

# Perceived diabetes risk and related determinants in individuals with high actual diabetes risk: results from a nationwide population-based survey

Christin Heidemann,<sup>1</sup> Rebecca Paprott,<sup>1</sup> Lena M Stühmann,<sup>1,2</sup> Jens Baumert,<sup>1</sup> Kristin Mühlenbruch,<sup>3</sup> Sylvia Hansen,<sup>4</sup> Catarina Schiborn,<sup>3</sup> Daniela Zahn,<sup>4</sup> Paul Gellert,<sup>2</sup> Christa Scheidt-Nave<sup>1</sup>

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<sup>1</sup>Department of Epidemiology and Health Monitoring, Robert Koch Institute, Berlin, Germany

<sup>2</sup>Institute of Medical Sociology, Charité-Universitätsmedizin, Berlin, Germany

<sup>3</sup>Department of Molecular Epidemiology, German Institute of Human Nutrition Potsdam-Rehbruecke, Nuthetal, Germany

<sup>4</sup>Office for National Education and Communication on Diabetes mellitus, Federal Centre for Health Education, Cologne, Germany

**Correspondence to**  
Dr Christin Heidemann;  
HeidemannC@rki.de

## ABSTRACT

**Objective** The purpose of this study was first, to examine perceived diabetes risk compared with actual diabetes risk in the general population and second, to investigate which factors determine whether persons at increased actual risk also perceive themselves at elevated risk.

**Research design and methods** The study comprised adults (aged 18–97 years) without known diabetes from a nationwide survey on diabetes-related knowledge and information needs in Germany in 2017. Actual diabetes risk was calculated by an established risk score estimating the 5-year probability of developing type 2 diabetes and was compared with perceived risk of getting diabetes over the next 5 years (response options: 'almost no risk', 'slight risk', 'moderate risk', 'high risk'; n = 2327). Among adults with an increased actual diabetes risk (n=639), determinants of perceived risk were investigated using multivariable logistic regression analysis.

**Results** Across groups with a 'low' (<2%), 'still low' (2% to <5%), 'elevated' (5% to <10%), and 'high' (≥10%) actual diabetes risk, a proportion of 89.0%, 84.5%, 79.3%, and 78.9%, respectively, perceived their diabetes risk as almost absent or slight. Among those with an increased (elevated/high) actual risk, independent determinants of an increased (moderate/high) perceived risk included younger age (OR 0.92 (95% CI 0.88 to 0.96) per year), family history of diabetes (2.10 (1.06–4.16)), and being informed about an increased diabetes risk by a physician (3.27 (1.51–7.07)), but none of further diabetes risk factors, healthcare behaviors or beliefs about diabetes.

**Conclusions** Across categories of actual diabetes risk, perceived diabetes risk was low, even if actual diabetes risk was high. For effective strategies of primary diabetes prevention, attention should be directed to risk communication at the population level as well as in primary care practice.

## INTRODUCTION

Type 2 diabetes and its complications can lead to disability and premature death in affected individuals, cause enormous costs for health-care systems and thus, represent a major public health challenge for most countries across the globe.<sup>1,2</sup> In addition to the high

## Significance of this study

### What is already known about this subject?

- ▶ Some previous studies observed a slightly higher perceived diabetes risk with higher actual diabetes risk. However, an underestimation of risk seems to be evident among persons with a high-risk profile.
- ▶ Determinants that might explain the discrepancy between perceived and actual diabetes risk among high-risk individuals, who are an important target group for primary prevention, have scarcely been investigated.

### What are the new findings?

- ▶ The current nationwide data reflect a relatively low perception of diabetes risk in the general adult population in Germany, even if actual diabetes risk measured by a multifactorial risk score is high.
- ▶ Focusing on adults with an increased actual diabetes risk revealed that besides younger age and family history of diabetes, being informed about an increased diabetes risk by a physician was strongly and independently related to a higher risk perception.
- ▶ In contrast, potentially modifiable risk factors of diabetes, preventive healthcare behaviors, and psychological factors such as beliefs in general and personal control of diabetes risk seemed to play no determining role for perceived risk.

### How might these results change the focus of research or clinical practice?

- ▶ The findings could inform the strategic orientation of diabetes prevention strategies by emphasizing the need to raise the awareness of diabetes risk and also highlight the importance of effective risk communication between health professionals and patients at elevated diabetes risk.

burden of diagnosed diabetes, most countries face a considerable number of people with undiagnosed diabetes<sup>3</sup> along with a high number of people with prediabetes that are

at high risk for future diabetes.<sup>4</sup> In USA, for example, at least one in five adults with diabetes is undiagnosed and about a third of the adult population has prediabetes.<sup>5</sup>

