.9-1.3)	2.3 (2.0-2.6)
11-14 years	81	57.7%	140	0.9 (0.7-1.1)	1.6 (1.3-1.9)
15-18 years	192	49.3%	389	2.0 (1.7-2.3)	4.0 (3.6-4.4)

CR=coverage rate, ESPED=German Paediatric Surveillance Unit, DPV=diabetes patient documentation, AICC=Akaike information criterion, adjusted version for small samples, CI=Confidence interval

¹ per 100,000 person-years

² Estimated coverage rate based on capture-recapture analysis using three sources of data (ESPED, practices, DPV) according to best log linear model based on AICC criterion with main effects ESPED, practices and DPV for models of incidence and prevalence, and interactions ESPED*practices and ESPED*DPV for prevalence models for the data from the diabetes registry North Rhine-Westphalia (type 1 diabetes 18- to 34-years-old, type 2 diabetes 11- to 18-years-old)

³ Adjusted according to the estimated underreporting

⁴ The sum of adjusted case numbers for both genders and/or age groups may not correspond to the adjusted case number for the total group because the number of cases is estimated based on different log linear models.

⁵ Estimated based on registered number of cases

⁶ Response rate for surveys of paediatric and diabetological practices in Saxony

⁷ Estimated total coverage rate by [14]

Table 3

Incidence and prevalence of type 2 diabetes in Germany

Source: Baden-Württemberg DIARY (Diabetes Incidence Registry), diabetes registry of North Rhine-Westphalia, diabetes registry of Saxony, Diabetes patient documentation (DPV registry) [1, 19-23]

Continued on next page

Table 3 Continued
Incidence and prevalence of type 2 diabetes in Germany

Source: Baden-Württemberg DIARY (Diabetes Incidence Registry), diabetes registry of North Rhine-Westphalia, diabetes registry of Saxony, Diabetes patient documentation (DPV registry) [1, 19-23]

Study population	Prevalent cases			2016 (2015, 2014)	
	Registered	CR ²	Adjusted ^{3,4}	Registered ⁵	Prevalence (95% CI) ¹ Adjusted ³
North Rhine-Westphalia 11-18 years					
Total	150	77.3%	194	10.4 (8.8-12.2)	13.5 (11.7-15.5)
	167	76.6%	218	11.6 (9.9-13.5)	15.2 (13.2-17.3) (2015)
	165	78.2%	211	11.5 (9.8-13.4)	14.7 (12.8-16.9) (2014)
Girls	91	76.5%	119	13.1 (10.6-16.1)	17.2 (14.2-20.6)
Boys	59	78.7%	75	7.9 (6.0-10.2)	10.1 (7.9-12.6)
11-14 years	30	71.4%	42	4.5 (3.0-6.4)	6.2 (4.5-8.4)
15-18 years	120	78.4%	153	15.7 (13.0-18.8)	20.0 (17.0-23.5)
Baden-Württemberg <20 years					
	80	90.0% ⁶	89	3.8 (3.0-4.6)	4.2 (3.4-5.2) (2016)
	50	90.0% ⁶	56	2.4 (1.8-3.1)	2.7 (2.0-3.5) (2015) ⁶
Germany 11-18 years					
Total	445	58.7%	758	7.1 (6.5-7.8)	12.2 (11.3-13.0)
	554	57.2%	968	8.8 (8.1-9.5)	15.4 (14.4-16.3) (2015)
	652	57.4%	1,136	10.5 (9.7-11.3)	18.2 (17.2-19.3) (2014)
Girls	273	60.4%	452	9.1 (8.0-10.2)	15.1 (13.7-16.5)
Boys	172	55.8%	308	5.3 (4.5-6.1)	9.6 (8.5-10.6)
11-14 years	106	54.8%	194	3.6 (2.9-4.3)	6.6 (5.6-7.5)
15-18 years	339	60.1%	564	10.4 (9.3-11.5)	17.2 (15.8-18.7)

CR=coverage rate, ESPED=German Paediatric Surveillance Unit, DPV=diabetes patient documentation, AICC=Akaike information criterion, adjusted version for small samples, CI=Confidence interval

¹ per 100,000 persons

² Estimated coverage rate based on capture-recapture analysis using three sources of data (ESPED, practices, DPV) according to best log linear model based on AICC criterion with main effects ESPED, practices and DPV for models of incidence and prevalence, and interactions ESPED*practices and ESPED*DPV for prevalence models for the data from the diabetes registry North Rhine-Westphalia (type 1 diabetes 18- to 34-years-old, type 2 diabetes 11- to 18-years-old)

³ Adjusted according to the estimated underreporting

⁴ The sum of adjusted case numbers for both genders and/or age groups may not correspond to the adjusted case number for the total group because the number of cases is estimated based on different log linear models.

⁵ Estimated based on registered number of cases

⁶ Estimated total coverage rate by [14]

Against a total of 252,919 person-years, this was an incidence of 4.0 per 100,000 person-years (Table 3). Adjusted for the response rate, the incidence was 4.3 per 100,000 person-years. For 2014 to 2015, previous surveys estimated

an incidence – adjusted for the estimated coverage rate – of 5.1 per 100,000 person-years.

Around 950 children and adolescents aged 11 to 18 years have type 2 diabetes.

Incidence of type 2 diabetes in children and adolescents aged 11 to 18 years in Germany between 2014 and 2016

Between 2014 and 2016, 273 patients with newly diagnosed type 2 diabetes aged 11 to 18 years were registered in the DPV diabetes registry. With a total of 18,774,057 person-years [31], this resulted in an incidence of 1.5 per 100,000 person-years (Table 3). The DPV coverage rate was 51.6%, so that a underreporting-adjusted incidence of 2.8 per 100,000 person-years was estimated. Accordingly, there was an absolute number of 529 new cases between 2014 and 2016, i.e. an average of 176 new cases per year. Adjusted for underreporting, the incidence for girls was 50% higher than for boys (3.4 vs. 2.3 per 100,000 person-years). Adjusted for underreporting, the incidence in the 15- to 18-year-old age group was 2.5 times higher than in the 11- to 14-year-old age group (4.0 vs. 1.6 per 100,000 person-years). Table 3 moreover shows the incidence for recorded cases by age and gender, as well as corresponding estimates of coverage rates and incidences.

3.4 Prevalence of type 2 diabetes in children and adolescents

Prevalence of type 2 diabetes in children and adolescents aged 11 to 18 years in North Rhine-Westphalia between 2014 and 2016

In 2016, 150 patients with type 2 diabetes aged 11 to 18 years were registered in the diabetes registry of North Rhine-Westphalia. For a population of 1,437,776 adolescents of this age group [31], this is a prevalence of 10.4 per 100,000 persons (Table 3). The estimated coverage rate was 77.3%, and the underreporting-adjusted prevalence was therefore

estimated at 13.5 per 100,000 persons. For 2015, the underreporting-adjusted prevalence was 15.2, and for 2014 14.7 per 100,000 persons. Accordingly, in 2016, 194 11- to 18-year-old children and adolescents had diagnosed type 2 diabetes, 218 in 2015 and 211 in 2014. In 2016, the underreporting-adjusted prevalence was 70% higher for girls than for boys (17.2 vs. 10.1 per 100,000 persons) and around three times higher for 15- to 18-year-olds compared to 11- to 14-year-olds. Table 3 also shows the prevalence for recorded cases by age and gender as well as the corresponding coverage rates and prevalence estimates.

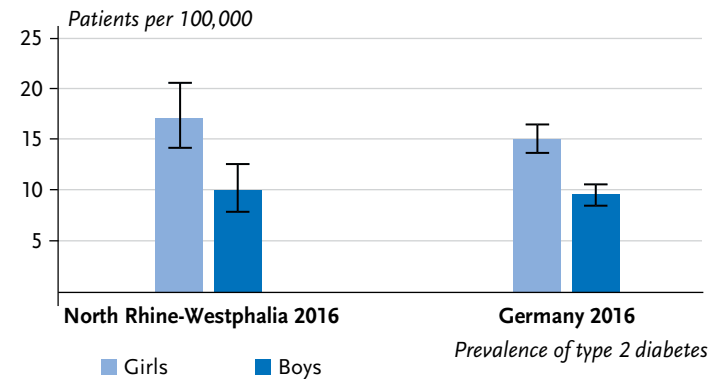
Prevalence of type 2 diabetes in children and adolescents under 20 years of age in Baden-Württemberg

In the 2017 survey in Baden-Württemberg, the response rate for the paediatric DIARY network (31 paediatric clinics and 1 diabetes centre) was 78.1% (25/32) and for diabetologists caring for adults 21.4% (57/266) (BVND 14.5% (35/242), ADBW 8.3% (22/266)).

In 2016, a total of 80 patients with type 2 diabetes under the age of 20 years were recorded in Baden-Württemberg (Table 3), 34 patients in the DIARY network, i.e. in paediatric care, 26 BVND patients and 20 patients in the regional ADBW association. For a population of 2,097,929 children and adolescents [31], this is a prevalence of 3.8 per 100,000 persons. Taking account of the estimated 90% coverage rate provides a prevalence of 4.2 per 100,000 persons. A previous estimate had reported a lower prevalence of 2.4 (95% CI 1.8-3.1) and a lower adjusted prevalence of 2.7 (95% CI 2.0-3.5) per 100,000 persons.

Figure 2
Underreporting-adjusted prevalence
of type 2 diabetes according to gender
in the age group 11 to 18 years

Source: Diabetes registry of North Rhine-Westphalia, Diabetes patient documentation (DPV registry) [1, 19]



Prevalence of type 2 diabetes in children and adolescents aged 11 to 18 years in Germany between 2014 and 2016

In 2016, 445 patients with type 2 diabetes aged 11 to 18 years were registered in the DPV diabetes registry. Against a population of 6,237,040 children and adolescents (as at 31.12.2016) [31], this is a prevalence of 7.1 per 100,000 (Table 3). Coverage rate was an estimated 58.7%, giving an estimated underreporting-adjusted prevalence of 12.2 per 100,000 persons. The underreporting-adjusted prevalence was 15.4 for 2015 and 18.2 per 100,000 persons for 2014. Accordingly, in 2016, 758 11- to 18-year-old children and adolescents had type 2 diabetes. In 2014 and 2015, it was 1,136 and 968 children and adolescents, respectively, i.e. an average of around 950 children and adolescents in the years 2014 to 2016. In 2016, the underreporting-adjusted prevalence was nearly twice as high for girls compared to boys (15.1 vs. 9.6 per 100,000 persons, Figure 2) and around 2.5 times higher for 15- to 18-year-olds compared to 11- to 14-year-olds. Table 3 also shows the prevalence for recorded cases by age and gender as well as the corresponding coverage rates and prevalence estimates.

4. Discussion

4.1 Results

Type 1 diabetes

For the first time, current estimates for the incidence of type 1 diabetes across all age groups for adults aged over 18 are provided. For young adults aged 18 to 34 years, the incidence estimates from North Rhine-Westphalia fit well to national incidence figures (12.0 vs. 11.8 per 100,000 person-years). For the group of all adults (aged over 18) a lower incidence of an estimated 6.1 per 100,000 person-years was found, which reflects the decreasing incidence of type 1 diabetes with age. Statutory health insurance data provides a similar incidence, yet only for the limited age ranges 15 to 55 (7.1 per 100,000 person-years) and 20 to 55 (6.1 per 100,000 person-years) [11]. As the incidence of type 1 diabetes decreases with age, the incidence estimates for all adults based on statutory health insurance data should be lower.

According to the current prevalence estimate (493 per 100,000 persons), about 341,000 adults at the age of at least 18 years are affected by type 1 diabetes at the national level. This estimate is higher than previous ones based on statutory health insurance data. According to the reports of the structured treatment programs run by statutory health insurances (DMP programs), there were around 279,000 type 1 diabetes patients over 18 years of age in Germany in 2014 [9]. Prevalence estimates based on statutory health insurance data estimated that there were 229,000 adults aged over 20 with type 1 diabetes in Germany in 2009 and 224,000 in 2010. Prevalences calculated on the basis of claims data yielded 262,000 type 1 diabetes

Incidence and prevalence of type 1 diabetes is lower in women than in men.

patients in 2009 and 230,000 in 2015 [3]. However, because they fail to account for the privately insured – around 10% of the population – incidence and prevalence estimates based on statutory health insurance data most likely underestimate the true number of cases.

Combined with estimates for the 0- to 17-year-old age group, there are around 7,250 new cases of type 1 diabetes annually in Germany and there is a total of about 373,000 type 1 diabetes patients.

Type 2 diabetes

At the turn of the millennium, reports on a significant increase of cases of type 2 diabetes at adolescent age began to multiply. Such reports came mainly from North America and Asia, and were based on an increase in the obesity prevalence in this age group [33, 34]. This was contrasted by European surveys, which pointed at a significantly lower prevalence of type 2 diabetes in adolescents [14, 35-37].

Between 2004 and 2006, the first comprehensive cross-sectional study of type 2 diabetes among children and adolescents was conducted in Baden-Württemberg [14]. With its population of 10.7 million, of which 22.7% are under 20 years of age, Baden-Württemberg is the third largest federal state. With the DIARY network (Diabetes Incidence Registry), Baden-Württemberg has a federal state wide comprehensive surveying structure that binds in all paediatric clinics in the state, as well as one diabetes centre. The first cross-sectional survey was conducted within the framework of this network and with the participation of internal medicine clinics and diabetological practices. In 2016, ten years later, a new cross-sectional survey was conducted as a sub-project with the national diabetes

surveillance at the RKI. Both DIARY clinics, all ADBW (working group diabetes in Baden-Württemberg) members, as well as the BVND (German association of diabetologists) in Baden-Württemberg took part in the survey.

The first prevalence survey in Baden-Württemberg was conducted between 2004 and 2006 and indicated a prevalence of 2.4 per 100,000 persons (95% CI 1.7-3.1) for the age group under 20 years. For 2015, the prevalence was 2.3 per 100,000 persons (95% CI 1.7-2.9). During a ten year period, the prevalence of type 2 diabetes in adolescents therefore remained stable [14]. An update within the context of this sub-project of the national diabetes surveillance showed a prevalence of 2.4 (adjusted for underreporting 2.7) for 2015 for 100,000 persons, yet a significantly higher prevalence of 3.8 (adjusted for underreporting 4.2) per 100,000 persons for 2016.

Point estimates for the incidence of type 2 diabetes vary significantly for North Rhine-Westphalia, Saxony and Germany overall, yet taking into account the uncertainty of estimates relativises these differences. All current estimates are higher than the average incidence in North Rhine-Westphalia between 2002 and 2014, a fact which indicates an increase in the rate of new cases. The incidence between 2012 and 2014 for under-20-year-olds estimated on the basis of claims data is many times higher [8]. Presumably this is due to the differences in forms of data collection and different case definitions. The observed changes to the incidence in Saxony are probably related to random fluctuations in incidence of this ultimately rare disease, as well as the potential factor of differences in the quality of data collection. Due to the great uncertainty of estimates (broad confidence intervals), evidence for incidence changes is

lacking and results from longer periods of observation are to be seen.

Point estimates for the prevalence of type 2 diabetes in North Rhine-Westphalia, Baden-Württemberg and Germany overall likewise show substantial discrepancies. Particularly notable is the low prevalence in Baden-Württemberg (2015/2016: 2.4/3.8 and adjusted for underreporting 2.7/4.2 per 100,000 persons) compared to North Rhine-Westphalia and nationwide estimates (12 – 18 per 100,000 persons). Based on statutory health insurance data, the estimates for the prevalence for under-20-year-olds were many times higher. For 2009 to 2010, the prevalence was estimated as 30 to 40 per 100,000 persons [7]. Age-specific estimates reported in [8] provided an estimated prevalence of 66 or 41 per 100,000 persons for 2009 and 2015, respectively. The great discrepancy with regard to other surveys is presumably linked to differences in surveying methods and a different classification of type 2 diabetes.

All data sources point to a higher number of female adolescent type 2 diabetes cases. Higher body fat and a lower insulin sensitivity, as well as lower levels of physical activity among obese female children and adolescents could play a causal role here.

