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Self-rated quality of care in adults with chronic conditions: results of the 2024 'Health in Germany' panel

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Abstract

Background: A high quality of chronic illness care can help to improve quality of life and reduce the burden of disease and premature mortality.

Methods: Using data from the 2024 'Health in Germany' panel of the Robert Koch Institute (RKI), self-rated quality of care was examined with the Patient Assessment of Chronic Illness Care (PACIC-S11) among adults with chronic conditions (n = 10,001). Mean values for the PACIC-S11 and for each of the eleven individual components (scale: 1–5 for each) were analysed in relation to sociodemographic, health-related and care-related factors, with higher values indicating higher quality of care.

Results: The quality of care was rated as fair (mean: 2.67). Younger people, women, and those with higher education, health-related long-term activity limitations, depressive symptoms, experiences of discrimination in the health sector, lower levels of social support and statutory health insurance rated it lower. Of the eleven individual components, satisfaction with the organisation of care was rated highest (3.61), while encouragement to participate in a support group or structured self-management education programme (1.76) was rated lowest.

Conclusions: There is room for improvement in patient-centred care, e.g. in supporting self-management.

Keywords: Healthcare, Quality of care, Medical services, Self-assessment, Chronic diseases, Self-management, Structured self-management education programme, PACIC

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1. Introduction

High-quality care for people with chronic conditions is one of the greatest public health challenges worldwide and in Germany, as chronic conditions affect more than half of the adult population [1] and contribute considerably to mortality [2]. Chronic conditions such as diabetes mellitus or cardiovascular diseases require, in addition to the treatment of acute episodes, above all continuous care. Continuous care often includes lifestyle measures, taking medication and self-monitoring, such as measuring blood glucose or blood pressure, which are carried out by those affected as part of their self-management. Adequate care for chronic conditions can help to reduce the burden of disease and premature mortality, improve the quality of life of those affected, and lower healthcare costs, e.g. by avoiding hospital admissions. A prerequisite for good care of chronic conditions is that people with chronic conditions, their treating physicians and the medical practice team actively discuss treatment and work together proactively [3, 4].

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Key messages

- Adults with a chronic condition rate the quality of their care as fair (2.67 on a scale of 1–5).
- Younger people, women, those with higher education and those with statutory health insurance rate it lower.
- In particular, experiences of discrimination in the health sector and lower levels of social support are associated with a lower self-rated quality of care.
- Over 60 % of participants are usually or almost always satisfied with the organisation of their medical care.
- Over 75 % stated that they had almost never or usually not been encouraged to participate in a support group or structured self-management education program.

Productive collaboration between patients and healthcare providers is the aim of care based on the *Chronic Care Model* (CCM). The CCM concept comprises approaches for improving the quality of care for chronic conditions [4, 5] (Infobox 1). The aim is to actively involve patients in their treatment, setting goals together and developing solutions for managing the condition [6]. Positive effects on care processes, clinical outcomes and costs have been reported for interventions that include aspects of care in line with the CCM [7–10].

How often people with chronic conditions experience individual components of care in accordance with the CCM can be assessed using the validated short or long version of the *Patient Assessment of Chronic Illness Care* (PACIC) instrument [6, 11, 12]. The self-rated quality of care using the PACIC has been measured internationally in various settings (general practice, outpatient or inpatient care) among people with specific conditions or symptoms, as well as across conditions [6, 13–19]. Differences in self-assessed quality of care were observed in some cases according to sociodemographic, health-related and care-related characteristics.

For Germany, results are available on self-rated quality of care for specific conditions [20–25], population groups (older people with multiple conditions [26], relatives of people during the last year of life [27]) or general practice settings [12, 28], but not generically for the healthcare of adults with chronic conditions at a population level. The aim of this study was therefore to use the short version of the PACIC (PACIC-S11) in a nationwide, population-based panel to investigate how adults with chronic conditions in Germany rate the quality of care, i.e. to what extent care is structured in accordance with the CCM from their perspective. To derive specific approaches for improving chronic illness care, the study examined how the individual components assessed in the PACIC were rated. To determine whether patient-centred care is experienced independently of sociodemographic, health-related and care-related characteristics, the self-rated

Infobox 1: Chronic Care Model (CCM): an evidence-based approach to improving the quality of chronic illness care [3–6]

According to the CCM, the quality of care can be improved by specifically strengthening the interaction between informed, activated patients and proactive healthcare teams. This can be achieved through the following approaches:

- Optimising the organisation of healthcare
- Improving delivery system design (e.g. structuring healthcare processes)
- Strengthening decision support (e.g. through evidence-based guidelines)
- Making effective use of clinical information systems (e.g. to map long-term course of disease)
- Promoting self-management through the healthcare system
- Supporting self-management through community resources in the patient's social environment

Patient Assessment of Chronic Illness Care (PACIC): Instrument for measuring self-rated quality of care [6]

Using the PACIC, patients assess whether the care for their chronic condition has been provided in accordance with the CCM principles. The short version of the PACIC (PACIC-S11) [11, 12] asks whether and how often, over the past six months, they have received or experienced the following individual components:

1. Presentation of different treatment options to choose from
2. Satisfaction with the organisation of medical care
3. Help in setting specific goals for a healthier lifestyle
4. Receipt of a written treatment plan, e.g. a medication plan
5. Encouragement to participate in a support group or structured self-management education programme
6. Questions about health behaviour
7. Help with creating a treatment plan for daily life
8. Help with creating a plan even for difficult times
9. Questions about how chronic conditions affect one's life
10. Being contacted by someone from the medical practice after a visit to see how things were going
11. Explanation of how visits with another physician help the treatment

quality of care and the individual components were also analysed regarding differences between the respective subgroups.

2. Methods

2.1 Study design and sampling

The analyses use data of the panel 'Health in Germany' established in 2024 as part of a recruitment study by the Robert Koch Institute (RKI). The sampling was based on a double-stratified random selection: 359 *primary sampling units*, known as sample points, were randomly drawn from all municipalities in Germany, taking into account the regional structure (first selection stage). In the second selection stage, addresses were drawn for each sample point from the address registers of the respective residents' registration offices, with stratification by age group. The selected individuals were invited to participate in a short survey and asked for their consent to participate in future surveys as part of the panel [29].

