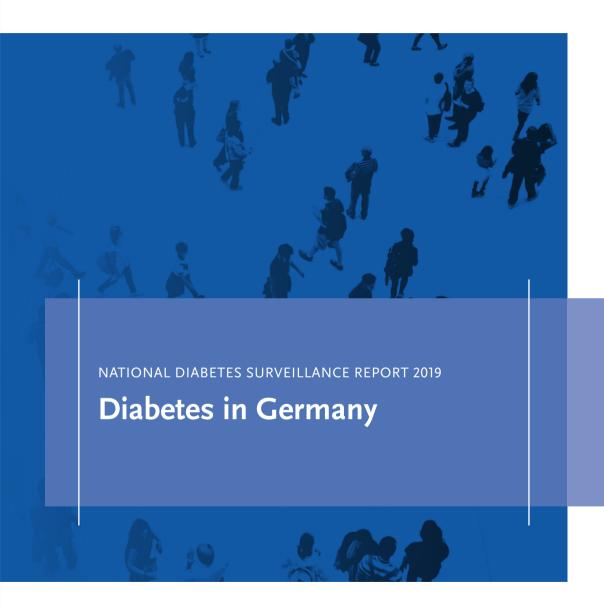
ROBERT KOCH INSTITUT







NATIONAL DIABETES SURVEILLANCE REPORT 2019

Diabetes in Germany

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Introductory remarks

There are currently around seven million people with diabetes living in Germany, a figure which is predicted to rise. We must confront this trend head-on! Diabetes is not a harmless condition, it has a negative effect on quality of life and can lead to severe complications including renal failure, amputations and blindness. There are various modifiable risk factors for the common type 2 diabetes as well as some which are unmodifiable. For this reason, it is important – without stigmatising anyone – to increase health literacy among the population in regard to both prevention and a healthy lifestyle.

To effectively improve prevention and health care specific to the target groups, health policy, health research, health care and public health practice need reliable data and facts. These are provided by the "Diabetes in Germany" report and by the National Diabetes Surveillance at the Robert Koch Institute, thereby helping to address the following questions: How many people are affected? How will the prevalence of diabetes and the number of new cases per annum develop? How many people face an increased risk of developing diabetes? Have specific treatment programmes improved care? How common are the various secondary diseases? What costs are associated with diabetes?



The establishment of the National Diabetes Surveillance in Germany has given us a reliable and comprehensive tool that will provide regular diabetes reporting based on relevant indicators, one which distinguishes between age, sex and regional distribution and illustrates trends over time.

I would like to thank everyone who was involved in establishing the National Diabetes Surveillance in Germany, in particular, those who contributed to the report "Diabetes in Germany – National Diabetes Surveillance Report 2019". I would also like to thank the co-operation partners, whose key contributions helped secure external data sources. Finally, my sincere thanks to the members of the National Diabetes Surveillance advisory board for their comprehensive scientific and specialist advice and support.

Jens SpahnFederal Minister of Health Member of the German Bundestag

Foreword

As a national public health institution, the Robert Koch Institute (RKI) bears responsibility for protecting and promoting the health of the population (public health) in Germany. This includes both averting the acute threats posed by infectious diseases to health and promoting measures to protect against serious non-communicable diseases. Faced with these challenges, the RKI is tasked with the continuous analysis of health developments and threats to the population via reliable data sources. The information gained provides a basis for health policy decisions on the planning and implementation of long-term measures. The World Health Organization (WHO) defines this fundamental task as "Public Health Surveillance".

Over the past century, the spectrum of diseases and health risks faced by the population has changed fundamentally. While infectious diseases continue to pose an acute threat, non-communicable diseases are now among the most common causes of illness and death in adulthood worldwide. This shift has been fuelled by changes in lifestyle and living conditions as well as an increase in life expectancy.

Diabetes is one of the main non-communicable diseases in Germany and many other countries and is a major public health challenge as a result. Despite improvements in early detection and treatment, many of those with diabetes develop serious complications such as heart attack, stroke, amputation, blindness and dialysis. By far the most common form of diabetes is type 2 diabetes, which mostly develops in late adulthood. Physical inactivity, smoking and obesity are some of the known and potentially modifiable risk factors. These factors correlate strongly with psychosocial stress and disadvantageous life circumstances. As a consequence, international WHO action plans on non-communicable diseases specifically target diabetes as well as cardiovascular diseases, cancer, chronic respiratory diseases and mental illnesses.

Against this backdrop, the Federal Ministry of Health (BMG) commissioned the RKI to establish a diabetes surveillance system in Germany within the scope of a research project. The objective was to systematically collate information on diabetes from available data sources in order to map the

dynamics of the disease over time. The data sources were selected based on timely and constant availability, allowing for continuous reporting.

Now at the end of the initial project phase, the report of the Diabetes Surveillance in Germany is complete. It graphically depicts the disease's development and the distribution of risk factors. Aspects of diabetes care, co-morbidities and secondary diseases have also been taken into account. The report has been prepared by the RKI in close collaboration with an interdisciplinary scientific advisory board and is supplemented by an interactive website (http://diabsurv.rki.de).

An important milestone for public health reporting on diabetes has now been reached. And what are the next steps? As a public health institute, we want to expand our surveillance system to include other major public health challenges. The surveillance of infectious diseases and cancer is already well-established at the RKI. Our goal is to analyse and provide relevant data on other major diseases such as cardiovascular diseases, lung diseases and mental illnesses such as depression. In this way, we can provide an information base with which to develop strategies together with policymakers and players within the health care sector so that as many people in Germany as possible can lead a long and healthy life.

Prof. Dr. Lothar H. WielerPresident of the Robert Koch Institute

Summary

Diabetes is a chronic disease that represents a significant public health challenge in Germany as well as globally. Against this backdrop, the Federal Ministry of Health (BMG) is funding the establishment of a diabetes surveillance system for Germany at the Robert Koch Institute (RKI). Based on a set of defined indicators (key figures), the Diabetes Surveillance aims to collate essential information on diabetes from available data sources and to timely process this information so it can be used as a basis for action for health policy, health research, health care and public health practice. This is carried out in close co-operation with the Federal Centre for Health Education (BZgA), which is developing communication and information strategies on the prevention of diabetes and related secondary diseases.

During the initial phase of the project (2015-2019), a structured, consensus-finding process was used to develop a scientific conceptual framework for the Diabetes Surveillance with four fields of action and 40 indicators or indicator groups. Following this, data sources were identified for these indicators and initial reporting formats were developed. The current report presents the first results from the Diabetes Surveillance and is complemented by a website (http://diabsurv.rki. de). Further expansion of the data basis and further development of analyses and reporting formats are planned for the second phase of the project until the end of 2021. Within the four fields of action, initial findings on diabetes in Germany can be summarised as follows:



Field of action 1 "Reducing the risk of diabetes"

Differing temporal developments and considerable social differences are evident for key type 2 diabetes risk factors.

- Claims data for all people covered by statutory health insurance shows that over 500,000 adults develop diabetes every year (fact sheet "Incidence of documented diabetes").
- ▶ Gestational diabetes increases the risk for complications in pregnancy and for the development of type 2 diabetes for the mother at a later stage. According to documentation in pregnancy records 5.9% of women giving birth in hospitals have gestational diabetes (fact sheet "Prevalence of gestational diabetes").
- ▶ Between 1998 and 2010, RKI surveys show that the prevalence of overweight (including obesity), an important risk factor in the development of type 2 diabetes, remained constant at 60% for the 18- to 79-year-old population. However, the proportion of obesity increased for men (fact sheet "Overweight and obesity").
- Physical inactivity and smoking are further behavioural risk factors linked to the development of type 2 diabetes. An RKI survey from 2014 indicates that just over half of all adults in Germany do not meet World Health Organization recommendations for weekly endurance exercise, while nearly one-quarter of adults say they smoke occasionally or daily (fact sheet "Physical inactivity" and fact sheet "Smoking"). Nevertheless, RKI surveys show a reduction in smoking between 2003 and 2014.
- ► There are significant social differences regarding the risk factors considered. The prevalence of risk factors for people in the low-education group is considerably higher (http://diabsurv.rki.de).



Field of action 2

"Improving the early detection and treatment of diabetes"

There is an increasing number of people being diagnosed with diabetes and receiving treatment within the health care system.

- According to an RKI survey, 7.2% of the 18- to 79-year-old population in 2010 had known diabetes, and a further 2.0% had previously unknown diabetes. While the prevalence of known diabetes had increased since 1998 across all education groups, there was a similar-sized decrease in the prevalence of unknown diabetes during the same period (fact sheet "Prevalence of known and unknown diabetes").
- Claims data for all people covered by statutory health insurance shows significant regional differences in the prevalence of documented diabetes (fact sheet "Prevalence of documented diabetes").
- ▶ RKI surveys show that in 2010, around 80% of 45to 79-year-olds with known type 2 diabetes achieved the recommended HbA1c target, which takes factors such as age and diabetes-related co-morbidities into account. This is a marked increase in comparison with 1998 (fact sheet "Graded HbA1c target").
- Around 70% of 45- to 79-year-olds with known type 2 diabetes are on antidiabetic medication, a figure which remained almost constant between 1998 and 2010. Findings of RKI surveys indicate that the proportion of those receiving metformin monotherapy or a combined therapy of insulin and oral antidiabetic agents increased (fact sheet "Treatment profiles").
- ▶ Health-related quality of life is lower for people with diabetes than for those without. RKI surveys indicate that there were no changes in this relation between 1998 and 2010 (fact sheet "Health-related quality of life").



Field of action 3

"Reducing the complications of diabetes"

Not only diabetes itself, but also co-morbidities and secondary diseases signify an increased burden on the individual.

- According to an RKI survey, around 15% of people with diabetes in 2014 presented with depressive symptoms, approximately twice that of people without diabetes (fact sheet "Depressive symptoms").
- Cardiovascular co-morbidities are far more frequent among 45- to 79-year-olds with type 2 diabetes than among people who do not have this condition. According to RKI surveys, between 1998 and 2010 the prevalence of cardiovascular co-morbidities decreased particularly among women with type 2 diabetes (fact sheet "Cardiovascular diseases").
- Over time, diabetes can damage small blood vessels and nerves, leading to secondary diseases specific to diabetes. Analyses of statutory health insurance data show that in 2013, over 15% of all insured persons with diabetes had documented chronic kidney disease, and over 13% had documented polyneuropathy (fact sheet "Diabetic kidney disease" and fact sheet ""Diabetic polyneuropathy"").
- Polyneuropathy increases the risk of developing diabetic foot syndrome, which can lead to amputation if an infection becomes uncontrollable. Around 6% of persons with diabetes insured by statutory health insurance in 2013 had documented diabetic foot syndrome. In 2017, there were approximately 11 amputations of the lower limb above the ankle among persons with diabetes per 100,000 residents, according to Diagnosis-Related Groups (DRG) statistics (fact sheet "Diabetic foot syndrome" and fact sheet "Diabetes-related amputations").



Field of action 4

"Reducing the burden and costs of disease"

Diabetes markedly reduces the number of healthy life years and is associated with high costs to the health care system.

- According to disease-related cost calculations by the Federal Statistical Office, diabetes care costs EUR 7.4 billion in 2015. Estimates from 2009 taking co-morbidities and secondary diseases into account calculated the cost of diabetes at approximately EUR 21 billion for that year (fact sheet "Direct costs").
- ▶ Diagnosis-Related Groups (DRG) statistics indicate that the number of inpatients with diabetes as their documented main diagnosis decreased for both sexes between 2015 and 2017, with rates for women lower than for men. The regional distribution of these so-called ambulatory care-sensitive hospitalisations is related to the regional distribution of diabetes prevalence (fact sheet "Ambulatory care-sensitive hospitalisations").
- ▶ The number of pension applications to the German Pension Insurance Scheme on the grounds of diabetes-related reduced earning capacity decreased between 2013 and 2016. These rates show clear regional differences that relate to the prevalence of diabetes in the federal states (fact sheet "Reduced earning capacity pension").
- ► The mortality rate for people with documented diabetes aged 30 and over is around 50% higher than for people of the same age who do not have diabetes (fact sheet "Mortality").
- ▶ The expected number of healthy life years is lower for people who have diabetes than for those who do not. Depending on age, as many as 12 remaining healthy life years may be lost (fact sheet "Healthy life years").

Conclusion and outlook

In view of the predicted rise in the prevalence of known diabetes1, prevention and care of diabetes remains a challenge for public health. For this reason, it is important to continue reducing the diabetes risk of the population through behavioural and settings-based measures. Persons with diabetes face increased rates of mortality, more frequent co-morbidities and a lower quality of life than those without diabetes, all of which indicates a need to further improve quality of diabetes care. The next project phase of the Diabetes Surveillance will look to strengthen the data basis for the future surveillance of non-communicable diseases. In addition, specific target groups and all life phases will be considered with the aim of developing targeted public health measures.

Introduction and background

What is diabetes mellitus?

Diabetes mellitus is a non-communicable disease characterised by chronically elevated blood glucose levels. Secondary diseases include serious and multiple organ complications stemming from damage to small blood vessels and nerves. These reduce not only the life expectancy but also the remaining healthy life years for people with diabetes in comparison to those of the same age without diabetes.^{2,3}

There are different types of diabetes (Table 1),4 with type 2 diabetes being the most frequent form in adults.5 While factors such as more advanced age and genetic disposition are unmodifiable, many type 2 diabetes risk factors are, in principle, modifiable. This provides opportunities for behavioural and settings-based prevention measures. Such prevention measures should either be evidence-based or accompanied by scientific evaluation if their effectiveness has not yet been shown. Looking beyond type 2 diabetes, the risk factors also contribute to the development of other common, non-communicable diseases, many of which frequently appear as co-morbidities of diabetes. Demographic and social changes since the mid-1960s have led to a profound shift in the spectrum of diseases observed in the population, with an increased prevalence of non-communicable diseases. During this period, the prevalence (frequency of cases in the population over a defined period of time) and incidence (frequency of new cases relative to the population over a defined period of time with no previous history of diabetes) of type 2 diabetes increased in Germany and around the world.^{6,7} Frequency, sequelae, potential to prevent individual and environmental risk factors as well as the strong link to other non-communicable diseases are the reasons why type 2 diabetes is hugely significant for public health.8-10

Table 1. The most frequent types of diabetes. 4, 12

Type 1 diabetes

Pathogenesis

Absolute lack of insulin due to the destruction of insulin-producing & cells in the pancreas

Cours

Usually immune-mediated

► Treatment

Always with insulin

Type 2 diabetes

Pathogenesis

Relative lack of insulin due to insulin resistance and partially diminished insulin production

► Cause

Interaction of several risk factors such as age, genetics, obesity and lack of physical activity

► Treatment

Lifestyle changes, oral antidiabetic agents, GLP-1 analogues or insulin (depending on state of disease)

Gestational diabetes

Pathogenesis

Develops during pregnancy due to greater insulin resistance in the second half of the pregnancy

Caus

Similar to type 2 diabetes, an interaction of genetic factors and health-related lifestyle

► Treatment

Primarily lifestyle changes; should these prove ineffective then insulin therapy is recommended

There are also other comparatively rare forms of diabetes with entirely different causes. The second main form of diabetes, type 1 diabetes usually develops in children and adolescents and requires lifelong insulin therapy. It represents a great burden on the individual and places heavy demands on the quality of medical care. There are other rare forms of diabetes related to congenital or acquired underlying diseases. Unlike in adults, type 2 diabetes is rare in children and adolescents.

One particular form of diabetes is gestational diabetes. This is a metabolic disorder that develops during pregnancy and which often causes pregnancy complications.^{4,5} Gestational diabetes increases the mother's risk of developing type 2 diabetes at a later stage⁵.

What are the aims of the Diabetes Surveillance in Germany?

Public health surveillance is understood to be the systematic, continuous and problem-oriented collection and analysis of health data. The aim is to provide important, up- to date, tailored information to key players within the health care system, thereby supporting the planning, implementation and evaluation of public health measures. ^{13,14} Originally used in the field of infectious diseases and infection protection, surveillance is now becoming more important in the prevention and control of non-communicable diseases. ¹³ This can also be seen in the international action plans of the World Health Organization (WHO). ¹⁵

Due to the high relevance of diabetes for public health, the Robert Koch Institute (RKI) began establishing a diabetes surveillance system in Germany in 2015, as part of a Federal Ministry of Health (BGM) project. The project is overseen by an interdisciplinary scientific advisory board (see http://diabsurv.rki.de). The goal of the Diabetes Surveillance is to establish a transparent, consistent and comprehensive data and information basis on disease and health care specifically in regard to diabetes in Germany. This data and information basis is aimed at players within health policy, research and health practice. As a consequence, there was close co-operation with the department for "Prevention of Diabetes Mellitus, Associated Risk Factors and Secondary Diseases" at the Federal Centre for Health Education (BZgA), the former "National Education and Communication Strategy on Diabetes Mellitus in Germany". The BZgA strategy aims to provide a range of educational and informative materials on all stages of the disease that are target-group oriented, comprehensive, quality-assured and evidence-based. The BZgA's diabetes network compiles and organises existing education, information and communication measures on diabetes prevention and treatment, as well as developing and promoting new material.16 Among these is the diabetes information portal developed by the German Diabetes Centre (DDZ), the German Centre for Diabetes Research (DZD) and Helmholtz Zentrum München.¹⁷ In 2017, the RKI and the BZgA collaborated on a nationwide telephone interview survey to assess what information was needed by adults

in Germany with and without diabetes.¹⁸ The long-term experience of the federal states with health reporting can also be utilised. In future, results of the Diabetes Surveillance should be presented with regionalised figures as possible, thereby supporting reporting at federal state level.¹⁹

What content comprises the Diabetes Surveillance?