To tackle the growing burden from diabetes and its antecedents, implementation of primary prevention approaches aiming at risk factor control through behavioral and environmental changes is regarded as an essential cornerstone.<sup>6,7</sup> Indeed, several randomized clinical trials succeeded in reducing the progression from prediabetes to diabetes by lifestyle modifications.<sup>8</sup> However, for primary prevention measures to be effective in a real world setting, people, especially those with a high-risk profile, need to be aware of their risk of developing a disease.<sup>9,10</sup>

Some previous studies suggested that a higher actual risk defined by measured glycemic status or multifactorial risk scores is associated with a slightly higher perceived risk.<sup>11–17</sup> However, among persons with high actual diabetes risk, an underestimation of risk seems to be evident.<sup>11–15,18,19</sup> For the development of effective risk communication strategies, it is therefore important to recognize factors that might explain this discrepancy. So far, only few studies have addressed this question and consistently found that among considered sociodemographic and diabetes risk factors, lower age and a family history of diabetes were related to a higher risk perception in persons at high actual risk.<sup>11,12,18</sup> However, these studies were confined to middle-aged or elderly adults living in geographically small areas and did not include factors such as risk communication by the physician or diabetes-related control beliefs, which could potentially also be related to perceived risk.

Against this background, the aims of the study were first, to evaluate perceived diabetes risk in comparison to actual diabetes risk in a representative sample of the general adult population and second, to investigate whether sociodemographic and diabetes risk factors as well as healthcare and psychological factors contribute to explain diabetes risk perception in the subgroup of adults at high actual diabetes risk.

## RESEARCH DESIGN AND METHODS

### Study on “Disease knowledge and information needs – Diabetes mellitus (2017)”

A national telephone interview survey focusing on diabetes-related knowledge, perceptions, and information needs was conducted by the Robert Koch Institute between September and November 2017 as previously described in detail.<sup>20</sup> In brief, landline and mobile telephone numbers were randomly generated to assure that over the phone reachable private households were representatively considered for the study. In a next step, a Kish selection grid was applied for random sampling of adult German-speaking household members (aged at least 18 years) for interview. Computer-assisted interviews were performed by trained personnel based on separate questionnaires for persons without and with

diagnosed diabetes. By this random sampling procedure, 2590 persons (n=2327 without and n=263 with self-reported diagnosed diabetes) were included. The response rate calculated as a proportion of conducted interviews in relation to private households theoretically reachable over the phone (ie, response rate 3 according to the criteria of the American Association for Public Opinion Research) was 17.9%.<sup>21</sup> In a further step, a direct screening procedure for persons with diagnosed diabetes was applied to gain a larger subsample for diagnosed diabetes. Only in the case of more than one person with diagnosed diabetes in a household, a Kish selection grid was used to randomly select the household member for interview. By this screening procedure, 1216 persons with self-reported diagnosed diabetes were interviewed. Thus, the final study sample comprised 3806 participants (n=2327 without self-reported diagnosed diabetes aged 18–97 years and n=1479 with self-reported diagnosed diabetes aged 18–96 years). 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.

### Study population

For descriptive analyses, all 2327 participants without diagnosed diabetes were included. For logistic regression analyses that specifically focused on participants with an elevated or high actual diabetes risk, 639 participants with an actual diabetes risk  $\geq 5\%$  were considered.

### Assessment of actual 5-year diabetes risk

Actual diabetes risk was defined by the German Diabetes Risk Score (GDRS) that estimates the 5-year probability of developing type 2 diabetes.<sup>22</sup> The updated and validated simplified GDRS version was applied that considers age, waist circumference, body height, physical activity, smoking, history of hypertension, family history of diabetes, red meat intake, wholegrain intake, and coffee consumption as categorical score components.<sup>23,24</sup>

In the current survey, physical activity was assessed by asking whether participants are usually physically active  $\geq 5$  hours per week, also including sport, gardening, and cycling. Smoking habit was assessed by asking for current and former smoking as well as the average number ( $<20$  or  $\geq 20$ ) of cigarettes, cigarillos, or cigars smoked per day. History of hypertension was obtained by asking whether participants ever had a diagnosis of hypertension. Family history of diabetes was assessed by asking for a diabetes diagnosis in one or both biological parents, or in at least one biological sibling. Red meat intake was assessed as frequency of consumption of beef, pork, and lamb (ranging from never or rarely to several times a day). Whole grain intake was obtained as sum of consumed slices of whole grain bread, whole grain rolls, and portions of muesli (3 table

spoons per portion) per day. Coffee consumption was assessed as cups of coffee (including espresso, cappuccino, latte macchiato) per day. Waist circumference was not assessed in the current survey and therefore, was estimated based on self-reported body weight (in kg), body height (in cm), age, and sex using the following equations:

$$\text{Waist circumference for men} = 93.4692084 - 0.4147528 * \text{height (cm)} + 0.7517554 * \text{weight (kg)} + 0.2589500 * \text{age (years)}$$

$$\text{Waist circumference for women} = 82.4905304 - 0.3990789 * \text{height (cm)} + 0.8359074 * \text{weight (kg)} + 0.1983362 * \text{age (years)}$$

The authors derived equations from linear regression analysis based on data from the nationally representative German Health Interview and Examination Survey for Adults (2008–2011)<sup>25</sup> with waist circumference measured by trained health professionals as the dependent variable and age and self-reported body weight and height as independent variables.