The fact that the frequency of type 2 diabetes in this age group in central Europe is far lower than for example in North America can be explained by the ethnic composition of the population. People of Afro-American and Hispanic-American background, from Asia and the Pacific Islands, as well as Native Americans have a significantly higher type 2 diabetes risk and are not an important proportion of the European population [38]. The prevalence rates found in Baden-Württemberg are comparable to those found in

neighbouring countries such as Sweden [36], the UK [35] or Austria [37]. Compared to North America and Asia, type 2 diabetes among children and adolescents therefore remains a (still) relatively rare disease in Germany [39].

While the observed regional differences in the incidence and prevalence of type 2 diabetes among children and adolescents may point to actual regional differences, they could also be related to differences in surveying methods and coverage rates. Regional differences in the disease rate of type 2 diabetes among adults, in particular a North-South and an East-West gradient have been described by the DIAB-CORE (Diabetes-Collaborative Research of Epidemiologic Studies) project of the diabetes competency network and secondary analyses of statutory health insurance data [8, 40, 41]. Type 2 diabetes, as well as the key risk factor obesity, are closely tied to individual social status and regional levels of deprivation [42-44]. However, differences in surveying methods and the quality of data collection also influence incidence and prevalence estimates. In North Rhine-Westphalia, more than 20% of patients were found in general practitioners' practices, a care level that was not comprehensively covered by the survey in Baden-Württemberg. Due to local and historical specificities, there are differences in the diabetological treatment patients receive depending on whether they are living in Baden-Württemberg, Saxony or North Rhine-Westphalia.

4.2 Limitations

Type 1 diabetes

The analyses only took into account patients with a medical diagnosis of 'classical' type 1 diabetes. In routine care,

however, without full laboratory analysis, a clear distinction between type 1 diabetes and LADA often cannot be made. Therefore, it cannot be ruled out that a certain number of patients is categorised with the wrong diabetes type. However, the numbers of false categorisations are presumably so small that they do not relevantly influence incidence and prevalence estimates.

The coverage rate for new cases of type 1 diabetes in young adults aged 18 to 34 years was only 30%. The coverage rate for the prevalence of type 1 diabetes in young adults was 73% and, hence, substantially higher. Therefore, a bias in the incidence estimates for North Rhine-Westphalia cannot be entirely ruled out; prevalence estimates are to be considered as more valid.

The coverage rate of the DPV registry for type 1 diabetes could only be estimated for young adults (18- to 34-years-old) using the data of the North Rhine-Westphalian registry. In this case too, the coverage rate for incident cases (around 17%) were far lower than for prevalent cases (around 61%). Moreover, it should be noted that uncertainties in the estimation of coverage rates were not considered when estimating adjusted incidences and prevalences.

For coverage rates at older ages, plausible assumptions on the completeness of capture of the DPV registry had to be made. For incident cases, the estimated coverage rate for young adults (18- to 34-years-old) was applied to older age groups, for prevalent cases a coverage rate of 15% was chosen. An underreporting of adult prevalent cases must already be expected, because prevalent type 1 diabetes cases at the age of e.g. over 26 in 2016, who therefore developed diabetes before 1990, were less likely to be registered due to the late start of registries (DPV mid 1990s, North

Rhine-Westphalia registry 2002). Assumptions on the coverage rate of the DPV registry used could lead to distortions of national incidence and prevalence estimates. In terms of a sensitivity analysis, however, the assumptions regarding the completeness of capture were varied.

Type 2 diabetes

The registries only include diagnosed cases of type 2 diabetes in children and adolescents. They therefore estimate only the incidence and prevalence of known type 2 diabetes. However, a significant number of undiagnosed cases cannot be ruled out, though precise estimates for children and adolescents do not exist. For adulthood, a proportion of unknown type 2 diabetes in the total prevalence of 20% to 50% has been reported [45]. Moreover, a clear distinction between type 2 diabetes and monogenetic diabetes forms is not always easy in children and adolescents, which may lead to erroneous categorisation.

The coverage rate of the North Rhine-Westphalian registry for the incidence and prevalence of type 2 diabetes in 11- to 18-year-old children and adolescents was estimated at 72% or 77%. The corresponding rates in the DPV data for North Rhine-Westphalia were 52% or 59%. The estimates of national incidence and prevalence are therefore more uncertain than the estimates from North Rhine-Westphalia.

For the surveys in Saxony and Baden-Württemberg no formal estimates of total coverage rate were possible. The figures in Saxony were adjusted based on the survey response rate and in Baden-Württemberg based on an earlier estimate of the coverage rate [14]. Due to the anonymised data collection, double reporting could lead to an overes-

timation if the patient is treated simultaneously in a specialised diabetological practice and an outpatient clinic or if patients move. However, the determined case numbers probably underestimate the true prevalences. The estimates presented here are therefore only rough approximations.

4.3 Conclusion and outlook

Initially, the project 'Type 1 diabetes in adults and type 2 diabetes in children and adolescents' focused on developing and providing methods and procedures to estimate the incidence and prevalence of type 1 diabetes at adult age and type 2 diabetes at child and adolescent age in close co-operation with the available local registries in Baden-Württemberg, North Rhine-Westphalia and Saxony, as well as the national DPV registry. For paediatric clinics (participants in the diabetes registries in Saxony and Baden-Württemberg) and diabetological clinics, surveys were established on treated child and adolescent type 2 diabetes in Baden-Württemberg (prevalence) and newly diagnosed child and adolescent type 2 diabetes in Saxony (incidence). Furthermore, in a co-operation between the DPV registry Ulm and the diabetes registry in North Rhine-Westphalia, methods and procedures to estimate the national incidence and prevalence of type 1 diabetes in adults and type 2 diabetes in children and adolescents were provided. Gender-specific aspects were also taken into account.

The structures to estimate the national incidence and prevalence of type 1 diabetes in adults and type 2 diabetes in children and adolescents established by this project provide the basis for a continuous surveillance of these

epidemiological parameters in the future and therefore also to assess trends over time. The provided data complements the available epidemiological data on child and adolescent type 1 diabetes (three incidence registries in Baden-Württemberg, North Rhine-Westphalia and Saxony, as well as the national DPV registry) and on type 2 diabetes in adults (regional and national surveys, as well as analyses of the data provided by statutory health insurances), so that diabetes surveillance can monitor the epidemiology of type 1 and type 2 diabetes across all age groups. For health policy and public health institutions this is key to planning future health care needs, and is also important for the interested public. Annually updating this data is furthermore important to assess whether prevention measures are effective at the population level.

To consolidate the diabetes surveillance, data on type 1 diabetes in adults and type 2 diabetes in children and adolescents should also be collected and evaluated in the coming years. For the manifestation year 2018 this has already occurred (co-operation project 2019). A further perspective for the future of diabetes surveillance could be to expand the scope beyond type 1 and type 2 diabetes and include analyses of rare forms at national level which are nevertheless relevant for an overall evaluation of diabetes, such as genetic-based (for example MODY diabetes) or secondary diabetes forms (for example in mucoviscidosis patients) because valid epidemiological data on rare forms of diabetes cannot be collected through population-based representative samples [46].

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Data protection and ethics

All four sources of data were assessed and approved by the corresponding ethics committee. The aggregated and evaluated data for National Diabetes Surveillance and for this article are based entirely on anonymised data.

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Conflicts of interest

The authors declared no conflicts of interest.

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Secondary data in diabetes surveillance – co-operation projects and definition of references on the documented prevalence of diabetes

Abstract

In addition to the Robert Koch Institute's health surveys, analyses of secondary data are essential to successfully developing a regular and comprehensive description of the progression of diabetes as part of the Robert Koch Institute's diabetes surveillance. Mainly, this is due to the large sample size and the fact that secondary data are routinely collected, which allows for highly stratified analyses in short time intervals. The fragmented availability of data means that various sources of secondary data are required in order to provide data for the indicators in the four fields of action for diabetes surveillance. Thus, a milestone in the project was to check the suitability of different data sources for their usability and to carry out analyses. Against this backdrop, co-operation projects were specifically funded in the context of diabetes surveillance.

This article presents the results that were achieved in co-operation projects between 2016 and 2018 that focused on a range of topics: from evaluating the usability of secondary data to statistically modelling the development of epidemiological indices. Moreover, based on the data of the around 70 million people covered by statutory health insurance, an initial estimate was calculated for the documented prevalence of type 2 diabetes for the years 2010 and 2011. To comparably integrate these prevalences over the years in diabetes surveillance, a reference definition was established with external expertise.

DIABETES SURVEILLANCE · DIABETES MELLITUS · SECONDARY DATA · EPIDEMIOLOGY · PUBLIC HEALTH

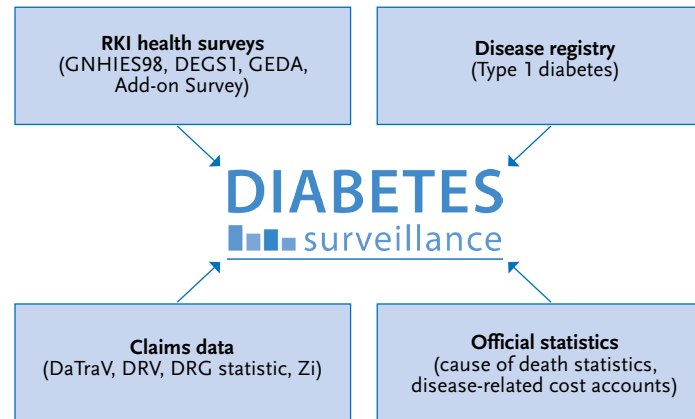
1. Introduction

A pilot project to establish diabetes surveillance at the Robert Koch Institute (RKI) was launched in 2016. This step highlights diabetes mellitus' great relevance to public health as a disease and cause of complications. Based on indicators agreed upon in consensus by experts, in future diabetes surveillance will report on diabetes-relevant developments as defined by its conceptual framework [1]. The presentation of results based on these indicators makes

use of further data sources in addition to the data provided by the RKI in the context of health monitoring (primary data). The main objective of health monitoring is to provide representative information on the trends for the most important diseases, health behaviour and subjective assessments of the health of the population in Germany stratified by age, gender and socioeconomic status (see the article on [Social inequality and diabetes mellitus](#) in this issue)[2].

Conducting interview and examination surveys is time-consuming because the content must be coordinated

Figure 1
Data model of diabetes surveillance
Own diagram



RKI = Robert Koch Institute
 GNHIES98 = German National Health Survey 1998
 DEGS1 = German Health Interview and Examination Survey for Adults (2008-2011)
 GEDA = German Health Update
 DaTraV = Data according to the Data Transparency Regulations
 DRV = German pension insurance
 DRG statistic = Diagnosis-Related Groups Statistic
 Zi = Central Research Institute of Ambulatory Health Care in Germany

with each other, and organisational planning and meticulous quality and data protection procedures also take time. Furthermore, as the objective is to collect information as efficiently as possible, the number of cases in primary studies is limited. To fully implement the objective of surveillance, i.e. provide in-depth stratification for specific indicators and at short time intervals, requires further sources of data. Reviewing potential sources of data, modes of accessing this data and adequate analyses were therefore key project tasks in the establishment of diabetes surveillance. To achieve these objectives, tenders for co-operation projects were organised in order to help define evaluation potentials, identify and close data gaps, and reveal options for data analysis for the entire duration of the project.

Out of the 40 indicators of diabetes surveillance 14 require only secondary data. A detailed description of

indicators, their definition and the sources of data has been published on the [RKI website](#) [3]. 11 indicators that rely mainly on RKI health monitoring data also require secondary data. The diabetes surveillance data model (Figure 1) therefore includes RKI health monitoring, type 1 diabetes registry data (see the article on [Type 1 diabetes in adults and type 2 diabetes in children and adolescents](#) in this issue) as well as claims data of the statutory health insurance. This latter data is primarily collected for accounting and only secondarily used in scientific analyses, which is why such data has become known as secondary data [4]. Secondary data is process-produced data and therefore contains only limited information on socioeconomic status, subjective health, risk factors or undiagnosed diseases. The advantages of this data, however, are large samples and the availability of a constant inflow of new data.

Data from the social security system provides the core of secondary data, i.e. the data from the main providers of outpatient, inpatient and rehabilitative medicine: statutory health insurances (GKV) and the German pension insurance (DRV). Due to Germany's regionally segregated health care structure, much of this routinely collected data is not centrally available, is processed by different institutions and therefore not always equally available to research [5]. Data on the provision of rehabilitation services through DRV for example are kept by the German pension insurance. Evaluating the use of medical rehabilitation services by diabetes patients is therefore only possible based on this data [6]. And GKV data is for example segregated by insurance providers and sector. While some health insurances do use the data of insured persons to calculate disease prevalences, the demographic and socioeconomic

Info box 1:**Data by the Data Transparency Regulations (DaTraV)**

The data processing unit at the Institute of Medical Documentation and Information (DIMDI) can provide analyses based on the routine data of the around 70 million people covered by statutory health insurance (DaTraV data), which help plan, manage and assess the needs of the German health care system while ensuring the protection of the identity of insured persons. DaTraV data can be evaluated across sectors of care and health insurance companies. It allows long-term assessments of disease progress for individual patients. As various publications have shown, using DaTraV data in the surveillance of noncommunicable diseases in particular principally makes sense. Yet there is room for improvements and an amendment to the data transparency regulations is planned. Changes will probably include

- ▶ Transferral of the diagnoses and medication data from the morbidity-oriented risk structure compensation scheme (Morbi-RSA), also of deceased individuals by the German Federal Insurance Office,
- ▶ reducing the delay in data provision from four to two years.

One aim is to reduce the current processing time for applications. Based on an external evaluation of the organisation, an increase of staff was applied for. Already, data on place of residence for 2009, 2010 and 2011 are available for analyses. From 2020, it will be possible to continuously analyse reporting years regionally by postal codes.

differences, as well as the differences in health risks between those insured by different insurers make comparisons difficult [5]. This makes it difficult to generalise, for example on the prevalence of diabetes among all people with statutory health insurance, and means prevalence can only be estimated based on assumptions [7].

The Central Research Institute of Ambulatory Health Care (Zi) in Germany holds a complete set of outpatient claims data for all people covered by statutory health insurance. However, this data does not contain information on people covered by statutory health insurance with no outpatient consultations and totally lacks data on inpatient care [8]. Information on all people covered by statutory health insurance is contained in the data set held by the German Institute of Medical Documentation and Information (DIMDI) on the basis of Germany's Data Transparency Regulations (DaTraV) [9]. However, this data too has its limitations. While it contains complete data on out- and inpatient diagnoses as well as prescribed medicines, it provides no information on inpatient or outpatient medical services. Furthermore, this data currently comes with a four-year delay and can so far only be evaluated regionally for individual reporting years. Moreover, neither the Zi nor the DIMDI data set provide information on people covered by private insurance. [Info box 1](#) describes the data provided by DaTraV and its usability in surveillance systems, as well as an overview of planned reforms.

Beyond the problems posed by fragmented and incomplete data described above, the criteria to define diabetes in routine data (selection criteria) also vary. Differences in selection criteria, which can be justified based on content, produce different results and make comparability over time

more difficult. Furthermore, particularly with diabetes, the differentiation between the different forms of the disease in analyses of secondary data is tied to a set of assumptions. Frequently one finds unspecific or aetiologically mutually exclusive diagnoses, such as a diagnosis of type 1 and type 2 diabetes simultaneously coded together [10]. A reference definition, which will be applied to DaTraV data, aims to increase the reliability, transparency and comparability of documented prevalence within the framework of diabetes surveillance. The definition of prevalence also provides the basis to determine further indicators such as those of mortality and incidence.

This article provides an overview of the results of the co-operation projects developed and co-operation partners found in the context of diabetes surveillance, who have all contributed significantly to the development of this project. We also present initial results on the prevalence of type 2 diabetes based on DaTraV data. The critical review of and experiences with this first set of results led to the definition of a frame of reference, which we also present here and which will provide the foundation for future diabetes surveillance reporting of documented prevalence and the calculation of further indicators.

2. Methodology

Since 2016, diabetes surveillance has published tender notices annually to promote co-operation projects. Suitable projects were selected based on specifically developed, standardised application and evaluation criteria, which were annually adapted in accordance with the stage of the project. The main criteria by which to evaluate the projects

25 of 40 indicators of diabetes surveillance were either entirely or at least partially populated with secondary data.

included a high public health relevance and easy integration within current surveillance, replicability of results, clarity of the method and feasibility of the project proposal within a one year time span. Developing indicators, sifting suitable sources of data and selecting co-operation projects were all done in parallel.