The first phase (2015-2019) of the Diabetes Surveillance project has focused on developing a scientific framework. In a multi-step, consensus-finding process,40 indicators or indicator groups relevant to health policy were selected and assigned to four fields of action to illustrate the disease and care situation (Figure 1).20 While the first field of action Reducing the risk of diabetes addresses the prevalence of type 2 diabetes risk factors and the incidence of diabetes, the second field of action Improving the early detection and treatment of diabetes focuses on the prevalence of diagnosed and unknown diabetes, as well as on various aspects of process and outcome quality in the early detection and treatment of diabetes. The third field of action Reducing the complications of diabetes is concerned with the frequency of secondary diseases and co-morbidities. The fourth field of action, Reducing the burden and costs of disease outlines aspects of the diabetes disease burden for individuals and for society as a whole.

Figure 1. Consensus-based indicator set for the Diabetes Surveillance 21



Field of action 1 Reducing the risk of diabetes

Core indicators

- ▶ Incidence of documented diabetes
- ▶ Prevalence of gestational diabetes
- Overweight and obesity
- ▶ Physical inactivity
- ▶ Smoking
- ► Social deprivation

Supplementary indicators

- ► Prediabetes
- ► Sugar-sweetened beverages
- ► Absolute diabetes risk
- ► Contextual factors



Field of action 2 Improving the early detection and treatment of diabetes

Core indicators

- ▶ Prevalence of known/documented diabetes
- ▶ Prevalence of unknown diabetes
- ▶ DMP participation rate
- ▶ Achievement of DMP quality objective
- ▶ Quality of type 2 diabetes care
- ► Treatment profiles
- ▶ Health-related quality of life
- ► Screening for gestational diabetes
- ► Age at diagnosis

Supplementary indicators

- ► Health check-up
- ▶ Patient satisfaction



Field of action 3 Reducing the complications of diabetes

Core indicators

- ► Depressive symptoms
- ► Cardiovascular diseases
- ▶ Diabetic retinopathy
- ▶ Diabetic kidney disease
- ► Renal replacement therapy
- ► Diabetic polyneuropathy
- ▶ Diabetic foot syndrome
- ▶ Diabetes-related amputations
- ▶ Frequency of severe hypoglycaemia

Supplementary indicators

- ► Risk of a cardiovascular events
- ▶ Pregnancy complications



Field of action 4 Reducing the burden and costs of disease

Core indicators

- Direct costs
- ► Ambulatory care-sensitive hospitalisations
- ▶ Reduced earning capacity pension
- ▶ Mortality
- ▶ Years of life lost (YLL)
- ► Healthy life years (HLY)

Supplementary indicators

- ► Years lived with disability (YLD)
- ▶ Disability-adjusted life years (DALYs)

Which data sources are used by the Diabetes Surveillance?

The Diabetes Surveillance uses multiple data sources for their indicators (Figure 2). These can be divided into primary and secondary data sources. Primary data are systematically captured via predefined questions. Secondary data are originally collected or documented for another purpose or in answer to other questions.

Primary data used in the Diabetes Surveillance notably comprises data from RKI interview and examination surveys which are representative of the German population (German National Health Interview and Examination Survey 1998 (GNHIES98); German Health Interview and Examination Survey for Adults (DEGS); German Health Update (GEDA)).

Advantages of RKI health surveys

- Contain measurement and laboratory data and therefore allow for example detection of hitherto unknown diabetes
- Contain subjective aspects of health as well as behavioural and social risk factors, thereby for example allowing the population groups most affected to be identified according to social status

Limitations of RKI health surveys

- Relatively long intervals between data collection waves, in particular for surveys including examinations
- Results have limited representativity for certain population groups such as the seriously ill, the very old, people living in care homes, and people with insufficient German language skills

The secondary data used notably includes claims data routinely documented by statutory health insurance (SHI), the so-called DaTraV data, Diagnosis-Related Groups (DRG) statistics provided by the Federal Statistical Office, pension entitlement diagnoses for people with a reduced capacity to work from the German Pension Insurance, data from obstetrics quality assurance based on federal perinatal statistics, and documentation data from the Disease Management Programmes (DMP).

Figure 2. Current data sources for the National Diabetes Surveillance²²



Advantages of claims and documentation data

- Usually include a large number of cases that allow for example differentiated analyses by region as well as detailed evaluations for the assessment of secondary diseases and co-morbidities
- Periodic analysis without large time lag are possible

Limitations of claims and documentation data

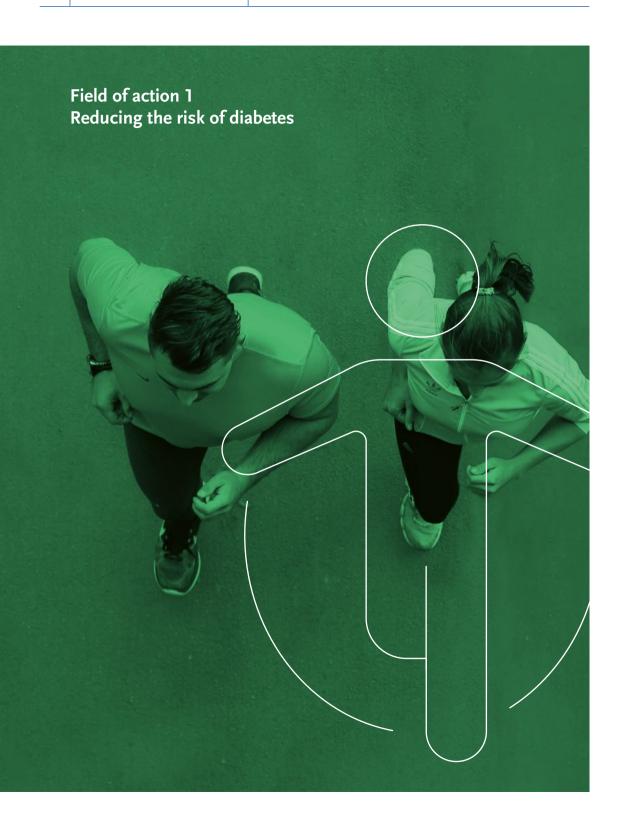
- Data are documented for treatment and billing purposes, data quality depends on coding which in turn affects the completeness and validity of data
- Data from individual SHI are not representative of all people covered by SHI and do not provide information on privately insured persons

In addition, the Diabetes Surveillance uses data from national diabetes patient documentation history (DPV) and from regional epidemiologic diabetes registries. These registry data play an important role, in particular for the less frequent type 1 diabetes and the equally rare type 2 diabetes in children and adolescents. Calculation of individual indicators also requires data from official statistics such as cause of death statistics from the Federal Statistical Office.

What does this report contain?

This first report of the Diabetes Surveillance in Germany summarises the key results from the initial project phase. The report is divided into four chapters, one for each field of action. Each chapter begins with a summary of results for that field of action, followed by a short, two-page fact sheet describing the core indicators (approximately five) for each field of action. These core indicators were selected in discussions with the scientific advisory board and with data availability in mind. Depending on data availability, indicators are described as they develop over time, and are stratified by sex, age, education and region.

These initial results of the Diabetes Surveillance are presented here in the form of a report, supplemented by a website (http://diabsurv.rki.de). The website describes the methodology in detail, as well as the results for those indicators not included as fact sheets in this report. Periodic reports in a printed format are also planned. Reporting formats will be differentiated and developed appropriately in close consultation with specific target groups.



Background

Different predictive scenarios related to type 2 diabetes consistently indicate an increase in the number of diabetes patients in the future. The speed of this predicted increase will depend in particular on how many new cases develop and thus on temporal development in key type 2 diabetes risk factors.¹ As is the case with other non-communicable diseases that are highly relevant to public health, these include factors that are potentially modifiable such as health-related behaviour, living conditions and environmental conditions.²³ With this in

mind, two key issues were selected for the field of action 1 Reducing the risk of diabetes and described with indicators. These are the incidence of diabetes and the prevalence of key influencing factors related to behaviour or settings which can be influenced by health policy. In a structured, consensus-finding process, six of the ten indicators selected for this field of action were classified as core indicators, while four were classified as supplementary indicators (Figure 3). The following fact sheets in this chapter present the current data situation and – where possible – the temporal developments for five core indicators.

Figure 3. Indicators field of action 1

Core indicators	Supplementary indicators
► Incidence of documented diabetes	Prediabetes
► Prevalence of gestational diabetes	Sugar-sweetened beverages
► Overweight and obesity	Absolute diabetes risk
► Physical inactivity	Contextual factors
► Smoking	
Social deprivation	

The indicators presented in fact sheets in this issue are marked in colour.

Please note: Results for the other field of action 1 indicators as well as information on methodology and data sources are available on the Diabetes Surveillance website http://diabsurv.rki.de.

Results at a glance

Seen as a whole, the few studies on the incidence of diabetes in Germany indicate a significant increase in incidence rates over the past decades.6 Unhealthy lifestyle and behaviour have contributed to this development, as have changes to diagnostic criteria and improved clinical diagnostics. Having said this, a recent analysis of claims data from statutory health insurance physicians by the Central Research Institute of Ambulatory Health Care in Germany (Zi, Zentralinstitut für die kassenärztliche Versorgung in Deutschland) indicates that between 2012 and 2014, there was a slight decline in the incidence of type 2 diabetes among adults aged 40 and over.²⁴ The Diabetes Surveillance indicator on the incidence of documented diabetes, which was based on DaTraV data, provides a basis for the future monitoring of incidence over shorter

intervals. According to an initial analysis for the year 2012, about 500,000 people, or 1.2% of the adult population, develop diabetes every year (fact sheet "Incidence of documented diabetes").²⁵

Gestational diabetes is a particular form of diabetes that can develop temporarily during pregnancy. This form of diabetes is a risk factor for both pregnancy complications and the development of type 2 diabetes at a later stage.26 Using perinatal statistics, the quality assurance in obstetrics collects data on the number of hospital births where the mother has gestational diabetes documented in her maternity log relative to the total number of hospital births in a given year. 27,28 According to this, gestational diabetes prevalence increased from less than 2% in 2002 to over 4% in 2011, and – after universal screening for gestational diabetes was introduced in 2012 - reached 5.9% in 2017 (fact sheet "Prevalence of gestational diabetes"). It should be noted that these prevalence estimates rely on the documentation of gestational diabetes in maternity logs. Analyses of other data sources indicate it is likely that the prevalence of gestational diabetes based on perinatal statistics is being underestimated.^{29,30} Missing information in maternity logs can result in inaccurately low reported figures.³¹

Nationwide RKI health surveys provide the data basis for assessing the prevalence of key behavioural type 2 diabetes risk factors over time. Between 1998 and 2010, the prevalence of overweight (including obesity) among 18- to 79-yearolds remained constant at 60.0% (fact sheet "Overweight and obesity"). Overall, the prevalence of physical inactivity^{32,33} and of smoking^{34,35} has decreased in the past few years. Nevertheless, more than half of all adults do not meet the WHO minimum recommendation of 2.5 hours of aerobic physical activity per week (fact sheet "Physical inactivity"), and nearly one-quarter of adults smoke occasionally if not daily (fact sheet "Smoking"). With significantly higher prevalences recorded for socially deprived groups, pronounced differences in the distribution of behavioural risk factors remain. Regional differences for indicators can also be observed (see http://diabsurv.rki.de).

Information on a further three of the ten indicators (Prediabetes, Sugar-sweetened beverages and Absolute diabetes risk) are available on the Diabetes Surveillance website (http://diabsurv.rki. de). These indicate that in recent decades, there has been an increase in the frequent consumption of sugar-sweetened beverages. Currently, around one in six 18- to 79-year-olds consume at least one sugar-sweetened beverage per day. A comprehensive evaluation of the risk situation could be supported by a summary measure of known diabetes risk factors such as risk scores for the development of type 2 diabetes, as well as by data on prediabetes from lab measurements of sugar metabolism. Analyses of the indicators Absolute diabetes risk36 and Prediabetes³⁷ indicate a slight improvement in overall diabetes risk between 1998 and 2010. The selection and operationalisation of settings-based risk factors relevant to health policy (indicator groups Social deprivation and Contextual factors) have not yet been completed for this initial report. The scientific evidence must first be assessed. The results for the settings-based risk factors will be a key issue to the further development and completion of the Diabetes Surveillance indicators.

Within the health policy context

Since many of the risk factors for the predominant type 2 diabetes and for gestational diabetes are modifiable, there is potential for primary prevention. Preventable risk factors for type 2 diabetes such as physical inactivity, smoking and obesity are shared by other relevant non-communicable diseases (cardiovascular diseases, cancer, chronic lung diseases). As a result, there is a social responsibility to implement settings-based prevention measures so that all social groups can be reached. These prevention measures should be both sensitive to the effects of stigmatisation and evidence-based. In addition, they should be accompanied by scientific evaluation if their effectiveness has not yet been shown. Major primary prevention objectives and measures are embedded in the WHO's Global Action Plan for the Prevention and Control of Non-communciable Diseases 2013-2020,15 in the national health targets for Type 2 diabetes mellitus (Diabetes mellitus Typ-2), Health and motherhood (Gesundheit rund um die Geburt), Growing up healthy (Gesund aufwachsen) and Healthy ageing (Gesund älter werden),³⁸ in Germany's National Sustainable Development Strategy³⁹ and in the National Action Plan IN FORM.40 As declining smoking rates show, measures that apply to the entire population such as increasing the tax on tobacco and legally regulating the protection of non-smokers⁴¹ have already had a positive effect. However, social disparities in the prevalence of behavioural and settings-related risk factors persist. Establishing the Health in all Policies approach and implementing public health measures within high-risk population groups – at the municipal or regional level and in particular settings (such as in childcare facilities, schools, or work environments) - thus remains a challenge for the future. Contact with players within the health care system will likewise provide important opportunities for targeted advice and support on how to promote health (for example during pregnancy and birth) that could be used in scientifically monitored advisory programmes.

Next steps for the Diabetes Surveillance at the Robert Koch Institute

- 1. Further development of stratified analyses for all age groups (including children, adolescents and the very old), and to identify differences in the distribution of risk factors dependent on region, social status and migrant background.
- **2.** Operationalisation of settings-based risk factors and measures relevant to health policy (indicator groups Social deprivation und Contextual factors).
- 3. Differentiation of diabetes types in terms of diabetes incidence. This builds on previous analyses from co-operation projects between the Diabetes Surveillance and regional diabetes registries, as well as documentation on diabetes patients (DPV) in Germany.⁴²

Incidence of documented diabetes

Definition

The indicator Incidence of documented diabetes is defined as the proportion of newly documented diabetes cases among all adults covered by SHI in a given year who have not been diagnosed with diabetes in the previous year. A new case is defined as at least one documented hospital diagnosis of diabetes or at least two verified outpatient diagnoses (E10-E14) in the space of four calendar quarters.

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation.

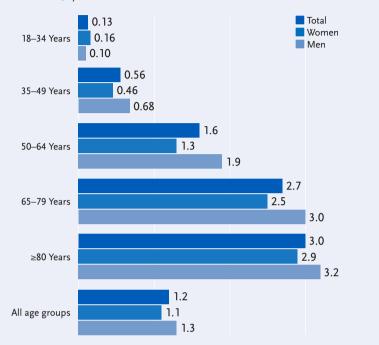
The rate of new cases (incidence) and the corresponding absolute number of new cases are critical for assessing disease dynamics. Incidence influences the future development of prevalence and the expected number of patients. Incidence itself is dependent on the development of major diabetes risk factors. 43

In 2012, the incidence of documented diabetes in Germany was 1.2% of all people covered by SHI (women 1.1%; men 1.3%). This is equivalent to 560,762 adults. An analysis by age groups shows that for both men and women, incidence increased with age and peaked in the 80-plus age group (Figure 4).

Overall, the number of documented new cases increases significantly with age. Generally, the assessment of incidence within the Diabetes Surveillance will help predict changes to the risk of developing the disease. Current results indicate a decrease in the incidence of documented type 2 diabetes.²⁴



Figure 4. Incidence of documented diabetes (in %) among adults covered by SHI in 2012 by age and sex. Source: DaTraV data; by Schmidt et al. 25



Prevalence of gestational diabetes

Definition

The indicator Prevalence of gestational diabetes is defined as the proportion of women giving birth in hospital (including stillbirths) in a given year with a diagnosis of gestational diabetes documented in their maternity log.

Data source

Obstetrics quality assurance based on federal-state perinatal statistics. 27, 28

Data quality

Incomplete documentation of gestational diabetes in maternity logs means it is likely that prevalence is being underestimated.

In 2017, around 45,000 pregnant women had gestational diabetes.

Gestational diabetes is a blood glucose disorder first diagnosed during pregnancy. In most women, this form of diabetes disappears postpartum, although it increases the risk of pregnancy complications for both mother and child as well as the risk of the mother developing type 2 diabetes at a later stage.

In 2017, 44,907 out of 761,176 women giving birth in hospital in Germany had documented gestational diabetes (5.9%). Since 2002, this number steadily increased (Figure 5). The prevalence of documented gestational diabetes varies from region to region (Figure 6).