Based on the previously published algorithm, points were assigned to each GDRS component to calculate actual diabetes risk.<sup>23</sup> For the current analysis, actual diabetes risk was categorized into <2% ('low risk'), 2% to <5% ('still low risk'), 5% to <10% ('elevated risk'), and ≥10% ('high') following the currently used classification for risk communication of GDRS test results.<sup>26</sup>

### Assessment of perceived 5-year diabetes risk and potential determinants

#### Perceived diabetes risk

Perceived diabetes risk was assessed by the question "What do you think is your risk for getting diabetes over the next 5 years?" (response options: "almost no risk", "slight risk", "moderate risk", "high risk") in alignment to a previous study.<sup>27</sup>

#### Sociodemographic and diabetes risk factors

Age was self-reported by participants and sex was recorded by interviewers. General educational graduation (9 categories) and vocational qualification (15 categories) were obtained to categorize educational level into low, middle, and high as previously described.<sup>28</sup> Diabetes risk factors were assessed as described above.

#### Preventive healthcare behavior

Biennial health check-up for early detection of cardiovascular disease, diabetes, and kidney disease is recommended for adults ≥35 years in Germany as 'health check-up 35' by private and statutory health insurance. Participants were asked whether they know this offer by their health insurance. Those answering 'yes' were further asked whether they have ever attended a 'health check-up 35' and whether this has occurred within the last 2 years. Self-reported last blood sugar measurement by a health professional was assessed by the categories

'within last 12 months', 'one to less than 2 years ago', 'two or more years ago', and 'never'.

#### Information about diabetes risk

Being informed about an increased diabetes risk by a physician was assessed by asking "Has your physician ever told you that you have an increased diabetes risk?". Whether information about diabetes was obtained by oneself was assessed by the question "Have you ever actively gathered information about diabetes?". An occupational relation to the topic of diabetes was obtained by asking "Are you familiar with diabetes because of your current or former occupation?".

#### Beliefs on health and diabetes

Subjective health was assessed by asking "How is your state of health in general?" (response options: "very good", "good", "moderate", "poor", "very poor"). Perception of the seriousness of diabetes was obtained by the question "How serious is diabetes in your view?" (response options: "not serious", "moderately serious", "serious", "very serious", "no opinion") adopted from an earlier study.<sup>13</sup> Belief in general control of diabetes risk was assessed by the statement "People who make a good effort to control their risk of getting diabetes are much less likely to get diabetes". Belief in personal control was assessed by the statement "I think that my personal efforts could help control my risk of getting diabetes". Participants were asked to indicate their grade of agreement (response options: "fully agree", "agree", "disagree", "fully disagree") to the two previous statements extracted from a personal control subscale.<sup>29</sup> Perception of the knowledge of diabetes was obtained by the question "How would you rate your knowledge of diabetes?" (response options: "very good", "good", "poor", "absent") in alignment to a previous study.<sup>30</sup>

#### Statistical analyses

Analyses were performed using the SAS statistical software package V.9.4 (SAS Institute, Cary, North Carolina, USA) and included a specific weighting factor as previously described.<sup>20</sup> In brief, this weighting factor corrects for deviations of the study sample from population figures of the Federal Statistical Office with regard to sex, age, federal state of residence, and educational level as of December 31, 2016.

To handle missing values, multiple imputation was applied including perceived risk, all potential determinants, and the weighting factor in the imputation model. Overall, 16.6% of participants had a missing value in at least one variable and the percentage of missing information per variable ranged from 0.04% to 5.6%. The authors applied multiple imputation by chained equations (m=10) using the fully conditional specification method assuming an arbitrary pattern of missingness.<sup>31</sup> Based on the separate imputed data sets, descriptive and logistic regression analyses were performed. Estimates from the individual data sets were then combined according to Rubin's rules taking into account variability within and

between the imputations.<sup>31</sup> The level of statistical significance was set at  $p$  values  $<0.05$  based on two-sided tests.

For descriptive analyses, means (SE) or percentages were calculated and tests for trend across categories of actual diabetes risk were performed using linear or logistic regression. For the subgroup of participants with an elevated or high actual diabetes risk, logistic regression was performed to calculate ORs and 95% CIs for perceived diabetes risk as dichotomized dependent variable (high/moderate perceived risk vs slight/almost no perceived risk as reference category). Independent variables were all the potential determinants as described above and as operationalized in table 3 and were considered unadjusted in separate models for each determinant as well as mutually adjusted in a multivariable model.