In 2024, the participants were invited to take part in health surveys at three points in time (sub-waves). In each sub-wave they received one of the four questionnaire variants in German [30] (Infobox 2). Additional in-depth questions on sociodemographic information were appended to their questionnaire variant in the first sub-wave. The response rate (the proportion of participants in relation to the people registered in the panel), calculated in accordance with the standards of the *American Association for Public Opinion Research* (AAPOR [31]), ranged from 75 % to 81 % across the three sub-waves. A detailed description of the methodology can be found elsewhere [32].

2.2 Survey content and instruments

Self-rated quality of care

Self-rated quality of care was examined among individuals who reported having a chronic disease or a long-term health problem and who also reported having received medical treatment for a chronic disease or long-term health problem in the last six months. These individuals were asked, using the validated German version of the PACIC-S11, how often the individual components specified in eleven questions had been applied during their treatment in the past six months (Infobox 1) [11, 12]. They were asked to think about the chronic condition for which they had been treated that had caused them the greatest impairment [6]. The sum of the points assigned to each response ('Almost never' = 1, 'Usually not' = 2, 'Sometimes' = 3, 'Usually' = 4, 'Almost always' = 5), divided by the number of the eleven questions, results in the PACIC sum score (scale 1–5). Higher values indicate a higher self-rated quality of care.

Infobox 2:
The 2024 RKI 'Health in Germany' panel

Data holder: Robert Koch Institute

Objectives: To provide comprehensive data on the health status, health-related behaviour and health care of the population in Germany and to enable future longitudinal comparisons and analysis of trends over time

Study design: Panel study with a mixed-mode approach (participation online or by postal questionnaire) [33]

Population: German-speaking population aged 18 and over who live in private households and have their main residence in Germany

Sample: Probabilistic/representative sample of the 'Health in Germany' panel infrastructure

Participants in the 2024 annual wave: A total of 41,376 of the individuals registered in the panel took part in at least one of the three sub-waves in 2024.
Questionnaire A: 14,759 women, 12,374 men, 66 persons with other gender identities
Questionnaire B: 14,828 women, 12,258 men, 61 persons with other gender identities
Questionnaire C: 14,709 women, 12,329 men, 64 persons with other gender identities
Questionnaire D: 14,872 women, 12,368 men, 66 persons with other gender identities

Data collection:
1st sub-wave: 28.05.2024–05.08.2024
2nd sub-wave: 12.08.2024–14.10.2024
3rd sub-wave: 28.10.2024–06.01.2025

More information at www.rki.de/panel-en

Sociodemographic, health-related and care-related characteristics

In the analyses, gender was classified based on the question regarding gender identity [34]. The data presented here relates to individuals who identify as female or male. Gender-diverse people who do not identify with these categories were not included in the analyses due to the low number of cases. The age groups considered were 18–44 years, 45–64 years, 65–79 years and 80 years and older. Three education groups (low, medium, high) were distinguished using established questions on school and vocational education, in accordance with the *Comparative Analysis of Social Mobility in Industrial Nations* (CASMIN) [35].

Health-related long-term activity limitations were collected as part of the *Minimum European Health Module* (MEHM). This included the percentage of people who answered the

question 'Are you limited by a health problem in activities of your normal everyday life?' with either 'Severely limited' or 'Moderately limited' (versus 'Not limited') and who answered the question 'How long have your limitations lasted?' with '6 months or longer' (versus 'Less than 6 months') [36].

Depressive symptoms were assessed using the internationally established PHQ-9 [37]. Participants were asked to indicate the frequency with which they had been affected by nine symptoms over the past two weeks (response categories: 'Not at all' = 0, 'Several days' = 1, 'More than half the days' = 2 and 'Nearly every day' = 3), resulting in total scores ranging from 0 to 27. In this paper, the presence of depressive symptoms is assumed with a PHQ-9 total score of ≥ 10 [37, 38].

Perceived social support was measured using the established 3-item *Oslo Social Support Scale* [39]. A sum score is calculated based on points assigned to each response for three questions; scores of 3 – 8 indicate 'low social support', 9 – 11 'moderate social support' and 12 – 14 'high social support'.

Furthermore, participants were asked about the frequency of self-reported experiences of discrimination in the health or care sector. First, participants were asked about their experiences of discrimination in everyday life using an adapted version of the *Everyday Discrimination Scale* [40, 41]. This scale asks, e.g. whether participants were treated with less courtesy or respect than other people, or whether others acted as if they think they were not smart. Participants were then asked whether they had been treated unfairly or less favourably accordingly within the health or care sector. For the purposes of the analysis, the categories 'Very often/Often', 'Sometimes/Rarely' and 'Never' were distinguished.

The type of health insurance was determined by asking the question: "What type of health insurance or healthcare cover do you have?" For the analysis two categories were used: statutory health insurance ('AOK' or 'Other statutory health insurance (e.g. Barmer, Techniker, DAK, company health insurance fund)') and private/other/no health insurance ('Private health insurance, allowance. This does not refer to private supplementary insurance in addition to statutory health cover' or 'Other healthcare cover' (e.g. free medical care, foreign health insurance)' or 'No health insurance/self-paying patient').

2.3 Statistical methods

Within the study population, the overall self-rated quality of care (PACIC-S11 sum score) and the eleven individual PACIC components were examined, differentiated by gender, age, education and health-related long-term activity limitations. Information on the PACIC-S11 and health-related long-term activity limitations was collected using Questionnaire A. The relevant data from the participants (data set version 5) were merged with data on gender, age and education from the recruitment study (data set version 3). A *complete case analysis* was carried out based on participants who reported having a chronic condition and having received treatment in the last six months (n = 10,762), in which only individuals with complete data for the relevant variables were included (n = 10,001 after excluding n = 633 with incomplete PACIC-S11 data and n = 128 missing values for the variables under consideration).

In a subpopulation (n = 6,069) of the study population, additional information from Questionnaire C (data set version 5) was analysed. In this subpopulation, the PACIC sum score and the individual components were examined, differentiated by depressive symptoms, social support and experiences of discrimination in the health sector, as well as by the type of health insurance (based on in-depth questions on sociodemographic characteristics in the questionnaire from the first sub-wave, data set version 5) (n = 5,836 after excluding n = 233 missing values for the characteristics under consideration).