During a workshop in March 2017 [11], co-operation partners presented the identified data sources and exemplary analyses from projects implemented during the first funding years and discussed them with experts. During the workshop, DaTraV data and the possibilities to analyse this data using the data processing unit of DIMDI were presented and discussed. At the same time, we applied for an initial DaTraV output data set to calculate the prevalence of diabetes in 2010 and 2011. The results for type 2 diabetes were presented stratified by age group and gender and put in the context of current literature. Based on a critical contextualisation of results, in co-operation with the data processing unit and external expertise, we developed the reference definition presented here, which will serve as a basis to calculate documented prevalence and further indicators.

3. Results

In the following, the results of the cooperation projects from 2016 to 2018 will be presented first. Then the figures from the initial analysis of DaTraV data in the context of diabetes surveillance on the documented prevalence of type 2 diabetes during 2010 and 2011 will be presented and critically discussed.

3.1 Results of co-operation projects

Table 1 presents the authors of the co-operation projects, the indicators or contributions they worked on and the benefits these provide to diabetes surveillance.

3.1.1 Time series on amputations and hospitalisation in patients with diabetes

Hospitalisations due to lower limb amputations (major amputations) or other diabetes-related complications in diabetes patients are considered potentially preventable because diabetes can be controlled well with adequate structures for outpatient treatment. The Organisation for Economic Co-operation and Development (OECD) therefore uses hospitalisations as a population-related indicator that allows conclusions to be drawn on availability and quality of outpatient care [12]. These indicators are calculated for diabetes surveillance based on the Diagnosis-Related Groups Statistic (DRG statistic). 76,139 women with diabetes were hospitalised due to complications and 2,560 had amputations in Germany in 2016; for men, the figures were 108,386 hospitalisations due to complications and 5,402 amputations. After age standardisation using the German standard population in 2005, the number of hospital cases in the female population declined over time from 234 cases per 100,000 inhabitants in 2005 to 174 cases per 100,000 inhabitants in 2016. For men, the decrease was from 311 cases per 100,000 inhabitants in 2005 to 302 cases per 100,000 inhabitants in 2016 (Figure 2). The amputation rate for women during this same period dropped from 11.6 cases per 100,000 inhabitants to 5.4 cases per 100,000 inhabitants and from 23.0 cases per

Table 1
Co-operation projects of diabetes surveillance, role within the project, authors and project description
 Own table

Co-operation project	Project year	Contribution	Use	Authors
Surveillance of ambulatory care-sensitive conditions in diabetes mellitus	2016	Amputations and hospitalisation (Section 3.1.1)	Regular presentation of indicators as a time series in surveillance	Johannes Pollmanns, Maria Weyermann, Saskia Drösler
Use of DMP documentation data for diabetes surveillance	No funding	All indicators of DMP quality assurance (Section 3.1.2)	Exclusive evaluation of DMP data for diabetes surveillance	Bernd Hagen
Measuring quality of care based on routine data	2016-2017	Feasibility study on the potential of GKV data (Section 3.1.3)	Comprehensive estimate as a basis for definitions and analyses based on secondary data	Gunter Laux, Joachim Szecsenyi, Stephanie Kümmel
Projections of prevalence and incidence of diabetes in Germany	2017	Prevalence prognosis models (Section 3.1.4)	Innovative epidemiological methods to model different scenarios for the development of number of cases	Ralph Brinks, Thaddäus Tönnies, Annika Hoyer
Co-operation with the data processing department to improve the use of DaTraV data in epidemiological research	No funding	Providing an overview of DaTraV data (Info box 1)	Reference evaluation with DaTraV data	Jochen Dreß
Feasibility study on the applicability of data on obesogenic environments in the surveillance of diabetes risk factors	2017	Obesity in tight-knit association with environmental factors (Section 3.1.5)	Analyses that make use of georeferential coding	Maximilian Präger, Christoph Kurz, Julian Böhm, Michael Laxy, Werner Maier
Updating of public health-relevant indices for diabetes surveillance and projections for the prevalence of diabetes and its limitations	2018	Disease burden figures (Section 3.1.6)	Use of biometric methods to estimate and provide prognoses for disease burden figures	Annika Hoyer, Thaddäus Tönnies, Ralph Brinks
Evaluation of St. Vincent targets based on diabetes mellitus-related complications: terminal renal insufficiency in patients with or without diabetes	2018	Renal replacement therapy and renal insufficiency (Section 3.1.7)	Results from diverse data sources/development of definitions to use routine data	Heiner Claessen, Tatjana Kvitkina, Maria Narres, Andrea Icks

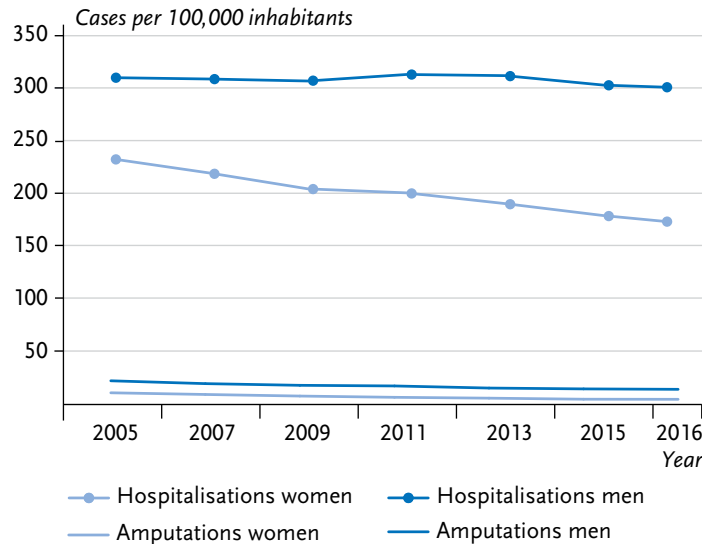
GKV=statutory health insurance, DaTraV=Data according to the data transparency regulations, DMP=disease management program(s)

100,000 inhabitants in 2005 to 14.9 cases per 100,000 inhabitants in 2016 for men. The development of rates could indicate an improved quality of outpatient care for diabetes patients over time or otherwise a greater adherence of patients to prescribed therapies [13].

Adjusted for age and gender, a regional focus reveals particularly high rates of hospitalisations due to complications as well as for amputations in the former East German federal states with the exception of Berlin [13]. The great influence of diabetes prevalence is an important factor to

Figure 2**Hospitalisations and amputations over time (age standardised rates) for diabetes mellitus in Germany according to gender**

Source: Diagnosis-Related Groups Statistic (DRG statistic) 2005 to 2016



Over the course of the project, co-operation projects are promoted that specifically encourage the use of secondary sources of data.

take into account here, i.e. regional differences in prevalence already explain the differences in rates of amputations and hospitalisations [14].

Integrating the OECD indicators in diabetes surveillance is easily feasible in terms of methodology, however, the changing definitions of indicators are challenging for comparisons over time. Over the course of the co-operation project, for example, the definition of amputations changed to exclude patients who had died in hospital. When interpreting indicators regarding their spatial distribution, predictors such as the regional differences in diabetes prevalence or socioeconomic factors must be taken into account.

3.1.2 Potential uses for the Disease Management Programs

Disease Management Programs (DMP) are structured treatment programs for specific diseases that aim to improve treatment processes and the quality of care of

chronically ill patients. A central feature of the disease management programs introduced for type 2 diabetes in 2003 and type 1 diabetes in 2006 is the quarterly or semi-annual documentation of standardised indicators by the participating doctor's surgeries. Based on these indicators the DMP defines a set of quality objectives to describe the quality of treatment for patients in DMP cross-sectionally and longitudinally. Across Germany, 4.4 million patients are registered in the diabetes DMP. On average, inscribed patients have been attended to for 7.5 years (type 2 diabetes) or 7.1 years (type 1 diabetes) in the DMPs of the Association of Statutory Health Insurance Physicians Nordrhein (KV-Nordrhein) [15]. This provides a large data set that permits differentiated findings on quality of care by age or duration of illness.

The usability of DMP data is limited particularly due to the following factors:

- (1) As participation in DMPs is generally voluntary and programs are only open to patients in statutory health insurance who can still actively and independently handle their illness, selection effects are likely.
- (2) Documentation parameters and quality targets change over time, new indicators are created or indicators are replaced that have been used for many years. This creates gaps in surveillance over time.
- (3) Although the group of patients in the type 2 diabetes DMP is very large and probably very diverse regarding the duration of illness, there are no contractual bases to represent this diversity with regard to quality of care.

In spite of these limitations DMPs have provided a number of important results: diabetes DMPs reach a large pro-

Co-operation project results indicate increasing case numbers by 2040 but also improved treatment for diabetes patients.

portion of diabetes patients. Over the course of time, the guideline-based treatment that diabetes patients receive has significantly improved. Continuous participation in DMPs increases the chances to achieve quality targets, and there is a clear decrease of severe complications for patients participating in type 2 DMPs. For diabetes surveillance, DMP data from North Rhine-Westphalia is presented to demonstrate the achievement of quality targets for both type 1 and type 2 diabetes. In future, the different frequencies of target achievement stratified by gender and age group over time will be reported and integrated into diabetes reporting.

3.1.3 Routine data to measure quality: definitions and measurement

As part of this co-operation project, a complete data set for one statutory health insurance (AOK Baden-Württemberg) was used to analyse to what extent secondary data can contribute towards the overall project of establishing diabetes surveillance at the RKI.

To start, the aQua Institute for Applied Quality Improvement and Research in Health Care in Göttingen conducted a review of literature searching for type 2 diabetes indicators. In a first step it defined inclusion and exclusion criteria. Included were all indicators that can be applied to adult type 2 diabetes patients. Indicators of type 1 diabetes or gestational diabetes were excluded.

In November 2016, an expert panel took place in Göttingen. With external expertise, an indicator set was agreed in consensus. The experts evaluated all the indicators that had been found in the search in terms of their relevance for diabetes surveillance. The meeting offered room to fur-

ther expand the indicator set. Consensus was found on 70 quality indicators.

47 of these 70 indicators, i.e. over two thirds of the set, can be calculated using secondary data. Importantly, however, this always requires evaluating the validity of the underlying secondary data. In addition, adequate procedures must ensure both internal and external validity, i.e. performing plausibility checks for results regarding the data itself (internal) as well as regarding other data sources (external) [17]. A report for the DIMDI on the access to and potential uses of data for care research [18] enumerates a number of advantages of GKV data as well as its limitations. This report also considers other social insurance carriers, official statistics and federal health reporting, as well as private health insurance data.

Overall, the project made it very clear that secondary data, such as the data from AOK Baden-Württemberg used here, if specifically prepared and analysed, has the potential to close certain data gaps within a comprehensive diabetes surveillance approach. To reach a consensus on the set of 40 indicators, the indicators identified during the project were compared against the indicators found by the diabetes surveillance literature search. The project results led to the inclusion of these four additional indicators in the indicator set of diabetes surveillance: diabetic neuropathy, diabetic foot syndrome, renal replacement therapy and age at diagnosis.

3.1.4 Epidemiologic parameters and projections for diabetes surveillance

The constant spread of diabetes poses considerable challenges to the healthcare system. Beyond taking stock of

Initial results, which are based on the data of all people covered by statutory health insurance, indicate an increase in documented prevalences of type 2 diabetes from 7.7% (2010) to 8.1% (2011) for women and 8.2% to 8.6% for men, respectively.

current case numbers, resource planning will require the most accurate prediction possible of future developments. Current estimates for Germany indicate that the number of diabetes patients is set to increase sharply in the future, these projections are however either based on figures for specific age ranges or solely on the data from particular statutory health insurances [19]. Due to the diversity of the demographic and socioeconomic characteristics of the groups insured by different health insurances, basing predictions on the data provided by individual insurances is problematic.

To better predict future figures of people with type 2 diabetes, this project applies the age- and gender-specific prevalence of type 2 diabetes from the year 2015 to the future age structure of the German population until 2040 as predicted by the Federal Statistical Office [20]. The assumed prevalence is thereby based on the data of all statutory health insurances in Germany, or DaTraV data [10].

Assuming that demographic ageing continues, yet that the age-specific prevalence of type 2 diabetes for women and men remains constant between 2015 and 2040, the number of people with type 2 diabetes will increase from 6.9 million in 2015 to 8.34 million in 2040, which would be a 21% increase. Predicting the future number of diabetes cases by using current age-specific prevalence is the simplest form to calculate a projection. Improved treatment of diabetes patients due to medical progress and the resulting longer average life expectancy will very likely lead to a rising age-specific prevalence, making the results presented here a conservative estimate. More realistic scenarios are obtained by modelling the interaction between incidence and mortality rates, which, when based on realistic assump-

tions of the trends until 2040, predict increases of over 50% [20].

3.1.5 Using geocoding services to gain information on the obesogenicity of environments

A feasibility study tested the potential of data from online geocoding services to be used for the surveillance of environmental factors associated with type 2 diabetes. Using obesity as an example, initially the literature was searched for factors related to an obesogenic environment, i.e. an environment that is conducive to obesity [21-23]. Features of the environment that previous studies had associated positively with obesity were defined as obesogenic factors (for example fast food restaurants) and those defined as negative as protective factors (such as green areas). Subsequently, these factors were operationalised through expert interviews (n=4) based on the variables provided by the geocoding services Google Maps and OpenStreetMap. Using the statistics software R, new automated query scripts were developed to download and analyse relevant data in particular regarding the specific features of environments.

Site visits and an online search had the objective to validate the data from four pilot areas in Bavaria. This served to verify that the place and type of environmental features that had been detected were correct and whether there were additional relevant features that had been omitted from the identified data. The project showed that the demands for completeness of data, download capacity and the diversity of variables are relevant dimensions to select a particular geocoding service. Finally, for the city of Augsburg, kernel density estimations and heat maps were produced and cluster algorithms applied to describe the spa-

A definition was developed that will serve as a basis for future calculations and enhance the reliability and comparability of results for documented prevalence in the context of diabetes surveillance.

tial distribution of variables. Cartographic analysis was then used to identify the areas with a high density of either obesogenic or protective environmental factors. Correspondingly, this study helped develop a suitable method to prepare and represent data from online geocoding services for the description of obesogenic environments suitable for diabetes surveillance. However, to assess the predictive power of this method for actual obesity and/or diabetes risks, the method will need to be tested in further surveys with population-based data.

3.1.6 Indices relevant to public health and their projection relative to diabetes

The projection of diabetes-related years of life lost (YLL) and healthy life years (HLY) is based on prevalence, incidence and mortality rate ratio (MRR) data. Age- and gender-specific 2010 prevalences [10] were used to calculate YLL and HLY between 2015 and 2040 based on different scenarios of diabetes incidence and mortality.

As the long-term development of diabetes incidence in Germany is unknown, three hypothetical scenarios are currently being discussed: an unchanging incidence rate and an increase or a decrease in the incidence rate by 0.5%, respectively. Moreover, the advance of medicine will presumably lead to a greater decrease in the mortality of diabetes patients relative to people without diabetes, so the relative mortality risk is varied. We are therefore looking at scenarios with an annual 2% decrease in the mortality risk. YLL are calculated using a birth cohort framework, HLY by applying the Sullivan method [24].

During the period considered, the number of life years lost decrease for women and men. In 2040, people with

diabetes will lose less life years than people without diabetes compared to 2015. This applies to all age groups. Women, in general, will lose less life years than men. Assuming an annually decreasing relative death risk between 2015 and 2040 would result in a relative decrease of YLL of up to 64% over the same period.

The model scenarios in their majority in principle indicate an increase of healthy life years (HLY) for the period considered across almost all age groups. One exception are the results for the over-80 age group. For example, an over-80-year-old man in 2040 can expect on average to live another 5 years without diabetes, whereas in 2015 it was 5.5 years. Our results are in line with the results of international studies on changes to diabetes-related morbidity [25].