## RESULTS

### Actual diabetes risk and characteristics of the study population

Among the 2327 participants, actual risk to develop diabetes within the next 5 years was low for 59.5%, still low for 16.1%, elevated for 10.4%, and high for 14.1%. As expected according to the score-based definition, persons with a higher actual diabetes risk were older,

were more likely to be former smokers, had a higher body mass index (BMI), and more often had a hypertension diagnosis, a family history of diabetes, and low physical activity. In addition, they were more often male and less likely to have a high educational level (table 1).

Of all participants, 37.0% reported a 'health check-up 35' within the last 2 years and 60.7% reported a blood glucose measurement within the last year; these proportions increased across groups with increasing actual diabetes risk (from 28.0% to 56.9% and from 51.6% to 82.7%, respectively). A total of 6.1% of participants stated to have been informed by a physician about having an increased diabetes risk and this proportion increased with increasing actual risk (from 3.8% to 15.3%). Overall, 30.3% stated to have gathered information about diabetes themselves without significant differences across actual risk categories. A total of 18.9% stated to be familiar with diabetes due to their current or former occupation and this proportion decreased with increasing actual risk (from 22.2% to 12.9%; table 2).

Further, 72.7% of participants rated their health as very good or good and this proportion decreased with increasing actual risk (from 81.2% to 53.3%). Overall, 65.2% perceived diabetes as very serious or serious and

**Table 1** Sociodemographic and diabetes risk factors across categories of actual diabetes risk among adults without diagnosed diabetes from a nationwide population-based study in Germany (n=2327)

	Categories of actual diabetes risk					P for trend
	Total	Low risk (<2%)	Still low risk (2% to <5%)	Elevated risk (5% to <10%)	High risk (≥10%)	
Proportion of study sample (%)		59.5	16.1	10.4	14.1	
Sociodemographic factors						
Sex, male (%)	48.6	44.6	50.0	50.4	62.4	<0.0001
Age (years)	51.7 (0.6)	41.0 (0.6)	63.4 (1.0)	69.9 (1.0)	70.5 (0.9)	<0.0001
Educational level (%)						
High	25.9	30.6	24.2	19.0	13.3	<0.0001
Middle	40.9	46.6	37.6	32.7	27.0	<0.0001
Low	33.2	22.9	38.2	48.3	59.7	<0.0001
Diabetes risk factors						
Body mass index (kg/m <sup>2</sup> )	25.7 (0.1)	23.8 (0.1)	26.4 (0.3)	27.1 (0.3)	31.4 (0.4)	<0.0001
Waist circumference (cm)	89.8 (0.4)	83.1 (0.4)	94.6 (0.7)	96.8 (0.6)	107.7 (0.9)	<0.0001
Physical activity ≥5 hours/week (%)	72.6	74.6	74.7	71.9	62.0	0.005
Smoking (%)						
Never	47.9	48.2	49.5	51.3	41.9	0.35
Formerly	25.2	21.1	26.7	27.0	39.4	<0.0001
Currently	26.9	30.7	23.8	21.7	18.7	0.002
Hypertension diagnosis (%)	34.0	14.3	43.4	62.7	85.6	<0.0001
Family history of diabetes (%)*	22.4	17.0	22.5	34.4	36.2	<0.0001

Data are given as weighted mean (SE) or weighted percentage.

\*At least one parent or sibling with diabetes.



**Table 2** Healthcare behavior, information about diabetes risk, and beliefs on health and diabetes across categories of actual diabetes risk among adults without diagnosed diabetes from a nationwide population-based study in Germany (n=2327)

	Total	Categories of actual diabetes risk				P for trend
		Low risk (<2%)	Still low risk (2% to <5%)	Elevated risk (5% to <10%)	High risk (≥10%)	
<b>Preventive healthcare behavior</b>						
'Health check-up 35' in last 2 years (%)						
Yes	37.0	28.0	45.3	49.3	56.9	<0.0001
No	14.7	12.6	18.9	20.8	14.1	0.12
Don't know this recommendation	24.0	19.1	34.7	29.9	28.3	0.0002
Not relevant as aged below 35 years	24.2	40.3	1.1	–	0.7	<0.0001
<b>Last blood glucose measurement (%)</b>						
Within last 12 months	60.7	51.6	66.3	74.5	82.7	<0.0001
≥1 year ago	27.9	33.7	25.3	18.3	13.5	<0.0001
Never	11.4	14.7	8.4	7.2	3.8	0.0002
<b>Information about diabetes risk</b>						
Informed from physician about increased diabetes risk (%)	6.1	3.8	5.4	8.1	15.3	<0.0001
Actively informed about diabetes by oneself (%)	30.3	31.2	30.2	31.5	25.8	0.23
Occupational relation to diabetes topic (%)	18.9	22.2	13.2	17.2	12.9	0.001
<b>Beliefs on health and diabetes</b>						
Very good or good subjective health (%)	72.7	81.2	67.4	58.5	53.3	<0.0001
<b>Perceived seriousness of diabetes (%)</b>						
Very serious or serious	65.2	60.9	70.1	72.4	72.1	0.001
Moderately or not serious	22.1	25.0	21.0	14.3	16.7	0.001
No opinion	12.7	14.0	8.9	13.3	11.2	0.38
Belief in general control of diabetes risk (%)*	23.0	22.6	18.9	23.6	28.9	0.20
Belief in personal control of diabetes risk (%)*	9.7	8.5	8.9	10.0	15.3	0.06
Very good or good perceived knowledge about diabetes (%)	56.4	54.0	59.1	64.2	57.8	0.12