The differences in the mean PACIC sum scores were tested in bivariate linear regression models according to the categories of the characteristics under consideration (p-value (two-tailed) < 0.05). In addition, a sensitivity analysis was carried out to examine whether the differences remained statistically significant after adjusting for gender, age and education. The differences in the mean values of the eleven individual components according to the categories of the characteristics were also tested using bivariate linear regression models (due to the large number of statistical tests: p-value (two-tailed) < 0.001).

All results were calculated using a weighting factor that corrects for distortions between the composition of the sample and that of the population (i.e. the German-speaking population aged 18 years and older) [42]. The multi-stage sample weight accounts for the weighting factor of the initial recruitment study and a dropout weight to counteract any distortion caused by selective participation in repeated subwaves. Finally, adjustment against population figures as of December 31, 2023, and the 2021 Microcensus considering age, gender, BIK municipality size class [43], federal state, education (CASMIN [35]) and household size (single-person vs. multi-person household) was performed. The weighting from Questionnaire A was used for the present analysis. To properly account for the clustering of participants within the sample points and for the weighting when calculating confidence intervals (CI) and p-values, survey procedures for complex samples were used in all analyses. All analyses were carried out using Stata 17.0 (Stata Corp., College Station, TX, USA).

3. Results

3.1 Characteristics of participants

The study population (n = 10,001, mean age: 56.5 years (95 % CI: 56.0–57.1)) comprises women (54.7 %) and men (45.3 %) with a chronic disease or a long-term health problem for at least six months who received medical treatment in the past six months (Table 1). Within the study population, 73.4 % reported moderate or severe health-related long-term activity limitations.

In the subpopulation (n = 5,836, mean age: 56.6 years (95 % CI: 55.9–57.2)), 30.7 % had depressive symptoms, 25.3 % reported low social support, and 45.6 % reported experiences of discrimination in the health sector. A total of 89.6 % were covered by statutory health insurance.

Table 1: Characteristics (proportions with 95 % confidence intervals) of the study population* and subpopulation**. Source: RKI Panel 2024

	n[1]	%[2]	(95 % CI)
Study population	**10,001**		
Gender			
Women	5,698	54.7	(53.3–56.0)
Men	4,303	45.3	(44.0–46.7)
Age group			
18–44 years	2,311	26.4	(25.1–27.7)
45–64 years	3,781	39.1	(37.9–40.4)
65–79 years	2,862	23.5	(22.6–24.5)
≥ 80 years	1,047	10.9	(10.1–11.8)
Education group			
Low	2,305	39.4	(37.5–41.4)
Medium	4,744	43.4	(41.8–45.0)
High	2,952	17.2	(16.0–18.4)
Health-related long-term activity limitations			
Not limited	2,875	26.6	(25.4–27.9)
Moderately/severely limited	7,126	73.4	(72.1–74.6)
Subpopulation	**5,836**		
Depressive symptoms			
No	4,284	69.3	(67.6–70.9)
Yes	1,552	30.7	(29.1–32.4)
Social support			
Low	1,318	25.3	(23.7–26.9)
Moderate	2,982	50.8	(49.1–52.5)
High	1,536	23.9	(22.6–25.4)
Experiences of discrimination in the health sector			
Very often/often	325	6.4	(5.6–7.4)
Sometimes/rarely	2,169	39.2	(37.5–41.0)
Never	3,342	54.3	(52.6–56.1)
Statutory health insurance			
No	831	10.4	(9.5–11.4)
Yes	5,005	89.6	(88.6–90.5)

[1]unweighted, [2]weighted; CI = confidence interval
*study population: participants with a chronic disease or a long-term health problem for at least six months who received medical treatment in the past six months and for whom information was available on self-rated quality of care, sociodemographic characteristics and health-related long-term activity limitations
**subpopulation: part of the study population for which additional characteristics were available

3.2 Self-rated quality of care according to sociodemographic, health-related and care-related characteristics

People with chronic conditions under medical treatment rated the quality of care they experienced on average as fair (mean of the PACIC sum score = 2.67, Figure 1). Women rated the quality of care lower (2.59) than men (2.76). There is an age-related gradient, with the self-rated quality of care increasing from an average of 2.53 in 18- to 44-year-olds to 2.79 in 65- to 79-year-olds and stagnating on this level in people aged 80 years and older. Women aged 65 years and older rated the quality of care better compared to women in the younger age groups, whereas men from the age group 45–64 years onwards reported a higher quality of care. People in the low education group (2.77) rated the quality of care higher than those in the medium (2.59) and high education groups (2.63).

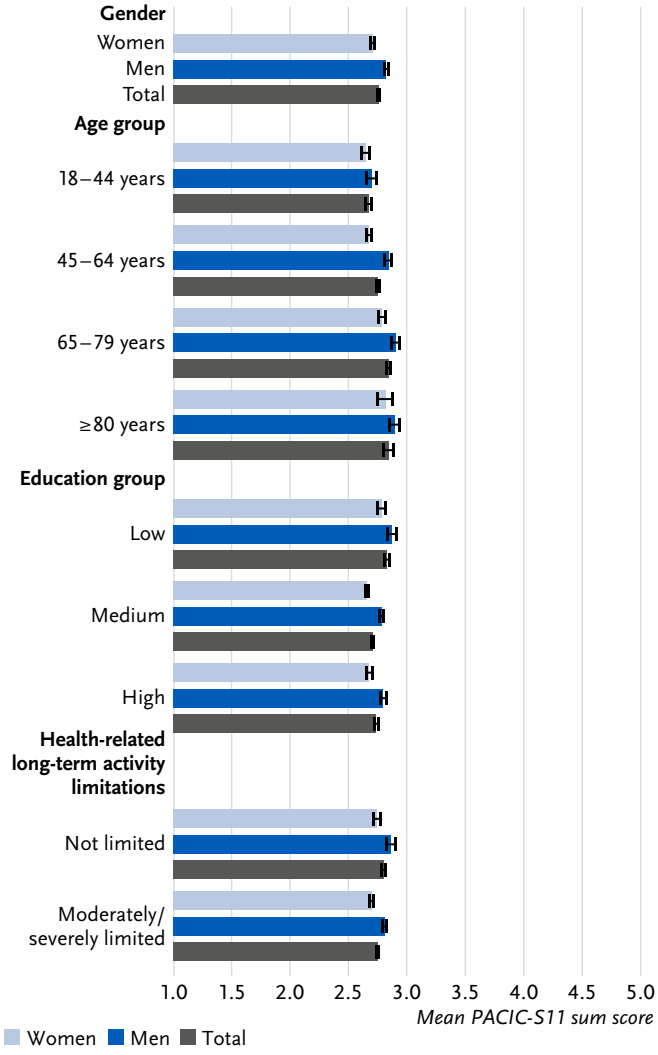


Figure 1: Mean (with 95 % confidence interval) of the self-rated quality of chronic illness care (PACIC-S11 sum score) according to sociodemographic characteristics and health-related long-term activity limitations (n = 5,698 women, n = 4,303 men, total N = 10,001). Source: RKI Panel 2024

