



JUNE 2018  
SPECIAL ISSUE **3**

FEDERAL HEALTH REPORTING  
JOINT SERVICE BY RKI AND DESTATIS

# Journal of Health Monitoring

## Diabetes Surveillance in Germany

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Journal of Health Monitoring · 2018 3(S3)  
DOI 10.17886/RKI-GBE-2018-063  
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# Selecting and defining indicators for diabetes surveillance in Germany

## Abstract

Mainly because of the large number of people affected and associated significant health policy implications, the Robert Koch Institute (RKI) is developing a public health surveillance system using diabetes as an example. In a first step to ensure long-term and comparable data collection and establish efficient surveillance structures, the RKI has defined a set of relevant indicators for diabetes surveillance. An extensive review of the available literature followed by a structured process of consensus provided the basis for a harmonised set of 30 core and 10 supplementary indicators. They correspond to the following four fields of activity: (1) reducing diabetes risk, (2) improving diabetes early detection and treatment, (3) reducing diabetes complications, (4) reducing the disease burden and overall costs of the disease. In future, in addition to the primary data provided by RKI health monitoring diabetes surveillance needs to also consider the results from secondary data sources. Currently, barriers to accessing this data remain, which will have to be overcome, and gaps in the data closed. The RKI intends to continuously update this set of indicators and at some point apply it also to further chronic diseases with high public health relevance.

 PUBLIC HEALTH · SURVEILLANCE · DIABETES MELLITUS · INDICATORS · NCD

## 1. Background

Public health surveillance is the systematic collection and analysis of relevant health data for the provision of up-to-date information and therefore provides an important basis for decisions by diverse (health) political stakeholders to protect and improve the health of the population [1-3]. Surveillance consequently is one of the key fields of public health [4] and is no longer limited merely to infectious diseases. In the 21st century, preventing chronic, noncommunicable diseases (NCD) and providing care to patients has become one of the great health challenges globally [5-7].

Cardiovascular diseases, cancer, chronic lung diseases and diabetes mellitus [8] are now ailments faced not only by wealthy countries, but increasingly and significantly also contribute to premature mortality in low and middle income countries, which has caused the World Health Organization (WHO) to define clear goals in its Global Action Plan 2013-2020 on NCD prevention and control.

Diabetes mellitus in particular has become a serious issue for healthcare systems globally [9-11]. Due to high incidence rates and the great potential offered by prevention measures, type 2 diabetes is currently a focus. The known type 2 diabetes risk factors specifically include

**Due to the high social relevance of diabetes and its sequelae, the Robert Koch Institute has started to establish a national diabetes surveillance system.**

obesity, lack of physical activity, unhealthy diet, smoking, stress and social deprivation [12]. However, the role played by environmental and psycho-social factors in type 2 diabetes is still not fully understood [13, 14]. Equally, the complex interactions between inherited and acquired risk factors over the course of a person's life necessitate further research. During gestation and infancy epigenetic mechanisms possibly leave their mark on metabolic processes later in life [15]. Gestational diabetes potentially plays a particularly important role here. Although in most cases women recover from this form of diabetes after pregnancy, the disease is related to a greater risk of complications during pregnancy as well as an increased risk for both the mother and the baby to develop type 2 diabetes at a later stage in life [16-18].

Importantly, the life-style related risk factors for type 2 diabetes also play a key role in other important NCDs [5, 19]. Often, the large socio-economic implications of type 2 diabetes mean that the great public health relevance of type 1 diabetes, which is a far rarer form and an autoimmune disease, is also often overlooked. Mostly, this form develops at childhood or adolescent age and requires patients to take insulin for the rest of their life, with a correspondingly severe impact on their quality of life. Moreover, over the past decade a so far unexplained global increase in the number of new cases of type 1 diabetes is recognised [20, 21].

According to data from the Robert Koch Institute (RKI), an estimated 6.7 million adults in Germany are affected by diagnosed or undiagnosed diabetes [22, 23]. For adults in Germany, the data from national health monitoring suggests that around one in five cases of diabetes goes unrecognised, with a significant decrease in this figure being reg-

istered since the end of the 1990s [23]. Notwithstanding the advances in early detection and treatment, diabetes mellitus continues to entail severe complications in many patients mainly due to the damages to small and large blood vessels, as well as the peripheral and autonomic nervous system. Cardiac insufficiency, infarction and stroke, diabetic foot and amputations of the lower extremities, diabetic eye diseases and blindness, renal insufficiency and dialysis, as well as diabetic neuropathy are among the most frequent complications of diabetes mellitus. Furthermore, in women, diabetes increases the risk for complications during pregnancy [24], as well as for depression and possibly dementia [25] and is associated with an increased risk for certain types of cancer [26]. Overall mortality for adults with diabetes remains significantly higher than for people of the same age without diabetes, although the diabetes-related excess mortality varies depending on age and gender [9, 27, 28].

This explains the central role played by diabetes mellitus as an NCD [19] and why the RKI, on behalf of the Federal Ministry of Health, chose diabetes as a model disease for developing an NCD public health surveillance. Public health surveillance [19] requires a scientific framework concept with defined goals and fields of activity, evidence-based and health politically relevant indicators [29-32], as well as an integration into the established health information systems [33]. This has not yet been achieved in Germany. While the indicator set of the federal states' health reporting [34] by default includes indicators to account for diabetes-related hospital admissions, early retirements and deaths, not all federal states so far have implemented this set of indicators. Some states have additional indicators that cover, for example, outpatient care. Moreover, some federal

**Surveillance systems require indicators that are evidence-based and consented among relevant stakeholders.**

states have already published reports on diabetes [35]. No federal state has so far established a global concept for diabetes surveillance [36]. Besides reviewing, analysing and gathering available sources of data, establishing diabetes surveillance in Germany will depend primarily on developing a corresponding scientific framework concept and selecting suitable indicators [37].

Following Germany's 2003 national health target Diabetes mellitus type 2 [38, 39], four fields of activity were identified: (1) reducing diabetes risk, (2) improving diabetes early detection and treatment, (3) reducing diabetes complications, (4) reducing the disease burden and overall costs of the disease [37]. The focus of this article is the methodological approach, which the RKI applied to select and define its set of indicators for diabetes surveillance in Germany.

## 2. Methods

The selection and definition of indicators relevant to health policy for diabetes was a multi-stage process, which was based on two independent reviews of the literature, as well as a structured consensus process that involved a national and international level interdisciplinary panel of experts ([Annex Table 1](#)).

### 2.1 Review of the literature

#### Diabetes mellitus and NCD indicators

Regarding diabetes mellitus and NCDs, the RKI conducted a selective review of publications and information systems at the population level between January and June 2016. The search covered the current international health indicator

systems of the Organisation for Economic Cooperation and Development (OECD), the European Union (European Community Health Indicators and Monitoring, ECHI) and the World Health Organization (WHO) [30, 32, 40]. A further focus were indicator-based scientific publications, reports and online information systems on diabetes mellitus and NCDs in OECD member states. The search considered publications regardless of date of publication, but was limited to publications and information in either German or English. For Germany, the health reporting, prevention, rehabilitation and social medicine working group of the Permanent Working Group of the Highest State Health Authorities (AOLG) in addition identified indicator-based, federal state level reports and publications on diabetes mellitus. Furthermore, a working group of experts from Baden-Württemberg proposed an initial indicator set [41]. Moreover, current national and selected international diabetes mellitus treatment guidelines [42, 43], cardiovascular disease prevention guidelines [44], as well as the quality targets of the type 1 and type 2 diabetes disease management programmes (DMP) were reviewed [45].

The scope of indicators considered was limited per definition to: (1) indicators on type 1 and type 2 diabetes, as well as gestational diabetes, (2) indicators related to one of the four defined fields of diabetes surveillance in Germany, (3) indicators defined in either German or English.

Indicators were excluded if they fell into one of the following categories: (1) indicators for rare forms of diabetes mellitus, (2) indicators for only specific target groups (such as patients with particular accompanying diseases), (3) and indicators that are not fully compatible with Germany's healthcare system.

### Quality indicators for type 2 diabetes care

A joint scientific cooperation project on diabetes surveillance [46], which was guided by the Institute for Applied Quality Improvement and Research in Health Care GmbH (aQua) in Göttingen, conducted an additional systematic review of the literature with a focus on type 2 diabetes and quality of care.

This review was conducted in the literature databases of Embase, Medline and the Cochrane Library, as well as in the indicator databases of the US Agency for Healthcare Research and Quality (AHRQ) and the British Health and Social Care Information Centre (HSCIC). Further international institutions and agencies that develop, compile or publish indicators were also reviewed. To take account of the German context, a partially automated text search was conducted of Germany's national guidelines (NVL) on diabetes treatment [43].

The following inclusion criteria were defined: (1) indicators for adults with type 2 diabetes, (2) indicators defined in either German or English.

The criteria to exclude indicators were defined as: (1) indicators that are incompatible with the German health system, (2) indicators without clearly defined numerators and denominators, (3) indicators that relate exclusively to the care aspects of diabetes in certain population groups (e.g. African Americans in the USA).

## 2.2 Selecting and assessing indicators

At the RKI, the diabetes surveillance working group reviewed all of the indicators identified based on these parameters and supplemented them with indicators for: diabetes risk

tests, rehabilitation, patient satisfaction, avoidable hospital admissions, screenings (gestational diabetes) and disease burden.

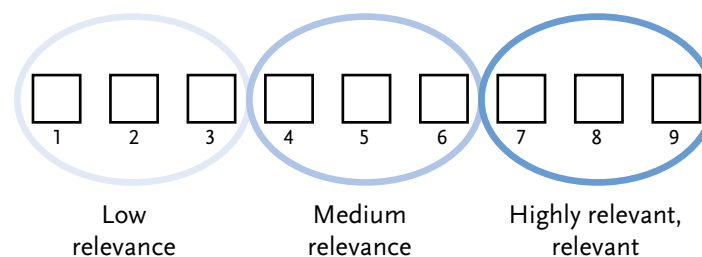
To ensure international compatibility, a national and international panel of experts conducted a structured assessment of the indicators provided by the RKI ([Annex Table 1a](#)); a process, which included a written assessment of indicators regarding their relevance to national diabetes surveillance. All members of the external panel of experts (n=35) received an email with an evaluation template attached to assess the relevance of indicators (essential, important, additional and negligible) that included blank boxes for further comments. The diabetes surveillance working group received back 17 assessment forms, which represents a 49% response rate. The results of this initial assessment were prepared in the run-up to an international scientific workshop at the RKI in July 2016 and then discussed and finalised during the workshop [37, 47].

The following step consisted of evaluating the health policy relevance of the selected indicators for diabetes surveillance in Germany. This was based on a two-tier Delphi method, which drew on the approach financed and started by the EU in the Joint Action on Chronic Diseases [48] programme, as well as the RAND/UCLA Appropriateness Method (RAM) [49].

In a first step, based on a nine-step scale, the 20 members of the diabetes surveillance scientific board ([Annex Table 1b](#)) were asked to rank all of the indicators according to their relevance for health policy. The members of the board received a corresponding assessment form as an email attachment and asked to return it to the RKI. The form permitted them to comment on the clarity, health

political influenceability and international comparability of indicators. The RKI received 13 assessment forms back, which represents a 65% response rate. Subsequently these forms were evaluated and the results for each indicator comprehensively prepared:

- ▶ Indicators were classified as highly relevant if they received at least 75% from the top three grades (7-9).
- ▶ Indicators were classified as relevant if they received between 50% and under 75% of ratings from the top three grades (7-9).
- ▶ Indicators were classified as being of medium relevance if at least 50% of ratings were from the medium rates (4-6).
- ▶ Indicators were classified as being of low relevance if at least 50% of ratings were from the lowest rates (1-3) (Figure 1).



**Figure 1**  
Evaluation template on indicator selection  
and relevance assessment  
Own diagram

In the second step of the Delphi method, the members of the scientific board were invited to a meeting in Berlin. 16 members participated in the meeting in March 2017, which corresponds to an attendance rate of 80%. During the meeting the participating board members were presented with the results of the first assessment round and provided with the opportunity to discuss or clarify open questions or unclear definitions for each indicator. Follow-

ing the discussion, all board members were asked to rate once again the indicators regarding their relevance for diabetes surveillance in writing and anonymously. The format of the assessment forms and evaluation criteria was identical to that of the first step of the procedure.

In a separate move, an additional panel of experts provided an evaluation of the indicators of the cooperation project on type 2 diabetes quality of care (Annex Table 1c). Here too, the evaluation of indicators was based on a two-tier Delphi method with a focus on type 2 diabetes quality of care. This was based on a modified RAND-UCLA appropriateness method (RAM) provided by the aQua institute [49, 50]. Relevance in this case too was assessed using the nine-step scale described in Figure 1. Both stages of the assessment procedure were conducted in writing and anonymously and included both filling out an online evaluation and an evaluation provided during a face-to-face meeting following a discussion of the results of the online evaluation.

For a final selection of indicators, the RKI evaluated the results from these review strategies. Initially, indicators from both indicator sets, which were rated as either highly relevant or relevant became part of the final selection and indicators with a medium or low relevance rating were excluded. In addition, from the indicators provided by the cooperation project those considering only specific aspects of treatment (such as amputations without vascular procedures, major amputations without a second opinion procedure) were also excluded. The remaining indicators were grouped into core and supplementary indicators for diabetes surveillance in Germany at the population level based on the following criteria:



#### Core indicators:

- ▶ Indicators classified as highly relevant, regardless as to whether they were classified as indicators for type 2 diabetes quality of care or not.
- ▶ Indicators classified as relevant, which in addition were classified as relevant for type 2 diabetes quality of care.
- ▶ Indicators classified as relevant for type 2 diabetes quality of care with a clear link to diabetes surveillance at the population level, which had so far not been included in the set of indicators used by the diabetes surveillance working group.

#### Supplementary indicators:

- ▶ Indicators classified as relevant, which were however not identified as indicators for type 2 diabetes quality of care.

The consensus-oriented closing discussion round prepared the indicators in line with the ECHI model [51] regarding the following aspects: operationalisation (definition, reference population), available stratification variables (such as age, gender and socioeconomic status), data availability, type and periodicity of appropriate data sources, scientific background, references, comments on specificities regarding definition or use. Moreover, indicators were pre-assigned to one of the four defined fields of activity in line with the 2003 national health target diabetes mellitus type 2 [38, 39].

### 3. Results

Initially, the described search strategy regarding the established diabetes and NCD reporting systems served to identify 32 indicators and/or groups of indicators. In addition, 13 indicators covering further hitherto insufficiently described fields were also adopted. This established an initial set of 45 indicators.

During the structured consensus process, in an initial evaluation round, the international panel of experts assessed 18 indicators as being 'essential', 14 indicators as being 'important', and 8 further indicators as being 'additional' indicators. Five indicators were rated heterogeneously, no consensus was achieved and they could therefore not be assigned to one of the categories. No indicator was classified as 'negligible'. Furthermore, the members of the diabetes surveillance scientific board proposed four additional indicators (gestational diabetes prevalence, early retirement, hypoglycaemia incidence and information needs). They also proposed to split the indicator 'environmental factors' into three separate indicators (traffic exposure, walkability and social deprivation). This produced an indicator set of 51 indicators. The following national level two-tier Delphi method assessed 18 indicators as being highly relevant, 18 as being relevant and 15 as being of medium relevance. No indicator was assessed as being of low relevance.

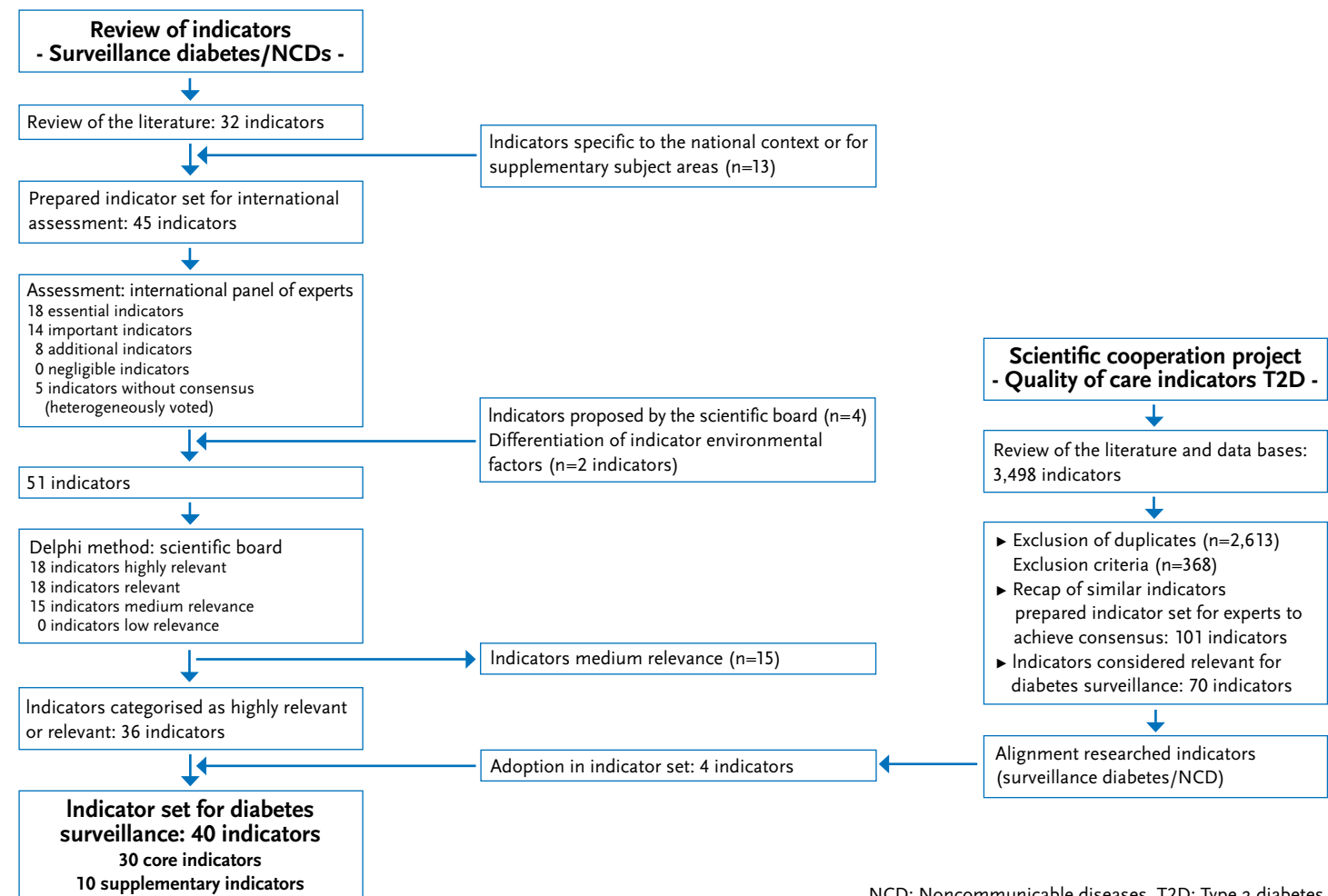
#### 3.1 Final selection of indicators

The final selection considered only indicators in the highly relevant ( $n=18$ ) and relevant ( $n=18$ ) groups. This step therefore excluded the 15 medium relevance indicators.



During the final step of the procedure, the remaining 36 indicators were compared to the results of the cooperation project on indicators for type 2 diabetes quality of care. Four additional indicators on relevant aspects of diabetes treatment were then added to the diabetes surveillance indicator set (age at diagnosis, renal replacement

therapy, diabetic neuropathy, and diabetic foot syndrome). Moreover, core and supplementary indicators were defined based on the described criteria. The flowchart (Figure 2) provides a detailed step-by-step description of the indicators that were identified over the course of the selection process.



NCD: Noncommunicable diseases, T2D: Type 2 diabetes

**Figure 2**  
Flowchart diabetes surveillance  
indicator selection  
Own diagram

Using a multi-stage consensus process, 30 core and 10 supplementary indicators for surveillance were consented and assigned to four fields of activity.