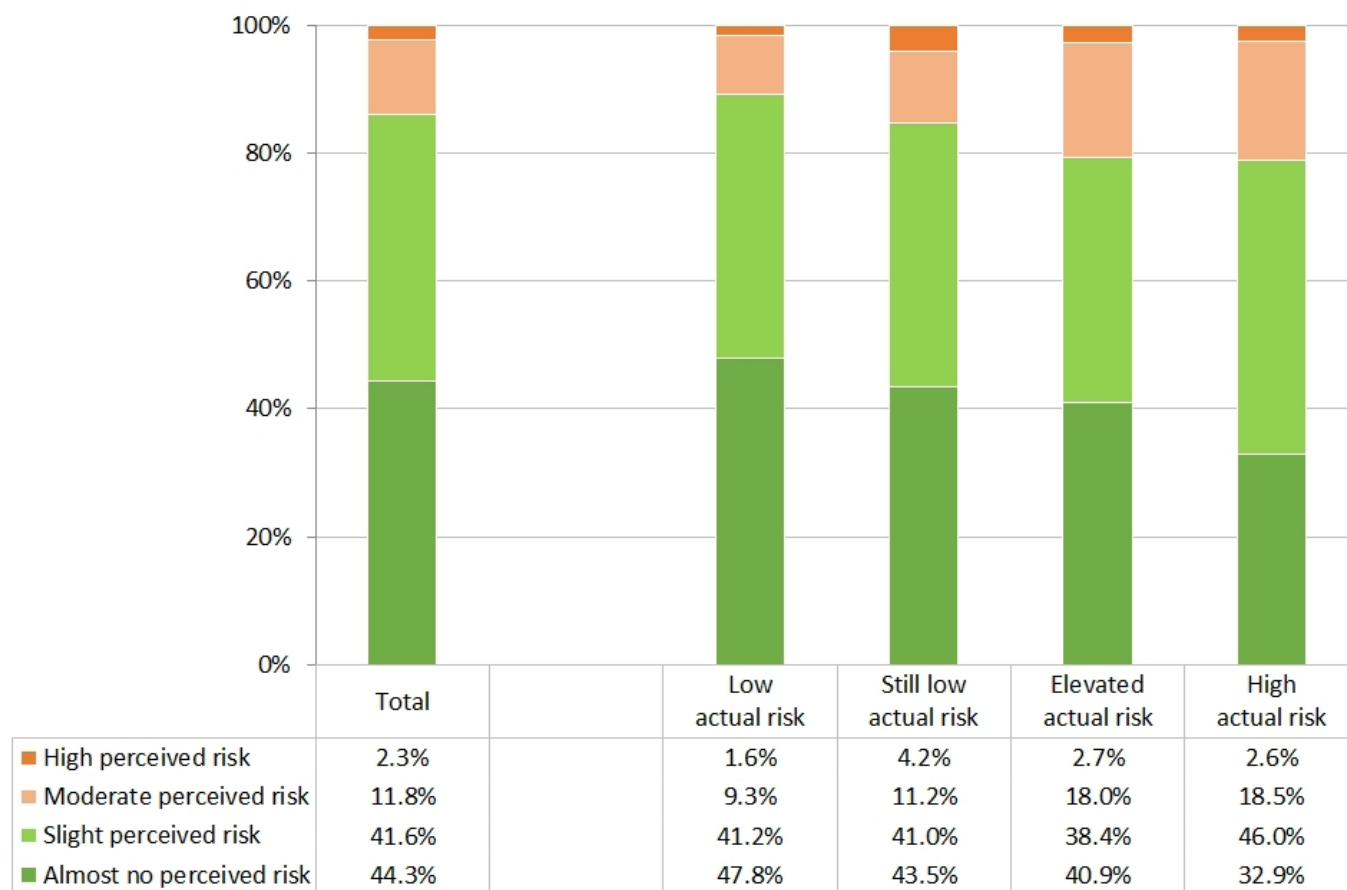
Data are given as weighted percentage.