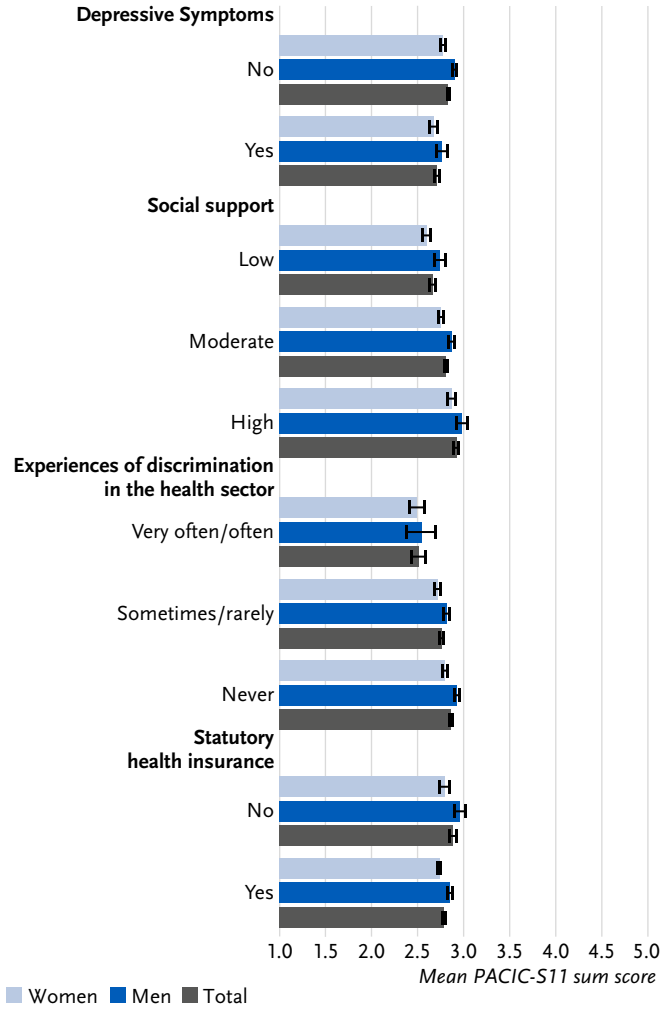


Figure 2: Mean (with 95 % confidence interval) of the self-rated quality of chronic illness care (PACIC-S11 sum score) according to depressive symptoms and care-related characteristics (n = 3,335 women, n = 2,501 men, total N = 5,836). Source: RKI Panel 2024

People with health-related long-term activity limitations reported on average a lower quality of care than people that did not experience limitations (2.64 versus 2.73). People with depressive symptoms rated the quality of care lower than people without depressive symptoms (2.54 versus 2.72, Figure 2).

People who reported low social support experienced the individual components corresponding to the CCM less frequently (2.47) compared to people with moderate (2.68) or high (2.85) social support. People who very often or often experienced discrimination in the health sector rated the quality of care lower (2.24) than people who experienced discrimination sometimes or rarely (2.61) or never (2.76).

People with statutory health insurance rated the quality of care lower than people who had private insurance, other insurance or were uninsured (2.65 versus 2.80), with a significant difference being observed only in men.

In the sensitivity analysis adjusted for gender, age and education, the differences described persisted (p-values for differences in means of the PACIC sum score < 0.05).

3.3 Self-rated quality of care in individual components

The percentage distribution of responses across the five possible categories ('Almost never' to 'almost always') varies across the eleven individual components, each of which reflects an aspect of care regarding the past six months (Figure 3). The aspects covered in questions 2 and 6 were most frequently part of the care provided: overall, over 60 % of participants were usually or almost always satisfied with the organisation of their medical care (question 2). More than half of the participants were usually or almost always asked about their health behaviour (question 6).

By contrast, the aspects covered in questions 5 and 10 were experienced least frequently: over 75 % of participants stated that they were almost never or usually not encouraged to participate in a support group or structured self-management education programme (question 5) or contacted by someone from the medical practice after a visit to see how things were going (question 10).

For the remaining questions, between approximately 40 % and 60 % of participants reported that they had almost

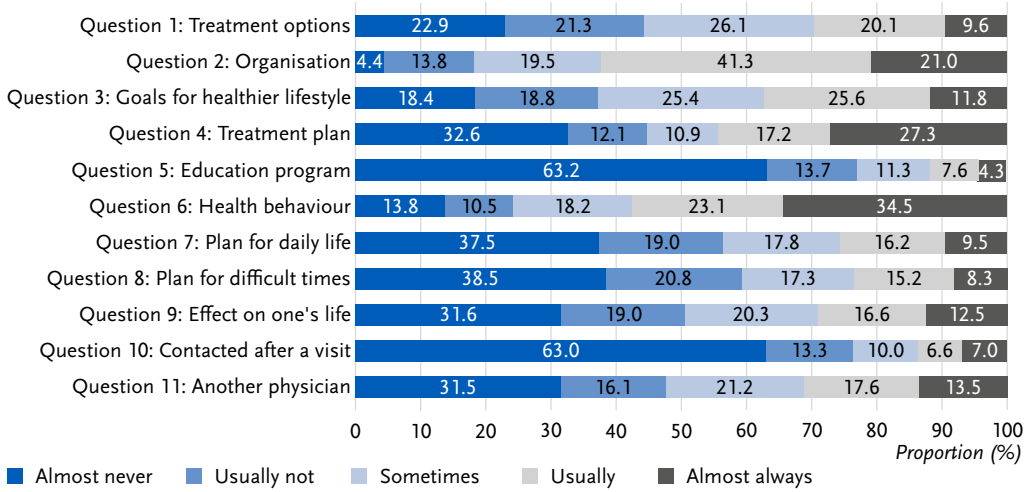


Figure 3: Percentage distribution of responses regarding the individual components of the PACIC-S11 in people with chronic conditions (n = 5,698 women, n = 4,303 men). Source: RKI Panel 2024

never or usually not experienced the corresponding individual components.