3.1.7 Renal replacement therapy in people with and without diabetes

Renal insufficiency belongs to the severe conditions diabetes patients may develop. At advanced stages this is treated with renal replacement therapy, which is associated with higher mortality and costs [26, 27]. For this reason, renal replacement therapy has been included as an indicator to diabetes surveillance, with the objective of analysing the disease burden over time [4]. However, there is so far no long-term data on whether the figures for renal replacement therapy (incidence) have decreased for people with and without diabetes in Germany.

So far, the incidence of renal replacement therapy has been analysed based on the data from doctors' surgeries in North Rhine-Westphalia [26], as well as from the Gmünder Ersatzkasse (statutory health insurance data) of people with and without diabetes in the 2000s and pro-

Info box 2:**Reference definition to define documented prevalence of diabetes mellitus in the context of diabetes surveillance based on DaTraV data****Total diabetes**

Denominator: people insured for at least 360 days of one year with data on year of birth and gender, no insured residing abroad or those opting for reimbursement of costs according to section 13 (2) or section 53 (4) of Book 5 of the German Social Code (SGB V).

Numerator: people with at least two assured outpatient or at least one inpatient documented ICD-10 diagnoses of diabetes mellitus (E10.- to E14.-1)

Type 1 diabetes

Denominator: see above

Numerator: people with at least two assured outpatient documented ICD diagnoses E10.- or with an outpatient assured documented ICD diagnosis E10.- and at least one further ambulatory assured documented ICD diagnosis diabetes mellitus according to E12.- to E14.- or an inpatient documented ICD-10 diagnosis E10.-

Excluded: people with at least one ambulatory or inpatient documented ICD diagnosis E11.-

Type 2 diabetes

Denominator: see above

Numerator: people with at least two outpatient assured documented ICD diagnoses E11.- or with one outpatient assured documented ICD-10 diagnosis E11.- and at least one further outpatient assured diagnosis ICD-10 diabetes mellitus according to E12.- to E14.- or an inpatient documented ICD-10 diagnosis according to E11.-

Excluded: people with at least one outpatient assured diagnosis or inpatient documented ICD-10 diagnosis according to E10.-

continued on next page

vided results that can be compared well [28]: the age standardised incidence rate for the population with diabetes was between around 190 and 215 per 100,000 person-years, for the population without diabetes roughly between 30 and 40. Therefore, for diabetes patients the risk to have renal replacement therapy was around six to eight times higher. No significant trend over time was found. During the current project, the evaluation of data from doctors' surgeries was expanded to cover the period between 2002 and 2016. The results are expected in 2019.

Moreover, there are plans to analyse the prevalence and incidence of renal replacement therapy in people with and without diabetes based on the data of several GKV across Germany during the last decade. The project aims to analyse the possibilities to reliably describe renal replacement therapy through diagnoses based on the International Statistical Classification of Diseases and Related Health Problems (ICD) using health insurance data. The objective of this project is to evaluate the suitability of DaTraV data for this project, which as described above contains information on all statutory health insured. In a final step, a meeting of experts will discuss the comparability of different data sources (doctors' surgeries, GKV and DaTraV data). One particular focus will be to discuss the possibilities to standardise the algorithms that apply to define renal replacement therapy and renal insufficiency in routine data.

3.2 Initial results for the documented prevalence of type 2 diabetes in DaTraV data

The first DaTraV application by diabetes surveillance referred to a comparison of the reporting years 2010 and

2011 for the documented prevalence of type 2 diabetes. Prevalent type 2 diabetes was defined as at least one assured documented out- or inpatient type 2 diabetes diagnosis coded according to the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10: E11.-).

Together with experts from the diabetes surveillance scientific advisory board and based on the feedback from the data processing unit, the results of the query and of co-operation projects served as a starting point to define a reference analysis to determine documented prevalence (Info box 2). In future, this should provide robust results on the overall prevalence of diabetes as well as segregated by type 1, type 2 and other forms of diabetes mellitus for Germany and German federal states. The reference analysis will apply validation data sets. For one, the number of people who receive diabetes medication without having been diagnosed with diabetes will be determined. Furthermore, diabetics who according to the data only have a secondary inpatient diagnosis of diabetes will also be determined. This validation data set should help to better assess the consensually agreed definition.

Irrespective of the results of the reference definition, the applied for results for the reporting years 2010 and 2011 show the DaTraV data potential for diabetes surveillance. Information on age, gender and diabetes diagnosis was analysed for a total of 66.2 million statutory health insured for the year 2010 and 66.4 million for 2011. The results in Figure 3 are stratified by gender and year for type 2 diabetes and evidence an increase in administrative prevalence. In women, documented prevalence increased from 7.7% (2010) to 8.1% (2011) and in men from 8.2% to 8.6%.

Info box 2 (Continued):**Other forms***Denominator: see above**Numerator: people with at least two outpatient assured or at least one inpatient documented ICD-10 diagnosis in groups E10.- to E14.-**Excluded: people who were already assigned to type 1 or type 2 diabetes based on the algorithm mentioned above.*

ICD-10 = International Statistical Classification of Diseases and Related Health Problems, 10th revision

E10 = Insulin-dependent diabetes mellitus (type 1 diabetes)

E11 = Non-insulin-dependent diabetes mellitus (type 2 diabetes)

E12 = Malnutrition-related diabetes mellitus

E13 = Other specified diabetes mellitus

E14 = Unspecified diabetes mellitus

An outpatient diagnosis can, depending on documentation, be a diagnosis that is suspected, related to a state following a certain illness (such as a heart attack), ruled out or assured. Only diagnoses classified as assured are used here to define documented prevalence.

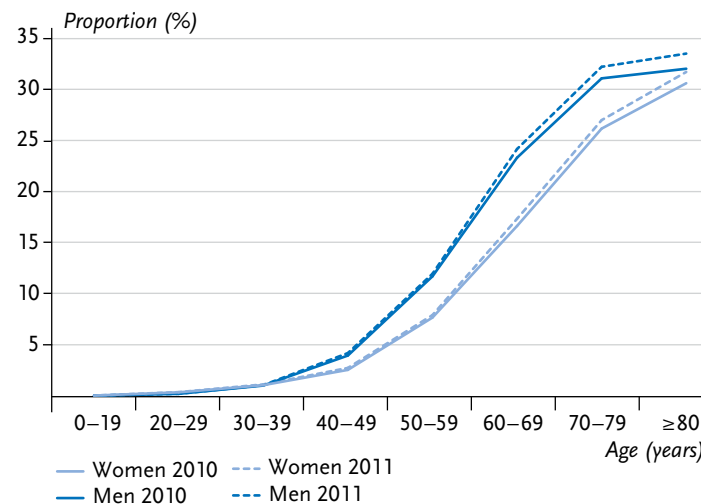
Validation data sets for total diabetes

- 1) people who have been prescribed antidiabetic drugs without documented diabetes
- 2) people with only an inpatient secondary diagnosis

Figure 3
Comparison of the documented prevalence of type 2 diabetes mellitus for the years 2010 and 2011 according to gender

Source: Data transparency ordinance data (DaTraV)

Furthermore, the results confirm the known age-relatedness of type 2 diabetes, as for both genders an increase of prevalence with age is observed. The results resemble other analyses based on DaTraV data [10]. However, the age group over 80 is too large to describe the effect of decreasing prevalence among the very old aged over about 85 [8]. The definition of diabetes used for Figure 3, which bases itself on a definitive out- or inpatient diagnosis in the reporting year, differs from the generally used criterion of at least two quarterly periods. According to this criterion, a definitive outpatient diagnosis of diabetes must be coded during at least two quarters of one year to rule out documentation effects. The analysis moreover showed, that for numerous cases instead of specific diagnoses of either type 1 or type 2 diabetes, diagnoses were either unspecific or mutually exclusive. For these reasons, in co-operation with experts from epidemiology and care, the reference definition described below was developed to allow future description



of the administrative prevalence of diabetes within the context of diabetes surveillance (Info box 2).

4. Discussion

Secondary data is an important element to determine indicators for diabetes surveillance. It can be used to prepare time series as a basis for numerous indicators.

In particular, DaTraV data is well suited for the purposes of surveillance, because it is a complete data set of all statutory health insured in Germany that is updated annually. The planned revision of DaTraV can overcome current limitations of this data set such as the transfer of diagnosis and medications data also for the year of leaving the GKV system and the current four-year delay. In addition, there is an objective to reduce the time required to process applications in particular by employing more staff. In future, this will ensure an even better depiction of regularly repeated observations of the disease burden at short intervals.

Meaningfully comparable analyses of secondary data require transparent and consensually agreed definitions of selection and applicability criteria. The presented reference definition to calculate the overall prevalence of diabetes, as well as differentiated by type 1, type 2 and other forms of diabetes based on DaTraV data is a step towards greater transparency. The developed definition thereby is not only important for comparisons of prevalence over time, but also serves as a reference for further indicators of diabetes surveillance. For example, the definition is also used to depict numerous diabetes complications, incidence and mortality based on DaTraV data.

Co-operation projects during the years 2016 to 2018 achieved a targeted transfer of results and methods in diabetes surveillance. In 2019, too, co-operation projects will be facilitated. Results from co-operation projects can be found on the diabetes surveillance website [29].

The German version of the article is available at: www.rki.de/journalhealthmonitoring

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Data protection and ethics

All co-operation projects that use personal data and applied for funding were asked to present the data protection aspects of their project and those using claims data of the statutory health insurance in particular were asked to include a statement of intent or a confirmation of co-operation in their application.

The presented own analyses on the administrative prevalence of type 2 diabetes are based on anonymised and aggregated data in accordance with the data transparency regulations.

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Conflicts of interest

The authors declared no conflicts of interest.

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An international comparison of noncommunicable disease reporting: the case of diabetes mellitus

Abstract

Against the background of the growing burden associated with diabetes mellitus, the German Federal Ministry of Health commissioned the Robert Koch Institute to develop a national diabetes surveillance. The periodic publication of up-to-date data needed by diverse target audiences (dissemination) to develop subsequent public health measures is a crucial aspect of disease surveillance. The study produced an overview of diabetes surveillance in various countries with the intention of developing a dissemination strategy. This involved a two-stage process beginning with an online survey of public health experts from 46 countries. Structured Internet research was then carried out for countries that did not provide a response (19 out of 46). The majority of countries (38 out of 46; 83%) include diabetes in their health reporting; three quarters (29 out of 38; 77%) of these countries rely on an indicator-based reporting system. The study found that the most common formats used to publish information about diabetes and other noncommunicable diseases were topic-specific reports (24 out of 36; 67%) and national health reports (23 out of 36; 64%), followed by online formats such as websites or databases (20 out of 36; 57%). Moreover, health reporting primarily targets politicians (19 out of 20; 95%) as well as the media and the press (16 out of 20; 80%). The study found that both printed and online publications form part of a comprehensive dissemination strategy, however address different audiences.

HEALTH REPORTING · DISSEMINATION · DIABETES MELLITUS · NCD SURVEILLANCE

1. Introduction

The burden associated with diabetes mellitus and other noncommunicable diseases (NCDs) is steadily increasing in Germany as it is throughout the world [1, 2]. In 2013, the World Health Organization (WHO) adopted the Global Action Plan for the Prevention and Control of NCDs as a means of facing up to the growing challenges posed by noncommunicable diseases [3]. The WHO's action plan contains six objectives, one of which includes monitoring

the trends and determinants of NCDs. This led the German Federal Ministry of Health to commission the Robert Koch Institute (RKI) to set up a diabetes surveillance system that could serve as a pilot project for the surveillance of other noncommunicable diseases in Germany. Together with the project's scientific advisory board, a framework for the surveillance of diabetes was developed and 40 indicators were defined [4].

Public health surveillance is defined as the continuous, systematic collection, analysis and interpretation of

83% of countries include diabetes in their national health reporting.

health-related data that is needed for the implementation of public health measures aimed at protecting and promoting the health of the population ('data for action') [5]. This definition implies that health monitoring data should be processed in a manner that reflects the needs of its various target audiences. Data from health surveillance can be used to (1) identify high-risk populations, (2) develop prevention strategies, (3) draw up new hypotheses on diseases dynamics, (4) raise awareness about trends and disease-related risk factors, and (5) encourage people to take conscious decisions about their health [6, 7].

In order for health reporting data to be used in this manner, target audiences must be provided with up-to-date information (dissemination). In public health sciences, as in other fields, a gap exists between the production of new knowledge and its translation into practice and policy [8]. This underscores the importance of developing a dissemination strategy as part of the surveillance system that can provide the basis for the development of informed health policy measures [9]. However, it is essential that formats and the communication channels used to disseminate the information reflect the competences and level of expertise that a specific target audience has with regard to a particular aim [10, 11].

The WHO identifies four target audiences as part of its Global Monitoring Framework for the surveillance of non-communicable diseases: (1) healthcare providers, (2) policy makers, (3) service providers, and (4) the general population [12]. In addition, other groups that also need to be addressed include patients, doctors who treat diabetics, and scientists and scientific institutions. The WHO does not state which formats or communication channels should

be used to provide NCD-related information, nor does it provide guidance on which information should be provided to the various target audiences. When it comes to formats and communication channels, however, advances in digitisation, in particular, are opening up new ways of visualising and processing data [13]. Moreover, social media and social networks offer further opportunities with which to disseminate health-related information [10, 14].

In addition to building on the experience gained by other public health institutes, best practice examples from other countries are to be used as a model to develop a dissemination strategy for diabetes surveillance at the RKI. An international workshop was held in this context at the RKI in June 2018 that also involved the presentation of innovative formats [15]. Furthermore, a study of health reporting on NCDs was performed using diabetes as an example. The aim of the study was to provide an overview of formats and target audiences of health reporting by the member states of the Organisation for Economic Co-operation and Development (OECD), the European Union (EU), and other selected European countries.

2. Methodology

The study used a two-step approach to collect data about national health reporting of diabetes and noncommunicable diseases (Figure 1). The first step involved surveying national public health experts from the selected countries using an online survey in English. The survey focused on diabetes and NCD-specific health reporting including the formats that were being used and the target audience that was being addressed. The results were supplemented by

Infobox 1: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus

Data owner: Robert Koch Institute

Aim: To develop an overview of the strategy, content, formats and target audiences of the health reporting of noncommunicable diseases conducted in OECD and EU countries.

Geographical focus: 46 OECD or EU member states, as well as other selected European countries

Study design: Two-stage process

- ▶ Online survey of public health experts
- ▶ Structured Internet research into countries that did not participate in the online survey

Participants:

- ▶ Experts from 27 countries participated in the study
- ▶ Structured Internet research was carried out for 19 countries

Study period: April to September 2018

structured Internet research into countries that did not participate in the expert survey. Finally, examples of best practices from successful health reporting were also selected. The selection was based on a narrative analysis of the results of the online survey and Internet research.

The survey was limited to OECD and EU member states and other selected European countries; 46 countries were included in the study (Table 1).

2.1 Online survey

The online survey of public health experts took place between April and July 2018. The survey used a questionnaire created with the Acuity4 survey software (version 5.5.1.205) from Voxco®. In order to recruit suitable participants, the RKI's network was used to contact EU and OECD public health institutes as well as those from other European countries. The aim was to ensure that people with expertise in diabetes and health reporting participated in the study. In cases where it was impossible to find someone suitable to answer the questionnaire, a request to participate in the survey was sent to health ministries and national statistical offices. Other institutions were only contacted if they had been named by a member of one of these institutions.

The online survey comprised 39 questions and was divided into two subject areas (Annex Table 1). On the one hand, the questionnaire focused on the framework behind diabetes-specific health reporting, its integration into a diabetes strategy, and the indicators and data sources that were used. On the other hand, it also examined the formats that were being used and the target audiences that health

reporting sought to address. Furthermore, respondents were also asked to upload the reports they mentioned during the questionnaire or to provide a link to documents that were available online. After the online survey had been completed, a review was undertaken to ensure that each country had only provided one response. If more than one survey existed for a country, the data provided on these questionnaires were merged.