As a result, the resulting set of 30 core and 10 supplementary indicators/indicator groups for the four fields of activity were presented to the scientific board and approved in unanimous consensus (Table 1). The complete prepared indicator set including information on indicator opera-

tionalisation is available via the internet pages of the RKI ([www.rki.de/diabsurv](http://www.rki.de/diabsurv)). Furthermore, the detailed assessments underlying the selection of indicators is included for all indicators as well as their division into core and supplementary indicators (Annex Table 2).

| (1) Reducing diabetes risk   | (2) Improving diabetes early detection and treatment  |
|--|---|
| <b>Core indicators</b><br>Incidence<br>Prevalence gestational diabetes<br>Overweight/obesity<br>Physical activity<br>Smoking<br>Social deprivation   | <b>Core indicators</b><br>Prevalence of known diabetes<br>Prevalence of unknown diabetes<br>Disease management programme participation rate<br>Disease management programme quality objectives achievement<br>Quality of care<br>Treatment profiles<br>Health related quality of life<br>Screening gestational diabetes<br>Age at diagnosis |
| <b>Supplementary indicators</b><br>Prediabetes<br>Sugary beverages consumption<br>Absolute diabetes risk (based on the German diabetes risk test)<br>Contextual factors  | <b>Supplementary indicators</b><br>Check-up 35<br>Patient satisfaction  |
| (3) Reducing diabetes complications  | (4) Reducing the disease burden and overall costs of the disease  |
| <b>Core indicators</b><br>Depression<br>Cardiovascular diseases<br>Diabetic retinopathy<br>Diabetic nephropathy<br>Renal replacement therapy<br>Diabetic (poly-)neuropathy<br>Diabetic foot syndrome<br>Amputations related to diabetes<br>Frequency of severe hypoglycaemia | <b>Core indicators</b><br>Direct costs<br>Hospitalisation rate<br>Reduced-earning-capacity pension<br>Mortality<br>Years of life lost<br>Healthy life years   |
| <b>Supplementary indicators</b><br>Risk of cardiovascular events<br>Complications during pregnancy   | <b>Supplementary indicators</b><br>Years lived with disability<br>Disability-adjusted life years (DALYs)  |

Table 1

Subject areas for indicators for diabetes surveillance in four fields of activity  
Own diagram

**Data from the nationwide health monitoring of the Robert Koch Institute and routine data will be used for continuous data analysis and timely reports of results.**

Where possible, and depending on the available data, the diabetes types are differentiated, and, depending on the available data, the results also stratified by age, gender, social status, education and region.

#### 4. Discussion and outlook

The selected set of indicators for diabetes surveillance in Germany aims to collect detailed, comparable and successive data on diabetes mellitus in Germany. This should establish a firm basis for diabetes surveillance, and aims to ensure an up to date and comprehensive analysis of disease dynamics, potential for prevention and care needs. The epidemiologic development of incidence and prevalence will be covered, as will the development of the known risk factors, associated diseases and quality of care that can largely be influenced. What is crucial here is a differentiation by gender, age, socioeconomic status and region. This last factor establishes a bridge to federal state level health reporting.

In Germany, potentially useful and ample data is already available. As each source of data has its specific advantages and disadvantages, the described consensually agreed indicator set references different sources of data for calculating indicators depending on the availability of such data. Primary RKI health survey data for example permits an analysis stratified by socioeconomic status and further individual level aspects, and, by referring to laboratory analysis, allows estimating the prevalence of unknown diabetes in the population. Furthermore, information on a set of risk factors is collected, which facilitate predicting the development of a type 2 diabetes by means of established risk

models [52]. Furthermore, population representative estimates on quality of life and a comparison of the functional limitations faced by adults with and without diabetes mellitus are possible, as are estimates on diabetes comorbidity [53] and for selected indicators on the quality of care for adults with diabetes mellitus [54]. Secondary sources of data often offer in particular the advantage of providing information on a large number of cases, the regular availability of this data and a lack of distortion effects due to non-participation. Data from statutory health insurances (GKV) for example or the associations of statutory health insurance physicians (KVen) provide up to date, periodically recurrent estimates on the development of the incidence of medically diagnosed diabetes including the possibility of differentiating between types of diabetes and region [55, 56]. An assessment of the quality of care is possible, based as much on the results of regular DMP analyses [45, 57] as on GKV routine data provided on out and inpatient treatment [58, 59].

Diabetes surveillance will therefore also need to establish the specific strengths and weaknesses of each source of data. This should also lead to recommendations regarding the use of this data and its application to other diseases for a broader surveillance of NCDs in the future. Implementation of the data transparency act (DaTraV) in particular, which was begun by the German Institute of Medical Documentation and Information (DIMDI) in 2014, meanwhile provides data for morbidity-oriented risk structure compensation (Morbi-RSA) from all statutory health insurers for research. Processing of this data constitutes a first and important step towards using routine data for surveillance. In spite of providing data for everybody

**The consented set of indicators is to be continuously adapted and the methodological approach could be applied to other noncommunicable diseases of high public health impact.**

insured in the GKV, the data set currently remains limited to outpatient and inpatient diagnoses and the outpatient provision of medicines. Further data on outpatient services, as well as on operations, procedures or general measures in inpatient care is not included. Certain process-oriented indicators, however, require such information. A satisfactory solution to accessing sources of data that include such information (GKV and KV routine data, as well as DMP documentation data) is still lacking. Generally, these bodies of data are only accessible in the context of research cooperation projects. Surveillance, however, would demand a regular access to such sources of data. Clearing these obstacles in a dialogue with the holders and users of such data is desirable. In addition, the indicators of quality deducted from DMP are subject to a certain degree of change over time regarding their definition and target population (definition of the numerator and denominator sample).

To define indicator sets, this process of seeking consensus seems appropriate. Establishing an interdisciplinary advisory committee has meant that indicators for relevant fields of activity in the areas of public health and prevention as well as medical treatment could be defined. Combining online assessments in writing and consensus-oriented discussion rounds during the bi-annual face-to-face board meetings is evidently a practicable and efficient approach. The established indicator set now for the first time provides a concept for a German surveillance system for one chronic, noncommunicable disease – diabetes mellitus. Initial analyses based on these newly established indicators will now begin and health reporting formats will be developed to ensure that the results are adequately pre-

pared for the different target groups (universities, politics, patients, the general public etc.).

In the future, diabetes surveillance should serve as a model for a broader surveillance of NCDs, whereby the transferability of the model to other diseases still needs to be tested. Importantly, the indicator set should not be too rigid and developed further. This applies for example to the indicators for diabetes-related health competency in the overall population and among adults, who already have diabetes. Currently, a population representative telephone survey on [disease knowledge and information needs](#) is being conducted by the RKI in close cooperation with Germany's Federal Centre for Health Education (BZgA). Furthermore, for a surveillance of NCDs, describing social and health policy context factors and the implementation of measures through indicators will be key. Moreover, the indicator system should be continuously further developed regarding compatibility with the nascent health information systems at the international level (WHO, EU). This applies in particular to activity field 1 (reducing diabetes risks), which will require the indicator group 'context factors' to be developed. Indicators in activity fields 2 and 3 (reducing diabetes complications, diabetes early detection and treatment) are defined relatively completely as regards the current quality target criteria (DMP, St Vincent criteria). Minor modifications, however, owing to the continuous updating of current definitions must be expected.

Regarding a future broader surveillance of NCDs, the goal remains to also define lead indicators analogous to the Swiss model over and above the differentiation between core and supplementary indicators which have already been established [60]. Lead indicators are defined as having an

overarching relevance in terms of indicators to NCD surveillance and are collected at regular intervals and reliably in the context of a national NCD targets yet to be defined. From the current set of indicators, the epidemiological figures for prevalence, incidence and mortality, the regularly published treatment indicators of the OECD on diabetes-related amputations [30], as well as the indicators to quantify the disease burden such as disease costs or the years of life lost due to disease could serve as such lead indicators.

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#### Please cite this publication as

Gabrys L, Heidemann C, Schmidt C, Baumert J, Teti A et al. (2018) Selecting and defining indicators for diabetes surveillance in Germany. *Journal of Health Monitoring* 3(S3):3-21.  
DOI 10.17886/RKI-GBE-2018-063

#### Funding

The project 'Establishing national diabetes surveillance at the Robert Koch Institute' receives funding from Germany's Federal Ministry of Health, funding note: GE 2015 03 23.

#### Conflicts of interest

Joachim Szecsenyi is CEO and shareholder of the aQua Institute. For the other co-authors and for herself, the corresponding author declares that there is no conflict of interest.

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**Annex Table 1 (in German)**  
**Participants Expert Committees**  
**a) International Panel of Experts**

|                                 |   |
|---------------------------------|---|
| Prof. Dr. Winfried Banzer       | Johann Wolfgang Goethe-Universität Frankfurt am Main, Institut für Sportwissenschaften  |
| Prof. Dr. Michael Böhme         | Landesgesundheitsamt Baden-Württemberg, Stuttgart   |
| Dr. Brigitte Borrmann           | Landeszentrum Gesundheit Nordrhein-Westfalen (LZG.NRW)  |
| Dr. Ralph Brinks                | Deutsches Diabetes-Zentrum (DDZ), Leibniz-Zentrum für Diabetes-Forschung an der Heinrich-Heine-Universität Düsseldorf, Institut für Biometrie und Epidemiologie |
| Prof. Dr. Reinhard Busse        | Technische Universität Berlin, Fachgebiet Management im Gesundheitswesen  |
| Prof. Dr. Fabrizio Carinci      | University of Surrey, Guildford, School of Health Sciences  |
| Diana Droßel                    | diabetesDE – Deutsche Diabetes-Hilfe  |
| Prof. Dr. Saskia E. Drösler     | Hochschule Niederrhein, University of Applied Sciences, Medizin, Medizin-Controlling und Informationssysteme  |
| Prof. Dr. Michael Freitag       | Deutsche Gesellschaft für Allgemeinmedizin (DEGAM)<br>Carl von Ossietzky Universität Oldenburg, Department für Versorgungsforschung                             |
| Prof. Dr. Edward W. Gregg       | Centers for Disease Control and Prevention (CDC), Division of Diabetes Translation  |
| Dr. Bernd Hagen                 | Zentralinstitut für die kassenärztliche Versorgung in Deutschland (Zi)  |
| Prof. Dr. Hans-Ulrich Häring    | Universitätsklinikum Tübingen, Medizinische Klinik IV   |
| Dr. Dirk Hochlenert             | Deutsche Diabetes Gesellschaft  |
| Prof. Dr. Reinhard Holl         | Universität Ulm, Institut für Epidemiologie und medizinische Biometrie  |
| Prof. Dr. Rolf Holle            | Helmholtz Zentrum München, Deutsches Forschungszentrum für Gesundheit und Umwelt (GmbH), Institut für Gesundheitsökonomie und Management im Gesundheitswesen    |
| Prof. Dr. Andrea Icks           | Heinrich-Heine-Universität Düsseldorf, Medizinische Fakultät, Institut für Versorgungsforschung und Gesundheitsökonomie   |
| Dr. Michael Jecht               | Medizinisches Versorgungszentrum Havelhöhe  |
| Prof. Dr. Jeffrey Johnson       | University of Alberta, School of Public Health  |
| Dr. Matthias Kaltheuner         | Gemeinschaftspraxis Kaltheuner – v. Boxberg, Leverkusen   |
| Dr. Klaus Koch                  | Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (IQWiG), Ressort Gesundheitsinformation  |
| Prof. Dr. Bernhard Kulzer       | Diabetes Zentrum Mergentheim  |
| Dr. Joseph Kuhn                 | Bayerisches Landesamt für Gesundheit und Lebensmittelsicherheit, Dienststelle Oberschleißheim   |
| Prof. Dr. Oliver Kuß            | Deutsches Diabetes-Zentrum (DDZ), Leibniz-Zentrum für Diabetes-Forschung an der Heinrich-Heine-Universität Düsseldorf, Institut für Biometrie und Epidemiologie |
| Prof. Dr. Gunter Laux           | Universitätsklinikum Heidelberg, Abteilung Allgemeinmedizin und Versorgungsforschung  |
| Prof. Dr. Jan Mainz             | Aarhus University, Studienævne på HE – Studies in Health Science  |
| Dr. Wolfgang Rathmann           | Deutsches Diabetes-Zentrum (DDZ), Leibniz-Zentrum für Diabetes-Forschung an der Heinrich-Heine-Universität Düsseldorf, Institut für Biometrie und Epidemiologie |
| Helmut Schröder                 | Wissenschaftliches Institut der AOK (WiDO)  |
| Dr. Ingrid Schubert             | PMV forschungsgruppe, Klinik und Poliklinik für Psychiatrie und Psychotherapie des Kindes- und Jugendalters, Universität zu Köln                                |
| Prof. Dr. Jochen Seufert        | Deutsche Diabetes Gesellschaft<br>Universitätsklinikum Freiburg, Abteilung Endokrinologie und Diabetologie  |
| Dr. Dominik Graf von Stillfried | Zentralinstitut für die kassenärztliche Versorgung in Deutschland (Zi)  |
| Dr. Heidrun Thaiss              | Bundeszentrale für gesundheitliche Aufklärung (BZgA)  |
| Dr. Til Uebel                   | Deutsche Gesellschaft für Allgemeinmedizin (DEGAM)<br>Praxisgemeinschaft Uebel, Ittlingen   |
| Dr. Dietmar Weber               | Deutsche Diabetes Gesellschaft  |
| Prof. Dr. Sarah Wild            | Centre for Population Health Sciences, University of Edinburgh  |

**Annex Table 1 (in German)**  
**Participants Expert Committees**  
**b) Scientific Advisory Board**

|                              |  |
|------------------------------|--|
| Prof. Dr. Winfried Banzer    | Johann Wolfgang Goethe-Universität Frankfurt am Main, Institut für Sportwissenschaften   |
| Prof. Dr. Michael Böhme      | Landesgesundheitsamt Baden-Württemberg, Stuttgart  |
| Dr. Brigitte Borrmann        | Landeszentrum Gesundheit Nordrhein-Westfalen (LZG.NRW)   |
| Prof. Dr. Reinhard Busse     | Technische Universität Berlin, Fachgebiet Management im Gesundheitswesen   |
| Diana Droßel                 | diabetesDE – Deutsche Diabetes-Hilfe   |
| Prof. Dr. Michael Freitag    | Deutsche Gesellschaft für Allgemeinmedizin (DEGAM)<br>Carl von Ossietzky Universität Oldenburg, Department für Versorgungsforschung                                |
| Dr. Bernd Hagen              | Zentralinstitut für die kassenärztliche Versorgung in Deutschland (Zi)   |
| Prof. Dr. Hans-Ulrich Häring | Universitätsklinikum Tübingen, Medizinische Klinik IV  |
| Prof. Dr. Reinhard Holl      | Universität Ulm, Institut für Epidemiologie und medizinische Biometrie   |
| Prof. Dr. Andrea Icks        | Heinrich-Heine-Universität Düsseldorf, Medizinische Fakultät,<br>Institut für Versorgungsforschung und Gesundheitsökonomie   |
| Dr. Matthias Kaltheuner      | Gemeinschaftspraxis Kaltheuner – v. Boxberg, Leverkusen  |
| Dr. Klaus Koch               | Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (IQWiG), Ressort Gesundheitsinformation   |
| Dr. Joseph Kuhn              | Bayerisches Landesamt für Gesundheit und Lebensmittelsicherheit, Dienststelle Oberschleißheim  |
| Prof. Dr. Oliver Kuß         | Deutsches Diabetes-Zentrum (DDZ), Leibniz-Zentrum für Diabetes-Forschung an der<br>Heinrich-Heine-Universität Düsseldorf, Institut für Biometrie und Epidemiologie |
| Dr. Wolfgang Rathmann        | Deutsches Diabetes-Zentrum (DDZ), Leibniz-Zentrum für Diabetes-Forschung an der<br>Heinrich-Heine-Universität Düsseldorf, Institut für Biometrie und Epidemiologie |
| Helmut Schröder              | Wissenschaftliches Institut der AOK (WIdO)   |
| Dr. Ingrid Schubert          | PMV forschungsgruppe, Klinik und Poliklinik für Psychiatrie und Psychotherapie des<br>Kindes- und Jugendalters, Universität zu Köln                                |
| Prof. Dr. Jochen Seufert     | Deutsche Diabetes Gesellschaft<br>Universitätsklinikum Freiburg, Abteilung Endokrinologie und Diabetologie   |
| Dr. Heidrun Thaiss           | Bundeszentrale für gesundheitliche Aufklärung (BZgA)   |
| Dr. Til Uebel                | Deutsche Gesellschaft für Allgemeinmedizin (DEGAM)<br>Praxisgemeinschaft Uebel, Ittlingen  |

**Annex Table 1 (in German)**  
**Participants Expert Committees**  
**c) Expert Panel on Type 2 Diabetes Care**

|                           |   |
|---------------------------|---|
| Prof. Dr. Michael Freitag | Deutsche Gesellschaft für Allgemeinmedizin (DEGAM)<br>Carl von Ossietzky Universität Oldenburg, Department für Versorgungsforschung |
| Prof. Dr. Michael Böhme   | Landesgesundheitsamt Baden-Württemberg, Stuttgart   |
| Dr. Dirk Hochlenert       | Deutsche Diabetes Gesellschaft  |
| Dr. Dietmar Weber         | Deutsche Diabetes Gesellschaft  |
| Dr. Petra Kaufmann-Kolle  | AQUA-Institut, Göttingen  |

**Annex Table 2**  
**Template for consensus on the**  
**diabetes surveillance indicator set**  
 Own diagram

| No.  | Indicator  | Median | Min | Max | QRange | Q1 | Q3 | Type |
|--|--|--------|-----|-----|--------|----|----|------|
| <b>Field of activity 1: Reducing diabetes risk</b>                           |  |        |     |     |        |    |    |      |
| 1  | <b>Incidence</b>   | 9      | 9   | 9   | 0      | 9  | 9  | C    |
| 2  | <b>Prevalence gestational diabetes</b>                                       | 8      | 1   | 9   | 2      | 8  | 9  | C    |
| 3  | Prediabetes  | 8      | 3   | 9   | 3      | 5  | 8  | S    |
| 4  | <b>Overweight/obesity</b>  | 8      | 5   | 9   | 1      | 7  | 8  | C    |
| 5  | <b>Physical activity*</b>  | 7      | 4   | 9   | 3      | 5  | 8  | C    |
| 6  | <b>Smoking</b>   | 8      | 5   | 9   | 1      | 7  | 8  | C    |
| 7  | Sugar-sweetened beverages  | 7      | 1   | 9   | 5      | 3  | 8  | S    |
| 8  | Absolute diabetes risk   | 7      | 1   | 8   | 3      | 5  | 8  | S    |
| 9  | <b>Social deprivation</b>  | 8      | 1   | 9   | 1      | 7  | 8  | C    |
| 10   | Contextual factors   | 7      | 4   | 9   | 2      | 6  | 8  | S    |
|  | Metabolic syndrome   | 5      | 1   | 7   | 3      | 3  | 6  | M    |
|  | Traffic load   | 4      | 1   | 6   | 3      | 2  | 5  | M    |
|  | Walkability  | 6      | 1   | 8   | 3      | 4  | 7  | M    |
|  | Perceived versus objective diabetes risk                                     | 5      | 1   | 9   | 3      | 4  | 7  | M    |
|  | Participation in prevention  | 4      | 1   | 9   | 4      | 3  | 7  | M    |
| <b>Field of activity 2: Improving diabetes early detection and treatment</b> |  |        |     |     |        |    |    |      |
| 11   | <b>Prevalence of known diabetes</b>  | 9      | 8   | 9   | 0      | 9  | 9  | C    |
| 12   | <b>Prevalence of unknown diabetes</b>  | 8      | 5   | 9   | 1      | 8  | 9  | C    |
| 13   | <b>Disease management programme participation rate*</b>                      | 7      | 4   | 9   | 2      | 6  | 8  | C    |
| 14   | <b>Disease management programme quality objectives achievement</b>           | 8      | 6   | 9   | 1      | 7  | 8  | C    |
| 15   | <b>Quality of care</b>   | 8      | 3   | 9   | 1      | 7  | 8  | C    |
| 16   | <b>Treatment profiles</b>  | 8      | 3   | 9   | 2      | 7  | 9  | C    |
| 17   | <b>Health related quality of life*</b>                                       | 8      | 5   | 9   | 3      | 6  | 9  | C    |
| 18   | Check-up 35  | 7      | 1   | 8   | 5      | 3  | 8  | S    |
| 19   | <b>Screening gestational diabetes</b>  | 8      | 3   | 9   | 2      | 7  | 9  | C    |
| 20   | Patient satisfaction   | 7      | 1   | 9   | 5      | 3  | 8  | S    |
| 21   | <b>Age at diagnosis**</b>  | 9      |     |     |        | 7  | 9  | C    |
|  | Blood sugar measurement (included in 'quality of care')                      | 5      | 3   | 8   | 4      | 3  | 7  | M    |
|  | Medical rehabilitation services use  | 5      | 1   | 9   | 3      | 3  | 6  | M    |
|  | Care at the intersection of rehabilitation and disease management programmes | 4      | 1   | 9   | 4      | 3  | 7  | M    |
|  | Vaccination  | 4      | 1   | 7   | 4      | 2  | 6  | M    |
|  | Awareness, information needs, treatment preferences                          | 6      | 1   | 8   | 3      | 5  | 8  | M    |