The prevalence of gestational diabetes is potentially increasing due to several factors. On the one hand, the average age of mothers giving birth and the rate of obesity have increased, both of which are risk factors for gestational diabetes. ^{28,44} On the other hand, gestational diabetes guidelines were changed in 2012, and SHI began to cover screening examinations, which may have led to an increase in diagnoses and documentation. Studies based on other data sources show higher estimates of gestational diabetes. ^{29,30} This underscores the need for studies to improve data quality, for example by reviewing possible gaps in documentation.

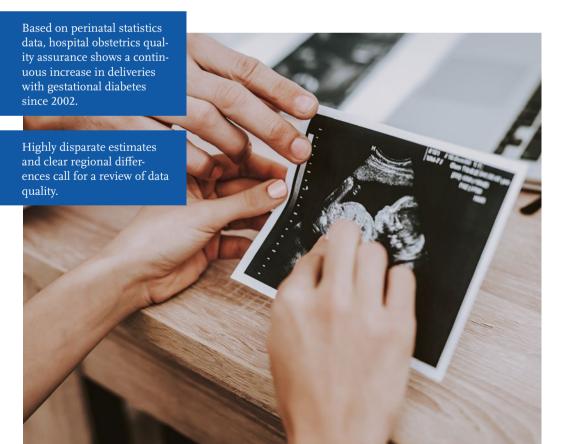
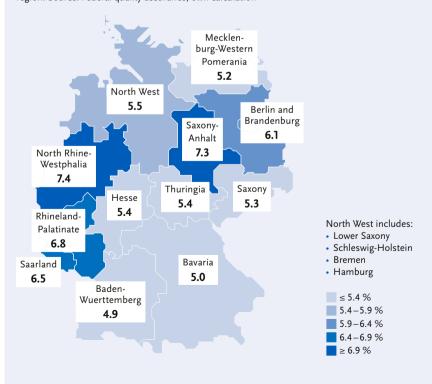






Figure 6. Proportion of women giving birth in hospital in 2017 (in %) who have documented gestational diabetes by region. Source: Federal quality assurance; own calculation



Overweight and obesity

Definition

The WHO⁴⁵ classification scheme defines the indicator Overweight as the proportion of the population with a Body Mass Index (BMI) of $\geq 25.0 \ kg/m^2$ and the indicator Obesity as the proportion of the population with a BMI of $\geq 30.0 \ kg/m^2$. BMI is calculated using measurement data on body weight and height.

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1).

Data quality

RKI interview and examination surveys are based on measurement data and provide representative results for the 18- to 79-year-old resident population of Germany.

Nearly one-quarter of all 18- to 79-year-olds is obese.

Overweight describes a condition in which the weight of a given body is higher than normal relative to its height. Severe overweight is termed obesity. Overweight and obesity are major risk factors for the development of non-communicable diseases such as type 2 diabetes.⁴⁵

In 2010, the prevalence of overweight (including obesity) for the 18- to 79-year-old population was 60.0% (women 53.0%; men 67.1%), while 23.6% of adults (women 23.9%; men 23.3%) were obese (Figure 7). There are twice as many obese people in the low-education group as in the high-education group (Figure 8). When compared with 1998, the prevalence of overweight (including obesity) remained stable for both sexes (Figure 7), while the prevalence of obesity among men increased.

Nearly one-quarter of 18- to 79-year-olds living in Germany is obese. It is vital to prevent any increase in the prevalence of obesity by expanding appropriate measures as per the WHO's Global Action Plan objectives¹⁵ and the German government's 2016 sustainable development strategy.

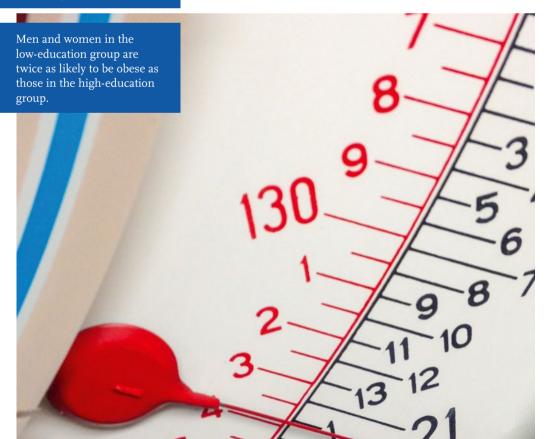


Figure 7. Temporal development of the prevalence of overweight (including obesity) and obesity (in %) in the 18- to 79-year-old population by sex. Source: GNHIES98, DEGS1; by Mensink et al. 46

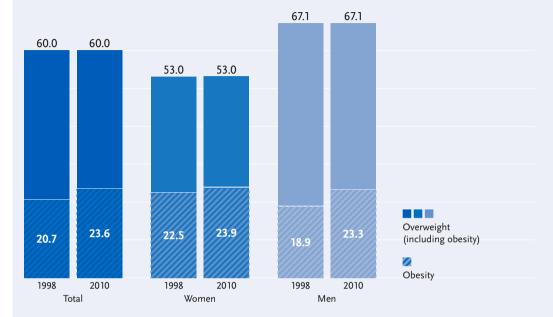
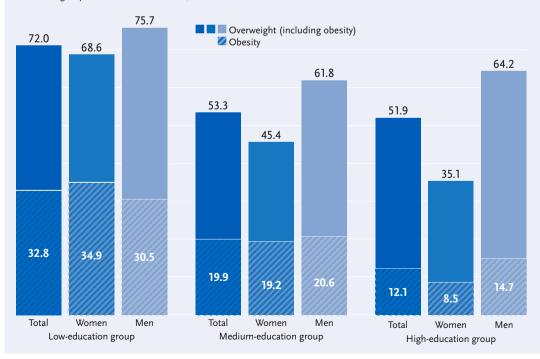


Figure 8. Prevalence of overweight (including obesity) and obesity (in %) in the 18- to 79-year-old population in 2010 by education group and sex. Source: DEGS1; own calculations



Physical inactivity

Definition

The indicator Physical inactivity is defined as the proportion of the population who do not meet WHO⁴⁷ recommendations on moderate-intensity aerobic physical activity (≥ 2.5 hours per week) during leisure time.

Data source

National RKI interview survey (GEDA 2014/2015-EHIS).

Data quality

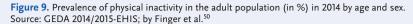
RKI interview surveys provide representative results for the resident population of Germany aged 18-plus.

Over half of all adults do not meet the WHO recommendations of 2.5 hours of moderate-intensity aerobic physiPhysical activity describes any form of movement that increases energy metabolism. This can take place in different areas: as recreation, in the work environment, at home or as movement from one place to another. The indicator used here focusses exclusively on physical activities during leisure time.⁴⁸ Work-related physical activity is not included. Physical inactivity (i.e. failure to meet the recommendations mentioned above) is a major risk factor for the development of non-communicable diseases such as type 2 diabetes.

In 2014, the prevalence of physical inactivity in the adult population was 54.7% (women: 57.4%; men: 52.0%) (Figure 9), with only minor differences between age groups. At an advanced age, physical limitations lead to an increase in inactivity. There are slight differences between federal states: whereas over 60% of the population in Saxony (women: 65.5%; men: 60.2%) and Mecklenburg-Western Pomerania (women: 60.8%; men: 60.6%) were physically inactive, less than 50% were in Bremen (women: 52.4%; men: 42.1%) and Schleswig Holstein (women: 53.7%; men: 45,2%) (Figure 10). In addition, fewer people in the high-education group (44.3%) were physically inactive in their leisure time than those in the low-education group (62.3%) (http://diabsurv.rki.de).

Across all age groups, more than half of all adults in Germany do not meet the WHO recommendation of at least 2.5 hours of aerobic physical activity per week. As a result, it is vital that public health measures promoting physical activity, such as those included in the National Recommendations for Physical Activity and Physical Activity Promotion, be further expanded.⁴⁹





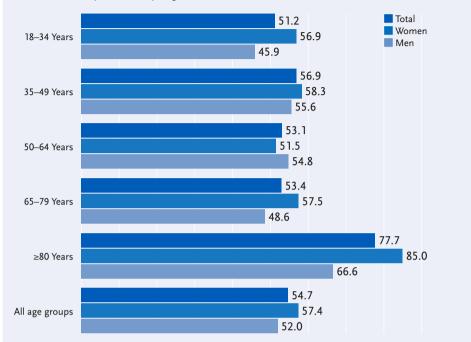
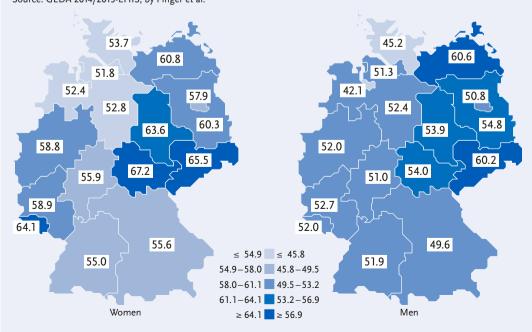


Figure 10. Prevalence of physical inactivity in the adult population (in %) in 2014 by sex and federal state. Source: GEDA 2014/2015-EHIS; by Finger et al. ⁵⁰



Smoking

Definition

The indicator Smoking is defined as the proportion of people who smoke occasionally or daily.⁵¹

Data source

National RKI interview surveys (GESTel03, GEDA 2009, GEDA 2010, GEDA 2012, GEDA 2014/2015-EHIS).³⁵

Data quality

RKI interview surveys provide representative results for the resident German population aged 18-plus.

In 2014, nearly one-quarter of adults in Germany reported that they smoked, women less frequently than men.

Smoking cigarettes and other tobacco products is one of the most significant risk factors for non-communicable diseases, in particular for lung and cardiovascular diseases.⁵¹

In 2014, the prevalence of smoking in the adult population was 23.8% (women: 20.8%; men: 27.0%). The prevalence of smoking is significantly higher for younger and middle-aged people and decreases with age (Figure 11). More people in the low-education (22.9%) and medium-education groups (26.5%) smoke than in the high-education group (16.5%). From a regional perspective, smoking prevalences in Germany are higher in the north than in the south, and higher in the east than in the west. Prevalence is also higher in the federal city-states than in the territorial federal states (http://diabsurv.rki.de). Between 2003 and 2014, the prevalence of smoking among adults decreased (Figure 12).

Despite a decrease in smoking prevalence in Germany in recent years,^{34,35} nearly one-quarter of adults still report that they smoke occasionally or daily. Further efforts to prevent smoking are therefore vital public health measures that can reduce the risk of diabetes and other non-communicable diseases. Such measures should consider new forms of nicotine consumption such as e-cigarettes and (e-)shishas.



Figure 11. Prevalence of smoking in the adult population (in %) in 2014 by age and sex. Source: GEDA 2014/2015-EHIS; by Zeiher et al.⁵¹

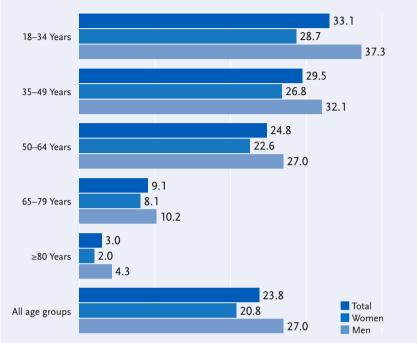
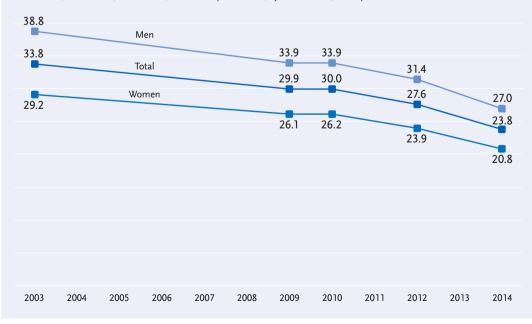


Figure 12. Temporal development of the prevalence of smoking in the adult population (in %) by sex. Source: GESTel03, GEDA 2009, GEDA 2010, GEDA 2012, GEDA 2014/2015-EHIS; by Hoebel et al.³⁴ Lampert et al.³⁵





Background

The latency period between the onset of diabetes and its diagnosis is estimated to be several years.⁵² Some persons with unknown diabetes are already presenting with diabetic complications or cardiovascular co-morbidities by the time they are diagnosed with diabetes.^{53,54} This highlights the importance of early detection and improving treatment for persons with diabetes.

Against this backdrop, nine core indicators and two supplementary indicators or indicator groups were selected for the field of action 2 Improving the early detection and treatment of diabetes. These include the prevalence of known and unknown diabetes, participation rates for checkups and various aspects of diabetes care. The following fact sheets describe five core indicators with available data on the current situation and development over time (Figure 13).

Figure 13. Indicators for the field of action 2.

Core indicators	Supplementary indicators	
► Prevalence of known/documented diabetes	Health check-up	
► Prevalence of unknown diabetes	Patient satisfaction	
DMP participation rate		
Achievement of DMP quality objective		
➤ Quality of type 2 diabetes care: graded HbAlc target		
► Treatment profiles		
► Health-related quality of life		
Screening for gestational diabetes		
Age at diagnosis		

The indicators presented in fact sheets in this issue are marked in colour.

Please note: Results for the indicators of the field of action 2 not included here as well as information on methodology and data sources are available on the Diabetes Surveillance website http://diabsurv.rki.de.

Results at a glance

Different data sources consistently show that there has been a significant increase in the prevalence of known diabetes in Germany since the 1960s.6 The interpretation of overall diabetes development requires the parallel collection of data on cases of known and unknown diabetes. Data collected in RKI interview and examination surveys show an increase in the prevalence of known diabetes to 7.2% in the 18- to 79-year-old population between 1998 and 2010. This increase was proportional to a decrease in the prevalence of unknown diabetes to 2.0% in the same age group, which means that the total prevalence of diabetes remained fairly stable during this period. Inequalities in health across education groups also remained unchanged (fact sheet "Prevalence of known and unknown diabetes"). Prevalence estimations of documented diabetes across all age groups and at a regional level have been enabled by claims data of people covered by SHI (DaTraV data) (fact sheet "Prevalence of documented diabetes"). There are considerable differences in prevalence between federal states, differences which reflect the regional patterns observed in previous epidemiologic analyses. 55, 56 Here, it should be noted that prevalence estimates for documented diabetes based on DaTraV data are generally around 2 percentage points higher than prevalence estimates for known diabetes in epidemiological studies. 6

Up until 2018, people aged 35 and over who were covered by SHI were offered a preventive medical examination (Check-up 35) for diabetes and other chronic diseases once every two years. Zi data show a 48.0% participation rate for the years 2016/2017 (http://diabsurv.rki.de). Since April 2019, people aged 35 and over have been offered a health

check-up (Gesundheits-Check-up) every three years, while 18- to 34-year-olds are offered the same check-up on a one-off basis.⁵⁷ Any decrease in the average age that diabetes is diagnosed could either indicate advances in diabetes screening or other factors such as the earlier onset of diabetes, RKI surveys show that between 1998 and 2010, the average age that diabetes was diagnosed (including gestational diabetes) decreased for women aged 18 to 79 years and remained almost constant for men of the same age (http://diabsurv.rki.de). Moreover, screening for gestational diabetes was introduced in 2012 for pregnant women without manifest diabetes. This aimed to prevent potential pregnancy and birth complications related to elevated blood glucose.58 Estimates from 2014/2015 based on data from state associations of SHI-accredited physicians show that 80.8% of pregnant women had a pre-test or diagnostic test for gestational diabetes.29

Several studies indicate that the introduction of DMPs for type 2 diabetes in 2003 and type 1 diabetes in 2006 has significantly improved the quality of diabetes care. 59,60 In a DMP, a patient's doctor is responsible for monitoring and documenting specific quality objectives, e.g. the attainment of specific blood pressure and HbA1c values or attendance at a structured diabetes self-management program. Detailed analysis of DMP data on type 2 diabetes is available for North Rhine-Westphalia.61 This data shows that between 2010 and 2017, around 90% of patients who participated in a DMP had an HbA1c value of 8.5% or lower. In 2017, stipulated target quotas were met for ten out of 14 quantifiably evaluated DMP quality objectives for type 2 diabetes.⁵⁹ Analyses of DMP data for the region North Rhine-Westphalia also show that regular participation in a DMP increases the chances of meeting defined targets for indicators of quality of type 2 diabetes care compared to irregular participation. 59 If the number of patients registered in DMPs (according to official statistics) is correlated with the documented number of people with type 1 or type 2 diabetes in SHI (based on DaTray data), DMP participation rates are 63% for type 1 diabetes and 58% for type 2 diabetes (http://diabsurv.rki.de). Furthermore, data from national RKI interview and examination surveys show that selected quality of care indicators improved between 1998 and 2010⁶² (http://diabsurv.rki.de). To give an example: the number of persons with type 2 diabetes who met an HbA1c therapy objective graded by age and

cardiovascular co-morbidities increased significantly from 1998, reaching around 80% in 2010 for 45- to 79-year-old women and men (fact sheet "Graded HbA1c target").⁶³

In regard to treatment profiles, RKI surveys indicate that in over 70% of 45- to 79-year-old persons with type 2 diabetes, the impaired glucose metabolism continues to be treated with antidiabetic medication. However, a shift in prescriptions took place between 1998 and 2010, with an increase in the proportion of persons with type 2 diabetes receiving metformin monotherapy, or a combination therapy with insulin and oral antidiabetic agents (fact sheet "Treatment profiles").