2.2 Structured Internet research

Between August and September 2018, structured Internet research was conducted into countries that had not supplied any data by the end of the online survey period (July 2018). The analysis focused on the country's framework, indicators, and the formats used for diabetes and NCD-specific health reporting. The Internet research was carried out in the following manner: first, a search was conducted of the websites of the respective national public health institutes, health ministries and statistical offices for keywords linked to diabetes and noncommunicable diseases. The Google search engine was then used to search for a combination of terms. In each case, the search term consisted of either diabetes, noncommunicable disease or NCD, alongside surveillance, monitoring, strategy, report, health reporting or indicators. Lastly, the respective country name (in English) was added to the search term. The study then examined the first 30 search results. Public health institutes, ministries of health or statistical institutes do not always provide relevant information in English, German or French. In these cases, their websites were translated into English using Google Translate and

Table 1
Countries included in the survey and Internet research
Own table

OECD	OECD and EU		EU	Other countries
Australia	Belgium	Austria	Bulgaria	Albania
Canada	Denmark	Czech Republic	Croatia	Liechtenstein
Chile	Estonia	Hungary	Cyprus	Montenegro
Iceland	Finland	Poland	Malta	North Macedonia
Israel	France	Portugal	Romania	Serbia
Japan	Germany	Slovakia		
Mexico	Greece	Slovenia		
New Zealand	Ireland	Spain		
Norway	Italy	Sweden		
South Korea	Latvia	The Netherlands		
Switzerland	Lithuania	United Kingdom		
Turkey	Luxemburg			
United States of America				

EU = European Union, OECD = Organisation for Economic Co-operation and Development

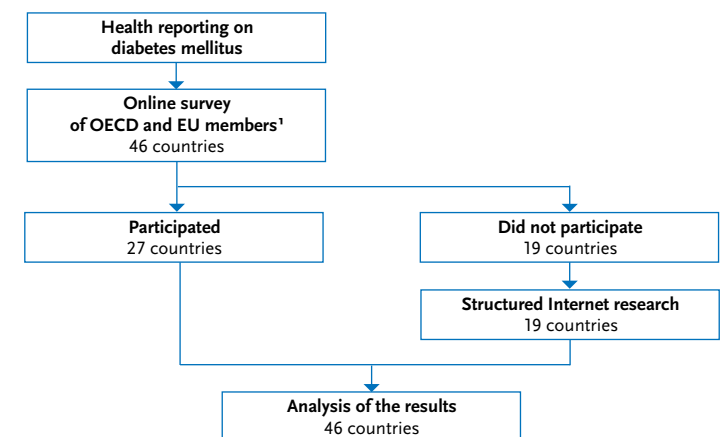
the resulting translations were searched for the keywords mentioned above.

The research was limited to the framework (strategy, indicators, data sources) and formats (reports, websites, databases) used by the country for health reporting. Furthermore, only reports and formats published in or after 2000 were included in the study. Unfortunately, it was impossible to identify the reports' target audiences as the websites that published them provided no relevant information about this issue.

3. Results

Of the 46 countries included in the overall study, 27 (59%) participated in the online survey (Figure 1). The majority of participants were from public health institutes (20 out of 27; 74%) and, albeit less frequently, from health ministries (5 out of 27; 19%). Structured Internet research was

carried out for the remaining 19 countries so that diabetes-specific health reporting could be evaluated for all 46 countries included in the study.

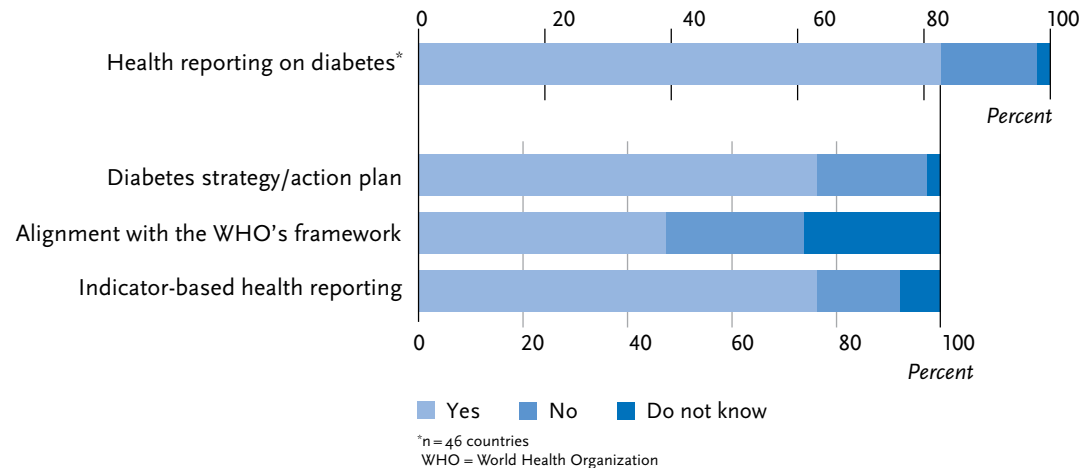


¹ Includes further selected European countries
EU = European Union, OECD = Organisation for Economic Co-operation and Development

Figure 1
Overview of the process of surveying expert participants and Internet research
Own diagram

Figure 2
Concept of diabetes-specific health reporting
(n=38 countries)

Source: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus



77% of countries use an indicator-based surveillance system for health reporting on diabetes.

The first part of the study focused on the framework employed for diabetes health reporting and the indicators used to depict developments in the course of the disease. In total, four out of five countries include diabetes mellitus in their national health reporting (Figure 2). Of these, over three quarters have defined a national diabetes strategy or action plan. In addition, half of the countries that conduct diabetes health reporting state that they follow the WHO's NCD Global Monitoring Framework [16]. However, no conclusions could be made about ten of the 38 (26%) countries. The majority of countries (29 out of 38; 77%) use an indicator-based system for reporting diabetes, with eight countries using a system exclusively for diabetes mellitus and 21 countries including diabetes in their surveillance of non-communicable diseases.

The evaluation of the indicators determined by the study led to the identification of 142 different indicators or indicator clusters that are used in diabetes surveillance. These were divided into the following six areas: epidemiology,

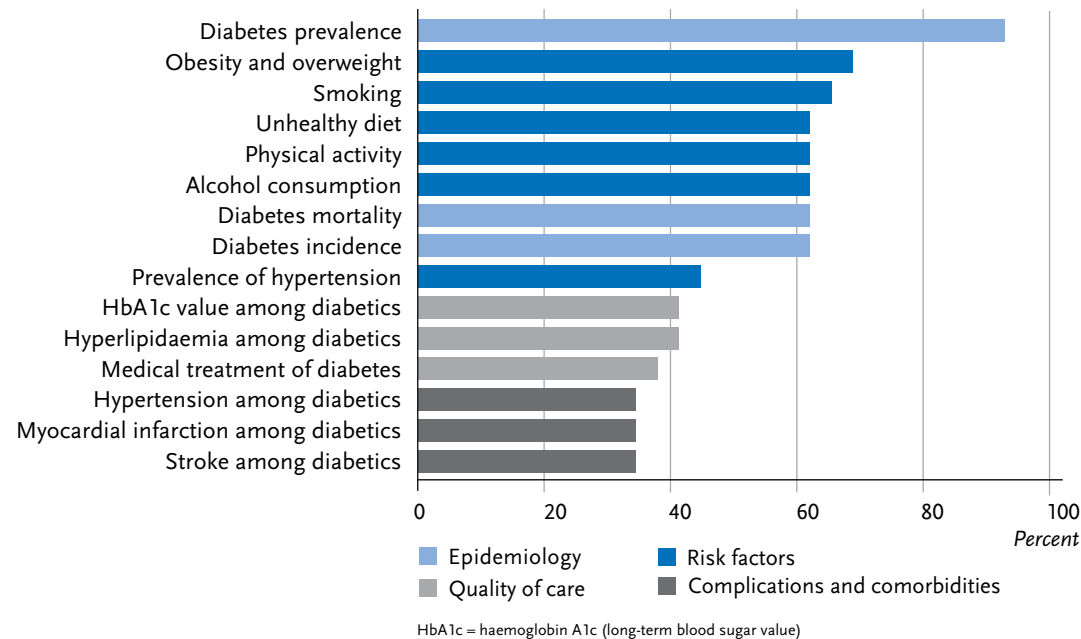
disease burden, complications and comorbidities, risk factors, quality of care, and public health measures. The 15 most common indicators are shown in Figure 3. The ranking demonstrates that most countries use epidemiological indicators such as incidence, prevalence and mortality of diabetes as well as behavioural risk factors. Indicators covering quality of care, complications and comorbidities were reported less frequently. In 23 out of 28 countries (82%), the indicators relied on data sources that included regularly conducted national health surveys. Routine data, such as claims data from hospitals and medical practices, insurance data and data from other institutions, are included in diabetes health reporting in 19 out of 28 (68%) countries.

In addition to questions about the framework governing diabetes surveillance, the study focused on the formats used and the intended audience of diabetes-specific health reporting. The study found that different formats were being used to deliver the results (Figure 4). These can be

Figure 3

The 15 most commonly used indicators in diabetes mellitus surveillance (n=29 countries)

Source: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus



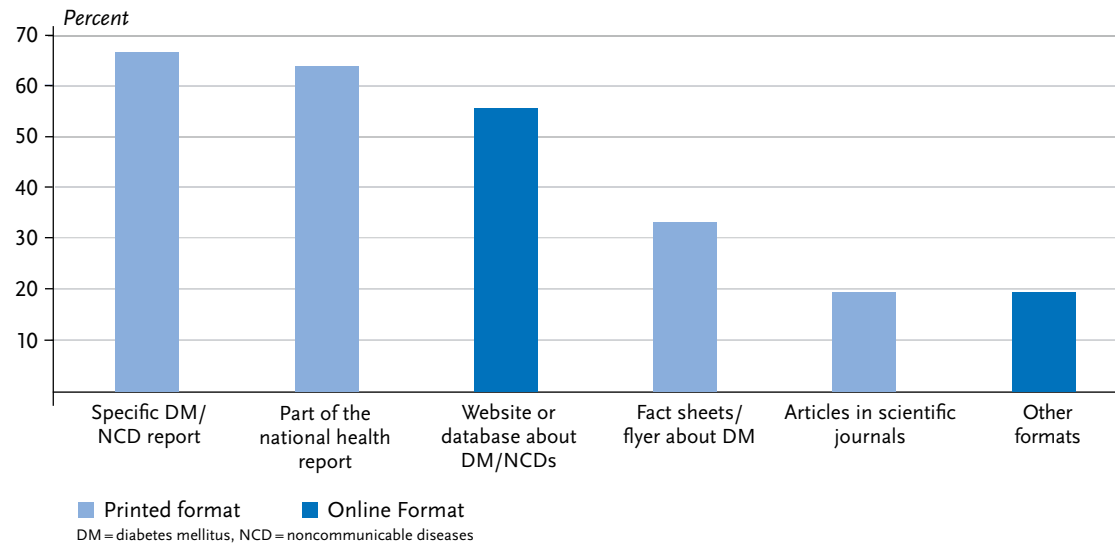
Topic-specific and general health reports (67%) are the most commonly used formats to publish information about diabetes.

divided into printed formats (including digital formats in print layouts such as Word and PDF) and formats that were only available online (web pages and databases). The study evaluated a total of 67 reports, 25 online formats and nine other formats from 36 countries. These were either provided as links, uploaded by the respondents, or were found during the Internet research. Due to the common ground covered by the reports and for reasons of clarity, health reports on diabetes mellitus (DM) and on noncommunicable diseases (NCD) were summarised as DM/NCD reports. Two thirds of countries (24 out of 36; 67%) publish their results in a specific report on diabetes or together with other noncommunicable diseases. Furthermore, results are often included in countries' interdisciplinary national health reports. Flyers and fact sheets

(12 out of 36; 33%) as well as scientific publications (7 out of 36; 19%) are used to a much lesser extent. In addition to traditional printed formats, results in 20 out of 36 (56%) countries are provided on a website or online database, with 9 out of 36 (25%) countries providing a database that enables the results to be queried directly. More than half of the websites and online databases included tools for interactive data visualisation. Furthermore, 7 out of 36 (19%) countries use other formats to publish results. These are mainly newer formats related to social media such as Twitter, Facebook or YouTube, but also include press releases. According to the respondents, these formats are primarily used to draw attention to the issue of diabetes and to raise awareness in society about this health problem.

Figure 4
Formats used in diabetes health reporting
(n=36 countries)

Source: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus



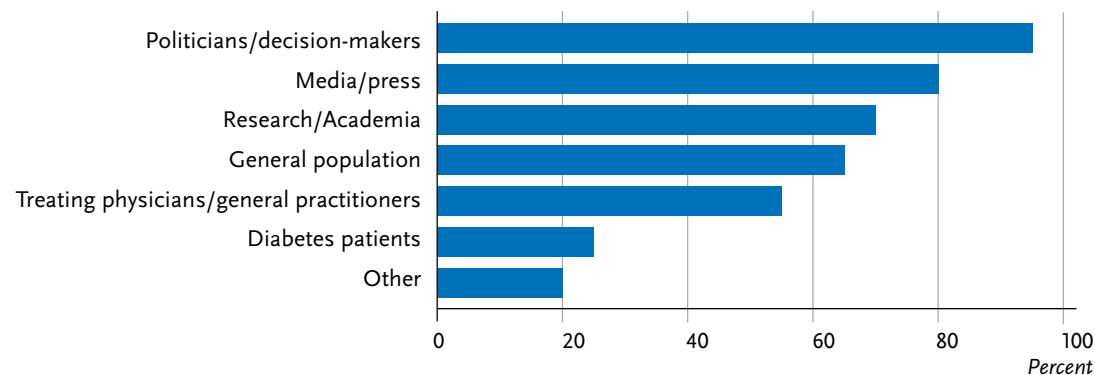
Reports, flyers, websites and online databases are generally made available in a country's own language. In about half of the cases (48 out of 92; 52%), they are also available in English. However, English is an official language in seven of these countries. Most formats (67 out of 92; 73%) are published or updated regularly. The majority of reports, websites and databases are updated once

a year (35 out of 67; 52%) or within two to five years (28 out of 67; 42%).

The public health experts were also asked about the target audiences that diabetes-specific health reporting was seeking to address (Figure 5). Almost all of the countries surveyed primarily target policy and decision-makers in the health sector, followed by the media and the press, and

Figure 5
Target audiences of diabetes-specific health reporting
(n=20 countries)

Source: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus



56% of countries use websites or online databases to provide information about diabetes.

scientists and the general population. Slightly more than half of the surveyed countries list doctors who treat diabetics as their target audience. Diabetes patients are specifically addressed by just one in four countries. These results are based entirely on the data gathered from the countries that participated in the online survey; no information was available about the audience targeted by the documents identified through Internet research. In total, 20 countries provided information about the audiences that their formats were seeking to address (seven countries provided no information about this at all).