**Annex Table 2** *Continuation*  
**Template for consensus on the**  
**diabetes surveillance indicator set**  
 Own diagram

| No.  | Indicator   | Median | Min | Max | QRange | Q1 | Q3 | Type |
|--|---|--------|-----|-----|--------|----|----|------|
| <b>Field of activity 3: Reducing diabetes complications</b>                              |   |        |     |     |        |    |    |      |
| 22   | <b>Depression*</b>  | 8      | 5   | 9   | 2      | 6  | 8  | C    |
| 23   | <b>Cardiovascular diseases</b>                            | 9      | 8   | 9   | 1      | 8  | 9  | C    |
| 24   | Risk of cardiovascular events                             | 7      | 1   | 9   | 5      | 3  | 8  | S    |
| 25   | <b>Diabetic retinopathy</b>                               | 9      | 7   | 9   | 0      | 9  | 9  | C    |
| 26   | <b>Diabetic nephropathy</b>                               | 9      | 7   | 9   | 1      | 8  | 9  | C    |
| 27   | <b>Renal replacement therapy**</b>                        | 9      |     |     |        | 7  | 9  | C    |
| 28   | <b>Diabetic (poly-)neuropathy**</b>                       | 9      |     |     |        | 7  | 9  | C    |
| 29   | <b>Diabetic foot syndrome**</b>                           | 9      |     |     |        | 7  | 9  | C    |
| 30   | <b>Amputations related to diabetes (OECD indicator)</b>   | 9      | 8   | 9   | 0      | 9  | 9  | C    |
| 31   | Complications during pregnancy                            | 8      | 3   | 9   | 3      | 6  | 9  | S    |
| 32   | <b>Frequency of severe hypoglycaemia*</b>                 | 8      | 1   | 9   | 2      | 6  | 8  | C    |
|  | Avoidable hospital admissions                             | 6      | 3   | 9   | 3      | 5  | 8  | M    |
| <b>Field of activity 4: Reducing the disease burden and overall costs of the disease</b> |   |        |     |     |        |    |    |      |
| 33   | <b>Direct costs*</b>                                      | 7      | 3   | 9   | 3      | 5  | 8  | C    |
| 34   | <b>Hospitalisation rate<sup>a*</sup> (OECD indicator)</b> | 7      | 1   | 8   | 2      | 5  | 7  | C    |
| 35   | <b>Reduced-earning-capacity pension*</b>                  | 7      | 1   | 9   | 3      | 5  | 8  | C    |
| 36   | <b>Mortality</b>  | 9      | 7   | 9   | 0      | 9  | 9  | C    |
| 37   | <b>Years of life lost</b>                                 | 8      | 3   | 9   | 2      | 7  | 9  | C    |
| 38   | <b>Healthy life years</b>                                 | 8      | 3   | 9   | 2      | 7  | 9  | C    |
| 39   | Years lived with disability                               | 7      | 1   | 9   | 5      | 3  | 8  | S    |
| 40   | Disability-adjusted life years                            | 8      | 2   | 9   | 3      | 5  | 8  | S    |
|  | Doctors' appointments                                     | 5      | 1   | 7   | 3      | 3  | 6  | M    |
|  | Days of sick leave  | 6      | 1   | 8   | 3      | 4  | 7  | M    |
|  | Early retirements   | 5      | 1   | 7   | 1      | 5  | 6  | M    |
|  | Indirect costs  | 6      | 1   | 9   | 2      | 5  | 7  | M    |

Evaluation template on indicator selection and relevance assessment (s. Figure 1):  Low relevance  Medium relevance  Highly relevant, relevant

Q: Quantile; Q1: 25% Quantile, Q3: 75% Quantile

C: Core indicator

S: Supplementary indicator

M: Indicator of medium relevance (indicators were initially excluded from the final indicator set for diabetes surveillance)

\* Supplementary indicator that became a core indicator after considering the reviewed indicators for type 2 diabetes care

\*\* Adopted in the indicator set for diabetes surveillance after review of type 2 diabetes treatment indicators

<sup>a</sup> Formerly: days spent in hospital

OECD: Organisation for Economic Co-operation and Development

Bold type: Core indicator

## Imprint

### Journal of Health Monitoring

#### Publisher

Robert Koch Institute  
Nordufer 20  
D-13353 Berlin, Germany

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ISSN 2511-2708

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the portfolio of the German Federal Ministry of Health

Journal of Health Monitoring · 2018 3(S3)  
DOI 10.17886/RKI-GBE-2018-064  
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# First results from the study ‘Disease knowledge and information needs - Diabetes mellitus (2017)’

## Abstract

Very little research has been undertaken into what people in Germany know about diabetes, the information they may require about the condition, where they look for such information and how they rate the information currently available. In 2017, the Robert Koch Institute (RKI) carried out a nationwide telephone survey aimed at answering these questions. The study entitled ‘Disease knowledge and information needs - Diabetes mellitus (2017)’ focused on people aged at least 18 years. A total of 2,327 people without diabetes and 1,479 people with diagnosed diabetes were interviewed for the study. First results show that 56.7% of people without diabetes and 92.8% of those with diabetes rate their knowledge about the condition as ‘very good’ or ‘good’. People without diabetes were found to have the strongest need for information in terms of ‘lifestyle changes, health promotion and disease prevention’, whereas respondents with diabetes stressed the strongest need for information about ‘treatment and therapy’. Almost a third of respondents without diabetes have actively sought information about diabetes at least once, mostly via print media. Patients with diabetes stated that their general practitioner was their most frequent source of information about the condition. In both groups, about half of respondents reported that they found it difficult to judge the trustworthiness of the information published in the media about diabetes. The results of the study form part of the German National Diabetes Surveillance, which is coordinated by the RKI. The data are also intended to be used by the Federal Centre for Health Education to develop a strategy to improve the information provided about diabetes.

DIABETES MELLITUS · TELEPHONE SURVEY · DISEASE KNOWLEDGE · DISEASE PERCEPTION · INFORMATION-SEEKING BEHAVIOUR

## 1. Introduction

Diabetes mellitus is a chronic metabolic disorder characterised by elevated blood-sugar levels [1]. The condition can be divided into a number of different types. Type 1 diabetes is an autoimmune disease that is thought to be primarily caused by a genetic predisposition and

environmental factors [2, 3]. In contrast, genetic but also individual, social and contextual factors such as the person’s living environment or health care conditions as well as the way in which these factors interact with one another play a role in the development of a much more common form: type 2 diabetes [4-6]. A family history of diabetes, lifestyle and individual patterns of behaviour such



### Info box 1: Study 'Disease knowledge and information needs - Diabetes mellitus (2017)'

**Data holder:** Robert Koch Institute

**Objectives:** To provide reliable information from adults in Germany about their perception of the risk associated with diabetes mellitus, their perception and knowledge of the condition, their information needs and information-seeking behaviour, the subjective burden of diabetes and the quality of care

**Survey method:** Telephone interview

**Population:** The German-speaking general population aged at least 18 years with or without a diagnosis of diabetes living in private households who were reachable by telephone

**Sampling:** Individual private households in Germany that are reachable using randomly selected landline or mobile telephone numbers

**Sample size:** 2,327 people without diabetes (1,313 women, 1,014 men) and 1,479 people with diagnosed diabetes (740 women, 739 men)

**Response rate:** 17.9% (of all households reachable by telephone in Germany)

**Survey period:** September - November 2017

**Data protection:** the participants were informed about the study's aims and content and provided their informed consent to participate in the study

More information in German is available at:  
[www.rki.de/krankheitswissen\\_diabetes](http://www.rki.de/krankheitswissen_diabetes)

as smoking, a lack of physical activity and dietary aspects are associated with a higher risk of type 2 diabetes [4-6].

Individual patterns of behaviour can be influenced by a variety of subjective factors which may play a key role in the condition but have often been under-studied. These factors include an individual's subjective perception of their risk of developing diabetes [7], their knowledge about the disease [8], their perception of the condition [9] and their health-related information behaviour [10, 11]. In the context of this study, health-related information behaviour refers to the issues of whether people actively seek information about health related topics and, if so, the sources of information that they turn to. Ultimately, contextual factors such as social support and the conditions associated with care also affect people's risk of developing diabetes [12]. Moreover, international studies have shown that the perception of the risk associated with complications linked to diabetes, the way in which people deal with the condition, the social support they receive, as well as various aspects linked to care and access to the information required to deal with the disease can influence the way in which the disease develops over time [13-19].

According to data from the Robert Koch Institute (RKI), an estimated 6.7 million adults in Germany are affected by diagnosed or undiagnosed diabetes [20, 21]. Although diabetes can be treated with medication, the disease is still associated with serious complications and increased risk of mortality [22, 23]. In addition, diabetes also incurs a large amount of direct and indirect costs to society, mainly because of these complications [24]. In order to tailor healthcare services towards

people's needs and requirements, it is essential that data be collected on the burden caused by the disease, on people's knowledge about the condition, and the need for information and support among people with diabetes. Furthermore, data from the general population - in particular on knowledge about the disease, disease perception and, above all, information needs and information-seeking behaviour - are vital if measures in population-wide health promotion and the primary prevention of type 2 diabetes are to be effective.

At the present time, only a limited number of population-representative data are available on these issues at the national level for people with or without diagnosed diabetes [25-29]. Moreover, the data on information-seeking behaviour and information needs [26, 28] is fragmentary and only a small proportion of participants with diabetes took part in these studies [26, 29]. The 'Disease knowledge and information needs - Diabetes mellitus (2017)' study (Info box 1), therefore, aimed to close these gaps in the data. In order to do so, the study collected data on knowledge about the disease, disease perception, the risk of diabetes and the risk associated with diabetes-related complications, subjective aspects of the disease as well as specific diabetes-related information (Info box 2). This article aims to set out the study's first descriptive findings for the key topics of knowledge about disease, disease perception and diabetes-related information from people with and without diabetes.

Finally, the study also provides a foundation with which to develop the educational and communications-related strategy on diabetes that is currently being drawn up by the Diabetes Office of the Federal Centre

### Info box 2: Diabetes-related information

Diabetes-related information includes the following aspects:

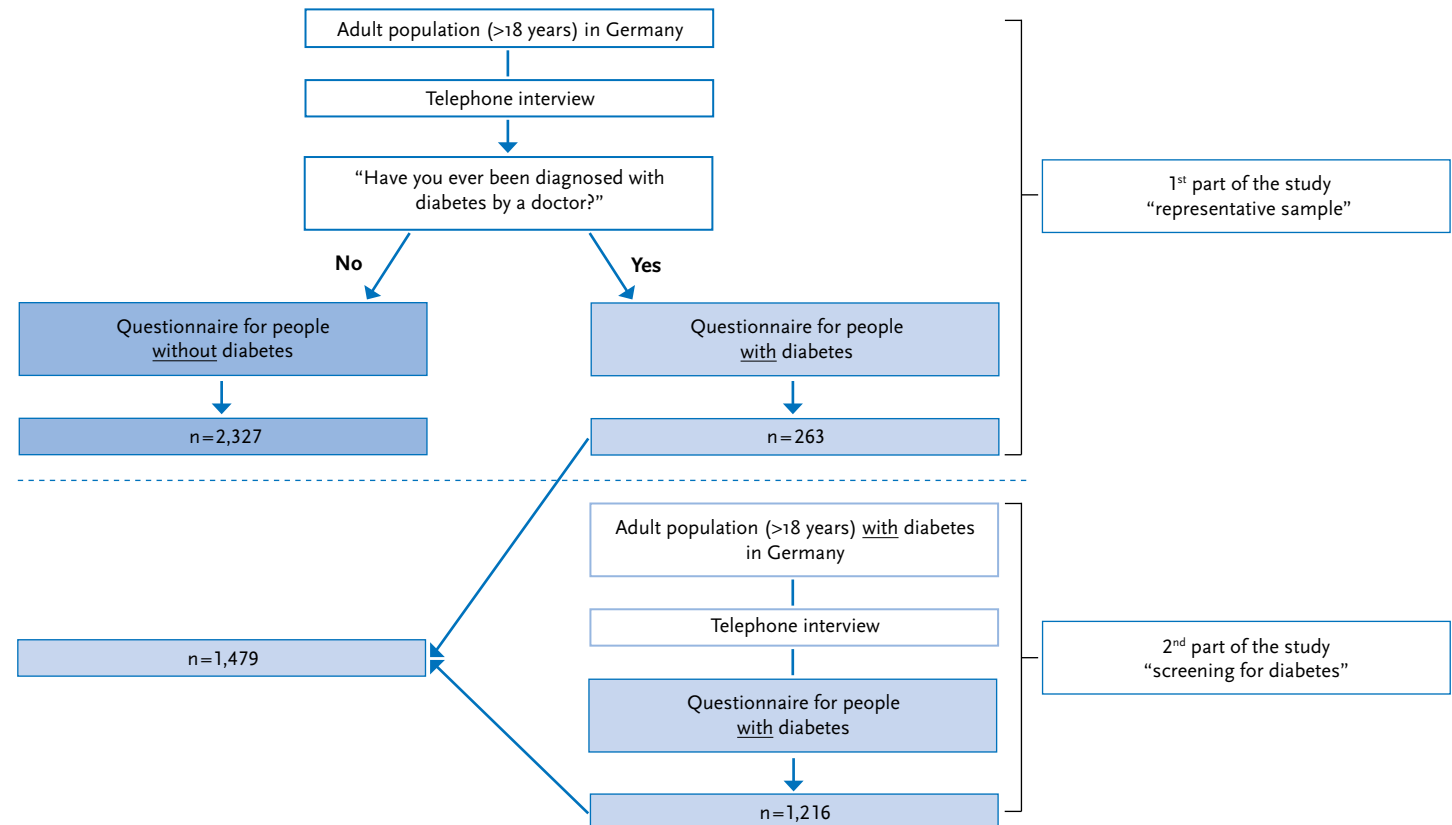
- (1) **Perceived level of information**  
How informed do respondents feel about different diabetes-related topics?
- (2) **Subjective information needs**  
Which diabetes-specific topics do respondents require more information about?
- (3) **Information-seeking behaviour**  
Are respondents actively looking for information and, if so, which sources do they turn to?
- (4) **The perceived trustworthiness and clarity of information about diabetes published in the media**

for Health Education (BZgA). This strategy is to reflect people's current needs and will be tailored to specific target groups [30]. The goal is to improve diabetes prevention, including primary prevention (reducing the incidence of diabetes), secondary prevention (early detection of previously unknown diabetes) and also tertiary prevention (prevention of the progression of diabetes). Furthermore, the results of the study have been integrated into the National Diabetes Surveillance which is currently being established at the RKI [31].

## 2. Methods

### 2.1 Study design and sample

The study 'Disease knowledge and information needs - Diabetes mellitus (2017)' (Info box 1) was undertaken in two parts that were conducted using a standardised telephone survey (Figure 1). The first part of the study focused on the German-speaking general population aged at least 18 years (including people with diabetes); the second part only included people with diabetes.



**Figure 1**  
Flowchart for sampling in the study  
'Disease knowledge and information needs -  
Diabetes mellitus (2017)'  
Own diagram

**Around half of adults without diabetes and over 90% of adults with diabetes rate their knowledge of the condition as 'good' or 'very good'.**

Sampling was undertaken using the ADM Telephone Survey System, which is provided by Arbeitskreis Deutscher Markt- und Sozialforschungsinstitute e.V. (ADM) [32]. This system can be used together with a special procedure to generate all usable German landline and mobile phone numbers. This even includes numbers that are not registered in public telephone directories. The study applied the dual-frame principle, which provided a sample of 60% landline numbers and 40% mobile telephone numbers. This method ensured a representative sample of all potentially reachable private households in Germany. A detailed description of the methodology used by the RKI for telephone interviews and the sampling applied in this case will be provided in an article that is due to be published in 2018 in the Journal of Health Monitoring [33].

Interviewees (target persons) for the first part of the study were randomly selected from multi-person households using the Kish Selection Grid method. For this procedure, all potential target persons have the same probability of selection. The number of adults in the household in question and their age are first determined in order to draw up a particular sequence of these individuals. An algorithm is then employed as part of computer-assisted random selection to select the target person for interview. In the case of this study, the aim was to gain a sample of 2,500 people without diabetes with which to assess the different groups within the general population and to provide stratified analysis with the lowest possible level of error tolerance.

The second part of the study focused on people with a physician diagnosed diabetes. The aim was to gain a

sample of 1,500 individuals (including those with diabetes from the first interview part) also in order to ensure that stratified analysis had the lowest possible tolerance of error. The study was implemented using a direct screening procedure to find participants for the category 'people with diabetes'. In these cases, the person who answered the call (the contact person) was asked whether they or another person in the household had ever been diagnosed with diabetes by a physician (the target person). If a household had more than one potential target person, in other words, more than one person with a physician diagnosed diabetes, the target person was randomly selected using the Kish selection grid [33].

## 2.2 Study procedure

Two questionnaires were developed for the study: one for people with a physician diagnosed diabetes, and one for those without. The two questionnaires deliberately used overlapping questions so that the results for people with diabetes could be compared to those without the condition. Wherever possible, the questions were selected using validated German-language instruments. In case only English-language instruments were available they were translated into German before translating them back into English (forward-backward translation) [34, 35]. The translations were shown to be very similar to the original texts.

A number of further questions had to be newly developed for the study to cover other topics of interest. A detailed description of this process and the psychometric properties of the selected constructs and instru-

ments is currently being summarised for a methodological publication. Cognitive testing was conducted to assess how understandable the questions and certain terminology were. Furthermore, in order to assess the completeness of the questionnaires, find out how long the interviews would take, and address any remaining ambiguities, a standard pretest was carried out in the field between the 23 August and 17 September 2017 (203 participants: 28 with diabetes, 175 without). The results from the pretest were used to shorten the questionnaires to an average of 32 minutes (for respondents without diabetes) and 43 minutes (for respondents with diabetes) and to adapt the questions.

The first part of the main study was conducted between 18 September and 31 October 2017, with the second taking place between 1 November and 30 November 2017. 2,592 interviews were conducted for the first part of the study (the representative part). This figure also includes 263 people who had been diagnosed with diabetes. The response rate, which was calculated using criteria from the American Association for Public Opinion Research (AAPOR) (in this case: response rate 3, proportion of interviews conducted in relation to all probable households in the population) was 17.9% [36]. 1,216 interviews were conducted for the second part of the study.