Care indicators reliant on patient-reported outcomes have not, to date, been systematically surveyed in practice. RKI survey data show that persons with diabetes regard their health-related quality of life as worse than persons without diabetes. The difference between the two groups is greater for physical components than for mental components of quality of life, and remained almost constant between 1998 and 2010 (fact sheet "Health-related quality of life"). In the context of the Diabetes Surveillance, data collected for the first time on a nationwide level by an RKI telephone survey on the subjective perception of quality of care for persons with diabetes indicated moderate satisfaction⁶⁴ (http://diabsurv.rki.de).

Within the health policy context

Declining rates of unknown diabetes in the context of increasing rates of known diabetes may indicate that early detection has improved. However, in view of the projected rise in the number of people diagnosed with type 2 diabetes in coming decades, diabetes remains one of the most significant non-communicable diseases in Germany. For this reason, it is vital that developments in diabetes be continuously monitored, including those related to sociodemographic and regional differences.

Positive developments in regard to several aspects of quality of care may indicate that ambulatory care has improved. These improvements may, in turn, be linked to the implementation of DMPs for type 1 and type 2 diabetes, as well as to the introduction of national disease management

guidelines (NVL, Nationale VersorgungsLeitlinien) for specific diabetes complications. ⁶⁵ In future, diabetes patients' own assessment of quality of care should be taken into account alongside indicators already established within care and reporting practice. It is also important to agree on objectives for diabetes care at the population level based on the NVL for type 2 diabetes therapy anticipated for 2020.

Next steps for the Diabetes Surveillance at the Robert Koch Institute

- Assess whether care indicators need to be adapted following publication of the new NVL on type 2 diabetes treatment.
- 2. Further development of stratified analyses by consideration of the entire lifespan (including children, adolescents and the very old) and by identification of differences by region, social status and migrant background.
- 3. Differentiation of the diabetes prevalence by diabetes type. For documented diabetes, this will build on previous DaTrav analyses and include medication, 66 as well as continue the co-operation between the Diabetes Surveillance, regional diabetes registries and the Diabetes-Patient-Documentation (DPV, Diabetes-Patienten-Verlaufsdokumentation) 12; for known and unknown diabetes, this will include an extension in biomarker measurements in the next RKI interview and examination survey (gern study, 2020 2022).
- 4. Mapping of the indicator Screening for gestational diabetes following an application for data access filed jointly with a co-operation partner at the National Institute for Quality and Transparency in Healthcare (IQTIG, Institut für Qualität und Transparenz im Gesundheitswesen).

Prevalence of known and unknown diabetes

Definition

The indicator Prevalence of known diabetes is defined as the proportion of people in the population who report they have ever been diagnosed with diabetes by a doctor, or who have a documented current antidiabetic medication. The indicator Prevalence of unknown diabetes is defined as the proportion of people in the population who do not have known diabetes and who currently have an HbA1c value (long-term blood glucose level) of 6.5% or higher.

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1), including data on medication collected automatically.

Data quality

RKI interview and examination surveys provide representative results for the 18- to 79-year-old resident population of Germany. Although the HbA1c threshold used is a guideline-based diagnosis criterion for diabetes, as a single blood glucose parameter it underestimates the prevalence of unknown diabetes in population-based studies. 67

Concomitant data collection on the prevalence of both known and unknown diabetes is the only way to assess the overall prevalence of diabetes. It also allows the proportion of unknown cases of diabetes to be identified, where persons already face an increased risk of diabetes-specific complications and cardiovascular diseases, 54.68 as well as an increased risk of mortality in comparison to persons without diabetes. Figures on the prevalence of known and unknown diabetes are therefore essential for the assessment of disease occurrence and care needs, as well as for the planning of health policy measures.

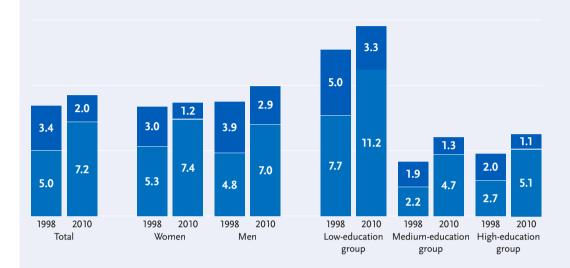
In 2010, the prevalence of known diabetes for the 18- to 79-year-old population was 7.2% (women 7.4%; men 7.0%), which shows an increase from 1998. In comparison, the prevalence of unknown diabetes in 2010 was 2.0% (women 1.2%, men 2.9%), showing a decrease over the same period. The total prevalence was therefore 9.2% (women 8.6%, men 9.9%), which was not significantly different from 1998 (Figure 14). Age-standardisation of the 1998 results to fit the 2010 age structure yields slightly higher prevalences for 1998. However, the differences in prevalence for known and unknown diabetes over time remained statistically significant. The prevalence of both known and unknown diabetes is higher in both sexes in the low-education group than in the medium-education and high-education groups (Figure 14).

The increase in prevalence of known diabetes is due to demographic ageing as well as to other potential influencing factors such as changes in diagnosis criteria^{69,70} and improvements in the treatment of known diabetes.⁶² The proportional decrease in prevalence of unknown diabetes within the same period may be linked to improvements in screening. The persistently high overall prevalence of diabetes and the continuing social differences highlight the need to adapt measures to the needs of particular target groups. In addition, DaTraV data (fact sheet "Prevalence of documented diabetes") enable analyses of regional differences. It should be noted that analyses of DaTraV data provide slightly higher estimates for diagnosed diabetes⁶ than do analyses of population-related survey data, a fact which stems from differences in reference population, age spectrum and data collection⁶.



Figure 14. Temporal development of the prevalence of known and unknown diabetes (in %) for the 18- to 79-year-old population by sex and education group. Source: GNHIES98, DEGS1; by Heidemann et al.³⁷





While the prevalence of known diabetes in the 18- to 79-year-old population increased over time to 7.2%, the prevalence of unknown diabetes decreased to 2.0% in the same period.

The prevalence of known and unknown diabetes is still significantly higher in the low-education group than in the medium-education or high-education groups.



Prevalence of documented diabetes

Definition

The indicator Prevalence of documented diabetes is defined as the proportion of people covered by SHI with either a documented hospital diagnosis of diabetes in at least one calendar quarter, or a verified outpatient diagnosis (E10- E14) in at least two calendar quarters, relative to all people covered by SHI in a given year.

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation.

Documented prevalence for women and men increases steadily up to the 80- to 84-year age group and then decreases. Alongside the prevalences based on RKI population-representative surveys (fact sheet "Prevalence of known and unknown diabetes"), the additional use of DaTraV data enables even greater stratification of the documented prevalence. In particular, people of advanced age are also included, and the results can be depicted by at federal state level.

In 2013, there was a clear increase in prevalence up to the 80-to 84-year-old age group, while values for women in the 35-to 89-year-old age group were consistently lower than for men. In the 40- to 44-year-old age group, the prevalence for women was 2.6% and 3.5% for men. In the 80- to 84-year-old age group, this figure rises to 33.2% for women and 36.3% for men. In the 85- to 89-year-old age group, the value drops to 32.1% for women and 33.5% for men (Figure 15). In 2011, the highest prevalences for both women and men (16.1% and 16.4% respectively) were found in Saxony-Anhalt. Overall, prevalence was highest in the former East German federal states and Saarland (women 12.5%, men 13.7%), and lowest in Schleswig-Holstein (women 8.6%, men 10.3%) and Hamburg (women 7.8%, men 9.5%) (Figure 16).

The documented prevalence according to 5-year age groups initially increases for both sexes before decreasing again at an advanced age. The regional distribution is similar to that of RKI interview surveys and can be partly explained by the different population structures of the federal states.⁵⁵ Further possible causes are regional differences in diabetes risk factors,⁵⁵ in diabetes diagnosis³⁷ and in levels of social deprivation.⁷¹



Figure 15. Prevalence of documented diabetes among adults covered by SHI (in %) in 2013 by age and sex. Source: DaTraV data; by Schmidt et al. ²⁵

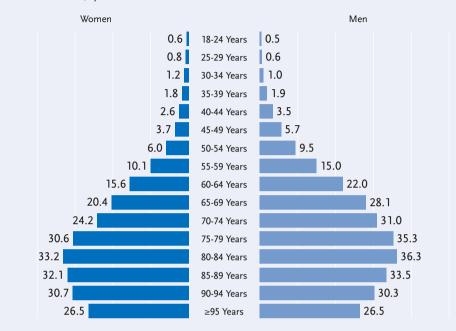
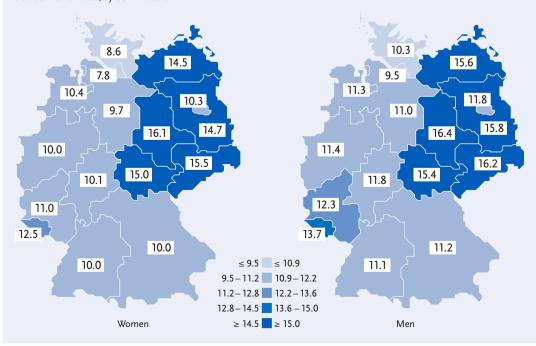


Figure 16. Prevalence of documented diabetes among adults covered by SHI (in %) in 2011 by federal state and sex. Source: DaTraV data; by Schmidt et al. ²⁵



Graded HbA1c target

Definition

The indicator Graded HbA1c target is defined as the proportion of people with known type 2 diabetes who meet the following HbA1c targets allowing for patients' age and diabetes-related comorbidities:^{62,72–75}

- HbA1c in the presence of diabetesspecific complications or cardiovascular comorbidity:
 - up to 7.0% for 18- to 44-year-olds
 - ▶ up to 8.0% for 45- to 79-year-olds
- HbA1c in the absence of diabetes-specific complications and cardiovascular comorbidity:
 - up to 6.5% for 18- to 44-year-olds
 - up to 7.0% for 45- to 64-year-olds
 - up to 7.5% for 65- to 79-year-olds

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1). The indicator Graded HbA1c target is based on data analysis of the 45- to 79-year-old age group.

Data quality

RKI interview and examination surveys provide representative results for the 18- to 79-year-old resident population of Germany.

HbA1c levels indicate the long-term control of blood glucose in people with known diabetes. A lower HbA1c level is associated with a reduced risk of developing microvascular complications. Having said this, intensive therapy to lower blood glucose can also increase the risk of mortality. It should also be noted that HbA1c physiologically increases with age. For this reason, national and international disease management guidelines on the prevention of secondary complications recommend that HbA1c targets take patients' age and diabetes-related comorbidities into account. Such targets may differ from the individual HbA1c targets stipulated in a patient's DMP.

In 2010, 80.7% of 45- to 79-year-olds with type 2 diabetes in Germany met their HbA1c targets (women: 81.4%, men: 80.0%) (Figure 17). No statistically significant differences were found between the low-education (79.7%), medium-education (81.3%) and high-education groups (84.8%) (Figure 18). A higher proportion of older persons with type 2 diabetes met their HbA1c targets than did middle-aged ones (Figure 18). In 2010, HbA1c targets were met more often than in 1998 (Figure 17).

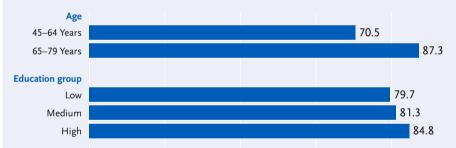
It may be that the marked increase in the number of people with type 2 diabetes meeting their HbA1c targets was due to the introduction of DMPs in 2003, which aimed specifically at improving the quality of care for people with type 2 diabetes. Moreover, the blood glucose thresholds used to diagnose type 2 diabetes were lowered in 1999, i.e. in between the two survey points. This means that the 2010 survey potentially included more persons in an early stage of type 2 diabetes and thus with lower HbA1c levels than the 1998 survey.



Figure 17. Temporal development of the proportion of 45- to 79-year-olds with type 2 diabetes (in %) who met HbAlc targets by sex. Source: GNHIES98, DEGS1; by Du et al., 62 Heidemann et al. 76



Figure 18. Proportion of 45- to 79-year-olds with type 2 diabetes (in %) in 2010 who met HbA1c targets by age and education group. Source: DEGS1; by Du et al., 62 Heidemann et al. 76



Over time, there was a significant increase for both sexes in the proportion of people meeting their HbA1c targets.

Older persons with type 2 diabetes are more likely to meet their HbA1c targets than middle-aged ones.





Treatment profiles

Definition

The indicator group Treatment profiles consists of two indicators:

- Treatment is defined as the proportion of persons with known type 2 diabetes currently receiving one of the following forms of treatment:
 - No treatment (neither lifestyle interventions nor medication)
 - Only lifestyle interventions
 - Antidiabetic medication (with or without lifestyle interventions)
- Medication is defined as the proportion of persons with known type 2 diabetes currently receiving one of the following forms of medication:
 - No medication
 - Metformin monotherapy
 - Other oral antidiabetic agents (apart from metformin monotherapy)
 - Only insulin
 - Insulin and oral antidiabetic agents, including metformin

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1), including data on medication collected automatically. The indicator group Treatment profiles is based on data analysis of the 45- to 79-year-old age group.

Data quality

RKI interview and examination surveys provide representative results for the 18- to 79-year-old resident population of Germany.

One of the treatment objectives in Germany's national disease management guideline (NVL) on type 2 diabetes therapy is to reduce diabetes-related comorbidities and secondary diseases. Controlling blood glucose according to risk profiles and subjective needs therefore plays a key role.^{72,77} Metformin is regarded as the first-line choice of medication when it comes to drug therapy.

In 2010, 17.3% of 45- to 79-year-olds with type 2 diabetes were not receiving treatment, 9.3% received lifestyle interventions only and 73.4% were on medication (Figure 19). Of all persons with type 2 diabetes, 33.6% received metformin monotherapy, 14.6% were on other oral antidiabetic agents, 11.6% received insulin only therapy and 13.6% received a combination therapy of insulin and oral antidiabetic agents (Figure 20). A comparison over time shows that the proportion of persons receiving medication remained almost unchanged (Figure 19). The figures for metformin monotherapy and insulin therapy particularly in combination with oral antidiabetic agents, show an increase over time (Figure 20). While treatment modes for men barely changed, the proportion of women receiving no treatment had increased in 2010.

Over time, there was an increase in the number of persons receiving metformin monotherapy and a combination therapy of oral antidiabetic agents and insulin. At the same time a decrease in the number of persons receiving lifestyle interventions only was observed. Whereas the proportion of those receiving metformin is higher in an AOK analysis,⁷⁷ it is lower in analyses of data from medical practices specialising in diabetes.⁷⁸ The increase in the proportion of women with type 2 diabetes not currently receiving treatment may be due to the nature of the analyses, which did not entirely exclude women with gestational diabetes.

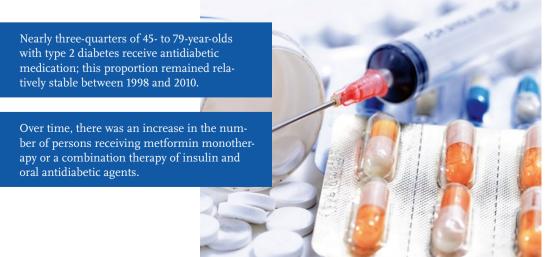


Figure 19. Temporal development of the proportion of 45- to 79-year-olds with type 2 diabetes (in %) by treatment type and sex. Source: GNHIES98, DEGS1; by Du et al.⁶²

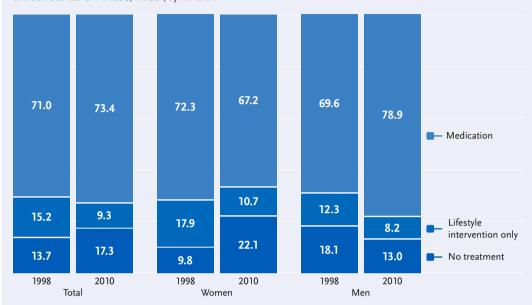
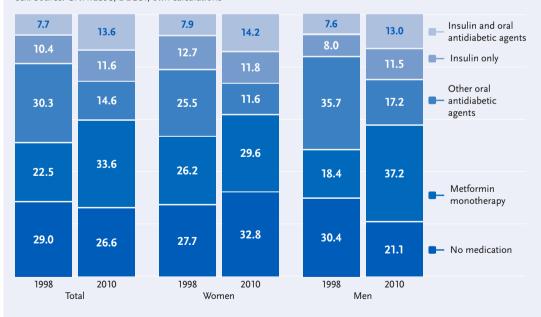


Figure 20. Temporal development of the proportion of 45- to 79-year-olds with type 2 diabetes (in %) by medication and sex. Source: GNHIES98, DEGS1; own calculations



Health-related quality of life

Definition

The indicator Health-related quality of life (HRQoL) describes subjective perception of health regarding physical and mental dimensions as assessed in people diagnosed with diabetes, in comparison with people who have not been diagnosed with diabetes, and is evaluated here using two sum scores based on the Short Form 36 questionnaire (SF-36).⁷⁹ Higher score values indicate better HRQoL than lower values.

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1).

Data quality

RKI interview and examination surveys provide representative results for the 18- to 79-year-old resident population of Germany.