Among both women and men, the distribution of responses across the eleven individual components showed a similar pattern (Supplementary material Figure S1, Figure S2).

3.4 Further examination of the individual components

The mean values for the individual components reflect the average distribution of responses ('Almost never' = 1 to 'Almost always' = 5). The highest mean values are found for the question regarding satisfaction with the organisation of medical care (question 2: 3.61) and for the question of whether the patient was asked about the health behaviour (question 6: 3.54). By contrast, the question regarding encouragement to participate in a support group or structured self-management education programme (question 5: 1.76) and the question regarding being contacted by someone from the medical practice after a visit to see how things were going (question 10: 1.81) had the lowest mean values (Table 2).

In the analysis stratified by gender, almost all individual components (with the exceptions of questions 1 and 11) show lower mean values for women than for men. The greatest difference is observed in relation to receiving a written treatment plan (question 4, difference in mean value for men versus women: 0.30).

In terms of age, differences in the mean values were found in around half of the individual components, to the disadvantage of 18- to 44-year-olds (questions 1–4, 8, 11). The greatest difference is related to receiving a written treatment plan (question 4, difference in mean value for the age group 65–79 years and the age group 80 years and older versus the age group 18–44 years: 1.00 and 1.55, respectively).

When comparing those in the low education group to those in the medium education group, higher mean values are found for seven out of eleven individual components (questions 4–8, 10, 11); when comparing those in the low education group to those in the high education group, higher mean values are found for three individual components (questions 4–6). Again, the greatest difference is found in relation to receiving a written treatment plan (question 4; difference in mean value for low versus medium or high levels of education: 0.54 and 0.62, respectively).

People with health-related long-term activity limitations have lower mean values than those without limitations in terms of satisfaction with the organisation of care (question 2) and creating a treatment plan for daily life (question 7). By contrast, people with limitations show higher mean values in relation to receiving a written treatment plan (question 4) and being encouraged to participate in a support group or structured self-management education programme (question 5). The greatest difference is observed in terms of sat-

Table 2: Mean of the individual components of the PACIC-S11 in people with chronic conditions according to sociodemographic characteristics and health-related long-term activity limitations (n = 5,698 women, n = 4,303 men, total N = 10,001). Source: RKI Panel 2024

	Question 1 Treatment options[1]	Question 2 Organisation[1]	Question 3 Goals for healthier lifestyle[1]	Question 4 Treatment plan[1]	Question 5 Education programme[1]	Question 6 Health behaviour[1]	Question 7 Plan for daily life[1]	Question 8 Plan for difficult times[1]	Question 9 Effect on one's life[1]	Question 10 Contacted after a visit[1]	Question 11 Another physician[1]	PACIC-S11 sum score
Total	2.72	3.61	2.94	2.95	1.76	3.54	2.41	2.34	2.59	1.81	2.66	2.67
Gender												
Women	2.69	3.54	2.83	2.81	1.70	3.46	2.34	2.26	2.49	1.72	2.61	2.59
Men	2.76	**3.69**	**3.07**	**3.11**	**1.84**	**3.64**	**2.50**	**2.44**	**2.72**	**1.93**	2.71	**2.76**
Age group												
18–44 years[2]	2.59	3.36	2.77	2.37	1.71	3.46	2.33	2.23	2.63	1.83	2.54	2.53
45–64 years	**2.76**	**3.58**	2.93	**2.81**	1.81	3.59	2.43	2.34	2.57	1.74	2.60	**2.65**
65–79 years	**2.82**	**3.81**	**3.12**	**3.37**	1.76	3.61	2.47	**2.43**	2.61	1.86	**2.80**	**2.79**
≥ 80 years	2.67	**3.85**	2.98	**3.92**	1.73	3.38	2.42	2.40	2.57	1.95	**2.81**	**2.79**
Education group												
Low[2]	2.79	3.62	3.00	3.29	1.87	3.65	2.47	2.43	2.64	1.91	2.76	2.77
Medium	2.69	3.56	2.87	**2.75**	**1.71**	**3.48**	**2.32**	**2.25**	2.54	**1.74**	**2.59**	**2.59**
High	2.66	3.69	2.95	**2.67**	**1.64**	**3.46**	2.51	2.36	2.65	1.78	2.60	**2.63**
Health-related long-term activity limitations												
Not limited	2.74	3.89	3.05	2.80	1.66	3.61	2.56	2.40	2.65	1.87	2.75	2.73
Moderately/ severely limited	2.72	**3.50**	2.90	**3.00**	**1.80**	3.52	**2.36**	2.32	2.57	1.79	2.62	**2.64**

[1]For more detailed questions see Infobox 1
[2]Reference category in case there are more than two categories for a sociodemographic characteristic
Bold type: indicates a significantly higher or lower mean value for a component when comparing groups with different levels of a characteristic ($p < 0.001$ for individual components; $p < 0.05$ for the PACIC-S11 sum score)

isfaction with the organisation of care (question 2; difference in mean value between those with no limitations versus those with moderate/severe health-related long-term activity limitations: 0.39).

People with depressive symptoms have lower mean values for around half of the individual components than those without depressive symptoms (questions 1–3, 7, 8). The difference is most pronounced in terms of satisfaction with the organisation of care (question 2; difference in mean value for those without versus those with depressive symptoms: 0.50; Table 3).

Compared with people who report low social support, those with high social support have higher mean values across almost all individual components (except for questions 5 and 10). For four individual components (questions 1–3, 11), a higher mean value is also observed for people with moderate support than for those with low support. The greatest differences are shown in relation to satisfaction with the organisation of care (question 2, difference in mean value for high or moderate versus low social support: 0.63 and 0.39 respectively) as well as in relation to help in setting specific goals for a healthier lifestyle (question 3: 0.53 and 0.33, respectively) and in relation to explanations of how visits with another physician help the treatment (question 11: 0.50 and 0.34, respectively).