Two respondents were excluded from the first part of the study due to an unclear answer to the question 'Have you ever been diagnosed with diabetes by a doctor' ('don't know') or missing information about the federal state of residence (this was needed to calculate the weighting factors). The final sample, therefore, consisted

of 2,327 people without a diagnosis of diabetes and 1,479 people with a physician diagnosed diabetes.

### 2.3 Definition of diabetes

Participants with diabetes were identified using the question 'Have you ever been diagnosed with diabetes by a doctor?'. This group was further subdivided into: 1) Diabetes in the last 12 months: in this case, a participant either answered 'Yes' to the follow-up question as to whether they had had diabetes in the last 12 months, or stated that they were undergoing medical treatment for diabetes ( $n=1,396$ ); 2) No diabetes in the past 12 months: the respondent answered 'No' to the question about whether their diabetes had been present in the last 12 months, and also provided no indication that they were currently undergoing medical treatment for diabetes ( $n=89$ ); 3) Gestational diabetes: the respondent answered 'Yes' to the question as to whether they were pregnant at the time of their diagnosis ( $n=52$ ). A current case of gestational diabetes was identified by asking whether diabetes had been diagnosed during a current pregnancy ( $n=1$ ). Of the female participants who had ever been diagnosed with gestational diabetes, twelve women had type 2 diabetes at the time of the study.

### 2.4 Concepts and instruments

The study collected information on disease knowledge, disease perception, diabetes risk, the risk of complications, diabetes-related information, health-related behaviour and lifestyle, health care services utilisation, the

characteristics of disease, diabetes self-management, the subjective burden of disease and mental health. An overview of all of the subject areas and instruments employed in the survey can be found in [Annex 1](#). This article presents the first results for selected topics, including disease knowledge, disease perception and diabetes-related information.

#### Survey instruments used for respondents without diabetes

In order to study knowledge about disease, data was collected about the respondents' perceived level of knowledge about diabetes [37] and their objective level of knowledge about the disease. [Annex 2](#) provides a list of the questions that were posed and acceptable response options.

The topic of disease perception included an assessment of whether the respondents' considered diabetes to be a serious disease [38], and whether they believed that diabetes was a condition that people had for the rest of their life [39]. In addition, data was also collected on various aspects of stigmatisation [26, 40].

In the case of diabetes-related information, data was gathered on the respondents' perceived level of information and personal need for information in terms of the causes of diabetes, the course of the disease, its treatment and therapy, the complications it can lead to, lifestyle changes as well as health promotion and prevention [41]. With regard to information-seeking behaviour, participants who had previously informed themselves about diabetes were asked which sources of information they had used to do so [29]. The remaining participants were asked where they gained information

about general health issues [29]. In each case, several sources of information could be provided.

Respondents who had already actively sought information about diabetes were also asked about their view of the trustworthiness and clarity of the information about diabetes that is published in the media [42].

#### Survey instruments used for people with diabetes

Respondents with diabetes were asked the same questions about their level of knowledge about diabetes and about the severity of diabetes that were posed to respondents without the condition. However, the question as to whether a respondent believed that they would have diabetes for the rest of their life [43] and the questions linked to stigmatisation [26, 40] were only posed to respondents who had stated that they had had diabetes in the last 12 months. These questions only differed in perspective from those posed to people without diabetes: people with diabetes were not only asked about diabetes in general, but also about their own condition. Moreover, the questions on their perceived level of information, individual information needs and sources of information were posed for a broader range of topics than for people without diabetes. For example, data was also collected on support services, helplines and sources of information [41]. Finally, both groups were also asked the same questions about the trustworthiness and clarity of the information published in the media.

## 2.5 Statistical analysis

In order to ensure that a sample is representative of the general population, it is important to take into account all relevant population groups, especially those who are less willing to participate in the study. As such, this study also employed a weighting factor. First, the distribution of household sizes in the sample was adjusted to reflect the known distribution within the population in Germany (as of 31 December 2016) [44]. The sample was then adjusted to take into account the different probabilities of selection. This was followed by a standard method of calculation that is recommended by the ADM and that takes into account the study's dual-frame design [45]. Finally, adjustment weighting was applied. For the representative part of the study (the first section with 2,591 interviews including the 263 interviews of people with diabetes), a gradual weighting in terms of age x gender (in 7 x 2 steps), education x gender (in 3 x 2 steps) and federal state (in 16 steps) was implemented to ensure that these characteristics were distributed in a manner that was comparable to the German-speaking, resident population aged at least 18 years. Data supplied by the Federal Statistical Office were used (as of 31 December 2016) to make these adjustments [44].

As the Federal Statistical Office's data do not enable conclusions to be drawn about individuals with diabetes among the German-speaking resident population aged at least 18 years they could not be applied to the sample of respondents with diabetes (1,479 interviews including 1,216 from the screening conducted for diabetes and 263 interviews from the representative part of the sur-

vey). Instead, a gradual weighting was implemented for age x gender (in 6 x 2 levels) and education x gender x age (in 3 x 2 x 2 levels) to reflect the distribution of people with diabetes identified by the German Health Update study (GEDA) 2012 (n=1,828) [46]. The GEDA 2012 sample was used because the study applied a comparable methodology. The distributions identified by GEDA 2012 were assumed to correspond to those within the current German-speaking resident population aged at least 18 years.

Finally, a third weighting factor was employed to enable comparisons to be made between respondents with and without diabetes in the overall data set. This was necessary because the screening method used in the study led to a significant overrepresentation of respondents with diabetes in the overall sample. The weighting factor adjusted the ratio of respondents with and without diabetes to ensure that it reflected the level identified by the representative part of the study; as such, the proportion of respondents with diabetes in the overall data set was the same as the proportion identified in the representative part of the study (9.7%).

All results presented here were calculated using the respective weighting factor. Averages or percentages (including 95% confidence intervals, 95% CI) were calculated using SAS (Version 9.4, SAS Institute Inc., Cary, NC). The results from both samples are presented as totals and separately for women and men ([Annex 3](#)). In addition, differences in terms of educational group (low, middle and high) were examined ([Annex 4](#)). These groups were classified using the CASMIN scale (Comparative Analysis of Social Mobility in Industrial Nations)



[47], which takes both general and vocational training into account.

### 3. Results

#### 3.1 Population without diabetes

In total, 2,327 people (1,313 women, 1,014 men) between the age of 18 and 97 years without a previous diagnosis of diabetes participated in the telephone survey. Their average age was 50.4 years (women 51.7 years, men 48.3 years).

##### Knowledge about the disease

More than half of the participants without diabetes perceived their knowledge about the disease as very good or good (Figure 2). The proportion of people who perceived their own level of knowledge as very good was almost twice as high among women as men. Respondents with low levels of education were more likely to rate their knowledge of diabetes as 'non-existent' than

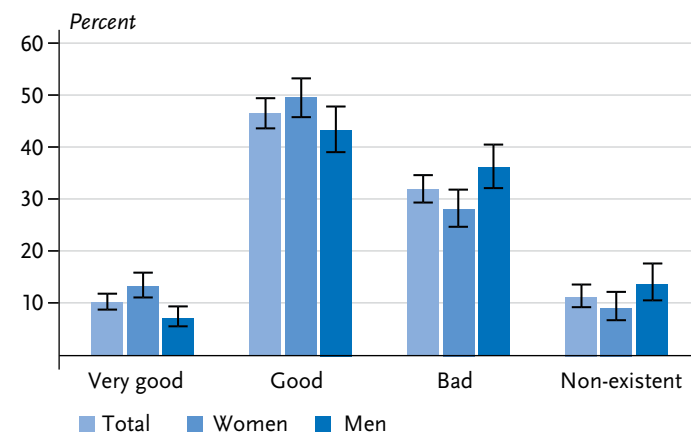
people with middle or high levels of education. Furthermore, respondents with low or middle levels of education also perceived their knowledge of diabetes as very good less frequently than those with high levels of education (Annex 4 Table 3).

A total of six questions were used to collect data about the respondents' objective level of knowledge about diabetes (Annex 3 Table 1). The participants were most frequently aware of the fact that people with diabetes had elevated blood-sugar levels (66.2%) and that the symptoms of diabetes usually develop gradually (62.6%). Almost half of the respondents (49.6%) were aware that more people are affected by type 2 diabetes in Germany than type 1. By contrast, less than a third of respondents (31.3%) knew that diabetes was not a blood cell disorder. Respondents were the least familiar with type 1 diabetes. Only 26.9% of respondents knew that type 1 diabetes does not disappear with puberty and only 17.2% knew that it cannot be treated with tablets. An educational gradient was identified among answers to the question as to whether diabetes was a blood cell disorder. Four further questions were answered correctly more frequently by respondents with high levels of education than those with low levels of education (Annex 4 Table 1).

##### Disease perception

Almost two-thirds of respondents (65.0%) considered diabetes to be a serious or very serious disease (Annex 3 Table 2). In contrast, only 1.2% of respondents felt that diabetes was not a serious condition, while 12.6% of respondents expressed no opinion on this issue. The results were similar among women and men.

**Figure 2**  
Self-assessed level of knowledge about diabetes among adults without diagnosed diabetes according to gender (n=1,305 women, n=1,008 men)  
Source: Disease knowledge and information needs - Diabetes mellitus (2017)





## Almost one third of respondents without diabetes have already informed themselves about diabetes.

Respondents with low levels of education rated diabetes less often as not or moderately serious compared to the two higher educational groups ([Annex 3 Table 3](#)).

60.1% of respondents believe that diabetes is a condition that people have for the rest of their lives. However, 28.2% rejected outright or partially disagreed with this statement ([Annex 3 Table 2](#)). The results were similar for women and men and across the three educational groups ([Annex 4 Table 2](#)).

A small proportion of respondents believed that people with diabetes are discriminated against ([Annex 3 Table 2](#)). Overall, 20.6% felt that people with diabetes are often unable to meet their everyday needs, and 28.8% believe that individuals with diabetes cause the disease themselves through an unhealthy lifestyle. Only 14.0% of respondents felt that people with diabetes face disadvantages. No differences according to gender were identified in attitudes towards people with diabetes. Participants with middle or high levels of education were more likely than those with low levels of education to believe that people with diabetes can meet their everyday needs ([Annex 4 Table 2](#)).

### Diabetes-related information

#### *Perceived level of information*

44.0% of participants felt that they were well or very well informed about the 'causes of diabetes'; between 36.0% and 41.2% felt the same way about the 'course of the disease', 'treatment and therapy' and 'complications'. Furthermore, this was the case with 48.9% of respondents when it came to 'lifestyle changes, health promotion and disease prevention'. Women considered

themselves better informed than men on all issues. Participants with lower and middle levels of education more frequently felt completely uninformed about these issues than those with a high level of education ([Annex 4 Table 3](#)).

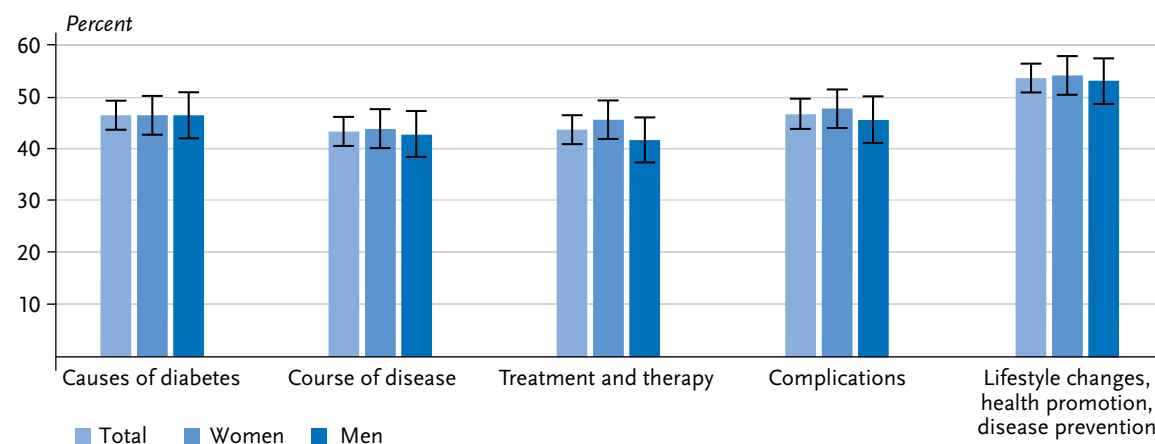
#### *Subjective information needs*

The greatest need for information was identified for the issues of 'lifestyle changes, health promotion and disease prevention' ([Figure 3](#)). No differences were found between women and men in this regard. The need for information on 'causes of diabetes', 'course of the disease' and 'complications', was higher among people with a middle level of education than among those with a high level of education ([Annex 4 Table 4](#)). Participants who felt uninformed about the 'causes of diabetes', 'course of the disease', and 'complications' also expressed a greater need for information than those who saw themselves as well or very well informed (data not shown).

#### *Information-seeking behaviour*

Almost a third (31.0%) of respondents stated that they had actively sought information about diabetes at least once. However, this was more common among women (37.0%) than men (24.7%). Printed information such as brochures, newspapers, magazines and books were the most commonly used source of information (83.9%), followed by websites on health and diabetes (49.3%), general practitioners and other doctors (47.2%) as well as radio or television broadcasts (43.4%). In this context, women more frequently cited printed information than men (88.9% compared to 75.9%). Respondents with low levels of education more frequently sought

**Figure 3**  
Subjective information needs about diabetes-specific issues among adults without diagnosed diabetes according to gender (n=1,313 women, n=1,014 men)  
Source: Disease knowledge and information needs - Diabetes mellitus (2017)

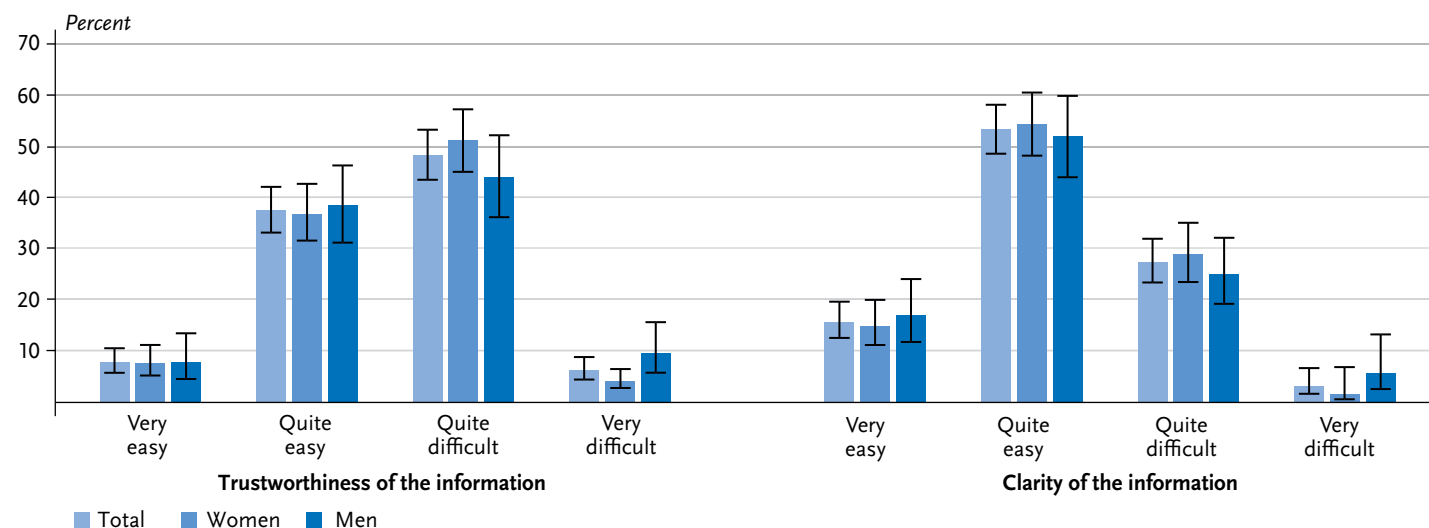


**Respondents without diabetes were particularly in need of information about 'lifestyle changes, health promotion and disease prevention'.**

information from their general practitioner or other doctors than respondents with middle or high levels of education (65.9%, 43.4% and 41.8% respectively; data not shown). The most frequently mentioned sources of information on health issues in general were general practitioners or other doctors (72.0%), followed by printed

information (69.6%), radio or television broadcasts (60.0%) and websites covering health issues (53.7%). Participants with middle or high levels of education use websites more frequently as sources of information than those with low levels of education (70.6%, 60.0% and 35.5% respectively; data not shown).

**Figure 4**  
Perceived level of trustworthiness and clarity of information among adults without diagnosed diabetes according to gender. Only participants who had already actively sought information about diabetes were asked this question (n=550 women, n=318 men)  
Source: Disease knowledge and information needs - Diabetes mellitus (2017)



### *The perceived trustworthiness and clarity of information*

More than half (54.7%) of people who had previously actively sought information about diabetes found it difficult or very difficult to judge whether the information published in the media about the condition was trustworthy (Figure 4). In contrast, 69.3% of respondents found it very easy or fairly easy to understand this information. No gender or educational differences were identified (Annex 4 Table 7).

### 3.2 Population with diabetes

In total, 1,479 people (740 women, 739 men) aged between 18 and 96 years with a physician diagnosed diabetes participated in the telephone survey; 263 of these respondents had taken part in the representative part of the study. Data for the prevalence of diabetes in the representative survey was gathered by asking respondents whether they had ever been diagnosed with diabetes; the prevalence rate was 9.7% (8.2%-11.5%). The average age of all participants with diabetes was 64.9 years (women 65.3 years, men 64.5 years). The mean duration of diabetes was 14.3 years (women 13.7 years, men 15.0 years). In total, 1,386 participants (92.1%) who had ever been diagnosed with diabetes had had diabetes during the last 12 months. The prevalence of diabetes in the last 12 months was 8.7% (7.2%-10.5%). Respondents who had diabetes within the last 12 months were also asked about the type of diabetes they were affected by: 14.1% of respondents who had had diabetes over the last 12 months stated that they had type 1 diabetes; 80% that they had type 2 diabetes; 1.4% another type; and 4.6%

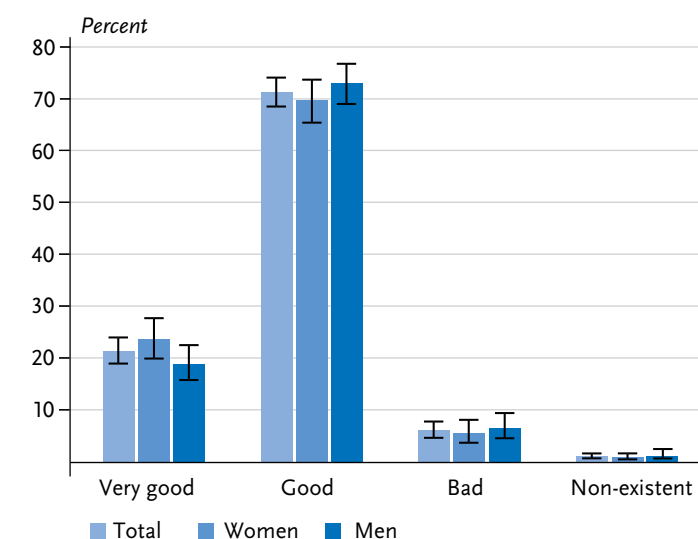
did not know which type of diabetes they were affected by. In terms of treatment, 90.2% of these respondents stated that they were receiving medication such as tablets, insulin or other injectable hypoglycaemic drugs. 7.4% were only in receipt of treatment through diet and sport, and 2.4% of these respondents said they were not receiving any treatment at all.

### *Knowledge about diabetes*

92.8% of respondents who had received a diagnosis of diabetes at some point viewed their knowledge of the condition as good or very good (Figure 5). The self-assessed level of knowledge was similar between women and men and across the various educational groups (data not shown).