Patients' self-assessment of physical functioning and mental health plays an important role when describing their state of health. For this reason, the national disease management guideline (NVL) on type 2 diabetes therapy includes the therapy objective 'maintaining or restoring quality of life'.⁷²

In 2010, the physical dimension of HRQoL of persons with diabetes was similar for both sexes, while women reported lower values regarding the mental dimension (Figure 21). In contrast to mental HRQoL, physical HRQoL decreases with age (Figure 21) and with lower levels of education (http://diabsurv.rki.de). In 1998 and 2010, persons with diabetes reported a lower physical component score (differences in the medium sum score: 1998: ~ 4.5; 2010: ~ 4.3) than persons without diabetes. Differences in the mental component score were smaller (1998: ~ 1.6; 2010: ~ 1.7) (Figure 22).

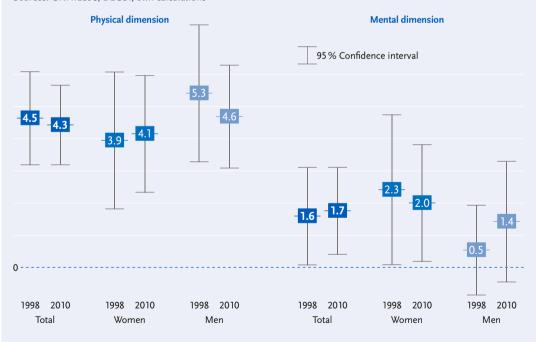
Health-related quality of life for people with diabetes in Germany, particularly in regard to the physical dimension, has remained largely unchanged over time and is consistently lower than that of people without diabetes of the same age. For this reason, it makes sense to implement targeted measures to improve diabetes patients' quality of life.

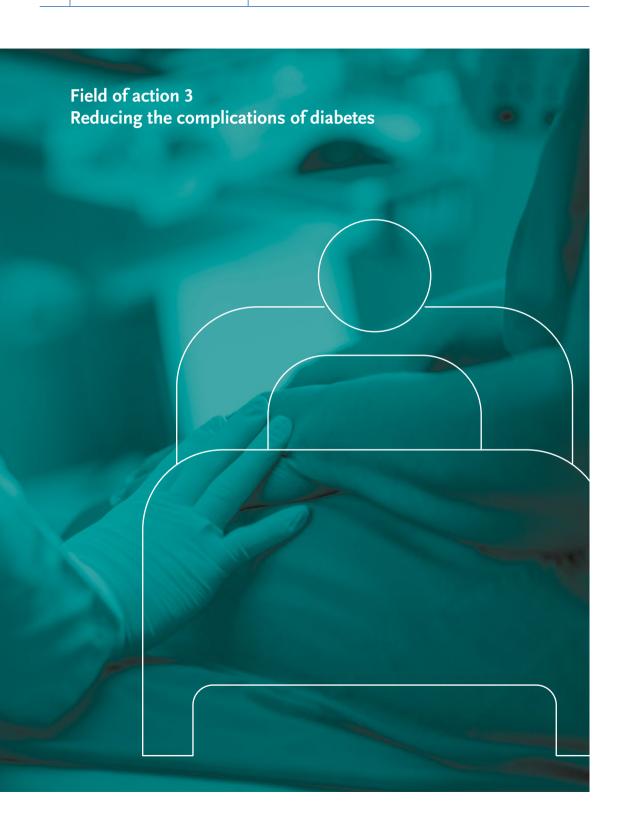


Figure 21. Medium sum score for the physical and mental component of HRQoL for 18- to 79-year-olds with diabetes in 2010 by sex and age. Source: DEGS1; by Ellert et al.⁷⁹



Figure 22. Temporal development of age-adjusted differences in the average sum score for the physical and mental component of HRQoL of 18- to 79-year-olds without diabetes compared with persons with diabetes, total and by sex. Sources: GNHIES98, DEGS1; own calculations





Background

Part of the total disease burden associated with diabetes is due to its comorbidities and secondary diseases. Over the long term, elevated blood glucose levels increase the risk of diabetes-specific secondary diseases such as diabetic kidney disease (nephropathy), eye disease (retinopathy) and nerve disease (neuropathy). ⁸⁰ In addition, adult diabetes patients, in particular women, face a significantly higher risk of cardiovascular diseases than non-diabetes patients of the same age. This holds particularly true for cardiovascular events such as heart

attacks and strokes, as well as for chronic coronary heart disease (CHD).⁶³ Additionally, depressions occur more frequently together with diabetes.^{81,82}

Against this backdrop, the field of action 3 Reducing the complications of diabetes consists of nine core indicators and two supplementary indicators that capture comorbidities and secondary diseases (Figure 23). At the time of writing this report, for six of these core indicators a conclusive national data basis with the possibility of establishing time series was available. These six core indicators are presented below. Currently, the data basis only allows a limited representation of developments over time and focuses on prevalence, i.e. the presence of comorbidities or secondary diseases in persons with diabetes.

Figure 23. Indicators for the field of action 3

Core indicators	Supplementary indicators
► Depressive symptoms	Risk of a cardiovascular event
Cardiovascular diseases	Pregnancy complications
Diabetic retinopathy	
► Diabetic kidney diseases	
Renal replacement therapy	
► Diabetic polyneuropathy	
► Diabetic foot syndrome	
► Diabetes-related amputations	
Frequency of severe hypoglycaemia	

The indicators presented in fact sheets in this issue are marked in colour.

Please note: The results for the other field of action 3 indicators as well as information on methodology and data sources are available on the Diabetes Surveillance website http://diabsurv.rki.de.

Results at a glance

For the first time, and with the aim of establishing time series, DaTraV data on all people covered by SHI were used to describe the prevalence of microvascular secondary diseases related to diabetes. This involved calculating the proportion of documented complications among insured persons with documented diabetes (fact sheet "Prevalence of documented diabetes"). There is currently a delay in data availability of several years, which means that analyses refer to the 2013 reporting year. Diabetic kidney disease, which is defined as

chronic kidney disease in persons with diabetes, is the most frequent microvascular secondary disease at 15.1% (fact sheet "<u>Diabetic kidney disease</u>"). This figure is comparable to the DMP findings for type 2 diabetes in North Rhine-Westphalia, where detailed analyses of secondary diseases and comorbidities are available.⁶¹ However, these figures are lower than those reported in studies^{62,83} that assess renal function using laboratory parameters, thereby taking undetected morbidity into account. Diabetic polyneuropathy was documented for 13.5% of adults with diabetes and diabetic foot syndrome for 6.2% (fact sheet "<u>Diabetic polyneuropathy</u>" and "<u>Diabetic foot syndrome</u>"). Inconsistent

standards in diagnosis and documentation make comparisons with other data sources difficult. In the case of diabetic polyneuropathy, DMP data and other studies, for the most part, offer higher estimates; for diabetic foot syndrome these estimates vary between 2% and 10%. 61.84–87 Secondary diseases affect men far more often than women, and their frequency increases significantly with age. The latter is to be expected, as the main risk factor for secondary diseases is the length of time a person has diabetes, which correlates with age. 88 DaTraV findings for diabetic retinopathy differ considerably from previous estimates, 89,90 and are not included in the present study for that reason. A deeper exploratory analysis of data is needed.

A continuation of time series from previous analyses of DRG statistics on diabetes-related major amputations shows a declining trend, 91,92 although this does not continue for men between 2016 and 2017 (fact sheet "Diabetes-related amputations"). Only limited data is available on the late sequelae loss of sight and dialysis. A study from Baden-Wuerttemberg based on secondary data on disability allowances for the blind shows a reduction in the incidence of loss of sight.93 According to Federal Health Reporting figures, the number of dialysis patients in Germany has remained constant over the past few years.94 A regional study from North Rhine-Westphalia shows the incidence of people having diabetes-related renal replacement therapy did not change between 2002 and 2008.95 These data are broadly consistent with DMP data, which indicate that figures for all longterm effects are in decline.96,97

According to RKI health survey data, over one third (37.1%) of adults with diabetes in 2010 presented with cardiovascular comorbidities, defined as self-reported medical diagnoses of coronary heart disease, heart failure or stroke (fact sheet "Cardiovascular diseases"). In comparison with 1998, these figures decreased only for women. The KORA study from the Augsburg region also shows that the incidence of heart attacks declined among women with diabetes but not among men.98 Since a reduction in the number of cases of cardiovascular disease can also be observed among people without diabetes, the chance of developing cardiovascular disease remains more than twice as high for people with diabetes than for people without diabetes. Estimations of cardiovascular risk for adults with diabetes who do not have a physician-diagnosed cardiovascular disease (women and men together) show a clear decline between 1998 and 2010⁶² (http://diabsurv.rki.de).

Results from the GEDA 2014/2015-EHIS RKI health survey indicate that symptoms of depression occur twice as often in adults with diabetes compared to adults without diabetes (fact sheet "Depressive symptoms"). As in the general population, the prevalence of depression is higher in women with diabetes than in their male counterparts. Overall, 15.4% of adults with diabetes report symptoms of depression, with the highest proportion in the 80-plus age group.

Another complication of diabetes is hypogly-caemia, which can develop as a result of medication to lower blood glucose. According to RKI health surveys, 2.5% of persons with diabetes report having had severe hypoglycaemia requiring outpatient or inpatient treatment (http://diabsurv.rki.de). It is not possible to make detailed estimates from RKI surveys due to the moderate number of cases. It is, however, possible to make detailed estimates based on the DPV registry, in particular for type 1 diabetes.⁹⁹ In future, these data will be integrated into the Diabetes Surveillance.

There was no federal data with the potential to be used in a time series available at the time of writing the present report for the supplementary indicator Pregnancy complications. Regional analyses of perinatal statistics from Bavaria show an increased risk of premature births, higher birth weight and malformations for mothers with gestational diabetes.¹⁰⁰

Within the health policy context

As early as 1989, the St. Vincent Declaration aimed to reduce the long-term microvascular complications of diabetes. ¹⁰¹ One of the five key goals was to reduce the risk of adults with diabetes developing coronary heart disease (incidence and mortality) to the same level as people of the same age without diabetes. Diabetes-specific, long-term microvascular complications are currently in decline in Germany, a development which should be followed closely. Analyses of comorbidities and secondary diseases should always be analysed within treatment contexts. In regard to cardiovascular risks,

the shared causes and risk factors of diabetes and cardiovascular diseases must not be forgotten. ¹⁰² In contrast to diabetes-specific microvascular complications, cardiovascular prevention measures must consider cardiovascular risks in the context of different life phases and social situations. ¹⁰³

For the future, it is crucial that insurance data for analysing the prevalence and incidence of long-term microvascular complications and cardiovascular comorbidities are regularly made available. Differences in temporal developments by sex, region and/or social deprivation are of huge importance for analysing the need for action and for evaluating health policy measures. In this respect, RKI surveys make a vital contribution toward developing time series for depressive symptoms and providing estimates of the risk of cardiovascular events faced by adults with diabetes.

Next steps for the Diabetes Surveillance at the Robert Koch Institute

- Deeper analyses of SHI data to further develop criteria to define diabetes-specific, secondary diseases (such as renal replacement therapy) and cardiovascular comorbidities. To achieve this, both incidence and prevalence of complications among adults with diabetes should be measured.
- **2.** Ensuring the availability of SHI data for recurrent analyses of indicators from field of action 3 that consider prevalence and incidence in people with and without diabetes. Furthermore, the possibility of differentiating according to diabetes type should be tested.
- **3.** In co-operation with the DPV registry, establishment of time series for complications (in particular severe hypoglycaemias) that differentiate between type 2 diabetes and type 1 diabetes.
- 4. For the indicator Pregnancy complications, an application has been filed with the IQTIG to analyse the obstetrics quality assurance data set. This should enable estimates for the whole of Germany⁹² in addition to the regional estimates already available.¹⁰⁰

Depressive symptoms

Definition

The indicator Depressive symptoms is assessed by the Patient Health Questionnaire-8 (PHQ-8). It is defined as the proportion of people with known diabetes (12-month prevalence) compared to those without diabetes who have had depressive symptoms in the previous two weeks (PHQ-8 sum $score \ge 10$). ¹⁰⁴

Data source

National RKI interview survey (GEDA 2014/2015-EHIS).

Data quality

RKI interview surveys provide representative results for the resident population of Germany aged 18-plus.

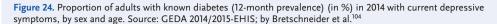
Depression is one of the most common mental illnesses. It is linked to a high individual and social burden of disease, ¹⁰⁵ and is regarded as one of the key comorbidities of diabetes. Patients with diagnosed diabetes and comorbid depression are less likely to comply with their treatment regimes. ¹⁰⁶

In 2014, 15.4% of adults with known diabetes in the past 12 months in Germany presented with current depressive symptoms (women: 19.1%; men 12.3%), with the highest proportion found in the 80-plus age group. The figures for women are higher than for men across all age groups (Figure 24). Proportions are lowest in the central-eastern region of Germany (6.4%) and highest in the northeast (20.1%) (http://diabsurv.rki.de). Adjusted for age, adults with diabetes are far more likely to report current depressive symptoms than those of a similar age without diabetes (total odds ratio: 2.20; women: 2.47; men: 2.06) (Figure 25).

One in seven adults with known diabetes in Germany exhibits current symptoms of depression. Depressive symptoms are far more common in adults with diabetes than in adults without diabetes. For this reason, the treatment of diabetes requires a particular focus on depressive symptoms.

Around 15% of adults with diabetes reported current depressive symptoms in 2014.





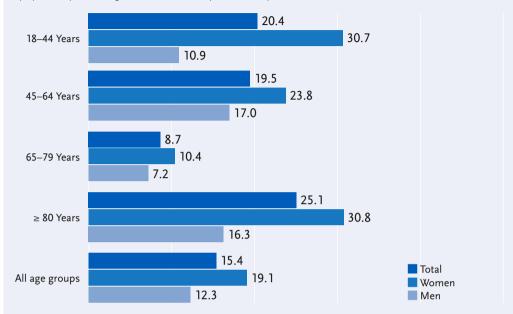
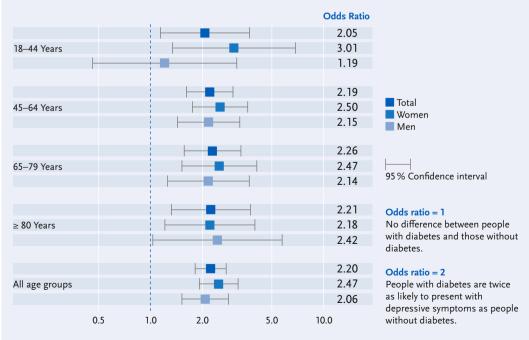


Figure 25. Odds ratio (with 95% confidence interval) for current depressive symptoms in adults with known diabetes (12-month prevalence) compared with adults without diabetes in 2014, by sex (age-adjusted) and age. Source: GEDA 2014/2015-EHIS; own calculations







Cardiovascular diseases

Definition

The indicator group Cardiovascular diseases refers to selected cardiovascular comorbidities in persons with type 2 diabetes: namely coronary heart disease (CHD), heart failure and stroke.

Data source

National RKI interview and examination surveys (GNHIES98, DEGS1), including data on medication collected automatically.

Data quality

RKI interview and examination surveys provide representative results for the 18- to 79-year-old population of Germany. The indicator group Cardiovascular diseases is based on self-reported data on ever physician diagnosed cardiovascular diseases, which was collected completely for the 45- to 79-year age group. 107, 108

People with diabetes have a greater risk of developing cardiovascular comorbidities, which contribute in turn to an increase in mortality.¹⁰⁹

37.1% of adults with type 2 diabetes have cardiovascular diseases, a proportion which is significantly lower for women (30.6%) than for men (42.8%). The difference between the sexes is especially pronounced in the 45- to 64-year-old age group (Figure 26). Between 1998 and 2010, the number of adults with type 2 diabetes presenting with cardiovascular comorbidities fell from 42.5% to 37.1%. This reduction is only statistically significant for women. After adjusting for age, both men and women with type 2 diabetes were twice as likely to present with cardiovascular comorbidities as their counterparts without diabetes in 2010 (Figure 27).

National RKI surveys on the proportion of persons with diabetes presenting with cardiovascular comorbidities and on the possible differences between the sexes should be closely monitored. Analysis of possible differences in the temporal development of cardiovascular comorbidities according to sex also requires incidence data, which is so far only available at a regional level and only for heart attacks. 98 Recurrent analyses of SHI data would be extremely valuable in this respect and should be implemented for this purpose.

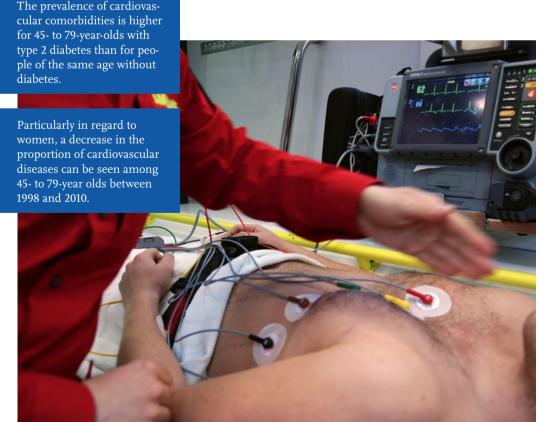


Figure 26. Proportion of cardiovascular diseases among 45- to 79-year-olds with type 2 diabetes (in %) in 2010, by age and sex. Source: DEGS1; own calculations

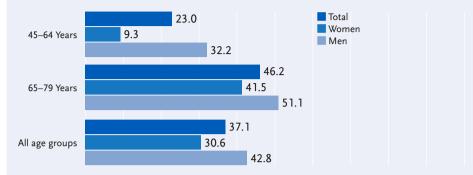
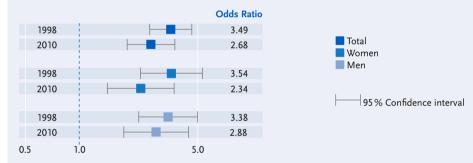


Figure 27. Temporal development of age-adjusted odds ratios (with 95% confidence interval) for cardiovascular diseases in 45- to 79-year-olds with diabetes compared with people without diabetes. Source: GNHIES98, DEGS1; own calculations



Odds ratio = 1

No difference between people with diabetes and those without diabetes.