\*Based on response 'fully agree' or 'agree'.

this proportion moderately increased with increasing actual risk (from 60.9% to 72.1%). A total of 56.4% rated their knowledge on diabetes as very good or good, only 23.0% believed in general control of diabetes risk, and even only 9.7% believed in personal control; these proportions did not significantly differ across actual risk categories (table 2).

### Perceived diabetes risk in relation to actual diabetes risk

Of all participants, the risk to develop diabetes within the next 5 years was perceived as almost absent for 44.3%, as slight for 41.6%, as moderate for 11.8%, and as high for 2.3%. The overall proportion of those who perceived their risk as almost non-existent or slight (85.9%) only modestly decreased across groups with



**Figure 1** Perceived diabetes risk across categories of actual diabetes risk among adults without diagnosed diabetes from a nationwide population-based study in Germany (n=2327). Data are given as weighted percentage.

increasing actual diabetes risk (from 89.0% to 78.9%; figure 1).

#### Determinants of perceived diabetes risk among adults at increased actual diabetes risk

In unadjusted logistic regression models focusing on 639 adults with an elevated or high actual diabetes risk, perceiving oneself at increased (ie, moderate or high) diabetes risk was significantly associated with lower age, higher BMI, higher waist circumference, a family history of diabetes, being informed about an increased diabetes risk by a physician, and a poor self-rated health status, whereas perceiving oneself at low (ie, almost no or slight) diabetes risk was significantly related to having no opinion on the seriousness of diabetes. In a multivariable model including all potential determinants, perceiving oneself at increased diabetes risk remained significantly associated with a lower age (OR per year 0.92 (95% CI 0.88 to 0.96)), a family history of diabetes (2.10 (1.06–4.16)), and being informed about an increased diabetes risk by a physician (3.27 (1.51–7.07); table 3).

#### DISCUSSION

The current nationwide survey showed that overall a relatively low proportion of the adult population perceived their risk to develop diabetes as moderate or high.

This proportion only slightly increased from 10.9% among those at low actual risk to 21.1% among those at high actual risk. Focusing on adults with a high or elevated actual diabetes risk revealed that younger age, a family history of diabetes, and being informed about an increased diabetes risk by a physician were strongly related to a higher perceived diabetes risk. In contrast, potentially modifiable risk factors of diabetes, preventive healthcare behaviors, perceived seriousness and knowledge on diabetes as well as beliefs in general and personal control of diabetes risk seemed to play no determining role for perceived risk.

#### Perceived diabetes risk in relation to actual diabetes risk

In line with results from the current study, previous studies reported a relatively low proportion of persons that is aware to be at diabetes risk, even if actual diabetes risk defined by a risk score or measured glucose or glycated haemoglobin (HbA1c) values was high.<sup>11–15 18</sup> For example, in a diabetes screening program among elderly residents of the Dutch Hoorn region (1998–2000), 40.1% of low-risk and 47.9% of high-risk participants could not give a quantitative estimate (in per cent) of their risk of having diabetes at the moment. Among the remaining persons, mean perceived risk was only slightly higher in those at high actual risk defined by a symptom risk

**Table 3** Association between perceived diabetes risk and potential determinants among adults with an elevated or high actual diabetes risk from a nationwide population-based study in Germany (n=639)

	OR (95% CI)* from separate models for each variable	OR (95% CI)* from the fully adjusted model
Sociodemographic factors		
Age (per year)	<b>0.91 (0.88 to 0.94)</b>	<b>0.92 (0.88 to 0.96)</b>
Sex (men vs women)	1.12 (0.62 to 2.03)	0.66 (0.22 to 1.98)
Educational level		
High	1	1
Middle	0.92 (0.54 to 1.59)	0.60 (0.27 to 1.34)
Low	0.79 (0.43 to 1.45)	0.87 (0.41 to 1.85)
Diabetes risk factors		
Body mass index (per kg/m <sup>2</sup> )	<b>1.13 (1.07 to 1.19)</b>	1.00 (0.82 to 1.20)
Waist circumference (per cm)	<b>1.05 (1.03 to 1.08)</b>	1.02 (0.94 to 1.11)
Physical activity (≥5 vs <5 hours/week)	0.63 (0.35 to 1.14)	0.79 (0.36 to 1.72)
Smoking		
Never	1	1
Formerly	1.13 (0.61 to 2.10)	0.85 (0.43 to 1.69)
Currently	1.75 (0.76 to 4.00)	0.69 (0.25 to 1.89)
Hypertension diagnosis (yes vs no)	0.97 (0.46 to 2.06)	0.80 (0.37 to 1.73)
Family history of diabetes (yes vs no)	<b>2.57 (1.41 to 4.68)</b>	<b>2.10 (1.06 to 4.16)</b>
Preventive healthcare behavior		
'Health check-up 35' in last 2 years†		
Yes	1	1
No	0.98 (0.47 to 2.08)	0.84 (0.37 to 1.93)
Don't know this recommendation	0.66 (0.30 to 1.44)	0.62 (0.27 to 1.47)
Last blood glucose measurement (%)		
Within last 12 months	1	1
≥1 year ago	0.87 (0.39 to 1.92)	1.30 (0.51 to 3.27)
Never	1.49 (0.39 to 5.65)	2.39 (0.53 to 10.7)
Information about diabetes risk		
Ever informed from physician on increased diabetes risk (yes vs no)	<b>6.43 (3.12 to 13.2)</b>	<b>3.27 (1.51 to 7.07)</b>
Ever actively informed about diabetes by oneself (yes vs no)	1.59 (0.90 to 2.82)	1.16 (0.59 to 2.30)
Occupational relation to diabetes topic (yes vs no)	0.88 (0.41 to 1.90)	0.51 (0.22 to 1.21)
Beliefs on health and diabetes		
Subjective health (very good/good vs moderate to poor)	<b>0.55 (0.31 to 0.98)</b>	0.52 (0.25 to 1.07)
Perceived seriousness of diabetes		
Serious or very serious	1	1
Not or moderately serious	1.47 (0.74 to 2.89)	2.02 (0.96 to 4.26)
No opinion	<b>0.31 (0.10 to 0.95)</b>	0.54 (0.16 to 1.81)
Belief in general control of diabetes risk (fully agree/agree vs disagree/fully disagree)	1.01 (0.55 to 1.86)	1.14 (0.50 to 2.58)
Belief in personal control of diabetes risk (fully agree/agree vs disagree/fully disagree)	0.88 (0.36 to 2.18)	0.73 (0.20 to 2.71)
Perceived knowledge on diabetes (very good/good vs poor/very poor)	0.88 (0.47 to 1.63)	0.58 (0.26 to 1.29)