**Figure 5**  
Self-assessed level of knowledge about diabetes among adults with diagnosed diabetes according to gender (n=732 women, n=732 men)

Source: Disease knowledge and information needs - Diabetes mellitus (2017)



## Respondents with diabetes were particularly in need of information about the 'treatment and therapy' of diabetes.

### Disease perception

Of the respondents who had ever been diagnosed with diabetes, 55.7% viewed the condition as serious or very serious ([Annex 3 Table 4](#)). 91.1% of respondents who had diabetes in the last 12 months agreed or completely agreed that they would have diabetes for the rest of their lives ([Annex 3 Table 4](#)). The levels of disease perception were similar among women and men and across educational groups ([Annex 4 Table 5](#)).

Regarding stigmatisation, 6.1% of respondents who had diabetes over the last 12 months felt that they often faced disadvantages because of their diabetes ([Annex 3 Table 4](#)). 22.3% of respondents felt that other people believed that they caused their diabetes themselves due to their unhealthy lifestyles. Men were more likely to agree with this statement than women. Furthermore, respondents with middle levels of education were more likely than those with a high level of education to believe that other people assumed that they would not be able to meet their day-to-day needs ([Annex 4 Table 5](#)).

### Diabetes-related information

#### Perceived level of information

Respondents who had received a diagnosis of diabetes at some point in time felt the least informed about 'support services, helplines and sources of information' ([Annex 3 Table 5](#)). Only 57.1% of these individuals believed that they were well or very well informed about these issues, although more than three quarters felt that they were well or very well informed about other diabetes-related topics. 72.2% stated that they were well or very well informed about 'lifestyle changes, health promotion and disease prevention'. No serious differences were identified between women and men. Participants with low levels of education more frequently felt completely uninformed about all of these issues than those with higher levels of education ([Annex 4 Table 6](#)).

#### Subjective information

The area where the need for information was highest was 'treatment and therapy'; it was lowest for 'the causes of

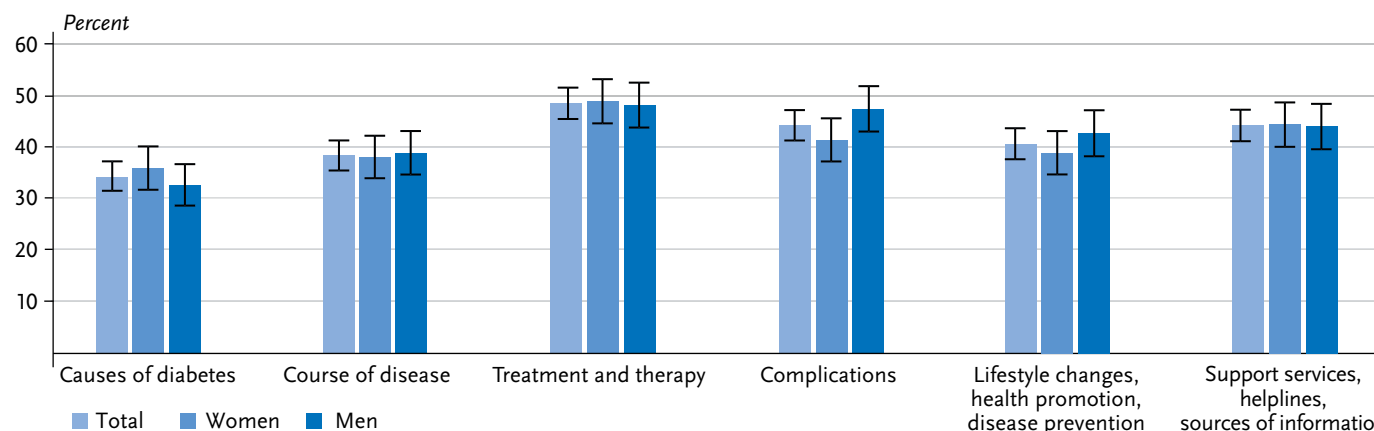


Figure 6

Subjective information needs about diabetes-specific issues among adults with diagnosed diabetes according to gender (n=740 women, n=739 men)

Source: Disease knowledge and information needs - Diabetes mellitus (2017)

## About half of respondents found it difficult to judge the trustworthiness of the information about diabetes published in the media.

diabetes' (Figure 6). Women and men have a similar need for information. Respondents with middle levels of education had a higher need for information about 'the causes of diabetes', 'course of the disease', 'treatment and therapy' and 'complications' than respondents with a high level of education. People with a lower level of education had the highest need for information about 'the causes of diabetes' (Annex 4 Table 7). On all issues except for 'lifestyle changes, health promotion and disease prevention', participants who considered themselves poorly informed or completely uninformed about these issues had a greater need for information than those who considered themselves well or very well informed (data not shown).

### Information-seeking behaviour

Participants who have been diagnosed with diabetes stated their general practitioners or other doctors who were treating their diabetes as their most frequent source

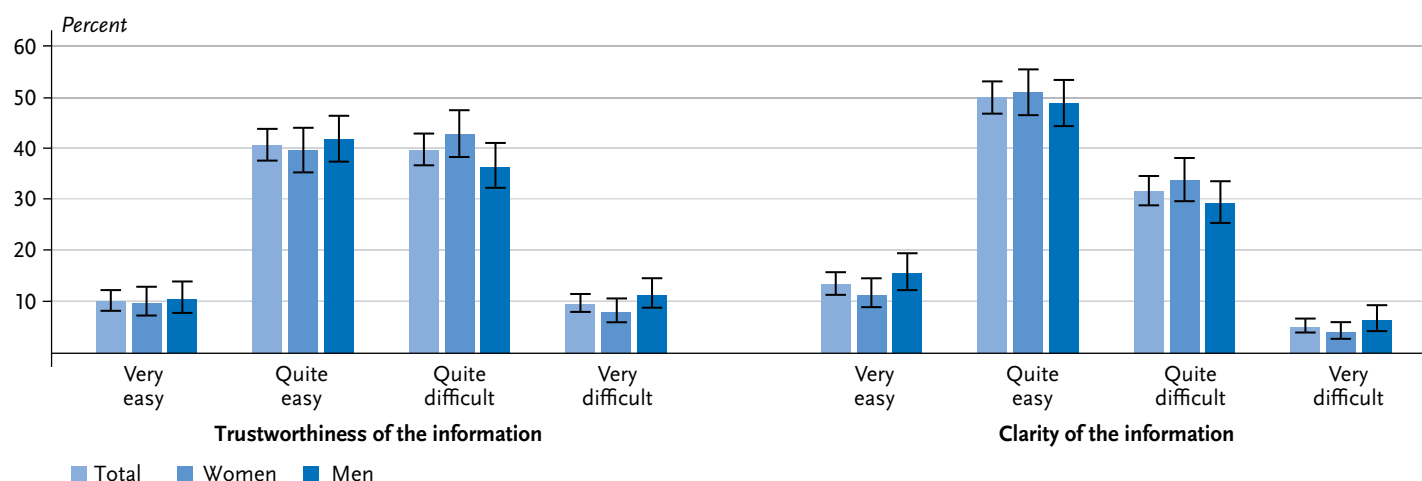
of information (91.8%). This was followed by printed information (83.7%), their diabetologist (59.6%), information programmes for people with diabetes (57.6%) and diabetes advisors (45.6%). Respondents with a low level of education indicated that diabetologists were their most frequent sources of information less frequently than people with high levels of education (54.0% and 67.5% respectively). Similarly, they were less likely than those with a high level of education to emphasise printed information as their main source of information (79.7% compared to 91.0%) or diabetes websites (24.0% compared to 55.3%) (data not shown).

### Perceived trustworthiness and clarity of information

About half of the respondents who had ever been diagnosed with diabetes found it difficult or very difficult to judge the trustworthiness of information published in the media about diabetes (Figure 7). Nevertheless, 63.2% stated that they found this information very easy or

**Figure 7**  
Perceived level of trustworthiness and clarity of information among adults with diagnosed diabetes according to gender (n=740 women, n=739 men)

Source: Disease knowledge and information needs - Diabetes mellitus (2017)



fairly easy to understand. No differences were identified between women and men on this issue. Respondents in this group with a high level of education stated more frequently that it was easy to understand the information published about diabetes in the media than those with low or middle levels of education (Annex 4 Table 7).

### 3.3 Comparison of the population with and without diabetes

Respondents who had ever been diagnosed with diabetes rated their knowledge of the condition as very good or good more frequently than those without diabetes. In addition, people who had ever been diagnosed with diabetes were less likely to view the disease as very serious or serious than respondents without diabetes. Participants who had ever received a diagnosis of diabetes felt better informed about all topics than those without diabetes. Respondents with diabetes expressed less of a need for information about 'the causes of diabetes' and on 'lifestyle changes, health promotion and disease prevention'; no differences were identified between the information needs of the two groups in terms of the remaining topics. Around half of both the respondents with and without diabetes found it difficult to judge the trustworthiness and clarity of information that is published in the media about diabetes.

## 4. Discussion

The method established at the RKI of using nationwide telephone health surveys was employed to collect comprehensive information from adults in Germany about

their knowledge, disease perception, information needs and information-seeking behaviour within the context of diabetes. The study included interviews from adults with a diagnosis of diabetes and those without the condition. In addition to collecting the same information from both samples, specific data was also collected for people with and without diabetes. The results can be stratified according to socio-demographic, psychosocial and - in the case of respondents with diabetes - disease-specific characteristics. The first descriptive results show that the study can help close important information gaps and help provide the foundation for the target-group-sensitive information and communications strategy that is being developed at the BZgA.

### 4.1 Discussion of the first results

It seems that hardly any studies have collected data from the general population about diabetes knowledge or disease perception. The results presented here show that only about half of the surveyed adults without diabetes felt that they were well or very well informed about diabetes. This corresponds to the results of a survey conducted of the general population by forsa, an opinion research institute, on behalf of Krankenkasse Knappschaft in 2016 [28]. The answers to questions about respondents' knowledge of diabetes also led to the identification of significant gaps in people's knowledge, some of which are more prevalent among men than women or are associated with a respondent's level of education. A 2016 study commissioned by the magazine Diabetes Ratgeber, which was carried out by GfK, a society for



consumer research, also identified gaps in knowledge among adults without diabetes, such as with regard to a cure and the treatment of the condition [26]. Furthermore, 54% of the present study's participants stated that they knew next to nothing about the triggers of diabetes [26]; in the forsa survey, 36% of respondents did not know the causes of type 2 diabetes [28]. In this context, the present study shows that only 45% of respondents felt very well or well informed about the causes of diabetes.

In the survey conducted for the Diabetes Ratgeber, 47% of participants without diabetes and 54% of those with diabetes rated the disease as serious. This result differed from our study, where 65% of respondents without diabetes considered the condition to be a serious or very serious condition. This difference is probably explained by the difference in the questions posed by both studies. Our study asked the participants directly whether they considered diabetes to be a serious disease, the Diabetes Ratgeber survey asked participants for their opinion of the following statement: 'Since diabetes can now be treated well with insulin or tablets, it is no longer a serious illness.' Our study also found less agreement among respondents with and without diabetes that people with diabetes had caused their condition through their unhealthy lifestyle than was identified by the Diabetes Ratgeber study. Finally, our study also identified a similar proportion of people with diabetes who felt disadvantaged or discriminated against compared to the results of the German 'Diabetes Attitudes Wishes and Needs 2' study (DAWN-2, 2012) and the Diabetes Ratgeber study [26, 48].

Very few studies have been conducted into the specific information needs concerning diabetes among people with and without the condition [49]. A recent systematic review by Kuske et al. [50] on information-seeking behaviour shows that people with diabetes most frequently look for information about the treatment process; this is consistent with the results of our study. In terms of socio-demographic differences between information needs, the first results from our study indicate a need for further research. However, this study can make an important contribution to this situation as it provides for in-depth analyses. A systematic review by Pieper et al. from 2015 [27] identified important information needs among the general population in Germany in terms of the causes, prevention, treatment and course of diabetes. In our study, the need for information among people without diabetes was highest when it came to disease prevention. Furthermore, a greater need for information about the causes of diabetes, its course and complications can be found among people who feel less well or not so well informed about these topics. The Diabetes Ratgeber study posed no detailed questions about the need for information; however, about 87% of the study's respondents without diabetes agreed that people should get more information about diabetes and about diabetes prevention [26]. The review article by Pieper et al. [27] found that many studies showed that women had greater health-related information needs than men; this result was not confirmed by our study. However, women did feel subjectively better informed than men about diabetes in general and on specific topics.



A review by Biernatzki et al. [49] shows that the sources of information used by people with diabetes differ according to the type of information sought. Doctors were important sources of information about all forms of treatment, whereas the internet and printed information seem to play a more important role when it comes to other issues. In our study, adults with diabetes most frequently cited their general practitioner as their most frequent source of information followed by printed information, diabetologists and the internet. Nevertheless, it is impossible to rule out the possibility that a respondent's general practitioner may have also been a diabetologist. Although the DAWN-2 study collected data on aspects that are relevant to the sources of information used by people with diabetes, the results have yet to be presented in detail [48]. Our study showed that respondents without diabetes informed themselves most frequently about the condition via printed media. Finally, adults without diabetes once again cited their general practitioner or other doctor as their most frequent source of information on general health issues.

Respondents with and without diabetes stated that their ability to judge the trustworthiness and clarity of the information published in the media about diabetes was limited. This problem was particularly pronounced among people with low levels of education. Although our study cannot really be used to measure health literacy, these results are in line with a 2014 representative survey of the health literacy of the German-speaking resident population aged 15 years or above. It found that 54.3% of respondents had limited levels of health literacy when measured using the German-language long

version of the European Health Literacy Survey Questionnaire (HLS-EU-Q47); the study also identified a clear educational gradient [25].

#### 4.2 Strengths and limitations

A strength of the study is that it is the first to implement a special procedure to collect data through interviewing large and population-representative samples of both the general population and adults with diabetes on some key issues including disease perception, information-seeking behaviour and information needs. By applying weighting factors, it is possible to directly compare the two groups. In addition, data was collected on further target group-relevant issues as well as on socio-demographic and psychosocial characteristics. Thus, information is available for the analysis of population subgroups, such as in terms of levels of knowledge about diabetes and information needs by gender and education. Our study also provides for the prospect of more in-depth investigations, such as into the relationship between psychosocial factors and disease burden among patients with diabetes or about the factors related to patient satisfaction.

However, our study also faces a limitation because telephone health surveys target the German-speaking population over the age of 18 years. This excludes adults without a sufficient knowledge of German. This method, therefore, does not allow for the representative collection of data from people with a recent family history of migration. Furthermore, the study also produced a relatively low response rate (17.9%). However, it is impor-

tant to note that the response rate was calculated as a percentage of all households that are theoretically reachable by telephone in Germany [36]. Moreover, survey research has recently shown that a low response rate does not necessarily result in biased results (increased non-response bias) [51].

A further limitation of the study consists in the fact that it was only possible to categorise the participants (as with or without diabetes) using the information provided by the respondents themselves on the question of whether they had been diagnosed with diabetes by a doctor. However, it has been demonstrated that self-reported information about clearly defined diseases such as diabetes provides a very similar rate to that of actual physician diagnoses [20].

It was not possible to use established and validated instruments for all research questions, as some of these were not yet available. Therefore, certain questions had to be newly developed for the study. In addition, due to the limited length of the questionnaire, not all relevant questions could be taken into account or posed in more detail. For example, data could not be directly collected about the objective knowledge of diabetes in people with diabetes. The same applies to the self-efficacy, in other words, the belief that people have the capacity to perform certain actions such as practicing a healthy diet and physical activity.

#### 4.3 Practical implications and outlook

Overall, the study shows a clear need for target group-specific information and communications on diabetes. Thus,

it identified significant gaps in knowledge among the general population that could be addressed as part of an informational and communications-based strategy. Although knowledge is not necessarily indicative of health promoting behaviour or results in changes to behaviour, it is a prerequisite for both. In addition, the topics that people with or without diabetes wish for more information about can be directly incorporated into the planning of educational activities. Further in-depth analyses of the data from the present study could also provide information about the issues and sources of information that are relevant to specific target groups, such as people of certain age groups. The results indicate that it is not enough to provide information about diabetes merely on the internet, and that it is still needed in print. The involvement of doctors treating people with diabetes is also essential, as they constitute important contacts for diabetes-related issues as part of educational and communications strategies. Extended and in-depth analyses of the data that has been collected ([Annex 1](#)) are necessary to identify barriers and other factors that influence the use of disease prevention and care services, as these play an important role alongside knowledge.

Finally, the study also provides for the possibility for follow-up studies to be conducted as part of the National Diabetes Surveillance under the scientific coordination of the RKI. A repeat of the current survey, for example, could provide an important source of information for the Diabetes Surveillance in Germany and provide a basis with which to assess the success of the educational and communications-related measures being put in place by the BZgA.

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Paprott R, Heidemann C, Stühmann LM, Baumert J, Du Y et al. (2018) First results from the study 'Disease knowledge and information needs - Diabetes mellitus (2017)'. *Journal of Health Monitoring* 3(S3):22-60. DOI 10.17886/RKI-GBE-2018-064

**Data protection and ethics**

The study was approved by the ethics committee of Berlin's Chamber of Physicians (No: Eth-23/17) and the Federal Commissioner for Data Protection and Freedom of Information. All participants were informed at the beginning of the telephone interview about the voluntary nature of their participation, the objectives of the survey as well as data protection and gave their informed consent to participate verbally.

**Funding**

The study 'Disease knowledge and information needs - Diabetes mellitus (2017)' is funded by the Federal Ministry of Health. Funding Code: GE20160358.

**Conflicts of interest**

The authors declared no conflicts of interest.

**Acknowledgement**

The authors would like to thank the study's participants for taking part.