Odds ratio = 2

People with diabetes are twice as likely to have cardiovascular diseases as people without diabetes.





Diabetic kidney disease

Definition

The indicator Diabetic kidney disease is defined as the proportion of persons with diabetes (fact sheet "Prevalence of documented diabetes") who also present with documented chronic kidney disease (N18.-).

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation.

In 2013, 15.1% of adults with diabetes had documented chronic kidney disease.

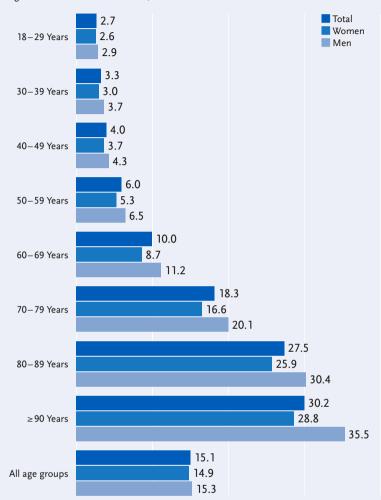
Inadequate control of blood glucose levels can lead to inflammation and damage of the small blood vessels in the kidneys. These changes are termed diabetic nephropathy and are diagnosed by histological examination of kidney tissue. 110 Diabetic nephropathy can cause chronic kidney disease, which has several causes apart from diabetes and therefore reflects a broader definition. Hypertension, in particular, is a common comorbidity of diabetes that increases the risk of chronic kidney disease. Chronic kidney disease is defined in the national disease management guidelines (NVL) as a reduction in the glomerular filtration rate (GFR). 110 In Germany, there are only selective national estimates on kidney function among patients with diabetes, as well as regional time series from DMPs in North Rhine-Westphalia. With this in mind, the proportion of people with chronic kidney disease has been determined for the first time using claims data from all the people with diabetes covered by SHI.

In 2013, 15.1% of adults with diabetes presented with documented chronic kidney disease (women: 14.9%; men: 15.3%). This figure increases markedly with age and peaks at 30.2% in the 90-plus age group (women: 28.8%; men: 35.5%) (Figure 28).

DaTraV data indicate that one in seven people has impaired kidney function, a figure comparable with DMP data for type 2 diabetes in North Rhine-Westphalia.⁶¹ Higher figures are indicated by analyses from RKI studies and DPV registry studies that use laboratory values to estimate kidney function.^{62,83} The higher figures in these studies can be partially explained by the inclusion of people with previously undetected chronic kidney disease. Unlike data from studies, DaTraV data enable a regionalised, time series analysis of chronic kidney disease in patients with diabetes.



Figure 28. Proportion of adults with diabetes covered by SHI (in %) with documented chronic kidney disease in 2013, by age and sex. Source: DaTraV data, own calculations





Diabetic polyneuropathy

Definition

The indicator Diabetic polyneuropathy is defined as the proportion of persons with diabetes (fact sheet "Prevalence of documented diabetes") with documented diabetic polyneuropathy (G63.2).

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation.

13.5 % of adults with diabetes have documented diabetic polyneuropathy.

The proportion of people with diabetes and documented diabetic polyneuropathy increases with age and peaks in the 80- to- 89-year age group.

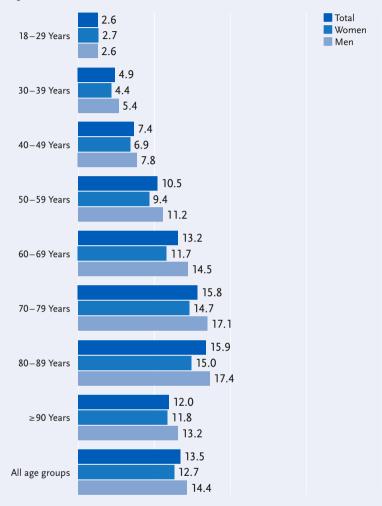
Over time, elevated blood glucose levels can damage both the autonomic and the somatic nerves. The most common form of nerve damage is distal, i.e. peripheral sensorimotor polyneuropathy that increases the risk of developing diabetic foot syndrome. The symptoms of polyneuropathy are diverse and require in-depth clinical examination with the subjective perceptions of patients taken into account. Differences in diagnostic criteria, survey methods and study populations mean that estimates of the frequency of diabetic polyneuropathy vary considerably between studies. The only data regularly available for analysis are the DMP data from North Rhine-Westphalia. For this reason, the proportion of people with diabetic polyneuropathy was calculated using claims data from all the people covered by SHI.

In 2013, 13.5% of adults with diabetes had documented diabetic polyneuropathy (women: 12.7%; men: 14.4%). This figure increases with age and peaks at 15.9% in the 80- to- 89-year age group (women: 15.0%; men 17.4%) (Figure 29).

Differences in documentation and diagnosis standards make comparisons between different studies and data sources difficult. According to DMP data for type 2 diabetes in North Rhine-Westphalia, the proportion of people with diabetic neuropathy is significantly higher⁶¹ than in the analysis of DaTraV data presented here. Differences are particularly evident in the higher age groups, where the analysis of DaTraV data may have underestimated the proportion. Most other studies also indicate a larger proportion of people with polyneuropathy.^{84–86} To increase comparability, simplified and practicable recommendations and diagnosis standards are urgently needed. In 2011, it became mandatory for doctors to document diabetic foot syndrome when prescribing podiatric treatments.¹¹² This may have contributed to a rise in the documentation of polyneuropathy.



Figure 29. Proportion of adults with diabetes covered by SHI (in %) with documented diabetic polyneuropathy in 2013, by age and sex. Source: DaTraV data, own calculations



Diabetic foot syndrome

Definition

The indicator Diabetic foot syndrome is defined as the proportion of persons with diabetes (fact sheet "Prevalence of documented diabetes") with documented diabetic foot syndrome (E10.74-14.74 / E10.75-14.75).

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation.

6.2% of adults with diabetes have a documented diabetic foot syndrome.

Since 2011, it has been mandatory for doctors to document diabetic foot syndrome when prescribing podiatric treatments which may have contributed to an increase in documentation.

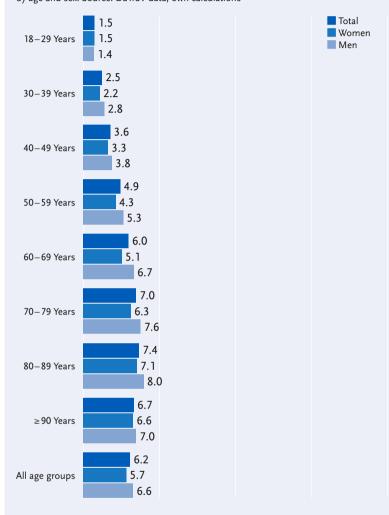
Diabetes can lead to the development of diabetic foot syndrome. Risk factors include polyneuropathy, occlusive peripheral arterial disease or a combination of both. These can lead to injuries and/or wounds on the feet that go unnoticed and which are characteristic of diabetic foot syndrome. 113 Amputation may be necessary if conservative treatment of infection is insufficient. Several classifications are available for diagnosis. 114 Different survey methods have produced heterogeneous data and, with the exception of DMP data from North Rhine-Westphalia, there are no available analyses of developments over time. The proportion of people with diabetic foot syndrome was therefore calculated using claims data from all the people covered by SHI.

In 2013, 6.2% of adults with diabetes had documented diabetic foot syndrome (women: 5.7%; men: 6.6%). This figure increases with age and peaks at 7.4% in the 80- to-89-year age group (women: 7:1%; men 8.0%) (Figure 30).

As is the case with diabetic polyneuropathy, varying documentation and diagnosis standards make it difficult to compare data sources. DMP data on type 2 diabetes in North Rhine-Westphalia put the proportion of patients with diabetic foot syndrome slightly higher. Once again, variance is most apparent in the older age groups.⁶¹ Other studies report prevalences of between 2% and 10%.84,85,87 Since 2011, it has been mandatory for doctors to document diabetic foot syndrome when prescribing podiatric treatments. 112 This may have contributed to an increase in documentation, a trend which can also be observed from DMP data.96



Figure 30. Proportion of adults with diabetes covered by SHI (in %) with documented diabetic foot syndrome in 2013, by age and sex. Source: DaTraV data, own calculations



Diabetes-related amputations

Definition

The indicator Diabetes-related amputations is defined as the number of amputations of the lower limb above the ankle (major amputations) per 100,000 residents (in patients aged 15 years and over) per year.

Data source

Diagnosis-Related Groups (DRG) statistics that include all inpatient cases in Germany.

Data quality

Complete record of all inpatient cases, although not at the individual level, meaning it is possible to have several cases for one patient. Data quality depends on coding practices and other aspects of documentation.

The rate of diabetes-related amputations declined between 2015 and 2017.

In contrast to men, rates for women show a steady decline. Over time, diabetes can lead to vascular disorders and nerve damage in the extremities. Late or inadequate treatment for conditions such as diabetic foot syndrome can necessitate amputation of the lower limb. This indicator is also part of the biennial Health at a Glance report from the Organisation for Economic Cooperation and Development (OECD).¹¹⁵

Between 2015 and 2017, major amputation rates related to diabetes per 100,000 residents decreased from 11.3 to 11.0 (Figure 31). During this period, rates for women dropped significantly from 7.1 to 6.2 (Figure 31). Rates for men are twice as high as rates for women, falling slightly between 2015 and 2016 (15.7 to 15.4) and then rising again in 2017 (15.9) (Figure 31). Significantly higher rates are found among diabetes patients in Thuringia, Saxony-Anhalt and Bremen (13.0, 10.4 and 10.3 for women and 26.6, 29.6 and 18.0 for men per 100,000 residents) than among diabetes patients in Baden-Wuerttemberg (women: 4.6; men: 12.4), Hesse (women: 4.6; men: 13.7) and Hamburg (women: 3.5; men: 9.6) (Figure 32).

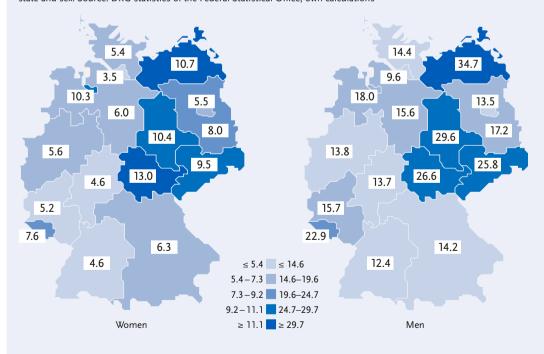
A review of the literature reveals a decrease in diabetes-related major amputation rates for both sexes between 2005 and 2016. 91, 92,116 This trend continues only for women in 2017. There are regional differences in diabetes-related amputations for both sexes that correspond to diabetes prevalence (fact sheet "Prevalence of documented diabetes"). Differences in amputations persist even after age standardisation. 117 Analyses of data on toe (minor) amputations show little or no change for women while the numbers for men significantly increase. 92 DMP data for type 2 diabetes in North Rhine-Westphalia indicate a negative trend for amputations, although it is not possible to distinguish between major and minor diabetes-related amputations. 96,97

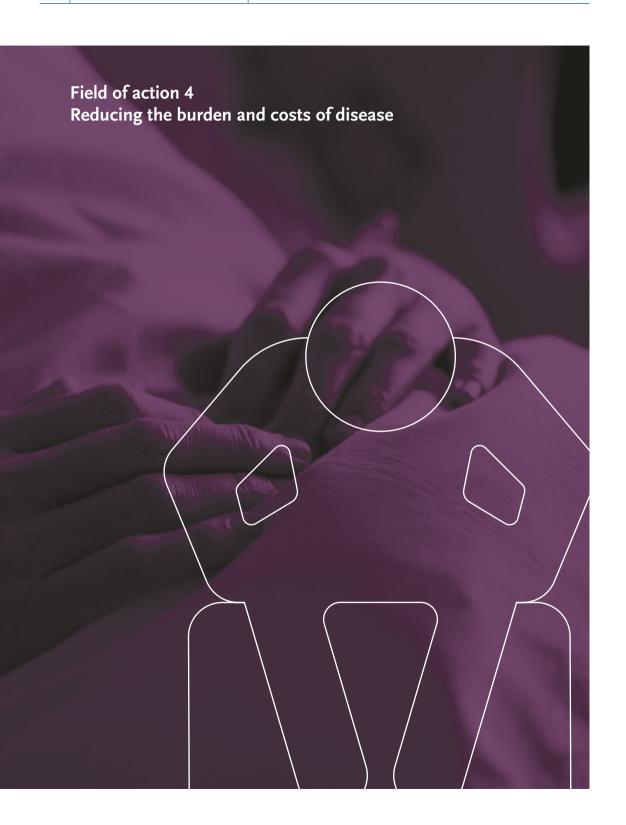


Figure 31. Temporal development of the number of major amputations related to diabetes per 100,000 residents aged 15 and over, by sex. Source: DRG statistics of the Federal Statistical Office; Schmidt et al. ¹¹⁶



Figure 32. Number of major amputations related to diabetes in 2017 per 100,000 residents aged 15 and over, by federal state and sex. Source: DRG statistics of the Federal Statistical Office; own calculations





Background

Diabetes is one of the most common non-communicable diseases and is related to a high burden of disease for both the individual and society. At the individual level, the burden of disease is expressed in loss of quality of life, income, life expectancy and healthy life years. At the level of society, the overall burden of diabetes is measured in various ways, including health care and social services accessed by diabetes patients, direct costs associ-

ated with diabetes, and differences in mortality and healthy life expectancy between people with and without diabetes.

For the field of action 4 Reducing the burden and costs of disease from the Diabetes Surveillance, six core indicators were selected along with two supplementary indicators (Figure 33). The current data availability enables assessment of five of these indicators; these are presented in the following fact sheets. In future, continuous analyses will be conducted, i.e. recurrent analyses that are comparable over time.

Figure 33. Indicators from the field of action 4.

Core indicators	Supplementary indicators
► Direct costs	Years lived with disability (YLD)
► Ambulatory care-sensitive hospitalisations	Disability-adjusted life years (DALYs)
Reduced earning capacity pension	
► Mortality	
Years of life lost (YLL)	
► Healthy life years (HLY)	

The indicators presented in fact sheets in this issue are marked in colour.

Please note: The results for the other indicators from field of action 4 as well as information on methodology and data sources are available on the Diabetes Surveillance website http://diabsurv.rki.de.

Results at a glance

According to calculations of the cost of illness by the Federal Statistical Office, the direct costs of diabetes totalled EUR 7.4 billion in 2015 (fact sheet "Direct costs"). Particularly heavy costs are incurred by society for the 65- to-79-year age group, a fact which reflects the exceptionally high prevalence of diabetes within this group. Across all age groups, costs are consistently lower for women than for men. Pensions owing to a reduced earning capacity involve both the direct cost of the pension itself and indirect costs to the economy due to loss of productivity. A declining trend can be seen in regard to diabetes-related pensions due to reduced earning capacity, with clear regional differences linked to the prevalence of diabetes in individual federal states (fact sheet "Reduced earning capacity pension"). Clear regional differences related to diabetes prevalence are also evident in the number of hospitalisations with a main diagnosis of diabetes (fact sheet "Ambulatory care-sensitive hospitalisations"). Over time, hospitalisations with a main diagnosis of diabetes decreased for both sexes, while rates for women, which were already lower than for men, fell more sharply than for their male counterparts.

A comparison between the mortality of the population with diabetes and without diabetes is made by calculating the ratio between the mortality rates of both groups according to age and sex (relative risk of mortality or excess mortality). The Excess mortality (fact sheet "Mortality") for the year 2014 was calculated using DaTraV data. The mortality rate for people aged 30 and over with documented diabetes was higher by a factor of 1.54 than for people without documented diabetes. Women had similar levels of excess mortality to men (1.52 versus 1.56), while excess mortality declined significantly across the age groups.

Diabetes prevalence, functional impairment and excess mortality by age and sex are considered when calculating the remaining healthy life years (HLY). An increase in life expectancy raises the importance of years of life free from functional limitations for both the individual and for society. On average, the healthy life expectancy of people with diabetes aged 30 and over is up to 12 years shorter than for people without diabetes. These differences are greatest in the younger age groups. The disparities between the HLY of people with and without diabetes converge with increasing age, although they are more pronounced among women aged between 40 and 80 years than among men (fact sheet "Healthy life years").