Bold numbers indicate statistically significant ORs (p value<0.05).

\*Calculated based on logistic regression with perceived diabetes risk as dependent variable (high/moderate risk (n(unweighted)=130) vs slight/almost no risk as reference (n(unweighted)=509)) and potential determinants as independent variables.

†The category 'not relevant as aged below 35 years' initially comprised only two participants with an elevated/high actual diabetes risk and thus, is excluded from the analysis of the results for this table.

questionnaire than in those at low actual risk (10.8% vs 8.1%). The qualitative risk perception question revealed that only 1.9% of high-risk persons labeled their risk as high or very high.<sup>12</sup> Among primarily African-American participants in a community-based screening programme in USA (2003/2004), the overall proportion of those that believed to be at any diabetes risk (49%) was similar to the proportion that scored high at a risk assessment score (44%). Further, among those with high actual risk, about a third believed to be not at risk of getting diabetes.<sup>14</sup> In the German cooperative health research in the region of Augsburg (KORA) study comprising residents of the Augsburg region without known diabetes (2013/2014), the proportion that believed to be 'at risk of developing diabetes in the next years' was 14.6% among those with normal glucose tolerance, 20.6% among those with impaired glucose tolerance or impaired fasting glucose, and even only 28.7% among those with a newly detected diabetes.<sup>11</sup> Similarly, studies that investigated perceived diabetes risk among persons with a history of gestational diabetes or a family history of diabetes also point to an underestimated susceptibility to diabetes development in these high-risk groups.<sup>27 32 33</sup> Furthermore, findings from a repeated telephone survey in USA revealed a stagnant proportion of  $\geq 45$ -year-olds who believed to be at risk for diabetes or prediabetes from 2006 to 2011 and this proportion was at a low level for those defined to be at risk for diabetes and at a moderate level for those with prediabetes.<sup>19</sup>

#### Determinants of perceived diabetes risk among adults at increased actual diabetes risk

Determinants of the discrepancy between perceived and actual risk have been scarcely investigated for high-risk individuals. In agreement with our findings, the Dutch study in the Hoorn region, a subsample of the Dutch study that was recontacted after several years, and the German KORA study have consistently shown that a family history of diabetes and lower age are associated with a higher perceived risk in adults at high actual diabetes risk, even after multivariable adjustment.<sup>11 12 18</sup> Possible explanations for the inverse association between age and perceived risk were that older people may think that if they were susceptible to diabetes, they would have already developed it<sup>18</sup> or that older people may have less knowledge about diabetes and risk factors than younger people.<sup>12</sup> Potentially modifiable risk factors of diabetes such as physical inactivity, unhealthy diet, high BMI, and hypertension were not or not consistently related to a higher perceived diabetes risk.<sup>11 12 18</sup> Similarly, we found no significant association of physical inactivity, smoking, or hypertension with perceived risk and the direct association between BMI and perceived risk diminished in multivariable analysis. Interestingly, in the KORA study, a higher educational level and poor subjective health were related to a higher perceived risk.<sup>11</sup> While we obtained a similar result regarding subjective health in the unadjusted analysis, this association was no longer significant