Among those who report experiencing discrimination in the health sector very often or often, the mean values for most individual components are lower than among those who report experiencing discrimination sometimes or rarely (exceptions: questions 4–6, 10) or never (exceptions: questions 5 and 6). In particular, satisfaction with the organisation of care (question 2) varies according to the frequency of experiencing discrimination (difference in mean value for 'Sometimes/rarely' or 'Never' versus 'Very often/often': 0.73 and 1.18 respectively). Considerable differences are also found with regard to the presentation of different treatment options (question 1), help in setting specific goals for a healthier lifestyle (question 3), with creating a treatment plan for daily life and even for difficult times (questions 7 and 8, respectively), questions about how chronic conditions affect one's life (question 9) and explanations of how visits with another physician help the treatment (question 11) (difference in mean value for 'Sometimes/rarely' or 'Never' versus 'Very often/often': 0.36–0.49 and 0.50–0.62, respectively).

Compared with those with private, other or no health insurance, people with statutory health insurance show lower mean values for around half of the individual components (questions 1–3, 7, 8). The greatest difference is shown in satisfaction with the organisation of care (question 2, difference in mean value for 'No' versus 'Yes' regarding statutory health insurance: 0.41).

The patterns described are largely similar for women and men (Supplementary material Tables S1–S4).

Table 3: Mean of the individual components of the PACIC-S11 in people with chronic conditions according to depressive symptoms and care-related characteristics (n=3,335 women, n=2,501 men, total N=5,836). Source: RKI Panel 2024

	Question 1 Treatment options[1]	Question 2 Organisation[1]	Question 3 Goals for healthier lifestyle[1]	Question 4 Treatment plan[1]	Question 5 Education programme[1]	Question 6 Health behaviour[1]	Question 7 Plan for daily life[1]	Question 8 Plan for difficult times[1]	Question 9 Effect on one's life[1]	Question 10 Contacted after a visit[1]	Question 11 Another physician[1]	PACIC-S11 sum score
Total	2.73	3.63	2.95	2.90	1.75	3.55	2.45	2.35	2.60	1.79	2.65	2.67
Depressive Symptoms												
No	2.79	3.78	3.05	2.96	1.70	3.59	2.52	2.42	2.63	1.82	2.71	2.72
Yes	**2.59**	**3.28**	**2.75**	2.76	1.85	3.46	**2.28**	**2.19**	2.55	1.71	2.54	**2.54**
Social support												
Low[2]	2.51	3.28	2.66	2.71	1.75	3.39	2.29	2.17	2.42	1.67	2.36	2.47
Moderate	**2.74**	**3.67**	**2.99**	2.92	1.74	3.52	2.42	2.34	2.62	1.81	**2.70**	**2.68**
High	**2.92**	**3.91**	**3.19**	**3.05**	1.78	**3.77**	**2.67**	**2.58**	**2.77**	1.86	**2.86**	**2.85**
Experiences of discrimination in the health sector												
Very often/often[2]	2.23	2.70	2.46	2.51	1.64	3.47	1.99	1.94	2.08	1.54	2.13	2.24
Sometimes/rarely	**2.70**	**3.43**	**2.87**	2.84	1.77	3.53	**2.40**	**2.30**	**2.55**	1.74	**2.62**	**2.61**
Never	**2.81**	**3.88**	**3.08**	**2.99**	1.74	3.57	**2.53**	**2.44**	**2.70**	**1.85**	**2.74**	**2.76**
Statutory health insurance												
No	2.95	3.99	3.19	2.97	1.64	3.59	2.69	2.55	2.74	1.85	2.66	**2.80**
Yes	**2.70**	**3.58**	**2.93**	2.89	1.76	3.54	**2.42**	**2.33**	2.59	1.78	2.65	2.65

[1]For more detailed questions see Infobox 1
[2]Reference category in case there are more than two categories for a characteristic
Bold type: indicates a significantly higher or lower mean value for a component when comparing groups with different levels of a characteristic ($p<0.001$ for individual components; $p<0.05$ for the PACIC-S11 sum score)

4. Discussion

4.1 Self-rated quality of chronic illness care

The results indicate that the self-rated quality of care for a chronic disease or a long-term health problem in the population aged 18 years and older in Germany is, on average, in the middle range (2.67). In a study from 2008/2009 involving older patients with multiple co-morbidities (mean age 74.4 years), recruited from 158 general practitioners' practices in eight German cities, a lower PACIC sum score (2.4) was reported, which could be related to complex care needs [26]. In nationwide interview surveys conducted in 2017 and 2021/2022, the diabetes-specific quality of care for people aged 45 years and older was 2.45 and 2.4, respectively [20, 21]. By contrast, higher values (3.0 and 2.84, respectively) than in the present analysis were found in a pooled analysis of studies conducted between 2005 and 2016 involving people with diabetes from 13 countries (primarily Europe and North America, with a mean age between 54.0 and 75.8 years) [16] and in an analysis carried out in 2008/2009 including people with coronary heart disease in five European countries (mean age 67.8 years) [13]. Overall, direct comparisons should be treated with caution due to the heterogeneity of the PACIC instruments used and of the age ranges of the participants, as well as the different healthcare contexts.

In the present study, participants rated the quality of care differently according to sociodemographic, health-related and care-related characteristics. Causes for the variation in the rating of the quality of care cannot be identified in this study and should be investigated further; they could include differences in the actual care provided, in response patterns, in expectations and in critical assessment [20, 26]. The absolute differences in the mean PACIC-S11 score between the observed subgroups range from 0.09 (not limited versus moderately/severely limited in usual everyday activities) to 0.52 (never versus very often or often experiencing discrimination in the health sector). It is not clear what size of difference in mean values is meaningful to patients [16]. To identify areas of healthcare with potential for improvement in line with the CCM, the following section focuses on which individual PACIC components have already been largely implemented in chronic illness care and which – including regarding subgroups – should be further strengthened.

4.2 Further examination of the individual components of chronic illness care

The individual components of care corresponding to the CCM varied in how frequently they were experienced. Almost two-thirds of those treated were usually or almost always satisfied with the organisation of their care (question 2). Other studies have also reported high levels of satisfaction regarding this individual component or the 'delivery system design' subscale of the long-form of PACIC [13, 15, 18, 19, 23, 26]. Although a greater variation was observed in satisfaction with the organisation of care than with any of the other individual components, the mean value indicates a higher-than-average level of satisfaction (all > 3.0) in all subgroups, except in those with frequent experiences of discrimination in the health sector (2.70). In this study, participants were asked e.g. about experiences of being treated with less courtesy or respect than other people or as if other people thought they were not smart. The literature includes reports of long waiting times, shortened consultations and the withholding of adequate pain management [44], which in turn can have a negative impact on patients' experience of the organisation of care. Regarding risks of discrimination, e.g. within processes and structures of care, further research is needed [44].