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## Annex 1

## Overview of the concepts and instruments employed in the study Disease knowledge and information needs - Diabetes mellitus (2017)

Own diagram

| Topic   | Questionnaire used with participants without diabetes  | Questionnaire used with participants with diabetes   |
|---|--|--|
| <b>Knowledge about disease</b>  |  |  |
| Self-assessed level of knowledge about disease  | 1 item adapted from PIKS [1]   | 1 item adapted from PIKS [1]   |
| Self-assessed level of knowledge about diabetes types   | 4 new items  | -  |
| Objective knowledge about disease   | 2 items adapted from Hoghton et al. [2]; four new items  | -  |
| Knowledge about diabetes due to occupation  | 1 new item   | 1 new item   |
| <b>Disease perception</b>   |  |  |
| Type of disease and possibility of influencing it   | 1 item adapted from Adriaanse et al. [3], RPS-DD ('personal control' subscale, 4 items) [4]; 1 item adapted from IPQ-R for healthy individuals (timeline acute/chronic subscale) [5] | 1 item adapted from Adriaanse et al. [3], IPQ-R ('personal control' subscale, 4 items) [6]; 1 item from IPQ-R for people with diabetes (timeline acute/chronic subscale) [6] |
| Stigmatisation  | 2 items adapted from Diabetes Ratgeber [7]; 1 new item based on DSAS-2 [8]   | 2 items adapted from Diabetes Ratgeber [7]; 1 new item based on DSAS-2 [8]   |
| <b>Diabetes risk/risk of complications</b>  |  |  |
| Subjective risk   | 1 item adapted from Kim et al. [9], RPS-DD ('optimistic bias' subscale, 2 items) [4]   | RPS-DM ('optimistic bias' subscale, 2 items) [10]  |
| Objective diabetes risk   | GDRS (18 Items) [11]   | -  |
| <b>Diabetes-related information</b>   |  |  |
| Perceived level of information  | 5 items from IND [12]  | 11 items from IND [12]   |
| Subjective information needs  | 5 items from IND [12]  | 11 items from IND [12]   |
| Information-seeking behaviour   | 7 items adapted from DAWN2 [13]  | 13 items adapted from DAWN2 [13]   |
| Perceived trustworthiness and clarity of information  | 2 items from HLS-EU-Q16 [14]   | 2 items from HLS-EU-Q16 [14]   |
| <b>Health-related behaviour and lifestyle</b>   |  |  |
| Physical activity, smoking, BMI   | 4 items from GDRS [11]   | 4 items from GDRS [11]   |
| Use of health apps  | 1 item adapted from Ernsting et al. [15]   | 1 item adapted from Ernsting et al. [15]   |
| <b>Health care services utilisation</b>   |  |  |
| Check-up 35   | 3 items adapted from DEGS1 [16], 2 new items   | -  |
| Disease management programmes (DMP), training   | -  | 3 items adapted from DEGS1 [16], 8 items adapted from DAWN2 [17], 1 new item   |
| Patient satisfaction  | -  | PACIC-DSF (9 Items) [17]   |
| <b>Disease characteristics</b>  |  |  |
| Time of diagnosis, type of treatment, need for insulin, type of insulin delivery, type of blood glucose measurement, complications, comorbidities | -  | Various items from DEGS1 [16] and GEDA 2014/2015-EHIS [18], partially adapted  |



## Annex 1 Continued

## Overview of the subject areas and instruments employed in the study Disease knowledge and information needs - Diabetes mellitus (2017)

Own diagram

| Topic  | Questionnaire used with participants without diabetes | Questionnaire used with participants with diabetes             |
|--|---|--|
| <b>Diabetes self-management</b>                |   |  |
| Self-care behaviour                            | -   | 5 items adapted from SDSCA-6 [17]                              |
| Self-efficacy                                  | -   | 4 items adapted from DCP [19]                                  |
| <b>Psychosocial distress/burden in general</b> |   |  |
| Diabetes distress                              | -   | PAID-5 (5 Items) [17, 20]                                      |
| Social support                                 | -   | DSDSP adapted (6 items) [17], one item adapted from DAWN2 [13] |
| Depressive symptoms                            | -   | PHQ-2 (2 Items) [21]   |
| Subjective health                              | 5 items from MEHM [22]                                | 4 items from MEHM [22]   |
| Quality of life                                | 1 item from GEDA 2014/2015-EHIS [18]                  | 1 item from GEDA 2014/2015-EHIS [18]                           |

**DAWN2:** Diabetes Attitudes Wishes and Needs 2; **DCP:** Diabetes Care Profile; **DEGS1:** German Health Interview and Examination Survey for Adults; **GDRS:** German Diabetes Risk Score; **DSAS-2:** Type 2 Diabetes Stigma Assessment Scale; **DSDSP:** DAWN Support for Diabetes Self-Management Profile; **GEDA 2014/2015-EHIS:** German Health Update 2014/2015-European Health Interview Survey; **HLS-EU-Q16:** European Health Literacy Survey Questionnaire (short form); **IND:** Information Needs in Diabetes Questionnaire; **IPQ-R:** Revised Illness Perception Questionnaire; **MEHM:** Minimum European Health Module; **PACIC-DSF:** Patient Assessment of Chronic Illness Care - DAWN Short Form; **PAID-5:** Problem Areas in Diabetes Scale 5; **PHQ-2:** Patient Health Questionnaire-2; **PIKS:** Perceived Kidney Knowledge Survey; **RPS-DD:** Risk Perception Survey Developing Diabetes; **RPS-DM:** Risk Perception Survey Diabetes Mellitus; **SDSCA-6:** Summary of Diabetes Self-Care Activities-6

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Annex 2  
Questions analysed in the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017)  
Own diagram

### Self-assessed level of knowledge about diabetes

How would you rate your understanding of diabetes?

**Possible answers:** very good, good, bad, non-existent

### Objective knowledge about diabetes

1. Diabetes is a disease of the blood cells.
2. Diabetes is a condition in which there is too much sugar in the blood.
3. Type 1 diabetes usually disappears with puberty.
4. Type 1 diabetes can be treated with tablets.
5. The symptoms of type 2 diabetes usually develop gradually.
6. In Germany, more people are affected by type 2 diabetes than type 1 diabetes.

**Possible answers:** correct, false, don't know

### Disease perception

#### A) Respondents without diabetes

1. How serious is diabetes in your view?

**Possible answers:** not serious, moderately serious, serious, very serious, no opinion

2. I assume that people who have diabetes will have the condition for the rest of their life.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree

3. Due to their illness, people with diabetes are often unable to meet their daily needs, for example, at work or in the family.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

4. Most people who have diabetes have caused it themselves through an unhealthy lifestyle.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

5. People with diabetes are often disadvantaged at work or privately.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

#### B) Respondents with diabetes

1. How serious is diabetes in your view?

**Possible answers:** not serious, moderately serious, serious, very serious, no opinion

2. I assume that I will have diabetes for the rest of my life.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree

3. Other people often think that I will not be able to meet my daily needs, for example, at work or in the family because I have diabetes.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

4. Other people think that I caused my diabetes due to my unhealthy lifestyle.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

5. I am often disadvantaged at work or in my personal life because I have diabetes.

**Possible answers:** completely disagree, disagree, neither agree nor disagree, agree, completely agree, don't know

**Annex 2 Continued**  
**Questions analysed in the study**  
**Disease knowledge and information needs -**  
**Diabetes mellitus (2017)**  
 Own diagram

## Diabetes-related information

### (I) Perceived level of information

How well informed are you about the following topics?

1. Causes of diabetes
2. Course of the disease
3. Treatment and therapy
4. Complications
5. Lifestyle changes, health promotion and disease prevention
6. Only respondents with diabetes: support services, help-lines and sources of information

**Possible answers:** very well, well, not well, not informed at all

### (II) Subjective information needs

Would you currently like information on the following topics?

1. Causes of diabetes
2. Course of the disease
3. Treatment and therapy
4. Complications
5. Lifestyle changes, health promotion and disease prevention
6. Only respondents with diabetes: support services, help-lines and sources of information

**Possible answers:** yes, no

### (III) Information-seeking behaviour

#### A) Respondents without diabetes

Which of the following sources of information have you used to find out about diabetes/health issues in general?<sup>1</sup>

Your general practitioner or other doctors

2. A pharmacist
3. Printed information such as brochures, newspapers, magazines, books
4. Radio or television broadcasts
5. Websites about health and diabetes
6. Forums or social networks on the internet
7. Other sources of information than those just mentioned

**Possible answers:** yes, no (Several answers possible)

#### B) Respondents with diabetes

Which of the following sources of information have you used to find out about diabetes?

1. A diabetologist
2. A diabetes advisor
3. Your general practitioner or other doctors
4. A pharmacist
5. Self-help groups where you meet other people with diabetes and/or their relatives
6. Natural health practitioners or doctors who practise alternative medicine, such as herbal medicine, acupuncture or homeopathy
7. People with diabetes in your social environment who advise or assist people with diabetes
8. Printed information such as brochures, newspapers, magazines, books
9. Information programs for people with diabetes such as those on the radio, television or DVD
10. Websites about health and diabetes
11. Forums or social networks on the internet

**Annex 2 Continued**  
**Questions analysed in the study**  
**Disease knowledge and information needs -**  
**Diabetes mellitus (2017)**  
Own diagram

12. Diabetes hotlines or medical hotlines from your health insurance provider

13. Other sources of information than those just mentioned

**Possible answers:** yes, no (Several answers possible)

**(IV) Self-assessed trustworthiness and clarity of information**

1. How easy do you think it is to judge whether the information about diabetes in the media is trustworthy?

**Possible answers:** very easy, quite easy, quite difficult, very difficult

2. How easy do you think it is to understand the information about diabetes in the media?

**Possible answers:** very easy, quite easy, quite difficult, very difficult

## Annex 3

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to gender

Table 1

Specific knowledge about diabetes among  
adults without diagnosed diabetes  
according to gender

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Correct |       |             | False |             | Don't know |             |
|---|---------|-------|-------------|-------|-------------|------------|-------------|
|   | n       | %     | (95% CI)    | %     | (95% CI)    | %          | (95% CI)    |
| <b>Diabetes is a disease of the blood cells</b>                                     |         |       |             |       |             |            |             |
| Total   | 2.323   | 14.5  | (12.3-16.9) | 31.3* | (28.7-34.0) | 54.3       | (51.3-57.2) |
| Women   | 1.311   | 13.5  | (11.0-16.5) | 33.9* | (30.5-37.5) | 52.6       | (48.7-56.5) |
| Men   | 1.012   | 15.5  | (12.1-19.5) | 28.4* | (24.7-32.6) | 56.1       | (51.5-60.6) |
| <b>Diabetes involves having too much sugar in the blood</b>                         |         |       |             |       |             |            |             |
| Total   | 2.325   | 66.2* | (63.3-69.0) | 11.8  | (9.9-13.9)  | 22.0       | (19.6-24.7) |
| Women   | 1.312   | 65.6* | (61.7-69.3) | 11.9  | (9.3-15.1)  | 22.5       | (19.4-25.9) |
| Men   | 1.013   | 66.9* | (62.4-71.0) | 11.6  | (9.2-14.6)  | 21.5       | (17.9-25.7) |
| <b>Type 1 diabetes disappears with puberty</b>                                      |         |       |             |       |             |            |             |
| Total   | 2.327   | 8.2   | (6.7-10.0)  | 26.9* | (24.4-29.5) | 64.9       | (62.1-67.7) |
| Women   | 1.313   | 8.0   | (6.1-10.3)  | 32.9* | (29.4-36.7) | 59.1       | (55.2-62.9) |
| Men   | 1.014   | 8.5   | (6.2-11.4)  | 20.4* | (17.1-24.1) | 71.2       | (67.0-75.0) |
| <b>Type 1 diabetes can be treated with tablets</b>                                  |         |       |             |       |             |            |             |
| Total   | 2.326   | 36.3  | (33.4-39.2) | 17.2* | (15.0-19.6) | 46.6       | (43.6-49.6) |
| Women   | 1.312   | 37.2  | (33.5-41.0) | 22.5* | (19.3-26.1) | 40.3       | (36.5-44.1) |
| Men   | 1.014   | 35.2  | (31.0-39.7) | 11.4* | (8.9-14.6)  | 53.3       | (48.7-57.8) |
| <b>Symptoms of type 2 diabetes usually develop slowly</b>                           |         |       |             |       |             |            |             |
| Total   | 2.327   | 62.6* | (59.6-65.6) | 1.4   | (0.8-2.5)   | 35.9       | (33.0-39.0) |
| Women   | 1.313   | 64.9* | (61.0-68.7) | 1.4   | (0.7-2.7)   | 33.7       | (29.9-37.6) |
| Men   | 1.014   | 60.2* | (55.5-64.7) | 1.5   | (0.6-3.6)   | 38.4       | (33.9-43.0) |
| <b>In Germany, more people are affected by type 2 diabetes than type 1 diabetes</b> |         |       |             |       |             |            |             |
| Total   | 2.325   | 49.6* | (46.6-52.6) | 2.5   | (1.6-3.9)   | 47.9       | (45.0-50.9) |
| Women   | 1.312   | 55.2* | (51.2-59.1) | 1.6   | (0.9-2.9)   | 43.2       | (39.4-47.2) |
| Men   | 1.013   | 43.6* | (39.2-48.1) | 3.4   | (1.8-6.2)   | 53.0       | (48.4-57.5) |

\* Indicates the correct answer  
CI: Confidence interval

## Annex 3

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to gender

Table 2

Disease perception and stigmatisation among  
adults without diagnosed diabetes  
according to gender

Source: Disease knowledge and information  
needs-Diabetes mellitus (2017)

|  | Total     |             | Women     |             | Men       |             |
|--|-----------|-------------|-----------|-------------|-----------|-------------|
|  | %         | (95% CI)    | %         | (95% CI)    | %         | (95% CI)    |
| <b>Disease perception</b>  |           |             |           |             |           |             |
| <b>Diabetes is ...</b>   | (n=2.314) |             | (n=1.304) |             | (n=1.010) |             |
| Not serious  | 1.2       | (0.8-1.9)   | 1.2       | (0.6-2.2)   | 1.3       | (0.7-2.4)   |
| Moderately serious   | 21.3      | (18.9-23.8) | 20.1      | (17.2-23.4) | 22.5      | (19.0-26.4) |
| Serious  | 48.1      | (45.1-51.1) | 51.2      | (47.3-55.1) | 44.7      | (40.2-49.2) |
| Very serious   | 16.9      | (14.7-19.2) | 17.9      | (15.2-20.9) | 15.7      | (12.5-19.6) |
| No opinion   | 12.6      | (10.5-15.1) | 9.6       | (7.2-12.7)  | 15.8      | (12.4-19.9) |
| <b>People have diabetes for the rest of their life</b>             | (n=2.213) |             | (n=1.244) |             | (n=969)   |             |
| Completely disagree  | 4.9       | (3.6-6.6)   | 5.1       | (3.4-7.5)   | 4.7       | (2.9-7.3)   |
| Disagree   | 23.3      | (20.9-25.9) | 24.1      | (20.9-27.5) | 22.5      | (18.9-26.5) |
| Neither agree nor disagree   | 11.7      | (9.9-13.9)  | 13.8      | (11.0-17.2) | 9.6       | (7.3-12.4)  |
| Agree  | 42.9      | (39.9-46.0) | 40.7      | (36.8-44.7) | 45.3      | (40.7-50.0) |
| Completely agree   | 17.2      | (14.9-19.7) | 16.4      | (13.6-19.6) | 18.0      | (14.5-22.2) |
| <b>Stigmatisation: People with diabetes ...</b>                    |           |             |           |             |           |             |
| <b>Are usually unable to meet their daily needs.</b>               | (n=2.318) |             | (n=1.311) |             | (n=1.007) |             |
| Completely disagree  | 11.9      | (10.2-13.9) | 13.2      | (10.8-16.1) | 10.6      | (8.3-13.4)  |
| Disagree   | 41.6      | (38.7-44.6) | 42.4      | (38.6-46.2) | 40.8      | (36.4-45.5) |
| Neither agree nor disagree   | 9.4       | (7.9-11.2)  | 9.5       | (7.5-12.0)  | 9.2       | (7.0-12.1)  |
| Agree  | 17.9      | (15.7-20.4) | 15.6      | (12.9-18.7) | 20.4      | (16.9-24.5) |
| Completely agree   | 2.7       | (1.8-4.0)   | 2.6       | (1.5-4.7)   | 2.7       | (1.5-4.9)   |
| Don't know   | 16.4      | (14.2-18.9) | 16.6      | (13.7-20.0) | 16.2      | (13.0-19.9) |
| <b>Have caused their condition through an unhealthy lifestyle.</b> | (n=2.312) |             | (n=1.305) |             | (n=1.007) |             |
| Completely disagree  | 5.8       | (4.7-7.3)   | 6.3       | (4.6-8.6)   | 5.3       | (3.9-7.2)   |
| Disagree   | 33.4      | (30.6-36.3) | 34.1      | (30.6-37.9) | 32.6      | (28.4-37.2) |
| Neither agree nor disagree   | 18.9      | (16.7-21.4) | 18.9      | (16.0-22.2) | 18.9      | (15.6-22.7) |
| Agree  | 25.1      | (22.7-27.8) | 25.1      | (21.9-28.6) | 25.2      | (21.4-29.3) |
| Completely agree   | 3.7       | (2.7-5.1)   | 3.5       | (2.1-5.7)   | 4.0       | (2.7-6.1)   |
| Don't know   | 12.9      | (11.0-15.2) | 12.0      | (9.5-15.0)  | 14.0      | (11.0-17.6) |
| <b>Often face disadvantages.</b>                                   | (n=2.315) |             | (n=1.311) |             | (n=1.004) |             |
| Completely disagree  | 9.6       | (7.9-11.6)  | 9.3       | (7.2-11.9)  | 9.9       | (7.4-13.1)  |
| Disagree   | 45.2      | (42.3-48.2) | 47.5      | (43.6-51.4) | 42.8      | (38.4-47.4) |
| Neither agree nor disagree   | 8.5       | (7.0-10.2)  | 7.9       | (6.2-10.2)  | 9.0       | (6.8-12.0)  |
| Agree  | 12.9      | (10.8-15.3) | 10.7      | (8.3-13.6)  | 15.2      | (11.9-19.3) |
| Completely agree   | 1.1       | (0.6-2.0)   | 1.4       | (0.7-3.1)   | 0.8       | (0.4-1.6)   |
| Don't know   | 22.7      | (20.3-25.3) | 23.2      | (20.0-26.7) | 22.2      | (18.7-26.3) |

CI: Confidence interval

## Annex 3

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to gender

Table 3

Perceived level of information among adults  
without diagnosed diabetes according to gender

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Total |             | Women |             | Men  |             |
|---|-------|-------------|-------|-------------|------|-------------|
|   | %     | (95% CI)    | %     | (95% CI)    | %    | (95% CI)    |
| <b>Level of information</b>                                       |       |             |       |             |      |             |
| <b>Causes of diabetes</b>   |       |             |       |             |      |             |
|   |       | (n=2.312)   |       | (n=1.306)   |      | (n=1.006)   |
| Very well   | 4.5   | (3.6-5.7)   | 6.2   | (4.8-8.1)   | 2.7  | (1.7-4.1)   |
| Well  | 39.5  | (36.7-42.4) | 43.0  | (39.2-46.9) | 35.7 | (31.6-40.2) |
| Not well  | 36.5  | (33.7-39.5) | 30.7  | (27.3-34.4) | 42.8 | (38.3-47.4) |
| Not informed at all   | 19.4  | (17.0-22.1) | 20.0  | (16.9-23.6) | 18.8 | (15.2-22.9) |
| <b>Course of disease</b>  |       |             |       |             |      |             |
|   |       | (n=2.312)   |       | (n=1.304)   |      | (n=1.008)   |
| Very well   | 4.2   | (3.2-5.6)   | 5.2   | (3.9-7.0)   | 3.2  | (1.8-5.6)   |
| Well  | 32.4  | (29.7-35.1) | 37.2  | (33.5-41.0) | 27.2 | (23.6-31.2) |
| Not well  | 43.1  | (40.1-46.1) | 37.9  | (34.2-41.8) | 48.7 | (44.1-53.3) |
| Not informed at all   | 20.3  | (17.9-23.0) | 19.7  | (16.6-23.3) | 20.9 | (17.3-25.1) |
| <b>Treatment and therapy</b>                                      |       |             |       |             |      |             |
|   |       | (n=2.312)   |       | (n=1.304)   |      | (n=1.008)   |
| Very well   | 4.2   | (3.3-5.4)   | 5.4   | (4.0-7.1)   | 3.0  | (1.9-4.7)   |
| Well  | 37.0  | (34.2-39.9) | 42.7  | (38.8-46.6) | 31.0 | (27.2-35.1) |
| Not well  | 39.7  | (36.8-42.7) | 35.1  | (31.4-39.0) | 44.6 | (40.1-49.2) |
| Not informed at all   | 19.1  | (16.7-21.7) | 16.8  | (14.1-20.0) | 21.4 | (17.7-25.8) |
| <b>Complications</b>  |       |             |       |             |      |             |
|   |       | (n=2.307)   |       | (n=1.301)   |      | (n=1.006)   |
| Very well   | 5.0   | (3.9-6.3)   | 6.5   | (4.9-8.6)   | 3.3  | (2.1-5.1)   |
| Well  | 31.0  | (28.4-33.7) | 35.1  | (31.6-38.9) | 26.5 | (22.8-30.6) |
| Not well  | 40.7  | (37.7-43.7) | 38.4  | (34.7-42.4) | 43.0 | (38.6-47.6) |
| Not informed at all   | 23.4  | (20.8-26.3) | 19.9  | (16.8-23.4) | 27.2 | (23.0-31.8) |
| <b>Lifestyle changes, health promotion and disease prevention</b> |       |             |       |             |      |             |
|   |       | (n=2.301)   |       | (n=1.295)   |      | (n=1.006)   |
| Very well   | 4.9   | (3.9-6.2)   | 6.7   | (5.1-8.7)   | 3.1  | (2.0-5.0)   |
| Well  | 44.0  | (41.1-47.0) | 45.9  | (42.0-49.8) | 42.1 | (37.7-46.6) |
| Not well  | 33.6  | (30.7-36.5) | 30.1  | (26.4-34.0) | 37.3 | (32.9-41.9) |
| Not informed at all   | 17.5  | (15.2-20.0) | 17.4  | (14.5-20.8) | 17.5 | (14.1-21.5) |