Different formats are used to address different audiences and, as such, they were evaluated with respect to

their intended audience (Figure 6). However, since articles in scientific journals are primarily aimed at scientists, and the category 'other formats' contained a diverse range of formats, neither was included in the overall evaluation. Health sector professionals had provided information about the target audiences of 54 reports, all of which were then used in the study. The analysis demonstrated that interdisciplinary national health reports primarily target healthcare policy and decision-makers (21 out of 22; 96%) and the media and the press (20 out of 22; 91%). However, researchers (16 out of 22; 73%) and the general population (13 out of 22; 59%) were addressed in more than half of these cases. A similar picture emerges for topic-specific

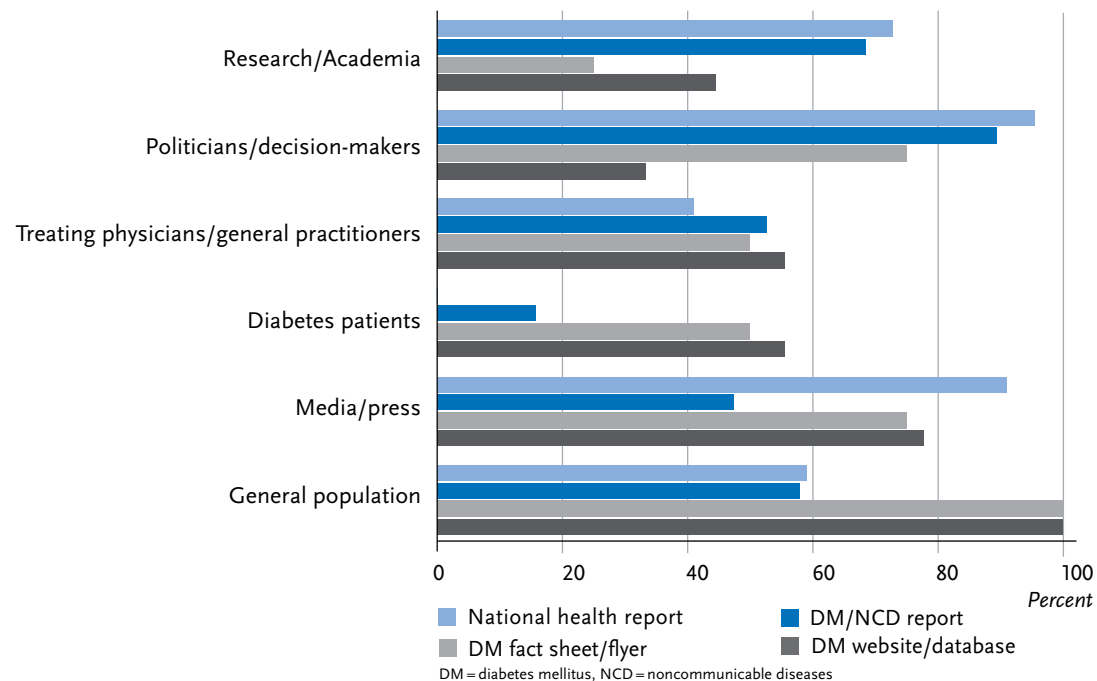


Figure 6
Presentation addressees depending on the format used for diabetes-specific health reporting (n=54 formats)

Source: An international comparison of noncommunicable disease reporting: the case of diabetes mellitus

The study's participants maintained that policy and decision-makers in the healthcare sector were the most important target audiences of diabetes health reporting.

health reports on diabetes and noncommunicable diseases. Just under half of these reports target the media and the press. In contrast, flyers and fact sheets on diabetes were primarily aimed at the general population (4 out of 4) and, to a lesser extent, at political decision-makers and the media (3 out of 4). In addition, treating physicians as well as diabetes patients themselves are also named as target audiences in these cases (2 out of 4). Online formats (mainly websites) were aimed at the general population (9 out of 9) as well as the media and the press (7 out of 9). However, some online formats were also directed at diabetes patients (5 out of 9; 57%) and their physicians (5 out of 9).

This results in a clear picture: whereas political decision-makers are particularly targeted by interdisciplinary and topic-specific health reports, online formats, flyers and fact sheets are mainly used to address the general population. The media and the press, as the second most commonly mentioned target audiences, are addressed via both

more traditional printed publications and more modern online formats.

The study also sought to select examples of best practices from the formats identified by the online survey and the Internet research (Table 2). Ultimately, the study identified print and online publications from four countries that the authors view as having successfully implemented various aspects of health reporting.

4. Discussion

The online survey of public health experts and the Internet research enabled a structured overview of diabetes-specific health reporting in the EU and OECD countries to be developed. The majority of countries under study include diabetes mellitus in their national health reporting and have established indicators for disease surveillance. Health reports that were either printed or typeset and published online were the most commonly used formats. Online

Table 2
Best practice examples from diabetes health reporting
Own table

	Interactive graphics	Flexible data analysis	An informative, illustrated health report	An informative flyer for social media use
Institute	Federal Office of Public Health	Public Health England	National Institute for Public Health and the Environment	Centers for Disease Control and Prevention
Country	Switzerland	United Kingdom	The Netherlands	United States of America
Special feature	User-friendly and nuanced graphical depiction of various indicators	Platform enabling a flexible visualisation of data on diabetes and a variety of options for evaluation	A well-structured report on the development of health in the Netherlands. Implements a balanced design using text and illustrations	Informative infographics and innovative formats involving social media aimed at the general population
Format	Website	Database/website	Report	Flyer/social media
Link	https://www.obsan.admin.ch/de/MonAM	https://fingertips.phe.org.uk/	https://www.rivm.nl/publicaties/volksgezondheid-toekomst-verkenning-2018-gezond-voorzicht-synthese	https://www.cdc.gov/diabetes/library/socialMedia/index.html

formats such as websites and databases are used in more than half of the countries under study, some of which also provide innovative visualisation tools. All of the countries principally targeted policy makers, followed by the media and press, individuals and institutions involved in public health research, and the general population.

The literature provides very little information that could offer an overview of the surveillance systems used to collect data on noncommunicable diseases in various countries. However, as part of its action plan for the prevention and control of NCDs, the WHO regularly reports on the progress that each member state is making towards reaching the action plan's objectives, and also publishes relevant documents [17]. The proportion of countries with an identified diabetes strategy is comparable to the results of the online survey. The few exceptions that did occur were due to the fact that five cases from the online survey involved general NCD strategies that only implicitly included diabetes.

Although the WHO Framework [16] recommends that countries monitor behavioural risk factors (alcohol consumption, tobacco consumption, physical inactivity, obesity and overweight, unhealthy dietary habits) as part of their disease surveillance, the study found that only half of countries do so. However, closer analysis of the indicators demonstrates that two thirds of indicator systems include behavioural risk factors as indicators, and, thus, the majority of indicator systems do indeed reflect the WHO's approach. Moreover, the majority of countries also use data sources that contain both primary and secondary data. Diabetes surveillance at the RKI also includes behavioural risk factors among its indicators [4] as well as data from health

surveys and routine data to map the dynamics of the disease. Information about the strengths and weaknesses as well as the opportunities offered by these data sources can be found in this issue of the Journal of Health Monitoring in the contributions entitled [Social inequality and diabetes mellitus](#) and [secondary data in diabetes surveillance](#).

At the same time, the literature also provides very few recommendations or reviews of the formats and communication channels that are used for health reporting in the context of diabetes and other NCDs. As part of its framework, the WHO recommends the publication of fact sheets and data books (comprehensive volumes containing tables) that are entirely focused on the data [12] and that only take the requirements of target audiences with regard to format and data processing into account to a limited extent.

The study found that traditional printed reports are the most common publications used to provide information from disease surveillance. However, websites and online databases also offer a variety of options for data visualisation and are already being used by some countries to present the results from the surveillance of noncommunicable diseases. These tools are already being used to a greater extent in the surveillance of infectious diseases [18]. For example, the AIDS-Vu project uses regional analyses to identify vulnerable groups and subsequently implement targeted public health interventions in the most affected communities [19]. This approach could also open up diverse opportunities for NCD surveillance. For example, the Fingertips platform operated by Public Health England ([Table 2](#)) provides detailed analyses of various diabetes indicators that are used at the regional level to plan public

health measures [15]. In addition, social media offer new opportunities to provide information to the public [10] and are already being used in some countries. In these cases, the focus is on raising awareness about diseases such as diabetes and their related risk factors. Similarly, the CDC (Centers for Disease Control and Prevention) in the United States of America have developed infographics that provide information about diabetes to the general public (Table 2). However, more research is needed into the effectiveness of public health interventions via social media [14].

The online survey found that diabetes reporting primarily seeks to address policymakers and health-care decision-makers, followed by the media and press. The WHO also identifies policymakers and health-care decision-makers as two of its four target audiences for information from NCD surveillance in addition to service providers and the general population [12]. The literature also emphasises the importance of addressing service providers and the general public during the establishment of public health surveillance systems [6, 7, 10]. Whereas diabetes surveillance tends to target politicians with the aim of encouraging the development of interventions and other public health measures (data-based decision-making) [20], the primary purpose of providing information to the general public is to raise awareness about diseases and risk factors as well as to provide other information that is relevant to public health [7]. The media and the press can serve as important disseminators of information aimed at the general public and, therefore, indirectly raise awareness among politicians of the importance of specific topics [9]. However, a discussion is currently taking place in the literature about the effectiveness of the media in terms of its impact on

politics; as of this time, the impact of the media is yet to have been unequivocally proven [21]. Moreover, personal contact, which can take place during individual meetings and symposia, is particularly important when it comes to addressing politicians [10]. In summary, it is crucial that the needs of different target audiences are considered [22, 23] and that indicators are used to review the use of the formats provided [10, 24, 25].

4.1 Limitations

The two-step approach and the use of two different methods to collect data on diabetes-specific health reporting means the study faces a number of limitations. As some countries did not participate in the online survey, the only information and documents available in these cases were those that were found on the Internet. These were available in English, German or French or via Google Translate. Moreover, as data about target audiences are not freely available and can only be supplied by public health experts, the Internet research was unable to provide information about the intended target audiences in these cases. Similarly, as no information was available about the people who were actually using the respective formats, it was impossible to judge whether the intended audiences were actually being reached. Furthermore, the study was limited to publications by state institutions and ministries; publications by non-governmental organisations, such as patient associations or professional associations, were not included in the analyses. Equally, the study's focus on national health reporting meant that regional reports or other regional formats were not considered. Finally, it is unclear

whether the results of the study can be applied to all non-communicable diseases, as diabetes receives greater attention than other diseases.

4.2 Conclusion and outlook

Public health surveillance systems provide the data required to make health policy decisions and to establish public health policies. The growing complexity caused by the increasing number of data sources and findings from scientific research means that information needs to be provided transparently and understandably. In addition to more traditional formats, such as reports, new tools for visualisation and interactive databases can enable data to be depicted in a manner that is understandable and which facilitates access to different target audiences.

Health reports about NCDs primarily address politicians and health policy decision-makers. However, these individuals can be reached in different ways. In addition to reports, established communication tools and social media also provide appropriate communication channels that can raise the priority and awareness of specific public health challenges. Discussions and symposia also constitute an important aspect of dissemination strategies.

The study's findings are to be used to develop a dissemination strategy for diabetes surveillance at the RKI. Diabetes surveillance particularly targets politicians and decision-makers in the healthcare sector. In line with the results of this study, a diabetes report is to be drawn up for this target audience. In addition, information is also to be provided to the general public and the media with the aim of raising awareness about the growing challenges posed by

noncommunicable diseases. In order to address these audiences, a website is to be developed to provide visual representation of the results of diabetes surveillance; social media, such as Twitter and YouTube, are also to be used more regularly. The examples of best practices, which were collected during the survey and Internet research, will provide an important basis for the further development of these formats.

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Data protection and ethics

All of the Robert Koch Institute's studies are 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). Before the online survey was carried out, it was coordinated with the data protection officer of the Robert Koch Institute and a positive vote was obtained to conduct the survey. The participants were informed about the purpose of the study, and about data protection. Participation was voluntary and non-participation did not result in any disadvantages.

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Conflicts of interest

The authors declared no conflicts of interest.

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Annex Table 1
Online survey
'Health reporting on diabetes mellitus'
 Own table

1. Introduction

1.1 Would you like to participate in this survey?

- 1: Yes
 2: No

1.2 For which country do you answer this questionnaire?

Please enter the country here

1.3 What kind of institution are you working for?

- 1: Ministry
 2: National public health institute
 3: Regional or local public health institute
 4: Other governmental institution
 5: University
 6: Research institute
 7: Health insurance body
 8: Think tank, private consultancy
 9: NGO, association or interest organization
 10: Medical care facility
 11: Social care facility
 12: Others, namely:
 13: No reply

1.4 What is the name of the institution you are working for?

Text field
 No reply

2. Diabetes mellitus surveillance

2.1 Do you know whether there is a national health reporting on diabetes mellitus in place in your country?

- 1: Yes
 2: No
 3: Do not know

2.2 Does the national diabetes reporting follow the WHO framework for surveillance of noncommunicable diseases?

Table 1: Framework for national NCD surveillance

Exposures

Behavioural risk factors: *tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diet.*

Physiological and metabolic risk factors: *raised blood pressure, overweight/obesity, raised blood glucose, and raised cholesterol.*

Social determinants: *educational level, household income, and access to health care.*

Outcomes

Mortality: *NCD-specific mortality.*

Morbidity: *Cancer incidence and type (as core).*

Health system capacity and response

Interventions and health system capacity: *infrastructure, policies and plans, access to key health-care interventions and treatments, and partnerships.*

Surveillance of Noncommunicable Diseases. Report of a WHO Meeting. Geneva, World Health Organization, 2010.

- 1: Yes
 2: No
 3: Do not know

Annex Table 1 *Continued*
Online survey
 'Health reporting on diabetes mellitus'
 Own table

2.3 Has there been a national diabetes strategy (action plans or health targets) developed in your country?

- 1: Yes
- 2: No
- 3: Do not know

2.3.1 Is the national diabetes strategy (action plans or health targets) available in English?

- 1: Yes
- 2: No
- 3: Do not know

2.3.2 Please enter the corresponding internet link/ URL address or upload the national diabetes strategy here.

Text field

2.4 Is there an established set of health-related indicators (social and environmental determinants, risk factors, health-related outcomes) in your country, which is used for health reporting of noncommunicable disease and/or diabetes mellitus?

- 1: Yes, for noncommunicable disease including diabetes mellitus
- 2: Yes, specifically for diabetes mellitus only
- 3: No
- 4: Do not know

2.4.1 Please enter the corresponding internet link/URL or upload the document of the indicator system for health reporting on diabetes mellitus or NCDs in your country here.

Text field

2.4.2 Do you distinguish within your set of health-related indicators between core indicators and additional indicators?

- 1: Yes, we have defined a subset core indicators
- 2: No, we do not distinguish within the set of indicators
- 3: Do not know

2.4.3 How many core indicators for diabetes mellitus have you defined?

Text field

Do not know

Annex Table 1 *Continued*
Online survey
'Health reporting on diabetes mellitus'
 Own table

3. Formats

3.1 What formats are used for publication of health reports covering diabetes mellitus in your country at national level?

Multiple answers allowed

Information on diabetes mellitus is published...

- 1: ... as specific chapter in a comprehensive national health report.
- 2: ... as part of a comprehensive report on noncommunicable diseases.
- 3: ... as comprehensive report solely on diabetes mellitus.
- 4: ... as short report on diabetes mellitus.
- 5: ... as fact sheet/flyer.
- 6: ... as publication in a peer-reviewed journal.
- 7: ... as statistical online-database.
- 8: ... as main topic on the website of a national public health institute or another institution.
- 9: ... as another report format.
- 10: Do not know

3.2 For the health reports including diabetes mellitus you know, please name the ...

- Title
- Type of report
- Publishing institution
- Year of publication/Regular publication

In case of regularly published national health reports please list only the latest issue.

If the reports are available in English we invite you to upload the document in a later step.

	Title of the report	Type of report	Publishing institution	Report is regularly published		Year of publication (latest issue)	Report available in English	
				Yes	No		Yes	No
1								
2								
...								

Annex Table 1 *Continued*
Online survey
 'Health reporting on diabetes mellitus'
 Own table

3.2.1 For the reports, which are published regularly, could you please indicate the publication frequency?

Publication frequency (<1 year, annually, biannually, every 3-5 year, every 5-10 year, >10 year)

Report 1

...

3.2.2 For the reports you have mentioned, could you please indicate the target audience?

Multiple answers allowed

Report title	Research/academia	Politicians/decision makers	Treating physicians/GPs	Diabetes patients	Media/press	General population	Other	Do not know
Report 1								
Report 2								
...								

4. Database (only if applicable)

4.1 You have indicated that surveillance data on diabetes mellitus is part of an online database. What is the name of the online database?

Text field

4.2 Which institution hosts the database?

Text field

4.3 Is the database available in English?

- 1: Yes
- 2: No
- 3: Do not know

4.4 Does the database include a tool for regional visualization, e.g. an interactive map showing different indicators like prevalence by region within the country?

- 1: Yes
- 2: No
- 3: Do not know

4.5 How frequently is the information of the database updated?

- 1: Regularly - Please indicate timeframe in years____
- 2: Only irregular updates
- 3: Do not know

4.6 Is the database publically available?

- 1: Yes - Please indicate the link/URL _____
- 2: No
- 3: Do not know

Annex Table 1 *Continued*
Online survey
 'Health reporting on diabetes mellitus'
 Own table

5. Website (only if applicable)

5.1 You mentioned that diabetes mellitus is a main topic of the website of a national public health institute or another institution in your country. What is the name and link/URL of the website?