Years of life lost (YLL), Years lived with disability (YLD) and the sum of these, Disability-adjusted life years (DALY), are key factors when calculating the burden of disease. ¹¹⁹ These parameters will be calculated at national level in the RKI research project Burden 2020, and the results then integrated into the Diabetes Surveillance. ¹²⁰

Within the health policy context

Calculations of the cost of illness by the Federal Statistical Office do not take comorbidities and secondary diseases into account. As a result, their estimates are considerably lower than those which take all the care received by insured persons with a main or secondary diagnosis of diabetes into account.121 The indicator Ambulatory care-sensitive hospitalisations is based on the assumption that hospitalisations for diabetes and some other chronic diseases can be avoided by providing adequate ambulatory care.91 The indicator is defined according to specifications from the OECD, which publishes an international comparison of this indicator every two years together with other indicators for quality of ambulatory care. 115 Estimation of the excess mortality of adults with diabetes in Germany is also enabled by findings from the population-based mortality follow-up of participants from the German National Health Interview and Examination Survey 1998.118 These findings are highly congruent with the results based on all people insured by SHI presented here. Likewise, the convergence of mortality rates at an advanced age can also be found for adults with and without diabetes.118 Taken as a whole, DaTraV data allows observation of diabetes-related excess mortality via the establishment of time series and additionally the

opportunity of regional analyses. However, estimation of excess mortality due to unknown diabetes must be based on data from health examination surveys, especially as results, to date, indicate this is even greater in Germany than excess mortality due to diagnosed diabetes. ^{118,122}

Results on pensions due to reduced earning capacity and the rate of ambulatory care-sensitive hospitalisations indicate significant regional differences when it comes to diabetes. In-depth analyses are needed to clarify links between the burden of disease and quality of care. The Diabetes Surveillance in Germany can contribute in this respect by providing more regional analyses. Type 2 diabetes and other non-communicable diseases share decisive influencing factors, including social conditions such as changes in life expectancy, socioeconomic developments and advances in medicine. For diabetes, as well as for other non-communicable diseases, a form of surveillance that takes risk factors, morbidity rate, effects of disease and aspects of treatment into account is therefore essential.

Next steps for the Diabetes Surveillance at the Robert Koch Institute

- **1.** Expand regional analyses and establish or continue time series for the indicators.
- 2. Fill data gaps for the burden of disease indicators in collaboration with national burden of disease calculations (Burden 2020) and in co-operation with the Global Burden of Disease (GBD) study.^{119,120}
- **3.** Further develop methods to link data sources, particularly data from epidemiological studies and SHI data, for analyses and projections that also include unknown diabetes.

Direct costs

Definition

The indicator Direct costs is defined as the proportion of total health care expenditure related to diabetes care. Direct costs include the cost of outpatient and inpatient treatment, rehabilitation and medication.

Data source

Calculations of the cost of illness by the Federal Statistical Office. Starting with total health expenditure, costs are allocated to sectors and then to individual diseases using diagnoses (top-down approach).

Data quality

Cost of illness calculations by the Federal Statistical Office provide data on the costs of all diseases in Germany. Differences in data collection, e.g. on billing and modes of payment, lead to variations in diagnostic density and quality of data sources.

Data on the direct treatment costs of diabetes are key for planning diabetes care.

Direct costs for persons with diabetes were estimated at EUR 7.4 billion for 2015 (women: EUR 3.3 billion; men: EUR 4.0 billion) (Figure 34). This equates to 2.2% of the total direct costs of all diseases (women: 1.8%; men: 2.7%) (Figure 35). Both the direct costs of diabetes, as well as their proportion in relation to the direct costs of all diseases, are highest in the 45- to- 64-year (2.4%) and 65-to- 84-year age groups (3.1%) (Figures 34 and 35).

The direct costs of diabetes in 2015 were estimated by the Federal Statistical Office at EUR 7.4 billion. 123 With comorbidities and secondary diseases taken into account, estimates based on 2009 SHI data calculate that diabetes patients incurred at least EUR 21 billion more additional costs than people without diabetes. 121,124

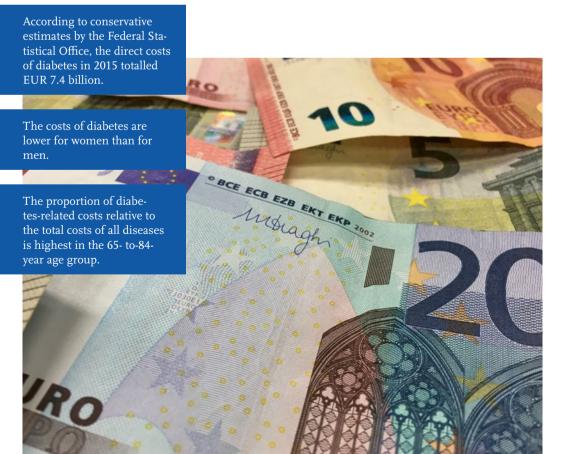


Figure 34. Direct costs of diabetes in billion EUR in 2015, by age and sex. Source: Cost of illness calculations of the Federal Statistical Office¹²³

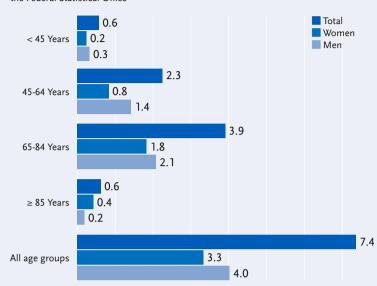
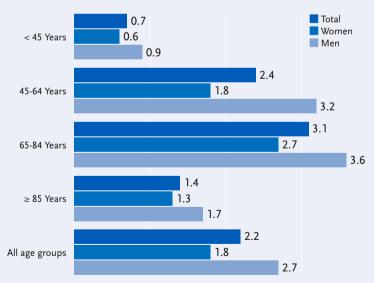


Figure 35. Proportion of the direct costs of diabetes (in %) relative to the direct costs of all diseases in 2015, by age and sex. Source: Cost of illness calculations of the Federal Statistical Office 123



Ambulatory care-sensitive hospitalisations

Definition

The indicator Ambulatory caresensitive hospitalisations is defined as the number of inpatient cases with diabetes as the main diagnosis per 100,000 residents (aged 15 years and over) per year.

Data source

Diagnosis-Related Groups (DRG) statistics on all inpatient cases in Germany.

Data quality

Complete record of all inpatient cases, although not at the individual level, meaning it is possible to have several cases for one patient. Data quality depends on coding practices and other aspects of documentation.

The declining trend observed for ambulatory care-sensitive hospitalisations is more pronounced for women than for men. Complications related to diabetes and its management including hypo- or hyperglycaemia can require hospital treatment. This indicator has been established on an international level and is published by OECD statistics every two years as part of an international comparison of the quality of ambulatory care. Following OECD guidelines, only hospitalisations with diabetes as the main diagnosis are considered. While inpatient hospitalisations with diabetes as a secondary diagnosis are not taken into account, these make up a large number of hospitalisations due to the fact that diabetes prevalence increases with age (fact sheet "Prevalence of documented diabetes"). 125

Between 2015 and 2017, rates of hospitalisation with diabetes as the main diagnosis per 100,000 residents decreased from 263 to 254. Rates of hospitalisation for women dropped from 217 to 203 cases and for men from 312 to 306 cases per 100,000 residents (Figure 36). Rates in Mecklenburg-Western Pomerania and Saxony-Anhalt were significantly higher (377 and 323 for women; 539 and 454 for men per 100,000 residents) than in Schleswig-Holstein (women: 161; men: 263) and Hamburg (women: 139; men: 241) (Figure 37).

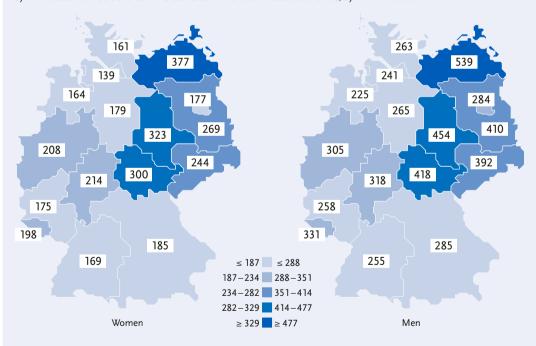
Over time, there has been a slight decrease in the number of ambulatory care-sensitive hospitalisations for diabetes. Rates for women are significantly lower than for men and decrease more sharply over time. The regional differences observed are associated with regional differences in diabetes prevalence. The present analysis does not include rates of hospitalisation for patients with diabetes as a secondary diagnosis.



Figure 36. Temporal development of diabetes-related ambulatory care-sensitive hospitalisations per 100,000 residents aged 15 and over, by sex. Source: DRG statistics of the Federal Statistical Office; by Schmidt et al.²⁵



Figure 37. Diabetes-related ambulatory care-sensitive hospitalisations per 100,000 residents aged 15 and over in 2017, by federal state and sex. Source: DRG statistics of the Federal Statistical Office, by Pollmanns et al.⁹¹



Reduced earning capacity pension

Definition

The indicator Reduced earning capacity pension is defined as the number of pensions granted due to a primary or secondary diagnosis of diabetes per 100,000 people who are actively insured (people in work who pay insurance) per year.

Data source

Statistics of the German Pension Insurance (special analysis).

Data quality

A high quality, complete record of all new cases of pensions linked to benefits for policyholders. Diabetes can seriously limit physical functioning and thus compromise the ability to work. People who receive a reduced earning capacity pension are unable to work at full capacity.

Between 2013 and 2016, there was a reduction in the number of reduced earning capacity pensions due to diabetes for both sexes per 100,000 people insured with the German Statutory Pension Insurance Scheme (Figure 38). During this period, fewer women received a pension due to a reduction in earning capacity than men (Figure 38). Clear differences can be seen at federal state level in regard to reduced earning capacity pensions due to diabetes. In 2016, for example, men and women in Saarland (women: 14.2; men: 25.5), Brandenburg (women: 14.6; men: 25.6) and Mecklenburg-Western Pomerania (women: 17.6; men: 35.2) received comparatively more pension payments due to a reduction in earning capacity than in Hamburg (women: 8.6; men: 11.2), Baden-Wuerttemberg (women: 7.1; men: 10.7) and Bavaria (women: 4.5; men: 8.3) (Figure 39).

There is a declining trend in the number of reduced earning capacity pensions granted to both men and women due to diabetes. The number of persons with diabetes receiving a pension owing to a reduced earning capacity varies by region and corresponds to diabetes prevalence (fact sheet "Prevalence of documented diabetes") as well as socioeconomic deprivation.⁷¹

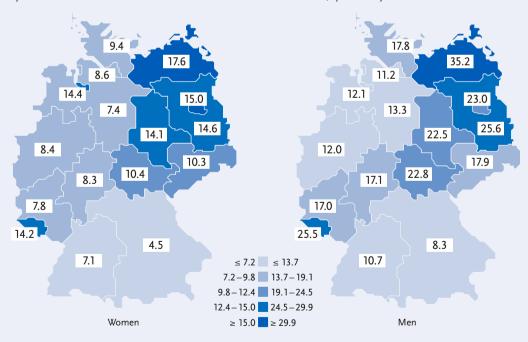
The number of reduced earning capacity pensions based on a diagnosis of diabetes decreased over time, while figures are lower for women than for men.



Figure 38. Temporal development for reduced earning capacity pensions due to a diagnosis of diabetes per 100,000 actively insured persons, by sex. Source: Statistics of the German Pension Insurance, special analysis and own calculations



Figure 39. Reduced earning capacity pensions due to a diagnosis of diabetes per 100,000 actively insured persons in 2016, by federal state and sex. Source: Statistics of the German Pension Insurance, special analysis and own calculations



Mortality

Definition

The indicator Excess mortality (relative mortality risk) is defined as the ratio of the mortality rate of people with diabetes (fact sheet "Prevalence of documented diabetes") to the mortality rate of those without diabetes in a given year.

Data source

Claims data from the approximately 70 million people covered by SHI (DaTraV data).

Data quality

The quality of claims data from SHI depends on conduct of documentation

Age-adjusted excess mortality for people with diabetes aged 30 years and over is 1.54 times higher than for people without diabetes.

One of the St. Vincent declaration goals is to align the lifespans of people with diabetes with those of people without diabetes. On a selective set of data or their low case numbers have prevented stratification by age and sex.

In 2014, age-adjusted mortality rates for people with diabetes aged 30 years and over were 1.54 times higher than for people without diabetes. The risk of death for people with diabetes is 1.52 times higher for women and 1.56 times higher for men. This excess mortality drops significantly with age, at 6.76 times higher in women and 6.87 times higher in men in the 30- to 34-year age group, 1.94 times higher in women and 1.71 times higher in men in the 70- to 74-year age group and 1.13 times higher in women and 1.11 times higher in men in the 95-plus age group (Figure 40).

Mortality rates in 2014 were around 50% higher for people with diabetes than for those without diabetes. These results are consistent with findings from population-based analyses for Germany. These previous analyses and international studies are also consistent in showing that the mortality rates of people with and without diabetes converge at an advanced age when most deaths occur. This confirmation of DaTraV data results opens up the prospect of using this data basis for regionalised analyses and for observing the development of excess mortality over time.

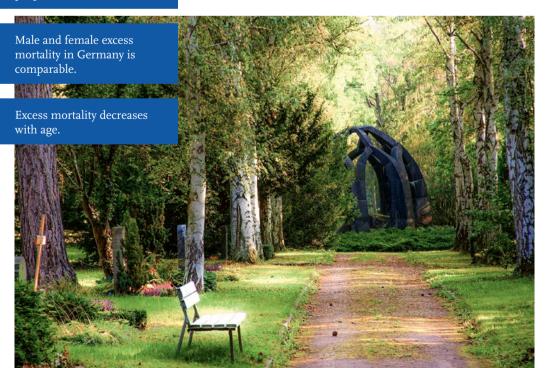
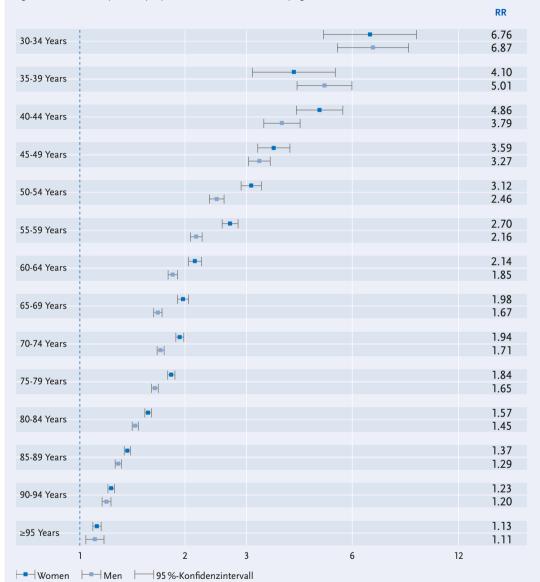


Figure 40. Excess mortality (relative risk of mortality with 95% confidence interval) of people with diabetes covered by SHI aged 30 and over compared to people without diabetes in 2014, by age and sex. Source: DaTraV data; own calculations



Relative risk (RR) of mortality = 1

People with and without diabetes have the same risk of mortality.

Relative risk (RR) of mortality = 2

The risk of death for people with diabetes is twice as high as for people without diabetes.





Healthy life years

Definition

The indicator Healthy life years (HLY) is defined as the expected number of remaining years free of health impairments ^{129, 130} of people with diabetes compared to people without diabetes.

Data source

The prevalences of diabetes and health impairments are based on three RKI interview surveys (GEDA 2009–2012); the figures on diabetes-related excess mortality are based on DaTraV data from 2014 (fact sheet "Mortality"), and the mortality rates are based on 2014 data from the Federal Statistical Office.

Data quality

RKI interview surveys provide representative results for the adult resident population of Germany. DaTraV data is based on the approximately 70 million people covered by SHI. Mortality rates for Germany are drawn from the official statistics of the Federal Statistical Office.

Increasing importance is being given to both life expectancy and the number of years a person can live free from health impairments. For this reason, the difference between people with and without diabetes is, alongside excess mortality, an important indicator of the burden of disease associated with diabetes.

In 2014, the healthy life expectancy of women and men with diabetes was 36.4 and 32.4 years for the 30- to 34-year age group, 20.3 and 18.7 years for the 50- to 54-year age group and 9.2 and 8.5 years for the 70- to 74-year age group (Figure 41). The healthy life expectancy for people with diabetes is lower than for people without diabetes, by as much as 8.8 years for women and 7.3 years for men for the 50- to 54-year age group. The healthy life expectancy of both groups converges with age (Figure 41).

People with diabetes can lose up to 12 years of healthy life compared with people without diabetes depending on age group. Future analyses should focus on identifying particularly disadvantaged groups in order to promote health policy measures that reduce inequalities.