CI: Confidence interval



## Annex 3

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to gender

**Table 4**  
**Disease perception and stigmatisation in adults**  
**with diagnosed diabetes according to gender**  
Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Total     |             | Women   |             | Men     |             |
|---|-----------|-------------|---------|-------------|---------|-------------|
|   | %         | (95% CI)    | %       | (95% CI)    | %       | (95% CI)    |
| <b>Disease perception</b>   |           |             |         |             |         |             |
| <b>Diabetes is ...</b>  | (n=1.469) |             | (n=737) |             | (n=732) |             |
| Not serious   | 9.4       | (7.8-11.2)  | 11.0    | (8.6-13.9)  | 7.6     | (5.8-10.0)  |
| Moderately serious  | 27.1      | (24.3-30.1) | 26.6    | (22.7-30.9) | 27.7    | (23.8-31.9) |
| Serious   | 45.8      | (42.5-49.0) | 43.6    | (39.2-48.1) | 48.1    | (43.5-52.7) |
| Very serious  | 9.9       | (8.2-12.0)  | 9.3     | (7.2-12.1)  | 10.6    | (7.9-14.0)  |
| No opinion  | 7.8       | (6.1-10.0)  | 9.5     | (6.8-13.2)  | 6.0     | (4.2-8.5)   |
| <b>I will have diabetes for the rest of my life.*</b>                                     | (n=1.386) |             | (n=671) |             | (n=715) |             |
| Completely disagree   | 1.4       | (0.7-2.8)   | 1.4     | (0.5-3.8)   | 1.5     | (0.6-3.6)   |
| Disagree  | 2.9       | (1.7-4.9)   | 4.2     | (2.1-8.3)   | 1.6     | (0.9-2.8)   |
| Neither agree nor disagree  | 4.7       | (3.3-6.6)   | 4.2     | (2.6-6.6)   | 5.1     | (3.1-8.4)   |
| Agree   | 45.1      | (41.8-48.4) | 44.6    | (40.0-49.2) | 45.5    | (40.9-50.2) |
| Completely agree  | 46.0      | (42.7-49.3) | 45.6    | (41.0-50.4) | 46.3    | (41.7-51.0) |
| <b>Stigmatisation</b>   |           |             |         |             |         |             |
| <b>Other people think that I cannot meet my daily needs because I have diabetes.*</b>     | (n=1.382) |             | (n=668) |             | (n=714) |             |
| Completely disagree   | 33.5      | (30.6-36.6) | 37.7    | (33.4-42.3) | 29.4    | (25.5-33.6) |
| Disagree  | 37.4      | (34.3-40.6) | 38.5    | (34.0-43.2) | 36.3    | (32.1-40.8) |
| Neither agree nor disagree  | 4.0       | (3.0-5.5)   | 2.9     | (1.7-4.7)   | 5.2     | (3.5-7.7)   |
| Agree   | 11.4      | (9.2-13.9)  | 7.0     | (5.1-9.6)   | 15.7    | (12.1-20.1) |
| Completely agree  | 3.5       | (2.2-5.6)   | 4.4     | (2.3-8.4)   | 2.7     | (1.5-4.6)   |
| Don't know  | 10.1      | (8.2-12.4)  | 9.5     | (7.2-12.5)  | 10.7    | (7.8-14.5)  |
| <b>Other people think that I have caused my diabetes through my unhealthy lifestyle.*</b> | (n=1.377) |             | (n=673) |             | (n=704) |             |
| Completely disagree   | 26.5      | (23.8-29.4) | 29.5    | (25.6-33.7) | 23.5    | (19.8-27.7) |
| Disagree  | 32.3      | (29.3-35.5) | 34.5    | (30.2-39.2) | 30.1    | (26.2-34.4) |
| Neither agree nor disagree  | 7.0       | (5.5-8.9)   | 5.9     | (4.1-8.5)   | 8.1     | (5.9-11.1)  |
| Agree   | 17.3      | (14.8-20.1) | 12.6    | (9.8-15.9)  | 22.0    | (18.1-25.5) |
| Completely agree  | 5.0       | (3.4-7.3)   | 4.5     | (2.2-8.6)   | 5.6     | (3.7-8.3)   |
| Don't know  | 11.9      | (9.9-14.1)  | 13.0    | (10.3-16.4) | 10.7    | (8.1-14.0)  |
| <b>I often face disadvantages because I have diabetes.*</b>                               | (n=1.392) |             | (n=674) |             | (n=718) |             |
| Completely disagree   | 42.0      | (38.8-45.3) | 44.5    | (39.9-49.3) | 39.5    | (35.1-44.0) |
| Disagree  | 46.7      | (43.4-50.0) | 46.5    | (41.8-51.2) | 46.9    | (42.2-51.5) |
| Neither agree nor disagree  | 2.4       | (1.6-3.7)   | 1.9     | (1.1-3.3)   | 3.0     | (1.6-5.4)   |
| Agree   | 4.5       | (3.4-6.0)   | 4.2     | (2.7-6.4)   | 4.9     | (3.3-7.2)   |
| Completely agree  | 1.6       | (0.8-3.1)   | 1.0     | (0.4-2.6)   | 2.1     | (0.8-5.3)   |
| Don't know  | 2.8       | (1.8-4.3)   | 1.9     | (1.1-3.5)   | 3.7     | (2.1-6.5)   |

\* Indicates questions that were asked only to participants with diabetes in the last 12 months

CI: Confidence interval

## Annex 3

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to gender

Table 5

Perceived level of information among adults  
with diagnosed diabetes according to gender

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Total |             | Women |             | Men  |             |
|---|-------|-------------|-------|-------------|------|-------------|
|   | %     | (95% CI)    | %     | (95% CI)    | %    | (95% CI)    |
| <b>Level of information</b>                                       |       |             |       |             |      |             |
| <b>Causes of diabetes</b>   |       | (n=1.471)   |       | (n=733)     |      | (n=738)     |
| Very well   | 17.1  | (14.9-19.6) | 15.8  | (12.9-19.1) | 18.6 | (15.4-22.3) |
| Well  | 65.4  | (62.3-68.4) | 64.8  | (60.5-68.9) | 66.0 | (61.5-70.3) |
| Not well  | 11.5  | (9.6-13.7)  | 10.8  | (8.5-13.7)  | 12.2 | (9.3-15.9)  |
| Not informed at all   | 6.0   | (4.7-7.7)   | 8.6   | (6.4-11.5)  | 3.1  | (2.0-5.0)   |
| <b>Course of disease</b>  |       | (n=1.470)   |       | (n=734)     |      | (n=736)     |
| Very well   | 16.1  | (13.9-18.5) | 14.2  | (11.4-17.4) | 18.1 | (14.9-21.9) |
| Well  | 68.3  | (65.3-71.2) | 65.9  | (61.5-70.0) | 71.0 | (66.7-75.0) |
| Not well  | 10.5  | (8.7-12.7)  | 12.8  | (10.1-16.1) | 8.0  | (5.8-11.0)  |
| Not informed at all   | 5.1   | (3.8-6.7)   | 7.2   | (5.1-10.0)  | 2.8  | (1.7-4.5)   |
| <b>Treatment and therapy</b>                                      |       | (n=1.469)   |       | (n=734)     |      | (n=735)     |
| Very well   | 17.1  | (14.9-19.6) | 15.4  | (12.5-18.8) | 19.1 | (15.8-22.8) |
| Well  | 67.6  | (64.5-70.5) | 67.6  | (63.2-71.7) | 67.5 | (63.1-71.6) |
| Not well  | 10.3  | (8.4-12.6)  | 10.7  | (8.0-14.2)  | 9.8  | (7.3-13.0)  |
| Not informed at all   | 5.0   | (3.8-6.6)   | 6.3   | (4.4-8.9)   | 3.6  | (2.2-5.8)   |
| <b>Complications</b>  |       | (n=1.467)   |       | (n=736)     |      | (n=731)     |
| Very well   | 16.1  | (13.9-18.6) | 14.7  | (11.9-18.1) | 17.7 | (14.4-21.4) |
| Well  | 63.2  | (60.0-66.2) | 60.8  | (56.3-65.1) | 65.8 | (61.4-69.9) |
| Not well  | 14.4  | (12.3-16.8) | 16.6  | (13.5-20.3) | 12.0 | (9.5-15.0)  |
| Not informed at all   | 6.3   | (5.0-7.9)   | 7.9   | (5.8-10.5)  | 4.6  | (3.1-6.7)   |
| <b>Lifestyle changes, health promotion and disease prevention</b> |       | (n=1.459)   |       | (n=730)     |      | (n=729)     |
| Very well   | 12.5  | (10.6-14.8) | 11.0  | (8.5-14.0)  | 14.2 | (11.3-17.7) |
| Well  | 59.7  | (56.5-62.9) | 59.1  | (54.5-63.5) | 60.5 | (55.9-64.9) |
| Not well  | 16.9  | (14.5-19.6) | 15.9  | (12.8-19.5) | 18.0 | (14.5-22.1) |
| Not informed at all   | 10.9  | (9.0-13.1)  | 14.1  | (11.0-17.9) | 7.3  | (5.4-9.8)   |
| <b>Support services, helplines, information sources</b>           |       | (n=1.451)   |       | (n=730)     |      | (n=721)     |
| Very well   | 8.6   | (7.0-10.5)  | 7.2   | (5.3-9.6)   | 10.2 | (7.7-13.3)  |
| Well  | 48.5  | (45.3-51.8) | 47.7  | (43.2-52.3) | 49.5 | (44.8-54.1) |
| Not well  | 26.5  | (23.6-29.5) | 25.9  | (22.1-30.1) | 27.1 | (23.0-31.6) |
| Not informed at all   | 16.4  | (14.2-18.9) | 19.2  | (16.1-22.8) | 13.3 | (10.3-16.9) |

CI: Confidence interval

**Annex 4**  
**Presentation of results of the study**  
**Disease knowledge and information needs -**  
**Diabetes mellitus (2017) according to**  
**educational status**

**Table 1**  
**Specific knowledge about diabetes among**  
**adults without diagnosed diabetes**  
**according to educational status**  
Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   |     | Correct |             | False |             | Don't know |             |
|---|-----|---------|-------------|-------|-------------|------------|-------------|
|   | n   | %       | (95% CI)    | %     | (95% CI)    | %          | (95% CI)    |
| <b>Diabetes is a disease of the blood cells</b>                                     |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 337 | 19.0    | (14.2-25.1) | 14.9* | (10.8-20.2) | 66.1       | (59.5-72.1) |
| Middle  | 986 | 14.1    | (11.3-17.5) | 32.5* | (28.7-36.6) | 53.3       | (49.0-57.6) |
| High  | 996 | 9.8     | (7.3-13.1)  | 47.7* | (43.0-52.5) | 42.4       | (37.8-47.2) |
| <b>Diabetes involves having too much sugar in the blood</b>                         |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 338 | 62.9*   | (56.3-69.0) | 7.1   | (4.2-11.8)  | 30.0       | (24.3-36.4) |
| Middle  | 988 | 67.2*   | (63.1-71.2) | 12.7  | (10.0-16.0) | 20.1       | (16.9-23.6) |
| High  | 995 | 68.3*   | (63.8-72.5) | 15.7  | (12.4-19.8) | 15.9       | (13.1-19.2) |
| <b>Type 1 diabetes disappears with puberty</b>                                      |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 338 | 7.2     | (4.5-11.2)  | 17.7* | (13.3-23.1) | 75.2       | (69.2-80.3) |
| Middle  | 988 | 9.8     | (7.7-12.5)  | 26.3* | (22.8-30.3) | 63.8       | (59.6-67.8) |
| High  | 997 | 6.9     | (4.5-10.4)  | 38.0* | (33.5-42.7) | 55.2       | (50.4-59.9) |
| <b>Type 1 diabetes can be treated with tablets</b>                                  |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 337 | 39.7    | (33.6-46.1) | 10.0* | (6.4-15.1)  | 50.3       | (43.9-56.8) |
| Middle  | 988 | 39.1    | (35.0-43.4) | 16.6* | (13.5-20.3) | 44.3       | (40.0-48.7) |
| High  | 997 | 28.0    | (24.2-32.0) | 26.0* | (21.9-30.5) | 46.1       | (41.3-50.9) |
| <b>Symptoms of type 2 diabetes usually develop slowly</b>                           |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 338 | 50.6*   | (44.1-57.0) | 1.4   | (0.3-5.8)   | 48.1       | (41.6-54.5) |
| Middle  | 988 | 66.5*   | (62.2-70.5) | 1.1   | (0.6-2.2)   | 32.4       | (28.4-36.7) |
| High  | 997 | 70.7*   | (66.1-74.9) | 1.9   | (0.9-4.3)   | 27.4       | (23.3-31.8) |
| <b>In Germany, more people are affected by type 2 diabetes than type 1 diabetes</b> |     |         |             |       |             |            |             |
| <b>Education</b>  |     |         |             |       |             |            |             |
| Low   | 338 | 37.1*   | (31.3-43.4) | 2.2   | (0.7-6.2)   | 60.7       | (54.3-66.7) |
| Middle  | 987 | 52.3*   | (47.9-56.7) | 3.0   | (1.6-5.6)   | 44.7       | (40.4-49.1) |
| High  | 996 | 59.5*   | (54.8-64.1) | 1.8   | (1.0-3.4)   | 38.6       | (34.1-43.3) |

\* Indicates the correct answer  
CI: Confidence interval

## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 2

Disease perception and stigmatisation among  
adults without diagnosed diabetes  
according to educational status

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|  | Low  |             | Middle |             | High |             |
|--|------|-------------|--------|-------------|------|-------------|
|  | %    | (95% CI)    | %      | (95% CI)    | %    | (95% CI)    |
| <b>Disease perception</b>  |      |             |        |             |      |             |
| <b>Diabetes is ...</b>   |      | (n=334)     |        | (n=985)     |      | (n=991)     |
| Not serious  | 1.1  | (0.4-3.0)   | 1.3    | (0.7-2.3)   | 1.3  | (0.5-3.0)   |
| Moderately serious   | 14.0 | (10.4-18.5) | 24.4   | (20.8-28.3) | 24.7 | (20.5-29.5) |
| Serious  | 47.8 | (41.4-54.3) | 48.3   | (44.0-52.7) | 47.6 | (42.9-52.3) |
| Very serious   | 19.5 | (14.8-25.3) | 14.4   | (11.7-17.7) | 17.7 | (14.5-21.5) |
| No opinion   | 17.6 | (12.7-24.0) | 11.6   | (9.0-14.8)  | 8.6  | (6.0-12.4)  |
| <b>People have diabetes for the rest of their lives.*</b>          |      | (n=307)     |        | (n=950)     |      | (n=952)     |
| Completely disagree  | 5.4  | (2.8-10.4)  | 4.1    | (2.6-6.3)   | 5.6  | (3.8-8.2)   |
| Disagree   | 23.7 | (18.7-29.7) | 22.2   | (18.9-25.9) | 24.5 | (20.4-29.2) |
| Neither agree nor disagree   | 9.8  | (6.4-14.7)  | 12.9   | (10.0-16.4) | 12.1 | (9.4-15.4)  |
| Agree  | 41.5 | (35.0-48.3) | 45.0   | (40.6-49.5) | 40.9 | (36.3-45.7) |
| Completely agree   | 19.5 | (14.7-25.5) | 15.8   | (12.8-19.3) | 16.9 | (13.2-21.4) |
| <b>Stigmatisation: People with diabetes ...</b>                    |      |             |        |             |      |             |
| <b>Are usually unable to meet their daily needs.*</b>              |      | (n=337)     |        | (n=988)     |      | (n=989)     |
| Completely disagree  | 7.0  | (4.6-10.5)  | 14.2   | (11.4-17.5) | 14.2 | (11.2-17.8) |
| Disagree   | 31.0 | (25.3-37.3) | 44.9   | (40.6-49.3) | 48.9 | (44.1-53.6) |
| Neither agree nor disagree   | 10.0 | (6.8-14.6)  | 7.7    | (5.8-10.0)  | 11.5 | (8.9-14.8)  |
| Agree  | 23.2 | (18.3-28.9) | 16.9   | (13.8-20.5) | 13.3 | (10.2-17.0) |
| Completely agree   | 5.1  | (2.7-9.4)   | 1.7    | (1.0-3.1)   | 1.4  | (0.7-2.8)   |
| Don't know   | 23.7 | (18.5-29.9) | 14.6   | (11.9-17.9) | 10.8 | (8.2-14.0)  |
| <b>Have caused their diabetes through an unhealthy lifestyle.*</b> |      | (n=337)     |        | (n=985)     |      | (n=986)     |
| Completely disagree  | 3.7  | (2.0-6.8)   | 6.6    | (4.8-9.0)   | 6.6  | (4.6-9.5)   |
| Disagree   | 30.3 | (24.7-36.5) | 34.1   | (30.1-38.3) | 36.1 | (31.4-41.1) |
| Neither agree nor disagree   | 14.1 | (10.2-19.3) | 22.4   | (18.7-26.6) | 19.0 | (16.1-22.4) |
| Agree  | 26.7 | (21.4-32.6) | 24.7   | (21.1-28.6) | 24.3 | (20.6-28.4) |
| Completely agree   | 6.2  | (3.7-10.3)  | 2.4    | (1.4-4.1)   | 3.0  | (1.8-4.9)   |
| Don't know   | 19.0 | (14.2-24.9) | 9.8    | (7.7-12.3)  | 10.9 | (8.1-14.6)  |
| <b>Often face disadvantages.*</b>                                  |      | (n=334)     |        | (n=987)     |      | (n=990)     |
| Completely disagree  | 8.3  | (4.9-13.5)  | 10.1   | (7.8-13.0)  | 10.5 | (8.1-13.5)  |
| Disagree   | 37.6 | (31.6-43.9) | 49.4   | (45.0-53.7) | 47.6 | (42.8-52.3) |
| Neither agree nor disagree   | 8.0  | (5.0-12.7)  | 8.2    | (6.3-10.7)  | 9.0  | (6.9-11.8)  |
| Agree  | 13.9 | (9.8-19.2)  | 13.0   | (9.8-19.2)  | 11.6 | (8.9-15.1)  |
| Completely agree   | 1.7  | (0.7-4.1)   | 0.8    | (0.4-1.7)   | 1.0  | (0.3-3.9)   |
| Don't know   | 30.6 | (25.0-36.8) | 18.6   | (15.5-22.1) | 20.3 | (16.7-24.4) |

\*Indicates questions that were asked only to participants with diabetes in the last 12 months  
CI: Confidence interval

## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 3

Self-assessed level of knowledge about  
diabetes and perceived level of information  
among adults without diagnosed diabetes  
according to educational status