Text field

5.2 Which institution hosts the website?

Text field

5.3 Is the website available in English?

- 1: Yes
- 2: No
- 3: Do not know

5.4 Who is the target audience for the website publishing information on diabetes surveillance?

Multiple answers allowed

	1 Research/ academia	2 Politicians	3 Treating physicians/GPs	4 Diabetes patients	5 Media/ press	6 General population	7 Other	8 Do not know
Website								

5.5 Does the website include a tool for regional visualization of data on diabetes mellitus, e.g. an interactive map showing different indicators like prevalence by region within the country?

- 1: Yes
- 2: No
- 3: Do not know

5.6 How frequently is the information of the website updated?

- 1: Regularly - Please indicate timeframe in months_____
- 2: Only irregular updates
- 3: Do not know

Annex Table 1 *Continued*
Online survey
 'Health reporting on diabetes mellitus'
 Own table

6. Other format (only if applicable)

6.1 You have indicated that health information on diabetes mellitus is published in a format other than those listed. Could you please describe the format in more detail (print vs. online, content of the format, etc.)?

Text field

6.2 Which institution publishes this format?

Text field

6.3 Who is the target audience for this format?

Multiple answers allowed

	1 Research/ academia	2 Politicians	3 Treating physicians/GPs	4 Diabetes patients	5 Media/ press	6 General population	7 Other	8 Do not know

6.4 Is this format published regularly?

- 1: Yes
- 2: No
- 3: Do not know

6.5 Is this format on diabetes mellitus available in English?

- 1: Yes
- 2: No
- 3: Do not know

6.6 Please enter the corresponding internet link/URL address or upload the diabetes mellitus report format here.

Text field

Annex Table 1 *Continued*
Online survey
 'Health reporting on diabetes mellitus'
 Own table

7. Data Sources

7.1 You have indicated that in your country there is an indicator system for the monitoring of diabetes mellitus in place. Which data sources are you using to collect this data?

Multiple answers allowed

Primary data using...

- 1: ... a national health survey **specifically on diabetes mellitus**.
- 2: ... a national health survey on **noncommunicable diseases** including diabetes mellitus.
- 3: ... a general national health survey covering several topics including diabetes mellitus.

Secondary data using

- 4: ... other institutions/ministries, namely _____
- 5: ... data from insurance companies
- 6: ... data from hospitals/doctors

Other

- 7: ... Other sources, namely _____
- 8: Do not know

7.2 What is the name of the health survey covering diabetes mellitus?

Text field

8. Closing

8.1 If you know of a relevant health report on the national, sub-national or international level which you consider a good-practice-model for reporting on noncommunicable diseases or diabetes mellitus, please indicate the internet link/URL address and/or upload the report here.

Text field

8.2 Do you have any further comments about health reporting on diabetes mellitus or this survey?

Text field

Thank you for your participation!

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The selection and definition of indicators in public health monitoring for the 65+ age group in Germany

Abstract

Selecting relevant indicators is an important step in the development of public health monitoring for older people. Indicators can be used to combine information comprehensively from various data sources and enable recurring, comparable findings to be made about the health of older people. Indicators were systematically compiled from existing international monitoring systems. An indicator set on health in old age was developed using a multistage, structured consensus-based process together with an interdisciplinary panel of experts. The resulting 18 indicators were assigned to three health areas: (1) environmental factors, (2) activities and participation, and (3) personal factors. Data sources that can be used for the indicators are the health surveys within the framework of the Robert Koch Institute's (RKI) health monitoring system, as well as surveys from other research institutes and official statistics. In the future, the indicator set is to be developed further and integrated into an overall approach that is geared towards health reporting and the monitoring of chronic diseases in all phases of life.

📌 PUBLIC HEALTH · SURVEILLANCE · AGE · INDICATORS · HEALTH MONITORING

1. Introduction

Public health monitoring involves the systematic and continual provision of health-related information from various data sources that enables health care stakeholders and health and social policy makers to use the best available evidence to make decisions [1, 2]. In its 2017 Global Strategy and Action Plan on Ageing and Health [3], the World Health Organization (WHO) describes the implementation of a sustainable and efficient system to monitor the health of older people as a priority area for improving health in old age. Moreover, the report stresses that agreement on important core concepts and internationally comparable

measures is essential. However, such agreement requires open debate about health priorities and values, and needs to involve key stakeholders, including older people. Despite the fact that promising indicator-based approaches to health monitoring for older people have already been advanced internationally [4, 5], Germany has yet to see comparable developments at the federal level.

The Improving Health Monitoring in Old Age (IMOA) project took place between 2016 and 2018 and was funded by the Robert Bosch Stiftung. The project set itself the goal of developing a concept for a nationwide system of public health monitoring that would cover the entire population aged 65 or above. Moreover, it was aimed at developing a

The selection of relevant indicators is an important step in the development of continual public health monitoring of older people.

conceptual framework and to select relevant indicators that would permit recurring and comparable health information to be made available for the population aged 65 and above. In addition to using data from the nationwide examination and interview surveys regularly undertaken as part of the health monitoring at the Robert Koch Institute (RKI), data from other sources, such as registry data and health insurance administrative data need to be considered in an indicator-based health information system to a greater extent, as these data are available regularly and cover all age groups [6].

This paper describes the selection and definition of indicators for a public health monitoring of the older population in Germany.

2. Methodology

Indicators were selected together with an interdisciplinary panel of experts consisting of fifteen appointees and two alternates from the fields of general practice, geriatrics, gerontology, public health, survey methods and nursing science as well as from a civil society organisation ([Annex Table 1](#)). In line with the WHO's World Report on Ageing and Health [7] and the International Classification of Functioning, Disability and Health (ICF) [8], the following three areas on health in old age were agreed upon: (1) environmental factors, (2) activities and participation, and (3) personal factors. These areas provided the overall framework for further indicator development. In March 2017, a joint one-day workshop – supported by a qualitative content analysis of national and international health goals for older people – chose relevant topics from each of the three areas on which the indicators were to focus [9]:

1. Health care provision, nursing and community care, physical environment, and social environment
2. Social participation and activities of daily living
3. Physical health, mental health, physical and cognitive functioning, and health behaviour

The systematic inventory of existing indicator sets was followed up by a multistage, structured consensus-based process that was used to select and define relevant indicators with which to monitor health in older age.

2.1 Indicator research

Between June and July 2017, comprehensive research was conducted into national, indicator-based monitoring systems of health in older age. A detailed description of the study's methods and findings has been published elsewhere [10]. The research was limited to the 35 member states of the Organisation for Economic Co-operation and Development (OECD). Indicator sets were only taken into account if they were written in English or German, had been published or updated after 1 January 2007, if data were available from more than one source, for example from survey data and from health insurance administrative data, and if information was available about how the indicators were being operationalised. No restrictions were placed on a particular format, meaning that indicator sets were accepted as reports, brochures, web pages or scientific papers. The research focused on the websites of national public health institutes, involved a supplementary search of the Internet using the Google search engine, as well as a literature review (via PubMed) of the Medline electronic

Indicator-based public health monitoring enables comparable assessments to be made of the health of older people over time and can be used to support policy-related decision-making.

database. Ten sets of indicators from Finland, the United Kingdom, Ireland, New Zealand, Switzerland and the US met the previously-defined criteria for inclusion, and their structure, related development processes and content were subsequently analysed.

2.2 Indicator selection and evaluation

Two independent reviewers assessed and evaluated the indicators identified by the research. Indicators that fitted into the previously-defined conceptual framework for indicator selection were included in the next step. In addition, the following exclusion criteria were defined: (1) duplicates of content, (2) indicators that were not fully compatible with the German health or social care system, (3) indicators that were not clearly worded and, thus, were difficult to interpret, and (4) indicators that were used for regional comparisons only and, therefore, could not be aggregated to the national level. The remaining indicators were supplemented by indicators proposed by the RKI project team that had not been included in existing monitoring systems but that provided information about the topics that had been given priority in the development of the conceptual framework.

This step was followed by a structured consensus-based process that was carried out as a three-stage modified Delphi technique based on an approach developed by the EU-initiated and funded Joint Action on Chronic Diseases initiative [11].

During the first stage, which took place between October and November 2017, the fifteen members of the expert panel were asked to use a 9-point scale (1=low relevance; 9=high relevance) to rate the indicators. On this account,

the experts were provided with a standardised evaluation form via e-mail. The panel was able to use this form to include additional notes and to raise questions about the indicators.

The panel used the following criteria to assess the indicators [12]:

- ▶ Higher indicator values point to improved health-related quality of life and/or a healthy life expectancy among older people.
- ▶ Higher indicator values point to reduced health inequalities among older people.
- ▶ Indicators can be influenced by policy measures or public health interventions.
- ▶ Indicators are meaningful and relevant for the public and for stakeholders from the fields of politics and health care.
- ▶ The indicator is easy to understand and interpret.
- ▶ The indicator is valid and reliable – it measures what it is intended to measure.

Fourteen of the fifteen evaluation forms were filled in and returned to the RKI. Each potential indicator was ranked according to the distribution of the points given in the evaluation sheets, taking into account the median and the first quartile ($Q_{0.25}$) (Figure 1):

- ▶ Indicators were classified as highly relevant if more than 75% of the ratings were in the top range (7-9 points), i.e. the median and the first quartile ($Q_{0.25}$) were 7-9 points.
- ▶ Indicators were classified as relevant if more than 50% and less than 75% of the ratings were in the top range

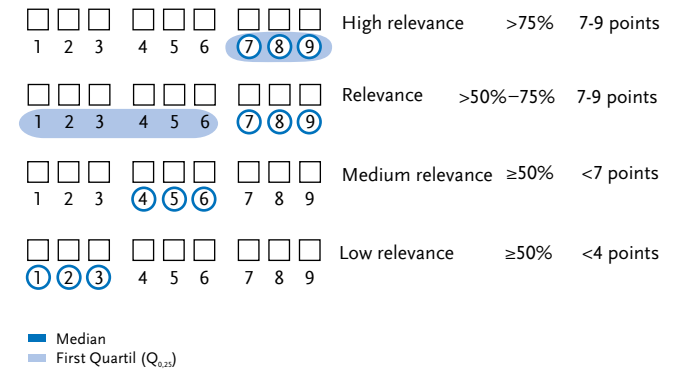
Figure 1
Grading system to rate indicators according to their relevance for public health monitoring for the 65+ age group
 Own diagram

(7-9 points), i.e. the median was 7-9 points and the first quartile ($Q_{0.25}$) was below 7 points.

- ▶ Indicators were classified as of medium relevance if at least 50% of the ratings were in the lower (1-3 points) and medium (4-6 points) range, i.e. the median was below 7 points.
- ▶ Indicators were classified as of low relevance if at least 50% of the ratings were in the lowest range (1-3 points), i.e. the median was below 4 points.

On 15 December 2017, the experts were invited to Berlin to take part in a one-day workshop – the second stage of the Delphi technique. Nine of the fifteen experts participated. The workshop began with a presentation of the results of the first stage. This also included a discussion of the questions and proposals regarding the individual indicators that had been raised on the evaluation forms. At the end of the workshop, the participants were once again asked to provide a written assessment of the indicators that had been classified as either highly relevant or relevant during the first stage. The evaluation was carried out in writing and the format of the evaluation sheets was identical to that used in the first stage.

Indicators that had been classified as highly relevant during the second stage of evaluation (those where at least 75% of the ratings were in the top range – between 7 and 9 points) went on to the third and final stage of the Delphi technique. Indicators that the participants had not classified as highly relevant were excluded in order to concentrate on those that they considered as most important. However, after reconsidering the scientific evidence, the participants requested a reassessment of some of the indi-



cators that had been categorised as of medium relevance during the first stage. In line with the framework provided by the European Core Health Indicators (ECHI) [13], the following factors were taken into account while preparing the indicator set: definition, available data sources, type and periodicity of the data sources, reference population, and the possibility of stratification by gender and socioeconomic status. In addition, a short summary was drawn up of each indicator's scientific background, which also included a list of important references. The resulting set was presented to the experts who were then asked to re-evaluate the indicators and to provide their views in writing (per e-mail). The experts used a 9-point scale and were able to make proposals, provide criticism and call for changes to be made to the proposed operationalization and listed data sources. Eleven of the fifteen evaluation sheets were returned to the RKI as part of the third evaluation stage.

The IMO project selected its indicators by systematically compiling indicators from existing international monitoring systems.

3. Results

The final indicator set contains 18 indicators (Table 1). Figure 2 summarises the selection process. The results of the structured consensus-based process on which the selection of indicators is based are set out in detail in the Appendix (Annex Table 2).

As part of the indicator research, ten indicator systems with a total of 293 individual indicators were identified using the described search strategy. A total of 133 of these indicators were assigned to one of the previously-defined topics. Of these, 56 indicators were excluded as duplicates, 21 indicators because they were not fully compatible with the German health or social care system, and ten indicators because they were not clearly formulated and difficult to interpret. A further indicator was excluded due to the fact that it allowed comparisons only at regional level. As the remaining indicators did not cover all of the issues that had been defined as relevant at the beginning of the study, the indicator set was supplemented by 21 additional indicators. These particularly covered long-term care provision, participation and physical functioning. This resulted in an indicator set comprising 66 potential indicators for inclusion in the structured consensus-based process. These indicators were attributed to the predefined topics as follows: health care (9), nursing and community care (8), physical environment (3), social environment (4), social participation (4), activities of daily living (2), physical health (9), mental health (10), physical functioning (11), cognitive functioning (2) and health behaviour (4).

During the first stage of the evaluation, 25 of the 66 indicators were classified as highly relevant and 24 as relevant.

The remaining 17 indicators were rated as of medium relevance and were excluded from the next stage of the evaluation. This led to 49 indicators for the second stage of evaluation.

The feedback provided during the second stage resulted in 33 indicators being classified as highly relevant, 13 indicators as relevant and 3 indicators as of medium relevance. During a workshop that preceded this stage of the evaluation, the participants had decided to make a number of modifications to the indicator set. This resulted in the combination of three potential indicators ('recipient of inpatient care', 'recipient of outpatient care' and 'level of long-term care needs') to form a single indicator ('recipient of long-term care'), and the addition of a further indicator – 'psychotropic medication'. Finally, five out of the 17 indicators classified as of medium relevance during the first stage ('influenza vaccination', 'pneumococcal vaccination', 'pressure sores', 'difficulty walking' and 'grip strength') were to be re-evaluated after a review of the scientific evidence.

The indicators that were not classified as highly relevant were excluded prior to the third and final stage. This process resulted in 37 indicators being selected. Information on these was documented in accordance with the schema described above (definition, data sources, type and periodicity of the data sources, reference population, options for stratification, scientific background and references) and was presented to the experts for evaluation and comment. By the end of the third stage, 18 of the 37 indicators were still classed as highly relevant, 14 were now viewed as relevant and five as of medium relevance.