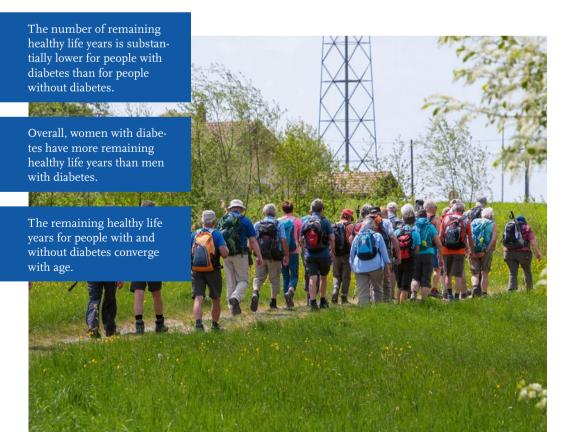
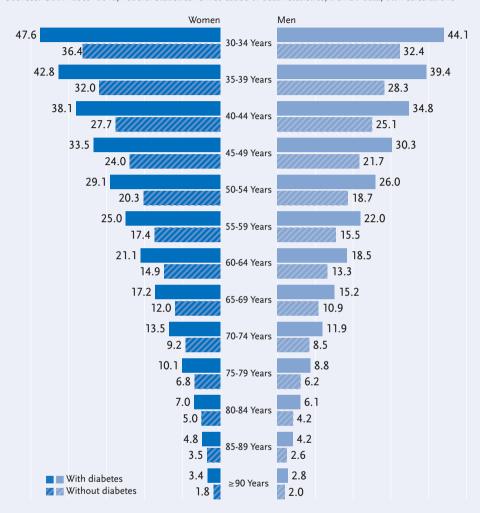


Figure 41. Expected healthy life years for persons aged 30 and over with and without diabetes in 2014, by sex and age. Sources: GEDA 2009-2012, Federal Statistical Office cause of death statistics, DaTraV data; own calculations



Background



The present report of the Diabetes Surveillance in Germany, together with the interactive visualization of findings for all indicators on the website (http://diabsurv.rki.de), is an important milestone that marks the completion of the first project phase (2015-2019). For most of the 40 indicators and indicator groups, which were first selected in a consensus process and then assigned to one of the four fields of action, data sources have been made accessible with the prospect of continuous reporting. It is currently possible to describe the temporal development and regional differences for some of the indicators, and this will be expanded to include most of the other indicators in future. Using the example of diabetes, it was thus possible to demonstrate in principle that a systematic and continuous aggregation and analysis of available health data is both possible and useful when monitoring the development and treatment of disease in Germany. This foundation of the Diabetes Surveillance must now be expanded to support the planning, implementation and evaluation of public health measures for the prevention and control of diabetes and other major non-communicable diseases. With this goal in mind, the Federal Ministry of Health is funding a second project phase until the end of 2021. A newly convened scientific advisory board will accompany the second project phase, which will focus on the following issues:

Expansion of the data basis

The data sources accessed in the first project phase will be used at periodic intervals and completed. It will thus be possible to continue or establish time series for those indicators that are still incomplete. The data basis will also be expanded to enable regionalised analyses within the Diabetes Surveillance. This will require the timely availability of relevant data - both secondary data (for example claims data from all people covered by SHI), as well as primary data collected for health reporting in the context of RKI national health monitoring. The improved and continuous availability of insurance data for health research is currently a high priority in public health policy. Periodic data collection in the context of national health monitoring is currently geared toward the needs of user-oriented

and action-oriented health reporting. Reporting on the prevention and control of diabetes and other non-communicable diseases is, therefore, a high priority. With the consent of study participants and in the interest of efficient data collection and timely reporting, it will become increasingly important for the Diabetes Surveillance to link data from national health monitoring with selected secondary data. To that end, a collaboration has been planned between the RKI and the Zi.

Initial analyses of DaTraV data indicate that it is often difficult to distinguish between diabetes types due to coding of unspecified diabetes or sequent coding of type 1 and type 2 diabetes.²⁵ An inclusion of medication should at the very least make it easier to attribute the documented prevalence of type 2 diabetes using DaTraV data.66 An observation of several diagnostic years could further help to clearly identify diabetes types. Furthermore, collaboration with existing regional diabetes registries and the federal treatment registries for patients with diabetes (DPV) will be expanded to include regular estimates within the Diabetes Surveillance of type 1 diabetes across all age groups and type 2 diabetes among 11- to 18-year-olds.42 In addition, the upcoming RKI interview and examination survey (gern study, 2020-2022) aims to distinguish between diabetes types in regard to both known and unknown diabetes by expanding the measurement of biomarkers.

For indicators of diabetes-specific complications and cardiovascular comorbidities, explorative analyses are planned within a research collaboration framework that should establish and validate definition criteria using claims data on people insured by SHI. In addition to analyses of prevalences, incidence data will also be analysed in order to gain insights into improvements in diabetes care.

Completion and further development of the indicator set

Indicators for gestational diabetes have either not yet been described or only incompletely. Options for closing these gaps in the data are being examined together with various collaborative partners. These options include a newly created opportunity from the IQTIG in regard to secondary data use, with a current application for regular data on the frequency of pregnancy complications. Collaborative partners in research and medical practice are also working to improve the data basis for measuring gestational diabetes. The aim here is to identify and close gaps in documentation of diabetes care.³¹

To date, it has only been possible to partially operationalise the Diabetes Surveillance indicator groups Social deprivation and Contextual factors from the field of action 1. According to the WHO International Classification of Functioning, Disability and Health (ICF),23 health determinants notably include environmental factors such as the physical environment and the built-up environment, social support and relationships, social values and attitudes, and health care services, as well as contextual factors related to individuals such as education and social background. A national workshop of experts is planned for 2020 which will initiate the selection and operationalisation of indicators key to the settings-based prevention of diabetes and other major non-communicable diseases.

Last but not least, the Diabetes Surveillance indicator set will be continuously reviewed and adapted to fit changing requirements. This is the case, for example, with adaptations to evidence-based treatment guidelines from the 2020 update of the national disease management guideline (NVL) on type 2 diabetes therapy, modifications of DMP quality achievement criteria for type 1 and type 2 diabetes as well as changes to health policy conditions that influence the use, billing or coding of treatment services.

Strengthening of reporting on all stages of life and on vulnerable groups

In the interests of producing reports relevant to health policy, the expansion of the Diabetes Surveillance will include a greater focus on the entire life span and on identifying health-related inequalities. Stratifications by age group and sex (where relevant for the indicators) are possible across all data sources. Greater importance will be given to the phases of childhood and adolescence, pregnancy and childbirth as well as advanced age. There are plans to integrate results from the current RKI project population-wide monitoring of influencing factors of childhood obesity (AdiMon, Bevölkerungsweites Monitoring adipositasrelevanter Einflussfaktoren im Kindesalter).131 In addition, a huge effort is being made within the context of national health monitoring to representatively include the very elderly and elderly people with severe health impairments (project: 'Expanding current monitoring at the RKI to include the very elderly and elderly people with severe health impairments', MonAge),132 as well as adults with a migration background (project: Improving Health Monitoring in Migrant Populations, IMIRA).133 A particularly useful goal in this regard would be to combine primary data from health monitoring with the claims data of all people covered by SHI, as barriers to participation are particularly high for these population groups and interviews and examinations should be kept as short as possible to limit drop-out. In future, data on social determinants of health will be collected at both the individual and regional levels. Data from national health monitoring on education and social status are available at the level of the individual, as are data on social deprivation at the regional level.71

Development of user-oriented and action-oriented reporting

The second project phase of the Diabetes Surveillance will also include a focus on the design of reporting. Alongside regular reports in printed format, the website will contain interactive visualization of results and a database to enable access for all target groups. The information needs of key players within the health care sector will be surveyed and reporting formats aligned accordingly. In co-operation with stakeholders from the federal states the Diabetes Surveillance will develop a concept on how to link the regionalised results with health reporting at federal state level. To that end, a workshop has been scheduled for 2021. Furthermore, the results can also be used for national reporting on prevention. In addition, a concept will be developed to evaluate the practical benefits of reporting. This will require a close and structured collaboration with stakeholders from health policy and public health at national and federal state levels, the BZgA, medical associations, as well as national and international scientific co-operation partners in public health.

Glossary

Age standardisation

Core indicator

DaTraV data

DEGS1

If the age structure of populations from various regions differ or if the age structure of a population from one area changes over time, the mortality and morbidity rates of these populations will not be fully comparable. Comparisons between regions and/or over time must therefore be standardised by age. The age-specific mortality and/or morbidity rates of a region or a specific time are weighted according to the age structure of a standard population. Age standardisation improves the comparability of data from different regions or different years.

Core indicators of the Diabetes Surveillance are those that (1) were assessed as highly relevant by the scientific advisory board during the consensus-finding process; (2) were assessed as relevant during the consensus-finding process and at the same time were assessed as relevant for type 2 diabetes quality of care in a co-operation project within the Diabetes Surveillance; (3) were assessed as relevant for type 2 diabetes quality of care in a co-operation project within the Diabetes-Surveillance and are clearly linked to diabetes surveillance at the population level, but had so far not been part of the indicator set of the Diabetes Surveillance working group.

DaTraV data are claims data on all people covered by SHI. These data are held by the German Institute of Medical Documentation and Information (DIMDI) and may be used by institutions as per the Regulation on Data Transparency (DaTraV). DaTraV data include documented outpatient and inpatient diagnoses as well as information on prescribed medications.

DaTraV data do not cover people insured by private health insurance and do not provide information on inpatient or outpatient care.

Between 2008 and 2011, the Robert Koch Institute conducted the German Health Interview and Examination Survey for Adults (DEGS1). The DEGS1 survey consisted of an interview and an examination and provided representative results for the 18- to 79-year-old resident population of Germany (N = 7,115). ¹³⁵

The population aged 80 and over will only be included in future survey waves. As is the case in all population-based studies, underrepresentation of the seriously ill and those living in institutions must be assumed.

This report presents the results weighted according to the population of 31 December 2010.

DMP for diabetes

Since 2003 and 2006, type 2 and type 1 diabetes patients can choose to participate in a structured treatment programme (disease management programme, or DMP). In this programme, the respective GP practice monitors and documents the patient's attainment of specific quality targets, for example threshold values (such as HbA1c) or attendance at courses. The achievement of targets by all registered participants is continuously monitored and published based on minimum quotas.

More in-depth analyses are currently limited to North Rhine-Westphalia. In addition, DMPs only contain information on people who participate in the programme.

Diagnosis-related Groups (DRG) statistics contain information on all hospitalisations in Germany. They include main and secondary diagnoses, operations and other procedures, as well as information on patients' age, sex and place of residence.

The data are documented on a case by case basis, which means that a person hospitalised more than once will be classified as several cases.

Excess mortality, also called relative mortality risk, is a statistical measure used to compare the mortality of a group of people presenting with a particular risk factor (diabetes in this case) with a group who do not have this risk factor. Mortality rates are compared in relation to the presence of the risk factor. Excess mortality of greater than 1 means that people with the risk factor are more likely to die than people who do not have the risk factor.

The German Health Update surveys were conducted by the Robert Koch Institute in 2003 (GESTel03), 2009 to 2012 (GEDA 2009–2012) and 2014/2015 (GEDA 2014/2015-EHIS). These interview surveys provide representative results for the resident population of Germany aged 18 and over (GESTel03: N=8,318, GEDA 2009: N=21,262, GEDA 2010: N=22,050, GEDA 2012: N=19,294 and GEDA 2014/2015-EHIS: N=24,016). N=20,0500 GEDA 2012: N=19,294 and GEDA 2014/2015-EHIS: N=24,016). N=10,0000 GEDA 2012: N=10,0000 GEDA 2014/2015-EHIS: N=24,016).

As is the case in all population-based studies, underrepresentation of the seriously ill and those living in institutions must be assumed. Furthermore, all information is self-reported and not based on personal interviews conducted by study physicians or standardized measurements or examinations.

This report presents results that are weighted according to the population at the selected reference date, i.e. on 31 December 2001 (GES-Tel03), 31 December 2007 (GEDA 2009), 31 December 2008 (GEDA 2010), 31 December 2011 (GEDA 2012) and 31 December 2014 (GEDA 2014/2015-EHIS).

DRG statistics

Excess mortality / relative mortality risk

GEDA

gern study

The Robert Koch Institute together with the Max Rubner Institute will conduct the Health and Nutrition Survey in Germany (gern survey) starting in spring of 2020. The gern survey will consist of an interview and an examination and provide representative results for the 18- to 79-year-old resident population of Germany (study population of N = 12,500 planned).

An additional module will also include the population aged 80 and over. However, as is the case in all population-based studies, underrepresentation of the seriously ill and those living in institutions

GNHIES98

The German National Health Interview and Examination Survey 1998 (GNHIES98) was conducted by the Robert Koch Institute between 1997 and 1999. GNHIES98 included both an interview and an examination survey and provided representative results for the 18- to 79-year-old resident population of Germany (N = 7,124). 134

The population aged 80 and over will only be included in future survey waves. As is the case in all population-based studies, underrepresentation of the seriously ill and those living in institutions must be assumed.

This report presents the results weighted according to the population of 31 December 1997.

Gestational diabetes

Gestational diabetes initially develops during pregnancy and is a risk factor for pregnancy complications and for the development of type 2 diabetes in the mother at a later stage. Gestational diabetes risk factors are similar to those for type 2 diabetes. Lifestyle changes are the therapy of choice for gestational diabetes, and if unsuccessful, then treatment with insulin is recommended.

HbA1c

Glycated haemoglobin (HbA1c) is given as a percentage of the total haemoglobin in the blood (%), or the millimoles per mole of haemoglobin in the blood (mmol/mol) and indicates the average blood glucose levels during the past two to three months. In diabetes patients, HbA1c values are used to assess the quality of blood glucose management.

Incidence

Incidence is a statistical measure of the frequency with which a disease occurs for the first time in a given period of time. It is expressed here as the percentage of new diabetes cases in a population in a given year (cumulative incidence). The proportion of new cases is defined as the number of people who develop diabetes for the first time relative to all the people who have not previously had diabetes.

Indicator

Indicators are defined and measurable key figures. An indicator can be mapped by corresponding data sources.

Known diabetes / documented diabetes

The terms known diabetes and documented diabetes are used to describe medically diagnosed cases of diabetes. Known diabetes refers to cases of diabetes recorded during RKI surveys and is defined as either a self-reported medical diagnosis or taking antidiabetic agents. The term documented diabetes is used in secondary data

Odds Ratio

The Odds Ratio (OR) is a statistical measure of the strength of a relationship between two characteristics. Typically, the presence of a trait is compared in people with and without a specific risk factor (in this report, diabetes). An OR of less than 1 would indicate that people with diabetes have a lower chance of having this trait than people without diabetes. Conversely, an OR greater than 1 means that people with diabetes have a greater chance of having this trait.

Prevalence

Prevalence is a statistical measure of the frequency with which a risk factor or disease occurs at a certain time or within a certain time period. RKI surveys, for example, calculate the prevalence of known diabetes from the percentage of people out of all the participants of the survey who report a physician-diagnosed diabetes or taking anti-diabetic agents. The prevalence of unknown diabetes is calculated from the percentage of people out of all the participants of the survey without known diabetes who have elevated HbA1c values ($\geq 6.5\%$).

Primary data

Primary data are data that are systematically collected based on pre-defined questions and survey modes.

Quality assurance in obstetrics at the IQTIG

The Institute for Quality Assurance and Transparency in Health Care (IQTIG) develops external quality assurance procedures for the Federal Joint Committee and assists in their implementation. For obstetrics (part of perinatal medicine since 2019), the IQTIG regularly reports on quality indicators based on federal perinatal statistics. This data set includes information from maternity logs, for example on gestational diabetes.

However, the dataset is collected by hospitals, which means it only contains information on hospital births. Furthermore, the data quality, e.g. for analysing gestational diabetes, depends on the documentation practices used for maternity logs.

Secondary data

Secondary data are data used for analysis that were originally collected for a different purpose or to answer a different set of questions.

Supplementary indicators

Supplementary indicators within the Diabetes Surveillance are those that were assessed as relevant by the scientific advisory board in the consensus process but were not identified as indicators for the treatment of type 2 diabetes in a co-operation project within the Diabetes Surveillance.

Surveillance

In the area of public health, surveillance refers to the continuous and systematic collection, aggregation, analysis and interpretation of relevant health-related data. The objective of surveillance is to support the planning, implementation and evaluation of measures to combat

Type 1 diabetes

Type 1 diabetes is an autoimmune disease characterised by absolute insulin deficiency. Type 1 diabetes is always treated with insulin.

Type 2 diabetes

Type 2 diabetes is characterised by a relative insulin deficiency. Risk factors include age, genetic disposition, obesity and physical inactivity. Depending on the severity, type 2 diabetes is treated with lifestyle changes, oral antidiabetics, GLP-1 analogues or insulin.

Unknown diabetes

The term unknown diabetes describes people who have not previously been diagnosed with diabetes, but who already have diabetes according to laboratory parameters (such as HbA1c). In RKI surveys, this is defined as the proportion of people without known diabetes whose HbA1c value is elevated (\geq 6.5%) out of all the participants of the survey.

List of abbreviations

BMG

Federal Ministry of Health

BMI

Body mass index

BZgA

Federal Centre for Health Education

CHD

Coronary heart disease

DaTraV

Regulation on Data Transparency

DEGS1

German Health Interview and Examination Survey for Adults

DMP

Disease management programme

DPV

Diabetes patient documentation

DRG statistics

Diagnosis-Related Groups statistics

GEDA

German Health Update

GNHIES98

German National Health Interview and Examination Survey 1998

HbA1c

Glycated haemoglobin

HLY

Healthy life years

HRQoL

Health-related quality of life

IQTIG

Institute for Quality Assurance and Transparency in Health Care

NVL

National disease management guideline

OECD

Organization for Economic Co-operation and Development

OR

Odds ratio

RKI

Robert Koch Institute

SHI

Statutory health insurance

WHC

World Health Organization

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Central Research Institute of Ambulatory Health Care in Germany

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