More than half of the participants stated that they had usually or almost always been asked about their health behaviour (question 6). According to the results, asking about health behaviour is well established in healthcare (with a mean value of > 3.0 in all subgroups). In accordance with clinical guidelines – e.g. for type 2 diabetes – this question is recommended as an integral part of the consultation between the physician and the patient, as lifestyle plays an important role in the treatment and long-term management of chronic conditions [45].

Less frequently, patients reported experiences of setting goals for a healthier lifestyle (question 3), presentation of different treatment options (question 1) or explanations how visits with another physician help the treatment (question 11) and receiving a written treatment plan (question 4), although the assessments varied somewhat across the subgroups (mean values 2.13 – 3.92). Strengthening these individual components would enable a more tailored approach to treatment, greater patient involvement and improved coordination with other specialists [6] – although the extent to which these measures are useful may also depend on the specific chronic condition and prognosis. In particular, older people receive treatment plans much more frequently than younger people, but people with a lower level of education also receive them more frequently than those with a higher level of education. Both older age and socioeconomic disadvantage can be associated with a higher prevalence of multimorbidity [46] and, as a result, with the use of a greater number of medications. Physicians are encouraged to ensure that patients with five or more long-term prescriptions have an up-to-date medication plan with explanations that are easy to understand [47]. But even people taking fewer medicines could benefit from a written treatment plan to help them make more informed decisions, e.g. in exceptional situations like an infection. Differences in goal setting (question 3), the presentation of different treatment options (question 1) and

the explanation of how visits with another physician might help the treatment (question 11) were associated with the frequency of experiences of discrimination in the health sector. These individual components are relevant for shared decision-making – which is also recommended in guidelines for type 2 diabetes – as this requires an equal relationship between patients and healthcare providers [45], which can be compromised or even made impossible because of discrimination [48].

Individual components with regard to support of self-management were even less common: over half of the participants reported that they had almost never or usually not been supported in creating a plan for daily life or for difficult situations (questions 7 and 8), or that they had almost never or usually not been asked how chronic conditions affect their lives (question 9). For these individual components, the mean values range between 2 and 3 depending on the subgroup considered; they are lowest among those who have often experienced discrimination in the health sector (in some cases <2). One reason why individual components that promote self-management – in the sense of 'talking medicine' – are less well established could be the limited time available per person for a consultation with a physician [49]. Furthermore, experiences of discrimination could counteract a supportive care relationship [48]. For instance, in a nationwide telephone survey, just under 20 % and 13 % of participants stated that they had at some point felt that their health concerns had not been taken seriously and that they had been treated unfairly, which they partly attributed to personal characteristics, such as their gender [50].

The greatest deviation from the CCM principles of care is shown in terms of encouragement to participate in a support group or structured self-management education programme (question 5) and in terms of being contacted by someone from the medical practice after a visit to see how things were going (question 10). Three-quarters of participants reported that they had almost never or usually not experienced these individual components. Low mean values were observed for these individual components (<2.0), regardless of sociodemographic, health-related and care-related characteristics. Structured self-management education programmes and support groups offer a less time-constrained setting than physicians' consultations for learning self-management skills and discussing how to cope with chronic conditions. Most *Disease Management Programmes* (DMP), e.g. for diabetes, are designed to provide access to structured self-management education programmes where needed [51]. Participants may not have experienced an encouragement to participate in a programme within the period they were asked about due to a lack of available programmes or because they were encouraged to participate more than six months before the survey – for instance, in the case of a new diagnosis, enrolment in a DMP or an acute need for education, e.g. because of medication changes – but it is also possible that the potential of structured self-management education programmes for chronic conditions has not yet been fully realised. The same applies to the follow-up: the CCM recommends that the care team proactively follows up after a physician's appointment [4, 5]; but the results – in line with other studies [15, 23] – indicate that such contacts are scarcely established in the German healthcare context outside of consultations. The DMP provides for regular contact – with physician's appointments every three or six months – which may be reflected in higher scores on the PACIC 'Coordination/Follow-up' subscale amongst DMP participants with type 2 diabetes [22]. Follow-up in various formats (structured follow-up appointments, contacts via telephone or telemedicine, including those with healthcare providers other than physicians) could strengthen continuity of care and prevent acute health events [52].

4.3 Strengths and limitations

The study is based on the nationwide, population-based RKI panel 'Health in Germany' 2024, comprising adults residing in Germany, of whom about 10,000 participants were included in the present analysis. Due to the study design, which involved a random sample drawn from residents' registry data and a written survey (online or on paper), it was possible to include very old people with chronic conditions more effectively than in earlier RKI studies based on telephone sampling and interviews [53]. However, in the RKI panel, people without German citizenship are under-represented [32]. Furthermore, the questionnaires are available in German language only, which excludes people with limited German language proficiency. As experiences of discrimination are more frequent among migrant population groups [54] and, according to the present study, are associated with a lower self-rated quality of care, the quality of care may be overestimated in this study. In future panel waves, it is planned to provide questionnaires in further languages to enable participation of people with limited German language proficiency [32].

The number of missing values relating to one or more individual PACIC components is relatively high (n = 633; 5.9 %), a finding also reported in other studies, which may be attributable to difficulties in understanding the questions [26, 55, 56]. Compared with the study population, the participants excluded due to missing values for the PACIC-S11 were more frequently female (67.0 % versus 54.7 %), older on average (mean age 71.8 versus 56.5 years) and more likely to be in the low education group (63.7 % versus 39.4 %).

The PACIC-S11 short form, translated into German, was examined in a validation study and demonstrated good to very good psychometric properties and a reliable measure-

ment of self-rated quality of care in accordance with the CCM [12]. Instead of the response scale proposed for the short form, ranging from 0% ('Never') in 10 per cent increments up to 100% ('Always') [11, 12], the five-point Likert scale was used, as with the long form. For the long-form instrument, five subscales (including one for the construct 'patient activation') can be calculated, each based on several individual components; such an analysis is not recommended for the short-form instrument [11]. However, an exploratory analysis of the eleven individual components of the short instrument appears informative and justified given that the instrument assesses concrete experiences rather than deeper, latent constructs [14, 57].