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Low     |             | Middle  |             | High    |             |
|---|---------|-------------|---------|-------------|---------|-------------|
|   | %       | (95% CI)    | %       | (95% CI)    | %       | (95% CI)    |
| <b>Self-assessed level of knowledge about diabetes</b>            | (n=331) |             | (n=983) |             | (n=995) |             |
| Very good   | 5.7     | (3.4-9.5)   | 9.2     | (7.3-11.5)  | 17.0    | (13.6-21.1) |
| Good  | 43.0    | (36.8-49.4) | 49.6    | (45.2-54.0) | 45.6    | (41.0-50.3) |
| Bad   | 31.1    | (25.4-37.4) | 33.5    | (29.4-37.9) | 30.4    | (26.1-35.1) |
| Non-existent  | 20.2    | (15.0-26.6) | 7.7     | (5.4-10.9)  | 7.0     | (4.6-10.5)  |
| <b>Perceived level of information about ...</b>                   |         |             |         |             |         |             |
| <b>Causes of diabetes</b>   | (n=331) |             | (n=986) |             | (n=991) |             |
| Very well   | 2.3     | (1.1-4.7)   | 4.1     | (2.9-5.8)   | 7.8     | (5.7-10.5)  |
| Well  | 27.6    | (22.2-33.8) | 44.0    | (39.7-48.3) | 45.8    | (41.2-50.6) |
| Not well  | 36.8    | (30.8-43.3) | 35.7    | (31.6-40.0) | 37.5    | (32.9-42.3) |
| Not informed at all   | 33.3    | (27.4-39.8) | 16.3    | (13.2-19.9) | 8.9     | (6.6-12.0)  |
| <b>Course of disease</b>  | (n=335) |             | (n=984) |             | (n=989) |             |
| Very well   | 3.5     | (1.6-7.5)   | 3.5     | (2.3-5.1)   | 6.3     | (4.5-8.9)   |
| Well  | 29.4    | (24.0-35.5) | 31.5    | (27.9-35.4) | 37.0    | (32.5-41.7) |
| Not well  | 38.3    | (32.2-44.8) | 45.2    | (40.9-49.7) | 45.1    | (40.4-49.9) |
| Not informed at all   | 28.8    | (23.2-35.1) | 19.8    | (16.3-23.8) | 11.6    | (9.0-14.8)  |
| <b>Treatment and therapy</b>                                      | (n=333) |             | (n=984) |             | (n=991) |             |
| Very well   | 2.6     | (1.2-5.4)   | 3.6     | (2.5-5.2)   | 7.1     | (5.1-9.8)   |
| Well  | 30.7    | (25.1-37.0) | 39.2    | (35.1-43.4) | 40.7    | (36.2-45.3) |
| Not well  | 38.6    | (32.5-45.1) | 39.4    | (35.1-43.9) | 41.4    | (36.8-46.3) |
| Not informed at all   | 28.1    | (22.6-34.3) | 17.8    | (14.7-21.4) | 10.8    | (7.8-14.6)  |
| <b>Complications</b>  | (n=331) |             | (n=985) |             | (n=988) |             |
| Very well   | 3.6     | (1.8-7.3)   | 4.1     | (2.8-5.8)   | 7.9     | (5.8-10.6)  |
| Well  | 26.9    | (21.6-32.9) | 29.8    | (26.2-33.7) | 37.2    | (32.7-41.9) |
| Not well  | 36.4    | (30.5-42.8) | 42.7    | (38.4-47.1) | 42.4    | (37.7-47.2) |
| Not informed at all   | 33.0    | (27.1-39.6) | 23.5    | (19.8-27.6) | 12.5    | (9.7-15.9)  |
| <b>Lifestyle changes, health promotion and disease prevention</b> | (n=329) |             | (n=981) |             | (n=987) |             |
| Very well   | 2.3     | (0.8-6.0)   | 4.8     | (3.4-6.7)   | 8.3     | (6.2-10.9)  |
| Well  | 34.0    | (28.2-40.4) | 45.5    | (41.2-49.9) | 52.8    | (48.0-57.6) |
| Not well  | 37.2    | (31.0-43.8) | 32.6    | (28.6-36.9) | 31.0    | (26.5-35.9) |
| Not informed at all   | 26.5    | (21.2-32.6) | 17.1    | (13.8-20.9) | 7.9     | (5.8-10.6)  |

CI: Confidence interval

## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 4

Subjective information needs on diabetes-  
specific topics, trustworthiness and clarity of  
information among adults without diagnosed  
diabetes according to educational status

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Low  |             | Middle |             | High |             |
|---|------|-------------|--------|-------------|------|-------------|
|   | %    | (95% CI)    | %      | (95% CI)    | %    | (95% CI)    |
| <b>Subjective information needs</b>                               |      |             |        |             |      |             |
| <b>Causes of diabetes</b>   |      | (n=338)     |        | (n=986)     |      | (n=994)     |
| Yes   | 41.4 | (35.2-47.9) | 52.9   | (48.5-57.2) | 42.0 | (37.3-46.8) |
| <b>Course of disease</b>  |      | (n=338)     |        | (n=986)     |      | (n=992)     |
| Yes   | 40.7 | (34.6-47.2) | 49.5   | (45.2-53.9) | 36.5 | (31.8-41.5) |
| <b>Treatment and therapy</b>                                      |      | (n=337)     |        | (n=986)     |      | (n=994)     |
| Yes   | 41.1 | (34.9-47.5) | 48.4   | (44.1-52.8) | 39.5 | (34.8-44.4) |
| <b>Complications</b>  |      | (n=337)     |        | (n=986)     |      | (n=994)     |
| Yes   | 43.3 | (37.0-49.7) | 52.5   | (48.2-56.8) | 41.9 | (37.2-46.8) |
| <b>Lifestyle changes, health promotion and disease prevention</b> |      | (n=336)     |        | (n=986)     |      | (n=994)     |
| Yes   | 50.1 | (43.7-56.6) | 57.3   | (53.0-61.5) | 52.4 | (47.7-57.1) |
| <b>Judge the trustworthiness of ...</b>                           |      |             |        |             |      |             |
| <b>Information about diabetes*</b>                                |      | (n=67)      |        | (n=338)     |      | (n=413)     |
| Very easy   | 7.2  | (3.2-15.3)  | 8.8    | (5.3-14.3)  | 6.9  | (4.0-11.5)  |
| Quite easy  | 27.5 | (17.7-40.1) | 36.9   | (30.4-43.8) | 43.8 | (36.7-51.2) |
| Quite difficult   | 58.0 | (44.0-70.9) | 47.3   | (40.2-54.5) | 44.6 | (37.3-52.3) |
| Very difficult  | 7.3  | (2.2-21.4)  | 7.1    | (4.5-11.0)  | 4.7  | (2.7-8.0)   |
| <b>Judge the clarity of ...</b>                                   |      |             |        |             |      |             |
| <b>Information about diabetes*</b>                                |      | (n=69)      |        | (n=337)     |      | (n=417)     |
| Very easy   | 11.4 | (4.6-25.5)  | 17.6   | (12.5-24.3) | 15.9 | (11.6-21.5) |
| Quite easy  | 58.3 | (43.7-71.6) | 48.7   | (41.7-55.8) | 56.7 | (49.2-64.0) |
| Quite difficult   | 25.7 | (15.1-40.2) | 30.2   | (24.1-37.0) | 25.1 | (19.0-32.4) |
| Very difficult  | 4.6  | (1.1-16.7)  | 3.5    | (1.2-9.7)   | 2.3  | (0.4-12.4)  |

\* Indicates questions that were asked only to participants who have actively sought information about diabetes previously  
CI: Confidence interval

## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 5

Disease perception and stigmatisation among  
adults with diagnosed diabetes  
according to educational status

Source: Disease knowledge and information  
needs - Diabetes mellitus (2017)

|   | Low     |             | Middle  |             | High    |             |
|---|---------|-------------|---------|-------------|---------|-------------|
|   | %       | (95% CI)    | %       | (95% CI)    | %       | (95% CI)    |
| <b>Disease perception</b>   |         |             |         |             |         |             |
| <b>Diabetes is ...</b>  | (n=412) |             | (n=632) |             | (n=423) |             |
| Not serious   | 11.5    | (8.8-14.9)  | 8.2     | (6.2-10.8)  | 5.8     | (3.8-8.6)   |
| Moderately serious  | 26.8    | (22.2-31.9) | 25.2    | (21.5-29.4) | 33.5    | (28.0-39.6) |
| Serious   | 43.1    | (37.7-48.6) | 48.8    | (44.2-53.4) | 46.0    | (40.0-52.2) |
| Very serious  | 7.2     | (4.9-10.5)  | 12.9    | (10.1-16.4) | 9.9     | (6.2-15.4)  |
| No opinion  | 11.5    | (8.2-15.8)  | 4.8     | (3.3-7.0)   | 4.7     | (2.9-7.7)   |
| <b>I will have diabetes for the rest of my life.*</b>                                     | (n=390) |             | (n=591) |             | (n=403) |             |
| Completely disagree   | 2.2     | (0.9-5.2)   | 0.8     | (0.3-2.4)   | 0.5     | (0.1-3.3)   |
| Disagree  | 2.9     | (1.0-8.0)   | 2.7     | (1.7-4.4)   | 3.2     | (1.3-7.4)   |
| Neither agree nor disagree  | 5.0     | (2.8-8.7)   | 3.5     | (2.2-5.7)   | 7.0     | (3.6-13.2)  |
| Agree   | 49.2    | (43.6-54.9) | 43.1    | (38.6-47.6) | 36.5    | (31.0-42.4) |
| Completely agree  | 40.6    | (35.2-46.3) | 49.9    | (45.3-54.5) | 52.8    | (46.5-59.1) |
| <b>Stigmatisation</b>   |         |             |         |             |         |             |
| <b>Other people think that I cannot meet my daily needs because I have diabetes*</b>      | (n=391) |             | (n=589) |             | (n=400) |             |
| Completely disagree   | 28.6    | (24.0-33.7) | 35.0    | (30.8-39.5) | 46.4    | (40.0-52.9) |
| Disagree  | 39.9    | (34.6-45.5) | 36.6    | (32.4-41.0) | 31.5    | (26.3-37.1) |
| Neither agree nor disagree  | 4.8     | (2.9-7.7)   | 2.7     | (1.7-4.3)   | 5.5     | (3.2-9.3)   |
| Agree   | 11.7    | (8.3-16.3)  | 12.0    | (9.0-15.8)  | 8.4     | (5.6-12.5)  |
| Completely agree  | 3.9     | (1.8-8.4)   | 4.0     | (2.4-6.5)   | 0.6     | (0.2-1.7)   |
| Don't know  | 11.0    | (7.8-15.4)  | 9.7     | (7.2-13.0)  | 7.6     | (5.1-11.2)  |
| <b>Other people think that I have caused my diabetes through my unhealthy lifestyle.*</b> | (n=389) |             | (n=588) |             | (n=398) |             |
| Completely disagree   | 22.8    | (18.5-27.6) | 28.1    | (24.2-32.4) | 35.0    | (29.1-41.4) |
| Disagree  | 31.8    | (26.9-37.2) | 33.9    | (29.6-38.3) | 29.5    | (24.3-35.2) |
| Neither agree nor disagree  | 7.1     | (4.7-10.7)  | 5.6     | (3.8-8.2)   | 10.8    | (7.4-15.4)  |
| Agree   | 18.6    | (14.4-23.6) | 17.8    | (14.4-21.7) | 11.2    | (8.2-15.3)  |
| Completely agree  | 5.7     | (3.1-10.4)  | 4.6     | (2.9-7.3)   | 3.5     | (1.8-6.7)   |
| Don't know  | 14.0    | (10.6-18.2) | 10.0    | (7.7-12.9)  | 10.0    | (7.2-13.7)  |
| <b>I often face disadvantages because I have diabetes.*</b>                               | (n=392) |             | (n=594) |             | (n=404) |             |
| Completely disagree   | 39.1    | (33.8-44.7) | 43.5    | (39.1-48.1) | 47.7    | (41.4-54.1) |
| Disagree  | 51.6    | (46.0-57.2) | 42.2    | (37.8-46.8) | 42.8    | (36.8-49.0) |
| Neither agree nor disagree  | 1.9     | (0.8-4.5)   | 3.5     | (2.1-5.7)   | 1.4     | (0.6-3.0)   |
| Agree   | 2.6     | (1.4-4.7)   | 6.4     | (4.3-9.3)   | 5.5     | (3.0-9.8)   |
| Completely agree  | 1.8     | (0.6-5.6)   | 1.6     | (0.7-3.7)   | 0.6     | (0.1-2.3)   |
| Don't know  | 3.1     | (1.6-5.7)   | 2.8     | (1.4-5.5)   | 2.1     | (0.9-4.7)   |

\* Indicates questions that were asked only to participants with diabetes in the last 12 months

CI: Confidence interval



## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 6

Perceived level of information among adults  
with diagnosed diabetes  
according to educational status

Source: Disease knowledge and information  
needs – Diabetes mellitus (2017)

|   | Low  |             | Middle |             | High |             |
|---|------|-------------|--------|-------------|------|-------------|
|   | %    | (95% CI)    | %      | (95% CI)    | %    | (95% CI)    |
| <b>Level of information</b>   |      |             |        |             |      |             |
| <b>Causes of diabetes</b> (n=412)   |      |             |        |             |      |             |
| Very well   | 11.6 | (8.6-15.5)  | 20.2   | (16.8-24.1) | 26.8 | (21.7-32.6) |
| Well  | 66.5 | (61.3-71.4) | 64.7   | (60.2-69.0) | 63.3 | (57.0-69.3) |
| Not well  | 13.8 | (10.6-17.8) | 9.7    | (7.3-12.8)  | 9.0  | (5.3-14.8)  |
| Not informed at all   | 8.1  | (5.8-11.2)  | 5.4    | (3.6-8.0)   | 0.9  | (0.3-2.8)   |
| <b>Course of disease</b> (n=410)  |      |             |        |             |      |             |
| Very well   | 11.1 | (8.1-15.1)  | 19.2   | (15.9-23.0) | 23.3 | (18.4-29.1) |
| Well  | 72.3 | (67.2-76.8) | 65.1   | (60.6-69.4) | 64.7 | (58.5-70.4) |
| Not well  | 10.0 | (7.3-13.7)  | 11.1   | (8.4-14.5)  | 10.4 | (7.1-14.9)  |
| Not informed at all   | 6.5  | (4.5-9.4)   | 4.6    | (2.9-7.5)   | 1.6  | (0.7-3.7)   |
| <b>Treatment and therapy</b> (n=410)                                      |      |             |        |             |      |             |
| Very well   | 12.9 | (9.6-17.0)  | 18.8   | (15.5-22.5) | 26.8 | (21.5-32.8) |
| Well  | 71.3 | (66.1-76.0) | 63.7   | (59.1-68.0) | 66.6 | (60.4-72.3) |
| Not well  | 9.1  | (6.3-12.9)  | 13.0   | (10.0-16.8) | 6.0  | (3.7-9.8)   |
| Not informed at all   | 6.8  | (4.6-9.8)   | 4.5    | (2.9-6.9)   | 0.6  | (0.2-1.6)   |
| <b>Complications</b> (n=408)  |      |             |        |             |      |             |
| Very well   | 11.0 | (8.1-15.0)  | 19.2   | (15.8-23.1) | 24.0 | (19.0-29.9) |
| Well  | 64.8 | (59.6-69.7) | 61.6   | (57.0-66.0) | 62.0 | (55.8-67.8) |
| Not well  | 15.8 | (12.4-19.9) | 13.9   | (10.9-17.5) | 11.5 | (8.0-16.2)  |
| Not informed at all   | 8.4  | (6.0-11.5)  | 5.3    | (3.7-7.6)   | 2.5  | (1.3-4.5)   |
| <b>Lifestyle changes, health promotion and disease prevention</b> (n=402) |      |             |        |             |      |             |
| Very well   | 9.7  | (6.8-13.6)  | 13.8   | (10.9-17.2) | 18.3 | (14.3-23.1) |
| Well  | 57.0 | (51.4-62.4) | 60.7   | (56.2-65.1) | 65.8 | (59.4-71.7) |
| Not well  | 18.5 | (14.5-23.2) | 16.2   | (13.0-19.9) | 13.5 | (8.8-20.1)  |
| Not informed at all   | 14.8 | (11.3-19.2) | 9.3    | (7.1-12.2)  | 2.5  | (1.3-4.8)   |
| <b>Support services, helplines, information sources</b> (n=402)           |      |             |        |             |      |             |
| Very well   | 6.7  | (4.4-10.1)  | 8.4    | (6.4-11.1)  | 15.4 | (11.1-21.0) |
| Well  | 46.1 | (40.6-51.7) | 50.0   | (45.4-54.5) | 52.4 | (46.2-58.6) |
| Not well  | 27.5 | (22.9-32.7) | 26.0   | (22.1-30.4) | 24.1 | (18.8-30.3) |
| Not informed at all   | 19.7 | (15.8-24.2) | 15.6   | (12.6-19.1) | 8.1  | (5.7-11.4)  |

CI: Confidence interval

## Annex 4

Presentation of results of the study  
Disease knowledge and information needs -  
Diabetes mellitus (2017) according to  
educational status

Table 7

Subjective information needs on diabetes-  
specific topics, trustworthiness and clarity  
of information among adults with  
diagnosed diabetes according to educational  
status

Source: Disease knowledge and information  
needs– Diabetes mellitus (2017)

|   | Low  |             | Middle |             | High |             |
|---|------|-------------|--------|-------------|------|-------------|
|   | %    | (95% CI)    | %      | (95% CI)    | %    | (95% CI)    |
| <b>Subjective information needs</b>                               |      |             |        |             |      |             |
| <b>Causes of diabetes</b>   |      | (n=413)     |        | (n=633)     |      | (n=427)     |
| Yes   | 37.0 | (31.9-42.3) | 35.1   | (30.9-39.6) | 23.7 | (18.5-29.7) |
| <b>Course of disease</b>  |      | (n=413)     |        | (n=634)     |      | (n=427)     |
| Yes   | 38.9 | (33.9-44.2) | 41.0   | (36.6-45.6) | 30.0 | (24.5-36.2) |
| <b>Treatment and therapy</b>                                      |      | (n=413)     |        | (n=633)     |      | (n=427)     |
| Yes   | 46.6 | (41.2-52.1) | 54.3   | (49.8-58.8) | 39.3 | (33.5-45.5) |
| <b>Complications</b>  |      | (n=413)     |        | (n=632)     |      | (n=427)     |
| Yes   | 42.7 | (37.4-48.1) | 49.3   | (44.7-53.9) | 35.8 | (30.2-41.9) |
| <b>Lifestyle changes, health promotion and disease prevention</b> |      | (n=411)     |        | (n=629)     |      | (n=425)     |
| Yes   | 40.5 | (35.3-46.0) | 43.6   | (39.1-48.2) | 33.7 | (28.0-39.8) |
| <b>Support services, helplines, information sources</b>           |      | (n=409)     |        | (n=631)     |      | (n=425)     |
| Yes   | 42.8 | (37.5-48.3) | 48.5   | (43.9-53.0) | 37.6 | (31.8-43.9) |
| <b>Judge the trustworthiness of ...</b>                           |      |             |        |             |      |             |
| <b>Information about diabetes</b>                                 |      | (n=379)     |        | (n=585)     |      | (n=399)     |
| Very easy   | 8.9  | (6.0-13.0)  | 12.3   | (9.1-16.3)  | 7.8  | (5.3-11.4)  |
| Quite easy  | 40.0 | (34.5-45.8) | 39.1   | (34.7-43.7) | 46.7 | (40.5-53.0) |
| Quite difficult   | 38.8 | (33.3-44.5) | 41.2   | (36.5-46.0) | 38.1 | (32.0-44.6) |
| Very difficult  | 12.3 | (9.2-16.2)  | 7.4    | (5.3-10.3)  | 7.4  | (4.0-13.3)  |
| <b>Judge the clarity of ...</b>                                   |      |             |        |             |      |             |
| <b>Information about diabetes</b>                                 |      | (n=383)     |        | (n=603)     |      | (n=406)     |
| Very easy   | 12.7 | (9.0-17.6)  | 12.8   | (10.0-16.3) | 17.7 | (13.6-22.7) |
| Quite easy  | 47.0 | (41.3-52.7) | 48.3   | (43.7-53.0) | 63.6 | (57.5-69.3) |
| Quite difficult   | 33.4 | (28.4-38.8) | 34.6   | (30.2-39.4) | 16.0 | (12.0-21.1) |
| Very difficult  | 6.9  | (4.5-10.5)  | 4.2    | (2.7-6.4)   | 2.7  | (1.3-5.4)   |

CI: Confidence interval

## Imprint

### Journal of Health Monitoring

#### Publisher

Robert Koch Institute  
Nordufer 20  
D-13353 Berlin, Germany

#### Editors

Susanne Bartig, Johanna Gutsche, Dr Birte Hintzpeter,  
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[www.rki.de/journalhealthmonitoring-en](http://www.rki.de/journalhealthmonitoring-en)

#### Typesetting

Gisela Dugnus, Alexander Krönke, Kerstin Möllerke

#### Translation

Simon Phillips/Tim Jack

ISSN 2511-2708

#### Note

External contributions do not necessarily reflect the opinions of the Robert Koch Institute.



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