in multivariable analysis. Further, we did not observe any association with education. A study among women with a history of gestational diabetes even found that those with a high risk perception had less education than those with a low risk perception.<sup>27</sup> It can be assumed that the operationalization of education and selection criteria of the study participants may play a role for these divergent results; for example, while mostly lower-educated older men and women (mean age: 59.1 years) were included in the KORA study,<sup>11</sup> the study among women with a history of gestational diabetes comprised mostly well-educated younger women (35.7 years).<sup>27</sup> Among the range of additional available factors in the current study, being informed about one's increased diabetes risk by a physician emerged as the only, but strong determinant of perceived diabetes risk. This result illustrates the importance of strengthening the healthcare system to enable physicians to implement primary prevention in daily practice.<sup>34</sup> Based on their medical expertise, physicians could then assess a patient's risk profile, comprehensively communicate an elevated risk<sup>35</sup> and, in a dialog, further provide decision aids to improve patient's knowledge and comfort regarding available options for lifestyle changes according to the personal daily life context.<sup>36 37</sup> Thereby, physicians can provide an essential contribution to effective risk communication and maintained behavioral modifications.

#### Public health relevance and practical implications

The public health relevance of the findings is based on the massive burden of prediabetes in many countries.<sup>3 4</sup> In Germany, 20.8% of the people aged 18–79 years (13.1 million) have HbA1c-defined prediabetes.<sup>28</sup> In line with this estimate, 24.5% of adults aged  $\geq 18$  years were identified to be at increased diabetes risk based on an established risk score in the current study, which represent a considerable proportion of the population as a potential target group for primary prevention. However, in contrast to the available evidence on risk factors of diabetes,<sup>1</sup> high-risk individuals of the current and previous studies did not or only barely link their prevailing modifiable risk factors with an increased perceived risk and ageing was even inversely linked with perceived risk. Thus, primary prevention approaches should include measures that increase the awareness of diabetes risk factors such as unhealthy lifestyle behaviors and ageing in the general public and improve patient education by health professionals with regard to prevailing personal risk factors. Application of multifactorial risk assessment scores could serve as a supporting tool in such awareness strategies.

According to health behavioral theories, an increased perceived risk for a disease is a prerequisite for preventive action, but needs to be supported by other components of precautionary behavior.<sup>9 10 38 39</sup> Behavioral changes seem to be more likely if the awareness of disease risk is prompted in conjunction with an increased awareness of disease severity or enhancing the control beliefs about disease-related risk factors.<sup>10 38 39</sup> While the proportion of



adults that acknowledged diabetes as a serious condition was relatively high in the current study (overall 65.2%), the proportions of adults that believed in general or personal control of diabetes risk (overall 23.0% or 9.7%) were surprisingly low. Thus, strengthening control beliefs also appears to be essential in diabetes prevention strategies, for example, by emphasizing the potential of lifestyle recommendations for prevention of diabetes development and advising people on lifestyle changes and how to specifically implement and maintain them.

### Limitations

Actual diabetes risk was not defined by an objective assessment of glucose parameters as in a previous study,<sup>11</sup> but by using a non-laboratory diabetes risk score. However, while glucose measurements at a single point in time have own inherent limitations,<sup>40</sup> the applied multifactorial score is an established tool for predicting type 2 diabetes risk<sup>22</sup> and previous validation of the used simplified score version reflected an excellent predictive ability.<sup>24</sup> In addition, the proportion of adults with an elevated or high diabetes risk that was calculated based on the risk score in the current study is in good agreement with a previously reported prevalence of HbA1c-defined prediabetes in Germany.<sup>28</sup> Still, due to the telephone interview mode, all data on score components were of self-reported nature and thus, misclassification may have occurred. In addition, actual diabetes risk was calculated quantitatively as absolute risk in per cent, whereas perceived diabetes risk was assessed qualitatively based on a four-categorical response option. These different scales and the subsequent categorizations for analyses could have led to false cross-classifications. Further, the response rate of the survey was relatively low. To adjust for deviations of survey participants with respect to certain characteristics (age, sex, federal state of residence, educational level) from the German resident population aged at least 18 years, a complex weighting factor<sup>20</sup> was used throughout our analysis. However, despite the weighting procedure, a selection bias due to non-response cannot be entirely excluded. In particular, non-responders may differ from survey participants in terms of other characteristics of major interest to the current study and these differences may have biased our results. Finally, the moderate sample size of persons with an elevated or high actual risk in regression models may have led to dismissing existing determinants of perceived risk.

### CONCLUSIONS

The current nationwide data reflect a relatively low perception of diabetes risk in the general adult population in Germany, even if actual diabetes risk measured by a multifactorial risk score is high. Findings of this study could inform the strategic orientation of prevention strategies on diabetes by emphasizing the need to increase the awareness and control beliefs about diabetes risk and by pointing out the importance of effective risk

communication with health professionals in high-risk groups.

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