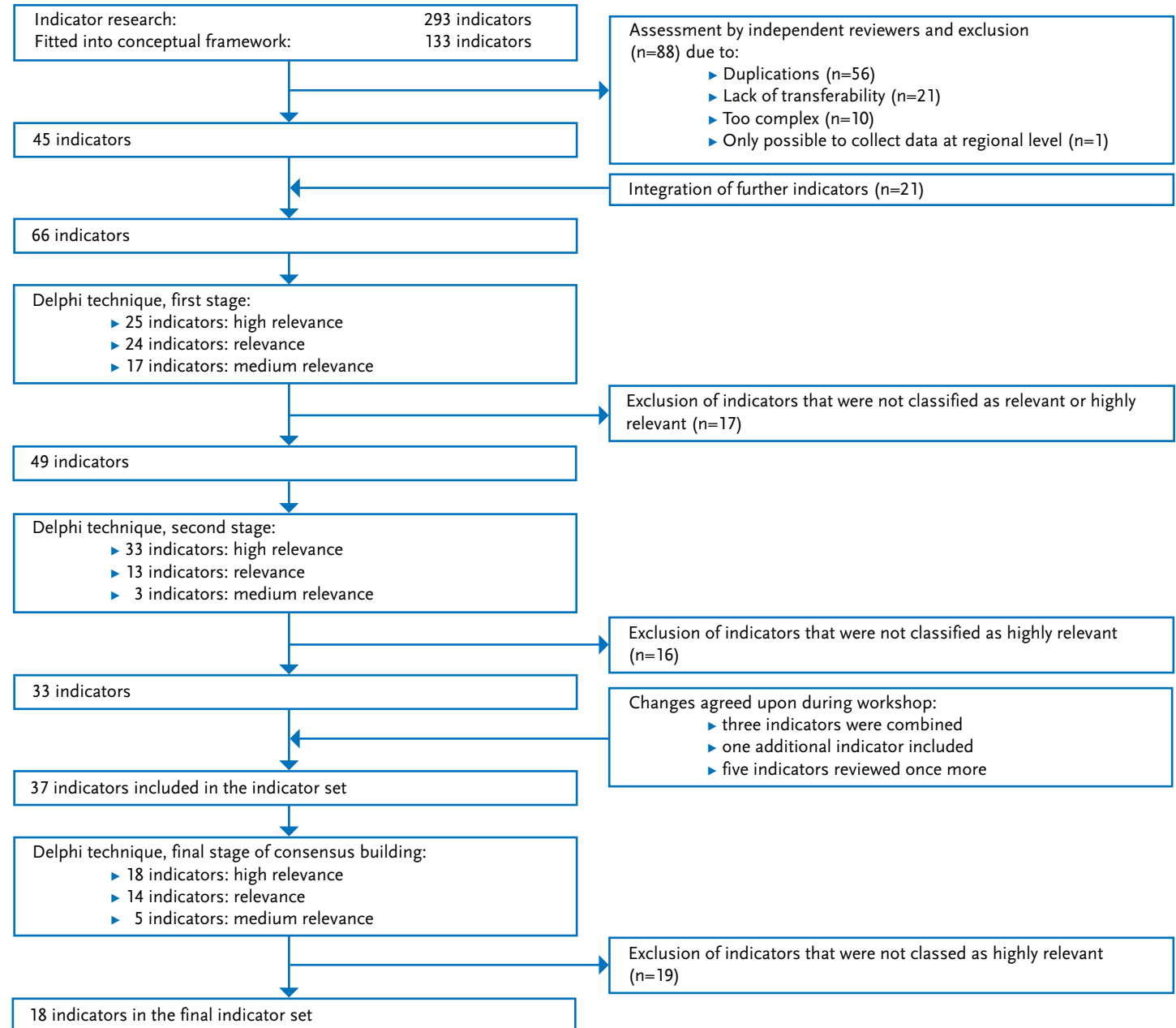
The final indicator set is available on the [RKI website](#). With 15 indicators, most of the 18 indicators selected in the

Table 1
Health areas, domains, and indicators for public health monitoring for the 65+ age group
 Own diagram

Indicators	Available data sources
Environmental factors	
Health care	
Unfulfilled care needs	German Health Update (GEDA) European Union Statistics on Income and Living Conditions (EU-SILC)
Dental care	German Health Update (GEDA) German Oral Health Study (DMS)
Psychotropic medication*	German Health Interview and Examination Survey for Adults (DEGS1)
Nursing and community care	
Recipient of long-term care	Nursing care statistics from the Federal Statistical Office
Caregiver burden*	German Health Interview and Examination Survey for Adults (DEGS1)
Physical environment	
Access to important infrastructure	European Quality of Life Surveys (EQLS)
Social environment	
Social support	German Health Update (GEDA) German Health Interview and Examination Survey for Adults (DEGS1)
Loneliness**	German Ageing Survey (DEAS)
Activities and participation	
Activities of daily living	
Restrictions in activities of daily living	German Health Update (GEDA)
Restrictions in instrumental activities of daily living	German Health Update (GEDA)
Personal factors	
Physical health	
Subjective health	German Health Update (GEDA) German Health Interview and Examination Survey for Adults (DEGS1) European Union Statistics on Income and Living Conditions (EU-SILC) Socio-Economic Panel (SOEP)
Multimorbidity	German Health Update (GEDA) German Health Interview and Examination Survey for Adults (DEGS1)
Mental health	
Depressive symptoms	German Health Update (GEDA) German Health Interview and Examination Survey for Adults (DEGS1)
Life satisfaction	German Health Update (GEDA)
Physical functioning	
Pain	German Health Update (GEDA 2013s special survey)
Falls*	German Health Interview and Examination Survey for Adults (DEGS1)
Urinary incontinence	German Health Update (GEDA)
Cognitive functioning	
Cognitive impairments*	Additional mental health module of the German Health Interview and Examination Survey for Adults (DEGS1)

Data only available up to a specified age limit: * Available for the age group 65 to 79 years; ** Available for the age group 65 to 85 years

Figure 2
Indicator selection for public health monitoring
of the 65+ age group
 Own diagram



The final set of indicators on the health of older people comprises 18 indicators that are to be continuously developed further.

final stage of the consensus-based process can be represented by data from the nationwide health surveys conducted at the Robert Koch Institute; three of the 15 indicators can be represented both by these and by surveys conducted by external data providers. Two indicators rely on data from external studies and one indicator on data from official statistics. The indicators draw on data from the following studies: the German Health Update (GEDA) [14], the German Health Interview and Examination Survey for Adults (DEGS) [15], the German Ageing Survey (DEAS) [16], the German Oral Health Study (DMS) [17], the Socio-Economic Panel (SOEP) [18], the European Quality of Life Surveys (EQLS) [19] and the European Union Statistics on Income and Living Conditions study (EU-SILC) [20].

For five of the 18 indicators data are currently available for the population aged 65 or above, but not for the population aged 80 or above. Four of these rely on data from the German Health Interview and Examination Survey for Adults (DEGS₁, 2008-2011) and are, therefore, restricted to an upper age limit of 79 [15]. A fifth indicator relies on data from the German Ageing Survey (DEAS) [16] and is limited to the age of 85. However, all of the data sources used allow for the indicators to be stratified by gender and age group (albeit with the limitations mentioned above). With the exception of the ‘recipient of long-term care’ indicator, which relies on official statistics, all other indicators can also be stratified by socioeconomic status or education.

4. Discussion and outlook

With the final indicator set, we hope to contribute towards building a sustainable and reliable health reporting for older age in Germany. All the 18 indicators selected in the final stage can be presented on a national level using adequate and sustainable data sources. Almost all of the indicators rely on primary data collected by the Robert Koch Institute or other research institutions; just one of the indicators (‘recipient of long-term care’) can be presented using routine data. Primary data are survey or examination data that have been collected mainly for scientific purposes. Routine data include administrative data from health insurance and other social insurances as well as data from official statistics such as long-term care and cause of death statistics. The combination of primary and routine data is particularly valuable [21]. Primary data not only enable indicators to be stratified by gender or age group, but also by socioeconomic status. In addition, subjective health outcomes, such as health-related quality of life and subjective care needs, can only be displayed using survey data. On the other hand, routine data are not affected by non-response bias and they enable indicators to be updated periodically. Besides, they are not affected by age restrictions often applied to interview and examination surveys [15, 16], because older adults, especially older adults in poor health, are harder to reach by conventional recruitment and survey methods [22, 23]. Data for five of the 18 indicators selected for this set are available with an upper age limit of 79 or 85.

The integration of routine data (research data sets collated by statutory health insurers that are made available due to Germany’s Data Transparency Regulations, DaTraV) provides

The indicators are to be integrated into a future overall approach to the monitoring of chronic diseases by the Robert Koch Institute.

for better representation of indicators related to health care provision and the possibility to display the indicators on a regional level, at least down to the federal state level. The data sources currently available allow only limited regional analysis of the 18 indicators. Here, examples from other countries demonstrate that merging indicators based on data collected at the national and regional level is technically possible and creates synergies [4]. Efforts are also being made to expand federal health reporting and reporting at the federal state level in Germany along similar lines [24, 25].

The approach to select indicators using a modified Delphi technique supplemented by a full-day workshop during which questions raised by the participants could be discussed and clarified, proved to be both effective and time-saving. However, the participants found the task of using various criteria to assess indicators in accordance with a single globally valid score challenging. Future consensus processes might ask participants to assess criteria separately, and, therefore, focus solely on the subject areas in which they have the most expertise. One limitation of the study is the fact that albeit representatives of different professions and institutions from practice and research participated in the selection process, the approach was mainly expert-led and older people's views had limited influence during the development of the indicator set. In the future, it may be useful to base selection processes more along the lines of the approach used to draw up Ireland's national positive ageing indicator set [5] – in addition to stakeholders from science and practice, older people participated equally as participants in the Delphi technique. Similarly, the International Consortium for Health Outcomes Measurement (ICHOM) also chose a

different approach to selecting relevant health care measures: it combined an expert-led Delphi technique with a focus group of older people to ensure that their views were taken into account during the selection process [26].

No claims are made as to the comprehensiveness of the indicator set presented here, nor is it assumed that the set fully captures the health and well-being of older people. Rather, this is an ongoing process, and the indicator set will need to be adapted to account for new health and methodological challenges. Nevertheless, agreement on a conceptual framework as well as on relevant indicators for public health monitoring of the population over the age of 65 means that it is now possible to conduct comparable assessments of the health of older people over time. The aim is also for these indicators to be integrated into an overall approach to the development of health monitoring and health reporting in the prevention of chronic diseases and to ensure good health in all stages of life in accordance with international action plans [27, 28]. The development and implementation of the national diabetes surveillance, which began in 2016, has laid valuable foundations for this undertaking [29]. Finally, in the long term, a data structure needs to be established that can be used to support policy decision-making processes, the evaluation of health goals and policy impact assessments.

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Data protection and ethics

All studies conducted by the Robert Koch Institute are subject to strict compliance with the data protection provisions set out within the EU General Data Protection Regulation (DSGVO) and the Federal Data Protection Act (BDSG). Participation in the development of the indicator set was voluntary and the participants were informed in advance about the aims and content of indicator development. The participants' assessments were made anonymous so that individual contributions were no longer identifiable.

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Conflicts of interest

The authors declared no conflicts of interest.

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Annex Table 1
Participants of the expert panel on
indicator selection for public health
monitoring of the 65+ age group

Prof Dr Michael Bosnjak	Leibniz Institute for Psychology Information Trier
Min Dir a.D. Rudolf Herweck	Federal Association of Senior Citizens Organizations, Bonn
Prof Dr Josefine Heusinger	Institute for Gerontological Research, Berlin
PD Dr Nils Lahmann	Charité – Universitätsmedizin Berlin
Prof Dr Gabriele Meyer	Martin Luther University Halle-Wittenberg
Prof Dr Ursula Müller-Werdan	Charité – Universitätsmedizin Berlin
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Prof Dr Martina Schäufele	Mannheim University of Applied Sciences
Prof Dr Martin Scherer	University Hospital Hamburg-Eppendorf
Prof Dr Clemens Tesch-Römer	German Centre of Gerontology, Berlin
Prof Dr Hans-Werner Wahl	Heidelberg University
Prof Dr Karin Wolf-Ostermann	University of Bremen
Prof Dr Susanne Wurm	Friedrich Alexander University Erlangen-Nuremberg
Prof Dr Susanne Zank	University of Cologne
Dr Stephanie Heinrich (as of stage 2)	Martin Luther University Halle-Wittenberg
Dr Dagmar Lüthmann (as of stage 2)	University Hospital Hamburg-Eppendorf

Annex Table 2
Results of the structured consensus-based process used to select indicators for public health monitoring of the 65+ age group

No.	Indicator	1st evaluation stage			2nd evaluation stage			Consensus round		
		Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}
Health area: environmental factors										
Domain: health care										
1	General practitioner (GP) care	6	3	8						
2	Medical home visits	4	3	5						
3	Unfulfilled care needs	8	3	9	8	8	9	8	7	9
4	Hospitalisations	6	5	8						
5	Dental care	7	6	8	7	7	8	8	7	9
6	Multimedication	7	5	8	8	8	8	8	6	9
	Psychotropic medication							8	7	9
7	Influenza vaccination	6	5	7				5	4	7
8	Pneumococcal vaccination	6	4	7				4	3	6
9	General practitioner (GP) with additional qualification for geriatrics	6	5	7						
Domain: community and nursing care										
10	Recipient of inpatient care	9	8	9	9	8	9			
11	Recipient of outpatient care	9	8	9	9	8	9			
12	Care level	9	8	9	9	8	9			
	Recipient of long-term care							8	8	9
13	Caregiver burden	8	7	9	7	7	8	8	8	9
14	Employed in care provision	7	6	8	8	5	8			
15	Burden due to employment in care provision	7	4	8	7	5	8			
16	Pressure sores	6	5	9				7	5	8
17	Violence, neglect, abuse	8	6	9	8	7	8	7	5	9
Domain: physical environment										
18	Safety of the living environment	6	3	7						
19	Access to important infrastructure	8	7	8	8	8	8	8	7	9
20	Accessibility of housing	7	6	8	5	4	8			
Domain: social environment										
21	Practical support in daily life	6	4	8						
22	Social support	8	8	9	8	8	9	7	7	8
23	Loneliness	8	7	9	8	8	9	8	7	8
24	Age discrimination	6	3	8						

Continued on next page

Annex Table 2 *Continued*
Results of the structured consensus-based process used to select indicators for public health monitoring of the 65+ age group

No.	Indicator	1st evaluation stage			2nd evaluation stage			Consensus round		
		Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}
Health area: participation and activity										
Domain: social participation										
25	Political commitment	5	3	6						
26	Voluntary/unpaid work	8	6	8	7	6	8			
27	Childcare	6	5	7						
28	Social leisure activities	8	7	8	8	7	9	7	6	8
Domain: activities of daily living										
29	Restrictions in activities of daily living	9	8	9	9	9	9	8	7	8
30	Restrictions in instrumental activities of daily living	8	7	9	9	9	9	8	7	9
Health area: personal factors										
Domain: physical health										
31	Further life expectancy	9	4	9	8	6	9			
32	Further life expectancy in health	9	5	9	8	6	9			
33	Subjective health	9	8	9	9	8	9	8	7	8
34	Chronic disease	8	5	9	8	6	9			
35	Multimorbidities	8	7	9	9	8	9	7	7	8
36	Frequency of various diseases	7	7	9	8	7	9	7	6	8
37	Obesity	7	3	8	5	2	7			
38	Malnutrition	8	6	8	8	8	8	8	6	8
39	Hip fractures	7	6	9	8	6	9			
Domain: mental health										
40	Depressive disorder	8	7	9	7	2	8			
41	Depressive symptoms	8	7	9	9	8	9	8	7	8
42	Anxiety disorders	7	6	8	7	2	7			
43	Quality of life	8	7	9	7	6	8			
44	Life satisfaction	8	7	9	9	8	9	7	7	8
45	Locus of control	7	5	8	8	5	9			
46	Addiction to medicines	6	4	8						
47	Alcohol dependency	7	5	7	6	5	8			
48	Suicide rate	8	7	9	8	8	9	8	6	9
49	Health literacy	7	4	8	8	7	9	7	5	8

Continued on next page

Annex Table 2 Continued
Results of the structured consensus-based process used to select indicators for public health monitoring of the 65+ age group

No.	Indicator	1st evaluation stage			2nd evaluation stage			Consensus round		
		Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}	Median	Q _{0,25}	Q _{0,75}
Health area: personal factors										
Domain: physical functioning										
50	Physical disability	8	7	8	8	8	9	6	6	8
51	Slow walking speed	5	2	8				5	3	7
52	Difficulty walking	7	7	8	8	7	8	7	3	7
53	Grip strength	6	5	7				5	3	6
54	Pain	8	8	9	8	8	9	8	7	8
55	Falls	8	8	9	8	8	9	8	7	8
56	Eyesight	8	6	8	8	8	8	7	6	8
57	Hearing	8	6	8	8	8	8	7	6	8
58	Dental health	8	7	8	7	7	8	7	6	8
59	Urinary incontinence	8	6	8	8	8	9	7	7	8
60	Faecal incontinence	8	7	9	8	8	9	7	6	8
Domain: cognitive functioning										
61	Cognitive impairment	8	6	8	8	7	8	8	7	8
62	Memory difficulties	6	5	8						
Domain: health behaviour										
63	Physical activity	8	7	8	8	8	9	8	6	8
64	Tobacco use	8	6	8	7	6	8			
65	Alcohol consumption	7	6	8	7	6	8			
66	Fruit and vegetable consumption	6	5	7						

Q_{0,25} = 25%-quantile, Q_{0,75} = 75%-quantile, bold = indicators included in the final indicator set

■ Considered at the next stage or for the final set of indicators

■ Not considered at the next stage

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