To investigate whether the PACIC-S11 sum score or the individual components differ according to sociodemographic, health-related and care-related characteristics, this study examined absolute differences in mean values; however, it remains unclear from what difference onwards a difference is meaningful for patients or in terms of a change in treatment [16]. Future studies should determine effect sizes for these differences and investigate the relevance of these differences in self-rated quality of care.

Unlike instruments that collect data on patient satisfaction, which is influenced by many factors, including subjective ones, the PACIC captures specific individual components of care [24] and is considered suitable for assessing self-rated quality of care across different conditions [58] and in the presence of multiple conditions [12]. Furthermore, prior to the eleven questions, participants were asked to consider the chronic disease or long-term health problem being treated that caused the greatest impairment. The extent to which participants with multiple chronic conditions find it easy or difficult to make such a distinction should be investigated. A differentiated analysis of self-rated quality of care by specific conditions or by participation in structured care programmes could not be carried out on the basis of the data used but could be investigated in future surveys to identify further areas for improvement. This could be particularly relevant where different care structures have been established for different conditions, e.g. depending on whether a DMP exists for the condition [24]. In addition to the PACIC, there are other instruments known as *patient-reported experience* measures (PREMs) that assess the patient's perspective on care. For the German-speaking world, the 'Experienced Patient-Centeredness Questionnaire' (EPAT) was developed and administered to about 2,000 people [59, 60]. EPAT and PACIC overlap conceptually, although the EPAT focuses more strongly on the individual relationship and communication between patients and healthcare providers. While the PACIC allows for international comparisons to a limited extent, the EPAT is specifically designed for the German-speaking context.

Finally, due to the cross-sectional design, no causal effects can be investigated: for example, it is not possible to determine whether lower quality of care contributes to depressive symptoms or vice versa, nor whether the absence of individual components is the cause or consequence of experienced discrimination.

4.4 Conclusion and practical implications

The results show that not all aspects of the CCM – and thus of patient-centered care – have yet been fully implemented. Analysis of the individual components shows that there is room for improvement in certain aspects of care. In particular, healthcare providers could more often inform about structured self-management education programmes and support groups. Education programs in various formats (e.g. in a group or individually, face-to-face or online) can enhance knowledge and self-management of the condition, as well as improve treatment outcomes (e.g. regarding the long-term blood glucose value) and mental health [61]. In the German context, it should be examined whether – and, if so, to what extent – there is a need and capacity for practice staff to follow up after a visit to ask how the patient is doing, with the aim of strengthening the continuity of care.

Internationally, measurable improvements have been demonstrated for interventions that support self-management in line with the CCM, particularly among people with diabetes and high blood pressure [9]. One example of an intervention with long-term improvements of care is a programme from Switzerland in which specially trained nurses helped people with diabetes in setting goals and evaluated the progress of clinical parameters and goals during consultations with the patients [62, 63]. It is difficult, though, to find examples of 'best practice' that can be directly applied to other countries, as the context for implementing the CCM varies, partly due to differences in healthcare systems [64]. Apart from the individual components considered, strengthening productive collaboration in line with the CCM overall by adapting processes in healthcare remains a challenge [65]. Strengthening skills related to the CCM principles in education and training [66] and ensuring that leaders prioritise the CCM principles [67] could be helpful for healthcare providers. One important potential starting point for improving care for people with chronic conditions could be the service provision under the statutory health insurance scheme, where the quality of care was rated lower than under private health insurance. An opportunity for improvement could be, e.g. the reimbursement of consultation services in line with the CCM. DMPs are an important framework in Germany in which care can be restructured in accordance with the CCM [22]. This study also shows an association between experiences of discrimination in the health sector and self-rat-

ed quality of care that requires further systematic research [44], and highlights that tackling discrimination must be understood as a duty for society as a whole, including within the health sector [68]. As part of a universal patient-centered healthcare system, one of the principles of the CCM is that all patients should receive the individual components [69].

For the first time, results are available for Germany – based on the nationwide RKI panel – regarding self-rated quality of care among the adult population with chronic conditions, which show that the potential for patient-centred, 'talking' medical care in line with the CCM has not yet been fully realised. This potential is of great relevance to the future need to optimise care for chronic conditions, which will increase due to demographic change. Future surveys will allow the assessment of trends in self-rated quality of care that need to be interpreted in the context of a changing healthcare delivery landscape and health-related crises.

Data protection and ethics
The 2024 'Health in Germany' panel was conducted in strict compliance with the data protection provisions of the EU General Data Protection Regulation (GDPR) and Germany's Federal Data Protection Act (BDSG). The Ethics Committee of the Berlin Medical Association reviewed the study from an ethical perspective in accordance with the current version of the Declaration of Helsinki and raised no fundamental ethical or legal concerns regarding the conduct of the study and the 2024 annual wave (Eth-SB-25-088; former reference number: Eth-63/23, Amendment 1). Participation in the study was voluntary. Participants were informed about the objectives and content of the 2024 annual wave as well as about the processing and protection of their personal data. They provided informed consent either electronically, as part of the online survey, or in writing.

Data availability
Access to the data underlying the results is restricted. The data is accessible for extended use via the Research Data Center (FDZ) of the Robert Koch Institute if there is a justified research interest. Requests can be made by e-mail to fdz@rki.de. Further information can be found on the following website (German): www.rki.de/fdz.

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Individual author contributions
Substantial contributions to the conception or design of the work: MB, CH, YD; to the acquisition of the data for the work: CH, KK; to the analysis of the data for the work: MB, YD, CH; to the interpretation of the data for the work: MB, YD, CK, LW, KK, CH. Drafting the work: MB, YD, CK, LW, KK, CH; revising the work critically for important intellectual content: MB, YD, CK, LW, KK, CH. Final version of the manuscript read and approved for publication: MB, YD, CK, LW, KK, CH.

Declaration of generative artificial intelligence (AI) and AI-assisted technologies
ChatGPT-5.3 and -5.5 and Claude Sonnet 4.6 and 5 were used for linguistic editing to improve the readability of individual passages, for occasional literature searches, to assist in the creation of analysis programmes. DeepL Pro 26.7.2 and 26.8.2 were used for translation into English. The authors reviewed and edited the translation and take full responsibility for the content of the published article.

Conflicts of interest
The authors declared no conflicts of interest.

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